

SPECIAL OLYMPICS

HEARING
BEFORE A
SUBCOMMITTEE OF THE
COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE
ONE HUNDRED NINTH CONGRESS
SECOND SESSION

SPECIAL HEARING
JULY 2, 2006—WASHINGTON, DC

Printed for the use of the Committee on Appropriations



Available via the World Wide Web: <http://www.gpoaccess.gov/congress/index.html>

U.S. GOVERNMENT PRINTING OFFICE

29-474 PDF

WASHINGTON : 2007

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512-1800; DC area (202) 512-1800
Fax: (202) 512-2250 Mail: Stop SSOP, Washington, DC 20402-0001

COMMITTEE ON APPROPRIATIONS

THAD COCHRAN, Mississippi, *Chairman*

TED STEVENS, Alaska	ROBERT C. BYRD, West Virginia
ARLEN SPECTER, Pennsylvania	DANIEL K. INOUE, Hawaii
PETE V. DOMENICI, New Mexico	PATRICK J. LEAHY, Vermont
CHRISTOPHER S. BOND, Missouri	TOM HARKIN, Iowa
MITCH McCONNELL, Kentucky	BARBARA A. MIKULSKI, Maryland
CONRAD BURNS, Montana	HARRY REID, Nevada
RICHARD C. SHELBY, Alabama	HERB KOHL, Wisconsin
JUDD GREGG, New Hampshire	PATTY MURRAY, Washington
ROBERT F. BENNETT, Utah	BYRON L. DORGAN, North Dakota
LARRY CRAIG, Idaho	DIANNE FEINSTEIN, California
KAY BAILEY HUTCHISON, Texas	RICHARD J. DURBIN, Illinois
MIKE DEWINE, Ohio	TIM JOHNSON, South Dakota
SAM BROWNBACK, Kansas	MARY L. LANDRIEU, Louisiana
WAYNE ALLARD, Colorado	

J. KEITH KENNEDY, *Staff Director*
TERRENCE E. SAUVAIN, *Minority Staff Director*

SUBCOMMITTEE ON DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND
EDUCATION, AND RELATED AGENCIES

ARLEN SPECTER, Pennsylvania, *Chairman*

THAD COCHRAN, Mississippi	TOM HARKIN, Iowa
JUDD GREGG, New Hampshire	DANIEL K. INOUE, Hawaii
LARRY CRAIG, Idaho	HARRY REID, Nevada
KAY BAILEY HUTCHISON, Texas	HERB KOHL, Wisconsin
TED STEVENS, Alaska	PATTY MURRAY, Washington
MIKE DEWINE, Ohio	MARY L. LANDRIEU, Louisiana
RICHARD C. SHELBY, Alabama	RICHARD J. DURBIN, Illinois
	ROBERT C. BYRD, West Virginia (Ex officio)

Professional Staff

BETILOU TAYLOR
JIM SOURWINE
MARK LAISCH
SUDIP SHRIKANT PARIKH
CANDICE NGO
LISA BERNHARDT
ELLEN MURRAY (*Minority*)
ERIK FATEMI (*Minority*)
ADRIENNE HALLETT (*Minority*)

Administrative Support

JEFF KRATZ

CONTENTS

	Page
Opening statement of Senator Tom Harkin	1
Statement of Timothy Shriver, Ph.D., chairman, Special Olympics International	3
Prepared statement	6
Statement of Dr. Julie Louise Gerberding, Director, Centers for Disease Control and Prevention, Department of Health and Human Services	9
Prepared statement	11
Statement of Dr. Antonia C. Novello, New York State Commissioner of Public Health	15
Prepared statement	19
Statement of Peter Farrelly, author, movie producer	28
Prepared statement	30
Statement of Kyler Prunty, Special Olympics athlete and Iowa resident	32
Statement of Peggy Boyle Whitworth, board member, Arc of East Central Iowa	36
Prepared statement	38

SPECIAL OLYMPICS

SUNDAY, JULY 2, 2006

U.S. SENATE,
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
Ames, IA.

The subcommittee met at 1 p.m., in Benton Auditorium, Iowa State University, Senator Tom Harkin presiding.
Present: Senator Harkin.

OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. Good afternoon. The Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies will come to order. I want to welcome everyone to this hearing, an official hearing of the Senate Appropriations Subcommittee. As I mentioned, that covers Labor, Health and Human Services, Education, and Related Agencies.

The chair of this subcommittee is Senator Arlen Specter of Pennsylvania. I am the ranking member. The two of us have served together as either chair or ranking member of this subcommittee going back now—I'm trying to think—18 years.

I might just add parenthetically that Senator Inouye, who is a Senator from Hawaii, once described our committee structure thusly. He said the Defense Appropriations Committee is the committee that defends America. He said this Subcommittee on Health and Human Services, Education, and Related Agencies is the committee that defines America because of what we do in terms of everything from early childhood to late in life.

It's an exciting afternoon to be here in Ames, as we all look ahead to the opening of the first-ever Special Olympics USA National Games. These games represent in microcosm a kind of ideal world for people with intellectual disabilities. The accent will not be on the participants' disabilities but on their abilities. The athletes will have abundant opportunities to compete and achieve on a level playing field. Their success will be determined by their own hard work and talent and determination.

Unfortunately, the world outside of Special Olympics is not nearly so hospitable to the 7 to 8 million Americans with intellectual disabilities. Too often they continue to stand alone as a silent and neglected minority. It's true that we've made significant progress thanks largely to the Americans with Disabilities Act, which was signed into law in 1990, 16 years ago. More and more adults with

intellectual disabilities are receiving appropriate educational services and opportunities, living independently and working.

But we have a long way to go. It is an appalling reality that some 90 percent of adults with intellectual disabilities are not employed. They want jobs, but often employers are reluctant to hire them. They want to be equal members of the community, but society is not always ready to accommodate them.

This situation certainly will not be helped by the decision announced this week by the U.S. Supreme Court. The Court held that parents who prevailed in special education cases brought under the Individuals with Disabilities Education Act, IDEA, cannot get reimbursed for expert testimony and expert fees. The Court made this ruling despite clear congressional intent to the contrary. So I would just say perhaps Congress needs to spell it out even more clearly.

In March 2001, in conjunction with the 2001 Special Olympics Winter Games in Anchorage, Alaska, my colleague, Senator Ted Stevens, chaired a similar hearing like this on promoting the health of individuals with intellectual disabilities. That was the first hearing of its kind devoted exclusively to the needs of people with intellectual disabilities.

So today's hearing aims to bring us up to date on changes that have taken place since that hearing 5 years ago. While Senator Stevens' hearing focused only on health issues, today's testimony will also focus on education and employment issues. I'm especially concerned that a growing number of Americans with intellectual disabilities do not have access to the most basic health care.

You'll hear testimony from former Surgeon General Novello on the higher prevalence of many illnesses affecting people with disabilities. She has three challenges that she will line up for us. Our director of the Centers for Disease Control and Prevention, Dr. Gerberding, will testify about the chronic illnesses and the research that's been done into the neglect of this population and the need for health promotion and prevention among people with intellectual disabilities.

When the Senate returns after the July 4 break, based upon this hearing and other information that we have obtained, I plan to introduce, with others, legislation focusing on the health of people with disabilities with a special emphasis on wellness and disease prevention.

As we will see vividly displayed at the Special Olympics this week, people with intellectual disabilities are in most ways just like the rest of us. They too aspire to the American dream of independence, self-determination, full participation as productive members of our society. We have a powerful interest in helping them to succeed because America is better and fairer and richer when we make full use of the abilities of all of our citizens.

So we are fortunate to have an exceptional panel of witnesses this afternoon. We'll have two panels, the first panel and the second panel. Timothy Shriver has been chairman of the Special Olympics for the last 9 years. In that capacity he serves nearly 2 million Special Olympics athletes and their families in more than 150 countries.

Dr. Gerberding, Julie Gerberding, is director of the Centers for Disease Control and Prevention and a tremendous leader in the

field of wellness and disease prevention. Dr. Antonia Novello, the former United States Surgeon General and now Commissioner of the New York State Health Department. That will be our first panel. I will introduce our second panel when they come up.

Although she is not testifying today in an official sense, she has testified by being the first person who invited some kids with special intellectual disabilities into her yard many, many years ago to participate in some athletics, and out of that little beginning grew the whole concept of Special Olympics. So she has testified in so many ways by devoting her life to helping people with intellectual disabilities, and she is the start of all of our Special Olympics. I'm proud to introduce Eunice Kennedy Shriver.

To show you how good she is, if only I could have gotten my kids to do certain things, but she got one of her kids to do something very great and to take over for her leadership and to become the CEO of our Special Olympics. It is an honor to have you here.

I just want to say to all of our witnesses, your statements will be made a part of the record in their entirety, and you can testify any way you wish. I would be pleased if you just sort of give us your best thoughts and take 5 minutes, 7 minutes, whatever it might take.

So we're privileged and proud to have you, Tim Shriver. Welcome back. We were here together 3 years ago when we stood here in this building and announced the first National Games to be held here. Thank you, thank you, and thank you for all you've done. Tim Shriver.

STATEMENT OF TIMOTHY SHRIVER, Ph.D., CHAIRMAN, SPECIAL OLYMPICS INTERNATIONAL

Mr. SHRIVER. Thank you, Senator Harkin, distinguished guests, Dr. Gerberding, Dr. Novello, and the next panel, which includes Kyler Prunty and Laurie Noll and Peggy Whitworth and Peter Farrelly. I want to join together with everyone in this room for thanking all of you, especially you, Senator. As we all know, certainly the people Iowa know and the people of the country as well, there is no greater champion of disability rights than you.

I've had a chance to share that message with your staff on many occasions as we've worked together. The country owes you and the world really. We've had the great honor in Special Olympics of seeing the rights and capabilities of people with intellectual disabilities begin to be understood around the world, and always they come back to the United States, for example, to the ADA, to your work and leadership.

There really is no finer representative of what we want to accomplish in public policy anywhere in the world than you are. It's no wonder that we are here in Iowa. The wonderful people of this State, this University, welcoming this movement as they have, have been extraordinary. We could not have asked for more. So we're very grateful.

I also want to join in thanking my mother for getting me a job. Thank you. There are other members of the Board of Directors here as well. Loretta Claiborne is here. Bruce Pasternack, our new president and CEO, is doing a terrific job. David Braddock is here,

and other distinguished members of our movement from around the world. So I want to thank all of them.

I want to just say briefly a few comments, Senator, if I could. We last ran into each other in an airport. I was on my way to San Salvador for the first ever Special Olympics Latin American Games which were held there in the capitol under the stewardship of President Saca there. We had athletes from all over the continents of South America and Central America. We had about 1,000 athletes in an extraordinary display of skill.

But when we met in that airport, I could have been going almost anywhere. This year alone we will have European Games in Rome, Middle East/North Africa Games in Dubai, Asia Pacific Games in Mumbai, Chinese National Games in Harbin, and, of course, these games here in Ames. Those are on top of some 25,000 national, provincial, county, local games that take place every day.

It has really become a reality that my mother wished for many, many years ago that Special Olympics would not be an event but a movement, not just something that happens once a year but something that happens every day, not just an invitation to pity or sympathy but an invitation to dignity and respect. We have learned a great deal from our growth as a movement, 2.2 million athletes. The most important thing we have learned is that this is not a movement about them. This is a movement about all of us.

I think as we come together for these games the message which I think is most important and which the people of Iowa have certainly come to understand is that there are no spectators in Special Olympics. Typically the lines of the field define the players. In this movement the lines do not demarcate player from nonplayer. Each of us is challenged to change. Each of us is challenged to get better when we come. Each of us is challenged to rethink expectations.

That is the demand of our athletes. They do not win on the playing field simply for the joy of sport, although that is the primary motive. But they win in a larger sense with the demand, the demand that we recognize the barriers and limitations that continue to thwart their full inclusion into society and that we change.

When we looked at what people with intellectual disabilities say is the greatest barrier to their happiness in life, they don't cite disability; they don't cite genetics; they don't cite cognitive delay; they don't cite function; they don't cite seizures. Over 80 percent cite attitudes, attitudes of discrimination, attitudes of misunderstanding, attitudes of fear. The biggest obstacle they face is what I think of as attitudes of mass destruction. For this population it is no minor issue.

Recently international organizations have released reports on conditions in institutions in places like Turkey and Romania documenting malnutrition, starvation, surgery without anesthesia, neglect as a routine course of life. In the city of Washington, DC., we have chronicled for over 7 years horrific conditions in the group homes under the leadership of the city. After 7 years the mayor announced just a few months ago that, sadly, progress had not been made, that despite over 50 deaths being accounted for there due to neglect or abuse largely on the part of the caretakers of the people in those group homes.

We are tired of hearing the stories that doctors say that they don't want a person with intellectual disabilities in their waiting room. We're tired of hearing children say they have no friends in middle school. We're tired of hearing the parents say there is no one to come to their child's birthday party. This is a population that despite the advances in law remains overlooked and underserved.

Attitudes play a major role in the issues that will be discussed today, health, education, employment, recreation, and it goes beyond those fields, but there are experts here much, much more gifted than I in discussing them. I'll look forward to hearing their testimony.

But we in our own way in Special Olympics have tried to be responsive. People sometimes ask, "Why? Aren't you a recreation, a sports organization?" Of course we are, but we think in this day and age that change has a new tune. It cannot be led simply by governmental, business, or community-based organizations, but there is a vast interlocking network that affects our population. It includes policy involved. It includes caregivers. It includes organizations. It includes public awareness. It includes the ways in which people with intellectual disabilities themselves build confidence.

There is no change we have found for our population just with policy. There is no change just with the joy of sport. It is the linkage between the confidence created in a movement like Special Olympics, the thought from people like Dr. Gerberding and Dr. Novello that goes into changing the way care is administered, the policy leadership that you have exemplified. We have to work together. So we have tried in our own way to do that.

Together with the CDC we launched Healthy Athletes a few years ago. 350,000 screenings have been performed for people with intellectual disabilities around the world, over 40,000 health care practitioners trained and exposed to the joys of giving care to a population they may have feared and at a minimum that they did not understand.

Together with educators around the world, we have created a curriculum that challenges young people themselves to become ambassadors of acceptance. We can no longer accept inclusion, mainstreaming, and equality to be simply the responsibility of the person with the disability. Young people need to be challenged to do this. We've created a curriculum together with many education organizations. It's in over 15 languages. It's reached a million children around the world, many of them in China. The challenge is to say to a young person, "You can become the messenger of acceptance in your school." That kind of partnership we believe has enormous potential.

We've done the same with our family leaders who are challenging governments in places as distinct as China and Ireland to pass new legislation. We've done it in attitude to help with public awareness. Who would have thought a few years ago that we would join with the Farrelly Brothers, with Peter and his brother, to create a film, a comedy marshaling the enormous creative energy of Hollywood, the genius of Peter, the acting presence of Eddie Barbanell to challenge people with joy and laughter to think differently?

We need new kinds of partnerships. Special Olympics is a platform for that. We are committed to continuing to try and play that role. We will continue, Senator, to try to build the platforms, to ask the questions, to celebrate what I like to think of as the plus side. But we have enormous needs. Now, we cannot do it alone. Thanks to your help, we have been able to expand our health work.

But it strikes me we got an authorization 2 years ago, and the one thing that drives me crazy sometimes in this movement is when people say it's nice. Not that I don't want to be nice and not that our athletes don't project an image of niceness sometimes and not that our volunteers aren't nice people. But we want more than nice. So we got a wonderful authorization \$15 million. Very nice, very nice. But it's not important if there's no money to support it.

So we will do whatever we can. We will marshal the energy of 2 million athletes, a million volunteers, people of goodwill all over the world. Most people want to join this work, but we don't want just nice. We want the important attention of the U.S. Senate and the U.S. House of Representatives and the President of the United States to fulfill the dream that my mother has challenged us to do and so many parents and so many people have challenged us to do, to shift out of disability into ability, to shift out of pity into dignity to fulfill what we're going to celebrate here in a few days on the 4th of July, which is a dream of equality, not based on the idea that everyone is the same but based on the idea that despite difference communities of inclusion and welcome are the best communities our country could hope to create.

PREPARED STATEMENT

So I thank you again, Senator, for your extraordinary leadership, for your help in making these games possible, and for your convening of this hearing. We promise all that we can do to fulfill the dream of equality for every athlete with intellectual disability and every person around the world. Thank you.

[The statement follows:]

PREPARED STATEMENT OF TIMOTHY SHRIVER

Senator Harkin, my fellow panelists Dr. Gerberding and Dr. Novello, upcoming witnesses Kyler Prunty, Laurie Noll, Peggy Whitworth and Peter Farrelly, the many Special Olympics athletes and family members who are here today—thank you for the opportunity to discuss the status and well-being of people with intellectual disabilities.

Senator Harkin, let me take this opportunity to thank you on behalf of the worldwide Special Olympics movement for convening this important Hearing, and for your unparalleled leadership in the United States Senate on behalf of ALL people with disabilities, including those with intellectual disabilities. You are a true champion—for Iowa, for America and indeed for people with disabilities around the world. Your lifelong, effective advocacy to break down barriers inspires us all.

Today's Field Hearing is, to my knowledge, just the second Senate Hearing in history to focus exclusively on the well-being of people with intellectual disabilities—a population that we know all too well has been—and continues to be—overlooked, marginalized and discriminated against. Five years ago, a similar Senate Hearing was convened by Senator Ted Stevens, another great friend of the Special Olympics movement. At that Hearing in Anchorage, Alaska, we heard about the barriers to full inclusion for people with intellectual disabilities—barriers to quality health care, appropriate and inclusive education, and employment.

Five years after the 2001 Hearing, I can gladly report that the Special Olympics movement has grown in size and quality around the world. Founded in 1968 by my mother, Eunice Kennedy Shriver, Special Olympics provides people with intellectual

disabilities continuing opportunities to realize their potential, develop physical fitness, demonstrate courage and experience joy and friendship. Special Olympics unleashes the power of sport to promote health, acceptance, volunteerism, and empowerment.

Since the 2001 Hearing in Anchorage, we have more than doubled the number of athletes in our movement. Today, more than 2.25 million people with intellectual disabilities from more than 150 countries are Special Olympics athletes. Our growth has helped bring millions of people with intellectual disabilities out of the shadows and into society—proudly and courageously. As we come together today, Special Olympics is the world's largest and most inspiring movement promoting the simple ideals of human dignity and acceptance.

While we at Special Olympics are proud of our global growth, we fully understand that much work remains to be done. More than 6 million Americans and over 170 million people worldwide with intellectual disabilities, including the athletes of Special Olympics, still face barriers to full inclusion and they still face outright discrimination. The fight for justice goes on, and that is why today's hearing is so important.

The title of today's hearing—A Better Future for People with Intellectual Disabilities—is both sobering and aspirational. It is sobering because the relatively weak research data we have on people with intellectual disabilities paints a picture that remains, on the whole, bleak. Far too many people with intellectual disabilities lack access to basic health care, education and employment opportunities. Too many people with intellectual disabilities remain institutionalized, marginalized and in some cases essentially sealed off from society. A stubborn but mostly silent crisis of neglect and discrimination persists around the United States and around the world. And the evidence is unmistakable.

Allow me to cite just a few examples.

The President's Committee for People with Intellectual Disabilities, in its 2004 Report to President Bush, A Charge to Keep, cited Special Olympics' 2003 Multi-national Study of Attitudes toward Individuals with Intellectual Disabilities when making the important point that "attitudes of the American public have not changed appreciably in the past 50 years." The Report to the President goes on to note that "The general public underestimates the capabilities of people with intellectual disabilities," perceiving them as less competent than they in fact are to handle activities of daily living.

Particularly alarming to me as an educator is that our study showed that more than two-thirds of the public believe that children with intellectual disabilities should be educated either in special schools or special classrooms within regular schools. More than half of the public expect that if children with disabilities were included in regular classes, they would disrupt the classroom and make it harder for other students to learn.

We find this ignorance particularly strong in the medical field. In a survey commissioned by Special Olympics in 2004 of over 2,500 U.S. medical and dental schools deans, residency directors, and students, 81 percent of medical students indicated they are not getting any clinical experience in school in treating people with intellectual disabilities. More disturbing was that half of medical and dental school deans surveyed said that their graduates were "not competent" to treat patients with intellectual disabilities.

When we learned of these stark statistics, we decided to create an online system to match willing and able health care providers with patients who have intellectual disabilities. Special Olympics reached out to more than 30 health care associations, including the American Medical Association and the various medical specialty associations, to urge them to enroll their members in this initiative. Unfortunately, without a financially compelling reason to serve this population, fewer than 800 providers have enrolled in this free service—that is less than one half of one percent of the health care providers in America.

One might wonder if these attitudes make any difference in policy or practice and the answer is sadly "yes." In our nation's capital, Washington, D.C., the treatment of people with intellectual disabilities has been horrific. Despite newspaper reports exposing a litany of abuse and neglect in the District's group homes, little has been done. One report suggested that over 53 people died from preventable causes in the care of the government, some from causes such as being given the wrong medication and others from being locked in parked cars. For some reason, officials have been unable to improve these conditions for over 5 years. It is a scandal but believe it or not, it is a common one in places around the world.

If we were to ask the 3,000 plus athletes gathered now in Iowa, we would hear literally thousands of stories describing the personal experiences of suffering: people turned away from doctors' offices; people subjected to humiliation in schools; people

exposed to vicious taunts, name-calling, and bullying. Senator, like so many others and like you, I am tired of these chronicles of despair and tired of the indifference to which they point. Our athletes and their families have done nothing to deserve 3rd class status in this country. They are being punished without guilt—victims of attitudes of mass destruction. With them, I appeal to you and your colleagues Senator: End the injustice! Please end the injustice now!

The theme of this hearing—which emphasizes progress towards a Better Future—is ultimately hopeful. The good news is that policy leaders, including you, are rising to the challenge to address the needs of this population. Last year, Surgeon General Anthony Carmona, who joined us at our Research Symposium yesterday, issued a Call to Action to Improve the Health and Wellness of Persons with Disabilities. The goals of this laudable Call to Action are ones which we at Special Olympics readily endorse, and in fact are working to achieve. They are as follows.

Goal 1: Educating the American public that people with disabilities can lead long, healthy, productive lives—our athletes illustrate this so well.

Goal 2: Giving health care providers the knowledge and tools to screen, diagnose and treat the whole person with a disability, with dignity—Our Healthy Athletes program helps to make this happen—but as good as it is, it reaches just a fraction of people with intellectual disabilities and the health practitioners who treat them. We need to advance this goal on a much broader scale by changing Medical and Nursing School curricula to improve training for all health care practitioners so that they are better able to treat people with intellectual disabilities.

Goal 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles. Special Olympics, through our core mission of sports training and competitions, does just that.

Goal 4: Accessible health care and support services to promote independence for persons with disabilities. We of course strongly support this goal and I look forward to hearing from my distinguished colleagues on this panel about how we as a society can achieve it.

