

LIVING WITH DISABILITIES IN THE UNITED STATES: A SNAPSHOT

HEARING

BEFORE THE
SUBCOMMITTEE ON HUMAN RIGHTS AND
WELLNESS

OF THE

COMMITTEE ON
GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED EIGHTH CONGRESS

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LIVING WITH DISABILITIES IN THE UNITED STATES: A SNAPSHOT

THURSDAY, JUNE 24, 2004

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HUMAN RIGHTS AND WELLNESS,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:40 p.m., in room 2154, Rayburn House Office Building, Hon. Dan Burton (chairman of the subcommittee) presiding.

Present: Representatives Burton, Watson, and Cummings.

Staff present: Mark Walker, staff director; Mindi Walker, Brian Fauls, and Dan Getz, professional staff members; Nick Mutton, press secretary; Danielle Perraut, clerk; Richard Butcher, minority counsel; Earley Green, minority chief clerk; and Jean Gosa, minority assistant clerk.

Mr. BURTON. Good morning. A quorum being present, the Subcommittee on Human Rights and Wellness will come to order.

I ask unanimous consent that all witnesses' and Members' written opening statements be included in the record. Without objection, so ordered.

I want to thank everybody for being here. I apologize for our tardiness, but it has been a pretty busy day; and we may get some votes during the hearing, and if we do, we will have to briefly adjourn and come back.

I also ask that all articles, exhibits and extraneous and tabular materials referred to be included in the record. Without objection, so ordered.

In the event of other Members attending the hearing, I ask unanimous consent that they be permitted to serve as a member of the subcommittee for today's hearing. Without objection, so ordered.

The subcommittee is convening today to examine the quality of life experienced by persons with disabilities in the United States. In addition, the subcommittee is going to discuss the ways in which the Federal Government and nongovernmental organizations are working to expand the participation and contributions of this population of Americans.

A disability is defined as a physical or mental impairment that substantially limits one or more life activities of an individual. According to the U.S. Census Bureau, there are over 49 million persons in the United States living with some form of disability.

Unfortunately, the rate of disability in our country is staggering and a majority of this underserved population does not enjoy the quality of life that many of us take for granted every day.

The U.S. Government has taken many actions over the years in order to better accommodate the population of disabled Americans. The Rehabilitation Act of 1973, which is Public Law 93-112, was the first civil rights act with regard to disability. This legislation represented the first step toward more sensitivity and accessibility for persons with disabilities, and established a roll for the Federal Government to provide vocational rehabilitation for disabled Americans.

After several years of researching the best solutions on disability policy in the United States, in 1990, Congress passed and the President signed into law the Americans with Disabilities Act, which is Public Law 101-336, which promulgated the first anti-discrimination guidelines on disability in the United States. This law prohibits discrimination in the hiring and continued employment of disabled persons in the workplace and provides that "no individual with a disability shall be excluded from participation and denied the benefits of or subjected to discrimination by a public entity." The act also dictates that no person shall be discriminated against the enjoyment of any place of public accommodation based on a disability.

The Honorable James R. Langevin, the Congressman from Rhode Island, is with us today. He was rendered paralyzed after an accident occurred while attending a Boy Scout event when he was 16 years of age. Since that time, the Congressman has worked diligently in the Rhode Island State Assembly, as the Secretary of State of Rhode Island, and now as a Representative of the Rhode Island Second Congressional District, to sponsor and support a variety of health and disability legislation and other efforts.

I did not know you were Secretary of State.

Mr. LANGEVIN. Yes, sir.

Mr. BURTON. Is that right?

Mr. LANGEVIN. For 6 years.

Mr. BURTON. Son of a gun.

In addition to proposing and supporting various health care initiatives, the Congressman founded and currently serves as a co-chair of the Bipartisan Disabilities Caucus in the Congress, and he is to be congratulated for his efforts in that area. The subcommittee has the distinct honor and privilege to have Congressman Langevin testify this afternoon about his numerous activities with regard to disability policy, as well as to give his personal experiences as an individual living with a disability in the United States.

The Federal Government has not only ensured that discrimination based upon disability is unlawful in the United States, but also has worked toward providing programs to assist with health care and educational opportunities for the disabled population. To explain these most important initiatives, Troy Justensen, Acting Assistant Secretary with the Office of Special Education and Rehabilitative Services at the Department of Education is here to speak on the educational programs made available to students with disabilities.

In addition, the subcommittee will be receiving testimony from the Honorable Don Young, Deputy Assistant Secretary for the Office on Health Policy at the Department of Health and Human Services. Mr. Young will testify on the various health care programs and services that the agency has implemented to assist the Nation's disabled population.

To further expound upon disability policy in the United States, Dr. Peter Blanck, Director of the Law, Health Policy & Disability Center at the University of Iowa College of Law will testify today on the status of disabilities in the country.

There is no question that persons with disabilities have to overcome physical or mental obstacles every day, and many times both, but there are some individuals who have conquered their impediment and gone on to achieve exceptional success and greatness. For example, even though a car accident rendered Robert David Hall a double amputee in 1978, he continued his career as an entertainer and went on to act professionally in numerous television and movies roles, most notably as a current star of the popular TV show, CSI, Crime Scene Investigation, where he has played the role of Dr. Al Robbins for several seasons. As a national figure, Mr. Hall has used his celebrity status to further the cause of disability awareness around the country, serving on various boards promoting disability support, including the National Organization on Disability. The subcommittee is delighted to have Mr. Hall here speaking on his involvement with the disability community.

While physical disabilities may be perceived as limitations preventing individuals from participating in athletic competition, more than 5,000 individuals with disabilities around the world participate in the Paralympics, a division of the Olympic Committee reserved for persons living with a disability. The Paralympic features 21 sports, 18 of which are also contested in the Olympics. To gain a better understanding of this competition, the subcommittee will receive testimony from Mr. John Register, manager of the Paralympic Academy for the U.S. Olympic Committee and a Paralympic Gold Medal winner.

Although there have been many advances in technology and disability policy in the United States, the quality of life of these individuals has been shown through many surveys to be less than non-disabled individuals. Recently, the National Organization on Disability commissioned a Harris poll survey regarding the life-styles of both individuals living with and without disabilities. The subcommittee has invited the President of NOD, Mr. Alan Reich, to testify on the results of this poll and potential initiatives that may lead to a better quality of life for individuals with disabilities.

I want to thank all of our witnesses for being here today and to speak on this very important matter and I look forward to their testimony.

Our first panel is the Congressman.

[The prepared statement of Hon. Dan Burton follows.]

**Opening Statement of Chairman Dan Burton
Government Reform Committee
Subcommittee on Human Rights & Wellness
“Living with Disabilities in the United States: A Snapshot”
June 24, 2004**

The Subcommittee is convening today to examine the quality of life experienced by persons with disabilities in the United States. In addition, the Subcommittee will discuss the ways in which the Federal Government and non-governmental organizations are working to expand the participation and contributions of this population of Americans.

A disability is defined as a physical or a mental impairment that substantially limits one or more life activities of an individual. According to the United States Census Bureau, there are over 49 million persons in the United States living with some form of disability.

Unfortunately the rate of disability in our country is staggering and a majority of this underserved population doesn't enjoy the quality of life that many of us take for granted everyday.

The United States government has taken many actions over the years in order to better accommodate the population of disabled Americans. The *Rehabilitation Act of 1973* (Public Law 93-112) was the first civil rights act with regard to disability. This legislation represented the first step toward more sensitivity and accessibility for persons with disabilities, and established a role for the Federal Government to provide vocational rehabilitation for disabled Americans.

After several years of researching the best solutions on disability policy in the United States, in 1990 Congress passed, and the President signed into law, the *Americans with Disabilities Act* (Public Law 101-336), which promulgated the first anti-discrimination guidelines on disability in the United States. This law prohibits discrimination in the hiring and continued employment of disabled persons in the workplace, and provides that “no individual with a disability shall be excluded from participation in, denied the benefits of, or subjected to discrimination by a public entity”. The Act also dictates that no person shall be discriminated against the enjoyment of any place of public accommodation based on a disability.

The Honorable James R. Langevin, Congressman from Rhode Island, was rendered paralyzed after an accident occurred while attending a Boy Scout event when he was sixteen years of age. Since that time, Congressman Langevin has worked diligently in the Rhode Island State Assembly, as the Secretary of State of Rhode Island, and now as a Representative of Rhode Island’s 2nd Congressional District to sponsor and support a variety of health and disability legislation and efforts. In addition to proposing and supporting various healthcare initiatives, Congressman Langevin founded and currently serves as a Co-Chairperson of the Bi-partisan Disabilities Caucus in Congress. The Subcommittee has the distinct honor and privilege to have Congressman Langevin testify this afternoon about his numerous activities with regard to disability policy, as well as to give his personal experiences as an individual living with a disability in the United States.

The Federal Government has not only ensured that discrimination based upon disability is unlawful in the United States, but has also worked toward providing programs to assist with healthcare and educational opportunities for the disabled

population. To explain these most important initiatives, Troy Justesen, Acting Assistant Secretary with the Office of Special Education and Rehabilitative Services at the Department of Education, is here to speak on the educational programs made available to students with disabilities. In addition, the Subcommittee will be receiving testimony from the Honorable Don Young, Deputy Assistant Secretary for the Office on Health Policy at the Department of Health and Human Services. Mr. Young will testify on the various healthcare programs and services that the Agency has implemented to assist the Nation's disabled population.

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There is no question that persons with disabilities have to overcome physical or mental obstacles every day, but there are some individuals who have conquered their impediment and gone on to achieve greatness. For example, even though a car accident rendered Robert David Hall a double-amputee in 1978, he continued his career as an entertainer and went on to act professionally in numerous television and movie roles, most notably as a current star of the popular TV show, CSI: Crime Scene Investigation, where he has played the role of Dr. Al Robbins for several seasons. As a national figure, Mr. Hall has used his celebrity status to further the cause of disability awareness around the country, serving on various boards promoting disability support, including the National Organization on Disability. The Subcommittee is delighted to have Mr. Hall speak on his involvement in the disability community.

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I would like to thank all of our witnesses for being with us today to speak on this most important matter, and I look forward to hearing their testimony.

Mr. BURTON. Ms. Watson just arrived and, Ms. Watson, since you have arrived, do you have an opening statement you would like to make before we introduce our colleague.

Ms. WATSON. Thank you, Mr. Chairman. But there is some important business I have to get out of the way first, and that is to say, "Happy birthday," to Richard Butcher on my staff.

Mr. BURTON. My birthday was 2 days ago, and I did not hear you call me and wish me, "Happy birthday." When you reach 29, like me, it really gets tough.

Ms. WATSON. Let me say to you, Mr. Chair, "Happy birthday for being 29 again and again."

I want to commend you for leading the subcommittee on this very important, important issue. I would also like to thank my colleagues and the Honorable James Langevin from Rhode Island for his testimony that he is about to give when I finish. Let me go through this real quickly.

The disabled in America are sometimes overlooked in the land where everyone supposedly has a voice. Americans with disabilities are Americans just the same, and according to the Constitution of the United States, the disabled are afforded the right to life, liberty, and the pursuit of happiness exactly the same as any other citizen.

Whether or not the disability is from a birth defect or an amputation or an accident or blindness or deafness, the disabled should have a voice, even those disabled that cannot speak and communicate their ideas through sign language, pictures, captions and in other ways.

Mr. Chairman, I do appreciate the opportunity we have to hear about living with a disability here in the United States of America, and I also extend a very special thanks to you and to those who are assisting our communications today. I understand that there are numerous challenges to life for every human being and a disability adds even more.

As a long-time public servant, I believe that it takes a very strong individual to overcome many of the obstacles in our society. I also believe that good public policy works to ensure the well-being of those with all these challenges. It is a difficult task, but it is something that we have to strive for.

Congress has stepped up to the plate and acknowledged the need for attention to the disabled. Unacceptably, Federal action in some areas has let the disabled community down. And I look forward to listening to the results of the Harris Poll survey that was commissioned by the National Organization on Disability. The poll is one instrument of the disabled constituency to speak out, and Congress must listen.

One area that I would like to highlight is education. As a former educator and a former school board member, disabled Americans are very close to my heart. Education can equip an individual with or without a disability to engage in society. The President and Congress are failing special needs children by breaking the promises we made when we enacted IDEA in 1975. When Congress passed the Education for All Handicapped Children Act, later known as IDEA, we explicitly promised to provide 40 percent of the excess costs of special education; 29 years later we have yet to keep that

promise. The Obey resolution, coincidentally being debated on the House floor today, puts us on the path to fully funding IDEA over a 6-year period. It would provide for a \$2.2 billion increase in special education funding. And this is \$1.2 billion over the President's request.

In perspective, President Bush has requested a \$1 billion increase in special education each year since he took office. At this rate of increase, we will have difficulty reaching full funding for IDEA. In education, we cannot afford to leave any child behind, especially those with disabilities.

So, in closing, Mr. Chairman, I would like to acknowledge the two very strong representatives of the disabled community that are here to testify today. The first is Mr. Robert David Hall, who is currently the character Dr. Al Robbins on CSI, that is, the Crime Scene Investigation series. And Mr. Hall is a double amputee that has successfully transferred his acting style to the award-winning CSI television drama. Mr. Hall's car accident in 1978 did not stop his desire for an acting career. I commend his dedication in furthering awareness on the disabled around the country. Mr. Hall also sits on several boards that promote support for the disabled, including the National Organization on Disability.

The second gentleman is Mr. John Register. And I had the pleasure of meeting Mr. Register at the Congressional Olympic dinner this year. Mr. Register is a model for all Americans and a testimony in perseverance. While training for the 1996 Olympics, Mr. Register severed an artery in his left leg. The resulting medical action was amputation below the left hip. Also an ambassador to the disabled community, Mr. Register trained for and won a medal in the Sydney Paralympic games in 2000, and we were there.

Mr. Chairman, I am very, very proud to be part of your committee, particularly with the subject matter today. These people in front of us offer us hope. Thank you. I yield back.

[The prepared statement of Hon. Diane E. Watson follows:]

**Government Reform Subcommittee
Human Rights and Wellness
Hearing on Disabilities
Opening Remarks
June 24, 2003
Congresswoman Diane E. Watson**

Thank you Mr. Chairman. I commend you for leading the Subcommittee on this very important issue. I also would like to thank my colleague, the Honorable James Langevin, from Rhode Island, for his testimony today.

The disabled in America are sometimes overlooked in the land where everyone supposedly has a voice. Americans with disabilities are Americans just the same. According to the constitution of the United States, the disabled are afforded the right to life, liberty, and the pursuit of happiness, exactly the same as any other citizen. Whether or not the disability is from a birth defect, an amputation, an accident, blindness, or deafness, the disabled should have a voice. Even those disabled that cannot speak can communicate their ideas through sign language, pictures, and captions. Mr. Chair, I appreciate the opportunity that we have to hear about living with a disability in the United States. I also extend a special thank you to those who are assisting our communication today (Note: You can acknowledge the hand signer if you want).

I understand that there are numerous challenges to life for every human being, and a disability adds a few more. As a long time public servant, I believe that it takes a very strong

individual to overcome many of the obstacles in our society. I also believe that good public policy works to ensure the well being of all citizens, which is sometimes a difficult task, but a standard to strive for. Congress has stepped up to the plate and acknowledged the need for attention to the disabled.

Unacceptably, federal action in some areas has let the disabled community down. I look forward to listening to the results of the Harris Poll survey that was commissioned by the National Organization on Disability. The poll is one instrument of the disabled constituency to speak out. Congress should listen.

One area that I would like to highlight is education. As a former educator, disabled Americans are very close to my heart. Education can equip an individual, with or without a disability, to engage in society. The President and Congress are failing special needs children by breaking the promise we made when we first enacted IDEA in 1975. When Congress passed the Education for All Handicapped Children Act, later known as IDEA, we explicitly promised to provide 40% of the excess cost of special education. Twenty-nine years later, we have yet to keep that promise. The Obey Resolution, coincidentally being debated on the House floor today, puts us on the path to fully funding IDEA over a six-year period. It would provide for a \$2.2 billion increase in special education funding. This is \$1.2 billion over President Bush's request. In perspective, President Bush has requested \$1 billion dollar increases in special education each year since he took office. At this rate of increase, we will **never** reach full funding of IDEA. In education, we can not afford to leave any child behind, especially those with a disability.

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Mr. Chairman, I yield back.

Mr. BURTON. Thank you for your kind remarks, and you can sing “Happy Birthday” to me later.

You might notice that we are the first committee to have closed captioning for the hearing impaired. And I think that is a giant step forward for this committee, and I hope the rest of the committees in the Congress will follow suit.

Representative Langevin, I appreciate very much your being here. We appreciate the contributions you are making, not only here, but in other areas, and we welcome your testimony.

**STATEMENT OF HON. JAMES LANGEVIN, A REPRESENTATIVE
IN CONGRESS FROM THE STATE OF RHODE ISLAND**

Mr. LANGEVIN. Thank you, Mr. Chairman. It is an honor to be here. Before I give my prepared remarks, let me just add something even more important and take the opportunity to wish you a happy birthday.

I want to thank Chairman Burton, Ranking Member Watson and the entire Subcommittee on Human Rights and Wellness for convening today’s hearings on Americans living with disabilities in the United States.

I commend you for your dedication to improving the lives of Americans with disabilities, and I am certainly grateful for the opportunity to participate in today’s hearing.

Mr. Chairman, as you mentioned in your opening remarks, at the age of 16, I served as a Boy Scout Explorer police cadet. I went through the program in my hometown of Warwick, RI, but on August 22, 1980, my dream of a career in law enforcement was shattered. I stood in a locker room with a fellow cadet watching two members of police SWAT team examine a handgun, which they believed was not loaded. That gun accidentally discharged, launching a bullet that ricocheted off a metal locker and into my neck severing my spinal cord and leaving me paralyzed.

At first, I was convinced that gun and this wheelchair had ruined my life. But I learned in time that a badge and a gun are not the only ways to make a difference or serve your community. I have been fortunate to be able fulfill my dreams of public service by serving as a delegate to the Rhode Island Constitutional Convention, a member of the State’s General Assembly, the Rhode Island Secretary of State, and now representing Rhode Island’s Second Congressional District in the U.S. House of Representatives.

The 24 years I have spent living with a disability in America have been very challenging, but also very fulfilling, both personally and professionally. These years have also seen great change. Discrimination in employment back then was legal; buildings were not designed with accessibility in mind; and accommodations of disability viewed really as charity, not as a civil right.

Looking back in my early years in a wheelchair, my college application process comes to mind. I was not able to go to my first choice school, because, quite simply, it just was not accessible. It was nearly 10 years before the passage of the Americans with Disabilities Act, and there was little that I could do about that. Fortunately for me, accommodations at my backup school, Rhode Island College, were better, and I was able to receive a quality education and the opportunity to put some of my new dreams to the test.

However, not all Americans have been so fortunate. Many Americans with disabilities today face a lack of access to health care and assistive technology, barriers to employment and a society that remains less inclusive than it could be. I want to discuss some of the most critical issues that I see facing Americans with disabilities today, and those are health care and employment.

People with disabilities are at risk in the health care system because of their wide-ranging health needs, their relatively heavy use of services and typically low incomes. The leading source of health coverage for people with disabilities is Medicaid. And while some States have established Medicaid buy-in programs for people with disabilities, too many people with disabilities are still barred from the workplace for fear of losing their eligibility for this program.

Meanwhile, in the face of rising costs and budget shortfalls, States are aiming to slow growing in program spending by curtailing benefits, increasing cost-sharing requirements, and restricting eligibility.

Mr. Chairman, I can personally attest that living with a disability is very expensive. Higher copayments and requirements for a person with a disability can simply be catastrophic.

Finally, Medicaid has yet to break away from the institutional bias. Only about 25 percent of Medicaid long-term care funds go to services and supports in home and community settings. Only three States spend more than 50 percent of their Medicaid long-term care funds on home- and community-based care. Individuals that are eligible for nursing home services should be able to choose between that and community attendant services and supports.

Congress has the power to level the playing field and give Medicaid beneficiaries equal access to community-based services and supports. We simply cannot achieve the goal of implementing the Supreme Court's Olmstead decision until we remove this institutional bias.

Several spending proposals in Congress would help to begin to rebalance and expand the long-term care system and provide quality supports and services in the community. These include MiCASSA, which would require States to include community-based personal assistance services in their Medicaid programs, and the Money Follows the Person Act and the NFI Medicaid Demonstrations Act, which provide demonstration grants to States to help individuals transition from institutions to community settings.

Moving to the topic of employment, I want to address the barriers that keep Americans with disabilities from the workplace. The unemployment rate in the disabilities community is a staggering 70 percent. Every day I hear stories from people who want to work, but are kept from doing so by barriers that we can easily pull together to overcome, primarily the concern over health benefits and the lack of transportation.

The cost of direct government and private payments to support people with disabilities of employment age without jobs is estimated to be approximately \$232 billion annually; another \$195 billion in earnings and taxes are lost each year because Americans with disabilities are unemployed.

Programs like a Ticket-to-Work, designed to promote work by providing SSI and DI recipients with a ticket to purchase rehabili-

tation from State VR agencies and other providers, begin to address these issues, but significant implementation challenges remain. Meanwhile, the 108th Congress has failed to agree on reauthorizing legislation through the Workforce Investment Act that would adequately provide displaced workers with the information, training and resources necessary to obtain or regain employment through the design and implementation of the one-stop delivery system.

Now, I am concerned that without increased investment and support for State vocational rehabilitation programs, much of the progress we have made will all be reversed, and more Americans will be relegated to a life spent in isolation, instead of sitting in a classroom, a board room or here with me in the U.S. Congress.

Mr. Chairman I want to thank you for the opportunity to raise some of the pressing issues facing Americans with disabilities. With the bipartisan passage of the Improving Access to Assistive Technology for Individuals with Disabilities Act earlier this month, we have seen commitment from members of both political parties to expand opportunities for people with disabilities in America. And I am certainly confident that we can make a great difference together for millions of American by continuing to work together in this fashion.

Thank you again for the opportunity to testify. It is an honor to be here.

[The prepared statement of Hon. James Langevin follows:]

CONGRESSMAN JAMES LANGEVIN
TESTIMONY FOR THE COMMITTEE ON GOVERNMENT REFORM
SUBCOMMITTEE ON WELLNESS & HUMAN RIGHTS
Oversight hearing "Living with Disabilities in the United States: A Snapshot"
June 24, 2004

I want to thank Chairman Burton, Ranking Member Watson, and the entire Subcommittee on Wellness and Human Rights for convening today's hearing on living with disabilities in the United States. I commend you for your dedication to improving the lives of Americans with disabilities and am grateful for the opportunity to participate in today's hearing.

At the age of 16, I served as a Boy Scout Explorer police cadet through a program in my hometown of Warwick, Rhode Island. But on August 22, 1980, my dream of a career in law enforcement was shattered. I stood in a locker room with a fellow cadet watching two members of the SWAT team examine a handgun. It accidentally discharged, launching a bullet that ricocheted off a metal locker and into my neck, severing my spinal cord and leaving me paralyzed.

At first, I was convinced that that gun, and this chair, had ruined my life. But I learned that a badge and a gun aren't the only ways to make a difference. I have been fortunate to be able to fulfill my dreams of public service by serving as delegate to the Rhode Island Constitutional Convention, a member of the state's General Assembly, Rhode Island's Secretary of State, and now representing the 2nd Congressional District of Rhode Island in the United States House of Representatives.

The 24 years I have spend living with a disability in America have been very fulfilling, both personally and professionally. These years have also seen a great deal of change. Discrimination in employment was legal, buildings were not designed with accessibility in mind, and accommodations of disability were viewed as a charity, not a civil right. Looking back to my early years in a wheelchair, my college application process comes to mind. I was not able to go to my first-choice school because it was inaccessible. Nearly ten years before the passage of the Americans with Disabilities Act, there was little I could do about that. Fortunately for me, accommodations at my back-up school were better and I was able to receive a quality education and the opportunity to put some of my new dreams to the test.

