

**THE ADA AND OLMSTEAD ENFORCEMENT:  
ENSURING COMMUNITY OPPORTUNITIES  
FOR INDIVIDUALS WITH DISABILITIES**

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**HEARING**  
OF THE  
**COMMITTEE ON HEALTH, EDUCATION,  
LABOR, AND PENSIONS**  
**UNITED STATES SENATE**  
**ONE HUNDRED ELEVENTH CONGRESS**

SECOND SESSION

ON

EXAMINING THE AMERICANS WITH DISABILITIES ACT (ADA) AND  
OLMSTEAD ENFORCEMENT, FOCUSING ON ENSURING COMMUNITY  
OPPORTUNITIES FOR INDIVIDUALS WITH DISABILITIES

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JUNE 22, 2010

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**TUESDAY, JUNE 22, 2010**

U.S. SENATE,  
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,  
*Washington, DC.*

The committee met, pursuant to notice, at 2:35 p.m., in Room SD-430, Dirksen Senate Office Building, Tom Harkin, chairman of the committee presiding.

Present: Senators Harkin, Casey, Hagan, Merkley, Franken, and Enzi.

OPENING STATEMENT OF SENATOR HARKIN

The CHAIRMAN. The committee on Health, Education, Labor, and Pensions will come to order.

Eleven years ago today, the U.S. Supreme Court decided *Olmstead v. L.C.*, a landmark case on the rights of individuals with significant disabilities to receive their necessary services and supports in the community rather than in a nursing home or in another institution. The *Olmstead* decision was a critical step forward for our Nation, articulating one of the most fundamental rights for all Americans with disabilities—having the choice to live independently.

The *Olmstead* case involved two women with disabilities who lived in the Georgia State Institution for Individuals with Mental Illness. Although treatment professionals eventually concluded that each woman was capable of living in a community-based program, both remained institutionalized. The women filed suit, requesting that they be allowed to move into their own homes in the community, and eventually the case wound its way up to the U.S. Supreme Court.

In the Americans with Disabilities Act in 1990, we described the isolation and segregation of individuals with disabilities as a serious and pervasive form of discrimination. In Title II of the ADA, which proscribes discrimination in the provision of public services, we specified that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or denied the benefits of a public entity's services, programs, or activities.

In addition, we authorized the Justice Department to issue regulations implementing title II's discrimination proscription. One such regulation was the so-called "integration mandate," which re-

quires a public entity to administer programs in the most integrated setting appropriate to the needs of individuals with disabilities. Simply stated, this means a setting which enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.

To accomplish this, public entities are required to make reasonable modifications in their policies, practices, and procedures. In *Olmstead*, the court held that the unnecessary institutionalization of individuals with disabilities constitutes discrimination and that the two women must be provided community-based options. In reaching this decision, the court said:

“Recognizing that unjustified institutional isolation of persons with disabilities is a form of discrimination that reflects two evident judgments: First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.

“Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

The *Olmstead* decision challenges Federal, State, and local governments to develop more community-based opportunities for individuals with disabilities. I've worked hard in Congress over those years to increase the availability of home and community-based services, first through the Money Follows the Person program, now the Community First Choice Option.

To date 30 States have been awarded grants under the Money Follows the Person program in order to transition individuals from institutions. In the new comprehensive health reform law, this program is extended through 2016 and its eligibility is expanded.

In addition, in the new health care bill, beginning in October 2011 the Community First Choice Option kicks in, the components of which are really the Community Choice Act. States that select it will receive enhanced Federal matching funds. Specifically, the Community First Choice Option will cover the provision of personal care services to help with the activities of daily living such as dressing, bathing, grooming, and eating that allow people to be able to live independently.

On this score, I always tell the story about my nephew Kelly, who became paraplegic while serving in the U.S. Navy. Again, because he was in the military all of his disability functions are paid for by the Veterans Administration. So the VA pays for his attendant services. He lives by himself in his own home, drives his own van. But his attendant services on a daily basis allows him to get up in the morning, go to work, operate a small business, pay taxes, and be a fully contributing member of our society, plus having those contacts and social contacts and interaction that so many of us just take for granted in our daily lives.

Community-based services and supports allow people to lead these independent lives and have these jobs, and participate in the community. Many will become taxpayers. Many will participate in civic life. But all will have a chance to make their own choices and govern their own lives.

Today we have gathered a number of distinguished witnesses from the Department of Justice and CMS, as well as disability advocates who have been in the forefront of making *Olmstead* a reality. I will introduce our first panel, but first I'll yield to Senator Enzi for his opening statement.

#### OPENING STATEMENT OF SENATOR ENZI

Senator ENZI. Thank you, Mr. Chairman, and I want to thank you for your leadership on this important issue and all of the issues that deal with Americans with Disabilities. You've been a champion on that for decades and were one of the prime movers on this one before.