I know our time is limited today, so I'd like to briefly conclude with some Special Olympics "Calls to Action:"

1. First, I urge you and your colleagues on the Senate Appropriations Committee to continue to support Special Olympics. The federal funding which you, Senator, have been so instrumental in securing for our Healthy Athletes program allows us to reach more athletes and more health practitioners in Iowa and beyond. In fact, since the last Field Hearing on intellectual disability, we have provided over 350,000 health screenings free-of-charge to our athletes in the United States and abroad, utilizing the volunteer services of over 30,000 health care practitioners. Federal dollars that support Healthy Athletes are fully leveraged—in short, these public funds are well spent.

2. I urge you and the Appropriations Committee to support Special Olympics' Education authorization, including support for our new "Young Athletes" program that is showing great promise. This imitative reaches children in the formative years of ages 2–7, and helps them to develop physically, cognitively and emotionally. As you know, investments in our youngest children are especially cost effective.

3. I urge you and the Appropriations Committee to heed the call of the President's Committee on Intellectual Disability for a National Campaign specifically targeted to school-age children and employers to change negative attitudes toward people with intellectual disability. The President's Committee goes on in its Report to cite its intention to partner with Special Olympics in this important work. It is not enough for the law to allow people with intellectual disability to attend school; we must create opportunities for children to lean about human exceptionality, to overcome their fear of difference, to practice the skills and values of citizenship and acceptance. "Special Olympics SO Get Into It" is a national effort to do just that but it needs support. In an age of high standards for academic achievement, we must remember that children learn best when they feel engaged, safe, valued, and challenged. The call to meaningful acceptance must include a challenge to non disabled young people, otherwise we condemn children with intellectual disabilities to being strangers in their own schools—present in body but left out in spirit.

Senator, we at Special Olympics hope to greatly expand our public education and youth outreach efforts, but it will require resources. I hope you and your colleagues will support these outreach efforts through the Appropriations process. Even modest federal support will create a ripple effect of more engaged youth of greater character who give back to their communities through increased volunteerism.

In closing, let me thank you again Senator Harkin for holding this Hearing and for inviting me to testify at it. When thousands of Special Olympics athletes from all 50 States and the District of Columbia march in to the Coliseum this evening, they will be showing Iowa and the world that they are people with abilities—capa-

ble of competing in sports, getting educated at school, making friends, holding jobs and being valued members of the community. But even more, they march in a long tradition of Americans who, generation after generation, march to challenge the nation to fulfill its highest ideals.

In just a few days, we will celebrate the birthday of our nation all across the land—a nation conceived in liberty and equality. But in a larger sense, we do not celebrate an event, but rather an idea—and not just an idea but a quest. The athletes here in Iowa, Senator, are on a quest of their own—to challenge the nation anew to the dream of human equality. Their challenge is unique in the history of our country: they claim equality not based on sameness but on differences; not based on disability but on the different abilities of every human being; not based on some arbitrary standard of achievement but on the universal standard of the human spirit.

In 2006, the athletes of Special Olympics are appealing to the nation not as a cause, but as a constituency, prepared to demand of their government a redress of grievances and protection from bias and discrimination. As they compete for excellence in sports, they are also competing for acceptance in this great nation. Our movement and its athlete leaders want respect on the playing field and off it too.

Senator Harkin, the athletes of Special Olympics are not here for pity and they are not here with a plea. They are here for dignity and they are here with a demand: give them a chance, a real chance, an American chance. Give them a chance worthy of the Declaration of Independence itself. They will not disappoint you or our country. On the contrary, as my mother said years ago, “as we hope for the best in them, hope will be reborn in us.” And hope cannot come soon enough.

Thank you.

Senator HARKIN. When I come back on questioning you, Tim, you had in your written testimony a couple, three or four things that you’re urging us to do. I want you to kind of spell those out for the record when we come back to that. I just got a note from the director—well, she’s the staff director that runs our committee. You know really staff runs everything.

Mr. SHRIVER. Yes. Ellen is the boss. We know that.

Senator HARKIN. Ellen Murray just handed me a note that says, “The House did not fund the authorization in the fiscal year 2007 bill. We will.”

Mr. SHRIVER. Thank you.

Senator HARKIN. If Ellen Murray says so, that’s it.

Mr. SHRIVER. She’s taught us that lesson. Believe me.

Senator HARKIN. Now we turn to Dr. Julie Gerberding, the director of the Centers for Disease Control and Prevention. I welcome you back to Iowa. Again, just my heartfelt thanks for everything you’re doing from aid and including everything else in making us a more healthy society. Dr. Gerberding, welcome, and please proceed.

STATEMENT OF DR. JULIE LOUISE GERBERDING, DIRECTOR, CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. GERBERDING. Thank you. It’s always a privilege to be in a leadership position, but I can’t really think of any more privileged vantage point than to be here and part of the Special Olympics and to have a chance to testify on this really important subject. So thank you for your leadership and hosting us.

You and Senator Specter are responsible for the committee that defines America, we at the CDC thank you for your support of the agency that’s responsible for protecting America’s health. Many of you may not know that Senator Harkin is the person who put the “Prevention” in the title of CDC. We are the Centers for Disease

Control and Prevention because of your championing for our agency.

You know, we're here celebrating the Special Olympics, and I can't wait for the games to begin. I've already met so many wonderful athletes, and my heart is just open to the excitement and the energy. We are seeing athletes capable of extreme athleticism. We have extreme ability. They have extreme passion. They have extreme courage, and they have extreme commitment to doing their very best.

I'm sorry to say we're also learning about extreme health disparities in this context. This morning we visited the Healthy Athletes Program, and I had the chance to review some of the statistics about the health status of our Special Olympics athletes that were obtained from previous encounters. It's embarrassing. It's tragic.

Among athletes, 30 percent fail hearing tests, 45 percent have periodontal disease and need better dentistry, 20 percent have vision test failures, and 70 percent of those with glasses need a different prescription because their prescription is out of date. Our athletes suffer disproportionately from osteoporosis. They suffer from obesity, from lack of physical fitness, from poor nutrition, and many, many other health conditions that are going unrecognized or untreated for a variety of reasons. But we need to get to the bottom of them.

Among those reasons are lack of access to health care and attitude that you've already discussed. When access does occur, the quality of the access is all too often lacking. I have been trying to do my homework and understand how could this be? How could this wonderful population of people who we've made such progress in terms of improving survival still suffer disproportionately from such poor quality of health?

People with disabilities in our country have a 40 percent increase in chronic diseases like diabetes, cardiovascular disease, and all of the other complications that people without intellectual disabilities or development disabilities have and these are continuing to challenge our health system. For these people the problem is even greater. They often are neglected, rejected, or left out of the opportunities that so many of us have access to.

I think we recognize that access and quality are part of the problem. There are many places to start to address it. But I just wanted you to be aware of two facts that I found astonishing. One fact is that 80 percent of medical students in this country do not have any clinical experience in taking care of people with disabilities. Fifty percent of the dental students in our country have never taken care of a patient with an intellectual disability.

We are not training our clinicians to even know how to go about doing this let alone providing the sorts of health care insurance and access that we would need to encourage them to provide services even if they knew how to do it. So our work is cut out for us.

I think we do have some opportunities to make extraordinary improvements very fast. It does take a network. You've described the whole coalition of people who need to engage. But I think there are three things that we need to specifically concentrate on. One is to make this problem visible. This hearing is a part of that. Everyone

here in the room can be a part of making this very tragic, extreme health disparity as conspicuous as possible.

We also do need to work on our health system. We can have a conversation about specifically what can be done right now today to change the way our clinicians are educated and their ability to provide care. They want to do it, but they don't have the training and the experience to be able to do it right or to be able to do it with confidence. So we do need to deal with it.

I'd like to congratulate the Family Practice Association, because they have stepped up to the plate and are making information available to their constituents, publishing providers in the community who will provide the kind of follow-up services that many of our athletes need and going out of their way to provide leadership for other physicians.

The last thing I would like to say needs to be done is to empower individual people, particularly the athletes and their families themselves. This morning I saw a wonderful tool. I am so excited about it I can hardly stay off my BlackBerry. I saw in the context of the health screenings, that are going on in this very building as we're sitting here, an electronic health record, a personalized health record for our athletes.

That health record as we are sitting here is inputting specific information about the health status of the athletes into a format that's standardized around the world. That's why we have the kind of information we have. In fact, I have here a report from last week's Olympics that is already assembled, and I know the health status of the people who were participating in Special Olympics last week because it's already been compiled and published.

But that's not enough. We saw an example of how an individual athlete in the future would be able to have their health information on a Smart Card or on the Internet so that wherever they go when they leave this room, they will be able to access that information or their physician will be able to access it or the people who are responsible for their comprehensive care.

PREPARED STATEMENT

That is technically possible to do today. But I think we have some exciting opportunities to look at how we can scale that project, perhaps speed that project up, and let the Special Olympic athletes be the leaders of our transition to electronic health records in our country. Thank you very much for your interest and your support of this, Senator.

[The statement follows:]

PREPARED STATEMENT OF JULIE LOUISE GERBERDING

Thank you for the opportunity to appear on behalf of the Centers for Disease Control and Prevention (CDC) to discuss the promotion of health and wellness for people with intellectual disabilities. Thank you also for your support of CDC's health protection goals. CDC's work on intellectual disabilities is consistent with our commitment to improve people's health through all stages of life and in all places. Today, our nation is focused on urgent health threats such as pandemic influenza, yet we must also continue to pay attention to urgent realities such as injury, obesity, and cardiovascular disease. In particular, we must ensure that our efforts in reducing the impact of urgent realities reach the most vulnerable members of our communities, including those living with intellectual disabilities.

Over the past several years, we have seen many improvements in the health and well-being of people who have intellectual disabilities. Thanks to advances in clinical medicine, more people with such disabilities are living into older adulthood. People with intellectual disabilities have more choices about how they are educated, where they live, and how they conduct their lives. Today, fewer people with intellectual disabilities are entering institutions, and the majority of those who do enter institutions eventually leave to live with their families or reside elsewhere in the community.

We are learning, however, that as more people with intellectual disabilities live longer, they like everyone else experience the natural challenges to health and wellness that accompany the aging process. Individuals with intellectual disabilities and their families have reported that they feel excluded from efforts to promote healthy living, and evidence suggests that we must do more to ensure that our efforts are inclusive of this community. When compared with other populations, individuals with intellectual disabilities experience poorer health across their life span and experience greater difficulty in finding, accessing, and affording appropriate healthcare. Moreover, the specific disorders associated with intellectual disabilities are found in higher rates among low-income communities that often have more limited access to health services.

In order to meet the health challenges facing the intellectual disability population, individuals, family members, and healthcare workers need better access to evidence-based, culturally relevant, and understandable information. Like every other American, people with intellectual disabilities need high quality, readily available, community-based health services to support healthy living. As a part of CDC's goal of having healthy people who start strong, grow safe, and live healthy and productive lives, CDC is committed to further advancing the health and wellness of this population. However, the support of a wide range of institutions and agencies is needed to effectively improve the well-being of people with intellectual disabilities.

HEALTH OF THE POPULATION

People with disabilities represent about 17 percent of the overall population, but account for as much as 47 percent of all medical spending. An estimated two to four million people in the United States experience some form of intellectual or developmental disability. Direct lifetime costs associated with mental retardation are estimated to exceed \$12 billion. In comparison, direct costs associated with asthma, a chronic illness with a prevalence approximately six times that of mental retardation, have been estimated at \$9 billions.

Although the life expectancy of individuals with moderate to severe mental retardation is nearly 20 years longer than it was in 1970, it is still, on average, 10 to 20 years shorter than that of the general population. Additionally, many individuals with intellectual disabilities also have other health problems, particularly when the disability is associated with an underlying condition or disease. For example, people with Down syndrome commonly have heart problems that can result in premature death or impaired health if not corrected. When such identifiable health problems are not present, however, the causes of shortened life span are not entirely understood.

Chronic health problems may be an important contributing factor in the reduced life expectancy of people with intellectual disabilities. In the general population, longer life expectancy brings increased risk for a number of chronic conditions, and this also holds true for people with intellectual disabilities. For example, the prevalence of obesity for people with intellectual disabilities is much higher than the already troubling rate of 30.5 percent found in the general population. Obesity is associated with increased morbidity and mortality from hypertension, diabetes, heart disease, arthritis, stroke, sleep apnea, and some cancers. Anecdotal evidence suggests that the prevalence of obesity may vary significantly in sub-groups of people with intellectual disabilities. In one sample of adults with intellectual disabilities, 70.7 percent of those with Down syndrome were obese, compared to 60.6 percent of individuals without Down syndrome.

HEALTH PROMOTION

People with intellectual disabilities represent a significant group that would benefit from health promotion programs. Whereas health education and health promotion have resulted in reduced medical care need for the general population, little research has explored such benefits for people with intellectual disabilities. Clearly, there is a need for research-based interventions that enhance health and wellness for this group. With public health research being one of the six key strategies of CDC to reach its health protection goals, CDC is committed to advancing the science

and mobilizing programs to improve the wellness of this population, but CDC cannot do this alone. We rely extensively on our partners, including Special Olympics, AAMR, The Arc, The Association for University Centers on Disabilities, state and local public health agencies, community organizations, academic institutions, and other federal agencies such as the Office of the Surgeon General and the National Institutes of Health. These partnerships are crucial to achieving improvements in the health and quality of life of people with intellectual disabilities.

CDC-Sponsored Research

CDC supports researchers at the University of Montana's Rural Institute on Disability, who have worked to better understand the health of people with intellectual disabilities and develop accessible and sustainable community-based intervention models. They have found that the typical diet of a group of people with intellectual disabilities contained excessive amounts of nutrient-poor, higher fat items, with the daily per person calcium intake in this group being less than 600 milligrams, considerably below the Recommended Dietary Allowances of 1,000 milligrams per day for adults and 1,200–1,300 per day for adolescents and the elderly. In response to these and similar findings, the team in Montana has developed and is currently testing The Wellness Club, a model for organizing community-based services and support to establish and maintain healthy lifestyles in adults with intellectual disabilities. The Club engages individuals in a process of managing their own health, and is offered in their own residences with the support of service staff and case managers. Participants who enroll in The Wellness Club program agree to work on at least one health objective and to participate in the structured activities of the program. Activities include setting personal goals, self-monitoring, receiving feedback, and participating in social support meetings. Wellness goals are prioritized, and plans are developed to assist with progress toward goals. Typical target areas include physical activity, healthy eating, oral hygiene, and personal care behaviors.

In another example, CDC-supported investigators at the University of South Carolina School of Medicine have developed an evidence-based, community-oriented model to curb obesity and unhealthy weight among those with intellectual disabilities. They have developed an intervention called Steps to Your Health, which provides eight 90-minute classes conducted by community-based disability service providers. Steps to Your Health also includes two home visits to establish an individual exercise regime, develop a dietary plan, and make grocery store visits to identify healthy food choices. In the pilot study, participants showed significant improvements in healthy dietary habits and increases in physical activity, as well as decreases in unhealthy weight and obesity. Study results were published in January 2006 in the *American Journal on Mental Retardation*.

Both of these examples show that it is possible to overcome the barriers associated with reaching a diverse population of people with particular health needs who are dispersed among communities. Additional implementation of these and other successful programs holds great promise for addressing the health disparities in obesity and other chronic conditions experienced by people with intellectual disabilities.

CDC-Sponsored Programs

CDC is proud of its work with Special Olympics. Special Olympics exemplifies CDC's goals of growing strong and living healthy, productive and satisfying lives. Special Olympics is rapidly expanding overseas, sharing CDC's goal of working globally. Special Olympics also does an exceptional job of raising awareness about the issues faced by people with intellectual disabilities. They have shown us that people with intellectual disabilities have hopes and dreams, and that they can achieve remarkable things. In many cases, Special Olympics events are the only opportunity that people with intellectual disabilities have to challenge themselves physically, to participate in physical conditioning or sports, and to compete and win.

Since 1996, Special Olympics has provided Healthy Athletes venues for athletes to receive free screening tests, referrals, and healthy lifestyle counseling during sports competitions. Through the Healthy Athletes program, Special Olympics is working to improve the ability of athletes to train and compete, to improve their general health and fitness, and to support overall improvement in personal well-being. During the 2005 Special Olympics World Games in Nagano, Japan, Healthy Athletes gave free health screenings to 1,200 athletes. More than 4,200 screenings—including foot care, oral health, vision, and hearing—were offered, as well as counseling on safety, nutrition, and physical conditioning.

The physical fitness shown by the participants at Special Olympics is a model and inspiration for all people with intellectual disabilities, encouraging them to engage in physical activity. When regular physical activity becomes a routine at an early

age for people with intellectual disabilities, and is promoted by the agencies and professionals working with them, this will encourage healthy lifestyles and lead to longer and healthier lives for the entire population of people with intellectual disabilities. In order for habits to meaningfully change, efforts to increase exercise and improve lifestyle choices have to be ongoing. Such efforts should involve families and caregivers in the communities where people with intellectual disabilities live.

PREVENTING INTELLECTUAL DISABILITIES

Intellectual disabilities can be caused by brain abnormality, injury, or disease—any of which can occur before, during, or after birth. Some of the most commonly known causes of intellectual disabilities include Down syndrome, fetal alcohol syndrome, and fragile X syndrome; all of which occur before birth. Other prenatal causes include structural birth defects like hydrocephalus and infections from pathogens such as cytomegalovirus. Some causes, such as asphyxia, occur during or soon after childbirth. Still other causes of intellectual disabilities may not occur until later in life. These include traumatic brain injury, stroke, and certain infections such as meningitis. However, in the majority of cases, the exact cause of a person's intellectual disabilities is not known.

U.S. public health efforts have been very successful in limiting and even eradicating some of the preventable causes of intellectual disabilities. In 2005, a major public health milestone was reached when CDC announced the elimination of the rubella virus in the United States. If a woman is infected by the rubella virus during pregnancy, it can be passed to her baby and cause congenital rubella syndrome. Congenital rubella syndrome is characterized by the presence of birth defects, which may include blindness, deafness, heart defects, and mental retardation. The rubella virus is still common worldwide, with approximately 100,000 cases of congenital rubella syndrome reported annually. This remarkable achievement is a tribute to a safe and effective vaccine and a successful immunization program, and CDC will continue working to ensure that rubella remains eliminated within our country.

CDC also has activities underway to address fetal alcohol syndrome, one of the leading known preventable causes of mental retardation and birth defects. Fetal alcohol syndrome is 100 percent preventable if women do not drink during their pregnancies. Implementing intervention strategies to reduce alcohol consumption during pregnancy is, therefore, an important component of reducing intellectual disabilities and other conditions associated with prenatal alcohol exposure. A challenge in preventing fetal alcohol syndrome is that alcohol consumption can damage the fetus early in pregnancy, often before a woman knows she is pregnant. Research has established that provider-based screening and interventions for women of childbearing age can reduce their risk of having an alcohol-exposed pregnancy. CDC has developed and published targeted recommendations on provider-based screening and interventions for women of childbearing age, and is currently working to further translate these recommendations into practice by developing a quick-reference tool to facilitate their use among health care professionals.

CDC also works to prevent traumatic brain injuries, which are sustained by at least 1.4 million people in the United States every year and cost an estimated \$60 billion annually, including the costs of lost productivity. A traumatic brain injury is caused by a blow or jolt to the head that disrupts the function of the brain and can ultimately lead to a wide range of changes that affect thinking and learning, sensation, language, and emotions. When these injuries occur during the developmental period, they can result in developmental delay and related disabilities. In addition, traumatic brain injury poses an increased risk for epilepsy, as well as other brain disorders that become more prevalent with age, including Alzheimer's and Parkinson's disease. CDC is committed to preventing injuries in youth and currently supports a number of state and university-based research programs to identify successful intervention strategies. One ongoing project is called "Heads Up: Concussion in High School Sports," an initiative to help coaches, parents, and other school officials prevent, recognize, and manage concussion in high school sports. The "Heads Up" kit contains practical, easy-to-use information, including a video and DVD, a guide for coaches, posters and fact sheets in English and Spanish, a CD-ROM with downloadable materials, and additional resources. Additionally, CDC supports programs that monitor traumatic brain injury, link people with traumatic brain injury to information about services, and prevent traumatic brain injury-related disabilities.

CONCLUSION

As we approach the 16th Anniversary of the passage of the Americans with Disabilities Act, we can be proud that as a nation we have made important commit-

ments to people with intellectual disabilities. Because of federal laws like the Americans with Disabilities Act, court decisions that have led to widespread community integration of people with intellectual disabilities, and national policy initiatives such as the President's New Freedom Initiative, people with intellectual disabilities are not only living longer lives, today they are more integrated into their communities. Despite these positive changes, however, people with intellectual disabilities continue to be at greater risk for chronic health conditions. There is still much to be done, and CDC and its partners are committed to promoting health and wellness for every individual, through leadership, customer-centricity, public health research, and accountability.

Senator Harkin, thank you for the opportunity to discuss these important public health issues. Thank you also for your interest in the health of people with disabilities, and for your continued support of CDC's vision of healthy people in all stages of life living in healthy places.

Senator HARKIN. Thank you, Dr. Gerberding. Now we turn to Dr. Antonia Novello. As you know, Dr. Novello is a former Surgeon General of the United States and is now the director of Public Health for the State of New York.

Before I return to that, I wanted to recognize your director for the Center for Birth Defects and Disability. Dr. Jose Cordero is here with his team. I just want to point him out there.

Dr. Novello, welcome to Iowa. Good to see you again.

**STATEMENT OF DR. ANTONIA C. NOVELLO, NEW YORK STATE
COMMISSIONER OF PUBLIC HEALTH**

Dr. NOVELLO. Thank you. The only problem I have is that your corn is not ready. Having been here during the Governors Association meeting and having eaten about a dozen on my own, I can tell you there's no better corn in the world. So, Senator, I sometimes feel like I'm following Dr. Gerberding. We have the same statement, but I'm going to say it in Spanish.

At this stage of the game, I'm going to come here with three hats, the former Surgeon General, the director of the Department of Health of the State of New York, and a member of the Board of the Special Olympics for the last 8 years. Having been this morning already in the Healthy Athletes where I got my ears checked, my eyes checked, my feet checked, and I even have my milk exercise, I can tell you that we preach what we do. Therefore there's no better place to come and try to put out a plea for working in a place like Iowa where you take your things seriously and you have a Senator who cares. Thank you very much for having this hearing.

In the United States we're always talking about statistics. 288 million people. 14 percent Hispanics, 14 percent African-American, 5 percent Asian-Pacific Islands, 1 percent Native American, and 7 million multiracial. But no one talks about the 6 million people with intellectual disabilities. I think the time has come to put that in the record.