However, not all Americans have been as so fortunate. Many Americans with disabilities today face a lack of access to health care and assistive technology, barriers to employment and a society that remains less inclusive than it could be. I want discuss the most critical issues that I see facing Americans with disabilities today: health care and employment.

People with disabilities are at risk in the health care system because of their wide-ranging health needs, their relatively heavy use of services, and typically low incomes. The leading source of health coverage for people with disabilities is Medicaid. While some states have established Medicaid buy-in programs for people with disabilities, too many people with disabilities are still barred from the workforce by a fear of losing their eligibility for this program.

Meanwhile, in the face of rising costs and budget shortfalls, states are aiming to slow growth in program spending by curtailing benefits, increasing cost-sharing requirements, and restricting eligibility. Mr. Chairman, I can personally attest that living with a disability is very expensive. Higher co-payment requirements for a person with a disability can be catastrophic.

Finally, Medicaid has yet to break away from the institutional bias. Only about 25% of Medicaid long-term care funds go to services and supports in home and community settings. Only 3 States spent more than 50% of their Medicaid long-term care funds on home and community based care. Individuals that are eligible for nursing home services should be able to choose between that and community attendant services and supports. Congress has the power to level the playing field and Medicaid beneficiaries equal access to community-based services and supports. We simply cannot achieve the goal of implementing the Supreme Court's Olmstead decision until we remove this institutional bias. Several pending proposals in Congress would help to begin to rebalance and expand the long term care system and to provide quality supports and services in the community. These include MiCASSA, which would require states to include community based personal assistance services in their Medicaid programs; and the Money Follows the Person Act and the NFI Medicaid Demonstrations Act, which would provide demonstration grants to states to help individuals transition from institutions to community settings.

Moving to the topic of employment, I want to address the barriers that keep Americans with disabilities from the workplace. The unemployment rate in the disability community is a staggering 70 percent. Every day I hear stories from people who want to work, but are kept from doing so by barriers that we can easily pull together to overcome – primarily concern over health benefits and lack of transportation.

The cost of direct government and private payments to support people with disabilities of employable age without jobs is estimated to be \$232 billion annually. Another \$195 billion in earnings and taxes are lost each year because Americans with disabilities are unemployed. Programs like Ticket-to-Work, designed to promote work by providing SSI and DI recipients with a "ticket" to purchase rehabilitation from state VR agencies and other providers, begin to address these issues -- but significant implementation challenges remain. Meanwhile, the 108th Congress has failed to agree on reauthorizing legislation for the Workforce Investment Act that would adequately provide displaced workers with the information, training, and resources necessary to obtain or regain employment through the design and implementation of the One-Stop Delivery System. I am concerned that without increased investment and support for state vocational rehabilitation programs, much of the progress we have made will be reversed, and more Americans will be relegated to a life spent in isolation instead of sitting in a classroom, a boardroom, or with me here in Congress.

Mr. Chairman, I thank you for the opportunity to raise some of the pressing issues facing Americans with disabilities. With the bipartisan passage of the Improving Access to Assistive Technology for Individuals with Disabilities Act earlier this month, we have seen commitment from Members of both political parties to expand opportunities for people with disabilities in America. I am confident that we can make a great difference for millions of Americans by continuing to work together in this fashion.

Mr. BURTON. Thank you, Congressman.

There is not supposed to be any discrimination against people with disabilities in employment, but we obviously know that there are. And I imagine a lot of those discriminations are silent in nature. They are not responsible.

I do not know if this has ever been talked about, and I do not know if it is something doable or not, but it sounds to me that it is something that is doable, and that is tax incentives for business and industry to hire the disabled, an incentive for them to go the extra mile to make sure the large number of people who have disabilities do have gainful employment. Have you ever looked into that?

Mr. LANGEVIN. Sure, and I think that there may be some. And I do not want to speak off the cuff about that, but certainly tax incentives would be helpful and there is definitely a payoff return on the investment. For every dollar that is spent on putting someone to work as opposed to having the recipient on a social program, there is a benefit begun in terms of wages that are earned and also in taxes that are paid. So there is truly demonstrated research that says investment in putting people to work is far better and a bigger payoff than there is in the cost of actually supporting the program.

Mr. BURTON. You cited some very large figures, in the hundreds of billions of dollars, I believe, in your testimony, that is being lost because we have so many people who have disabilities who are not employed. We passed legislation, I think in the last 15, 20 years, that helped train the unemployable in the area of giving them skills so they could go out into the workplace. I think the Job Training Partnership Act and a couple of others were incentives for industry to hire people and train them, and I think there were tax incentives to do that.

I do not know—maybe Ms. Watson or somebody else knows; I cannot think of anything like that has been done to encourage the private sector to hire people or train people with disabilities so they could be gainfully employed. If there is not something like that, I would be very happy to work with you to draft legislation that I think would probably be looked upon favorably by the entire Congress, that might help in this area. It seems like to me that giving a tax incentive to the private sector to train and hire people with disabilities would be a real plus and a winner for everybody.

So if that is not the case, I would like to work with you and others to see if we cannot come up with something like that.

Mr. LANGEVIN. I look forward to working with you on that, Mr. Chairman.

Ms. WATSON. May I respond? Public Law 97-142 required, I know, school districts to provide accessibility and gave grants to school districts; and in a way, that relates to your question, tax incentives. They gave grants, and so maybe there is some way we can combine that. If they are able to adjust their facilities to make them accessible, then they could go after a grant and receive it. Also they would get a tax credit and they could be combined.

Maybe somebody could speak on that, who is an expert in that area. But I do remember that particular part.

Mr. BURTON. Most businessmen and -women respond to tax incentives that save them money and make them money. And to get

a talented employee and at the same time get a tax break for it, I think, like I said, would be a winner for everybody.

Let me just ask one or two more questions quickly.

Mr. LANGEVIN. Mr. Chairman, if I could offer something else too that would be helpful.

Back when the Americans with Disabilities Act was passed, there was money within DOJ to do a public education program, especially with employers about what is required under the ADA and what it really means. It has been about 12 years since ADA was passed, and I think that one of the barriers to people hiring with disabilities is the fear about what ADA requires. I think if there were money that was spent in helping to educate employers about how the ADA works and it is not something that requires an onerous burden, that would help eliminate some of the fear of what it means to hire people—someone with a disability, that would go a long way toward encouraging employers to bring people with disabilities into the work force.

Mr. BURTON. Well, maybe we could look at that at the same time we are looking at the incentive approach.

Are there other any other programs, other than what we have just been talking about, that you have been working on, or with other groups to push legislatively to get passed, that would help in this area?

Mr. LANGEVIN. Well, as cochairman of the Bipartisan Disability Caucus, we are trying to draw attention to programs that are working. The caucus, for example, has hosted events highlighting the contribution of a range of discretionary programs from the Developmental Disability Act to the Help America Vote Act. We have also done a great deal of outreach to educate members on the programs that have come up for reauthorization in the last few years, such as IDEA and the Workforce Investment Act.

Also, the programs that I mentioned earlier, programs that I found to be beneficial to people with disabilities, today the State assistive technology programs funded by the Assistive Technology Act certainly played a tremendous role in promoting awareness of and access to devices that allow individuals with disabilities to contribute to society, and also vocational rehabilitation programs, which are also administered through the States, are an important tool in placing people with disabilities into the work force.

Mr. BURTON. Ms. Watson, do you have any questions?

Ms. WATSON. Mr. Langevin, I would just like to have you let us know what other kind of programs, based on barriers that are still in the way for the disabled to find jobs—what kind of programs do you think we ought to develop here in Congress that might be effective?

So think about it, get back to us. I know that the tax incentive would work, but you might want to be more specific in terms of the barriers that you see still existing.

Mr. LANGEVIN. Clearly, the health care and the transportation barriers are the biggest ones to overcome, and I think the greatest benefit would be to bring people with disabilities into the work force. If people with disabilities were not afraid at any time to have to worry about losing their health care benefits, that would be a

tremendous incentive to get people off of social programs and get them out into the workplace.

But even that needs to be coupled with programs that provide transportation for people. It is no good to be able to get an application in if you are not able to get back and forth to work. So more assistance for public transportation programs would be of great benefit. I think those are the two biggest and most important tangible examples that I can give you.

Ms. WATSON. Thank you so much.

Thank you, Mr. Chairman.

Mr. BURTON. Thank you, Congressman. We really appreciate your hard work, and we will look forward to working with you in the future to try to solve some of these problems.

Mr. LANGEVIN. I look forward to that, Mr. Chairman. Thank you for the opportunity.

Mr. BURTON. Thank you.

Our next panel consists of the Honorable Troy Justesen. He is the Acting Assistant Secretary for the Office of Special Education and Rehabilitation Services at the Department of Education; and the Honorable Don Young, Deputy Assistant Secretary for the Office of Health Policy for the Department of Health and Human Services.

If you gentlemen would come forward, we would appreciate it.

Now we do not swear in Congressmen because we understand all Congressmen are above reproach, so we let them get away with this, but gentlemen, we will swear you in.

So will you raise your right hands, please?

[Witnesses sworn.]

Mr. BURTON. We will start with you, Mr. Justesen. Do you have an opening statement?

Mr. JUSTESEN. I do, Congressman.

STATEMENTS OF TROY JUSTESEN, ACTING ASSISTANT SECRETARY, OFFICE OF SPECIAL EDUCATION AND REHABILITATION SERVICES, U.S. DEPARTMENT OF EDUCATION; AND DONALD A. YOUNG, M.D., DEPUTY ASSISTANT SECRETARY, OFFICE OF HEALTH POLICY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. JUSTESEN. First of all, thank you for having me here again before you today. It is a pleasure to be here. And, Congresswoman, it is a pleasure to see you again.

I am the Acting Deputy Assistant Secretary for the Office of Special Education and Rehabilitative Services within the Department of Education. So much of what you discussed with Congressman Langevin is directly related to the work that I have the privilege and responsibility for implementing in the Department of Education.

I want to frame my discussion with you today around the President's New Freedom Initiative and how the New Freedom Initiative is our guiding principle for providing services to people with disabilities from birth through the life span, because that is the challenge within the Office of Special Education and Rehabilitation Services in the Department.

The New Freedom Initiative is the President's goal and vision for expanding and building upon the successes of Congress' success in special education, rehabilitation services and basic civil rights, like the Americans with Disabilities Act and section 504 of the Rehabilitation Act of 1973. But we want to move and build upon that success and that foundation.

The New Freedom Initiative [NFI], has four basic components, and I will outline those components for you and give you some examples about the work we are doing to improve services for children, youth and adults with disabilities throughout the country.

Now, NFI is basically divided into four main pillars or components, as I call them. The first is increasing access to assistive technologies, universally designed technologies for individuals with disabilities.

The second is expanding educational opportunities for children, youth and adults with disabilities.

The third is integrating these individuals, Americans with disabilities, successfully into the work force.

And the fourth and most encompassing component of the New Freedom Initiative is to make sure the community, community life and accessibility is fully available to all people with disabilities. So the fourth component is mainly the broad theme which the other three components fall under.

Now, with respect to increasing access to assistive technologies, universally designed technologies, the Department administers the programs of assistive technology in our National Institute on Disability Rehabilitation Research. We do what Congressman Langevin alluded to, which is we implement the Assistive Technology Act of 1998.

That act provides opportunities for State systems to change programs and opportunities for direct loan programs for individuals with disabilities to obtain the assistive technology devices and services they need in order to live independently in the communities of their choice. We are working very closely through our partners at the State level on making these funds available to provide low-interest and long-term loans of affordability, so that individuals with disabilities can purchase any device or service they need to live independently.

That is a major achievement and one in which the President's New Freedom Initiative builds upon, and we are working very closely with our partners at HHS and the other partners in the Federal agencies because the New Freedom Initiative is the President's challenge for agencies to look beyond the boundaries of their own programs and services and look at ways in which we can work in partnership at the Federal level and be a role model for State and local entities to improve services for people with disabilities.

The President has signed an Executive memorandum, and this is just one example of how we move technology forward for people with disabilities. And his EM, his Executive memorandum, challenged all of the Federal agencies to work together and develop a cross-agency Web site that was available to all Americans, including Americans with disabilities, to access a single site location, a single one-stop center whereby individuals can go to that Web site and access information directly about any of the variety of services

that people with disabilities and their family members would need to access, including Social Security programs, information about job opportunities and job accommodations, about accessible transportation and accessible housing, which continues to be a major challenge for people with disabilities. Emergency preparedness has become increasingly more important in recent years, and the opportunities for expanding educational programs and services for people with disabilities is particularly emphasized in the Individuals With Disabilities Education Act [IDEA], which Congresswoman Watson alluded to.

Under the President's administration, grants and programs have received an increase of more than \$3.7 billion in annual funding, and the President has requested an additional billion dollars in funding for the IDEA in fiscal year 2005. We are working very closely to also provide opportunities and mesh very well the President's No Child Left Behind Act in elementary and secondary education with the IDEA, which is special education programs and services, making sure that children with disabilities are fully integrated and provided the educational services and benefits they need to participate in the regular classroom environment with their peers without disabilities, which is a very important aspect.

Now, integrating Americans with disabilities into the work force is a profound challenge. The Department of Education is working with its sister partners at Labor, HHS, HUD and all of the other Federal agencies to increase the employment opportunities for people with disabilities, because people with disabilities are underemployed at higher rates than any other class of people in America. The research shows it is between 50 and 70 percent. And we know from our basic research that has been conducted with our partners in both the public and private sector, including the National Organization on Disability, that these rates consist primarily because of attitudinal barriers toward the abilities of people with disabilities.

The Rehabilitation Services Administration in the Department of Education is focused primarily on helping people with disabilities obtain the skills, knowledge and experience they need to fully integrate into every aspect of society, including employment. Last year, the Rehabilitation Services Administration, with its State partners, was successful in finding fully integrated, gainful employment for more than 223,000 people last year.

This year, we will serve in special education at least 6.5 million young people with disabilities in this country. All of this serves toward our greatest implementation, which is making sure that communities of individuals with disabilities have accessibility to the programs and services they need to live independent, fully productive lives in the communities of their choice.

Transportation, as the Congresswoman mentioned to you, is one of the most key components of accessibility and access, including employment and basic enjoyment for people with disabilities.

In February of this year, the President challenged, through an Executive order, all of his Federal agencies to work together to figure out what the Federal barriers are that currently exist in the systems and programs posing impeded access to basic integrated transportation services for people with disabilities. All of the Federal agencies under the New Freedom Initiative today are working

through plans to make Federal funding and remove Federal barriers in transportation services for people with disabilities. This is a model that we have at the Federal level to show how well State and local entities can provide programs and services for their children, youth and adults with disabilities.

The NFI is designed to realize a plan for equal access and full participation in American society for individuals with disabilities, and that plan is for now and also for the future. We at the Department of Education look forward to working with our sister agencies and working even more closely on collaboration so that we remove all of the barriers that are posed for people with disabilities in American society.

Thank you, Congressman.

Mr. BURTON. Thank you, Secretary Justesen. We appreciate you being with us today.

[The prepared statement of Mr. Justesen follows:]

Department of Education

Statement by Troy R. Justesen, Ed.D.

Acting Deputy Assistant Secretary

Office of Special Education and Rehabilitative Services

On

Living with Disabilities in the United States: A Snapshot

June 24, 2004

Mr. Chairman and Members of the Subcommittee:

Good afternoon, I am Troy Justesen, the Acting Deputy Assistant Secretary for Special Education and Rehabilitative Services at the Department of Education. Thank you for the opportunity to describe Federal program initiatives affecting the quality of life for U.S. citizens living with disabilities. On February 1, 2001, fewer than two weeks after his administration began, President George W. Bush announced the New Freedom Initiative (NFI). In doing so, the President said: "I am committed to tearing down the remaining barriers to equality that face Americans with disabilities today." The NFI is designed to affect every aspect of the quality of life of individuals with disabilities by increasing access through technology, expanding educational opportunities for youth, integrating Americans with disabilities into the work force, and promoting full access to community life. NFI outlines a comprehensive strategy for full integration of people with disabilities and serves as a set of guiding principles for change. The goals of the NFI reach across the agencies of the Federal government and across America. I

intend to summarize some of the most recent accomplishments in the four major areas under the NFI.

Increasing Access Through Technology

New technologies are providing individuals with greater access to school, work, and community life. In addition to promoting the development of new assistive and universally designed technologies, the New Freedom Initiative helps to put assistive technology into the hands of more individuals with disabilities through policies that reduce barriers associated with cost. The Office of Special Education and Rehabilitative Services (OSERS) administers a loan program to assist individuals with disabilities to purchase assistive technologies under Title III of the Assistive Technology Act of 1998. The program matches state dollars with Federal dollars to create alternative financing mechanisms, such as low interest, long-term loans. OSERS also provided a total of approximately \$40 million in fiscal years 2002 and 2003 to support Rehabilitation Engineering Research Centers to promote research on assistive and universally designed technologies.

The NFI has provided Americans with greater access to work opportunities. President Bush has highlighted the importance of section 508 of the Rehabilitation Act of 1973 for its role in making the world of information technology more readily accessible. Section 508 requires that all electronic and information technology purchased and used by the Federal government be accessible and usable by individuals with disabilities. President Bush is strongly committed to implementing section 508 and, since its inception, significant strides have been made in improving the accessibility of information technology for employees of the largest employer in

the United States, the Federal government. With every new acquisition of information technology, section 508 uses the natural forces of the market to increase the prevalence of accessible information technology tools and resources for both Federal employees and citizens using e-Government resources.

In August 2002, President Bush signed an Executive Memorandum requiring the creation of a cross-agency website to make disability information easily accessible to all Americans. Less than sixty days later, DisabilityInfo.gov was launched. Operated by the Department of Labor's Office of Disability Employment Policy, DisabilityInfo.gov streamlines access to information about Federally sponsored employment, housing, job accommodations, transportation, income support, health care, state and regional assistance programs, technology, emergency preparedness, and other programs relevant to the daily lives of people with disabilities.

Expanding Educational Opportunities for Youth

The President has delivered on his promise in the New Freedom Initiative to increase funding for the Individuals with Disabilities Education Act (IDEA), which requires that all children with disabilities be provided a free appropriate public education. Since FY 2001, the IDEA Part B State Grants program has received an increase of more than \$3.7 billion in annual funding and the President is proposing another \$1 billion increase for FY 2005. In FY 2004, nearly \$10.1 billion are available for this program, which represents an increase of 59 percent since 2001.

In order to improve the educational outcomes for students with disabilities, on October 2, 2001, the President's Commission on Excellence in Special Education was created and charged with collecting information, studying issues related to Federal, state and local programs, and recommending policies for improving the educational performance of students with disabilities. The Commission submitted its final report to the President on July 1, 2002.

In September 2003, the Department of Education and the Department of Health and Human Services funded eight research projects to explore the effectiveness of curriculum interventions or programs in preparing at-risk children for school. These two Departments also formed a partnership to support research to enhance literacy and employment skills of adolescents.

Here at the Department of Education, OSERS collaborates with Department offices on the implementation of the No Child Left Behind Act to improve teacher quality and to include all students in accountability systems. Weekly meetings are held at leadership and staff levels, where the challenges of including students with disabilities are discussed and options for change are considered. Results from those meetings include new regulations and guidance on the inclusion of children with the most significant cognitive disabilities in State accountability systems and additional flexibility in how the highly qualified teacher standards may be met. OSERS is also collaborating with offices across the Department, including the Office of Vocational and Adult Education on the "Preparing America's Future High School Initiative" and the Office of English Language Acquisition on a National Symposium on Learning Disabilities in English Language Learners.

As the New Freedom Initiative results in better educational opportunities and outcomes for more students with disabilities, it is critical that efforts are undertaken to promote the successful transition of youth to post-secondary school, work, and other goals that will enhance the lives of these individuals. One such effort is a joint effort between the Department of Labor and the Department of Education, in which over \$880,000 was awarded in 2003 to six faith-based and community intermediary organizations to help build the capacity and knowledge of faith-based and community organizations to provide mentoring services to young people with disabilities. Another interagency effort involves work being done through the National Alliance on Secondary Education and Transition to identify evidence-based guideposts as to what all youth, including youth with disabilities, need to transition successfully.

Integrating Americans with Disabilities into the Workforce

In OSERS, the Rehabilitation Services Administration is working with the Social Security Administration on the implementation of the landmark Ticket to Work and Work Incentives Improvement Act. Under the Ticket to Work program, eligible individuals receiving Social Security or Supplemental Security Income benefits due to disability receive a ticket that they may use to obtain vocational rehabilitation services, employment services, or other support services from an employment network or a State vocational rehabilitation agency of their choice. The Ticket to Work program is being rolled out in three phases, the first two of which have already been completed. Over 8 million tickets have been issued throughout the States and the District of Columbia. As of December 2003, the Social Security Administration had awarded 1,150 contracts to public and private entities wishing to serve as employment networks for ticket

holders. In addition, the Rehabilitation Services Administration and the Social Security Administration are developing a Memorandum of Understanding to share data and to better coordinate program administration.

Additionally, the President supports full implementation of the Americans with Disabilities Act (ADA), but recognizes that more needs to be done. Federal agencies, including the Department of Justice and the Equal Employment Opportunity Commission, enforce the ADA through complaint investigations and litigation. The New Freedom Initiative also calls on agencies to develop new, innovative strategies to educate covered employers about the ADA and about the benefits of hiring qualified individuals with disabilities. The Department of Justice created the “ADA Business Connection,” a project to bring about increased compliance with the ADA by fostering a better understanding of ADA requirements among the business community and by increasing dialogue and cooperation between the business community and the disability community. Continuing work between the Department of Justice and the Department of Education has resulted in productive discussions and promising collaborations between the business and disability communities.

Promoting Full Access to Community Life

The Supreme Court’s landmark decision in Olmstead v. L.C. affirmed the right of individuals with disabilities to live in the community rather than in institutions whenever possible. The President recognizes, however, that making the promise of full integration a reality for people with disabilities means not only changing existing practices that favor institutionalization over

community-based treatment, but also providing the affordable housing, transportation, and access to state and local government programs and activities that make community life possible.

As part of his promise in the New Freedom Initiative to swiftly implement the Olmstead decision, the President issued an executive order, which requires coordination among numerous Federal agencies that administer programs affecting access to the community for people with disabilities. On March 25, 2002, nine Federal agencies, including the Department of Education, submitted to the President a report entitled *Delivering on the Promise*. The report summarizes agency activities that support Olmstead's goal of integration, identifies barriers that exist within programs to full implementation of Olmstead, and proposes more than 400 solutions aimed at removing these barriers.

Access to transportation is critical for achieving full integration of individuals with disabilities into the community. People with disabilities need reliable transportation so that they can obtain and keep jobs, access medical care, and participate in all of the activities a community has to offer. The "United We Ride" program is a five-part initiative to assist states and communities in coordinating human service transportation. The Departments of Transportation, Health and Human Services, Labor, and Education are working together to remove barriers at the Federal level, and to provide assessment tools, technical assistance, peer-to-peer sharing opportunities, and modest grants to help states and communities deliver appropriate and cost-effective transportation services for all individuals with disabilities.

On April 29, 2002, the President established the New Freedom Commission on Mental Health. Composed of fifteen members representing providers, payers, administrators, consumers of mental health services, and family members of consumers, the Commission was charged with conducting “a comprehensive study of the United States mental health service delivery system, including public and private sector providers,” and was directed to advise the President on methods of improving the system. In July 2003, the Commission issued its recommendations in a final report entitled *Achieving the Promise, Transforming Mental Health Care in America*. The report identifies barriers to care within the mental health system and examples of community-based care models that have proven successful in coordinating and providing treatment services. While this is certainly not an exhaustive list of programs initiated to improve the quality of life for individuals with disabilities, we at the Department of Education, and specifically OSERS, remain committed to programs, policies, and initiatives that do just that- improve the quality of life from our youngest citizens to our oldest. Our work across the Department and the Federal government, through the ideals of the New Freedom Initiative, are designed to improve outcomes for individuals with disabilities now and into the future.