I'd also like to thank the witnesses for taking time out of their schedules to be with us. It's a pleasure to welcome all of you to our hearing.

Today's hearing recognizes an important event that took place 11 years ago today as, as the chairman mentioned, on June 22, 1999, the U.S. Supreme Court ruled in the *Olmstead* decision, which requires that States must provide individuals with disabilities with community-based long-term care services and transfer people into such settings when a State treatment professional has determined such an environment is appropriate, the community placement is not opposed by the individual, and the placement can be reasonably accommodated.

The *Olmstead* decision, as it is known, was a landmark that has helped to reshape years of policy in which more costly institutional care was the norm and not helpful. Today we will be discussing this important decision and also where we are today in our efforts to implement it.

Shortly after the court issued its ruling, President Bush announced the New Freedom Initiative as part of a nationwide effort to remove barriers to community living for people with disabilities. On June 18, 2001, President Bush also issued Executive Order 13217, "Community-Based Alternatives for Individuals with Disabilities." The order called upon the Federal Government to assist States and localities so the U.S. Supreme Court's decision could be implemented swiftly and without delay.

Several agencies, including the Department of Justice and the Department of Health and Human Services, were required to work with the States to help them determine how well they were complying with the *Olmstead* decision and develop work plans to provide services to qualified individuals with disabilities in the most integrated settings. The Departments of Justice and Health and Human Services were also charged with enforcing Title II of the Americans With Disabilities Act and investigating and resolving complaints filed on behalf of individuals who had alleged that they had been victims of unjustified institutionalization.

In June 2009, President Obama announced the Year of Community Living to mark the 10th anniversary of the *Olmstead* decision. Shortly thereafter, the Department of Health and Human Services announced the Community Living Initiative, which includes implementing solutions that address barriers to community living for individuals with disabilities and older Americans.

I look forward to hearing from witnesses from the Department of Justice and from the Department of Health and Human Services, specifically the Centers for Medicare and Medicaid Services, and learning more about what's working and what needs to be improved as States across the Nation work to ensure that the requirements of the *Olmstead* decision are met.

More important than any bureaucracy, the decision is about helping people so they can live where they want to live. As previous HELP hearings have highlighted, many Americans do not have the resources necessary to pay out-of-pocket for long-term care in an institution. According to the Congressional Budget Office, fewer than 7 percent of seniors have annual incomes equal to or greater than the annual cost of a nursing home stay.

Even more important, most Americans do not want to live in nursing homes and other institutions. When speaking with seniors and those with long-term care needs in my home State of Wyoming, one thing I often hear is that they would rather stay in the community than live in a nursing home or other institution.

Not only is the community the preferred living option among Americans, it's also less costly. The Amerigroup Corporation reports being able to provide services for three people living in the community for the cost of one person living in a nursing home. They also report that the Texas Health and Human Services Commission has concluded that community-based services cut health care and long-term care costs by 6.5 percent.

Less costly, community-based services and supports are being actively pursued and funded through Aging and Disability Resource Center programs which were authorized by the Older Americans Act and the Centers for Medicare and Medicaid Services' Money Follows the Person, MFP, demonstration program, as well as by Medicaid Infrastructure Grants. Additionally, Wyoming is using the Green House Project as a model for community-based service delivery. The Green House Project has taken the next step in de-institutionalizing skilled nursing care by moving care into real neighborhoods and small towns across rural America. This model reduces the reliance on costly institutional care and provides community-based options and services in the neighborhoods where beneficiaries and their families live.

I hope this hearing will make it clear that we need to think more creatively and figure out ways in which all Americans can access community services and receive the support they need to lead more rewarding and fulfilling lives in the community.

Again, I want to thank the witnesses for their participation and I want to congratulate and thank the chairman for his continued active, constant interest in Americans with Disabilities. I look forward to the testimony.

The CHAIRMAN. I thank you very much, Senator Enzi, for those kind words, and thank you for all of your willingness to work together on these issues. This truly has been a very bipartisan issue. From the ADA on, we have done everything we can to make this strictly bipartisan, the ADA Amendments Act that we worked on together, that was signed in the Bush administration, the previous administration, that we got passed. So it always has been a very strong bipartisan effort and I appreciate that.



Well, we have two panels today. Our first panel is, Mr. Thomas Perez. Mr. Perez is the Assistant Attorney General for the Civil Rights Division at the U.S. Department of Justice. He's spent his entire career in public service, first as a career attorney at the Civil Rights Division, then as Assistant Attorney General for Civil Rights at the Justice Department, and then later as Director of the Office for Civil Rights at the U.S. Department of Health and Human Services.