In particular, people with intellectual disabilities, you never hear about the 31 percent of them smoke. National average is 20 percent. When you talk about the lack of physical activity, it's 53 percent compared to 34 percent of the other type of public. When you talk about not receiving preventative medicine, mammography, 65 percent only when you are incapacitated intellectually while it's 71 percent for the average public. When you talk about dental visits, 37 percent versus 46 percent in children and adults without dis-

ability. When you talk about high cholesterol, 19 percent versus 17, and high blood pressure, 37 percent versus 29 percent.

So when I took into this, a large body of research also shows what we have done in the Special Olympics. Like Dr. Gerberding says, 30 percent of the athletes have hearing loss. When I look into that, that's a rate six times higher than the normal population. When you're looking to tooth decay, 35 percent of them hurt. When you hurt, you cannot be able to express yourself, and then you shy away more so than by being disabled.

When you have vision, 25 percent cannot see far, and 10 percent cannot see near. When you look at bone health, 29 percent of males and 30 percent of females have below normal bone mineral density. Only women over the age of 65 have these numbers.

When you look at foot health, 50 percent of the athletes either have bunions or calluses or they have fungal infection. When you look at obesity, 30 percent of them are obese, and 20 percent of them are overweight. The problem is that they might not be able to understand the message of nutrition.

So when I look into this, the multiple health problems that they are are totally compounded by something that I find totally appalling. That is the lack of health care access in this Nation for people that by no fault of their own happen to be at the part of the line in the back. When I look into that, I say we need to take better health care. But when they do finally get it, it's usually inadequate, inappropriate, or it's sporadic, if at all. This is even more pronounced if you happen to be a minority.

Think about the example of the race of the people with Trisomy 21, the people with Down syndrome. The median age of death is 50 years if you are a white person with Down syndrome. It's 20 years if you are a person that is African-American and 12 if you are a person that is Hispanic. There has to be something that has to do with health care delivery, and that is unacceptable.

When I look into this, I'm reminded of the words of Martin Luther King. He used to say, "The ultimate measure of a man is not where he stands at times of comfort and convenience. It is where he stands at times of challenge and controversy." I think we have a problem in this country in challenge and controversy. The health of the people with disabilities in spite of the benefit of (inaudible).

Could it be the lack of training? Could it be the societal misunderstanding of people who speak different, walk different, and act different? Could it be the lack of health promotion and education? Could it be the lack of research? How can you do research if you don't even understand the health difficulties that they have? Could it be the lack of enforcement when somebody is not doing their job?

At this moment I can't tell you where we are going. We have disparities. Everybody knows that. But what are we going to do about it? I think I have five challenges for you, Senator. The first one I think is Challenge No. 1, health care providers must receive training and acquire experience in taking care of people with learning disabilities and intellectual.

As Dr. Gerberding said, we did a study. I was in shock. 52 percent of medical schools and 53 percent of dental schools, they do not know how to take care of a person because they do not feel

competent enough to take care of people with disabilities. 58 percent of deans and 50 percent of dental school deans say, "That's not a high priority in our school." Most medical school deans, 81 percent of them say, "We do not have the curriculum time, and we do not have the faculty expertise." Then get your act together. The time has come to take care of these people.

The good news is that the study shows that there is no discrimination if given the equipment and the training, all deans of schools of medicine and all deans of schools of dental are out there in the front line trying to do what is best for them. So let's get the teachers back into the teaching regarding health care access for the people with disabilities.

It stands to reason that inadequate prepared health professionals are less likely to be motivated to treat a population that they do not know that they could be reached. With any patient I have to tell you they have the right to be informed of their needs. They have the right to be informed of their options, and they have the right to be asked as individuals, "What is best for you?" As I've always said, don't ever do anything for an individual ever unless you ask them what is needed from their perspective. As the Indian says, "Don't tell me what to do unless you have walked a mile in my moccasins."

Challenge No. 2, we have to ensure that individuals born with an intellectual disability are found early. When you find them early, you treat them accordingly. Fifty States provide some level of newborn screening, most of them between 12 and most of them between 16. In New York State we do 44. I will not do a testing on the newborn unless I have something to offer to that mother, and 44 can do it. If you test early, you will discover it early, and I can tell you that you will be able to take care of the people. It has been confirmed that children with genetic and metabolic conditions that are discovered early will be able to incorporate themselves into society with the right treatment.

Challenge No. 3, you have to support prevention. You have to support diagnosis, and you have to support the treatment of people with intellectual disabilities. Think about the program of Early Intervention. This program has been here since 1993 and serves over 70,000 children between the age of birth and 3 years. You know that this goes with the Individuals with Disabilities Act and provides treatment from birth to 3 years and diagnoses anyone with physical or mental conditions that have developmental delays.

I have to tell in you New York we test 4.3 percent of all these children, and we have been extremely successful. So I encourage this committee, Senator Harkin, to explore the ways that the Federal Government can support the reputation and expansion of Early Intervention in all the States of this great Nation of ours because we are in all the States as well.

Regarding the Surgeon General's report of 2002 where he says identification of a package of health care services is specifically designed for individuals with intellectual disabilities is great and should produce good outcomes. But I don't want one more research protocol found on anybody's shelves. I feel the time has come to get that package and then put it in the hands of the State medical so-

cieties and distribute it to people who can make it a reality. I'm tired of fighting (inaudible).

We know that bias and discrimination have detrimental effects on the health and the well-being of people who are affected by intellectual disabilities. Lack of acceptance and inclusion accompanied by ridicule and disrespect absolutely contribute to the depression and the problems of people with intellectual disabilities.

Therefore my Challenge No. 4 is don't educate us anymore. We know. We are your theater. Educate every single American in this United States to help to promote the full acceptance and inclusion of those people that by no fault of their own makes us feel bad, because we believe that we are in charge of our destiny and God has a way of always showing you that you are as fragile as anybody else.

I believe that we need an educational campaign in which we remove the stigma. The more people know about something, the more people will come forward and try to help you and solve it. Therefore let's take away the perception that people that look different has nothing to do with their brain. The disability is in those ones that judge, not in the ones who are disabled.

More than anything I am asking for you to support a national public information campaign to promote the understanding and the acceptance of individuals with disabilities. Those are 50 million of our citizens who through no fault of their own traditionally lack the clout of being heard and for the world to stand up and notice.

If you can, get the \$15 million that Tim has said in your appropriation and also get into what we have as what we call the "SO Get Into It" program. That one is outstanding, a curriculum-based program that is using 3,500 schools. This in the elementary and the middle and the high school students, it teaches them about intellectual disabilities. It is a great program, and it is in our portfolio.

Finally, Senator, No. 5 is a challenge to support and fund research or interventions that focuses specifically on the health needs of the individuals with disabilities. Senator, persons with ID need lifelong families. Group homes, although useful, are not a family environment conducive to the dignity that they need. Parents are going to be in need of support and life learning.

We're also going to need research in dental coverage. Dentistry is in need of a specialty recognition. We must have oral health affordable, and we must make sure that in States where it's necessary that Medicaid waiver should purchase additional insurance benefits. Special Care Dental Act needs to be considered and passed. These people's teeth are no different from anybody else's teeth, and they have to be taken care of.

I urge the committee to support federally funded research and an investigation program that focuses on identifying the causes of and the solutions to health disparities. After all, we cannot expect to determine the needs of the future if all that we have today is incomplete data.

PREPARED STATEMENT

So, Senator Harkin, I have presented five challenges, and I offered some suggestions of how can we meet them. I thank you for

allowing me to do this, and I leave you as good Iowans with the words of the great holocaust historian who said three extra commandments. One is thou shall not be a victim. The second one is thou shall not be a perpetrator, and the third one is thou shall not be a bystander. Don't let anyone say that Senator Harkin from Iowa ever was a bystander in the life of Special Olympics. Thank you.

[The statement follows:]

PREPARED STATEMENT OF ANTONIA C. NOVELLO

Good afternoon. Senator Harkin, other committee members (if present), staff members and special guests—thank you for giving me the opportunity to speak with you today on the important subject of protecting and improving the health and well-being of Americans with intellectual disabilities.

Today, I will be speaking to you wearing three hats.

My first hat is that of New York State Commissioner of Health. In this capacity, I am responsible for protecting and improving the health of 19 million New Yorkers, including approximately 350,000 New Yorkers with intellectual disabilities.

My second hat is that of a former Surgeon General. As this nation's 14th Surgeon General, and the first woman and first Hispanic to hold that position—and earlier when I served as deputy director of the National Institute of Child Health and Human Development, where research issues regarding intellectual disabilities were addressed—I had a unique opportunity to observe the health needs of Americans, including those with intellectual disabilities.

My third hat is as a member of the Board of Directors for Special Olympics, a position I have held since 1998. In this capacity, I have had the opportunity to learn about the many health needs of persons with intellectual disabilities. I have attended many of the Healthy Athletes Screenings sponsored by Special Olympics, where I have seen first hand the tremendous health care needs that these Americans have.

Colleagues, the facts are well known:

- Over 50 million Americans have some kind of disability.
- Up to 3.1 percent of the general population have some form of mental retardation.
- The Centers for Disease Control estimates that 17 percent of U.S. children under 18 years of age have a developmental disability.
- And 12.8 percent have a special health care need.
- A large body of research—including the 2002 Surgeon General's Report, as well as studies commissioned by Special Olympics and the American Association of Persons with Intellectual and Developmental Disabilities—have clearly demonstrated that, compared to the general population:
 - Individuals with intellectual disabilities have a higher prevalence of:
 - Hearing and vision loss
 - Tooth decay
 - Obesity
 - Foot problems
 - Reduced bone density
 - And other health problems
- Furthermore, research has also demonstrated that these individuals' access to health care services are at lesser rates than the general population.
- And when they do receive health care, it is known that individuals with intellectual disabilities are more likely to receive inappropriate, inadequate and sporadic treatment, if at all.
- These disparities are even more pronounced if the individual with an intellectual disability is of African American or Hispanic descent.

I see these statistics and I am reminded of, Dr. Martin Luther King, who said “the ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy.

Today I believe that we in America face a time of challenge and controversy as we seek to fulfill our responsibility of assuring full access by all individuals to high-quality health care.

I think it is time to candidly admit that—here in the year 2006—despite strong efforts on the part of many—the health of individuals with intellectual disabilities still lags behind that of the general population.

Through no fault of their own, Americans with intellectual disabilities continue to face huge obstacles in obtaining even basic health care services that many of us take for granted.

The causes of these disparities regarding health care access are many and include:

- Lack of training for physicians and other health care providers in the treatment and care of persons with intellectual disabilities.
- Societal misunderstanding of mental and developmental disabilities, even within the healthcare system.
- Lack of health promotion and education targeted to individuals with intellectual disabilities and their families.
- Lack of research focusing on the specific health needs of persons with intellectual disabilities.
- And, finally, lack of enforcement, education initiatives, and promotion of governmental policies and regulations designed to ensure full inclusion of this group at all levels of society and the community.

Colleagues, it distresses me that the lack of prevention, diagnosis and treatment of common health conditions in these individuals is compounding the complex set of challenges they already face—challenges that prevent them from accessing and enjoying optimal health and well-being.

We are at a threshold today, colleagues. Which way will we go? We have disparities—it's a tragic fact—individuals with intellectual disabilities live sicker and die younger—we know that—But what now?

Will we continue age-old initiatives that have achieved progress at a snail's pace, or will we dare to go in a bold new direction?

Hippocrates said that extreme illnesses require extreme remedies. My friends, the lack of equality in health for individuals with intellectual disabilities is an extreme illness that requires an extreme remedy.

What are we to do, then, you might ask? I don't pretend to have all the answers, but allow me to share with you Five Basic Challenges that I believe we must meet if we are to reduce health disparities affecting individuals with intellectual disabilities in this country of ours.

Challenge Number One is the challenge of ensuring that this nation's healthcare providers receive training and acquire experience in caring for persons with intellectual disabilities.

The results of a research study commissioned by the Special Olympics—which surveyed more than 2,500 medical and dental school deans, medical and dental residency directors, and medical students—are disturbing, to say the least.

Physicians and dentists surveyed in this study reported a general lack of competency to treat individuals with intellectual disabilities.

Some 52 percent of medical school deans, 53 percent of dental school deans, 32 percent of medical residency program directors, and 56 percent of students responded that graduates of these programs were "not competent" to treat people with intellectual disabilities!

Furthermore, 58 percent of medical school deans and 50 percent of dental school deans reported that clinical training regarding individuals with intellectual disabilities was not a high priority.

Most medical school deans—81 percent—said the primary reason for not training students in more specialized ways was "lack of curriculum time."

Similarly, 81 percent of medical school students lack any clinical training regarding individuals with intellectual disabilities.

The good news is that the majority of medical and dental school students—around 75 percent—indicated they are interested in treating people with intellectual disabilities as part of their career.

Furthermore, nearly all medical and dental school deans and residency program directors reported that they would implement a specific curriculum regarding treatment of persons with intellectual disabilities, if given one.

However, it is clear from this study that changes are not going to be made in medical and dental school training unless schools and residency programs receive help in developing and implementing a curriculum that focuses on the care for persons with intellectual disabilities.

With the help of federal funding, in New York State we are doing just that. The State Health Department and the Developmental Disabilities Planning Council have partnered on a new initiative to provide pediatric and family medicine resident physicians with a curriculum designed to improve their knowledge, skills and awareness of issues facing individuals with intellectual disabilities.

This curriculum provides medical residents with direct experience regarding individuals with intellectual disabilities and their families in their homes, in community

agency settings, and in clinical settings, so that they can see first-hand the multi-dimensional and complex issues facing these individuals.

Currently, 12 residency programs in New York State are participating in this pilot program, which uses the “Parent Partners in Health Education” training curriculum that includes lectures, clinical experiences, and at-home parent interviews.

This is a great program, but additional funding from the federal government and foundations will be needed in order to reach our goal of training all medical and dental providers in the special needs of individuals with intellectual disabilities.

Challenge Number Two is the challenge of ensuring that individuals born with an intellectual disability are identified early in their lives and provided with access to critical health related services. This can make a tremendous difference in their long-term health and well-being.

Currently, all 50 states provide some level of newborn screening for diseases and conditions that can cause disabilities. New York State provides the largest free newborn screening program of its kind in the nation. While most of the disorders we test for are rare, they are serious and could cause illness, mental retardation, or even death if not treated in the first weeks or months of life.

Therefore, by testing infants shortly after birth, we can identify conditions and diseases early, so that these children get treatment right away.

Studies have confirmed that children with genetic and metabolic conditions identified by newborn screening experience fewer developmental health problems and function significantly better in daily living than children who are later identified with these conditions by their physicians.

Regarding the higher prevalence of hearing loss in people with intellectual disabilities, New York is among 37 states that are conducting Universal Newborn Hearing Screening.

It is known that early identification of hearing loss and provision of appropriate interventions—including amplification and teaching and therapeutic services—has been well established in preventing intellectual problems that are associated with hearing loss in young children, whose hearing loss otherwise may go undetected and untreated until later in childhood.

Challenge Number Three is the challenge of supporting and expanding healthcare initiatives that have been shown to increase prevention, diagnosis, and treatment of health problems in individuals with intellectual disabilities.

Again, I must emphasize how important it is to identify individuals with intellectual and developmental disabilities as early as possible, because early intervention is critical. The importance of early intervention services in improving children’s development and in helping families to enhance their children’s development is very well established in scientific literature.

As you know, the Early Intervention Program, which is established in Federal Law under the Individuals with Disabilities Education Act, provides therapeutic and supportive services to children ages birth to three years who have diagnosed physical or mental conditions known to result in developmental delays.

I am proud that in New York State we are leading the nation in identifying young children with developmental disabilities and providing them with access to critical services. Based on the latest data, New York State’s Early Intervention program serves nearly 4.3 percent of children ages birth to 3 years old—the highest percent of children served by any state.

Similarly, I am proud that New York State is leading the way in the development and implementation of clinical practice guidelines designed to achieve optimal health and development for these young children.

To date, with the help of independent panels made up of professionals and parents, the New York State Health Department has issued three evidence-based clinical practice guidelines on the assessment and intervention of young children with autism and pervasive developmental disorders; communication disorders; and children with Down syndrome.

Shortly, we will also be issuing three additional guidelines governing the assessment and interventions for children with motor disorders, hearing loss, and vision impairment.

These and other science-based clinical guidelines would benefit children with intellectual disabilities across the United States. I encourage the Subcommittee to explore ways the federal government can support the replication and expansion of these New York guidelines and have them supported nationwide.

Regarding the 2002 Surgeon General’s Report, among its many recommendations it calls for the identification of a package of health care services specifically designed for individuals with intellectual disabilities that are known to produce good outcomes.

I think that is good, but I recommend we take that one step further. Let's develop a set of science-based clinical guidelines covering the recommended care and treatment of individuals with intellectual disabilities, and work with the state medical societies in each state to distribute the guidelines and provide education to physicians on how to use them. This is another initiative in which this Subcommittee and the federal government could play an important supportive role.

Colleagues, we know that bias and discrimination have major detrimental effects on the health and well-being of those who are affected by intellectual disabilities.

Lack of acceptance and inclusion—frequently accompanied by ridicule and disrespect—are known to contribute to depression and behavioral problems in persons with intellectual disabilities.

Therefore, Challenge Number Four is the challenge of educating all Americans, particularly our young people, to help prevent and dispel stereotypes—thereby promoting full acceptance and inclusion of individuals with intellectual disabilities.

Colleagues, if we are going to reduce stigma and discrimination, we have to understand and address its root causes.

Let there be no doubt—stigma is rooted in ignorance. It is based on a fear of the unknown.

Colleagues, the reality is that individuals with disabilities may make some of us feel uncomfortable because they remind us of our own vulnerability.

We need to be aware, not only of individuals with disabilities in our midst, but also of our own attitudes and feelings toward them. Often we find it easier to isolate and ignore those whose experiences confront the myth that we have control over our lives and destiny.

In New York State, we have extensive experience in conducting educational campaigns that have focused on dispelling stigma. Take AIDS for example. Our experience in dispelling stigma made one thing very clear:

The more people know about a disease or a condition, the less fearful and more understanding they will become.

So, colleagues, we need to ensure that the public gets the correct information about what intellectual disabilities are all about. Not their perception, but its reality.

To start accomplishing this, we must promote public understanding and acceptance of people with learning disabilities by raising their visibility. In a sense, we must put a human face on this condition. Too often, individuals with intellectual disabilities are invisible in our society. We may know their numbers, but we don't know their faces.

Therefore, I am asking for your support, Senator Harkin, and that of this Subcommittee. We are in need of a national public information campaign to promote understanding and acceptance of individuals with intellectual disabilities.

I am talking about over 50 million of our citizens—those who by no fault of their own are found in communities that traditionally lack clout to make the world stand up and take notice.

To start in this national campaign, I urge you to support the Special Olympics funding request to expand its "So Get Into It" program—a curriculum-based program currently being used in 3,500 schools across the country.

This initiative teaches elementary, middle and high school students about intellectual disabilities while empowering them to include, understand and respect these individuals.

Finally, Challenge Number Five is the challenge of supporting and funding research that focuses specifically on the health needs of individuals with intellectual disabilities—research that should result in the development and identification of "best practices" and clinical practice guidelines specifically targeted to this group.

Colleagues, I urge you, however, not to develop a single research study or intervention without the input of the individuals and families we are trying to help.

I believe that, if we are to succeed, researchers must be able to step into the shoes of the those they seek to help.

As the proverb says—you cannot tell me what to do unless you have walked a mile in my shoes!

I urge this Subcommittee, therefore, to support federally-sponsored clinical research investigation programs that focus on identifying the causes of, and solutions to, health disparities affecting individuals with intellectual disabilities.

And added to that request is the equally important support for better data collection on individuals with intellectual disabilities. The lack of comprehensive data on persons with intellectual disabilities is one of the biggest barriers we face in overcoming the inequities and disparities of health affecting these individuals.

After all, we cannot expect to determine the needs of the future if all we have is the incomplete data of today.

Senator Harkin, I want to thank you individually and encourage your continued strong support for the Special Olympics Healthy Athletes initiative. This program has a proven track record of identifying and treating health problems affecting persons with intellectual disabilities through health screenings conducted in conjunction with the Special Olympics games.

With federal funding at the fully authorized level, this program could be strengthened and expanded, so that more Special Olympics athletes benefit from these screenings.

Members of the Subcommittee, today I have presented five challenges and offered some suggestions on how we can meet them. I thank you for allowing me to offer my thoughts and suggestions on ways to improve the health status of individuals with intellectual disabilities.

As we proceed with our collective efforts to improve the lives of individuals with intellectual disabilities—side by side and hand in hand with affected individuals and their families—let us remember the words of Yehuda Bauer, the holocaust historian, who said: “Thou shall not be a victim, thou shall not be a perpetrator, but above all, thou shall not be a bystander.”

As the future of individuals with intellectual disabilities is being decided, let us not be bystanders.

Thank you.

Senator HARKIN. That will take your breath away. Thank you very much, Dr. Novello. Quite a tour de force there. My goodness. Well, let's see now. Where was I?

Tim, again, my deepest thanks for your great leadership, and we all just admire you so much for you and your whole family.

Of course, I would be remiss if I didn't mention the male side of the Shriver family also. Also, as you all know, it was Sergeant Shriver who started the Peace Corps under President Kennedy. You know, I still see these young people going off or coming back from the Peace Corps and thinking, you know, that really is the face of America abroad. That's what America ought to be about.

We thank Sergeant Shriver for his great leadership for all the years of making the Peace Corps what it is today. Tim you had three things you were urging us to do. Now, obviously some of that Dr. Novello testified to. It's worth tell us again, what should we be doing?

Mr. SHRIVER. Listening to Dr. Novello. That's what we should be doing. I am used to in my family being upstaged by women but never two so rapidly. Let me just before I answer your questions also recognize another member of the Board, Stacey Johnston, who is here up front, an athlete representative on our board. I don't know if there's any others, but Stacey, will you stand, please? Another one of our international leaders.

Senator Harkin, I would just say we proposed really three areas of work where the Federal Government's role we think can play a significant role. Health, which we've heard a lot about today; education, which Dr. Novello mentioned, where extending the challenge of inclusion and the challenge of acceptance to nondisabled young people so that they become part of the solution, where we've tried to expand our “Special Olympics Get Into It” program, which is a service learning program, around the world. We're struggling to get support, of course, could use some additional support.

We have a new effort which we're focused on early intervention, as Dr. Novello said, children ages 2 to 6, home-based programs and day-care center programs to promote physical activity. So those kinds of things are very important, and again, support in those areas would be fantastic.

The third area we won't talk about a lot this week is our international work. We proposed to USAID over the last several years increased support that this kind of work, citizenship building, the creation of volunteer institutions and citizen-based organizations as a part of empowerment programs and education and development work around the world.

When I read the paper and people say, "Well, we're trying to figure out our strategy for public diplomacy. We're trying to figure out how to present the best face for America," to me I'm stunned. You mentioned Peace Corps. Special Olympics programs are a big one throughout the Muslim world. They bring together people across religious barriers, across gender, across age, and across income demographics. Frequently these are supported by members of the United States, expat people who live in these countries working alongside their indigenous volunteer networks.