Mr. Chairman, that concludes my prepared remarks. I will be happy to answer any questions.

Mr. BURTON. Mr. Young.

Mr. YOUNG. Good afternoon, Mr. Chairman, members of subcommittee. I am pleased to be here today to discuss the Department of Health and Human Services programs for people with disabilities.

This is an issue that President Bush took on early and vigorously. In February 2001, he announced the New Freedom Initiative, building on the landmark Americans with Disabilities Act.

HHS plays a major role in addressing the New Freedom Initiative. Our programs reflect a fundamental commitment to promote independence and quality of life, to enable people with disabilities to receive services in the most integrated settings, and so to support people with disabilities in their efforts to work.

Americans with disabilities are part of the population served by all HHS programs; however, I will highlight here the larger HHS programs focused on serving people with disabilities.

Dependable, high-quality health care is a critical need. Approximately 8 million people with disabilities qualify for Medicaid on the basis of the SSI financial and disability criteria. Medicare also provides health coverage for individuals who receive Social Security disability insurance. Approximately 6.4 million people under age 65 receive Medicare on the basis of disability.

The Medicaid program is by far the largest public payer of long-term support for people with disabilities. In 2003 Medicaid, paid \$45 billion for nursing home services, \$11 billion for institutional settings for people with mental retardation and \$28 billion for community support.

Medicaid law requires States to offer nursing home care, but it allows States the option to provide community-based services. In 1990, Medicaid spending for community care represented 14 percent of Medicaid long-term care spending; in 2003, it was 33 percent. Over the past 3 years HHS has awarded approximately \$121 million in grants to States to influence and accelerate the shift. The Real Choice Systems Change grant program funds States and other eligible entities to make systems changes that enable individuals with disabilities to live in the most integrated settings possible, to exercise meaningful choices about their lives, and to obtain quality services. We will be awarding another \$31 million this year.

One of the most promising developments is consumer-directed models of care. The best known model of Medicaid consumer-directed care is the cash and counseling program, which is designed and supported by HHS and the Robert Wood Johnson Foundation. Under this program and others like it, people who use Medicaid personal assistance are offered individual budgets rather than specific services. Satisfaction and quality are high, and there is less reliance on nursing home services. HHS promotes the use of these models through Medicaid Independence Plus Waivers and the LIFE Accounts Initiative included in the President's 2005 budget.

It has been estimated that the value of the free care provided by informal caregivers exceeds \$257 billion annually. HHS supports caregivers with initiatives such as the Administration on Aging's National Family Caregivers Support Program, which provided \$159 million this year in grants for information, counseling, training, respite care and supplemental services to over 500,000 caregivers.

When formal services are needed, it is critical that we have in place a committed work force to provide high-quality services. We address the issue with \$12 million in States to improve the recruitment, training, support and retention of workers with an emphasis on the provision of a health care benefit for direct service workers.

An important component of the President's New Freedom Initiative is doing everything possible to help people with disabilities to work. We work closely with our partners to effectively advance the goals of the Ticket-to-Work and Work Incentives Improvement Act of 1999, which encourages people with disabilities to work, but to work without fear of losing eligibility under Medicare, Medicaid and similar health benefits. To date, we have awarded \$57 million in Medicaid infrastructure grants to 42 States and the District of Columbia to help people with disabilities find and keep work without losing their health benefits.

The Administration on Developmental Disabilities provided over \$140 million in grants last year to assist the Nation's nearly 4 million people with developmental disabilities. Support for young children with disabilities and their family members is also important. The Maternal and Child Health program provides funds to States to improve the health of children with special health care needs and their families. In 2004, approximately \$200 million of this Federal investment is being allocated to community-based care for the estimated 18 million children with special health needs.

The HHS Office on Disability, created in 2002, coordinates Department initiatives and supports the "I Can Do It—You Can Do It" physical fitness program, providing mentors for children and youth with disabilities, as well as other programs for people with disabilities.

Many of the programs I have talked about today had their roots decades ago. Although we continue to improve and modernize them as individual needs and values change, working with our State and local partners and, most importantly, working with people with disabilities and their families, we have come a long way. But as President Bush has stated, there is much more to do.

We at HHS are firmly committed to meeting the President's challenge, and I am happy to answer any questions.

[The prepared statement of Mr. Young follows:]



TESTIMONY OF

DONALD A. YOUNG, M.D.
DEPUTY ASSISTANT SECRETARY FOR PLANNING AND
EVALUATION
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

COMMITTEE ON GOVERNMENT REFORM
SUBCOMMITTEE ON HUMAN RIGHTS AND WELLNESS
U.S. HOUSE OF REPRESENTATIVES

JUNE 24, 2004

Good afternoon, Mr. Chairman and Members of the Subcommittee.

It is a pleasure to appear before you today to discuss the Department of Health and Human Services' (HHS) programs for people with disabilities and the President's New Freedom Initiative. We are pleased that you are holding this hearing to better understand Federal initiatives and programs that affect the quality of life of Americans with disabilities.

This is an issue that President Bush took on early and vigorously when he came into office. In February 2001, one of the first initiatives he announced was the New Freedom Initiative, which builds on the Americans with Disabilities Act, the landmark legislation signed into law by President George H.W. Bush in 1990. In announcing the New Freedom Initiative, the President said, "We are more mindful now of the hardships that come with disability, more generous in responding to the needs of our citizens, more grateful for [their] contributions to society. Old misconceptions about physical and mental disability are being discredited. Old barriers are falling away. Our task is now clear: we must speed up the day when the last barrier has been removed to full and independent lives for every American with or without a disability."

Under the leadership of Secretary Thompson, nine Federal agencies formed the Interagency Council on Community Living to evaluate their policies, programs, statutes and regulations to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities and reported back to the President with their findings. On March 25, 2002, HHS presented the President with *Delivering on the Promise: Compilation of Individual Federal Agency*

Reports of Actions to Eliminate Barriers and Promote Community Integration. The Report consisted of more than 400 specific solutions each Department identified to support community living for the nearly 54 million Americans living with disabilities.

The Department of Health and Human Services plays a major role in addressing the New Freedom Initiative challenge set by the President. It conducts and supports a variety of programs and initiatives to provide assistance and support to people with disabilities and their families.

Through the Medicare and Medicaid programs, we provide health care and supportive services to approximately 13 million Americans with disabilities in a wide range of settings. Our Administration on Developmental Disabilities (ADD) is the President's New Freedom Initiative in action. ADD, through the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), funds and oversees over 180 grants to promote opportunities and services that result in individuals with developmental disabilities living in and contributing to their communities.

Our Administration on Aging (AoA) operates a comprehensive network -- Federal, State and local organizations that coordinate and deliver community supports to Americans over age 60, many with disabilities, and their caregivers. Our Substance Abuse and Mental Health Services Administration (SAMHSA) funds a variety of activities and services to meet the needs of individuals with mental disabilities and substance abuse disorders. Primary health programs funded by the Health Resources and Services Administration (HRSA) serve people with disabilities, as do several of our other "mainstream" programs such as those within the Indian Health Service, and programs in

the Administration for Children and Families (ACF) such as Head Start, Temporary Assistance for Needy Families (TANF) and other family services programs.

The Office of the Assistant Secretary for Planning and Evaluation maintains an extensive research agenda on a number of disability, aging and long-term care policy issues, and there are substantial disability related research initiatives underway within the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

Our Office for Civil Rights, in collaboration with the Department of Justice and other partners, works to ensure compliance with civil rights laws that prohibit discrimination on the basis of disability in HHS federally conducted and federally assisted programs and is responsible for ensuring that State and local government health and social service programs comply with the Americans with Disabilities Act.

In October 2002, Secretary Thompson created the Office on Disability in response to a key HHS solution recommended in the report *Delivering on the Promise*. The office serves as the focal point within HHS for the implementation and coordination of policies, programs and special initiatives related to persons with disabilities.

The array of HHS programs serving people with disabilities is broad and diverse but the programs are bound together by a fundamental commitment to: (1) promote the independence and quality of life of individuals with disabilities; (2) enable people with disabilities to receive the services they need in the most integrated settings possible; and (3) support people with disabilities in their efforts to work.

Who are People with Disabilities?

One of the Administration's key contributions to policymakers working on disability programs is the collection and dissemination of data on the number and characteristics of Americans with disabilities. At any one time, 40 to 50 Federal activities may be funding, collecting and/or compiling data on disabilities in the U.S. These activities include program eligibility information, administrative data, ongoing surveys, special surveys, and research. These activities focus on the general population or special subsets, such as children, working age adults, the elderly, or people disabled by mental illnesses. Data collection activities may focus on work, education, program utilization, or the national prevalence of disability. Data are collected as household surveys, in person interviews, or via telephone.

Within this array, there are major sources of information on people with disabilities. These include the following: (1) Decennial Census; (2) Survey of Income and Program Participation; (3) National Health Interview Survey; (4) Medicare Current Beneficiary Survey; (5) Health and Retirement Study; and (6) National Long-Term Care Survey. (See Attachment A for detailed descriptions.)

The term "disability" encompasses a wide range of functional limitations and conditions. Various data sources yield different estimates, depending upon how disability is defined. For example, the Survey of Income and Program Participation reported that 53 million Americans, or 19.7 percent of those living in non-institutional settings, had a disability in 1997. About 12.3 percent of the population reported a severe disability, and 3.8 percent had long-term care needs (need for assistance from another

person with basic activities of daily living such as eating, dressing, transferring from bed to chair, walking, and toileting).

One important type of disability occurs when functional limitations are severe enough to affect the ability to work. In 1997, about 16.9 million persons, or 9.8 percent of the population age 16 to 64 reported that they were limited in the amount or kind of work they can do.

Another indicator of disability is whether a person receives benefits under Federal disability cash benefit programs operated by the Social Security Administration (Social Security Disability Income [SSDI] or Supplemental Security Income [SSI]). In March 2004, about 10.5 million persons under age 65 received such benefits. To qualify for these cash benefit programs, individuals must meet strict disability standards, not be engaging in substantial gainful activity, and have a disability that is expected to continue for at least a year or result in death.

HIGHLIGHTS: MAJOR HHS PROGRAMS SERVING PEOPLE WITH DISABILITIES

Americans with disabilities, including those with mental, sensory, cognitive, developmental, or physical disabilities are part of the population served by all HHS “mainstream” programs because by the broadest definition, almost one in five Americans has a disability. For example, approximately 13 percent of the children enrolled in Head Start programs nationwide have a disability.

However, I will highlight here the larger HHS programs focused more precisely on serving people with disabilities.

Health and Long-Term Care Services

Dependable, high quality health care is a critical need for people with disabilities. HHS supports the delivery of health care services under the Medicaid, SCHIP, Medicare and Indian Health Service programs. People with disabilities qualify for Medicaid in a number of ways, but approximately 8 million people with disabilities qualify explicitly on the basis of meeting the SSI financial and disability eligibility criteria. These individuals are entitled to the full range of Medicaid financed services offered in their State, including physician and hospital care. Although Medicare is principally a health care program for people over the age of 65 (including many with disabilities), it also provides health coverage for individuals with disabilities who receive SSDI, generally after a two-year waiting period. Approximately 6.4 million people under age 65 receive Medicare on the basis of a disability.

Many individuals with functional impairments require assistance with the tasks of daily living. Medicaid, the State-Federal health care program for low-income people, is by far the largest public payer of long-term supports for people with disabilities. In 2003, States and the Federal government spent approximately \$44.8 billion Medicaid dollars on nursing home services, serving approximately 1.6 million people (at some point in the year); \$11.3 billion on institutional settings for people with mental retardation, serving 110,572 people with mental retardation or developmental disabilities. Still yet, \$27.8 billion was spent to support individuals in the community with home and community-based services, personal care and home health.

Promoting Community-Based Long-Term Care Services

The legislation that authorizes Medicaid requires participating States to offer nursing home care, but offers States the option to provide Medicaid community-based services. Yet, most consumers and their families prefer to receive services at home, in the community for as long as possible. As one American told us: “I fear that [as my needs increase] if I can’t have attendant care when I need it in my home, I will be institutionalized. And what I will lose, then, is the last thing that I have. It’s my freedom.”

The Administration and its State partners are listening. While Medicaid spending is still biased toward institutions, the ratio is shifting dramatically, with the proportion targeted toward home and community care increasing. For instance, in 1990 Federal-State Medicaid spending for community care represented 13.7 percent of Medicaid long-term care spending; in 2003, it was 33.2 percent.

Over the past three years, HHS has awarded approximately \$121 million in grants to States to influence and accelerate this shift. The “Real Choice Systems Change” grant program provides States and other eligible entities with funding to make lasting improvements to their home and community-based services programs. We will be awarding another \$31 million this year. This unprecedented, multi-year investment, is designed to support systemic changes that will enable individuals with disabilities to: (1) live in the most integrated community settings appropriate to individual support needs and preferences; (2) exercise meaningful choices about their living environments, the providers of service they use, the types of supports and the manner in which services are provided; and (3) obtain quality services in a manner as consistent as possible with their

community living preferences and priorities. These grants address a range of topical concerns, including “money follows the person,” quality, employment supports, community care for children, and respite care for adults, to name a few. This year, grants will address mental health systems, family to family health care information centers, quality of community-based services, integration of housing and services, and others areas.

Another component of this effort is the collaboration between the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) to provide States with an opportunity to effectively integrate their long-term support resources for consumers into a coordinated system. Twenty-four States have now received Aging and Disability Resource Center grants to develop streamlined access to long-term care for people with disabilities of all ages. And AoA and CMS are committed to funding additional States in FY 2005.

Promoting Consumer Choice and Control

One of the most promising developments in Medicaid community care is the development of consumer directed models and the policy changes to promote them. The best-known model of Medicaid consumer directed care is the “Cash and Counseling Program” which was designed and supported by the Office of the Assistant Secretary for Planning and Evaluation, CMS, and the Robert Wood Johnson Foundation. Under this program, and others like it, people who use Medicaid personal assistance are offered the opportunity to receive individual budgets, rather than services provided by an agency. The individual budget gives the consumer the flexibility to select what services he or she will use and who will deliver them; in addition, there may be flexibility to buy certain

products that contribute to the individual's independence. Consumers typically select caregivers who are family members or friends. The consumer's use of the funds is supported by a counselor, and "fiscal intermediary" agencies help with the paperwork. But the consumer is at the center of it all-in the driver's seat of his or her own life. According to rigorous research findings, participants in these programs report close to 100 percent satisfaction; quality is very high; and, there is less reliance on nursing home services. People stay at home and in control of their own lives much longer.

CMS promotes the use of these models through Medicaid Independence Plus Waiver Initiatives and grants to support consumer direction. In addition, the LIFE Accounts Initiative, included in the President's 2005 budget, would promote consumer and family directed services.

Caregiver Support

Most people with disabilities who receive community-based services rely exclusively on family members and friends. It has been estimated that the value of the "free care" provided by these "informal caregivers" exceeds \$257 billion annually, and that one of every four people in the U.S. is a caregiver for a family member or friend with a disability. These individuals report that they provide this care because of their personal relationship with the recipient. But we also know these caregivers sometimes need support. Prolonged caregiving can adversely affect one's physical and psychological health, current and future employment status, and earning capability. HHS supports key initiatives to support caregivers with training, information, and respite care. The Administration on Aging's National Family Caregiver Support Program provided \$159.1 million this year to provide outreach with information to about 8 million individuals, as

well as assistance, counseling, training, respite care, and supplemental services to over 500,000 caregivers. Family caregivers of individuals with disabilities who are over age 60 or under age 18 are eligible for assistance under this program.

In his 2005 budget, the President proposed innovative demonstrations under the Medicaid program that would enhance the ability of individuals with disabilities to live and fully participate in the community. With \$18 million proposed for FY 2005 (\$327 million over the five-year demonstration period) these demonstrations would address adult respite-testing the provision of respite for caregivers of adults as a Medicaid service; children's respite-testing the provision of respite for caregivers of children as a Medicaid service; and alternatives to psychiatric residential treatment for children-providing family and community-based programs for children with psychiatric disabilities as an alternative to psychiatric residential treatment facilities.

In addition, in his 2005 budget, the President proposed a \$3,100 personal tax exemption for certain qualified individuals with disabilities and their caregivers when the person with a disability lives with the caregiver.

Supporting a Quality Long-Term Care Workforce

When "formal" services are needed, it is critical that we have in place a committed workforce to provide high quality services. Secretary Thompson has done a great deal to bring a national focus to addressing the crisis in recruiting and retaining such a workforce for community-based and institutional settings. Providers report turnover rates that are sometimes in excess of 100 percent a year. The Office of the Assistant Secretary for Planning and Evaluation recently co-sponsored a national conference on this issue with the Department of Labor, bringing together workers,

researchers, providers, policy makers, and people with disabilities to explore new solutions. In addition, we are conducting the first nationally representative survey of direct care workers who serve people with disabilities, starting this summer with nursing home workers. We will explore the characteristics, attitudes, and job satisfaction of these individuals. Finally, CMS has awarded approximately \$12 million since 2003 in grants to States to improve the recruitment, training, support and retention of direct service workers with an emphasis on the provision of a health care benefit for direct service workers.

Promoting Independence Through Work

An important component of the President's New Freedom Initiative is doing everything possible to help people with disabilities to work. Secretary Thompson has said, "Fear of losing access to health coverage is a major obstacle for people with disabilities who want to work." We in HHS work closely with our partners in the Departments of Education and Labor and the Social Security Administration to ensure that our programs: (1) support this important vehicle to independence; and, (2) effectively advance the goals of the Ticket to Work and Work Incentives Improvement Act of 1999, which encourages people with disabilities to work without fear of losing eligibility under Medicare, Medicaid or similar health benefits.

In March, we awarded \$15.7 million in Medicaid Infrastructure Grants to 28 States and the District of Columbia to help people with disabilities find and keep work without losing their health benefits. These grants bring the total number of States with such grant programs to 42, with dollars totaling \$57 million.

Developmental Disabilities Programs

The ACF Administration on Developmental Disabilities (ADD) provided over \$140 million in grants last year to assist the Nation's nearly 4 million people with developmental disabilities (disabilities that begin prior to age 22 and result in major, lifelong impairments). The ADD network in each State consists of a State Developmental Disabilities Council (55 total), appointed by the governor, that promotes innovation and statewide change in service delivery; a State Protection and Advocacy System (57 total) that focuses on the civil rights of individuals with developmental disabilities; and one or more University Centers (61 total) for Excellence in Developmental Disabilities that conducts training, research, community outreach, and information dissemination. In addition, ADD, through its Projects of National Significance, is funding the design and implementation of family-friendly one-stops (31 total) to assist families with a member with a developmental disability to secure the services and supports they need and not navigate multiple human service systems alone. The ADD grantees have a broad portfolio. The DD Act authorizes these grantees to address health, education and early intervention, employment, housing, child care, transportation, recreation, quality assurance and/or formal and informal community services and supports that will enhance the independence, productivity, integration, and quality of life of individuals with developmental disabilities. A sample of ADD's numbers illustrates the New Freedom Initiative in terms of real people. In 2002, 40 States' grantees assisted 5,616 adults with developmental disabilities secure jobs; 32 States' grantees assisted 60,176 children with developmental disabilities secure the services and supports they needed to achieve their educational goals; 22 States' grantees helped 16,775 individuals with developmental

disabilities secure essential care services; and 29 States' grantees helped 5,921 to live in homes of their choosing.

ADD also administers the \$14.9 million dollar disability-related grant programs authorized by the Help America Vote Act. Each State receives a grant to make its election polls accessible to individuals with the full range of disabilities, to develop procedures and acquire equipment that allows individuals with disabilities to vote independently in private, to train election officials and poll workers on how to assist individuals with disabilities in an appropriate manner when they are participating in the voting process, and to inform individuals with disabilities about where accessible voting places are located. Moreover, ADD also administers grants to Protection and Advocacy Systems specifically to assist individuals with disabilities to participate in the voting process from registering, to getting to the places of election, to casting votes.

Support for Young Children with Disabilities and their Family Members

The Maternal and Child Health Bureau, within the Health Resources and Services Administration (HRSA), provides funds to States to improve the health of all mothers, children-including children with special health care needs-and their families. In FY 2004, approximately \$200 million of this Federal investment is being allocated to community-based care for children with special health care needs. These services target the estimated 18 million children with special health care needs who are at increased risk of chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Special Initiatives

While we are proud of our continued support for and improvement of our disability programs, we are always seeking new avenues to ensure that the needs and interests of people with disabilities are considered and addressed. The HHS Office on Disability, created by Secretary Thompson in 2002, has undertaken several innovative interdepartmental initiatives, including the “Cross Agency and Intergovernmental Young Adult Initiative” to prepare young adults, 16 to 30 years old, for adulthood by supporting States and Tribal Governments in the development of comprehensive systems of care; the “I Can Do It – You Can Do It” physical fitness program for children and youth with disabilities through a mentor approach, and the development of a Surgeon General’s “Call to Action” to increase prevention, awareness and accessibility for people with disabilities seeking to ensure their health and well being.

A Sustained Research Investment

I have described a number of data, program and policy activities and initiatives; these efforts are critical to ensuring that our Nation has consumer responsive services in place to ensure the quality of life and independence of people with disabilities. However, it is important not to lose sight of the substantial investments of our National Institutes for Health and Centers for Disease Control and Prevention in research to prevent, treat, and cure conditions that may result in disability. In addition, AHRQ supports the development of empirical research to promote quality services. AHRQ has conducted workshops and provided tools for consumers, providers, advocates, and State and local policymakers to assess consumer needs and plan for successful transition from institutions to community settings.

CONCLUSION

Many of the programs I have talked about today had their roots decades ago, although we continue to improve and modernize them, as individual needs and values change. Working with our State and local partners, and – most importantly – with people with disabilities and their families, we have come a long way, but as President Bush has stated: “...There is much more to do. Though progress has been made in the last decade, too many Americans with disabilities remain trapped in bureaucracies of dependence, denied the tools they need to fully access their communities....I am committed to tearing down the remaining barriers to equality that face Americans with disabilities today. My New Freedom Initiative will help Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of Americans with disabilities to integrate into the workforce, and promoting increased access into daily community life.”

We at HHS are firmly committed to meeting the challenge the President has set before us. We know we must continue to listen to people with disabilities and work closely with them, their family members, States, and service providers to continue to improve services and ensure that our Nation’s disability policies are inclusive and responsive to consumer needs.

I am happy to answer questions.

Attachment A

Major US Data Collection Activities on Disabilities

At any one time, 40 to 50 Federal activities may be funding, collecting and/or compiling data on disabilities in the US. These activities include program eligibility information, administrative data, ongoing surveys, special surveys, and research. These activities focus on the general population or special subsets within the population, such as children, working age adults, the elderly, or people disabled by mental illnesses. Data collection activities may focus on work, education, program utilization, or the national prevalence of disability. Data may be collected as household surveys, in person interviews, or via telephone.

Within this array, there are major sources of information on people with disabilities. These include the following:

- Decennial Census;
- Survey of Income and Program Participation;
- National Health Interview Survey;
- Medicare Current Beneficiary Survey;
- Health and Retirement Study; and
- National Long-Term Care Survey

The Decennial Census is conducted every ten years by the Bureau of the Census and is used to apportion seats in the U.S. House of Representatives. Every dwelling in the country received either a short form or a longer version in Census 2000 by post. The longer version contained the disability questions and was mailed to a subsample of 17 percent. Two questions about disability were asked in Census 2000. The first question asked if the person has any long-lasting condition, with two subquestions. The first subquestion asks about sensory impairments (i.e., blindness, deafness, severe hearing or vision impairments). The second subquestion queries about conditions limiting basic physical activities (e.g., walking, carrying). The second question asks whether a physical, mental or emotional condition lasting 6 or more months causes difficulty in a series of activities. The activities, asked as a subset of questions, include learning, dressing, going outside to shop and working. The responses to Census 2000 disability questions were either 'yes' or 'no'. Several Federal agencies use the Census data on disability to fulfill regulatory, mandatory, or programmatic reporting requirements. For the 2010 Census, the Census Bureau plans to ask only short form questions. Detailed questions, such as disability, are being asked in the ongoing American Community Survey.