I also note that he served as Special Counsel to the late Senator Edward Kennedy, serving as Senator Kennedy's principal adviser on civil rights, criminal justice, and constitutional issues. Mr. Perez is certainly no stranger to this committee here.

Mr. Perez received his master's degree from Brown University and a master's of public policy from the J.F. Kennedy School of Government, and a Juris Doctor from Harvard Law School in 1987.

Joining Mr. Perez on our first panel is Cindy Mann. Ms. Mann is Director of the Center for Medicaid and State Operations, which is part of the Centers for Medicare and Medicaid Services, CMS as we call it. She most recently served as a research professor and Executive Director of the Center for Children and Families at Georgetown University's Health Policy Institute.

She has also had extensive State-level experience, having worked on health care, welfare, and public finance issues in Massachusetts, Rhode Island, and New York. Ms. Mann received her law degree from New York University School of Law.

We welcome you here. Thank you for being here on our panel. Again, as you know, your statements will be made a part of the record in their entirety, and we welcome you to make whatever comments you want to make. Try to keep it at 5, 6, or 7 minutes, and then we can engage in a discussion.

So Mr. Perez, first of all we'll start with you. Welcome again back to the committee. It's always good to see you, and thank you for all your good work you do on behalf of people with disabilities.

**STATEMENT OF THOMAS E. PEREZ, ASSISTANT ATTORNEY GENERAL, CIVIL RIGHTS DIVISION, U.S. DEPARTMENT OF JUSTICE**

Mr. PEREZ. Thank you, Mr. Chairman. It's always a pleasure to be here. Senator Enzi, Ranking Member, thank you for your leadership on this issue. Indeed, disability rights has always been a bipartisan issue in this Congress and in this country. The Attorney General looks forward to celebrating the 20th anniversary of the ADA with former Attorney General Thornburg to mark the bipartisan history of the Department.

Eleven years ago when the decision came down, I was the Director of the Office for Civil Rights at the Department of Health and Human Services, and in that capacity I had the privilege of serving as one of Secretary Shalala's point people on *Olmstead*. We had hoped that the *Olmstead* decision would be more or less the Brown versus Board of the disability rights movement, catalyzing very quick and effective transformation from the institutional bias to the community biases. Undeniably, many States have made great strides in that effort, but we have undeniably a long way to go.

This is about real people, including the people in this audience behind me, including people I have had the privilege of meeting across the country, including people like Paul Boyd, someone whom I met recently in my outreach in Birmingham, AL. In 1995, he was a college sophomore. He had an accident that left him paralyzed below the collarbone. He eventually graduated from college, but by then he had entered a nursing home and, in his own words, it made it “next to impossible” for him to find work.

He wants to be just like your nephew. He wants to go to graduate school. He wants to be a counselor. He wants to be a productive taxpayer in this community. But he can't, because he's stuck in a nursing home and he doesn't need to be there. That is the story of Paul Boyd and, regrettably, there are quite literally millions of Paul Boyd's throughout this country who with the appropriate supports can, should, and ought to be living in community-based settings. As long as there are people like Paul, there is far too much work to be done.

As I've said in prior hearings, the Civil Rights Division is again open for business, and we have made *Olmstead* enforcement a top priority and we've had a landmark year. The division has filed amicus briefs in cases in Connecticut, Virginia, North Carolina, Illinois, Florida, New Jersey, and California. We have filed lawsuits in Arkansas and Georgia and we intervened in a case in New York.

These cases involve individuals with a wide range of disabilities who can and want to live in the community. The *Olmstead* decision applies to all people with disabilities, not simply people with certain kinds of disabilities.

In addition to stepping up our enforcement, our approach to institutional investigations has changed. We've built a new paradigm. In the past we conducted much of this work by asking one and only one question, which was whether the facilities were safe and met constitutional minimums. That continues to be a critically important question, but we must also ask another question: Are there individuals in that institution who can and want to live in the community with the appropriate supports?

So we are focused on the twofold analysis. We're conducting the *Olmstead* analysis, and that is, if they can live in the community, that we are equally rigorous and robust in ensuring that the community-based services they receive are adequate, appropriate, and carefully monitored.

My written statement provides more details about some of the efforts I've just described, but I'd like to talk to you about two of our recent actions. In January, the division filed a motion for immediate relief in a case involving seven State-run psychiatric hospitals in Georgia, including the facility that was at the heart of the *Olmstead* case more than a decade ago. The division found that hundreds of individuals who can and should be served in the community remained institutionalized and exposed to often dangerous conditions.