I mean the face of America is very clear to me. The best face of America has always been, as both Dr. Gerberding and Dr. Novello said, that side of the United States where citizens band together to try to do something that is right for their communities, for their families in a way that empowers them to make the dream of the United States, which is always what it will be, a reality. Why we can't—Federal policy doesn't run behind that, I don't quite understand. I don't have an answer for that.

But I would say that we have the capacity as a movement to expand rapidly in the developing world, not to mention in place of tension. We have postconflict programs in places like Bosnia and places like Rwanda. We have several thousand athletes competing in Kigali once a year and beginning with a community-based programs there across ethnic groups.

Do we have support from the Federal Government? Do we have support from political institutions? Largely not. Are they inexpensive? Incredibly inexpensive. You can do them for just a few thousand dollars in some of these countries. But it's an uphill battle to rethink, if you will, the potential of our population to be a powerful force for change, not just a force for pity.

We talk that rhetoric. Living it is a different story. So I would just say that quite specifically the support for the authorization which you and others have supported in the past for our work abroad and in schools and in health care here in the United States is obviously a priority for us. It's the place we think we can make the most difference.

Are there bigger issues? Absolutely. Dr. Gerberding has alluded to them. There are insurance issues. There are Medicaid issues well beyond our capacity to impact. But it is frustrating to hear person after person talk of the neglect and the oversight. To talk to people on the Hill and have them say, you know, "Busy year, tough year. Can't get to that now." Obviously that's not been the response we've gotten from you or from Ellen or from people on your staff. But we really would love to get to a point where some kind of a national convening would take place where people would come together and say, "Once and for all we are going to take this seriously." That would be my hope. Thank you.

Senator HARKIN. \$15 million?

Mr. SHRIVER. Right. We can't get it.

Senator HARKIN. Dr. Gerberding and Dr. Novello both—Dr. Gerberding, I need to know more what we can do for the training of clinicians and how we can get this as part of the training that they go through. I'd like to work with you on that. It seems to me most medical schools in the United States have some form of Federal support one way or the other. I'm just thinking ahead. That's all. Maybe we might want to do something along that line. Do you have any further thoughts on that that you might share with us?

Dr. GERBERDING. Well, it's clearly an absolute need. I agree with the statement that students want this education. They have the same passion you see in this room for treating people with intellectual disabilities or other disabilities, but they don't have the training. It is very possible to influence the curriculum in medical schools. We've done that in many examples where there were unmet needs in the past. I think about HIV infection and what's happened in medical schools to solve that problem.

I also wanted to show you, these are two videos that have been put together by the Lions Club in conjunction with the Special Olympics that are teaching how to improve the vision of people with intellectual disabilities, and one is targeting professionals in eye care, and the other is targeting students who are learning this. So, you know, these are cheap, very cheap ways to try to get the information, the learning out. Until we have an advanced curriculum within the professional schools itself, there are other things that we can do. We can do them right now to make a difference.

Senator HARKIN. I mentioned in my opening statement—and I want to get back to it—we've been working on it for some time with Lee Perselay and others about introducing legislation on preventative health care, wellness programs. I've been focused on that in the nondisabled sector, and I want to now focus on it in the disabled sector. Not just people with intellectual disability, but all people with disabilities.

You didn't mention it in your testimony, but in your text you mentioned something about a program in Montana and in South Carolina, I believe it was, funded by the Centers for Disease Control about demonstration—there were wellness demonstration programs. I just would like to know more about them and what you might have found in those programs.

Dr. GERBERDING. Yeah, I would be happy to provide the expert who can discuss it with you personally, but, for example, the program in South Carolina is a program that really demonstrated—in fact, data are published in a peer review journal—demonstrated that people who are intellectually disabled can lose weight using the same kind of structured steps that anybody would use if they wanted to commit to better nutrition and more exercise. Significant reductions in body mass index as a consequence of the supportive program.

Our challenge with this, as with so many of the things we do at CDC, it's one thing to be able to show you know the way forward. It's another thing to be able to scale that intervention appropriately so that all people have access to it. Where we really need help is the scaling. The research is important, but it's even worse

to know what to do and not be able to do it because you don't have the resources and the investment for the scaling.

Senator HARKIN. I need to know more about that. Our staff is going to work with you on that. To both Dr. Novello and Dr. Gerberding, I was talking to a group in Iowa. They wanted to start a program which would help coordinate the health care of persons with intellectual disabilities. In this program visiting nurses would actually go to a number of group homes for persons with intellectual disabilities to make sure they were receiving appropriate medical care, help them to coordinate that care.

In the case of the particular population in Iowa, the actual medical services would be paid by Medicaid. But not the coordination services. You can't really do this unless you have coordination services. So one of the purposes of this demonstration is to show that it will actually save Medicaid dollars.

I guess what I'm trying to ask you is if you've done anything like this in your State or if you know anything about this, Dr. Gerberding, or have done it elsewhere and how we might get over that hurdle of coordination services. That's a problem.

Dr. NOVELLO. One thing, Senator, that we're doing in New York that covers some of this issue is the issue is—when I worked in UNICEF for 5 years with Mr. Jim Grant, he used to tell me, "What you cannot get by altruism, then get it by guilt." I have found in New York I could not have anyone take care of the poor.

So what I did, I did school-based health clinics, which would be the same as you're proposing. I couldn't get doctors to come and take care of the children in the schools because Medicaid pays them a fee. So what I did is I was able to talk to the legislature, and they gave me the ability of paying them a fee for service, which is double the amount. Therefore I have no problems now with doctors coming into the school-based clinics.

But the issue which I thought was crucial, I got the deans of medical schools, the deans of nursing schools, and the deans of social work in the senior year of those to be then the doctors, the nurses, and the social workers of the school. It liberated the school nurse to know that there was a professional taking care.

But I have looked into the data now. I have seen, A, the kids believe that I can be you, because the age of the visitors that take care of their health is equal. So that makes them stimuli. The nurse doesn't send anyone to the emergency room because she has a specialist there that takes care of the kids. I send the senior of both because I don't want the parents to believe that I'm sending a guinea pig—your son or your daughter is a guinea pig of people learning medicine.

As of this moment I have seen less suicide. I have a lot of depression. I have seen parents staying to work because they don't have to come to the emergency room to pick up their kids, and I have seen the nurses in the school system working good and the doctors making sure that they come because I pay them fee for service. So there's always a way. All you have to do is find a program that works, and I would be more than happy to share that data of New York with you.

The other thing that I think is important is grab—You can take the horse to water, but you cannot make them drink. Therefore

graduate medical education is a lot of money that you feds give us. Therefore every hospital wants it. Every residency program wants it. If you are able to insert something in there that says, "Thou shall provide care and teaching regarding intellectual disability," they will.

The third thing is in New York we found during the Towers when September 11 came when I send everyone out there to take care of the psychological problem that I found on September 11, then I saw when I paid at the end of the month, my mental health was almost flat, but my cardiac was very elevated. When I asked why is that the case, the issue was that in moments of stress if you don't know the culture and you don't know the way people feel, you're going to misdiagnose. Therefore I found that every time that a minority went, they say, "I have a pain in my heart," which was overwhelmed depression, but they did an electrocardiogram.

So at this moment in New York no resident graduates unless they have 8 hours paid by the State for cultural competency. I think cultural competency would be something by which we can have the knowledge of what is a person with intellectual disabilities and cultural sensitivity of the place. So that's going to be great.

Finally in the nurse and the dental, the Dental Society of New York sued the Department of Health because they wanted more money. But I just inserted a little thing in there that says, "If you do not take care of the poor, in the third year I'm going to take away your raise." They didn't. I took away their raise. Now they're taking care of the poor.

Senator HARKIN. Good job. Anything else to add to that, Dr. Gerberding? Anything else anyone would like add before I go to the next panel? Let's thank this great, wonderful panel.

On the next panel we'll call the real experts here. Peter Farrelly; Kyler Prunty; Laurie Noll, special education teacher from Burlington High School; Peggy Whitworth, a parent and advocate, Arc of East Central Iowa.

Now, as they're getting seated, I just want to have you join me in thanking our sign language interpreter. His name is James Boyd. I want to thank you for interpreting today.

Mr. BOYD. This is Bill Ainsley.

Senator HARKIN. Bill Ainsley is now taking over. Bill Ainsley is also a sign language interpreter. We want to thank our court reporters, Jill Kruse and Theresa Ritland, Iowa court reporting. Thank you very much for being here today.

Well, Peter Farrelly, we'll start with you. Thank you very much for the wonderful movie you made, "The Ringer," and for all of your work for people with intellectual disabilities. Again, one of our previous witnesses said make the problem visible. That was Dr. Gerberding. You helped make it visible. We thank you.

As we did with the other panel, I'll just go down the line. We have your written testimony. It will be made a part of the record in its entirety. If you could just sum it up, I would sure appreciate it.

STATEMENT OF PETER FARRELLY, AUTHOR, MOVIE PRODUCER

Mr. FARRELLY. Absolutely. Thank you very much. I have to say I'm at a disadvantage here, because Dr. Novello stole my speech. So I jotted down a couple of notes. I'll see what I can do. I want to say, first of all, that I am extremely honored to be here today representing the interests of people with intellectual disabilities. Thank you so much for having me. It's a great honor.

My name is Peter Farrelly. I've written a couple books and made a bunch of movies. I'm here mainly I suppose because of my involvement in a film called "The Ringer," but we'll get to that later. First I'd like to give you a little background about myself. I grew up in a little town called Cumberland, Rhode Island, back in the 1960s and 1970s. It was a great time in most ways. I would get up in the morning and take off on my bike with my brother and our friends, and we wouldn't return home until dark. Our parents didn't have to worry about us even for a second.

I remember hitchhiking to Little League games, believe it or not. We wouldn't think twice about getting into a stranger's car. We had a milk man back then and a bread man and a fruit and vegetable man, and it was a time when dogs were free to roam the neighborhood. My dog Winnie actually had friends. Occasionally she and a bunch of other mutts would blast through the middle of our football game chasing a rabbit or some other furry thing, though I don't ever recall them catching one.

But not everything was perfect. Frequently one of those dogs would get hit by a car or would nip at some kid and be sent to the, "farm." At night there was a cloud of smoke that hung over the neighborhood because each household burned the day's trash in their backyard.

People thought nothing at that time about throwing their Burger Chef bags out the car window, and when we did eeny-meeny-miney-mo, it was the "N" word that got caught by the toe, and the kids in the special ed class were called "retards" or worse. It's not that we were racists or bad people. We knew no other description for the special ed students, and eeny-meeny-miney-mo was just a rhyme, a bunch of words that we were taught as children and made as much sense to us as "purple mountain majesty."

What I'm saying is we didn't know any better. Just as people today who say they got gypped probably don't realize that the term is disparaging to gypsies. But you know what? Eventually we learned, through education and concerted efforts by our Government, among other groups, to spread public awareness. One of the first times I remember thinking that littering was wrong was when I saw the public service announcement where Iron Eyes Cody sheds a tear as he walks down a polluted highway. So I stopped littering, and soon we amended our eeny-meeny-miney-mo-ing too.

So here we are 30 or 40 years later, and some things have gotten better. At least they did for a while. Yet still today most people have no qualms about throwing the word "retard" around. I did it just now, although I wouldn't have dared utter the "N" word at a congressional hearing.

That's a big problem. Not because the "R" word is so important. It's just a word after all, and words evolve, just as mentally retarded was replaced by mentally impaired and then mentally chal-

lenged and now intellectually disabled or challenged. Soon it will be something else. Personally I prefer intellectually different, though I'm sure in time that would sound pretty dumb too.

But it's that "R" word that most shows the lack of respect and understanding given to people with intellectual differences. Moreover, it highlights just how few steps we've taken toward integrating them into society, which leads me to "The Ringer," a movie I developed and produced for 20th Century Fox. It was written by Ricky Blitt and directed by Barry Blaustein. It's about a man named Steve who tries to fix the Special Olympics to win money.

He pretends to be intellectually different and enters the games, then places a bet on himself, figuring that winning will be a breeze. What he doesn't realize is that a lot of these people are just intellectually different, not physically different. Many of them are excellent athletes. So they kick his butt. Though Steve is able to fool the Special Olympics officials, he can't fool the athletes themselves, and soon a group of them are on to him.

They decide not to turn him in, however, simply because they're sick and tired of Jimmy, who has won the last several Special Olympics and made the cover of Wheaties and has let it all go to his head. Instead they train Steve, hoping to beat Jimmy, and in the process Steve bonds with a bunch of guys he never would have had the good fortune of meeting. He learns something and he changes.

I wanted to make this movie from the moment I heard the idea, not just because it was funny but because of the truth it revealed. There were 9 or 10 special athletes that the story focused on, and they were all different. Some were talkative. Some were quiet. A couple were funny. Others were boring. They were real, and they all had distinctive personalities just like everyone else in the world. But I'd never seen that in a movie of this type. Usually these things were about sad people living sad lives. Those movies were about pity. I saw what we could do. We could show the fun side of these guys, the joy of spending time with them. Make a movie about them without anyone shedding a tear.

I've been involved in the Best Buddies program for 10 or 15 years, and I've never cried, nor had my buddy Scott. It had been fun, all fun, except for one time when he plowed into me at a supermarket with a full carriage of groceries and almost severed my Achilles heel.

So I set out to get the movie made. After 5 years and a lot of help from Tim Shriver and Mrs. Shriver and the Special Olympics Board of Directors, we succeeded. "The Ringer" is my favorite movie of ours for several reasons. I got to work with over 100 Special Olympic athletes for 3 months, and there were huge laughs and lots of hugs, and nobody was stressed. I saw how it changed my crew and myself and the athletes, and the bonding was something I'd never experienced on a movie set before.

When it came out last Christmas, it was a dream come true, because it did exactly what we wanted. It entertained people, made them laugh, but most importantly it introduced millions of moviegoers to people with intellectual differences. It made them more human, more fun, less scary. It made them accessible. Several people told me after seeing "The Ringer" that they were nervous dur-

ing the first 20 minutes because they have never spent any time around special athletes, but by the end they wanted these guys to be their friends.

That's it in a nutshell right there. That's what we're doing here. We're trying to build a bridge that will bring people with intellectual differences into our world and us into theirs, and we're not there yet. We're not even close. My 7-year-old son actually asked me after watching "The Ringer," "Why had it been so hard to get made?" I couldn't answer him. You know, he was right. "The Ringer" should not be a groundbreaking film in the year 2006. It's not that crazy. It's just about treating people with respect. This kind of thing should have been done 30 or 40 years ago back when Iron Eyes Cody was just starting to tell us about pollution. If it had, then guys like me would be in a position to make something truly groundbreaking today. But we are where we are, and steps are steps, however small.

PREPARED STATEMENT

So I'm asking you please, please be the ones to help drive a concerted public awareness campaign linked to solid programs like Best Buddies and Special Olympics and NADC, the National Association of Childhood Development, as well as others that will provide young people with the opportunities to get to know and make friends with the 8 million people with intellectual differences in our country. Then maybe someday there won't be an "R" word or special this or an intellectual that or any other term for them. Maybe they'll just be, you know, people.

[The statement follows:]

PREPARED STATEMENT OF PETER FARRELLY

I want to say, first of all, that I am extremely honored to be here today representing the interests of people with intellectual disabilities. Thank you for having me.

My name is Peter Farrelly. I've written a couple books and made a bunch of movies, and I'm here mainly, I suppose, because of my involvement in a film called "The Ringer," but we'll get to that later. First I'd like to give you a little background about myself. I grew up in a town called Cumberland, Rhode Island back in the 1960's and 1970's. It was a great time in most ways—I would get up in the morning and take off on my bike with my brother and our friends and we wouldn't return home until dark, and our parents didn't have to worry about us even for a second. I remember hitchhiking to little league games and we wouldn't think twice about getting into a stranger's car. We had a milk man back then and a bread man and a fruit-and-vegetable man, and it was a time when dogs were free to roam the neighborhood. My dog Winnie actually had friends. Occasionally she and a bunch of other mutts would blast through the middle of our football games chasing a rabbit or some other furry thing, though I don't ever recall them catching one.

But not everything was perfect. Frequently one of those dogs would get hit by a car or would nip at some kid and be sent to the "farm", and at night there was a cloud of smoke that hung over the neighborhood as each household burned the day's trash in their backyard. People thought nothing at that time about throwing their Burger Chef bags out the car window, and when we did eeny-meeny-miney-mo, it was the "N" word that got caught by the toe, and the kids in the special-ed class were called "retards", or worse. It's not that we were racists or bad people. We knew no other description for the special-ed students and eeny-meeny-miney-mo was just a rhyme, a bunch of words that we were taught as children and made as much sense to us as "purple mountain majesty."

What I'm saying is, we didn't know any better—just as people today who say they got "gypped" probably don't realize that the term is disparaging to Gypsies. But you know what? Eventually, we learned. Through education and concerted efforts by our government, among other groups, to spread public awareness.

One of the first times I remember thinking that littering was wrong was when I saw the public service announcement where Iron Eyes Cody sheds a tear as he walks down a polluted highway. And so I stopped littering and soon we amended our eeny-meeny-miney-mo-ing, too. So here we are, 30 or 40 years later, and some things have gotten better—at least they did for a while—and yet still today most people have no qualms about throwing the word ‘retard’ around. I did it just now—though I wouldn’t have dared utter the N-word at a congressional hearing.

That’s a big problem. Not because the R-word is so important. It’s just a word after all. And words evolve. Just as “mentally-retarded” was replaced by “mentally-impaired” and then “mentally-challenged” and now intellectually-challenged and soon it’ll be something else. (Personally, I prefer intellectually-different, though I’m sure in time that would sound pretty dumb, too.) But it’s that R-word that most shows the lack of respect and understanding given to people with intellectual differences. Moreover, it highlights just how few steps we’ve taken toward integrating them into society.

Which leads me to “The Ringer”, a movie I developed and produced for 20th Century Fox. It was written by Ricky Blitt and directed by Barry Blaustein. It’s about a man named Steve who tries to fix the Special Olympics. To win money. He pretends to be intellectually-different and enters the games, then places a bet on himself, figuring that winning will be a breeze. What he doesn’t realize is that most of these people are just intellectually-different, not physically-different, and many of them are excellent athletes. So they kick his butt. Though Steve’s able to fool the Special Olympics officials, he can’t fool the athletes themselves and soon a group of them are on to him. They decide not to turn him in, however, simply because they’re sick and tired of “Jimmy” who’s won the last several Special Olympics and made the cover of Wheaties and has let it all go to his head. Instead, they train Steve (hoping to beat Jimmy) and in the process Steve bonds with a bunch of guys he never would have had the good fortune of meeting. He learns something. He changes.

I wanted to make this movie from the moment I heard the idea. Not just because it was funny, but because of the truth it revealed. There were nine or ten Special athletes that the story focused on, and they were all different. Some were talkative, some were quiet, a couple were funny, others were boring. They were real, and they all had distinctive personalities, just like everyone else in the world. But I’d never seen that in a movie of this type. Usually these things were about sad people living sad lives. Those movies were about pity. I saw what we could do. We could show the fun side of these guys, the joy of spending time with them; make a movie about them without anyone shedding a tear. I’d been involved in the Best Buddies program for 10 or 15 years and I’d never cried, nor had my buddy Scott. It had been fun. All fun. (Except for this one time when he plowed into me at the supermarket with a full carriage of groceries and almost severed my Achilles tendon.)

So I set out to get the movie made, and after 5 years and a lot of help from Tim Shriver and the Special Olympics board, we succeeded. And “The Ringer” is my favorite film of ours, for several reasons. I got to work with over a hundred Special athletes for three months and there were huge laughs and a lot of hugs and nobody was stressed. I saw how it changed my crew and myself and the athletes, and the bonding was something I’d never experienced on a movie set before. When it came out last Christmas, it was a dream come true. Because it did exactly what we wanted: It entertained people, made them laugh, but, most importantly, it introduced millions of movie-goers to people with intellectual differences. And it made them more human. More fun. Less scary. It made them accessible.

Several people told me after seeing “The Ringer” that they were nervous during the first twenty minutes because they’d never spent any time around Special athletes, but by the end they wanted these guys to be their friends. And that’s it in a nutshell. That’s what we’re doing here. We’re trying to build a bridge that will bring people with intellectual differences into our world, and us into theirs. And we’re not there yet. We’re not even close. My 7-year-old son actually asked me, after watching “The Ringer”, why it had been so hard to get made. And I couldn’t answer him. He was right. “The Ringer” should not be a groundbreaking film in the year 2006. It’s not that crazy. It’s just about treating people with respect. This kind of thing should’ve been done 30 or 40 years ago, back when Iron Eyes Cody was just starting to tell us about pollution. If it had, then guys like me would be in a position to make something truly groundbreaking today. But . . . we are where we are, and steps are steps, however small.

So I’m asking you to be the ones to help drive a concerted public awareness campaign linked to solid programs—like Best Buddies and Special Olympics, as well as others—that will provide young people with the opportunities to get to know and make friends with the 8 million people with intellectual differences in our country.

And then maybe someday there won't be an R-word or special-this or intellectual-that or any other term for them. Maybe they'll just be, you know . . . people.

Senator HARKIN. Thank you, Peter. Now we turn to Kyler Prunty. I have met Kyler a few times. I think he's in training to be a special lobbyist in Washington. He knows his way around the hallways pretty well by now. Kyler is from Marshalltown. He's a great athlete and has been in to see us lobbying in Washington and is well known to so many of us for his advocacy. So, Kyler, the floor is yours. Welcome to the hearing.

STATEMENT OF KYLER PRUNTY, SPECIAL OLYMPICS ATHLETE AND IOWA RESIDENT

Mr. PRUNTY. Good afternoon. My name is Kyler Prunty. I am very grateful for this hearing today because I think people should understand my abilities and my hopes as a person and not focus on the things that I cannot do. I am a very proud Special Olympics Iowa athlete. I want to welcome all of the out-of-town guests. I am so happy to have all of you here for Special Olympics National Games at Iowa State University. I can't wait until the games start. I am 19 years old and a 2006 graduate from Marshalltown High School. I graduated May 28.

I think I have accomplished a lot. You see, it is so good to be alive. Doctors told my mom that I might only live until I was 11. But look at me now. I am alive and 19 with plans for things ahead. I started to get seizures at the age of 3. Doctors said that I had TSC, which can affect the brain. It can be in other organs too, but they were not sure.

Today I am healthy, and I have a disability to live with. I read and write at a second grade level. Newspapers, books, and any form need to be read and explained to me for me to understand. I need help with shopping for groceries, making food, and checking to see if I have the right amount of change back. But I practice because I have goals and dreams. I want to be independent. I want to have my own home for my dog and me. I want to work. I want to be in Special Olympics.

I have been in Special Olympics since grade school. I have competed in bowling, golf, basketball, skiing, track and field, and my favorite is swimming. I have a collection of many medals. I have met many people and have made many new friends. Special Olympics means a lot to me. They are family. They make me smile. I feel like Special Olympics have taught me to be a leader and to enjoy life to its fullest, to be an athlete and to be physically fit.