The Survey of Income and Program Participation (SIPP) is conducted continuously with monthly interviewing by the Bureau of the Census. It obtains information on Federal program participation and describes the income distribution of the population, with a special focus on low income. Three topical modules in 2001 collected data on adult, child and work disability. Questions included age-appropriate activities of daily

living, instrumental activities of daily living, work, schoolwork, sensory impairments, movement and mobility, use of assistance, and the etiological conditions associated with limitations in functioning and disabilities. Responses to questions are in the 'yes/no' format and write-ins.

The National Health Interview Survey (NHIS) is conducted annually by the National Center for Health Statistics, Centers for Disease Control and Prevention to provide nationally representative data on the health status, health related behavior, and use of health services by the civilian non-institutionalized population. The 2002 NHIS contains three core interviews (family, child and adult) and special topic modules (e.g., alternative health supplement). Each core asks about health status and activity limitations. Activity limitation questions in the family core include activities of daily living, (e.g., self car), activity of daily living (e.g., household chores, shopping) and the causal health conditions. In the child core, the focus is on school attendance, basic mobility, sensory impairments, and emotional and behavioral difficulties. The adult core queries on movement and mobility, social and recreational limitations, sensory impairments, and the causal health conditions. Question responses are in 'yes/no' and scaled formats.

Medicare Current Beneficiary Survey (MCBS) is a continuous, multipurpose survey of a representative sample of the Medicare population designed to aid the Centers for Medicare and Medicaid Services' (CMS) administration, monitoring and evaluation of the Medicare program. The survey is conducted in three rounds per year, with each round being four months in length. MCBS has a multistage stratified random sample design and a rotating panel survey design. Each panel is followed for 12 interviews. In-person interviews are conducted using computer-assisted personal interviewing. Approximately 16,000 sample persons are interviewed in each round. However, because of the rotating panel design, only 12,000 sample persons receive all three interviews in a given calendar year. The MCBS collects information on health status and physical functioning of Medicare beneficiaries as well as their health care use, cost and sources of payment; health insurance coverage; household composition; sociodemographic characteristics; income and assets; access to care; satisfaction with care; usual source of care, and how beneficiaries get information about Medicare.

Health and Retirement Study (HRS) is a national panel study being conducted by the University of Michigan Institute for Social Research under a cooperative agreement with the National Institute on Aging. The study had an initial sample in 1992 of over 12,600 persons from the 1931–1941 birth cohort and their spouses. The HRS was joined in 1993 by a companion study, Assets and Health Dynamics Among the Oldest Old (AHEAD), with a sample of 8,222 respondents born before 1924 who were age 70 or older and their spouses. In 1998, these two data collection efforts were combined into a single survey instrument and field period. The HRS is intended to provide data for researchers, policy analysts, and program planners who are making major policy decisions that affect retirement, health insurance, saving, and economic well-being. The objectives of the study are: to explain the antecedents and consequences of retirement; examine the relationship between health, income, and wealth over time; examine life cycle patterns of wealth accumulation and consumption; monitor work disability; provide a rich source of

interdisciplinary data, including linkages with administrative data; monitor transitions in physical, functional, and cognitive health in advanced old age; examine the relationship of late-life changes in physical and cognitive health to patterns of spending down assets and income flows; relate changes in health to economic resources and intergenerational transfers; and examine how the mix and distribution of economic, family and program resources affect key outcomes, including retirement, spending down assets, health declines and institutionalization.

National Long-Term Care Survey (NLTC), conducted in 1982, 1984, 1989, 1994, and 1999, is a nationally representative survey of Medicare beneficiaries age 65 or older with chronic functional disabilities. The samples drawn from the Medicare beneficiary enrollment files are nationally representative of both community and institutional residents. As sample persons are followed through the Medicare record system, virtually 100 percent of cases can be longitudinally tracked so that declines as well as improvements in health status may be identified, as well as the exact dates of death. NLTC sample persons are followed until death and are permanently and continuously linked to the Medicare record system from which they are drawn. Linkage to the Medicare Part A and B service records extend from 1982 through 1995, so that detailed Medicare expenditures and types of service use may be studied. Through the careful application of methods to reduce nonsampling error, the surveys provide nationally representative data on: the prevalence and patterns of functional limitations, both physical and cognitive; longitudinal and cohort patterns of change in functional limitation and mortality over 12 years; medical conditions and recent medical problems; health care services used; the kind and amount of formal and informal services received by impaired individuals and how it is paid for; demographic and economic characteristics such as age, race, sex, marital status, education and income and assets; out-of-pocket expenditures for health care services and other sources of payment; and housing and neighborhood characteristics.

Administrative Data. There are numerous sources of administrative data with extensive disability information, collected to implement and administer programs. These data are frequently used for research purposes as well. Notable examples include the Medicaid Statistical Information System (MSIS), Social Security disability programs, the Minimum Data Set (MDS) used in nursing homes, and the OASIS data collected on home health users. The Departments of Education, Labor, HUD, Transportation and others maintain administrative and survey databases on their programs.

Mr. BURTON. Thank you, Mr. Young. I understand that Mr. Cummings is your Congressman, and I did not know if he had any comments he would like to make.

Mr. CUMMINGS. I want to thank you very much, Mr. Chairman.

Mr. Young, I want to welcome you and it is good to see you. Mr. Chairman, if I may do my opening statement very briefly, is that OK?

Mr. BURTON. Sure.

Mr. CUMMINGS. Mr. Chairman, I want to thank you for holding this important hearing which will offer us greater insight into the status of our disabled citizens, as well as present us with an opportunity to evaluate the efficacy of disability laws that affect these individuals.

Over 89 million people living in the United States have some form of mental or physical disability. Yet, of these 89 million people, an overwhelming number of disabled persons are still not enjoying equal protection under the law.

While I acknowledge the progress engendered by legislation such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, I still believe that more can be and must be accomplished. Men like Robert David Hall and my colleague, the Honorable James R. Langevin of Rhode Island, both of whom became physically disabled after tragic accidents and who will testify before us today, are inspirations to all Americans, as they are fighting the good fight for health care initiatives and legislation that will change the way we deal with disability in these United States.

This fight is no doubt a difficult one. Recent surveys indicate many Americans feel that they are not winning it. Although the Rehabilitation Act, ADA, the Individuals With Disabilities Education Act, IDEA, and other legislation were enacted to provide our disabled citizens with legal protection to prohibit discrimination and denial of benefits, as well as guaranteed access to any public place and equal education, they are still in many instances losing the battle.

In the 2004 Harris survey of ADA, 64 percent of the people surveyed said the ADA has made no difference in their lives, compared to 58 percent in the year 2000. This is a drop in the level of confidence in the law specifically drafted to protect and support this Nation's disabled persons. Even more disconcerting is that costs were reported as the main reason why disabled persons did not pursue the needed health care, technologies and devices that could be helpful to them as they integrate into mainstream society. Congress must make certain this trend is reversed.

The Federal Government and nongovernmental organizations must work together to expand the participation and contributions of the disabled population by putting into place effective processes and legislation that afford them greater access and better representation in American society.

Finally, Mr. Chairman, the true disability is not the physical or mental challenge that many of these citizens face, but rather the Nation's inability to provide proper protection that ensures the highest quality of life for all.

I look forward to hearing from our witnesses and I would like to especially recognize one of my constituents who I am extremely

proud of, Dr. Don Young, who is the Deputy Assistant Secretary of Planning and Evaluation of the Department of Health and Human Services.

And I thank you, Dr. Young, for your leadership and all that you do to enhance people's lives every day.

Mr. Chairman, I thank you for your courtesy and I would yield back.

[The prepared statement of Hon. Elijah E. Cummings follows:]

**Statement of Congressman Elijah E. Cummings
House Government Reform
Subcommittee on Human Rights and Wellness Hearing
On
“Living with Disabilities in the United States: A Snapshot”
June 24, 2004 at 2:00 p.m.**

Thank you, Mr. Chairman, for holding this important hearing, which will offer us greater insight into the status of our disabled citizens, as well as present us with an opportunity to evaluate the efficacy of disability laws that affect these individuals.

Over 89 million people living in the United States have some form of mental or physical disability. Yet, of these 89 million, an overwhelming number of disabled persons are still not enjoying equal protection under the law. While I acknowledge the progress engendered by legislation such as the *Rehabilitation Act of 1973* and *The Americans with Disabilities Act of 1990* (ADA), I still believe that more can be accomplished.

Men like actor Robert David Hall and my colleague the Honorable James R. Langevin (of Rhode Island), both of whom became physically disabled after tragic accidents and who will testify before us today, are inspirations to all Americans. As they are fighting the good fight for healthcare initiatives and

legislation that will change the way we deal with disability in the United States. This fight is no doubt a difficult one, and recent surveys indicate that many Americans are not winning it.

Although the Rehabilitation Act, the ADA, Individuals with Disabilities Education Act (IDEA), and other legislation were enacted to provide our disabled citizens with legal protection to prohibit discrimination and the denial of benefits, as well as guaranteed access to any public place and an equal education, they are still losing the battle. In the 2004 *Harris Survey* of the ADA, 64% of the people surveyed said that the ADA has made no difference in their lives, compared with 58% in 2000. This is a drop in the level of confidence in a law specifically drafted to protect and support this nation's disabled persons. Even more disconcerting, is that costs were reported as the main reason why disabled persons did not pursue the needed healthcare, technologies, and medical devices that could be helpful to them as they integrate into mainstream society. Congress must make certain this trend is reversed.

The federal government and non-governmental organizations must work together to expand the participation and contributions of the disabled

population, by putting into place effective processes and legislation that afford them greater access and better representation in American Society.

The true disability is not the physical or mental challenge that many of these citizens face, but rather ~~or~~ ^{the} nation's "inability" to provide proper protection that ensures the highest quality of life.

I look forward to hearing from our witnesses, and would like to especially recognize one of my constituents, Dr. Don Young, who is the Deputy Assistant Secretary For Planning And Evaluation at the Department of Health and Human Services. Thank you Dr. Young, for presenting testimony today.

And thank you, Mr. Chairman, for holding today's hearing.

I yield back the balance of my time.

Mr. BURTON. I thank you Congressman Cummings.

You heard the discussion that we had with our colleague who was the first panelist. Have any of the agencies of government, to your knowledge, given any consideration to tax incentives, like we were talking about, for the private sector to hire and train those with disabilities who are unemployed?

I mean, I understand the programs that you alluded to, both of you, that are very beneficial and the health problems that are connected, the health care cost problems with Medicare and Medicaid, but if we can get more of these people gainfully employed through the private sector, we might find that some of them will get coverage from their employers that would help take care of some of the benefits that are necessary.

So have any of the agencies, Health and Human Services or the Department of Education, given any thought to suggesting legislation that we create tax incentives for the private sector?

Mr. YOUNG. I am not aware that we have. It would not necessarily be a question that would be addressed to HHS. I certainly agree though that finding some way to assure that people who want to work are given the help they need so that they can find the job they need and go to work.

Mr. JUSTESEN. Congressman, directly to answer your question, it is an issue of some intellectual debate among some of the agencies, particularly the Department of Labor's newly created Office of Disability Employment Policy, that—some of my colleagues I believe are in the audience here, and there has been some discussion with the Rehab Services Administration of the Department of Education about what it is that we can do to address the existing barriers—those being, among other things, tax incentives for specifically hiring people with disabilities.

It is still under debate, but I do want to point out that the Americans with Disabilities Act, under Titles I and II—Title I being employment, II, State and local government programs and services—both cover employment aspects, and Title I, specifically with respect to the private sector of employment, does provide tax incentives, both deductions and credits, for making the buildings and facilities and job accommodations more affordable to the private business sector.

There is a cap on those amounts of deduction/credit depending on what it is that is used to provide either a more accessible work environment or providing specific job accommodations for those individuals with disabilities who would be employed.

But I think your question is most specifically with respect to hiring people with disabilities regardless of their need for accessible accommodations or job accommodations. And that is an issue that a number of us have discussed in terms of how we can formulate proposals. And we are at the very initial stages of being able to do that and would need a little bit more discussion among the agencies.

Mr. BURTON. Let me just say that I think that kind of a program, probably short term and long term, would pay for itself. If you give a tax incentive to get somebody who is unemployed the skills necessary to perform a task and they become a taxpayer instead of a

tax recipient, then I think it has to have a positive impact both on the individual and the company and on the government.

The tax credit that you are giving would take money out of the Treasury in the short run, but if the employee starts paying taxes, you are going to get it back in the long run. And it just seems to me that would be one of the things that we ought to take a look at.

I understand that—did you say Title II of the Americans with Disabilities Act talked about giving incentives for putting in facilities that will make it accessible for Americans with disabilities? But that does not solve the problem of the training that might be necessary for them to do a job, and that might be something that we can add as an adjunct to the Americans with Disabilities Act that would be very favorably received by the private sector as well as the government.

And toward that end, I wish you might take a hard look at it and maybe work with us and our colleagues who just testified, along with Ms. Watson and myself, to see if we could come up with a legislative proposal that would do just that.

Mr. JUSTESEN. Well, I think we look in order to doing that. If I may, the Rehabilitation Services Administration is making a great deal of investments in directly providing training and gainful employment preparation for individuals with disabilities, and that is a State and Federal partnership. And that is a strong foundation for us to build on what you are suggesting.

Mr. BURTON. Well, I understand, but that is a government-subsidized program. And what I am saying is if you give a tax incentive to the private sector, what you are doing is you are giving them a break to train these people. It isn't costing the government anything other than a tax deduction, and the government is going to get that back when these people become taxpayers and gainfully employed. So rather than have another government program that we create that just spends money, I would rather do it just the opposite. And that is why I would like for you to look at this as an additional approach.

Ms. Watson.

Ms. WATSON. I just wanted to query one thing that you said. The Federal and State partnership works through what? State government through the Department of Education training? How is it facilitated?

Mr. JUSTESEN. Question, Congresswoman. With respect to vocational rehabilitation services?

Ms. WATSON. The training of the individual.

Mr. JUSTESEN. The rehabilitation services of the Department of Education is a State and Federal partnership. It has a very long history, over 80 years.

Ms. WATSON. Yes, I know, but it goes through the State educational system?

Mr. JUSTESEN. Well, it goes through the State vocational rehabilitation agency. Sometimes they are within the State Departments of Education, other times State Departments of Labor or Health and Human Services, depending on the State.

Ms. WATSON. They have vocational programs, but you are talking about vocational programs through which they train the disabled?

Mr. JUSTESEN. They are—yes.

Ms. WATSON. For vocational—

Mr. JUSTESEN. For people with disabilities for vocational rehabilitation services. And this is a longtime partnership between Federal and State entities. Each State has chosen which State office is the lead agency in a sense in a given State. Some States it is mostly Departments of Labor or Education. But there are others HHS or whatever appropriate State agency has chosen to administer the rehabilitation vocational program.

Ms. WATSON. I think in my State, California—and I'm going to have my staff look it up—it is through the Department of Rehab. And the Department of Rehab has these programs. I think we need to do an assessment to see if they are really reaching out to the broad spectrum of the disabled; mentally disabled as well.

Mr. JUSTESEN. Well, people with psychiatric disabilities are the largest category of unemployed people who have disabilities in America. And it is a challenge for us, and we look forward to continuing to help State VR agencies be more efficient and more effective than even they are today. And that is a priority of ours in the Department of Education.

Ms. WATSON. I kind of like the proposal that the Chair is putting out there, because I was just reading something about our budget here, and what departments were cut? Department of Education, the Department of Rehabilitation, and so on.

So there are many, many people who won't get served. If there is a tax incentive, then maybe the private sector can take over, because these are kind of like entitlement programs. And I think that we need to try other ways of funding, because they are the first ones that get cut.

Mr. JUSTESEN. Well, Congresswoman, I look forward to taking back to Secretary Paige your challenge to us to provide technical assistance to the committee to improve the employment rates for people like myself with disabilities.

Ms. WATSON. Thank you, Mr. Chairman.

Mr. BURTON. Thank you very much. I don't have any further questions, but I do appreciate your testimony. It is good to have you back, and nice to have you with us. Mr. Young and I'm sure Mr. Cummings appreciates you being here as well.

Our next panel consists of Mr. Alan Reich, he is president of the National Organization on Disability; Mr. Robert David Hall, he is the actor on CSI, Crime Scene Investigation, which is a very popular TV show, as everybody knows; Dr. Peter Blanck, is a professor of law at the University of Iowa College of Law, he is the director of the Law, Health Policy and Disability Center there; and Mr. John Register, he is the manager of the Paralympic Academy, U.S. Paralympics, U.S. Olympic Committee. Appreciate you all being here.

Please raise your right hands.

[Witnesses sworn.]

Mr. BURTON. I think we will just go right down the line there, I think we will start from the right and go to the left. Mr. Reich. And if you could, since we have four panelists, keep your statements as close to 5 minutes as possible so we can have question and answer with you.

STATEMENTS OF ALAN A. REICH, PRESIDENT, NATIONAL ORGANIZATION ON DISABILITY; ROBERT DAVID HALL, ACTOR, CSI: CRIME SCENE INVESTIGATION, DOUBLE AMPUTEE; PETER BLANCK, CHARLES M. AND MARION KIERSCHT PROFESSOR OF LAW, DIRECTOR, LAW, HEALTH POLICY & DISABILITY CENTER, UNIVERSITY OF IOWA COLLEGE OF LAW; AND JOHN REGISTER, MANAGER, PARALYMPIC ACADEMY, U.S. PARALYMPICS, U.S. OLYMPIC COMMITTEE

Mr. REICH. Thank you, Mr. Chairman. And thank you to your committee on human rights and wellness for providing this important focus on our release today of the fourth NOD/Harris Survey of Americans with Disabilities.

In the last 12 years, we have been doing surveys to understand the status of people with disabilities in our country and how we are doing in comparison with counterparts without disabilities, and the picture that emerges today is one of continuing concern and continuing disparity between the situation of our 54 million Americans with disabilities and other Americans.

I am Alan Reich, president of the National Organization on Disability. I founded NOD in 1982, having joined the disability community two decades earlier when I broke my neck in a diving accident. People with disabilities want to participate and contribute to society, to work, support our families, pay taxes, contribute to the economy, and share in America's blessings and opportunities, just like everyone else. To us this means closing the gaps in the levels of participation between people with and without disabilities in employment, education, community life, voting, religious worship, transportation, housing, health care. Closing these gaps is America's disability agenda.

In the mid-1980's, while the Congress was preparing the Americans with Disabilities Act, we began surveying to identify and quantify these gaps and to report to the Nation on these critical issues. We have commissioned the Louis Harris organization now actually four times to conduct national surveys to measure and report on these gaps. These surveys have helped the disability community, legislators, officials of all levels, the media, the business community and other Americans understand the problems and opportunities for action.

So who are we, the 54 million citizens with disabilities? After all, you are taking a snapshot today. And how are we doing compared to other Americans?

This report identifies and defines the challenges our minority faces in terms of the gaps in major life areas. The survey results show that in 2004, these gaps are wide. We remain pervasively disadvantaged in 10 key indicator areas.

In employment, only a third of people with disabilities of working age are employed full or part time, compared to more than three-quarters of those without disabilities; 35 percent versus 78 percent.

In education, 21 percent of people with disabilities have received less than a high school education, compared with only 11 percent of those without disabilities.

Socializing. People with disabilities socialize less frequently with close friends, relatives or neighbors; 79 percent versus 89 percent.

Income. People with disabilities are far more likely to have a household income of \$15,000 or less; 26 percent versus 9 percent. Think of it, a household income of \$15,000 a year.

Religious worship, 49 percent of people with disabilities go to a place of worship at least once a month compared with 57 percent of those without disabilities.

And entertainment. People with disabilities are less likely to go out to a restaurant, for example, at least twice a month; 66 percent versus 73 percent.

Political participation. This was based on our 2000 survey. People with disabilities are less likely to be registered to vote; 62 percent versus 78 percent.

Transportation. People with disabilities are twice as likely as those without disabilities to consider inadequate transportation a problem; 31 percent versus 13 percent.

Health care, also egregious. People with disabilities are more than twice as likely to have gone without needed medical care at least once in the past year; 18 percent versus 7 percent.

Life satisfaction. Not surprisingly, in light of these other gaps, people with disabilities are much less likely to say they are very satisfied with life in general; 34 percent versus 61 percent.

And I might add another that we have added since we did this survey 4 years ago, and that is emergency preparedness. Shortly after September 11 we surveyed people with disabilities and found that our population is less prepared, more concerned and more anxious than the nondisabled.

Overall, this is a sorry picture. America can do better. We must do better. There are glimmerings of hope. Over the past 18 years, several gaps have closed, notably employment, education, income, eating out at a restaurant. In the past 4 years, discrimination toward people with disabilities in the workplace has decreased markedly, undoubtedly as a result of the Americans with Disabilities Act. However, there is still a long way to go before we can say that people with disabilities have the same opportunities to contribute to and participate in American life than other citizens do.

Closing these gaps as reported in today's Harris survey is our goal, and it must be America's goal, too. I respectfully request, Mr. Chairman, that the presentation of the survey by Harris chairman Humphrey Taylor, who is here with us today and that he presented earlier at the National Press Club, be appended to my remarks and placed in the record.

Mr. BURTON. Without objection, so ordered.

Mr. REICH. Thank you very much, Mr. Chairman. My distinguished colleagues on the panel will comment on the implications of the Harris survey findings.

NOD board member Robert David Hall is known to America as a lead member of the Nation's top-rated television show, CSI: Crime Scene Investigation. David, who is a double amputee, has traveled from Hollywood to appear before you today, and we are grateful to him.

He will be followed by Peter Blanck, also a member of the board of directors of the National Organization on Disability, and a professor at the University of Iowa law school, as well as a director

of its disability law center. He has published and spoken widely on the Americans with Disabilities Act.

Again, Mr. Chairman, I would like to commend you and the House Government Reform Subcommittee on Human Rights and Wellness for recognizing the 54 million Americans with disabilities who are disadvantaged and discriminated against. You are performing a vital service by placing disabilities squarely on the human rights agenda. As I had the opportunity to point out recently in testimony before Congressman Tom Lantos' Human Rights Caucus, citizens with disabilities, like our half-billion counterparts worldwide, are the poorest, least educated, and the most discriminated against people on our planet. Is this not a human rights disgrace? We want to participate fully and contribute to society just like everyone else. Thank you, Mr. Chairman.

Mr. BURTON. Thank you very much. We appreciate your testimony and will continue to work to see if we can't make things a heck of a lot better than they are right now.

[The prepared statement of Mr. Reich follows:]

**TESTIMONY OF ALAN A. REICH
PRESIDENT, NATIONAL ORGANIZATION ON DISABILITY
HOUSE GOVERNMENT REFORM SUBCOMMITTEE ON HUMAN RIGHTS
AND WELLNESS
U.S. HOUSE OF REPRESENTATIVES WASHINGTON, DC
JUNE 24, 2004**

Thank you, Mr. Chairman. I am Alan Reich, president of the National Organization on Disability. I founded this organization in 1982, having joined the disability community two decades earlier, when I broke my neck in a diving accident.

I sincerely thank you and the House Government Reform Subcommittee on Human Rights and Wellness for bringing to the attention of the American people the situation of our minority of 54 million Americans as illuminated in today's landmark N.O.D./Harris report.

Who are we, the 54 million citizens with disabilities? And how are we doing compared to other Americans? This report identifies and defines the challenges our minority faces in terms of the gaps in major life areas between those with and without disabilities. The survey results show that in 2004, these gaps are wide, and we remain pervasively disadvantaged in ten key indicator areas.