I personally traveled to the State of Georgia to meet with the governor and to express to him our seriousness about this matter and our desire to fix the problem, not to fix the blame. In one of the most egregious examples in Georgia, a 14-year-old girl with mental illness died after becoming lethally constipated. She had

been prescribed an assortment of medications, many of which commonly caused constipation. On the day before she died, she complained of stomach pain and had nausea and vomiting. An autopsy found that her colon was stretched almost to the point of bursting. An investigation found that her impacted bowels had developed over time and could have been detected with more rigorous medical care. We are currently involved in settlement negotiations in Georgia and I hope we will be able to resolve that case.

Last month in Florida, the Department filed a statement of interest to support Michele Haddad's lawsuit against the State. Ms. Haddad is a 49-year-old with a spinal cord injury who is quadriplegic and uses a wheelchair. Her lawsuit alleges that Florida fails to provide community-based services to Medicaid-eligible individuals with spinal cord injuries who are at risk of institutionalization.

Haddad has successfully resided in the community since 2007, but is at risk of entry into a nursing home due to changes in her caregiver situation. She's been on the waiting list for 2 years and she notified the State of her increased need for services. This is what the State told her. The State told her that she would be eligible for services only if she entered a nursing home and stayed there for at least 60 days. So go into the nursing home and then ask for a permission slip. That's why we filed a brief and a complaint and a declaration for a preliminary injunction, because she too wants to be just like your nephew, Mr. Chairman, and live in the community.

These efforts reflect just one piece of an administration-wide effort. Last year, as you know, President Obama proclaimed the Year of Community Living, recognizing the need for unprecedented collaboration to cultivate systemic, sustainable reform. We are doing just that. We are transforming our relationships with our key partners, our partners at HHS.

Cindy Mann is a rock star. I want to state that for the record. And her work at CMS has been invaluable. The work of the Office for Civil Rights in the Georgia case has been invaluable. The work of the Substance Abuse and Mental Health Service Administration providing technical assistance as we draw a blueprint for reform in Georgia has been invaluable. The work of the nonprofit partners who are involved in the Georgia case and in so many other cases has been invaluable. Many of those private attorneys general are sitting behind me today and many others are toiling away in Minnesota, Oregon, Wyoming, Iowa, and so many other places, making sure that the *Olmstead* decision is given full force and effect.

There are indeed those who argue that now is not the time to implement *Olmstead* aggressively due to the budget constraints that State governments are confronting. I do agree that now is not the time. We should have started years and years ago. And we are indeed making progress, but we have a long way to go, and the evidence has shown that you can implement *Olmstead* in ways that are indeed both cost-effective, legally sufficient, and humane.

I look forward to any questions you have and I'm very excited about describing the work that we're doing on behalf of vulnerable people across this country with disabilities. Thank you very much, Mr. Chairman.

[The prepared statement of Mr. Perez follows:]

PREPARED STATEMENT OF THOMAS E. PEREZ

Good morning Chairman Harkin, Ranking Member Enzi and members of the committee. Thank you for holding this hearing on the anniversary of the *Olmstead v. L.C.* decision, a ruling that has often been called the *Brown v. Board of Education* of the disability rights movement.

Indeed, *Olmstead* was a landmark decision that recognized the civil rights of individuals with disabilities as well as the benefits of community living, and has changed the lives of so many who would otherwise be hidden away behind institutional walls. The Court's decision acknowledged that segregating individuals with disabilities in institutional settings deprives them of the opportunity to participate in their communities, interact with individuals who do not have disabilities and make their own day-to-day choices; it also recognized that unnecessary institutionalization stigmatizes people with disabilities, reinforcing misunderstanding and negative stereotypes. Eleven years after the Supreme Court recognized that institutionalization of individuals who are capable of living in and would benefit from community settings is discrimination that deprives those individuals of their freedom, many States have made great strides in expanding treatment options.

But for all of the progress made, I continue to hear about people like Paul Boyd, who I had the opportunity to meet earlier this year while on a trip to Birmingham, AL. In 1995, while a sophomore at Troy State University, Paul was injured in an accident that left him paralyzed below the collar bone. Paul eventually returned to college in his hometown of Montevallo, graduating in 2007 with a bachelor of fine arts degree. In December 2006, Paul entered a nursing home, and in his own words, it is "next to impossible" for him to find work that would allow him to live independently. Earlier this year, Paul was accepted to a graduate program at the University of Montevallo to seek his master's degree in community counseling. However, his classes would be at night, and he is not sure that he will be able to begin the program because of lack of transportation from his facility, which is 13 miles from the University. Paul told us that if he could get out of the nursing facility and receive services in his community in Montevallo, he could easily make it to his classes. In order to live independently, he would need the assistance of healthcare workers to help him bathe and dress and get into his wheelchair. He would also need assistance with some basic household chores. Montevallo is Paul's hometown, and while he has an extended support network of siblings and friends there, that is not enough, and the community-based services he needs to live independently simply are not available.