Special Olympics have let me travel and as an Iowa Global Messenger to tell others about what Special Olympics has done for me and what it can do for others. In 2005 I was asked to help with the first Capitol Hill Day for Special Olympics in Washington, DC.

It was so good to meet many Special Olympics leaders like Eunice Kennedy Shriver, Iowa Senators Harkin and Grassley, and Iowa Congressmen Boswell, Nussle, and Latham. I got to travel with Iowa's very own CEO Rich and Board Member Lana. I got to tell my story to Congress and to thank them for all they do and to ask for funding support for Special Olympics. This past March I was asked to go back to Washington, DC. It was so fun to see

everyone again. Some say I should be a lobbyist. We all are lobbyists today.

After I got home, I was able to go to the State Capitol in Des Moines and hear everyone vote yes for the National Games bill. I was able to say thank you to State lawmakers. I am so happy to be a part of the Special Olympics family. I have learned to be a self-advocate to tell others about my needs and my feelings. But there have been many hard times to get to where I am today. My family helped me, and we told to get people to think outside the box. Remember, every one of us have disabilities (sic) and goals.

I continue a lot of my dreams already. I swam on my Marshalltown High School swim team for 4 years. My coach, Mike Loupee, who is here today, told me that I got better and better each year. I made friends and worked hard to help the team. I learned how to eat right and exercise and to just take care of my body.

As a new graduate of high school, now I have a new routine. I have a new job. I am told I do a good job at my work. I work as a bellman at the Best Western. I clean up the parking area, bring bed and pillows up to the rooms if they are requested, and set up for weddings and banquets. I want to work more, but I am limited in hours to work, as it makes problems with my disability benefits, which I need to survive.

I just don't understand all the reasons. I just want to work and be alive. If I work too much, I lose my benefit, but if I work too little, I can't pay for my car that I need to get to work. To make matters worse, the program I was in that helped me move from school to work has been shut down because of a lack of funding. One of the hard things to do is find work that I like and that I am good at. The TAP program really helped me, and I am sad that it won't be there for others.

I've had several jobs in the past few years. Some I like more than others. People with intellectual disabilities have different opinions, likes, and difference just like everyone else. I like people and being around people. I like the fact that my supervisor lets me do things that I enjoy.

By telling my story, I can get others to know how we feel and to help us be the best that we can be. So you see that is why I want you to know how much I love—Special Olympics means to me and many others. Senator Harkin, I wanted you to know how much I love Special Olympics, and now with being a Global Messenger, I can tell more people about it.

Senator Harkin, I want to take this opportunity to thank you for helping bring these games to Iowa. I also want to thank you for your leadership in the U.S. Senate and to get funding for Special Olympics Healthy Athletes program. This is so important. I hope you will continue to help Special Olympics and that you will convince other Senators to do the same. So now just watch me go. I am on fire. Thank you so very much.

Senator HARKIN. Do you know how much they pay lobbyists these days? I think you'll be getting some offers in. Let me just take this opportunity right now, if I can, to introduce and ask them to stand Kyler's parents, Vickie and Marvin, right here.

Now we're turning to Laurie Noll. Laurie Noll is a special ed teacher at Burlington High School. Laurie, welcome. As I said, your statement will be made a part of the record in its entirety. If you'll just summarize it for us, I'd sure appreciate it. Thank you.

STATEMENT OF LAURIE NOLL, SPECIAL EDUCATION TEACHER

Ms. NOLL. Thank you very much. I have been a special education teacher for 23 years. I have worked with students with learning disabilities, mental disabilities, hearing impairment, and I can tell you that my most favorite place to stand is where these guys are because I have interpreted for many, many people through my years, and that is my comfortable area, and this is out of my comfortable area.

I am also a mother of three, as you can see. My son is autistic. So—he just graduated from high school. My motto is children are true miracles, and a teacher is their tool to help these students find their strengths. Living independently is an American dream, and it is part of an educator's job to build as many skills of independence as possible.

I promote the old proverb, give me a fish, and I eat for a day. Teach me to fish, and I eat for a lifetime. When students are engaged, they help each other, and they learn even more. This picture is of my special education students with some general education students, and they're working together to learn leadership skills so that they can be partners in a program together.

Students that have been in my classroom have been able to perform and go out into the public after high school with these different jobs. I have had construction workers, stylists. They are families. They have children. They are in college right now. I have some that are businessmen. I have a welder, and I even have a teacher amongst my past former students.

Special education has progressed, but we have a long way to go, and our good teaching skills need to develop into great teaching skills. These are the barriers that they will face as they go forward in their teaching.

Today information is coming at all of us so quickly. Students with intellectual disabilities are not progressing like and they don't see the big picture that other people see. This causes much struggle. Other countries, China and India's children are passing our children along with many technology areas.

As America races ahead, many of our intellectual disability students are falling behind. The technology does have benefits for our students and provides learning opportunities which were never possible before, such as the scan reading pens and Curswell computers, talking dictionaries. These are all equipment that are used in my classroom to help my students so that they can go into the general ed classroom and perform just like everyone else.

The barriers with technology include the experience that the teachers need to train so that they can train the students. It also costs a lot of money to get these different types of equipment in the classrooms.

Many parents and educators may not see some of the intellectual disabilities that their child has before they reach the age of school. So the training is not there, and the detection to help these stu-

dents from an early on age is not prevalent. Educators need training and research needs supported to detect early warning signs of the intellectual disabilities.

Without support of the early interventions, the students are faced with such problems as suspension, absenteeism, not belonging, frustration, academic difficulties, failures, and health problems as they grow in their schooling.

One story I have is of a young man who was identified at a very early age. He was given the proper care and all of the technology and all of the training through the years. When I had him in my program as a freshman in high school, which carried him through his graduation, his vision—he told me, “I want to be a welder.” I’m going, “Okay. You’re going to be a welder. We just have to figure out how we’re going to do that.” This young man could not read anything. He could not find his name in a paragraph if he had to. So the technology and the equipment that we needed to use to help him be able to be successful was awesome.

He comes back, and he visits my classroom, and he tells stories to the students that I now have in my classroom. “You know, having a disability is a really hard job, and it’s even more difficult to get a job.” He said, “I am very lucky I have a job. I am a welder.” You know what? He makes more than the beginning teachers that have taught him. So I’m very proud of him.

Goals can be reached with the proper support and identification. We just need that early identification and the tools to help find those intellectual disabilities. No Child Left Behind is a word we all know. There are funding gaps in learning, and it has caused many problems with the funding.

However, one of the good things that it has done is it has helped us to identify where the gaps are in our students. So now we’re able to see this is where the problems are, and we can move on from here. No Child Left Behind has allowed special education teachers a new way to look at education. However, to make the need and meet this, we need the funding to support the impact that this program is showing us.

Prior to No Child Left Behind, special education was thought of as a second thought. We received the old leftover books for our students. We received the broken equipment to use for science, and we always got the closet for our classroom. Now with No Child Left Behind, our students are able to be out amongst their peers. They can be in classes with their peers, have the right textbooks, have the equipment they could not before.

We just need to make sure that our teachers have the proper support so that they can be with their students and help them have success. In order for special education teachers to keep up with the changing world, they need professional development, time to collect and analyze data, time to learn new curriculum, and time to learn the new technology. In today’s technological world, there are no limits. It just takes looking at things from a different perspective and reaching for the gold.

No Child Left Behind has changed how we look at data, and the accountability has teeth in the results. Through data educators realize we still have problems, and there is an urgency to solve these problems. No Child Left Behind has helped us to see where to

start. We now need the funding to help us with that early intervention. We need to start very early to provide support for our disabled students before they give up on us.

As a young child has bright eyes and eager to learn, with an intellectual disability as they reach the secondary education, they have had so many failures, you see what happens. A child does not wake up one morning, eat breakfast, tie his shoes, walk to school, and then declare to his teachers he's dropping out.

We as educators failed that child by not identifying his needs from the early on age is where we need to start, therefore to get the help right away before they even reach school so we don't have our students dropping out of school. We are making progress. However, our weaknesses are more evident today with the accountability of what is being shown.

In 1987 I worked with a team who went to homes of special education individuals to determine what they were doing after high school, what worked when they were in school, and what didn't work and what we still needed to try to do. It was such an eye-opener to walk to the address that I had on my paper and to be met at the door with a gun because they were so afraid it may be a bill collector or who was coming to that door.

Some of the people I found were living in dirt garages, and they had a cot in there. You could see a little stove that they had put up there. That was their home. Others I met in a jail. Others I found deceased. This showed me that we were not doing a very good job, and we had a long way to go in 1987. I think we're getting there. It became clear that we need to do a better job in preparing our special students for postsecondary needs.

As I reflect today on our past survey, I feel we are doing a much better job of educating our intellectual disabled youth than in the past and we're working to help them meet the demands of today. To build a successful future, we need to make connections, get funding, have the needed support, and provide enough of the funding and time to make all of this work. As a team we can move mountains and reach many goals if we all work together and have the same focus. I want to say thank you for allowing me this time to talk and share my vision.

Senator HARKIN. Great. Thank you. Laurie Noll, thank you very much. My goodness. That was great. I'll have some more questions.

Now we'll turn to our final panelist, Peggy Whitworth, a long-time friend of mine, parent, advocate with Arc of East Central Iowa. She's the executive director of Bruce more in Cedar Rapids, and her son Patrick, whom I know and have had the privilege of knowing for quite a while now. Quite a remarkable young man. There he is. I think he just gave you permission to go ahead. Peggy, welcome, and please proceed.

STATEMENT OF PEGGY BOYLE WHITWORTH, BOARD MEMBER, ARC OF EAST CENTRAL IOWA

Ms. WHITWORTH. Thank you very much for the invitation to be here. I think almost all the problems could be solved if we put Kyler and Dr. Novello on the road. What a duo that is. As Senator Harkin said, I am a parent and advocate and a fairly new member of the Arc Board in East Central Iowa. My 34-year-old son Patrick

lives in a group home, works at the Linn County Administration Building, and right now Patrick says to me, “You know, I like my life.” No parent can have anything better. Nothing could ever be more gratifying.

However, it’s all tenuous all the time. Patrick’s disability is a very minor part of who he is. He’s bright, funny, very social, compassionate, and an all-around good guy. Patrick got sick when he was 1 year old suffering three episodes of unconsciousness that resulted in brain damage and mental retardation. At that time we were told he might live 1 year. He would never walk, and he would never read. Fortunately, none of that happened. Patrick was born at the right time, because before Patrick 34 years ago there weren’t many programs. In the last 34 years there have been huge gains in attitudes and in services for people with disabilities.

My comments deal more specifically with the transition from school to work for people with disabilities. The Cedar Rapids school system has some of the best educators around, many of whom taught Patrick. There were some fairly bureaucratic ideas at the central administration. But the principals and the teachers in Patrick’s school saw him as a student, not a disability.

Through Options of Linn County, he has had some excellent work experiences. Specifically I would like to acknowledge Aegon USA, which is a real leader in employing people with disabilities. Patrick worked at Aegon for 7 years, had a very happy and rewarding experience. His supervisor changed, and suddenly the attitude changed. Patrick didn’t have a job. His coworkers still do not know what happened, but he didn’t have a job.

Patrick, like most of us, his identity is very closely tied to his work. Not having a real job was devastating, and he did have some problems with depression, and he was very, very down for a long time. Options of Linn County, which is a fine organization, part of the county, that is the vehicle through which Patrick and people like him find work. After several futile efforts to find a job, they turned to me and said, “You know more people than we do” and in essence just gave up.

At that point in tears, which isn’t my style, I called Linn County Supervisor Lu Barron, and I said, “This is a program of the County.” And she was at my work in 20 minutes. Talk about a responsive public servant. As a result of that call, she looked around and found out at the County Administration Building they had no Options employees. So she challenged the people at the County to—“What work, what tasks do you have that someone with special needs might be able to do?”

So technically Patrick now is a subcontractor to the Board of Supervisors. He is sort of farmed out to the auditor, the treasurer—he wanted me to list everybody—human resources, several different groups. But his office is actually in the purchasing department. There’s this wonderful head of purchasing, Britt Hutchins. It’s not his job at all, but he makes room for Patrick. He encourages Patrick, and he provides general supervision.

One thing we might also note is that many of the jobs that Patrick does like putting the property tax bills in envelopes, preparing packets for precinct workers at election time, these are all essential

things. Patrick gets paid a percentage of prevailing wage. So actually the county is saving money.

He really has a very good time at work, and there are some things that—parts of his job he doesn't like. Like he shreds a lot of documents. We have these discussions that every job has parts you like and some that you don't like, and there's a reason it's called work, you know.

Patrick does need assistance and supervision. There are times when he isn't totally attending to task. His temper is short, and he has to be corrected. But the people there are used to Patrick. They work with Patrick, and generally it is working very well.

Their only challenge is the funding pie is not growing, but the slices are. More and more people are asking for funds, and Patrick's job, his group home, all these things rely on people doing wonderful things. LinnHaven, who operates the group of 28 sites that are home to 82 people in Cedar Rapids, again, we have incredible people doing wonderful work.

Patrick lives with what he calls two great guys and has wonderful staff of Marlys Ingles and Lorie Sharp. They are supporting, caring, and appropriately demanding of the guys. They all have lots of responsibility. Patrick explained to me on the way over he has to get home tonight because Sunday night is when he cleans the bathroom.

But the funding problems and the rising health costs are cutting some of the benefits of the staff. These women don't make very much money, but they do make an independent life very possible for these three great guys. With cuts in benefits, they may have to seek other employment, and that's going to have a devastating effect on lots of lives.

The gains in the quality of life for people with disabilities are wonderful, but much more is possible. If we look at things in a new way, we might be able to try new things. With Iowa's approaching labor shortage, here is an untapped source. It will take a little effort. Okay. It will take a lot of effort, but it is worth it.

PREPARED STATEMENT

I'm not sure why I am on earth, but I know why Patrick is. He is here so people know that people with disabilities are still people. We all have disabilities. Some are just more apparent than others. Thank you, Senator.

[The statement follows:]

PREPARED STATEMENT OF PEGGY BOYLE WHITWORTH

Today I speak as a parent, an advocate, and a fairly new Board Member of the Arc of East Central Iowa. My 34 year old son, Patrick Whitworth, lives in a group home and works at the Linn County Administration Building. Right now, Patrick says, "You know I like my life." There are not words more gratifying for any parent.

However, it has not been easy to get to this point and it is all tenuous, all the time.

Patrick's disability is a minor part of who he is. Patrick is bright, funny, very social, compassionate and an all around good guy.

Patrick got sick when he was a year old suffering three episodes of unconsciousness that resulted in brain damage and mental retardation. At that time, we were told he might not live a year, would not walk and would never read. Fortunately, none of that happened. Patrick was born at the right time. In the past 34 years huge gains have been made in attitudes and services for people with disabilities.

My comments deal with the transition from school to life after school for people with disabilities. The Cedar Rapids School has some of the best educators, many of whom taught Patrick. Some attitudes by central administration were rather bureaucratic, but the teachers and principals saw Patrick as a student, not a disability.

Through Options of Linn County he had some excellent work experiences. Specifically, I mention Aegon USA which was an early employer of people with disabilities and continues to be a model company. However, after seven happy and rewarding years at Aegon, his direct supervisor changed, her attitude was different, and his job ceased. His "normal" co-workers did not know how this happened, but it did.

Like most of us, Patrick's identity is tied in part to his job. Not having a "real" job was devastating and he had some very down times. Options of Linn County, a fine organization, is the vehicle through which people like Patrick find work. After several futile initial efforts were futile and they turned to me. "You know more people, so you should, in essence, deal with this." At this point, literally in tears, I called Lu Barron, a Linn County Supervisor, since Options is an arm of the county. She came to see me in twenty minutes—talk about a responsive public official. Her action was immediate, that Options is part of the county and the county had none of their clients employed. Supervisor Barron didn't create a job for Patrick, but she called on the county staff to re-think some of their work and see what was possible.

As a result, Patrick is officially a sub-contractor of the Board of Supervisors and is farmed out to Purchasing, the Treasurer and Auditor. The positive environment, the support of many county employees, and a lot of hard work by many people result in a very happy employee. He does work that matters—mailing the tax bills or collating materials for precinct workers at election time. Those he likes. He isn't very fond of shredding, but knows in every job some things are fun and some aren't. There is a reason it is called work.

Patrick does need assistance and supervision. There are times when he is not totally attending to task, when his temper is short, when he should be corrected. Britt Hutchins, the head of purchasing for Linn County, provides over-all direction to Patrick. This wonderful man does much more than he is paid to do and as a result, Patrick has the dignity of being a worker. And the County is getting essential tasks completed as a lower cost. Patrick is paid a percentage of the prevailing wage based on productivity.

Unfortunately, the funding pie for many services is not growing but more slices are being made. The threat is that additional funds are taken from another important source.

The same problem holds true for LinnHaven, the operating group of 28 sites that are home to 82 people. Again, incredible people doing wonderful work. Patrick lives with "two great guys" as he expresses it. The staff, Marlys Ingles and Lorie, are supporting, caring, and appropriately demanding of the guys. They all have responsibilities. Sunday night, Patrick has to clean the bathroom! Something he tells me after spending time at my house.

But, funding problems and rising health costs mean cuts in the benefits for this staff. These women don't make much money and they do make an independent life possible for the three great guys. With cuts in benefits they may have to seek other employment and this will have a devastating effect on many lives.

The gains in the quality of life for people with disabilities are wonderful. But much more is possible, if we look at things in new ways and try new things. With Iowa's approaching labor shortage, here is an untapped source. It takes a little effort, o.k., it takes a lot of effort but it is worth it.

I'm not sure why I am on earth, but I know why Patrick is. He is here so people know that people with disabilities are still people. And we all have disabilities, some are just more apparent than others.

Senator HARKIN. Thank you all very, very much. Wonderful testimony.

Peter, let me ask you a question. Some of us notice things differently than others. Through all my work on disability issues, I go to movies. Now, "The Ringer," of course, was about people with disabilities. So it was the focus of the movie. But a lot of times I'll go to a movie, and I'll watch out of the corner of my eye. I watch just average scenes, you know, people moving in and out of buildings or doing this, you know, peripheral stuff of the movie that nobody ever notices. I just try to see how many people with disabilities I see, just the kind of people you see every day when you walk

into an office building or you go down the street or you go in a restaurant, whatever you want.

Well, I can count on just about one or two hands. Every once in a while when I see one, it registers. But more often I go see a whole movie. You won't see one person with a disability ever, ever. I mean not that it's central to the character but I mean just normal people that are the backdrop of a movie. Talk to me about that. Is this just hard to do? Why aren't they reaching out and showing us more in the movie?

Mr. FARRELLY. It's criminal that they're not. This has been a real concern of mine and my brother's for the last 12 years that we've been making movies. I cannot honest—I could probably say that we've had disabled people in every one of our movies.

There's a group called the Media Access Committee or Group in Los Angeles that represents actors with disabilities. There's a couple thousand actors. One percent of them work. They never get out there. It's insane. What I have done is I've been appealing to casting agents because, you know, I've never read a script that said, you know, "Bob's girlfriend enters the room" and in parentheses "excellent hearing" or "not in a wheelchair."

You know, there's an old joke—there was an old joke, and some of you—most of you have heard of it, but I'll repeat it just to make my point, which is that it was an old riddle which was years ago that there's a guy and his son in a car—you've probably heard this—and they're driving somewhere. They have an accident. They take the father to one hospital and the son to the other. When the son comes into the emergency room, the doctor comes out and says, "Oh, my God, that's my son." The question was, how could that be? People would scratch their heads. Well, the doctor was his mother, you know, but people think doctor, male. That's what they would think.

When people read scripts, they think able-bodied, and they shouldn't. They should not think that. They do. That's what we're trying to overcome. We do our best to do that. You know, I have a friend—I happened to be with a guy once who broke his neck. He's a good friend of mine named Danny Murphy. He broke his neck the day Richard Nixon resigned, August 8, 1974. He's a quadriplegic, and he's been in several of our movies. He's an actor now.

But he came to me after "Dumb and Dumber" and said, "You didn't do enough." We had a little in there, but he said, you know, "What I want to do, see, is I want to be in a movie, and I want to be a bad guy, because anytime you see somebody in a movie who's disabled, they're the angel. They're the sweet person."

He said, "People are afraid of us because they think we're better than them somehow." He said, "If there's going to be a stereotype about people in wheelchairs, maybe it's that they're a little crazy and did something nuts to break their neck," he said, "not that they're nicer or better than anyone."

So our next movie was "Kingpin." He was in it as the guy that pulls the—turns the—hits the switch when Woody Harrelson gets his arm cut off. He's the guy—we did "Something About Mary"—screaming at Ben Stiller as he's helping him pack and move into his house. He's in his wheelchair. He's saying, "Come on, move it," yelling at him. The point was if we could show people with disabil-

ities in all different ways—you know, we don't just show that, but if we could show them in many, many different ways, then people will be thinking, "Well, they're just like me, and they're more acceptable." But you're right. It is a problem, and we're trying to overcome that.

Senator HARKIN. Thank you. Good for you.

Thank you for your leadership on that, Peter Farrelly. Well, Kyler, I hardly know—first of all, Kyler, you mentioned your swim coach. I met him earlier. Mike Loupee is here. Could you stand?

Well, Kyler, I did not know until today about your new job. This is news to me, so congratulations on that. It is disturbing, however, to hear that you work but you can only work so much because then some of the money will be taken away.

Do you know how many hours a week, Kyler, you can work now? Do you know?

Mr. PRUNTY. They say 20 hours a week, but I can work more—

Senator HARKIN. I bet.

Mr. PRUNTY [continuing]. Than 20 hours, but I don't really want to lose my benefit.

Senator HARKIN. Yeah. 20 hours. You're limited to that?

Mr. PRUNTY. Yeah.

Senator HARKIN. Do you know more about that, Laurie? Does that vary State by State or what?

Ms. NOLL. No. That's across.

Senator HARKIN. That's across? That's it.

Ms. WHITWORTH. We find that with Patrick, of course, and—

Senator HARKIN. Say that again?

Ms. WHITWORTH. The same thing impacts Patrick that he can't work as much. He's perfectly able to work a whole lot more, but there are all these games. You have to, you know, balance this and this. The number of experts that Patrick deals with to keep all this stuff straight is ridiculous.

Senator HARKIN. Americans with Disabilities Act provides that employers must make reasonable accommodations. It would seem to me that the Federal Government ought to also make reasonable accommodations.

Ms. WHITWORTH. Too often, Senator, it's about the rules, not about the person.

Senator HARKIN. Kyler, we're going to work on that. We've got to rededicate ourselves to finding—getting over this hurdle that somehow that—because we have enough data to know that if you get supportive services, you or people with physical disabilities get supportive services, and work longer that in the long run not only is your life better, it saves the taxpayers dollars. We know that. We've got enough data to show that. It just makes no sense what we're doing right now.