- 1) Employment – only a third of people with disabilities of working age are employed full or part-time compared to more than three quarters of those without disabilities (35% versus 78%).
- 2) Education – 21% of people with disabilities have received less than a high school education, compared with only 11% of those without disabilities.
- 3) Socializing – people with disabilities socialize less frequently with close friends, relatives, or neighbors (79% versus 89%).
- 4) Income – people with disabilities are far more likely to have a household income of \$15,000 or less (26% versus 9%).

- 5) Religious worship – 49% of people with disabilities go to a place of worship at least once a month compared with 57% of those without disabilities.
- 6) Entertainment – people with disabilities are less likely to go out to a restaurant at least twice a month (66% versus 73%).
- 7) Political participation – people with disabilities are less likely to be registered to vote (62% versus 78%), as shown by our 2000 Harris survey.
- 8) Transportation – people with disabilities are twice as likely as those without disabilities to consider inadequate transportation a problem (31% versus 13%).
- 9) Healthcare – people with disabilities are more than twice as likely to have gone without needed medical care at least once in the past year (18% versus 7%).
- 10) Life Satisfaction – not surprisingly, in light of these other gaps, people with disabilities are much less likely to say they are very satisfied with life in general (34% versus 61%).

Overall, this is a sorry picture. America can do better. We must.

There are glimmers of hope. Over the past eighteen years, several gaps have closed notably, employment, education, income, and eating out. In the past four years, discrimination toward people with disabilities in the workplace has decreased markedly, undoubtedly as a result of the Americans with Disabilities Act. However, there is still a long way to go before we can say that people with disabilities have the same opportunities to contribute to and participate in American life that other citizens do. Closing these gaps is our goal and it must be America's goal too.

You will hear more about the trends since our 2000 and earlier surveys from Harris Interactive Chairman Humphrey Taylor, one of the worlds foremost survey

researchers. We are indebted to Humphrey for his work and his personal commitment to disability issues. I respectfully request that Humphrey Taylor's presentation on the survey, given earlier today at the National Press Club, be appended to my remarks and placed in the record.

My distinguished colleagues on the panel will amplify these comments. N.O.D. Board Member Robert David Hall is known to America as a lead member of the nation's top-rated television show CSI (Crime Scene Investigation). David, who is a double-leg amputee, has traveled from Hollywood to appear before the Committee today, and we are grateful to him. He will be followed by Peter Blanck, also a Member of the Board of Directors of the National Organization on Disability and professor at the University of Iowa Law School as well as director of their disability law center. Peter is a world authority on disability employment and the Americans with Disabilities Act. He has published and spoken widely.

Again, Mr. Chairman, I would like to commend you and the House Government Reform Subcommittee on Human Rights and Wellness for recognizing 54 million Americans with disabilities are disadvantaged and discriminated against. You are performing a vital service by placing disability squarely on the human rights agenda.

I had the privilege to note recently in testimony before the Congressional Human Rights Caucus that our citizens with disabilities, like our half billion counterparts worldwide, are the poorest, least educated, and the most disadvantaged humans on our planet. This is a human rights travesty.

We want to participate fully and contribute to society – just like everyone else.

Thank you, Mr. Chairman.

**2004 National Organization on
Disability/Harris Survey
of Americans with Disabilities**

Presented By:
Humphrey Taylor

June 24, 2004



interactive



***The 2004 National Organization on Disability/Harris
Survey of Americans with Disabilities is sponsored by:***

- American Express
- AstraZeneca
- Milbank Foundation for Rehabilitation
- Charles Stewart Mott Foundation
- NEC Foundation of America
- National Institute for Disability Research and Rehabilitation (NIDRR)
- RRTC on Workforce Investment and Employment Policy for Persons with Disabilities, U.S. Department of Education Grant #H133B980042-99, Law, Health Policy & Disability Center, University of Iowa College of Law

N.O.D. also thanks the Henry J. Kaiser Family Foundation for its collaboration on this survey and for funding the health-care section.



Survey Methodology

- Sample of 2,255 respondents ages 18 and over*
 - Nationally representative sample of 1,038 people with disabilities
 - Nationally representative sample of 988 people without disabilities
 - Oversamples of 109 blind and 120 deaf respondents
- Interviews were conducted by telephone, except for interviews with deaf respondents, which were conducted online.
- Among those with disabilities, 14% of the interviews were conducted with proxies able to speak on their behalf.
- Interviews were conducted between May 7 and May 28, 2004.

* All data are based on adults ages 18 and over, except the employment data, which are based on those ages 18-64 (the primary employment market).

3



Purpose of Research

- To re-examine 10 important indicators of the quality of life and standard of living of Americans with disabilities
- To measure the size of the gaps on these 10 indicators between people with and without disabilities
- To determine which gaps are, and are not, closing and by how much compared to surveys in 2000, 1998, 1994, and 1986
- To provide up-to-date measures in a number of areas unique to people with disabilities including:
 - Disability-specific health-care services
 - Use of assistive technology

4

**Preliminary Release**

- **These are only some of the findings from this research. Once we have completed the analysis, we will be releasing many more findings – particularly in the areas of employment, health care, and assistive technology, and visual and hearing impairment.**

5

**Major Findings for Gaps**

- People with disabilities still lag somewhat or far behind people without disabilities on all 10 key measures of quality of life.
- The gaps are much larger when comparing people with severe disabilities to the general population.
- Over the past 18 years, some social and economic indicators - most notably, education - have improved for people with disabilities and some gaps have closed. However, except for education, the gains have been small.

6



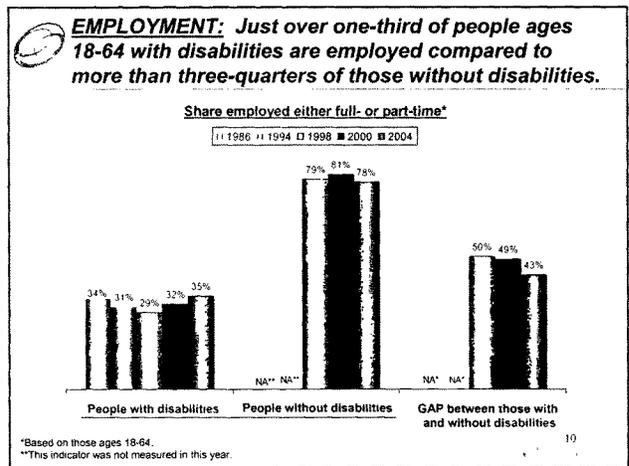
Definition of "Gaps"

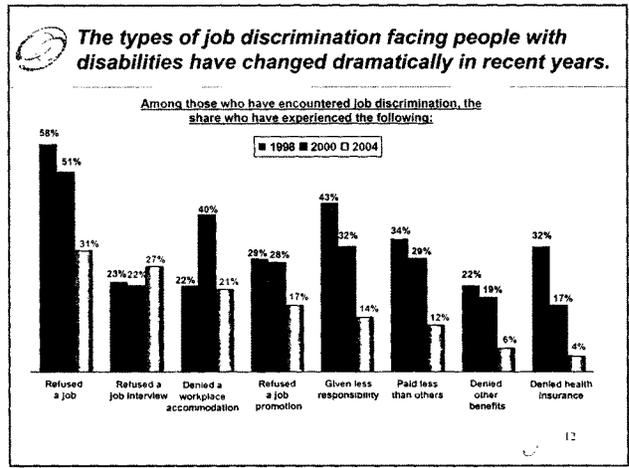
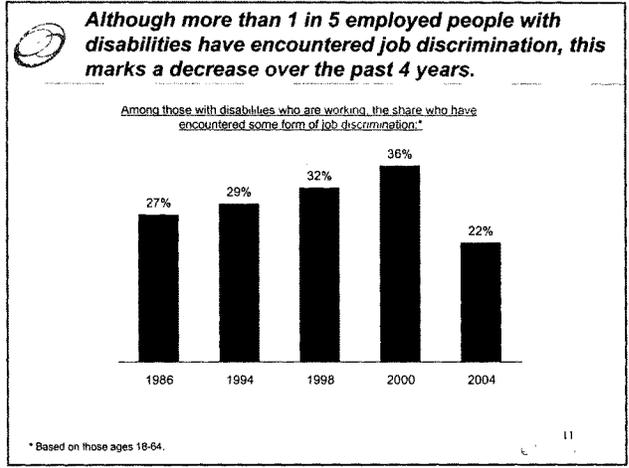
- A "gap" is defined as the number of percentage points between people with and without disabilities on a given indicator.
- To determine what gaps exist and to note changes over time, specific quantifiable measurements or "indicators" have been developed for 10 key life activities.

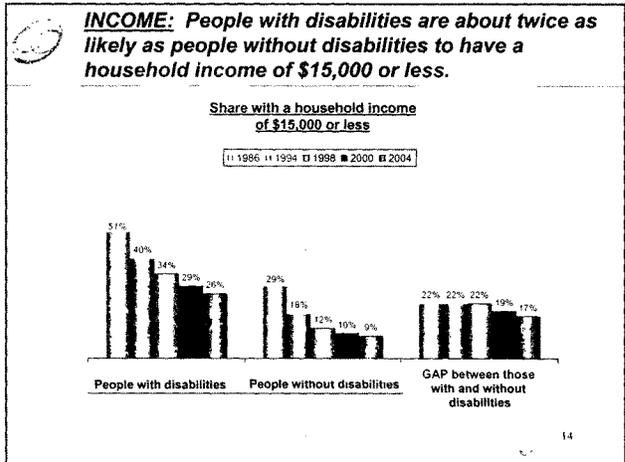
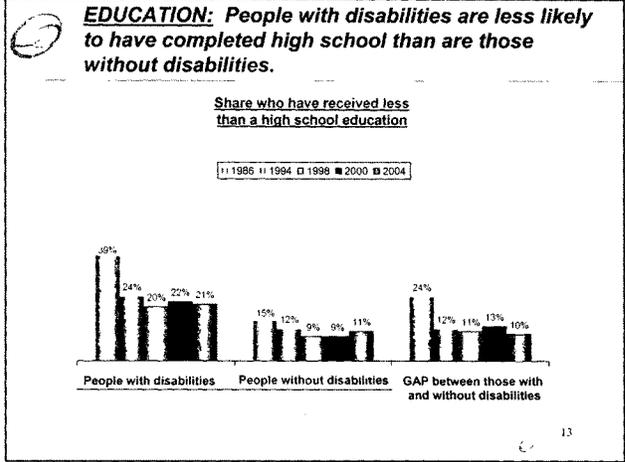
10 Indicators Where Gaps Are Measured

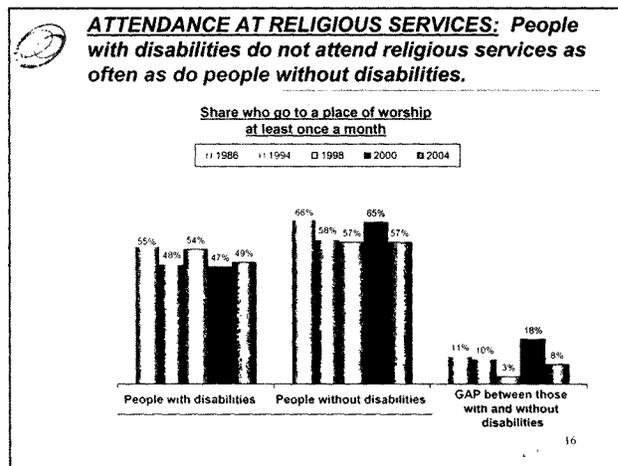
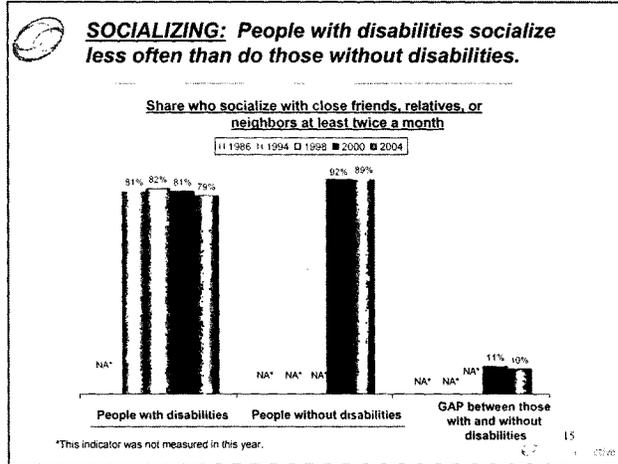
- Employment
- Education
- Income
- Socializing
- Attendance at religious services
- Eating out
- Political participation*
- Access to transportation
- Health care
- Life satisfaction

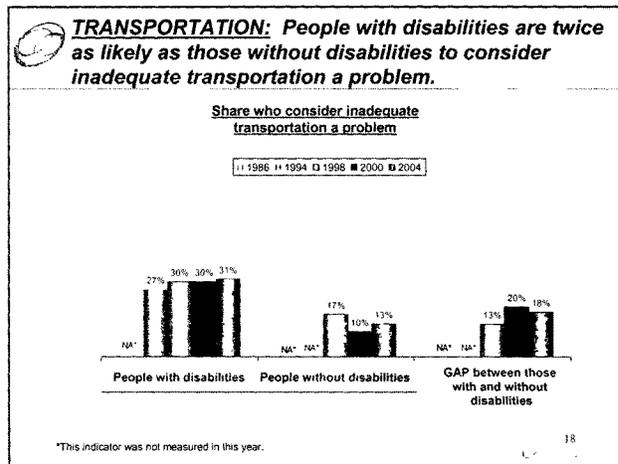
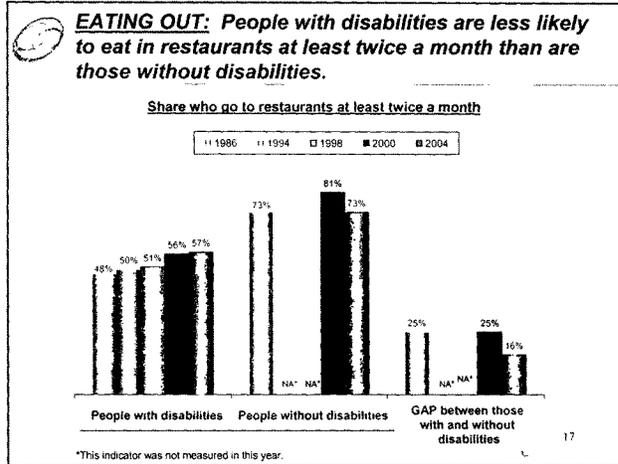
* To be updated after the 2004 election.

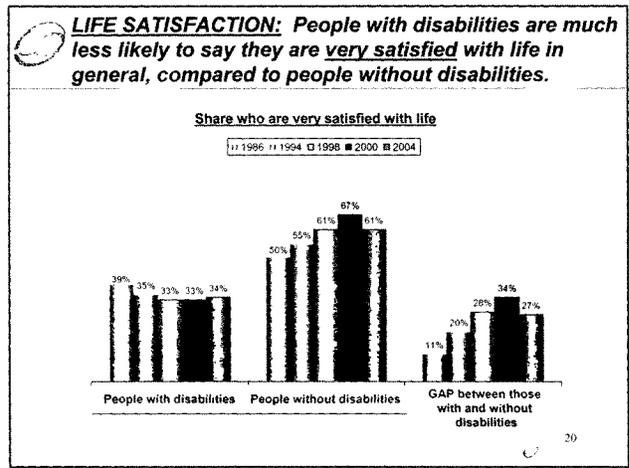
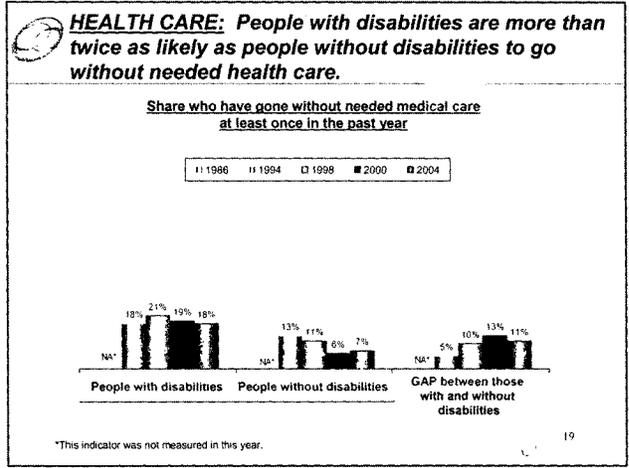










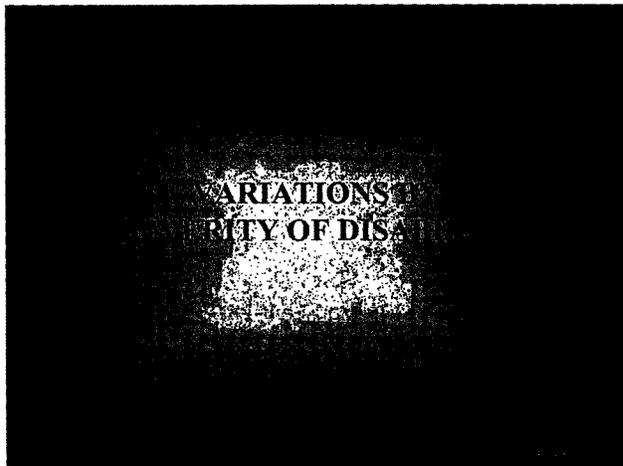


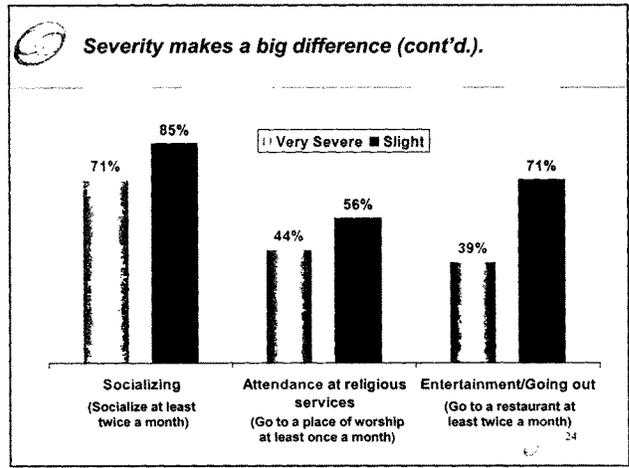
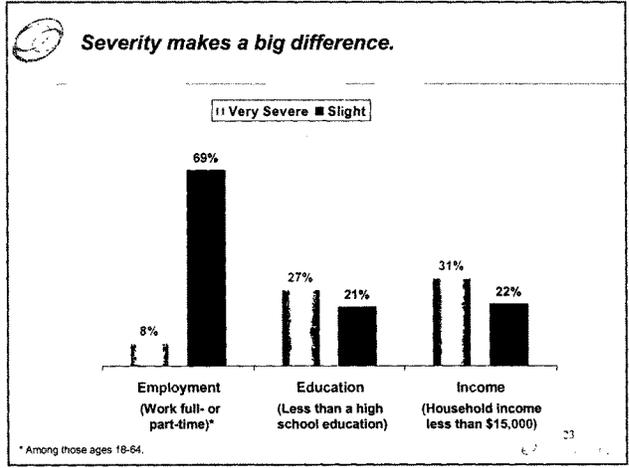
 **Over the past 18 years, 4 gaps have diminished:**

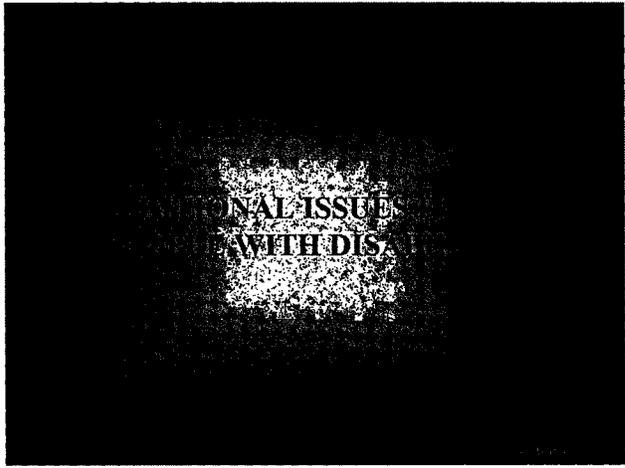
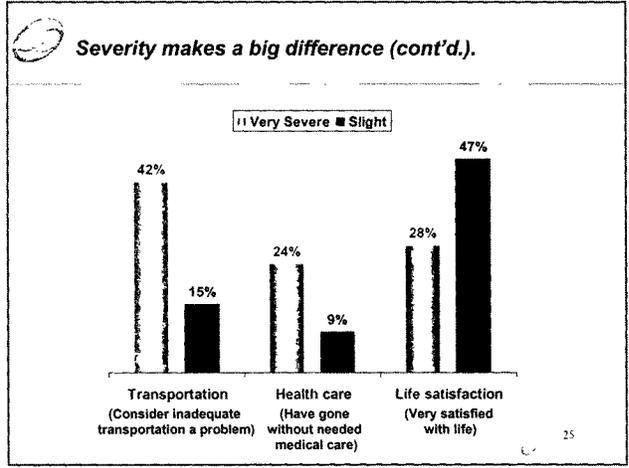
- Education (from 24 to 10 points)
- Income (from 22 to 17 points)
- Employment (from 50 to 43 points)*
- Eating out (from 25 to 17 points)

* From 1999-2004, the only years for which this gap measure is available.