Sadly, Paul's story is not an exception. According to the Kaiser Commission on Medicaid and the Uninsured, more than 393,000 people sat on waiting lists for home and community-based services in 2008, the most recent year for which figures are available. That number represents an increase of more than 200,000 since 2002.

We should celebrate progress made since the *Olmstead* ruling, but as long as people like Paul and the many others waiting for a chance to live in the community are segregated in institutions, there is clearly more work to be done. The real reason I am here on the anniversary of *Olmstead* is to discuss the work that still lies ahead and the efforts of the Justice Department and the Obama administration to address the challenges that remain.

CIVIL RIGHTS DIVISION OLMSTEAD ENFORCEMENT

The Civil Rights Division's Disability Rights Section, which enforces Title II and Title III of the ADA, and Special Litigation Section, which enforces the Civil Rights of Institutionalized Persons Act (CRIPA), have made *Olmstead* enforcement a top priority, and the first year of the Obama administration proved to be a landmark year. The Division has filed amicus briefs in cases in Connecticut, Virginia, North Carolina, Illinois, Florida, New Jersey and California; filed lawsuits in Arkansas and Georgia and intervened in a case in New York.

In addition to stepping up enforcement, our current approach to cases of unnecessary institutionalization represents a paradigm shift. In the past, we conducted much of our institutional investigatory work under our CRIPA authority by first asking whether the institutions under investigation were safe, and whether the conditions of confinement were constitutional. This is a critical question, and one that must be evaluated any time we investigate an institution. But it should be the second question we ask. First, we must ask whether there are individuals in those institutions who could appropriately receive services in a more integrated setting.

In January, the Division filed a motion for immediate relief in a case involving seven State-run psychiatric hospitals in Georgia, including the facility that was at

the heart of the *Olmstead* case more than a decade ago. A year prior to our motion, the Division and the State entered into an agreement to ensure that individuals in the hospitals were served in the most appropriate integrated settings and that unlawful conditions in the hospitals were remedied, but the court had not yet approved the agreement. After monitoring conditions at the hospital, the Division found that hundreds of individuals who could and should be served in the community remained institutionalized. In addition to this unlawful segregation, individuals in the hospitals are exposed to often dangerous conditions.

In one of the most egregious examples, 14-year-old Sarah Crider, 3 months after being admitted to Georgia Regional Hospital in Atlanta for mental illness, died after becoming "lethally constipated" while in the hospital. Sarah had been prescribed an assortment of psychotropic medications, many of which commonly caused constipation. One the day before her death, Sarah complained of stomach pain and had nausea and vomiting. An autopsy found that her colon was stretched almost to the point of bursting, and that she died of sepsis, an infection in her bloodstream. An investigation found that her impacted bowels had developed over time and could have been detected by more careful medical care.

In addition, our investigation found a number of other examples of dangerous conditions, including:

- In 2009, the State failed to adequately supervise an individual who had killed previously. The individual assaulted and killed another individual in the hospital.
- In 2008, hospital staff failed to intervene in a fight between individuals. One of the individuals was knocked unconscious and died a few days later from blunt force trauma to the head.
- In 2009, staff failed to adequately supervise an individual who raped another individual.
- In 2009, an individual committed suicide by tipping his bed up and hanging himself from the upended bed. The Justice Department's experts had repeatedly warned hospital staff during on-site visits of the dangers posed by these beds that were not bolted to the floor.
- In January of this year, the State failed to adequately supervise an individual who expressed suicidal thoughts the day before she committed suicide.

The Division is currently in settlement negotiations with the State of Georgia.

Last month, the Division filed suit against the State of Arkansas for systematically violating the ADA by segregating residents in six State-run institutions for individuals with developmental disabilities. While confined in the Arkansas Human Development Centers (HDCs), the 1,100 residents of the facilities have extremely limited access to community activities and amenities, as well as limited opportunities to interact with people without disabilities. The lawsuit also alleges that the State restricts development of adequate community supports and services to enable individuals to leave the HDCs and to offer viable alternatives to many individuals who are at risk of inappropriate institutionalization.

As the Division's complaint notes, the current wait list in Arkansas for home and community-based waiver services for individuals with developmental disabilities who are seeking community alternatives to institutionalization totals approximately 1,400 people. This wait list moves at an extremely slow pace, with most people waiting several years for community services. Individuals currently at the bottom of the list will likely wait more than a decade to receive community services. Yet, the State is actively expanding its HDC institutions at the cost of developing community alternatives.