Ms. NOLL. I also think that if they're able to work more hours, you're not going to have the obesity. You're not going to have all of those other parts that go with it, because they are healthier and happier.

Senator HARKIN. Are you keeping up your swimming?

Mr. PRUNTY. I'll be working on the weekend, like Saturday and Sunday when they—on their busy time with weddings. We have—last time we set up, like, 250 chairs for the wedding.

Senator HARKIN. Well, I was going to say, you ought to be doing something to keep—because I know you're a physical specimen. You're in great physical shape. Putting up all that stuff, I think you're probably keeping in pretty good physical shape.

Laurie Noll, what can I say? Thank you very much—23 years of being a special education teacher.

The kids are lucky to have you as a teacher. This is a special interest of mine also is how we train more special ed teachers and how we make sure that they have the support they need both in the classroom with all the supportive services you need. But I'm going to put you on the spot. I want to talk about No Child Left Behind.

Ms. NOLL. Ok.

Senator HARKIN. Now, we get a lot of input, I do, from teachers, school boards, principals about No Child Left Behind. But when we passed this bill—I'm on record. I voted for it. But when we passed it—I can remember sitting around a table, the administration with us, both parties talking about getting this passed and about the funding of it.

So one of the things that occurred to me at the time and my staff at that time was, wait a minute, No Child Left Behind. This means kids with disabilities. This means we're going to have one level playing field for every kid and we're going to have the funding for it to make sure that every kid is not left behind. Tell me what's happened since then. Tell me about No Child Left Behind, how you see it right now.

Ms. NOLL. I think whoever made the name No Child Left Behind had a great publicist to help them, because you cannot vote against No Child Left Behind because you want all children to be equal, and you want children to be with everyone else.

What I see happening in the field in this education realm is that all of the funding is going to meet the test. Make sure that students are able to be successful in math and in their reading abilities. This is very difficult for the arts, the liberal arts areas, where you need a whole well-rounded student, and you don't have that right now. The focus is on these academics.

Another sad part—and it goes along with the health and being a healthy individual—what they're doing for students that are not meeting that 40 percentile, they're taking them out of art, P.E. They're taking the students and putting them into an extra classroom.

So I have a child that doesn't test very well who is a pretty bright young lady who has to sit in an extra classroom and miss out on P.E. because she doesn't test well. So there's a lot of things that we need to look at the No Child Left Behind and change.

Senator HARKIN. Well, I'm glad you touched on that. One of the things that we have found, a lot of times kids with certain disabilities may not know math. They may not know science, hard to read. But a lot of times they're very artistic, and they can express themselves artistically. I pay another measure of respect to the wonderful Kennedy family for Jean Kennedy Smith, who started the Very Special Arts Program for kids with disabilities. To see these kids develop their artistic abilities is wonderful. How do you measure that? How do you put that in a test, you see?

I've asked Margaret Spelling that, the Secretary of Education. No Child Left Behind, how do you test for the care and concern that one child might have for another? How do you test for her kindness and her generosity? How do you test for artistic ability which may be very profound, yet you don't put it on a test anywhere? It seems to me this No Child Left Behind ought to encompass that too.

So I guess the bottom line for me is that right now when we passed No Child Left Behind, we agreed upon a funding trail, how much the funding would be. This year with this budget we are now—Let's see. We passed No Child Left Behind in 2001. So 5 years. 2006 we are now \$15 billion less than where we said we were going to be. \$15 billion that should have been put in has not been put in.

Ms. NOLL. Correct, correct.

Senator HARKIN. So I keep saying, you know, I think No Child Left Behind would work if, one, we got off of this testing for just one or two things and encompassed it more in a broader climate.

If we funded it, I mean if we paid for it like we said we would. God knows we need special ed teachers like you all over this country.

Ms. NOLL. I can tell you that my son if he was tested on his drumming ability would do awesome, and he received a 2.5 when he graduated. But it wasn't because of his academics. It was because of his music and artistic ability and his love of acting and his love of being in the theater and the stage. Those are the things that got him his 2.5, not his reading or his writing ability.

Senator HARKIN. I have seen so many kids with various forms of disabilities who just have so much talent in acting. I've seen them on stages. I've seen them—Well—

Mr. FARRELLY. Eddie Barbanell is actually here. He's one of the actors in "The Ringer." Eddie, could you stand up?

Senator HARKIN. Where is he? He's here somewhere.

Mr. FARRELLY. Eddie? Is Eddie still here? I think he left.

Senator HARKIN. He was here earlier.

Mr. FARRELLY. Yeah. Oh, I'm sorry. Getting your hopes up.

Senator HARKIN. But I've seen a lot of—I've seen them in school plays. We aren't nurturing that part of that ability that these young kids have.

Ms. NOLL. In my school alone, I had a group that's called Renaissance, and I put my special education students in that same realm with the regular ed kids. They partner up, and it's a leadership program. So they get to do a lot of special things. I've had my students in front of the school body. They have sung solos in front of their whole class. They have given speeches for their student body, and they do a great job. They're accepted, and it's wonderful that way.

Senator HARKIN. Well, that tells us what we've got to focus on, and that's what we have to focus on.

Peggy, just one last once. I made a note here. Who funds LinnHaven? You mentioned where Patrick lives.

Ms. WHITWORTH. Approximately two-thirds comes from Medicaid funding from HCBS and one-third then from the county. I didn't know that before I was coming here today. I had to ask. Then they do some private fund raising as well. Patrick was just asked—

They're having an event called Bowling for Mortgages, so—but it is primarily funded through Home and Community Based Services.

Senator HARKIN. Well, I'm going to close this down. I'm just going to ask you, is there any last thing that you would like to impart to me or on the record at all? I'll just go down. Peggy?

Ms. WHITWORTH. I would say the thing I'm specifically concerned with right now is after these people get through with wonderful teachers like Laurie here, then the next step and the transition thing. And simply making people aware, and I think Peter's doing as much as anybody to make sure that they are.

Mr. FARRELLY. Well, thank you very much. I'd also like to quickly say, you know, in talking about the arts, when we made "The Ringer," we had 10 main characters. Half of them were intellectually different and half were "normal actors." The intellectually different actors were way more prepared every day.

I'm telling you, I'm not being patronizing when I tell you that we would come in—what happens when you first start to shoot a scene is you rehearse it. You find out then that half your actors didn't get the lines down, and you have to spend an hour or two getting the lines down before you can shoot the scene adequately.

I never had one problem with any of the intellectually different actors. They were always the best. I think that, in fact, there seems to be—that seems to be their strength. They were ahead of the other actors in that way, and it was a great help for the movie.

Senator HARKIN. Anything else? Kyler, anything else you want to impart to us at all before we get out of here?

Mr. PRUNTY. Well, thanks for asking me to be on your hearing, and I appreciate what you're doing for Special Olympics and for Iowa.

Senator HARKIN. Well, I'm proud. We're proud of you. And like I said, you can come lobby me anytime.

Senator HARKIN. Laurie, any final thing, Laurie?

Ms. NOLL. Just thank you and help teachers to get that funding and support they need.

Ms. WHITWORTH. One thing everybody in this room wants to do is to thank you for all of your leadership, and I know it's not about you, but it's about you and the steps that you have taken, and you're such a leader, it makes us all proud to be from Iowa.

Senator HARKIN. Thank you very much. Thank you. Thank you very much. You're very generous and very kind. Thank you all for being here today. Just one moment. Well, I don't want to keep people here. I know you have other things, and the games start this evening, and I know you're all going to be there for that.

But it's not often that we have a field hearing like this, and Ellen Murray just suggested to me that, well, we're pretty much on time, which is kind of odd for us for hearings to be on time. We usually run over a half an hour or so. But since we do have a few more minutes, I'm just wondering—a lot of you came a long distance. I know you're greatly interested in the subject. And maybe you have something you'd like to impart to us, and so I'd like to just throw an open mike here if I could.

I'll excuse the panelists. I'm just going to open the mike only if you have a question or a statement. I don't care which, something you want to get across.

I would only ask that you, one, say your name. If it's Smith or Jones, fine. You don't have to spell it. But we have a court reporter here, and she needs to know the proper spelling of your name. So when you get the mike, say your name. If it needs to be spelled, spell it, and then go ahead and speak.

Dr. RADER. Right. My name is Dr. Rick Rader. I'm a physician from Chattanooga, Tennessee. I'm the editor-in-chief of *Exceptional Parent Magazine* and the president-elect of the American Academy of Developmental Medicine and Dentistry.

I hope following my remarks you will be compelled to say two things. One, I hope that you'll say, "I didn't know that," followed by, "How could that be?" The Institute of Medicine is a depository for a voluminous array of studies—you've heard some of the epidemiological statistics this afternoon—testing to the comorbid problems of people who are medically underserved.

Despite the fact that the Institute of Medicine, the CDC, the NIH, the Office of Minority Health, and the Office of Health Disparities relates to people with developmental disabilities and intellectual disabilities as being medically underserved, the Federal Government has never officially declared our population as being medically underserved.

I think that your facial expressions are starting to say, "How could that be?" Purser (phonetic) is the board that declares that. And right now the only populations that qualify for that moniker happen to be Native American Indians and some other indigenous populations.

The beauty and the need for having our population declared as being medically underserved would allow medical student loan forgiveness. It would allow foreign trained physicians to get their visas if they worked here in this particular population. It would allow funding in research for community health centers, and it would direct some funding mechanisms as a result of that too. At the end of the day, I'm afraid to say that populations that are underserved are undervalued, and we'd like you to think about that.

Senator HARKIN. Let me just ask you this, doctor. When you're saying population, are you talking about both physically and intellectually disabled?

Dr. RADER. I'm talking about our population, which is folks with intellectual and developmental disabilities. But, yes, folks with intellectual disabilities are not declared medically underserved by the Federal Government.

Senator HARKIN. Okay. Thank you. You're right. I didn't know that.

Mr. DONNELLY. J.D. Donnelly, D-O-N-N-E-L-L-Y. I'm the CEO for Special Olympics Utah. Thirty percent of my full-time staff are individuals with disabilities. I'm speaking to you on behalf of being an employer. The challenges that are put on the employer to hire a person with disabilities and trying to manage their hours so they don't lose their benefits and the challenges of that, make it very difficult.

So, if we want more of our individuals with disabilities to be employed, we've got to eliminate those barriers for the employer and make a positive experience both from the Government paperwork side and management of that as it is from the benefit of having

somebody with a disability on your staff. So, I encourage you to try to eliminate some of those barriers. Thank you.

Senator HARKIN. Thank you very much. We'll just go back and forth.

Mr. SEIDMAN. Good afternoon, Senator. I'm Michael Seidman, and I currently teach law at Harvard. I'm friends with Peter Blanks, who sends you his regards. Senator, I just wanted to emphasize earlier remarks about the lack of coordination for programs involving individuals with disabilities across the Federal Government. One example that we heard was the lack of ability for individuals with disabilities to work without losing their health care benefits and endangering their lives in some respects.

Another one has to do with the ADA, for which we're all very grateful to you. But 16 years later we have yet to see a job program, although Senator Dole did valiantly try to do that in 1993 and 1994. He lost that effort. We saw the welfare reform efforts, but we did not see job programs with individuals for disabilities.

To make the point even more graphically, with the recent hurricanes of Rita and Katrina, in the December previous to the hurricanes, there was a national action plan passed by FEMA, and the word "disability" or "disabled" does not appear in that very large document.

Some 6 months before the hurricanes, the President passed an executive order requiring all agencies involved with disaster relief to take account of persons with disabilities. But that program was not initiated either. Now almost a year after the hurricanes and with the hurricane season again rising, trailers that FEMA had issued are not accessible. Individuals with disabilities after the relief were not put into accessible shelters. They did not receive medical assistance, and we can go on and on, and I can give you many more examples.

But it seems to me that at the heart of it is that the Federal Government lacks a holistic approach towards disabilities. Even now with an interagency council that's supposed to address the needs of individuals with disabilities, there seems to be an awful lot of waste and lack of attention and understanding that disabled people are people who are involved in all aspects of society and a lack of understanding of how to engage with them as a whole person. I don't have the answer to that. I just reflect my colleague Dr. Rader's point that I hope you respond, "Gosh, I didn't know that, and what can we do?" Again, thank you so much for your efforts.

Senator HARKIN. Thank you very much. I just—you're right. We found out after Katrina some really terrible information, and we had some hearings on it where people with disabilities—people actually brought seeing eye dogs—had to leave their dogs and get on a bus or something like that. People who had lived independently before, were thrown in an institution. Just one thing after another. Trailers that were provided, as you said, were totally inaccessible.

So we've introduced some legislation, S. 2124 if you're writing things down, to address that. We also added an amendment for the Homeland Security bill coming through to set up one person in that whole Homeland Security thing whose only responsibility is to—is to be a resource for people with disabilities in case of any natural disasters and things like that.

They don't have that person right now. We want to get one person who's a go-to person, you know. If you're preparing for a disaster, what do we need to address this population of people with so you have that person to go to? Or if there is a disaster, what do we need to do so we've got one person who's in charge of that? Hopefully we'll get that done by the end of the year.

The other thing is, I hope we can make the changes in these things so in case of disasters we have plans in place to address the needs of people who are either physically or intellectually disabled. Thank you. Back here.

Mr. McDONALD. Hello. I'm Steve McDonald from Dubuque, and I have a 23-year-old daughter with multiple disabilities. Special Olympics has meant a great deal to my daughter and to our family in many, many ways. One struggle we have had is through the educational and governmental system and the roadblocks that have been constantly put in my daughter's way as she tries to succeed. Special Olympics never says to an athlete, "You can't do that." They say, "Let us find out a way."

For example, at the summer games a few years ago, there was a sight-impaired athlete who wanted to run a particularly long race. They got dozens and dozens of volunteers who encircled the entire track. They held a rope, and they put a ring on the track. As she ran, the volunteer would let go of the rope, and she was able to complete that entire race. Those of you who were here for those Summer Games might remember that event. It was really fantastic.

Special Olympics didn't say to her, "It's impossible. You can't do that." Yet the Government is constantly saying to my daughter and the educational system has said many times in the past, "We can't do that. It's impossible." What can you do to help change the Government and the educational system to look at my daughter and say, "Yes. You can do that?"

Senator HARKIN. I think what we said in terms of No Child Left Behind and everything is to make sure that it applies to all kids, that we tell kids with disabilities that they can do that. And then they're going to have the education and the teachers and the supportive services to do that. I mean it is a disgrace.

It's a national disgrace how little we spend of our resources in this area and how we still have this mentality of, well, we'll take care of them some way or another, usually through some institutional means or something like that, which is degrading and depressing and which really limits the horizons of people with disabilities. I take your point well. We just need to do more of this on the Federal level, and we need the funding there for it too.

I should have mentioned this earlier. We are in the district of State Representative Lisa Heddens. She represents the Ames area, is on numerous State boards for intellectual disabilities, works for Parent Training and Information Center, and is the parent of Paul, age 9, with Down syndrome.

Representative HEDDENS. Thank you, Senator. I just wanted to make a few comments. I appreciate the opportunity for you to have held the hearing today. I think it's very, very important for people to hear some of the challenges for people with disabilities.

One of the things I just wanted to say in regards to my son, Paul, you know, being thrown into this whole new realm of special education and Medicaid is really what drove me to run for office. It's because I found how bureaucratic it was and confusing, and I thought, here I'm a pretty intellectual woman, and I can't figure it out. I'm struggling through it. How can everyone else do it?

So, I give great credit to my son for pushing me to be in office. One of the questions I had is, how can we continue to pursue funding? I know we've talked about that a lot today. But in particular, funding the special education funding. You know, it was promised about 25 years ago that it would be at 40 percent. It is now at, what, 17 percent?

Senator HARKIN. Going down?

Representative HEDDENS. Going down. We're not asking 100 percent, although I'd like 100 percent. You know, where—"what's the stall?" is one of my questions. You know, what else do we need to do to lobby that? As a legislator, I find it very hard to work within our State to have adequate funding for education. It's a continuing struggle to make sure we have dollars for, you know, birth to 3, for that K through 12 level, and then for our students that are going into post secondary.

We also have struggles with our Medicaid system. I look at Medicaid that's being cut federally, and how are the States to match those dollars or to make up any loss of dollars? My fear is what Iowa will do is will either cut services or change eligibility criteria. I don't want that for my son, and I would assume everyone else would not want that as well.

So I guess I look to you not only as a parent but as our Federal counterpart is I'd like to continue ways to work together, because this is an important area. I do appreciate all the work that you have done. You have been a leader and a champion in this area, and I just want to thank you again for holding this important hearing today.

Senator HARKIN. Lisa, thank you. Thanks for letting us meet in your district today. I appreciate it very much.

For those of you who may not know, what Representative Heddens was just talking about was that when the Congress passed the Individuals with Disabilities Education Act—let's see, that's been about 36, 38—1971—31 years ago. Thank you. 31 years ago. We said in passing that, that our goal was that the Federal Government would provide up to 40 percent of the additional cost of educating kids with special needs.

Thirty-one years later we're at about 17 percent and going the other way. The high, I think, was, like, 18 to 19 percent. I think we're going the other way now. Again, it's just—that's not right. I mean the Federal Government should have been at 40 percent a long time ago, and we should have been at 40 percent now. It's just unconscionable that we've never gotten that. Yes.

Ms. PETERSON. Good afternoon, Senator Harkin. It's Mia. Hi. It's Mia Peterson, and I am a self-advocate. I've got to come up. Today, I just wanted to share with you about my independence and failures with transportation. It's been a long time. Eight years ago I made a big move from Iowa to Cincinnati, Ohio, and not because I had to, but I had a lot to learn about living on my own, independ-

ently, and I was included to work on a newsletter in Cincinnati, Ohio.

My family supported me because they wanted me to have this chance to live my own life and my sisters. I'm glad that they did. It was worth the risk. It was the beginning of my self-determination. Trust me. I am working on it. In Cincinnati things started changing, and I felt I needed to move on.

New things were happening in Iowa, so I wanted to move back. I wanted to be closer to my family and my other friends here in Iowa. Now I am back in Iowa living in Des Moines. I am glad to be working for Iowa Protection and Advocacy Services, and I'm full-time now, working 40 hours. I just want to say that.

Ms. PETERSON. I have experienced failure with my job. I have trouble with transportation. There was not a bus that goes close to my office, so I had to find another way to get to work. I finally got services from Parent Transit. I know that other people with disabilities have trouble with transportation too. If we are going to have a chance to work in our communities, we need transportation that works for us. Senator, there is no place like home. Thank you.

Senator HARKIN. I didn't recognize—I can't see from here very well. That's Mia; right? How are you? It's great to see you. Welcome back home. My gosh, yes. I've known Mia for a long time now. Thank you, Mia Peterson.

Ms. SATTERFIELD. My name is Deborah Satterfield, and I'm from Ames, Iowa, and I'm the parent of an 8-year-old boy who, 8 weeks ago, went through a very serious brain surgery, and he's on the brain injury waiver. What I observed as a parent is that we have some very serious problems in this country with nationwide malpractice insurance. Because of my son's brain situation, he was having about 700 seizures a day, and he could not be served by physicians locally, although I was referred to two very, very skilled neurologists and optologists in a neighboring State.

A few months prior my son's surgery, my neurologist sent me a letter saying that he was going to be possibly losing his malpractice insurance, not because he was incompetent, not because he had been sued, but because too many of his patients came from other States and his insurer was uncomfortable with that, and they were high-risk patients because of his specialty in epilepsy and autism.

That day I had to face the reality that my son could die if my physician lost his insurance. That was the most traumatic day I've ever lived through, Senator Harkin. I didn't realize in the United States of America that we didn't have the right to drive across a State line to get the right medical help.

I want to ask if somebody here—you know, when we find these physicians that are trained to work with our population, we have to support them. This isn't about protecting doctors who are negligent. This is about protecting patients.

I'm pleased to say that my son received the surgery because my doctor's insurance didn't fall through, thank God. He's now a happy little boy. But he did suffer from some of the medical issues. I'm very aware of the medical problems. At one point after his brain surgery, the nurses didn't want to give him pain medication because he can't talk, and he uses signed English, and he was crying and signing for pain medicine, and he couldn't get it.

So, I think when we get our skilled physicians, we've got to support them so that they can save the lives of these very, very important individuals in our society. I thank you for this hearing.

Senator HARKIN. How is your son now? How is he doing?

Ms. SATTERFIELD. Oh, he's doing fabulous, Senator. He's bright-eyed. He's learning more signs every day. He's a blessing. I am so blessed.

Senator HARKIN. Oh, that's wonderful.

Ms. SATTERFIELD. Thank you.

Senator HARKIN. Back over here.

Dr. HOLDER. Hello, Senator. My name is Dr. Matthew Holder. I am a physician. I also serve as the Global Medical Advisor for Special Olympics, but I don't think I need to represent Special Olympics here. I also serve as the executive director of the American Academy of Developmental Medicine and Dentistry, which is a national association of a few hundred physicians and dentists who are not only dedicated to serving people with intellectual disabilities, but also have the expertise to train others and other physicians to serve this population as well. So, I would like to pledge our help in the training piece of training our Nation's physicians and dentists to care for this population.

Senator HARKIN. I would just ask you, doctor, I just need advice. I mean I just need some guidance on maybe what we ought to be doing or what we could do to help in that endeavor from the Federal Government. I just need some advice. Not here, but you know how to get ahold of me.

Dr. HOLDER. I'll come to your office.

Senator HARKIN. All right.

Dr. HOLDER. Thank you. I also operate a clinic in Louisville, Kentucky, which is one of the Nation's few clinics that devotes its time specifically and only to caring for people with intellectual disabilities. I'm both happy and sad to say that our patients will drive sometimes 220 miles each direction to come to our clinic. Now, I'm happy because that means we're doing a good job. I'm sad because that means that they are passing a number of physicians and dentists along the way who aren't willing to take care of them.

One thing I'd like to point out is that a lot of our patients are adults. There are a lot of services out there for children with disabilities. But once those children grow up and they become 21, 22, 25, 40, 50 years old, those services drop off.

I have seen a few sad stories, and I'm just going to share two very short ones. One was a person who died because of complications that started because of tooth decay, and the neglect that happened for so long was that they—one event after another led to their death. The reason why was because our system just is not set to handle older people with intellectual disabilities. So that's my statement. Thank you.

Senator HARKIN. Thank you, doctor. Time is running out. We've got quite a few more people. Again, if you could keep it short, I'd sure appreciate it. I'd hate to cut anybody off. Go ahead.

Ms. MCKINNEY. I'm Elsie McKinney (phonetic). I'm from Maryland, from Frederick. I was listening to the concern about medical education on addressing the needs of intellectually disabled people. I want to tell you about a wonderful program practically right

under your nose on the campus of the National Naval Medical Center Uniformed Services University, which trains our physicians for the military and public health service.