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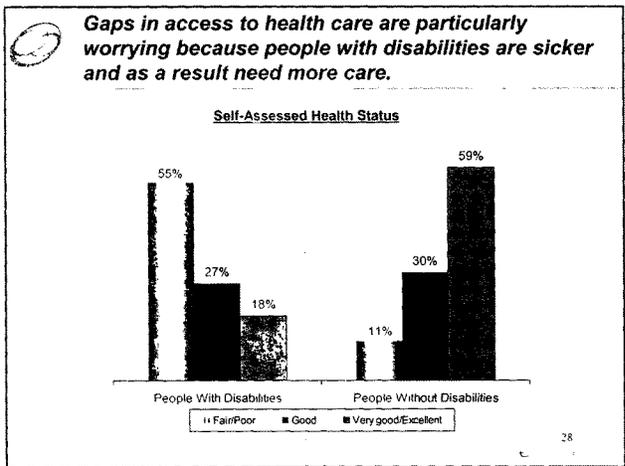


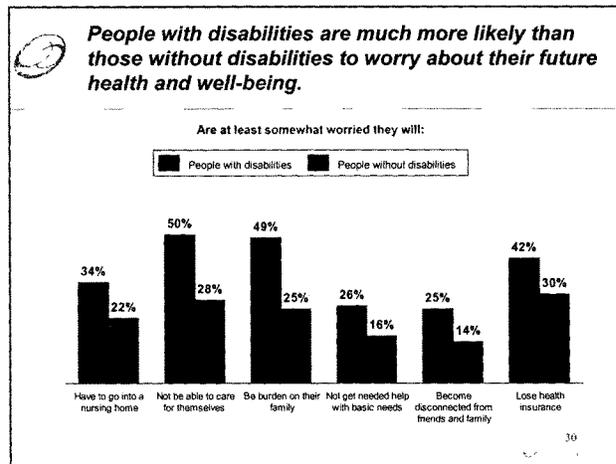
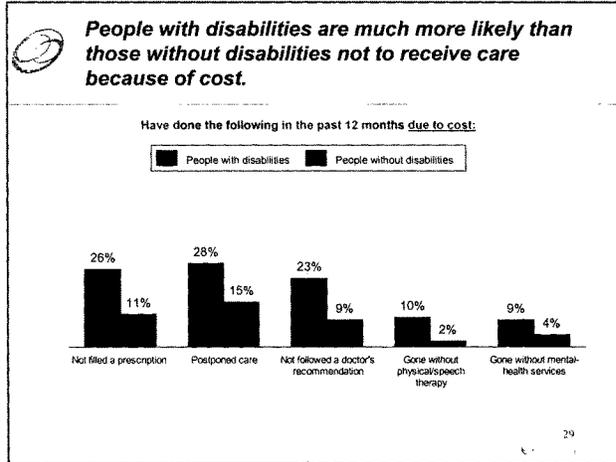


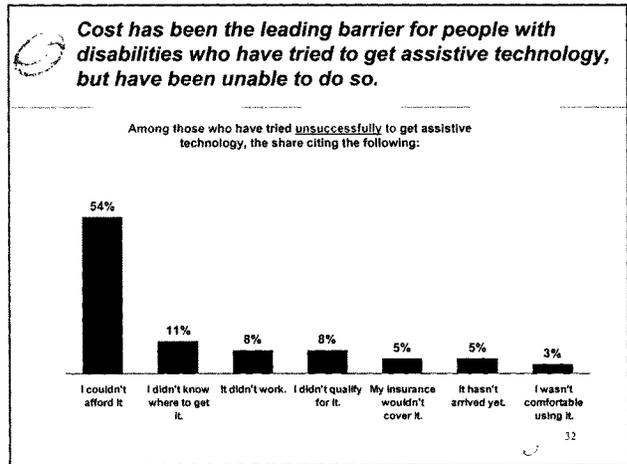
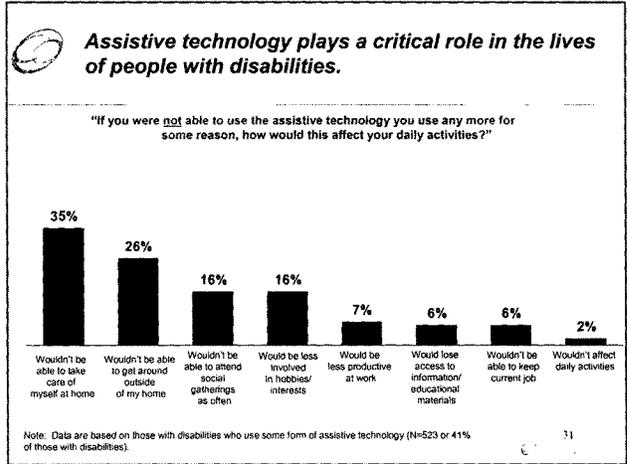
 **Additional Issues (A few preliminary findings)**

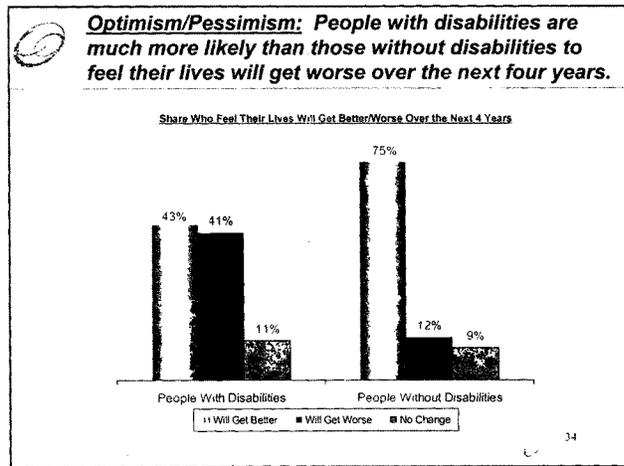
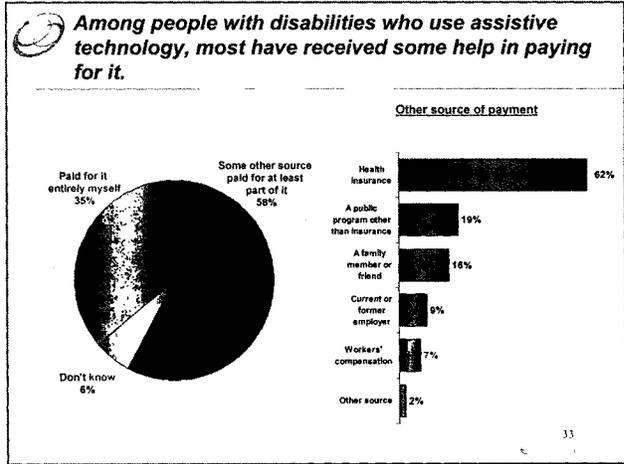
- Access to health care and cost-related barriers to services
- Use of assistive technology
- The impact of the Americans with Disabilities Act (ADA) on the lives of Americans with disabilities

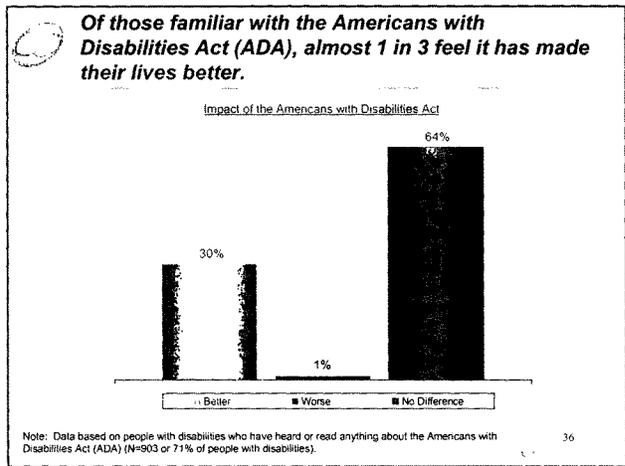
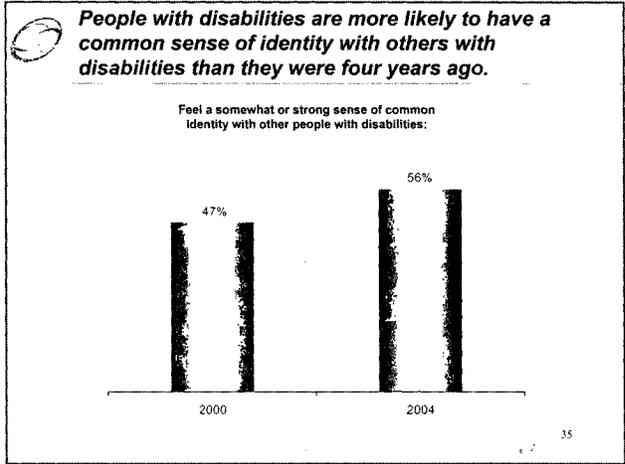
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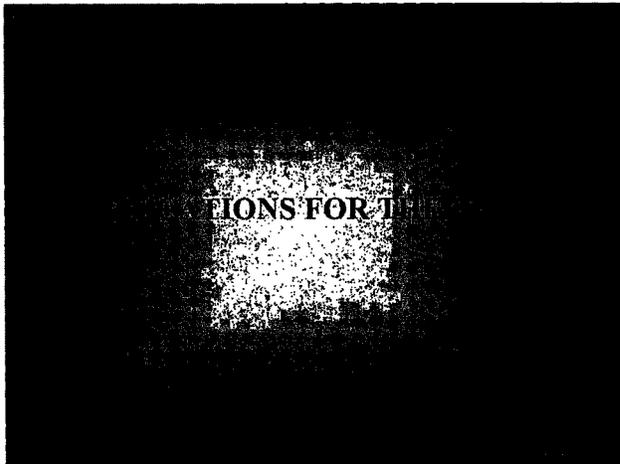
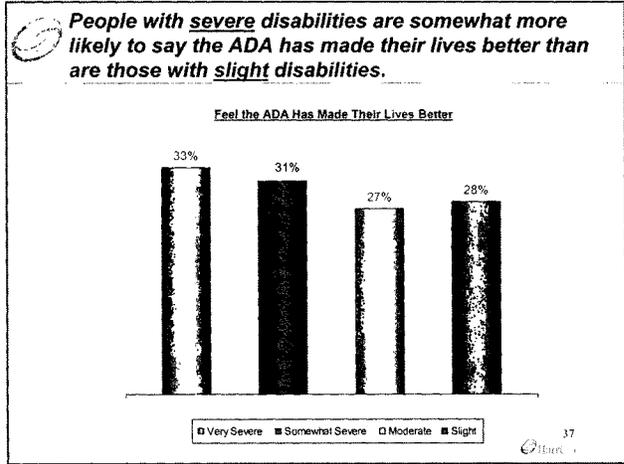














Conclusions and Implications for the Future

- While some social and economic indicators show that the gaps have closed a little over the past decade for people with disabilities, others have not changed or grown larger over time.
- The challenge for the next decade will be to close all of the gaps between people with and without disabilities.
- The improvement in employment, income, and education is good news. As these indicators improve for people with disabilities, other quality-of-life indicators are likely to follow.
- A special emphasis needs to be placed on improving the quality of life of people with severe disabilities.

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The 2004 National Organization on Disability/Harris Survey of Americans with Disabilities is sponsored by:

- American Express
- AstraZeneca
- Milbank Foundation for Rehabilitation
- Charles Stewart Mott Foundation
- NEC Foundation of America
- National Institute for Disability Research and Rehabilitation (NIDRR)
- RRTC on Workforce Investment and Employment Policy for Persons with Disabilities, U.S. Department of Education Grant #H133B980042-99, Law, Health Policy & Disability Center, University of Iowa College of Law

N.O.D. also thanks the Henry J. Kaiser Family Foundation for its collaboration on this survey and for funding the health-care section.

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**2004 N.O.D./Harris Survey
of Americans with Disabilities**

Thank You

June 24, 2004



Interactive

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Mr. BURTON. Mr. Register.

Mr. REGISTER. Thank you, Mr. Chairman and Congresswoman Watson. It is great to see you again. Good afternoon, and thank you for this time to address you today.

My name is John Register, and I am the director of the Paralympic Academy, a national outreach program that enables children with physical disabilities to become more active in life.

Before I lost my leg in a freak hurdling accident, I was a three-time All American and a graduate of the University of Arkansas. I twice went to the Olympic trials. In 1988, I went as a 110-meter high hurdler; and in 1992, I went as a 400-meter hurdler. I was also a soldier in the U.S. Army.

In 1988, I went through with the hurdle, and I dislocated my knee and severed my artery, and at that time had to really look at life from a different point of view, from a different perspective, and challenge some of the attitudes that I had myself.

In the hospital room I remember one of the things I remembered was my wife and understanding how important it was for me to think of who I was at that moment in time. Was I still a husband? Was I still a father? Was I still a son to my dad? Was I still a son to my own mother? And most importantly, as a soldier in the U.S. Army, was I still going to be gainfully employed?

And some of the things I was thinking about really caused an impact on my life, and I began to think of some of the outlooks that we see. And I think what I was thinking about then and what I think about now is of the testimony that we have heard. It looks like a dismal picture, and 75 percent of children with physical disabilities in the United States do not participate in physical education programs at school or health and wellness programs in their communities. Seventy-five percent of people with disabilities of working age are unemployed, as we have heard. And 56 percent of people with disabilities get no physical activity whatsoever.

And per capita health care costs are four times greater for people with disabilities than for those without. People with disabilities have high rates of chronic conditions such as diabetes, depression, high blood pressure and obesity.

When I was a long jumper at the University of Arkansas and with one leg taking the silver medal, I jumped the sum of a two-lane highway, 27 feet. With one leg, taking the silver medal at the Paralympic Games, I jumped half that distance. So I guess half a leg, half the distance.

I have seen personally the impact on health and wellness and how that transcends to other aspects of life. The attitudinal issues regarding disability are still a major barrier to change. As a former Olympic-level athlete and current Paralympic athlete, I have seen the benefits of the Olympic and Paralympic programs and their positive impact on attitudinal barriers. We must remove the barriers to independent living, community integration and employment.

For example, Federal disability benefits programs assume a person's ability to return to work or live independently is limited. And this is in my situation. I was on my way to officer candidate school and had to stop my progression to be a lifer in the U.S. Army be-

cause of my physical limitation, partly because of governmental and partly because of my own limitations I was placing on myself.

But I think we see with the Paralympic movement how great one's ability can be, as testimony is heard today. The U.S. Olympic Committee, through its Paralympic Division, is committed to addressing quality-of-life issues for people with disabilities through the Paralympic program. As a program director, I understand the role that the U.S. Olympic Committee can play in addressing health and wellness issues and attitudinal barriers.

The USOC is working with community-based organizations to deliver programs that expand participation by people with disabilities in health and wellness programs and increase awareness and resources for these programs. This program is known as the Paralympic Academy, and the key objectives of the Paralympic Academy are to enhance and increase opportunities for people with disabilities, develop a national message concerning persons with disabilities, and provide incentives and recognition for individuals and programs that have impact on all 50 States.

It provides a cost-effective preventive health and wellness program in the 50 States, and we will honor in this year and every year subsequently a select group of children with physical disabilities and coaches from all 50 States at the National Paralympic Academy. This year we are selecting six children, our pilot program, that will attend the games in Athens, Greece, and we will be leaving on September 14th to attend those games. Truly that will inspire those children once they see that.

The U.S. Olympic Committee would like to become a stronger partner in developing and implementing cohesive programs with the Congress, Federal agencies and the White House; to secure legislative amendments and ideas to fund a research study quantifying how involvement in health and wellness programs can impact the achievement levels in children with physical disabilities; engage congressional leadership in supporting adapt sports programs in your districts; and reorganizing and creating awareness of constituents who are delivering and participating in the health and wellness programs.

So today, I thank you very much for this opportunity to testify before your subcommittee. The U.S. Olympic Committee looks forward to working with Congress to expand the participation and contribution of people with disabilities in this country. Thank you.

[The prepared statement of Mr. Register follows.]

WRITTEN TESTIMONY TO THE
U. S. HOUSE OF REPRESENTATIVES
SUBCOMMITTEE ON HUMAN RIGHTS AND WELLNESS

"LIVING WITH DISABILITIES IN THE UNITED STATES: A SNAPSHOT"

Witness Name: John Register
Title: Manager, Paralympic Academy
City and State: Colorado Springs, Colorado
Institutional Affiliation: United States Olympic Committee
Date: June 24, 2004

Personal Story

Good afternoon and thank you for this opportunity to testify before you today. My name is John Register and I am the Director of the Paralympic Academy, a national outreach program of the United States Olympic Committee (USOC) that enables children with physical disabilities to become more active in life.

Before I lost my leg in a freak hurdling accident, I was a three time all-American and graduate of the University of Arkansas. I twice went to the Olympic Trials. In 1988 I went as a 110 meter high hurdler and in 1992 I went as a 400 meter hurdler. I also was a soldier in the United States Army and served in Operation Desert Storm and Desert Shield.

While preparing for the 1996 Olympic Trials in the 400 meter hurdles, I misstepped one hurdle and landed wrong. The landing dislocated my left knee and severed my popliteal artery. A vein graft 11 hours later was unsuccessful and after inadequate blood flow to my leg for 5 days, the decision was made to amputate.

My first reaction was not if and when I would compete in sport again, my first reaction was personal identification. Who was I now? Was I still a husband to my wife? Would she still desire me? Was I still a father to my then 5-year-old son? Was I still a son to my father and mother? How would I now be looked upon? Would I be accepted by society? Most importantly, could I continue my job with the United States Army?

Not only did I need to work through my own depression and attitude toward disability, I had to confront federal policy and program expectations that assumed that I would not return to work. Though I was accepted to Officer Candidate School at Fort Benning, Georgia for an October 1994 start date, it was assumed by the Army that I would take a medical retirement and accept a disability check for the rest of my life.

Current Outlook

Fourteen years after the enactment of the Americans with Disabilities Act, people with disabilities continue to face physical, attitudinal and economic barriers to work and full participation in society. While physical barriers are being addressed, the attitude barrier remains pervasive in our society.

To begin to address the attitude barrier, a change must take place in the national consciousness regarding disability. The government attitude toward disability must set the standard. Federal programs and policies assume I cannot work and cannot perform along side a non-disabled person, therefore our policies do little to make-work possible.

Just 18 months after my injury, I competed in the 1996 Paralympic Games in Atlanta Georgia, and 4 years later I earned the silver medal in the long jump in Sydney Australia. That silver medal jump was equivalent to bounding over a single lane highway. Prior to losing my leg, my longest jump was equal to leaping over a two-lane highway. Whether it is with one leg or two, long jumping these distances takes hard work, discipline and skill. All of which are critical elements to succeeding in life.

Some 14 years after passage of the Americans with Disabilities act, the employment outlook for people with disabilities is still grim. Today, 99.8% of people with disabilities who receive Social Security benefits never achieve employment and 70% of working age people with disabilities are unemployed. Additionally, lack of access to physical activity, health promotion and health management programs as evident by the following statistics present additional barriers to full participation in society:

- 75% of children with physical disabilities in the U.S. do not participate in physical education programs at school or health and wellness programs in there communities.

According to the Centers for Disease Control and Prevention:

- 56% of people with disabilities get no physical activity whatsoever
- Per capita health care costs are four times greater for people with disabilities than for those without.
- People with disabilities have higher rates of chronic conditions such as diabetes, depression, high blood pressure and obesity.

Opportunity

I have seen personally the positive impact health and wellness has on my peers with disabilities and how that transcends to other aspects of their life, especially employment. As a former Olympic-level athlete and current Paralympic athlete, I have seen the impact of the Olympic and Paralympic programs on eliminating attitudinal barriers.

The USOC through its Paralympic Division, is committed to addressing quality of life issues for people with disabilities through the Paralympic Academy program. As its program director, I understand how the Paralympic Academy can address quality of life issues for people with disabilities. The Paralympic Academy objectives are to:

- Partner with existing leadership organizations in all 50 states to enhance programming, training and support of comprehensive health and wellness programs for children with disabilities;
- Provide cost-effective and turn-key preventative health and wellness programs in 50 states;
- Provide train-the-trainer programs for physical education teachers and program directors in all 50 states;
- Provide more than 50,000 cost-effective sport wheelchairs to students throughout the U.S.;
- Develop a national message promoting the abilities of children and adults with physical disabilities, and
- Provide recognition and incentive state-wide and nationally for outstanding programs, teachers and students that are having impact in all 50 states.

In 2005, the USOC will select children with physical disabilities and coaches from all 50 states to attend a National Paralympic Academy establishing a network of ambassadors who promote the importance of a healthy, active lifestyle.

The USOC also is conducting a series of sports clinics with soldiers returning from Afghanistan and Iraq with permanent disabilities to demonstrate that there is life after a serious injury. Soldiers have the opportunity to connect with local adapted sports programs to pursue their interests in sports and remaining physically fit.

I know that for many others, and me there is no question that sport was the path to successful employment, as well as, to well being for my family and me.

Proposed Action Steps

The USOC would like to:

- Become a strong partner in developing and implementing comprehensive programs with Congress, Federal Agencies and the White House.
- Secure a legislative amendment in IDEA to fund a research study quantifying how involvement in health and wellness programs can impact the achievement levels of children with physical disabilities.
- Engage Congressional leaders in supporting adapted sports programs in your Districts and recognizing and creating awareness of constituents who are delivering or participating in health and wellness programs.

Thank you very much for the opportunity to testify before your Subcommittee today. In closing, the U.S. Olympic Committee looks forward to working with Congress to expand participation and contributions of people with disabilities in this country.

Mr. BURTON. How far did you say you could go with just one?

Mr. REGISTER. One leg, I jumped 18 feet, 4 inches.

Mr. BURTON. That is pretty good.

Mr. REGISTER. I'm that one-legged man in that butt-kicking contest.

Mr. BURTON. It is a heck of a lot further than I can, and I don't have those limitations. But then I am only 29 years old.

Mr. Hall, when I was 20 years old, I sent a picture of myself to Walt Disney Studios, and they haven't responded. Could you call them?

Mr. HALL. I'll talk to Walt. Oops.

Mr. BURTON. Mr. Hall, you are recognized.

Mr. HALL. Thank you very much. Good afternoon, Representative Burton, Chairperson Burton, and Ms. Watson. I knew you for so many years as Senator Watson, it's a great honor to speak to you as Representative Watson, so thank you.

I am Robert David Hall, and you have heard that I play Dr. Robbins on CSI. More importantly to these proceedings, I'm here as a new board member of the National Organization on Disability, and I guess most importantly I'm one of the 54 million Americans with a disability.

And with two legs and a pole, I only went 13 feet, so I'm looking at this man in awe.

It's an honor to speak before you today. I grew up here in Washington, and it is very nice to come home.

I'm especially grateful for the opportunity to draw attention to the National Organization on Disability/Harris Survey of Americans with Disabilities. To many of us who identify ourselves as people with disabilities, the NOD/Harris survey is the gold standard of surveys. I believe it is an accurate snapshot of what it is like to live as a disabled.

Now, I'm not a statistician or professor or pollster, but I have learned over the years from the various committees and groups that I belong to that numbers and statistics are important. We have to measure because that is what dictates what action is taken on behalf of any group.

And while others joining me today—and Alan—can speak a little bit more accurately on the specifics of this very important survey, I would like to speak briefly about my experience as a disability advocate and hands-on volunteer with burn victims and recent amputees.

I'd like to paint a picture of myself, of course, as a selfless humanitarian, but the truth is whatever advocacy or volunteer work I have been involved in has given me back far more than I have ever invested. Twenty-six years ago I was badly burned when an 18-wheel truck ran over my car on a California freeway. My gas tank exploded, and I was burned over 65 percent of my body. I spent months in a hospital burn ward, and I had both my legs amputated.

Now, following that trauma, I concluded that I am not exceptionally brave, but I am ambitious. I wanted a life, and as an actor once told me, if you are going to pray for something, be specific. Use lots of adjectives. I wanted not an average life, but something

out of the ordinary. I wanted to succeed, and I didn't want disability or prejudice to stand in my way.

Some people pitied me, and some helped me, especially my family and friends. I also helped myself quite a bit. I learned to use assistive technology, prosthetic limbs, hand controls for my car. I reentered the work force, and I began to face certain obstacles that many people with disabilities encounter. I am a college graduate, by the way, as are many people with disabilities. I faced accessibility issues, health care concerns big time, and attitudinal barriers. That was foremost among them.

I believe I have overcome many of these challenges, but I didn't do it alone. Along the way many other people with disabilities have fought long and hard to improve life for their peers. From my own experience, one thing I know very well is the cost of health care with disabilities and how particularly important good health care is to successfully stabilizing a disability so a person can make the most out of their life.

This is why one section of the NOD/Harris Survey of Americans With Disabilities that is being released today, the section on health care, causes me some particular concern for our community. Twenty-six percent of people with disabilities, as you have heard already, report not filling a prescription in the last year due to cost. Twenty-eight percent report putting off needed health care last year due to cost. Cost has also caused 23 percent of people with disabilities to bypass a doctor's recommendations, compared to only 9 percent of the nondisabled population. About a tenth of people with disabilities say they went without needed physical or speech therapy or mental health service last year.

It is no surprise, then, that the survey also finds people with disabilities have a greater fear of losing their independence. Thirty-four percent fear having to go into a nursing home. I know many folks who know that it is cheaper to have an attendant than to go into a nursing home. About half all Americans with disabilities fear they will not be able to take care of themselves or will become a burden to their families. That's twice as great a rate of concern as for other Americans.

People with disabilities are more worried about losing their health insurance. Now, I'm very aware—I serve on a couple of boards for the Screen Actors Guild—the cost of health care is a problem to anybody in this Nation of ours. It is especially of concern to people with disabilities.

The more severe the disability, the more intense the concern is. For people with severe disabilities, especially those who are not independently wealthy, independence is a tenuous asset if it has not already been lost. The Supreme Court's Olmstead Commission, which had its fifth anniversary this Tuesday, and President Bush's Olmstead order have helped us. These orders built on the rights that were secured by the Americans with Disabilities Act passed by President Bush, Senior, 14 years ago. And this body, I should say, not by President Bush.

The ADA has been a milestone piece of legislation bringing national attention to our concerns. And I commend all the legislators and activists who made it possible, who made possible its enactment and its enforcement.

NOD, by the way, currently supports another piece of legislation that is pending: The Medicaid Community Attendant Services and Support Act, which I know you are aware of, MiCASSA. We believe that it will do much more to ensure freedom for Americans with disabilities and their families, and I hope these NOD/Harris survey findings will help all of our legislators to understand how important this issue is for those of us who are Americans with disabilities.