Also last month, in Florida, the department filed a statement of interest to support Michele Haddad's lawsuit against the State for violations of the ADA's integration mandate. Haddad, a 49-year-old woman with a spinal cord injury resulting from a motorcycle accident, has quadriplegia and uses a wheelchair. Her lawsuit alleges that Florida fails to provide community-based services to Medicaid-eligible individuals with spinal cord injuries who are at risk of institutionalization. Instead, the State will fund those services only after an individual relinquishes his or her ties to the community and enters a nursing home. Haddad has successfully resided in the community since 2007, but is at risk of entry into a nursing home due to changes in her caregiver situation. Haddad, who has been on the waiting list for services for 2 years, notified the State of her increased need for services, but was told that community services would only be available if she was willing to enter a nursing home for 60 days. The United States' filing supports Haddad's complaint and declaration for a preliminary injunction against Florida.

In New York, the Justice Department intervened in *Disability Advocates Inc. v. David A. Paterson, ET al.*, a case brought by a protection and advocacy organization to challenge the State's placement of persons with mental disabilities in Adult

Homes. The Department filed a brief in support of the advocates' proposed remedial plan to require the State to create 6,000 new community-based placements, and against the State's proposed plan to create approximately 1,000 new placements.

It's important to note that enforcing *Olmstead* is not about placing every individual in a community-based setting regardless of their disability or their desire. The *Olmstead* decision makes clear that States have an obligation to provide services to individuals with disabilities in the most integrated setting appropriate to their needs.

#### YEAR OF COMMUNITY LIVING: ADMINISTRATION EFFORTS

As I said, this work is a priority for the Civil Rights Division, and we are committed to aggressive enforcement of *Olmstead* so that we can build upon progress made over the last 11 years. But our work is only one piece of a larger, Administration-wide effort to make the promise of *Olmstead* a reality for individuals with disabilities nationwide. Real reform requires a holistic approach. As a lifelong public servant, I recognize that the most vexing problems a government faces are those that require unprecedented inter-agency collaboration and coordination. The unnecessary and illegal institutionalization of individuals with disabilities who would be better served, and better able to contribute to their communities, if they were provided services in integrated settings, is one of those problems.

This is why last year, on the 10th anniversary of *Olmstead*, President Obama proclaimed the Year of Community Living. The Community Living initiative is marked by unprecedented collaboration so that we can be sure that as we enforce the ADA and the *Olmstead* decision, we are cultivating systemic, sustainable reform.

In our work at the Department of Justice, this collaboration helps us to craft consent decrees that lead to such systemic reform. By working with the Department of Health and Human Services and the Department of Housing and Urban Development, for example, we can ensure that the remedies laid out in a consent decree to increase community-based placements will have adequate financing, and that there will be adequate community infrastructure.

For this reason, the HHS Office for Civil Rights has been at the negotiating table with us as we work toward an agreement in Georgia. We have relied heavily on the technical assistance that the Substance Abuse and Mental Health Services Administration and the Centers for Medicare and Medicaid Services can provide, because that assistance will be critical in ensuring that any settlement reached leads to real, sustainable reform.

Meanwhile, those agencies have been actively pursuing strategies over the last year as part of the Year of Community Living. Last month, Cindy Mann, Director of the Center for Medicaid, CHIP, and Survey and Certification at CMS, sent a letter to State Medicaid Directors outlining an array of programs, both existing and new, to assist States in their efforts to provide more services in community settings. The services outlined include various technical assistance options, including a new program to assist States as they work to evaluate individuals with mental or developmental disabilities to determine the most integrated setting appropriate for their needs; a partnership between HHS and HUD that includes funding availability for Housing Choice Vouchers; and a variety of other resources and programs.

Meanwhile, HUD has provided tens of millions of dollars over the last year to fund housing choice vouchers for non-elderly individuals with disabilities, including funds specifically targeted to providing assistance for individuals transitioning out of institutional settings.

Additionally, the Affordable Care Act that you enacted earlier this year includes a number of provisions to provide more opportunities for individuals with disabilities to receive services in community-based settings. These include an extension of the Money Follows the Person demonstration through 2016, improvements to the Medicaid HCBS State plan option and other provisions to help States meet their *Olmstead* obligations. HHS plans to provide further guidance on these and other provisions from the Affordable Care Act.

#### LOOKING FORWARD

Next month, we will celebrate the 20th Anniversary of the Americans with Disabilities Act, a landmark civil rights law that has improved the lives of so many people with disabilities, and has changed perceptions and stereotypes and lessened the stigma of disability.

But, as we celebrate the progress made in the last two decades, we must think about what the next 20 years of ADA enforcement will look like.

Institutionalization has long been the default choice for providing services to people with disabilities. In the 11 years since *Olmstead*, this has begun to change, but

too many individuals in too many States continue to live in institutions when they could be better served in the community.

The Obama administration is committed to helping more people access community-based services, and by working collaboratively as a Federal Government and coordinating with State and local governments, we can accomplish real, systemic, sustainable change in the way we approach services and treatment.