There's a wonderful program through the Department of Pediatrics that is called Family Advocacy Program. They begin the first day of medical school by integrating into the medical education and seminars and classrooms and home visits the opportunity—the requirement that all of their students are exposed to these needs.

They interact with real-life intellectually disabled people and their families. They come out to your house. They have to go home and write a paper the next day. They relate to the kids, and my daughter Emily, who's here as an athlete, has been one of, I guess, their guinea pigs. She's been the model for how to do a pediatric interview.

Anyway so there are some things out there that are happening. From the first day of medical school when it's introduced to them, they're told this is a one-of-a-kind program in the world, and I just hope that the word gets out. Unfortunately, it's not publicly funded. It's funded by private enterprising and grants. But it's wonderful. I mean the students come out to our house. They meet Emily. They talk to her. She tells them about her problems. It's remarkable.

Senator HARKIN. Thank you. Doctor, do either one of you know about this?

Dr. NOVELLO. We have it in New York. I'm glad that they are doing this in Maryland, but I hate to hurt your feelings. We are doing it in New York too. We have 12 programs where I believe it's extremely important that people learn what disabled are, so we're making that as part of the curriculum of the school.

So we go to the houses. We go to wherever they go, and we train in getting it where the people are. But it wasn't easy, but it's a peaceability project, and we have 12 programs. I think it would be great if this would be across the United States. One was in your package, Senator.

Senator HARKIN. My time really is running out. I'll take a couple more. Then we're going to have to cut off. Yes. Go ahead.

Ms. ANDERSON. This is very brief. My name is Lisa Anderson from Ames. I wonder if anyone would vote down a compassion tax, compassion tax. To raise money for funding to have a tax, call it a compassion tax. But my question is if it is on the radar of anyone in Washington that 1 out of 166 children is now born with autism.

Senator HARKIN. I'm trying to understand something. I can't hear that well. You're saying something like a compassion tax? I don't understand.

Ms. ANDERSON. My question really is about the statistics for autistic children that are being born.

Senator HARKIN. Yes.

Ms. ANDERSON. If that's on the radar of Congress that 1 out of 166 children is now being born with autism. It's an epidemic.

Senator HARKIN. Oh, I see. Okay. I will answer thusly. This committee does have jurisdiction over the National Institutes of Health. I know that there's more and more research being done into this as to why this is happening. I don't know that we have any expert diagnosis or not.

I don't know if Dr. Gerberding is—the question was more and more kids seem to be diagnosed with autism and more and more kids are being born and diagnosed with autism, and we've asked NIH. I don't know. Maybe this is outside of your jurisdiction, but we've asked NIH to start looking at this and why, what's happening. I just want to know if you had any observations on that.

Dr. GERBERDING. I would never correct you, Senator, but you actually asked CDC to look into it.

Senator HARKIN. Oh, I asked CDC. I knew I asked somebody. I just didn't know who. I stand corrected. We asked CDC to look into it. So I have the expert person here to answer that question.

Dr. GERBERDING. Actually I have the expert. Dr. Cordero is the leader of the center that's responsible for this. But we are very interested and worried and concerned about the prevalence of autism. In Atlanta, in Georgia we have a very sophisticated study to try to understand what is happening with the trends in autism and, more importantly, we hope, why, why is this happening and what can be done about it.

But as you know, it's been very difficult because in many States we're not allowed to get the information that we need to understand the problem. We're also doing something that the Senator has helped us with, which is our campaign about learn the signs and acting early, and what we're discovering is that when parents know what the developmental milestones are and, more importantly, when their pediatricians or their family doctors know what the developmental milestones are, we can make that diagnosis earlier, and that's a wonderful thing, because people can get help earlier.

But it also changes the statistics, because we're finding more people. We're finding them earlier. So it's scientifically right now a little bit difficult for us to say 100 percent what's happening. What I say is whatever is happening to the trend, there are too many children with this problem, and we need to understand why.

Senator HARKIN. Very good. Thanks, Dr. Gerberding. Yes. Over here.

Dr. FRAY. I'm Dr. David Fray, F-R-A-Y. I'm the Chief of Developmental Disabilities for the state of Hawaii, and I'm also a dentist. There are a couple issues that I think are very important for our families. One is that the maze of Federal programs and regulations is confusing and difficult. People end up with different challenges, but they're unable to meet those challenges because they don't have direct control over how money is spent. I think it's very frustrating.

There's also the portability issues. When families move from Hawaii, we don't keep wait lists, but when they go to other States, they're put on a wait list, and they could wait years for home- and community-based services. I think that could be addressed federally.

On the issue of oral health, dentists are wanting to learn how to treat patients with developmental disabilities, but dental schools do not give any emphasis. So dentists come out of dental school untrained and feeling very, very vulnerable and refuse treatment to people with intellectual disability. I think that can be changed. I think you can do it.

I've got two dental students standing next to me that have confirmed this. They're not being trained to treat people with intellectual disabilities. I think it's unconscionable. I also believe that the myth is that dental is too expensive. You wouldn't purchase medical insurance if it didn't cover eyes, ears, feet, kidneys. Yet we do that with dental, and I think that also should be addressed. Thank you very much.

Senator HARKIN. Thank you, doctor. One more.

AUDIENCE MEMBER. I am a future teacher in special education going to Iowa State University. Having read about No Child Left Behind, it is a fantastic bill if it were not so into test, test, test. We have children in schools that literally cannot keep up because of their intellectual capabilities. It has been shoved into these children's minds that if you do not pass a test, you're stupid, you're dumb, and you're not worth the effort.

We need to change the attitudes, and that can only come from seeing results to—you know, seeing a difference in these children's lives. There are children out there that live out on the street on their own, and I could give you name after name after name, and it's sickening. Please, please get us the funding.

Senator HARKIN. Thank you. Yes.

Mr. LOUPEE. Senator Harkin, my name is Mike Loupee, L-O-U-P-E-E. I teach chemistry at Marshalltown High School, and I'm Kyler's swim coach. Kyler—I wanted to clarify one thing when Kyler talked to you. He competed in the varsity swimming program. He swam over 250 miles every season. He swam in a lane next to All-American swimmers and did everything they did.

Mr. LOUPEE. Kyler, stand up a second. Stand up. Kyler, pull your coat back. Unbutton and pull your coat back. Show everybody how skinny you are. When Kyler came as a freshman, he weighed over 230 pounds. He's now 190, I believe.

Mr. LOUPEE. He lost the weight, kept it off, and he did something that's very rare. He actually listened to his coach. When I told him that he needed to make a lifestyle change, watch what he ate, continue to exercise, and he's done those very things. That was one thing I wanted to say.

The other thing I wanted to make an important point of is in his years on a "regular swim team", Kyler made better men of all of us. What Special Olympics does for those individuals is outstanding, but the way that those people touch our lives is something that we need to do for all of our sakes, not just for our intellectually challenged individuals. Then we'll finish it up with my wife, who has been with Kyler also, has one more statement.

Ms. NELSON-LOUPEE. I'm Rachel Nelson-Loupee, hyphenated. I just wanted to say the Special Olympics is a wonderful thing. We've heard a lot of negative things about special ed and things like that. You need to be proud of yourselves for what you do for your kids, especially Kyler's parents. You guys do an awesome, awesome, awesome job, and I applaud you all, because I don't know if I could, but I hope I could. So thank you very much.

Senator HARKIN. Okay. There's just a couple left. I'm not going to cut anybody off, for crying out loud. Go ahead.

Ms. COLE. My name is June Cole (phonetic) from Albuquerque, New Mexico. I am a school teacher, teach elementary school. My

husband is here with me. He's a retired Marine Corps officer. He currently works for Southwest Airlines. The reason I mentioned that is we're two semi-intelligent people, and yet the system is horribly, horribly difficult to deal with.

We've recently been approved for SSI. Our daughter is 21. We got the SSI from Social Security primarily for Medicaid. Social Security said, "We don't know if you're qualified for Medicaid. Go ask Medicaid." We asked Medicaid. They said, "Why are you here? That's a Social Security issue." So we march between those two government offices, and I'm thinking, "Why can I not understand this?"

But last I want to state long term—our daughter's 21. She has no employment, no housing. She's at home with us, and we don't see any options out there. So I appreciate any and everything that everyone does to help us. Thank you very much.

Senator HARKIN. Thank you.

Dr. BERMAN. Thank you, Senator Harkin. I'm Dr. Paul Berman. I am the founding and global physical director of Special Olympics—Lions Club International Opening Eyes. My question is this. We have over tens of thousands of volunteers who have volunteered to help the athletes all over the United States and all over the world. One of the barriers seems to be malpractice. A lot of senior doctors who are no longer practicing can't volunteer for our program because they don't have malpractice.

A lot of doctors are very reluctant to practice when they have to go through State lines, and they're not sure if their malpractice covers them. Is there any thought by the Federal Government to have doctors who want to volunteer for philanthropic activities for their malpractice to be covered or for that issue so we can get more retired or people who want to do things and not do things just because they don't have malpractice insurance?

Senator HARKIN. Well, I don't know the answer to that question, and I don't know the extent of that. I'm going to ask Tim Shriver if there's any—I don't mean kick the ball down the field or anything, Tim. I just want to know, is this something that maybe we ought to look at?

Mr. SHRIVER. We have had some issues with Steve—I'll kick it over to Steve Corbin.

Mr. CORBIN. Is there anybody here that can catch? I'll kick.

Mr. SHRIVER. Steven Corbin is the local director of Health Athletes. We have had some issues with clinical protocols and certification issues with practitioners.

Mr. CORBIN. Well, the first issue is when we get volunteers from outside of State, even if they do have their malpractice, we do have to deal with the boards and the States allowing our people to volunteer, and we saw that here in Iowa.

But there are literally tens to hundreds of thousands of retired health care providers that could provide this care for free if there was a way of creating a malpractice pool. It would probably be ultra low risk. This would do a lot to create public service, giving back to communities, and really having an impact, I believe.

Senator HARKIN. So the thought would be some kind of a medical malpractice pool—

Mr. CORBIN. Yeah.

Senator HARKIN [continuing]. For those who want to volunteer their services in cases like this. I don't know how we'd define it, but there would have to be some definitional frame for it.

Mr. CORBIN. Right. I think some States have done this for volunteer programs within their States on a limited basis.

Senator HARKIN. Do you know of that? Dr. Novello seems to know something.

Dr. NOVELLO. During September 11 we have the same problem. People from Connecticut and New Jersey wanted to come help in New York, and they were afraid. So we have under the Good Samaritan Rule you're able to amend the malpractice law to be able to cover them and except them from any damages as long as they're doing jobs in good faith. So maybe you can do that for the whole country when we're going to need to have this.

Senator HARKIN. Is this just a law in New York you mean?

Dr. NOVELLO. Anytime that there is a crisis or something, it would be good for the country to have something that allows people to—

Senator HARKIN. You say you have a Good Samaritan law like that?

Dr. NOVELLO. We did that during September 11. Now we are just seeing what is going to happen during the next crisis, but at that time it worked.

Senator HARKIN. Well, maybe we could look at the New York law at what you did.

Dr. NOVELLO. You're always welcome to come to New York when you want good things to happen.

Senator HARKIN. Maybe we could pick up on that and find out if there's something there that we would look at. But that's a good question, and it's obviously a problem and something that needs to be addressed.

Well, thank you all very much. I thank all of our panelists, and many of you have come a long distance. Again in closing, let me just, again, thank Tim Shriver, our CEO to the Special Olympics, and your whole family for all that you've done to bring us this far and for bringing the games to Iowa. Thank all of you for being here. Wonderful testimony.

I want to assure you that my staff and Lee Perselay, who his only job on my staff is disability issues—that's his charge—and Ellen Murray who runs our Appropriations Committee and Adrienne Hallett who was here with us also, they've been taking all this down. Believe me, we're going to focus on a lot of these issues when we come back.

STATEMENTS RECEIVED FOR THE RECORD

We have received several written statements that will be made part of the hearing record.

[The statements follow:]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

INTRODUCTION

Senator Harkin, you have heard from our distinguished panelists about many of the challenges that face people with intellectual disabilities. You have heard Dr.

Shriver, Dr. Novello, Dr. Gerberding and others discuss, in particular, the health issues that face people with intellectual disabilities. Thank you, for the opportunity to add my voice and the voices of the practicing physicians and dentists from across the nation whom I represent, to the voices of the experts to whom you have listened today.

As you close these proceedings and contemplate the actions that will be taken by you and your colleagues, I ask you to think of the following words that were first recorded in ancient Greece but are near to the hearts of every American citizen, especially to those in my home State of the Commonwealth of Kentucky, which adopted the following words as the State Motto—"United we stand, Divided we fall."

These words have been used throughout history to give us strength in times of perilous uncertainty. These words have been used to remind us in such times, that the success of a nation, of a people and of a society is dependent upon us never seeing fit to abandon our brethren. For those who live by that code, there is no greater dishonor, no greater danger to the fabric that binds us all, than to willingly—or even inadvertently—allow any of those who are united with us to fall.

Senator Harkin, for people with intellectual disabilities, this is a time of perilous uncertainty. This is a time in which families, advocates and governments are divided. This is a time in which we, as a people, are undergoing the greatest test of our honor and civility—the protection of one is the protection of all, and the failing of one is the failing of all.

For decades, we have sought to improve the community services that support the ability of people with intellectual disabilities to thrive. We have focused on the rights of people with intellectual disabilities to have a choice—a choice of living environments, a choice of educational options, a choice of being employed. In our efforts to expand the choices for people with intellectual disabilities, however, we have neglected perhaps the most important choice of all—the choice of good health. For most people with intellectual disabilities, there are no choices for quality health services.

As I have heard Dr. Shriver state on many occasions, most people think that people with intellectual disabilities receive better healthcare than the rest of the population. Unfortunately, this could not be further from the truth.

So ignorant are we of the health disparities that exist for people with intellectual disabilities, that in 2004—2 years after the most definitive report in the history of the United States detailing the health disparities experienced by this population was published by Surgeon General David Satcher—a research proposal submitted by a physician to the NIH Office of Minority Health and Health Disparities was summarily rejected because the subject of the research, people with intellectual disabilities, had not been declared as a medically underserved population, and, as such, were not experiencing health disparities.

So ignorant are we of the health disparities that exist for people with intellectual disabilities, that though it has been over 25 years since HRSA devised the formula that determines if a group of people is "medically underserved," this formula has still not been applied to people with intellectual disabilities—despite the fact that infant mortality rates are the highest in the nation for people with intellectual disabilities, despite the fact that only 10 percent of this population will live past the age of 65, despite the fact that nearly one-third of this population lives in poverty and despite the fact that only 2 percent of primary care physicians who treat adults have had more than one hour of training in medical school and one hour of training in residency regarding the care of people with intellectual disabilities.

So ignorant are we of the health disparities that exist for people with intellectual disabilities, that most of the state Medicaid waiver programs designed to support people with intellectual disabilities living in the community, do not contain any provisions for community medical services! The irony, of course, is that the name Medicaid, is derived from the term "Medical Aid."

So ignorant are we of the health disparities that exist for people with intellectual disabilities that we have inadvertently turned our system of health care into systemized health neglect.

Our systemized healthcare neglect of this population has led us to a place where we accept, as a society, in ignorance of reality, that many people with intellectual disabilities will die unnecessarily because of medical conditions that have gone untreated for so long that they fester, spread and ultimately claim the life of the individual. I have personally been witness to, or know of professionals who have been witness to individuals dying due to complications from things as simple as tooth decay and constipation. Do you know how long it takes for tooth decay to claim a life? A very, very long time.

What are our solutions to these problems? They are as irresponsible as they are ineffective and expensive.

Constipation can be cured with a laxative at a cost of about a dollar. Constipation that is neglected for such a period of time that it leads to bowel rupture and peritonitis, will result in emergency room utilization, surgery, intensive care and possibly death at a cost nearing fifty thousand dollars.

Tooth decay can be treated for around two hundred dollars and prevented for nearly nothing. Tooth decay that is neglected for such a period of time that it results in painful dental abscesses which, in turn, result in behavior changes mismanaged by powerfully obtunding medications for behavior control have led to pneumonia, emergency room visits, intensive care and death at a cost of nearly thirty thousand dollars.

I have encountered both of these scenarios and other similar scenarios in just the last 2 years as Executive Director of the American Academy of Developmental Medicine and Dentistry. These two stories, and the many others that I have heard like them, illustrate just how poorly our health care system is addressing the needs of people with intellectual disabilities.

Senator Harkin, I am here as a representative of three organizations: The American Academy of Developmental Medicine and Dentistry, the nation's only organization of physicians and dentists dedicated to improving the quality of healthcare for people with intellectual disabilities; the American Board of Developmental Medicine, a newly formed organization which, like other medical boards, will test and certify the expertise of physicians in the care of people with neurodevelopmental disorders and intellectual disabilities; and, the Underwood and Lee Health Services Center which is currently being expanded, under the leadership of Governor Fletcher and Secretary of Health Birdwhistell, to become the nation's only multidisciplinary clinic which not only provides medical, dental and behavioral services to people with intellectual disabilities living in the community, but also performs clinical research to continually improve services and teaches young doctors how to provide these services. Aside from my responsibilities with these three organizations I have served as an advisor to the President's Committee for People with Intellectual Disabilities, the Surgeon General's Call to Action for People with Disabilities and to numerous state governments and international agencies dedicated to improving the lives of people with intellectual disabilities.

My colleagues and I have traveled the country and the world speaking with physicians, dentists, nurses, optometrists, podiatrists, audiologists, physical therapists, speech therapists, nutritionists, occupational therapists, direct support professionals and other health professionals. We have spoken with people with intellectual disabilities and their families, advocacy groups from all political persuasions and government officials at all levels and in all branches of government. Based on our collective experience as healthcare providers, health educators, health legislators and health advocates, we offer the following advice to consider as you and your colleagues endeavor to provide the nation with the leadership necessary to equalize the disparities that exist:

(1) *Health Professional Education.*—In order for educational efforts to be successful, professional schools must see the value in providing such education. The federal government has considerable influence in the requirements that must be fulfilled in order for schools to receive funding. These requirements should include not only didactic teaching, but also clinical experience in caring for children and adults with intellectual disabilities. Unfortunately, most professional schools do not have access to the knowledge necessary to create sound didactic and clinic curricula in this subject area. Therefore, an effort should be made to partner with academic groups such as the American Academy of Developmental Medicine and Dentistry, the American Academy of Family Physicians and Special Olympics University in order to develop a standard curriculum which can be distributed to the various schools.

Additionally, other professional organizations in other fields, such as the Developmental Disabilities Nurses Association and the National Alliance of Direct Support Professionals should be partnered with to create the standard curricula in their respective fields.

Finally, continuing medical education efforts that utilize low cost, high quality internet-based seminars, such as those being pioneered by Vemics and Exceptional Parent Magazine should be examined as a way of distributing the knowledge of the relatively few health professionals with expertise in this field to the many primary care providers and other health professionals it will take to meet the needs of this population.

(2) *Medicaid Reimbursement.*—For most providers, Medicaid is a losing proposition. In most cases, providers lose money every time they treat a Medicaid patient. In many cases, they lose money faster by treating a Medicaid patient than if they treated no patient at all. This particularly hurts people with intellectual disabilities, 70 percent of whom are on Medicaid, and many of whom require more time and ex-

pertise than the average Medicaid patient. Waiver reimbursements must be increased to a level that are not financially penalizing to physicians, dentists and other providers. Additionally, other Medicaid streams must be made available for centers whose sole mission is the provision of health services to people with intellectual disabilities.

(3) *Service Delivery*.—While it is true that with a relatively small amount of training, many primary care providers could provide services to many people with intellectual disabilities, there is a large segment of people with intellectual disabilities who would be better benefited by the expertise of a doctor whose specialty is in the care of people with intellectual disabilities. As such, model programs such as the Underwood and Lee Health Services Center, which can serve as a community center of health expertise, should be replicated across the country to not only provide medical and dental services to the more medically complex patients with intellectual disabilities but to also teach other doctors how to care for these patients as well.

(4) *Health Promotion and Prevention*.—There are very few universal truths in medicine; however, this is one: It is always more cost efficient and better for an individual's quality of life to prevent disease from occurring than to treat disease after it has occurred. With the alarming rates of obesity, periodontal disease and other preventable diseases in this population, effective methods of health promotion must be developed and widely implemented. These programs may range from producing health promotion literature and experiences, to providing individuals, families, groups homes and intermediate care facilities with financial incentive to eliminate these and other preventable diseases.

(5) *Research*.—Meaningful, clinically relevant research must continually be funded and propagated. While myriad psychosocial studies have been performed to enhance communication and provider sensitivity, relatively few studies have been performed that give providers the biomedically sound tools to treat the conditions associated with the thousands of recognized causes of intellectual disabilities.

(6) *Education Loan Forgiveness*.—Many physicians and dentists are willing to work with underserved populations if they can afford to do so. However, with the high price of medical and dental education, doctors who graduate from school are often saddled with student loan debts of between \$100,000 and \$300,000. The financial reality of this debt discourages doctors from providing care to patients who can only provide marginal payment for services. Reducing debt load would free up doctors from their own financial barriers to providing care to this population. Such a loan forgiveness program should be extended to physicians, dentists and other indebted health professionals who devote a large percentage of their professional careers, either in service or research, to providing care for people with intellectual disabilities.

(7) *Medically Underserved Population Designation*.—Congress should declare, definitively, that people with neurodevelopmental disorders and intellectual disabilities are a "Medically Underserved Population." Programs are currently in place that provide education loan forgiveness and research grants to professionals working with "Medically Underserved Populations." When this is declaration is made, it should be made for the entire population of people with neurodevelopmental disorders and intellectual disabilities and not just for certain geographical areas, which has been the traditional (although not mandated) method by which underserved populations have been defined.

(8) *Focus on the Lifespan*.—Children with intellectual disabilities grow to become adults with intellectual disabilities. There are literally hundreds of organizations that focus on the well-being of children with disabilities. This work is very important, but it is a disservice to both these organizations and to the individuals they serve to discontinue programs for people with intellectual disabilities simply because the patients attain the age of eighteen. It is both poor health practice and poor public policy to continue a system that provides ample opportunity for health maintenance until a certain age, only to see all of the progress made in that time obliterated within a few short years by systemized health neglect.

Senator Harkin, in closing, I would like to sincerely thank you for taking the time to listen to those of us whose passion is improving the lives of people with intellectual disabilities. I would like to thank you for your vision, for your leadership and most of all for giving us a reason to stand here today, united with our fellow American citizens with intellectual disabilities.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION ON MENTAL RETARDATION

The mission of the American Association on Mental Retardation (AAMR) is to promote progressive policies, sound research, effective practices, and universal human

rights for people with intellectual and developmental disabilities. The AAMR has been the leading professional organization focusing on the welfare and needs of persons with intellectual and developmental disabilities in this country for the past 130 years. This organization is recognized world-wide for its contributions to the field, most notably for its classification manual, *Mental Retardation: Definition, Classification, and Systems of Supports*, now in its 10th edition. The next edition will be altered to reflect intellectual and developmental disabilities as a more appropriate term. Additional areas of expertise for this organization are the development and dissemination of the supports paradigm that recognizes an individual's unique personal strengths and identifies needed supports, with a focus on health. The AAMR recognizes that good health includes physical, emotional, spiritual and environmental well-being. Recent efforts to address the health care needs of persons with intellectual and developmental disabilities and the effects of the environment on this population are noteworthy.