When I speak or visit with people that are newly disabled, who had just joined the disability community, I become reenergized, and I had also become reconcerned—on a recent visit with injured soldiers at Walter Reed Hospital, I was very pleased to see that these young men are receiving first-class medical care, and they are wearing the same expensive electronic prosthetics that I am, and I hope you are, too. Their spirit, by and large, is extremely positive, and our country is standing by these soldiers by providing them with the assistive technologies that is going to help them maximize their potential.

But I am also aware that they have a different life ahead of them. Whether you are a decorated war veteran or just an average citizen with a disability, you have a gauntlet to run, and as the Harris survey shows, for many, cost comes between them and the technologies they need. The benefits of assistive technology will not be fully realized as long as cost is a factor keeping people with disabilities from the technologies and devices that will help them lead fuller lives.

And then, of course, depending on the severity and time of disability, one has some doors open, and certain other doors close. This NOD/Harris survey does a good job of pointing out the societal problems and highlights the real gaps we face as disabled citizens. And in fairness—I want to keep this close to the 5 minutes that Representative Burton asked—whether we are labeled severely, moderately, or slightly disabled, no matter what our mental, physical, sensory or psychiatric disability may be, the bottom line, for me anyway, is that there remains discrimination against people who are perceived to be different.

I became involved in disability advocacy for several reasons. I am a person with disability. I faced other obstacles pursuing my career by—mainly because I think it is a colossal waste to exclude people from contributing to society based on their difference. I believe that with all my heart.

I mentioned earlier that I grew up in D.C. I'm a baseball fan. I've got a Washington Senators hat from 1959 on my bookshelf. I pray you will get a team soon. I'd like it in the inner city, but just have a Washington Senators. The time I left was the year Calvin Grif-fith took them to Minnesota, so this town has a big part of my soul. I love baseball because it is a lot like life. They tend to do things the way they have always done them, and they revere tradition.

In his wonderful book, *Moneyball*, the author Michael Lewis talks about the great unorthodox style used by Oakland Athletics general manager Billy Beane. Rather than relying strictly on old-school scouting reports and general overall physical impressions, Billy Beane selects his ballplayers on the basis of two very specific statistical events. It's called *sabermetrics*, and they want two

things out of their ballplayers. Do you get on base? Can you get people home who are there on base? And he doesn't look for his talent the traditional way. You have to do those two things to be a ballplayer on the Oakland A's. You must perform this way.

The author Michael Lewis writes: The inability to envision a certain kind of person doing a certain kind of thing because you have never seen someone who looks like him do it before is not just a vice. It's a luxury. What begins as a failure of the imagination ends as a market inefficiency: When you rule out an entire class of people from doing a job simply by their appearance, you are less likely to find the best person for the job.

And I believe that. You are less likely to find the best person for the job. I'm playing the coroner on CSI, the No. 1 show around the world, because a couple of enlightened producers and one network executive saw past my disability and focused on my skills as an actor. In Hollywood when I started, they were afraid disabled people would slow the production down. That they couldn't learn their lines, blah, blah, blah, blah. And it is a silly business to get into unless you are an actor, unless you really love it and are willing to jump off a cliff.

This issue is so much bigger than my minuscule problems. The NOD/Harris survey indicates there is a large gap in employment between college graduates who do and do not have disabilities. I think that is a failure of imagination. But I think a greater number of future doctors, lawyers, CEOs, and leaders of our country can and must come from the ranks of Americans with disabilities. Hiring and promoting people with disabilities is not just the right thing to do, it's the smart thing to do, and it's good business.

I'm aware that change takes time. I'm also aware that great things start in rooms just like these, and I thank you so much for your time.

Mr. BURTON. Thank you for that testimony. It is very, very effective and helpful.

[The prepared statement of Mr. Hall follows:]

**CONGRESSIONAL TESTIMONY OF ROBERT DAVID HALL
HOUSE GOVERNMENT REFORM
SUBCOMMITTEE ON HUMAN RIGHTS AND WELLNESS
JUNE 24, 2004**

Good afternoon. I'm Robert David Hall. Some of you may know me as the actor who plays Dr. Robbins, the Medical Examiner on CSI: Crime Scene Investigation. More importantly to these proceedings, I'm also a Board member of the National Organization on Disability, and most importantly, I'm one of our country's 54 million citizens with a disability

It's an honor to speak before you today. I grew up in Washington, so it is nice to come home; and I'm especially grateful for this opportunity to draw attention to the N.O.D./Harris Survey of Americans with Disabilities. To many of us who identify ourselves as People with Disabilities, the N.O.D./Harris Survey is the "gold standard" of surveys. I believe it's an accurate snapshot of what it's like to live as a disabled American. I'm not a statistician or a pollster, but I've learned over the years that numbers and statistics help dictate what action is taken on behalf of any group. While others joining me today are better able to discuss the specifics of this important survey, I would like to speak briefly about my experience as a disability advocate and hands-on volunteer with burn victims and recent amputees. I'd like to paint a picture of myself as a selfless humanitarian, but the truth is, whatever advocacy or volunteer work I've been involved in has given me back far more than I've ever invested.

Twenty-six years ago I was badly burned when an 18-wheel truck ran over my car on a California freeway. My gas tank exploded and I was burned over 65 percent of my body. I spent months in a hospital burn ward and had both legs amputated. Following this trauma, I concluded that I'm not exceptionally brave, but I AM ambitious. I wanted a life, and not just an average life, but something

out of the ordinary. I wanted to succeed, and I didn't want disability or prejudice to stand in my way.

Some people pitied me and some helped me... especially my family and friends. I also helped myself quite a bit. I learned to use assistive technology: prosthetic limbs, hand controls for my car. I re-entered the workplace and began to face certain obstacles that many people with disabilities encounter: accessibility issues, health care concerns, and attitudinal barriers foremost among them. I believe I overcame many of my own challenges, but I didn't do it alone. Many other people with disabilities have fought long and hard to improve life for their peers.

From my own experience, one thing I know very well is the cost of health care with a disability—and how particularly important good health care is to successfully stabilizing a disability so that a person can make the most of life. That is why one section of the N.O.D./Harris Survey of Americans with Disabilities being released today, the section on health care, causes me some particular concern for our community. Twenty-six percent of people with disabilities report not filling a prescription in the last year due to cost. Twenty-eight percent report putting off needed health care last year due to cost. These percentages are about twice as high as for people who don't have disabilities. Cost has also caused 23 percent of people with disabilities to bypass a doctor's recommendation, compared to only nine percent of the non-disabled. About a tenth of people with disabilities say they went without needed physical or speech therapy or mental health services last year.

It is no surprise, then, that the survey also finds people with disabilities have greater fear of losing their independence. Thirty-four fear having to go into a nursing home, compared to six percent of other Americans. About half of all

Americans with disabilities fear they will not be able to take care of themselves or will become a burden to their families, which is twice as great a rate of concern as for other Americans. They are also more worried about losing their health insurance. The more severe their disabilities, the more intense those concerns are. For people with severe disabilities, and especially those who are not independently wealthy, independence is a tenuous asset if it has not already been lost.

The Supreme Court's Olmstead Decision, which had its fifth anniversary this Tuesday, and President Bush's Olmstead Executive Order have helped us. These built on the rights secured by the Americans with Disabilities Act, passed 14 years ago. The ADA has been a milestone piece of legislation, bringing national attention to our concerns, and I commend all the legislators who supported its passage and enforcement. N.O.D. currently supports another piece of legislation that is pending, the Medicaid Community Attendant Services and Supports Act, MiCASSA, that we hope will do much more to ensure freedom for Americans with disabilities and their families. I hope these N.O.D./Harris survey findings will help all our legislators to understand how important this issue is for Americans with disabilities.

When I speak with or visit people who have newly joined the disability community, I become re-energized AND concerned. On a recent visit to injured soldiers at Walter Reed Hospital, I was pleased to see that these young men are receiving first class medical care and the latest in prosthetic equipment. Their spirit, by and large, is extremely positive, and our country is standing by these soldiers by providing them with the assistive technologies that will help them maximize their potential. But, I'm also aware that they have a different life ahead of them. Whether you're a decorated war hero or an average citizen with a disability, you have a gauntlet to run. And as the Harris survey shows, for many,

cost comes between them and the technologies they need. The benefits of assistive technology will not be fully realized so long as cost is a factor keeping people with disabilities from the technologies and devices that will help them lead fuller lives.

Depending on the severity and type of disability that one has, some doors open but certain other doors close. The N.O.D./Harris Survey does a good job of pointing out these societal problems and highlights the real gaps we face as disabled citizens.

One of the interesting findings of this study is that those of us with disabilities are increasingly feeling a common bond or identity with each other. I look forward to the day when the political power of 54 million disabled Americans is truly felt at the ballot box and in these halls.

Whether we're labeled "severely," "moderately," or "slightly" disabled, and no matter what our mental, physical, sensory or psychiatric disability may be, the bottom line, for me anyway, is that there remains discrimination against people who are perceived to be DIFFERENT.

I became involved in disability advocacy for several reasons:

I'm a person with a disability,

I faced certain obstacles pursuing my career...

but mainly because,

I think it's a colossal waste to exclude people from contributing to society based on their "differences"

I mentioned earlier that I grew up in Washington. I'm a baseball fan, a fanatic really. I've got a Washington Senators hat on my bookshelf. I actually left town

the same year Calvin Griffith moved Harmon Killebrew and the Senators to Minnesota. Now, baseball's a lot like life. They tend to do things the way they've always done them. They revere tradition.

In his wonderful book, "Moneyball," Michael Lewis talks about the unorthodox methods used by Oakland Athletics general manager, Billy Beane. Rather than relying strictly on old-school scouting reports and overall physical impressions, Beane selects his ballplayers on the basis of very specific statistical talents. He doesn't care if a member of his club "looks" like a ballplayer, they must perform like one.

Michael Lewis writes:

The inability to envision a certain kind of person doing a certain kind of thing because you've never seen someone who looks like him do it before is not just a vice. It's a luxury. What begins as a failure of the imagination ends as a market inefficiency: when you rule out an entire class of people from doing a job simply by their appearance, you are less likely to find the best person for the job.

I believe that. "You are less likely to find the best person for the job."

I'm playing the coroner on CSI today because a couple of enlightened producers and a network executive saw past my disability and focused on my skills as an actor. This issue, obviously, is much larger than my miniscule problems. As the N.O.D./Harris Survey indicates, there's a large gap in employment between college graduates who do and who do not have disabilities. I think that's a failure of imagination.

I think a greater number of future Doctors, lawyers, CEOs, and Leaders of our

country can and must come from the ranks of Americans with disabilities. Hiring and promoting people who have disabilities is not just the "right" thing to do. It's the smart thing to do, and it's good business.

I'm aware that change takes time. I'm also aware that great things start in rooms like this one. Thank you for your time today.

Mr. BURTON. I might take issue with one thing you said. You said that we ought to get the Washington Senators back. One of the reasons that we lost the Washington Senators is because there is only 100 of them. There are 435 of us. It should be called the "Washington Representatives."

Mr. HALL. Well, they were called the Nationals at one time, so maybe we can fix that.

Mr. BURTON. Maybe we can fix this.

Mr. Blanck.

Mr. BLANCK. Thank you, Mr. Chairman, for the honor to address this committee. And I will be brief.

As a professor, I do—I teach sometimes 70 law students in a course on Federal disability law every year, and we get these course evaluations. And I got one back that said: If I had 1 hour to live, I would spend it in your class. Feeling proud about that, I took it home to my wife, and she said, what is that asterisk that I see over here? And in big print it said: Because, Professor Blanck, your class seems like an eternity.

So I will be brief, unlike my usual style.

I want to make two central points today among the many that have been talked about today, and they focus on meaningful access to employment, what we mean by that, and economic independence for people with disabilities, both areas that are studied in the Harris poll, both areas in which I have done some work and others have as well. So I won't belabor that point. But I wanted to give you highlights of this area.

I think it is very relevant to the tax discussion we were having earlier. As you know, we now have in place in a comprehensive work force system which the Department of Labor oversees, the Employment and Training Administration oversees, and a core component of that system is what is called the one-stop centers. And I want to report to you today some encouraging news from the Harris poll about those one-stop centers.

In fact, almost half of the people polled with disabilities now report being aware of those one-stop centers and are beginning to use them. This is a particularly encouraging result, particularly given the high rates of unemployment we have been talking about and the need to present opportunities for the many, many qualified individuals with disabilities who want to work.

There are other important things going on in the Department of Labor. For example, in partnership with the Social Security Administration, they now have a Disability Program Navigator individual who creates these links among agencies for persons with disabilities to get meaningful employment. And the Harris poll, again, shows that expanding these opportunities, these meaningful opportunities, for individuals to have work, to train, to engage with employers is really needed.

Now, I'm skipping over some of my remarks, but this tax area that you mentioned is crucial. It is a central area for enhancing the employment and the integration into life for persons with disabilities, and the 2004 Harris poll unfortunately finds that only 1 in 10 people use these Federal tax credits. So it is very underused. It can go to workplace accommodations. It can go to helping small employers hire persons with disabilities. It can go to assisting and

getting personal assistant services. So we have to do a better job of thinking about tax policy in this regard.

Our center in Iowa has been very fortunate because we have received a grant from NIDRR in the U.S. Department of Education to start an aggressive campaign called TAX FACTS, and we are partnering with HHS and the IRS to basically improve the financial education of persons with disabilities and their families and their employers.

Now, that goes to the second area which I will touch upon briefly. What do we mean by this area of economic independence? Well, the reality is you can have all the tax credits you want, but if folks are earning \$6,000 a year or \$12,000 a year, just above the poverty level, how are they going to live? What is the incentive really to go off Federal programs?

So what our center and others have done at NOD is we have to start thinking about how people with disabilities can accumulate assets. We know that there is a strong program for people in poverty in place, the AFIA Act of 1998, which is financial education and the individual development accounts which you guys are familiar with. Yet when we studied this IDA program in the NOD/Harris poll, only 6 percent of people with disabilities report having an IDA, and that is really a shame and astounding, because we know on the TANF rolls, the welfare programs, over 50 percent of people who are on those rolls either have a disability or have a family member with a disability.

And this lack of financial education and tax savviness leads to disparities in banking relationships, in the ability to buy stocks and bonds, in homeownership. Even though people with disabilities own homes, particularly at older ages, at relatively high rates, again the Harris poll shows there are terrific disparities in people claiming what every American who owns a home claims, and that is the mortgage deduction credit.

So there needs to be awareness and education about the tax programs out there, and I believe that the Harris poll and studies like it go a long way toward helping improve the dialog about what we mean by economic independence and meaningful employment. And I believe that more facts-based evidence is required, as Mr. Hall and Mr. Reich have said, to measure the outcomes of these programs on the lives of persons with disabilities in America.

And I am under my time, so I will be very unprofessorial and conclude there. Thank you.

Mr. BURTON. Thank you very much, Doctor. We appreciate your comments.

[The prepared statement of Mr. Blanck follows:]

Testimony of Professor Peter Blanck¹

**Before the U.S. House of Representatives
Committee on Governmental Reform
Subcommittee on Human Rights and Wellness
Thursday, June 24, 2004**

Summary Page

Mr. Chairman, members of the Committee, my name is Peter Blanck. I am the Charles M. and Marion Kierscht Professor and director of the Law, Health Policy & Disability Center at The University of Iowa College of Law.

My testimony today will underscore two critical areas central to improving quality of life for persons living with disabilities: (1) meaningful access to employment and, (2) economic independence. The information in my testimony is derived from preliminary analysis of the 2004 N.O.D./Harris Survey of Americans with Disabilities. The N.O.D./Harris Survey has been commissioned by N.O.D. since 1986, and is one of the most comprehensive surveys examining life indicators of persons with disabilities.

I will describe how meaningful access to competitive employment is facilitated by engagement in the U.S. Department of Labor's comprehensive workforce system, access to assistive technology and universally designed products, and use of state and federal tax incentives to aid in the purchase of technology and workplace accommodations. Economic independence involves the ability to accumulate assets and equal opportunities for home ownership. Through public/private partnerships, these two areas improve employment status, access to the public employment service system, economic independence, self-determination, and inclusion into society of persons with disabilities.

¹ For additional copies, alternative formats, referenced materials, or other information contact Professor Blanck at The University of Iowa College of Law, 431 Boyd Law Bld., Iowa City, Iowa, 52242-1113, phone 319/335-9043, fax 319/335-9098, e-mail peter-blanck@uiowa.edu. See also the Law, Health Policy & Disability Center website at <http://disability.law.uiowa.edu>. The views expressed in this statement reflect only those of the author and not the views of the federal government or any other entities.

Testimony of Professor Peter Blanck
Before the U.S. House of Representatives
Committee on Governmental Reform
Subcommittee on Human Rights and Wellness

Thursday, June 24, 2004

Introduction

Mr. Chairman, members of the Committee, my name is Peter Blanck. I am the Charles M. and Marion Kierscht Professor² and director of the Law, Health Policy & Disability Center at The University of Iowa College of Law. The center has offices in Iowa, Washington, D.C., Boston, and elsewhere. It employs more than 20 professionals, many with disabilities, in disciplines including law, education, rehabilitation counseling, instructional design, public health, and computer science.³

I am the Principal Investigator for multiple grants from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education. These grants include the Rehabilitation Research and Training Center (RRTC) on Workforce Investment and Employment Policy for Persons with Disabilities, the Disability and Rehabilitation Research Project (DRRP) on Asset Accumulation and Tax Policy for People with Disabilities,⁴ and the DRRP on Technology for Independence: Community-Based Resource Center.⁵

I have conducted research and written on the implementation of federal and state disability law and policy, and the Americans with Disabilities Act (ADA), with a focus

² Ph.D. in psychology from Harvard University, J.D. from Stanford Law School.

³ See, <http://disability.law.uiowa.edu>

⁴ See, <http://disability.law.uiowa.edu/lhpd/projects/assetdevtaxpol.html>

⁵ See, <http://disability.law.uiowa.edu/cbrc/>

on employment and the civil rights of people with disabilities.⁶ I am a former member of the President's Committee on Employment of People with Disabilities, and have been a Senior Fellow of the Annenberg Washington Program.⁷ In 2003, I represented the National Council on Disability before the United States Supreme Court in *Chevron v. Echazabal*. I am a board member of the National Organization on Disability (N.O.D.).

My testimony today will underscore two critical areas central to improving quality of life for persons living with disabilities: (1) meaningful access to employment and, (2) economic independence. The information in my testimony is derived from preliminary analysis of the 2004 N.O.D./Harris Survey of Americans with Disabilities. The N.O.D./Harris Survey has been commissioned by N.O.D. since 1986, and is one of the most comprehensive surveys examining life indicators of persons with disabilities.

I will describe how meaningful access to competitive employment is facilitated by engagement in the U.S. Department of Labor's (DOL) comprehensive workforce system, access to assistive technology and universally designed products, and use of state and federal tax incentives to aid in the purchase of technology and workplace accommodations. Economic independence involves the ability to accumulate assets and equal opportunities for home ownership. Through public/private partnerships, these two areas improve employment status, access to the public employment service system, economic independence, self-determination, and inclusion into society of persons with disabilities.

⁶ See, e.g., Peter Blanck, *The Americans with Disabilities Act and the Emerging Workforce* (1998); Peter Blanck (ed.), *Employment, Disability, and the Americans with Disabilities Act* (2000); Peter Blanck, Eve Hill, Charles Siegal, & Michael Waterstone, *Disability Civil Rights Law and Policy*, Thomson/West Publishers (2003). See also related publications at the end of this document.

⁷ For related activities, see Blanck vita submitted with this testimony.

1. Meaningful access to employment

Competitive and meaningful employment remains a challenge for many people with disabilities. Meaningful employment opportunity includes adequate wages, hours, and health insurance, and the ability to accumulate assets and other benefits. Obtaining and maintaining employment are critical for people with disabilities to experience their civil rights of equal opportunity and inclusion, and, therefore, are an appropriate focus for this subcommittee's hearing.

a. Engagement with the DOL Comprehensive Workforce System

The Employment and Training Administration (ETA) of the U.S. DOL oversees the comprehensive workforce system. ETA's mission is "to contribute to the more efficient functioning of the U.S. labor market by providing high quality job training, employment, labor market information, and income maintenance services primarily through state and local workforce development systems."⁸ The primary vehicle for providing services to consumer in the workforce system is the One-Stop Center.

I report to you encouraging news for people with disabilities from the recent 2004 N.O.D./Harris Poll. Almost half (42%) of people with disabilities polled reported being aware of the workforce system's One-Stop Centers.⁹ Not only were people with disabilities aware of the One-Stop Centers, but also people with and without disabilities used the services of One-Stop Centers at similar rates.¹⁰

This is an encouraging result, particularly given the high rates of people with disabilities who presently are not working but who want to work. In addition, we would expect to see higher awareness and usage of the One-Stop Centers in the future. Analysis

⁸ <http://www.doleta.gov/etainfo/mission.cfm>

⁹ As compared to 41% of people without disabilities.

¹⁰ I.e., 26% of people with disabilities versus 22% of people without disabilities.

is underway by our center and others to examine the extent to which people with disabilities have adequate physical and program access to, and experience benefits from, the workforce system. In particular, during the past three years, ETA's Work Incentive Grant Programs have focused on improving effective and meaningful participation of people with disabilities in the One-Stop system.

DOL's partnership with the Social Security Administration in the Disability Program Navigator Demonstration project also is improving seamless and comprehensive services to persons with disabilities at the One-Stop Centers, including linkages to the employer community. Additionally, DOL's Office of Disability Employment Policy (ODEP) funds grants on customized employment services for One-Stop Centers. ODEP funds other work-related services for people with disabilities and employers, including the Employer Assistance Referral Network (EARN) and the Job Accommodation Network (JAN). Our center works with DOL on several of these projects, and directly with many of the grantees of these programs.

The One-Stop Centers are designed to improve employment rates for people with disabilities broadly defined, among other groups. In 2004, the N.O.D./Harris Poll reports that 35% of people with disabilities worked full or part-time, an increase in the employment rate of 3% from the 2000 poll.¹¹ Of those not working according to the 2004 poll, almost two-thirds (63%) of people with disabilities would prefer to work.¹² Of those who are disabled and not working, two-thirds (67%) say that they are unable to work due to a health problem or disability; a smaller proportion (8%) report they are not working because they cannot find a job that accommodates their disability. Expanding the

¹¹ As compared to 78% of people without disabilities working, as found in the 2004 poll.

¹² As compared to 42% of people without disabilities who would prefer to work, as found in the 2004 poll.

workforce system to serve people with disabilities will help improve employment opportunities for the large group of qualified people with disabilities who want to work.

b. Access to Assistive Technology and Universally Designed Products

Meaningful opportunity for people with disabilities to competitive employment and community inclusion is facilitated by access to new and universally designed technologies (i.e., products that allow use by almost everyone). Increasingly, people with disabilities are using universal design features at comparable rates as people without disabilities, especially those features integrated into mainstream products.

According to the 2004 N.O.D./Harris Poll, more than eight out of ten (83%) people with disabilities report using cordless telephones or speakerphones.¹³ Other accessible technology (AT) used by people with disabilities and found to be at comparable rates to people without disabilities include closed captioning (15%), automatic door openers or remotely controlled lights (26%), large text on computer monitors (16%), automatic check deposit (62%), and online banking (34%).

Yet, many features in mainstream products are reported to be costly for people with disabilities, indeed the people who could benefit most from these technologies. For example, the vibrate mode on pagers and cell phones (24% versus 37%) and keyless vehicle entry (30% versus 43%) show significantly less usage by people with disabilities than their non-disabled peers. These features frequently are sold as costly options, priced too high for many people with disabilities with lower incomes.