For the Department of Justice, turning the promise of the *Olmstead* decision into a reality for individuals with disabilities across the Nation has become a major component of ADA enforcement. Our success in that endeavor will be a determining factor in whether we will be able to celebrate more great progress in the next two decades of ADA enforcement.

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

Now we'll turn to Ms. Mann. Welcome, Ms. Mann. Please proceed.

**STATEMENT OF CINDY MANN, J.D., DIRECTOR, CENTER FOR MEDICAID, CHIP AND SURVEY AND CERTIFICATION, CENTERS FOR MEDICARE AND MEDICAID SERVICES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Ms. MANN. Good afternoon, Chairman Harkin, Ranking Member Enzi, and members of the committee. Thank you for the invitation to discuss the Centers for Medicare and Medicaid Services' role in encouraging and supporting community-based services and supports for people in need of long-term care. I want to begin by acknowledging the enormous and positive changes that have taken place in this country, brought about by the Americans with Disabilities Act and you in particular, Senator Harkin, for all you've done, both to bring about that act and to improve the way that Medicaid is able to serve people with disabilities.

The *Olmstead* decision marked the beginning of a fundamental change in how Medicaid serves people with disabilities. We have made enormous progress since June 22, 1999. To give you a little bit of the dimensions of the change that has occurred since the *Olmstead* decision, consider the following. Annual Medicaid expenditures for community-based services have increased from a little over a quarter of total Medicaid long-term care spending to almost 45 percent of those expenditures.

Today more than half of Medicaid's beneficiaries who are receiving long-term care services are receiving that care in community settings. While real and tangible progress has been made, much more needs to be done. Far too many people are waiting for the services they need in the community. There are 1.6 million Americans still receiving services in institutions, many of whom would prefer to receive services at home. Perhaps most worrisome is that, with State budget constraints, there's a real danger that the progress that's been achieved over the past 11 years will be slowed or even rolled back.

As the largest single source of funding for long-term care services and supports, Medicaid plays a unique role in the context of the Americans With Disabilities Act. Our mission in this area is to work aggressively to address the inherent statutorily based institutional bias within the Medicaid program by expanding and improving the opportunities for people to receive needed services in the community using all the tools available to us.

Many people need and benefit from receiving their care in an institutional setting. But no one should have to enter an institution

and relinquish their ability to participate in community life to get the medical care they need if those medical services could be provided in an appropriate manner in the community.

Working with the disability and aging communities as well as with States, CMS is currently building upon several existing initiatives to strengthen the choices available to people as we also begin to implement the new grants and State options enacted as part of the Affordable Care Act. Together we believe these provisions will do much to allow Medicaid beneficiaries living with disabilities to have the opportunity to receive the care they need in the community.

Our work at CMS is part of a broader initiative. Senator Enzi noted the Year of Community Living that has been established first by the President, followed by the Secretary of HHS, Secretary Sebelius. That initiative was designed to bring collaboration and it takes a lot of collaboration across Federal agencies to try and identify and eliminate some of the barriers that exist.

One of those key barriers, of course, is in the area of housing. We have been working particularly aggressively with HUD over the last year to identify ways to make vouchers and housing assistance available to people so that they have a better opportunity to receive care in the community. It's clear that for real progress to be made more is needed than just health care delivery and financing strategies, although those are obviously important.

Focusing on particularly how CMS and the Medicaid program can help States find solutions, on May 20, 2010 we issued a letter to State Medicaid directors underscoring the importance of continuing to work to make progress consistent with the *Olmstead* decision. We outlined several of the options that are available to States. Some of them are new options, some of them have been established over the last 10 years. They include new State plan options that allow States to serve people in the community without going through waivers, aging and disability resource center programs designed to streamline access to care, and person-centered hospital discharge planning, which helps bring in families and consumers to the planning process to find appropriate community-based alternatives to institutional care.

This is one of the examples of ways in which we think that improving quality for people can also reduce costs for Medicaid, for State and Federal Government, certainly by avoiding unnecessary institutional stays after hospital discharge.

The May 20 letter also referenced the learnings from the Money Follows the Person demonstration grants, which, as you noted, Chairman Harkin, Congress just extended and expanded. I'm pleased to announce today that we are issuing a new guidance on the MFP provisions that are in the new law to advise States of what those provisions are and to advise them that we will be doing a grant solicitation for the new dollars made available in the Affordable Care Act later this summer. We expect to do so in July. We're very excited to work with the States that already have MFP grants to expand their capacity, as well as to work with new States.

We are very excited also about implementing several of the new provisions in the Affordable Care Act. The Community First Choice



Option, effective, as you noted, on October 2011, allows States to cover home and community-based attendant services and supports, operating under a consumer's direction and through a person-centered plan of care.

Significantly, you have provided an additional 6 percentage point increase in State matches to make sure that States have the ability to move forward. Thank you, chairman, for your leadership in pushing forward the Community First Option.