Senator Tom Harkin has long supported efforts to improve the health of Americans by authoring and supporting legislation that would promote healthy living, especially through prevention measures. In this hearing, he is focusing on a group of Americans with intellectual and developmental disabilities that has long been disenfranchised and often not considered when disparities in health care are discussed. The AAMR supports Senator Harkin's efforts to promote adequate, accessible, and appropriate health care for persons with intellectual and developmental disabilities.

In 2005, AAMR published *Health Promotion for Persons with Intellectual and Developmental Disabilities*. This groundbreaking book, an outcome of a national conference supported by the Centers for Disease and Prevention, Special Olympics, and the Agency for Healthcare Research and Quality (AHRQ), highlighted the available research on the topics of hypertension, obesity, swallowing dysfunction, epilepsy, mental health, physical activity and fitness, access to health care, women's health, violence, case management, complementary and alternative medicine, substance abuse and tobacco use, and secondary conditions as they relate to persons with intellectual and developmental disabilities. Nationally recognized researchers and clinicians in the field authored these chapters, in which they identified the state-of-the-science on these topics.

Overall, these authors found that the available research was often conducted using nonempirical levels of research evidence such as anecdotal reports, case studies, and expert opinions. Only in the areas of epilepsy, mental health, and physical activity and fitness were there higher levels of randomized and controlled trials. It is imperative that efforts be made on the federal level to set aside funding for empirical research studies on areas concerning health promotion for persons with intellectual and developmental disabilities that not only involve such individuals as participants, but also as active partners in the conduct of the research. Specifically, these authors found that individuals with intellectual and developmental disabilities, depending on their diagnosis, may be at higher risk for hypertension, obesity, swallowing dysfunction, seizures, mental health conditions, and substance abuse and/or tobacco use. Such individuals may also be more vulnerable to acts of violence against them. Based on their diagnosis, individuals with intellectual and developmental disabilities are also at risk for the development of secondary conditions, such as heart conditions, motor problems, bowel and bladder conditions, and sensory problems. As a result, it is important that when guidelines are established for health conditions such as hypertension (e.g., *Guide to Clinical Preventive Services* by the U.S. Preventive Services Task Force), the specific evidence and interventions needed to assure optimal health for persons with intellectual and developmental disabilities be included in these guidelines.

An important chapter in this book was that on access to care for this population. This essential disparity has been highlighted by the Special Olympics and the current and past surgeon generals. Current research is focused on the areas of access to health care, access to insurance, satisfactions with health care, changes associated with deinstitutionalization, quality of health care, unmet health needs, health care barriers (individual, systemic, and financial), access to dental care (including access to preventive dental care, access to dentists, quality of dental care, unmet dental care needs, and barriers to dental care), as well as barriers to providing medical or dental care. The authors suggested that the following solutions are needed:

- Health care professionals, not just physicians and dentists, needed additional didactic and clinical experience in the care of persons with intellectual and developmental disabilities.
- Improvements are necessary in the communication between professionals, professionals and the individual, and professionals and the individual's family for better continuity of care.

- Health records that are regularly updated and readily available to professionals and family members are a necessity. The chaos after Hurricane Katrina emphasized such a need because many nonverbal people were relocated, professionals had no means of knowing their diagnosis, much less the medications and treatments that had been regularly provided.
- Increased reimbursement to health care providers for the care of persons with intellectual and developmental disabilities is essential because more time and additional equipment are necessary to accommodate their physical and emotional needs.
- Individuals with intellectual and developmental disabilities require access to appropriate and affordable health insurance.
- Health literacy should be a required skill for persons with intellectual and developmental disabilities. When necessary, caregivers should supplement or support the person with intellectual and developmental disabilities to gain as much health information as possible and as appropriate.
- Caregivers of persons with intellectual and developmental disabilities also require knowledge of the health care system and ways in which they can best navigate the system to obtain the services, knowledge, and supports they need for individuals with intellectual and developmental disabilities to have optimal health over the course of their lives.

This list is by no means complete, but it provides a look at the areas in which America needs to improve the health care system so that individuals with intellectual and developmental disabilities can achieve accessible, affordable, and appropriate health care. To this end, the members of the AAMR Health and Wellness Action Group have developed the AAMR Declaration on Health Parity for Persons with Intellectual and Developmental Disabilities which will be posted on the AAMR website in the coming months. This document succinctly summarizes the points made in this testimony and concludes that all persons with intellectual and developmental disabilities should have:

- An ongoing plan for health that crosses all settings and extends throughout a person's life.
 - A medical home.
 - A barrier-free access to health care.
 - Preventive health screening and assessments for common chronic conditions and other conditions associated with aging in the general population.
 - Opportunities for choice and self-determination in all areas that affect health and available support as needed when making difficult choices about health.
- In addition, systems of health care should achieve:
- Appropriate referrals to qualified and knowledgeable health care providers.
 - Multidisciplinary care.
 - Reduction in health disparities at all levels.
 - Reimbursement for health services and supports aimed at preventive care and healthy living.
 - The provision of and funding for all daily health services and supports needed in addition to those services and supports needed for the specific diagnosis.
 - The availability and requirement of didactic and clinical instruction in the care of persons with intellectual and developmental disabilities for all health care professionals prior to licensure and in continuing professional development.
 - Timely dissemination of evidence-based practices concerning the care of persons with intellectual and developmental disabilities.
 - Adequate available funding for continued research into preventive health topics and best practices for healthy living.

AAMR appreciates the opportunity to present their concern that increased efforts are needed to improve the health disparities present for persons with intellectual and developmental disabilities. We have presented our recent efforts in this area and extend our support to Senator Harkin. We welcome the opportunity to continue to work with our colleagues in the legislature and in the professional and self-advocacy spheres to create health parity for this important segment of our society.

PREPARED STATEMENT OF ROBERTA BLOMSTER

Thank you Mister Chair and members of the Committee. I wish that I could testify today, but with a lot of testimony from the list of witnesses and not a lot of time, I'm proud to submit my written testimony for the Hearing Record.

Hello, my name is Roberta Blomster and I am a Special Olympics athlete from Minnesota. I compete in Bowling & Golf. I am a certified Special Olympics' Athletics Coach, having just finished my third year. I compete in Sled Dog Racing (which is

not yet a S.O. sport, I'm working on that). I am a Special Olympics Global Messenger, a nationally trained Athlete Leader, and a Trainer. I am also involved with Self-Advocacy-helping to get the Modernization of Language, the Voter Rights and the Advocating Change Together bills to become law and serving on the Voting Machines Options Working Group in Minnesota, and getting involved with H.R. 4704. I am currently serving a 3-year term on the Minnesota Governor's Council on Developmental Disabilities. I'm a member of the Chaska Area Jaycees in Chaska, Minnesota. I have attended The Arc of Minnesota's Disability Day at the Capitol, and the 2006 Special Olympics Capitol Hill Day in Washington, D.C. I am certified in CPR/First Aid, which is extremely helpful when I'm coaching Athletics. I am proud to be the Athletes and Government Columnist for Special Olympics Incorporated's Quarterly Magazine, Spirit.

My experience with Healthy Athletes has been eye opening! I went through all of the programs at the 1999 Special Olympics World Summer Games in North Carolina and that made me realize that these programs are important to Special Olympics athletes worldwide. For many of the world's athletes, this is their only contact with medical, dental and eye services. Then Special Olympics Minnesota began to add Opening Eyes and Special Smiles, followed by Healthy Hearing, FUNFitness, Fit Feet, and Health Promotion. This year, they added MedFest to the roster. All of these programs are done at their State Summer Games over at the University of Minnesota and separately at the other State Competitions that Special Olympics Minnesota puts on. I had gone through Opening Eyes, Healthy Hearing and Special Smiles at a previous SOMN State Summer Games. I went through Opening Eyes, Special Smiles, Healthy Hearing, Fit Feet, FUNFitness, and Health Promotion, which was a Diabetes screening at the 2005 Special Olympics Minnesota State Summer Games, followed by going through FUNFitness again at the 2005 Special Olympics Minnesota Fall Sports Festival Golf Tourney. At the 2006 Special Olympics Minnesota State Summer Games, I had gone through FUNFitness, Health Promotion, which was a Nutrition Seminar; and the Diabetes screening (which is now separate). Each year we have athletes getting new glasses as needed. We have had athletes get major dental work done through this program. In Minnesota it is very difficult to find a dentist if you are on Medicaid. Very few dentists remain in the state program, stating they cannot afford to do the work at the price the State is willing to pay.

Healthy Athletes is vital, especially to the Special Olympics athletes who are under Medicaid in this country and who will have to face the steep cuts in the Deficit Reduction Act of 2005. I am not only on Medicaid, but Medicare also. I know how the Health Care thing works—Federal is primary and State is secondary, that's how it works. But I know that this wonderful initiative is helping me to realize that people with intellectual disabilities do need to have access to health care just like everybody else. It is not fair that the world's largest disability population is denied the right to accessible and affordable health care, but Healthy Athletes is one solution for people with intellectual disabilities worldwide who compete in Special Olympics, since the screenings are free.

I have run into a problem with the plan that I am on for Medicare Part D, that of course being Humana. They have refused to cover the Epilepsy medication that I have been on since the day that I was diagnosed, Phenobarbital. This situation has not only infuriated my mom, but also myself. My doctor, Joseph Moriarity, believes that if the medicine is still working for me, there is no need for me to go to another medication. This medication was covered when I was only on Medicaid, but it's not fair that Humana is refusing to cover a very important medication that I am taking. The Medicare Part D Program is very confusing. Trying to figure out which plan to use is impossible for my peers and myself. My mom, who is an insurance agent, is totally confused by it, so how are we supposed to make intelligent decisions about this program. I believe that there should be a drug list for all providers, not every provider making up their own.

The other issue with Medicare Part D, is that if someone is living in a group or nursing home they are only allowed around \$90 per month for person items, including their drug co-pays. Under the Medicaid plan we had a cap of \$20 medical co-pays per month from out of our money. Now there are no limits. Many may not have money to cover their medications. Are we going to have to go un-medicated? What happens if we hit the middle level when there is no coverage? I think Medicare Part D needs some serious looking into the impact on our population.

Thank you again Mister chair and members of the committee for allowing my voice to be heard on such an important topic.

PREPARED STATEMENT OF THE AMERICAN FEDERATION OF TEACHERS

Chairman Harkin and other members of the committee, on behalf the more than 1.3 million members of the American Federation of Teachers, I am pleased to offer my views on the importance of creating paths for people with intellectual disabilities to lead meaningful lives that enrich our nation.

Chairman Harkin, no remarks on the issue can begin without acknowledging and commending the way your long history as a tireless advocate for people with disabilities has improved the lives of countless children and families. The AFT shares your commitment to improving the lives of the students our members serve, especially the students with significant intellectual disabilities.

Every day in schools from Quincy, Illinois, just across the border, to Corpus Christi, Texas, AFT members teach students with disabilities, help them learn basic self care skills, nurture these children, and so much more. Our work aims to help students succeed in the classroom and in life. Preparing young people with intellectual disabilities for success in life is one of the common objectives of AFT members and groups like the Special Olympics, a truly noble institution.

As an organization, the AFT reflects these sentiments. Outside the classroom, our union has provided financial support to the Special Olympics, partnered with the organization to share the "So Get Into It" service learning curriculum with our members, featured the program in our flagship publication *American Teacher*, and asked our state and local leaders to partner with the Special Olympics at the local level.

We've already seen the response. I am proud to say that in my home state of New York, our AFT affiliate, the New York State United Teachers, has been very active for years with the Special Olympics. Our longtime president, Tom Hobart, as well as several officers, have served on the state board of directors. A number of our members work as volunteers and we have even helped with fundraising, where NYSUT auctioned off a pair of 2002 Yankees World Series tickets for more than \$3,000.

In the classroom, AFT members are unyielding in their efforts to improve the lives of all students, including the over 6 million with disabilities and the hundreds of thousands of students with intellectual disabilities. And we are seeing results.

The Individuals with Disabilities Education Improvement Act of 2004 focuses attention on helping students transition into life after school, preparing some students for the workplace and some for volunteer activities and other callings.

Yet, we know that there is still far more work to do to raise graduation rates for disabled students and offer them a chance to succeed in whatever they pursue. Along with supporters like you, Senator Harkin and organizations like the Special Olympics, we stand ready to run this race today—and in the future.

PREPARED STATEMENT OF DR. GARY N. SIPERSTEIN

As a researcher in the field of disabilities for more than 40 years, I have witnessed the evolution of policies and practices in the United States for people with intellectual disabilities (ID). Early on in my career, children with intellectual disabilities (then known as mental retardation) were physically segregated from their peers without disabilities. Teachers were hesitant about teaching students with special needs in their regular classrooms, and parents expected that the inclusion of students with intellectual disabilities would impede the academic and social achievements of their own children. Over the years, a myriad of research studies demonstrated that children did hold negative attitudes toward their peers with intellectual disabilities, and in fact socially rejected and isolated these peers (Johnson, 1950; Baldwin, 1958; Hughes et al, 1999; Siperstein & Bak, 1985b; Siperstein, Bak & O'Keefe, 1988; Wolfberg, Zercher, & Lieber, 1999; McDougal et al., 2004).

The United States has made important progress in promoting the rights and inclusion of people with disabilities through major legislative acts such as Public Law 94-142, ADA (1990), and the recent reauthorization of IDEA (2004). As a result, buildings are now accessible to people with disabilities, classrooms are now open to all learners, and the potential for employment exists for all groups. However, people with intellectual disabilities continually face significant barriers, the most significant of which is public attitudes.

The Center for Social Development and Education (CSDE) at the University of Massachusetts Boston has a long history of conducting research on the social development of children with disabilities, with a focus on peer attitudes and social acceptance. In 2001, CSDE and Special Olympics entered into a collaborative research partnership and created the Regional Collaborating Center (RCC), with the purpose of carrying out research on issues related to people with intellectual disabilities. The

RCC's work bolsters the strategic position of Special Olympics in "changing attitudes and changing the world." At the RCC, we strongly believe that public attitudes can open and close doors to society for individuals with intellectual disabilities, thereby affecting their dignity, self-esteem, and self-worth.

The first initiative of the RCC was to document the global attitudes toward people with intellectual disabilities. To do this, we have been engaged in a 5-year program carrying out a multinational survey that presently consists of eleven countries from every region of the world. As part of this study, a national survey was conducted in the United States. The results of this national survey provide evidence that the progress that we have made in disability policy in this country has not extended far enough. For example, despite the visibility of people with disabilities, and the increase in services available to people with disabilities, the American public perceives people with intellectual disabilities as having limited capability to be self-sufficient, live independently in the community, work in competitive employment, and learn in regular classrooms. More specifically, while most of the public perceive people with ID as capable of simple skills like washing and dressing (70 percent), and engaging in simple conversation (88 percent), many fewer perceive people with ID as capable of complex skills like handling money (45 percent) or handling emergencies (28 percent). This suggests that while the majority of people with intellectual disabilities are mildly impaired (85 percent), the American public underestimates their abilities and perceives them to be moderately to severely impaired.

The most significant and surprising finding from this survey is that after years of mandated inclusion, the American public continues to support the segregation of students with special learning needs. In fact, two-thirds of the public (64 percent) in the United States believe that children with intellectual disabilities should be taught in separate, special schools. This support for special schools mirrors the beliefs of the public in ten other countries, including Brazil, China, Russia, and South Africa. While beliefs for separate schooling are understandable in these other countries, where disability rights are still emerging, it is striking that such beliefs still exist in the United States. It is possible that Americans do not believe that the current education system can handle inclusion, as more than 40 percent of the public expect inclusion to impede the learning of other students, and more than 70 percent believe that there is a lack of sufficient resources for inclusion, including properly trained teachers.

Special Olympics and CSDE recognize that youth play an important role in the success of inclusion and in achieving real societal attitude change, as they are our future community members and policy leaders. Therefore, in 2004, the RCC expanded its global knowledge base of public attitudes toward people with ID by examining the attitudes of youth worldwide. This youth initiative started with more than 5,000 youth from the United States and more than 4,000 youth from Japan, and continues today in Europe and China.

In the United States, youth have grown up with inclusion as a standard practice in their schools. As a result there is an expectation that major improvements have occurred in youth attitudes toward people with intellectual disabilities when compared to the attitudes of youth in the 1960s and 1970s. However, our national survey of 5,800 youth suggests differently. In fact, the findings suggest that the perception youth hold of their peers with intellectual disabilities today is no different than the perceptions of youth 30 years ago (Gottlieb & Siperstein, 1976; Siperstein & Bak, 1980; 1985b). More specifically, youth perceive students with intellectual disabilities as moderately to severely impaired, and not capable of tasks that the average adolescent is able to carry out (e.g. choose their own clothes (63 percent), handle money (38 percent)). Further, while youth are much more supportive of the inclusion of students with intellectual disabilities than adults in the United States, they are still not fully supportive. For example, while most youth believe that students with ID can participate in non-academic classes like gym and art (77 percent), much fewer believe students with ID can take part in classes like math and English (40 percent).

Since the earliest days of inclusion, the most significant concern for students with intellectual disabilities has been the challenge of engaging in meaningful social interactions and relationships with their peers without disabilities. One of the major findings of the Youth Attitude Study is that youth are willing to interact with their peers with ID in the structured school setting, where roles and norms are clearly defined, but they do not extend their interactions beyond the schoolyard. For example, most youth indicate that they would lend a student with ID a pencil (91 percent) or say hello to the student in the hall (81 percent). However, outside of school, few youth in the United States would invite a student with ID to their house (35 percent), or talk with a student with ID about personal things (27 percent). This lack of social interaction outside of school is not surprising given that only 10 per-

cent of youth in the U.S. report having a friend with ID. These findings make clear that not much has changed in the past decades. Youth still do not view their peers with intellectual disabilities as potential friends (Zetlin & Murtaugh, 1988; Siperstein, Leffert, & Wenz-Gross, 1997; Siperstein, Norins, & Mohler 2006).

The Special Olympics movement clearly is a driving force in educating the public about intellectual disabilities as they work tirelessly to see that people with intellectual disabilities are fully accepted into society. With the knowledge gained through our research initiatives, the UMass Boston/Special Olympics RCC is working to identify ways to create lasting change in the public's attitudes toward individuals with intellectual disabilities. One approach to changing attitudes is through direct involvement in Special Olympics. In our survey of adults, we found that those with more involvement in Special Olympics are significantly more positive in their perceptions of people with intellectual disabilities and their beliefs about inclusion in school. Based on this finding, the RCC developed the Special Olympics Gradient as a way to determine how involvement in Special Olympics impacts attitudes toward individuals with intellectual disabilities. In our national survey of adult attitudes in the United States, those individuals with a lot of involvement in Special Olympics are more likely to believe in inclusion than those with little or no involvement in Special Olympics. This Gradient is strong evidence that Special Olympics as a movement can have a significant impact on attitudes towards individuals with intellectual disabilities.

Despite years of policies and legislation enacted to guarantee the rights of individuals with disabilities, and the movement in our society to be accepting and tolerant of diversity, we as a country have been slow to extend this acceptance to people with intellectual disabilities. As is evident from the results of our adult and youth surveys, there is a lack of support for full inclusion, suggesting that there is more work to be done if we are to ensure the acceptance of individuals with intellectual disabilities in our society. We need to expand our conception of diversity to include individuals with intellectual disabilities. We need to provide more opportunities for youth and adults to see the achievements of peers with intellectual disabilities, with the recognition that difference is okay. We need to bring about greater awareness about the educational, social, recreational, housing, and employment needs of people with intellectual disabilities. In sum, we need to recognize the value that people with intellectual disabilities can contribute to the social, cultural, and economic fabric of society.

REFERENCES

- Baldwin, W.K. (1958). The social position of the educable mentally retarded child in the regular grades in the public schools. *Exceptional Children*, 25, 106–108, 112.
- Gottlieb, J., & Siperstein, G.N. (1976). Attitudes toward mentally retarded persons: Effects of attitude referent specificity. *American Journal of Mental Deficiency*, 76, 412–417.
- Hughes, C., Rodi, M.S., Lorden, S.W., Pitkin, S.E., Derer, K.R. et al. (1999). Social interactions of high school students with mental retardation and their general education peers. *American Journal of Mental Retardation*, 104, 533–544.
- Johnson, G.O. (1950). A study of the social position of mentally-handicapped children in the regular grades. *American Educational Research Journal*, 16, 161–167.
- McDougal, J., DeWit, D.J., King, G., Miller, L.T., & Killip, S. (2004). High school-aged youths' attitudes toward their peers with disabilities: The role of school and student interpersonal factors. *International Journal of Disability, Development, and Education*, 51, 287–313.
- Siperstein, G.N., & Bak, J.J. (1985a). Effects of social behavior on children's attitudes toward their mildly and moderately mentally retarded peers. *American Journal of Mental Deficiency*, 90, 319–327.
- Siperstein, G.N., & Bak, J.J. (1985b). Understanding factors that affect children's attitudes toward mentally retarded peers. In C.J. Meisel (Ed.) *Mainstreaming handicapped children: Outcomes, controversies, and new discoveries* (pp. 55–75), Hillsdale, NJ: Lawrence Erlbaum Associates.
- Siperstein, G.N., Bak, J.J., & O'Keefe, P. (1988). Relationships between children's attitudes toward and their social acceptance of mentally retarded peers. *American Journal of Mental Deficiency*, 93, 24–27.
- Siperstein, G.N., Leffert, J.S., & Wenz-Gross, M. (1997). The quality of friendships between children with and without mental retardation. *American Journal of Mental Retardation*, 102, 55–70.
- Siperstein, G.N., Norins, J. & Mohler, A. (2006). Social Acceptance and Attitude Change: Fifty Years of Research. In J.W. Jacobson & J.A. Mulick (Eds.), *Handbook of Intellectual and Developmental Disabilities*. New York: Kluwer/Plenum.

Wolfberg, P.J., Zercher, C., & Lieber, J. (1999). "Can I play with you?" Peer culture in inclusive preschool programs. *Journal of the Association for Persons with Severe Handicaps*, 24, 69–84.

Zetlin, A.G., & Murtaugh, M. (1988). Friendship patterns of mildly learning handicapped and nonhandicapped high school students. *American Journal on Mental Retardation*, 92, 447–454.

CONCLUSION OF HEARING

Senator HARKIN. Thank you all very much for being here. That concludes our hearing.

[Whereupon, at 3:42 p.m., Sunday, July 2, the hearing was concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

○