In fact, 17% of 2004 N.O.D./Harris Poll respondents with disabilities reported there was AT that they needed but did not have. They reported needing complex devices such as motorized wheelchairs (19%), hearing aids (15%), and mechanized assists such

¹³ As compared to 87% of people without disabilities.

as lifts and chairs (7%), to simpler devices such as walkers or canes (8%), computer software (5%), and non-mechanized assists such as railings and bars (9%).

Only 57% of those who needed these devices attempted to acquire them, primarily because they were too expensive. Of those who attempted to obtain the devices, more than half (54%) reported they could not afford them. For the 43% who did not attempt to acquire these devices, 61% did not attempt to acquire them because the devices were too expensive.

AT enables people with disabilities to improve their participation in society. Of the respondents who needed AT that they did not have, 37% reported that the device would help them live independently, 25% to leave their homes, and 18% to socialize with family and friends. In addition, 7% reported these devices would improve their employment opportunities, and 4% said it would make them more productive at work.

More than one-third (35%) of respondents said they paid for the devices themselves. Of respondents who did not pay for it themselves, assistance to purchase devices was obtained from health insurance programs (62%), public programs (19%), from a family member or friend (16%), an employer (9%), or state Workers' Compensation payments (7%). People generally learned about AT from their doctors (49%) and healthcare or rehabilitation professionals (22%).¹⁴ The findings suggest that more needs to be known about medical and healthcare professionals knowledge about AT.

¹⁴ Other sources of information reported include government programs (4%), community centers and disability organizations (4%), the media (13%), and the Internet (5%). While these appear to be important sources of information about AT, along with family and friends (14%) and other people with disabilities (6%), healthcare professionals appear to be at least a major source of information for people with disabilities.

In addition, more may be learned about how AT improves inclusion and success in employment. NIDRR's "Technology for Independence" DRRPs, including Iowa's "Community-Based Resource Center," have been funded to help achieve this goal of independence.¹⁵ These collaborations between university researchers and disability community organizations include people with disabilities in the design, development, and execution of the research and the dissemination of information.¹⁶

c. Leveraging Tax Incentives

Another important means for enhancing employment opportunities relates to use of federal and state tax incentives available to employers and individuals with disabilities. In 2002, the GAO reported that the business tax incentives (e.g., the Work Opportunity Credit, Disabled Access Credit, and the Barrier Removal Deduction) were not widely used.¹⁷ One factor cited that limits usage is lack of familiarity with the incentives. Strategies to increase awareness and usage cited by the GAO include improving outreach through coordination and clarification of incentive requirements.

In accord with GAO's findings, the 2004 N.O.D./Harris Poll finds that only 12% of people with disabilities claim available credits or deductions, such as federal and state tax deductions and credits designed to assist people with disabilities in employment.¹⁸

¹⁵ Other programs are at the University of Pittsburgh, Washington University in St. Louis, and at the California Foundation for Independent Living Centers. For information on each of the Technology for Independence projects, and links to the projects, see http://disability.law.uiowa.edu/cbrc/research/ti_projects.htm.

¹⁶ In addition, NIDRR has funded "IT Works" at our center, which is learning through research about the use of AT and accommodations in the workforce. With results and input from experts on employment of people with disabilities, the Iowa center is developing training for employers and employees to use AT to improve outcomes for people with disabilities.

¹⁷ GAO Report GAO-03-39. Business Tax Incentives: Incentives to Employ Workers with Disabilities Receive Limited Use and Have an Uncertain Impact. (2002) (finding that 1 out of 790 corporations and 1 out of 3,450 individuals with a business affiliation used the Work Opportunity Credit in 1999. Only 1 out of 680 corporations and 1 out of 1,570 individuals with a business affiliation reported using the Disabled Access Credit).

¹⁸ Of those 12%, 55% claimed both federal and state and 25% claimed only federal.

Tax deductions and credits may be used to pay for workplace accommodations or personal assistant services. The questions posed by the N.O.D./Harris Poll provide preliminary but needed information for policymakers about tax incentives.

The Iowa disability center's new "Asset Accumulation and Tax Policy Project" (AATP) is studying these issues. One important initiative of the AATP project is TAX FACTS,¹⁹ a campaign to improve tax knowledge, financial education skills, and financial service relationships nationwide for persons with disabilities, their families and employers. TAX FACTS addresses underused tax credits and financial relationships with banking institutions by persons with disabilities, their families and employers. TAX FACTS will expand opportunities for persons with disabilities to achieve economic independence and build assets.

2. Economic Independence

Promoting social and economic independence is at the heart of disability-related legislation enacted in the past 50 years. The Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973, and the American with Disabilities Act (ADA), contribute to the groundwork for Americans with disabilities to gain social and economic independence through work, education and community participation and integration. However, much of the legislation for low-income Americans with disabilities in housing, health care, employment, education, and technology has focused primarily on the limits

¹⁹ TAX FACTS is a collaboration with the Office on Disability in the U.S. Department of Health and Human Services; the National Disability Institute in the NCB Development Corporation; the National Cooperative Bank; the Law, Health Policy & Disability Center; the Office of Special Education Rehabilitative Services, U. S. Department of Education; the Office on Disability and Employment Policy, U. S. Department of Labor; and the National Federation of Community Development Credit Unions, in collaboration with The Internal Revenue Service and the Federal Deposit Insurance Corporation.

of asset accumulation, not on its potentials. As such, asset-building strategies for people with disabilities often have been the result of unintended consequences of legislation, rather than the intended outcome.

a. Ability to Accumulate Assets

One component of economic self-sufficiency involves the ability to accumulate assets. The 2004 N.O.D./Harris Poll reveals that the majority of people with disabilities are “asset poor” (e.g., 58% responding compared to 36% of people without disabilities). Asset poor individuals and their families have insufficient financial resources to support themselves at the poverty level for three months without other means of support.²⁰

The mechanisms for enhancing asset accumulation for low-income Americans have focused on the development of financial education and savings strategies, such as the development of IDAs, which are matched savings accounts for the poor. Yet, only 6% of people with disabilities responding to the N.O.D./Harris Poll report having an IDA, compared with twice as many (13%) people without disabilities. One important goal of the Assets for Independence Act of 1998 (AFIA) is financial education in IDA programs for people in poverty, many of whom have disabilities.

The lack of financial education also leads to disparities in banking relationships. The 2004 poll finds that fewer people with than without disabilities have checking accounts with banks (69% versus 76%). The same disparity is true for savings accounts (46% versus 65%) and loans with banks (26% versus 36%).

In contrast, the 2004 poll finds that credit unions serve similar proportions of people with and without disabilities through checking accounts (22% versus 24%) and

²⁰ See Assets for Independence, a program of the Office of Community Services in the Administration for Children and Families within HHS, <http://www.acf.hhs.gov/assetbuilding/assets.html>

loans (19% versus 23%), but differ in the percentages with respect to savings accounts (28% versus 37%). People with and without disabilities use credit union online banking and automatic check deposit at similar rates.

A disparity also exists in stock and bond ownership between people with (21% have stocks or bonds) and without disabilities (34%), and in government savings bond ownership (15% and 21%, respectively). Differences in savings accounts, stock and bond ownership likely is due to asset limits in federal assistance programs, limited incomes, lack of employment, and other reasons.

We have begun to examine why these disparities exist and how banking may become more accessible for people with disabilities. Last year, our center co-sponsored a blue-ribbon panel on corporate culture and disability at Merrill Lynch's corporate headquarters.²¹ Merrill Lynch and several other financial services companies are examining how to hire and retain people with disabilities, but also they want to help people, including those with disabilities, manage and grow assets.

b. Opportunities for Home Ownership

One encouraging finding from the 2004 N.O.D./Harris Poll is that more than half (58%) of people with disabilities (and 61% without disabilities) report owning their homes. People with and without disabilities own homes at similar rates from the age of 18 to 29 (22% and 26%, respectively). People with disabilities lag in home ownership from the ages of 30 through 64: thus, between the ages of 30 and 44, 51% of people with disabilities, compared to 67% of people without disabilities, reported owning homes. For ages of 45 to 64, 63% of people with disabilities, compared to 78% of people without

²¹ The symposium is archived at http://disability.law.uiowa.edu/lhpdc/archives/2003_merrill_lynch/ml_symp_archive.html.

disabilities, owned homes. Similar to the trends for the youngest group (18 to 29 years of age), individuals with disabilities age 65 and over do not differ in home ownership from those without disabilities (72% and 75%, respectively). The findings suggest that home ownership occurs later in life for many people with disabilities.

There also is variation in home ownership among people with different disabilities, with people with physical as compared to mental disabilities report higher rates of ownership: those with physical disabilities, deafness or hard of hearing, and blind or vision impaired show higher rates of home ownership (rates ranging from 39% to 46%); people with emotional, mental, and learning disabilities have the lowest rate of home ownership (26% to 28% range).

There also is variation in the rate of home ownership by age of disability onset, with earlier onset associated with lower rates of home ownership. The poll finds that home ownership rates among those with onset of disability at birth through young adulthood is roughly 30%. For those with disability onset in middle age, home ownership rates were 41%, and for those with onset over 55 years, home ownership was 65%.

Educational level is related to home ownership rates. People with and without disabilities who are college graduates own homes at relatively high rates (73% and 77%, respectively). Those with less education are less likely to own homes (rates do not differ significantly for individuals with and without disabilities) -- less than a high school education, 42% and 53%, respectively; with a high school education, 63% and 57%, respectively; and some college 55% and 56%, respectively.

Although home ownership rates for people with and without disabilities are comparable, the poll finds people with disabilities less likely to use the home mortgage

interest tax deduction, which is one of the most widely used tax deductions for the accumulation of assets by the American public. Approximately 44% of people with disabilities reported claiming this deduction, as compared to 63% of people without disabilities.

This latter trend may be attributable to lower income levels among those with disabilities. People with disabilities who reported owning their home were less likely to claim the deduction because they do not file tax returns (22%), as compared to people without disabilities (2%). One reason for this may be that almost three times the number of people with disabilities (26%), compared to those without disabilities (9%), report household incomes \$15,000 or below.²² This may reflect that they do not have income required to file a return or they do not have expenditures to benefit from itemizing deductions.

Conclusion

Thank you for this opportunity to address this subcommittee.

My testimony underscored two areas critical to improving the quality of life for persons living with disabilities: (1) meaningful access to employment and, (2) economic independence. The information is derived from preliminary analysis of the 2004 N.O.D./Harris Survey of Americans with Disabilities.

Meaningful access to employment for people with disabilities is enhanced by awareness and use of the workforce system's One-Stop Centers. Initial findings show that people with disabilities benefit from AT and universally-designed technologies,

²² The poll finds that the \$15,001 to \$25,000 includes 20% of people with disabilities, compared to 12% of people without disabilities.

particularly when they are affordable and used in support of employment and community integration. In addition, although tax policy aids people with disabilities in paying for AT and their employers in paying for workplace accommodations, it remains underused.

Economic independence is derived from meaningful employment and adequate income, and sustained by asset accumulation and home ownership. There are disparities in the ability to accumulate assets for people with disabilities, yet home ownership is comparable for people with and without disabilities. The overall disparities in asset accumulation may be related to income maintenance programs for people with disabilities that place limits on assets other than homes.

The N.O.D./Harris Poll findings further inform the dialogue about meaningful employment and economic independence for Americans with disabilities. The information derived from this survey is useful to individuals with disabilities, their family members, policymakers, and employers. It will help the subcommittee on Human Rights and Wellness to better understand and address the status of people with disabilities in America.

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Mr. BURTON. One thing you mentioned in your statement is a number of government agencies, Health and Human Services, Department of Education, and others, that can and do help in some of these areas. You did not mention the U.S. Chamber of Commerce. Has anybody thought about talking to the Chamber of Commerce that represents business and industry all across this country about the possibility of tax incentives for them to hire the disabled and get the Chamber behind this sort of thing? Because the Chamber is a very powerful lobby here in Washington and in the States, and it seems to me that in addition to getting governmental entities like Health and Human Services and the Department of Education interested in positive changes, getting the Chamber involved would be very positive.

And I really believe that they would buy into this sort of thing, because they and the people that they represent realize the benefit of tax credits. I want to tell you, if you want to talk to businessman—and I was one once a long time ago—when you start talking about a way to get a good employee and get a tax break at the same time, I would jump all over that. I think most business and industry people would. And if your organizations would reach out to the Chamber of Commerce and talk to them about it, it might be a very positive thing and have a positive result. And I would be very happy, and I think Ms. Watson would probably as well, to work with you toward that goal.

Mr. BLANCK. If I may respond to that briefly. We have, in fact, worked with the Chamber, and I have spoken there. In Iowa we have worked with the legislature to pass a tax credit for small businesses to hire employees with disabilities, and the legislature set aside a subsidy of half a million dollars or so. Iowa is relatively small compared to some of your States. And we're excited about that we need your help and ideas. Do you know how many employers after year one claimed that tax credit? Three. So we're doing something wrong. The money is there, and my sense is that we need your help to make these programs less complicated and more accessible so small businesses don't have to spend a lot of time and paperwork on this stuff.

Mr. BURTON. There is no question about that. The paperwork scares the dickens out of a lot of businesspeople. But I believe a lot of businesspeople and industry people are not aware of some of these programs, and that is why I was talking about the Chamber of Commerce. They do an awful lot of education work with business and industry, and I think if business and industry was aware of this to a greater degree, that might be beneficial.

Mr. BLANCK. Good point. Thank you.

Mr. BURTON. I want to ask you a question about being an actor. All politicians have a latent desire to, you know—have you ever noticed how many movies we have Senators and Congressmen walking on, and they stumble all over their dialog? I don't know how they ever got elected, but nevertheless you see them on all of these shows.

But I want to ask you a question. As a person with disability, you have 60 percent burns over your body, and you lost both of your legs, and you had a terrible time in recovery. How difficult

was it to get employment in a very competitive field after having gone through that?

Mr. HALL. Well, thanks for asking. By the way, I feel the same way being on your turf that you might on mine. I'm completely awed and honored to be here, and having grown up in D.C., I am thinking about of the Godfather and Michael Corleone going: We run a respectable business here.

I was fortunate that I was a wild child. I worked as a musician in my twenties, and at the time I was injured, I was working as a disk jockey at a radio station, and this was before anybody knew about accessibility. So after I spent my months in the hospital, I was burning with a desire to get back to work and to be a human being again.

That is something people with disabilities—and all people—share. We want to be productive people. I loved my job working on the radio, up at 5 a.m. Fortunately, I was able to do my job in a wheelchair just as easily. I had to roll up to the console, put my headphones on—tells you how long ago it was—start spinning the records, and put the CDs in.

And radio is magical. It is just you and one person listening to you in the dark. And I did quite well at it. But as I started to heal and grow and tried to do other jobs at other stations, they were not accessible to me physically. I couldn't go to the bathroom there. There were a lot of problems.

Many places had never had a disabled entertainer, a disabled person work with them. So I was the first to be working here or working on this TV show or that show. They did not know what to do with me, so my job was mainly making able-bodied people feel comfortable. And I'm past that now.

You know, I think that if we have a talent, an ability, and it is something that society needs, people with disabilities have the same right to the same dreams as anybody else. You know, we have plenty of college graduates who are disabled. We have just got to get them job interviews; and not just any job interview, we need to get them the same quality job interviews that Harvard kids and Princeton kids. I care about—you know, I was not an overachiever myself, but I care about the C students. We have C students running the country.

But I care about the—no, I'm serious. You know college degrees, with due respect to Peter, who I met and enjoy immensely already, we need to make sure that people that can contribute who have disabilities get that opportunity to work. But we need to make sure that the excellent—you know, that the A-plus students who are disabled are moving into the highest echelons that they can. That they don't just say, gee, I'd like to be a lawyer. They say, I would like to be a lawyer at a top Washington, DC, law firm. You know, this competitiveness is what gets you ahead. And the more people with disabilities we have in higher positions and spread out across the country, the faster this stuff is going to change, in my opinion.

Mr. BURTON. I think in summary you were very, very determined, and you never gave up, no matter what happened.

Mr. HALL. Well, neither did you, I mean.

Mr. BURTON. I know, but you overcame some severe disabilities, and that is very admirable, but that is a quality that ought to be

communicated to everybody, but in particular people with disabilities right now because that determination really paid off for you.

How about you, Mr. Register? You had a tough time.

Mr. Register.

Mr. REGISTER. I think for myself it was a very kind of emotional time for me, and I think with my colleague Mr. Hall here as well. But when you are a world-class athlete, and you have an injury of that magnitude 2 years prior to the culmination of your whole life, so to speak, it really can be devastating. And I think for myself it was the family support that I had that really helped carry me through, and my faith as well.

But looking forward and kind of now to giving back with the Paralympic Academy, one of the things that we are doing is trying to inspire others to overcome those disabilities, those barriers. And I think some of the things that we see as disabilities are because of what we see, and we tend to place limitations on persons instead of looking for what is possible.

And I was doing that with myself, and it wasn't until I was at that Paralympic games as a swimmer—figure that one out—but I saw a gentleman on the long jump runway doing what I did with an artificial limb. And this man came down the long jump runway, and everybody was clapping for him, and as he leapt into the air, at the apex of his flight, his artificial leg flew off. And he landed in the sand here, and his artificial leg landed about 3 feet up in front of him. Everybody was hushed, because no one had seen that before. I certainly hadn't seen that before. As a long jumper in Arkansas, I never thought one of my legs would fly off running down the track. And he turned to one of the officials, and he said, Now, where you are going to measure that from? From right here or from where my artificial leg landed up there? And I thought that was an awesome paradigm shift to have. And it really challenged me to look at what I was limiting myself with.

And as we move forward with the Paralympic Academy and reaching out to these children, we are also developing a program that is affecting the lives of our servicemembers who are coming back from Afghanistan and Iraq that have physical disabilities. We put together a program for them, a wheelchair basketball clinic. At first they were very apprehensive about that, but when they got in the chair and they saw some of the other athletes get in there, and they were banging them around a little bit, it was on after that. The disability went totally away, and the possibility was present with them. And I think even though some of them may never play wheelchair basketball again, it was a sense of freedom that I can really do whatever I want to put my mind to do, and no one is going to stop me.

I think I saw an article in the New York Times a couple of days ago that called these soldiers tactical athletes. And what better way for sport to bring the world together, as we have the Olympic and Paralympic Games coming up at the end of the summer, to really show what is possible with humankind and that everybody is included in that endeavor.

Mr. BURTON. Thank you very much.

Ms. Watson.

Ms. WATSON. Well, I am just flabbergasted listening to all four of you, and certainly listening to Mr. Hall and Mr. Register as to how they overcame. And I am a school psychologist in my other life as well, and I would like to talk to you at another time about what it took emotionally, psychological and mentally to overcome and to achieve the success that all of you have.

I just want to tell you about an experience. I was called to go over to Walter Reed several months ago by a Micronesian family. That is where I was the Ambassador, and they called on me to come, and I went to Walter Reed. And thank you, Mr. Hall, for mentioning Walter Reed, and Ward 57 is where the wounded are and severely wounded.

When I got to the hospital, the son, 19-year old son, of the family was in one of the houses where—the transition house. And I took a look, and I immediately warned the house mother to watch the mother and the son for suicide, because in that culture when a male can't cope, he commits suicide. I had five suicides on my watch. One was the President's son. So I knew that if they didn't work with them properly, there could be suicide.

He lost an eye, an arm, and both legs and one at the hip, and I knew that he could not return home to an island 20,000 miles away where you go to the hospital to die. So he would never be able to return to his native home. He would have to, because they just didn't have the facilities there.

And I knew that we had lots of work to do, Mr. Chair, to address the needs of these new amputees and the newly disabled to have them fit back in to a normal or traditional life. I don't know if we have been able to solve that one yet.

Someone visited my office and presented to me something that looked like a credit card. And she said, I have created this credit card that you could use at an airport, and it has a chip in and it, and I want to ask you what you know about it. It has a chip in it that would identify your medical provider, would give your diagnosis, would tell of your handicap; because this young lady was in a terrible accident and had a metal rod in her leg, and, of course, every time she went through the security gate, it went off. It delayed her because she would be taken aside, wanded, and then taken to another room because they couldn't figure it out. I know you have experienced that time and time again.

Mr. HALL. Anything that gets me through security faster I will walk the Hill up and down with you.

Ms. WATSON. And she said it just makes traveling so inconvenient that I do very little of it by plane.

I told her—there is a picture on it. It was just like a credit card or a driver's license. And I said, put a thumbprint on it, and we will see. It could be used as international identification. It could be used as passport. It could be used in many different ways, because there is a chip in there that gives the pertinent information. In that, with another chip, we could give information on—any pertinent information that we can. This is something that I see as removing a barrier from you. We just have to get a machine there that you can put it into and it would say: Go through.

Mr. HALL. I applaud the security that people are doing and the reasons they have to do it, but I'm with you, Representative Wat-

son. It's not about unwillingness to go through security, but as my wife Judy, who has joined me today, can tell you, one time I'll go through security easily because somebody recognizes me from the show. The next time I'll go through a 20-minute thing where they will want me to take my prosthetic legs off and inspect them, and it is quite humiliating.

So it is not just me. I may be an extreme example. I am sure John has set a few off in his day, too. And most of the time you laugh about it, but there should be some way that all people are treated with a certain amount of respect while we are doing the security that is necessary in these times.

Ms. WATSON. Mr. Reich in the wheelchair, tell us about your experiences.

Mr. REICH. Well, Mr. Chairman, I feel that our Harris survey today presents a rather bleak picture, snapshot, if you will, but I just want to say that there has been progress. There is progress. We have identified it in several areas. And what I have always maintained in 42 years as a person with a disability is that if you have to have a disability, America is the place to have it.

Mr. HALL. Amen.

Mr. REICH. I have felt very fortunate, of course. I had a family of 4 children under 6 at the time of my injury. I had my education actually with three master's degrees, and I was an All American javelin thrower and All Ivy halfback in football. And I had a very—I felt a very beautiful future ahead of me.

But I came home from the hospital, and thanks to my wife and family and friends and all the people who have been supportive over the years, it has been possible to make a life that has been very rewarding.

And I would say that, you know, we can take the kind of ideas you have expressed today, I think they are terrific, and I am encouraged by what you suggested and challenged, if you will, in the whole idea of providing incentives. That is what America is all about. Leadership is—the assumption of leadership in this country. When you take those ideas, and I intend to—and we can cast those about and make known some of the wonderful programs that are out there. We didn't even talk about the Small Business Administration, the Veterans Administration. There are programs. The problem is nobody knows it. And we can—and sure, we can harness the Chamber of Commerce, the National Association of Manufacturers, the AARP, 50 other major associations, get the word out there, get it with a little encouragement, get the White House and the President's New Freedom Initiative behind this, and really stop talking just about what the government can do, but what the private sector can do, what the American people can do and want to do and will do if given the ideas, given the encouragement, and if shown the way.

So I think I am very proud that we have been able to provide some guidelines, suggest some problem areas, present some challenges, and I suggest that we, the American people, need bow our heads to no one when it comes to disability. We are at the forefront. We started, initiated the whole United Nations Initiative on Disability way back in the 1970's that is continuing to have a radi-

ating impact around the world. And we have more to present as a beacon of hope for all mankind. So thank God we're Americans.

Mr. BURTON. I didn't know you were a javelin thrower at one time. I've been a lifetime javelin catcher.

Mr. REICH. That can be dangerous.

Mr. BURTON. Ms. Watson, do you have any more questions?

I just want to thank all of you for being here today. I see a lot of people in the audience who are suffering from disabilities as well. I want you to know that this hearing will not be the end of government's looking into this. Ms. Watson and I and others who were here earlier today will work on initiatives to try to expand the help we can give to people with disabilities so that they can have a better quality of life and maybe help some of them find some real success in their lives that they haven't realized so far. And with that, this. I'm going to watch CSI, and if you ever need a walk-on, call me.

Ms. WATSON. And I'm going to go to the Olympics.

Mr. BURTON. We stand adjourned.

[Whereupon, at 4:40 p.m., the subcommittee was adjourned.]