We also have additional Federal match for the balancing incentive program to encourage States that haven't made very much progress to try and move forward as some other States have done.

I'll close my remarks by noting another important anniversary that is coming up. Of course, we all know that July 26 will mark the 20th anniversary of the ADA. Much progress has been made over the past 20 years, but, as everybody, I think, testifying before you today would agree, the work remains unfinished.

I can assure you that CMS is working and listening to people living with disabilities, working closely as well with States and our colleagues at the Department of Justice—he's also a rock star—and the other agencies, and taking a leadership role in assisting States to meet their obligations under ADA and the *Olmstead* decision.

We thank you for all that Congress and particularly the leadership of this committee has done, especially in this area. It is hard to imagine any work more important. Thank you.

[The prepared statement of Ms. Mann follows:]

PREPARED STATEMENT OF CINDY MANN, J.D.

Chairman Harkin, Ranking Member Enzi, and members of the committee, thank you for the invitation to discuss the Centers for Medicare and Medicaid Services' (CMS) role in encouraging and supporting community-based services and supports for individuals in need of long-term care. The Medicaid program plays a critical role in assuring that these services and supports are available and in promoting State efforts to comply with the Americans with Disabilities Act (ADA) and the U.S. Supreme Court's decision in *Olmstead v. L.C.* Working with the disability and aging communities, as well as States, CMS is currently building upon several current initiatives and looks forward to expanding State options that will ensure that Medicaid beneficiaries living with disabilities have the opportunity to receive the care they need in the community.

I would like to begin by commending the work of Chairman Harkin and this committee on the improvements in this area that are part of the recently enacted Affordable Care Act (ACA). Your tireless commitment to improving the lives of Americans with disabilities, as demonstrated by your instrumental contributions to passage of the ADA, manifested itself again in the inclusion of the Community First Choice Option program and other notable improvements to the Medicaid program within this important legislation.

Since the passage of the ADA and the *Olmstead* decision, the Nation has made great progress toward improving and expanding community living opportunities for people living with disabilities. Over the past 10 years, funding for long-term care services has grown at an average annual rate of 6.3 percent, while spending on community-based long-term services and supports has increased by an average of 11.8 percent per year from \$17 billion in 1999 to \$52 billion in 2009.<sup>1</sup> Annual Medicaid expenditures for community-based services have increased from a national average of only 27 percent of total Medicaid long-term care expenditures to almost 45 percent of long-term care expenditures over the period.<sup>2</sup> More than half of all Medicaid LTC beneficiaries now receive services in community settings.<sup>3</sup> However, the demand for community services continues to grow, and many individuals in need of these services struggle without them. And while the number of people served in

<sup>1</sup> Thomson Reuters analysis of CMS Form 64 Reports, 2010.

<sup>2</sup> Thomson Reuters analysis of CMS Form 64 Reports, 2010.

<sup>3</sup> Thomson Medstat, Medicaid Long Term Care Data Chartbook, CMS, 2003.

community settings has grown, there are still over 1.6 million Americans receiving services in institutions, many of whom would prefer to receive services at home; and many more individuals are at risk of institutionalization, waiting for access to community-based services. In addition, on-going State budget constraints threaten the progress that has been achieved, raising concerns about compliance with the ADA and *Olmstead*. In response to State budget constraints, however, the Administration has requested \$25.5 billion in its fiscal year 2011 budget submission to Congress for a 6-month extension of the Recovery Act's temporary FMAP increase.

In this context, we are very committed to moving forward with existing and new initiatives. Our commitment at CMS is, of course, shared Administration-wide. In June 2009, President Obama announced the "Year of Community Living" to mark the 10th anniversary of the *Olmstead v. L.C.* decision. In that decision, the U.S. Supreme Court affirmed that States are obligated to serve individuals in the most integrated setting appropriate to their needs, and held that the unjustified institutional isolation of people with disabilities is a form of unlawful discrimination under the ADA.

Following the President's announcement, Secretary Sebelius established the Community Living Initiative, led by the Department of Health and Human Services (HHS), but designed to coordinate the efforts of several Federal agencies, including CMS, to implement comprehensive solutions that address barriers to community living for individuals with disabilities and older Americans. Under this initiative, HHS is partnering with the Department of Housing and Urban Development (HUD) to improve access and affordability of housing for people with disabilities and older Americans with long-term care needs. In addition to the work of the Community Living Initiative to remove barriers and provide better options for community integration, the HHS Office for Civil Rights is collaborating with the U.S. Department of Justice (DOJ) to advance enforcement of the ADA under the directive of the *Olmstead* decision.

As you also know, Congress included several mechanisms in the Affordable Care Act to address gaps in the availability of community services for individuals with disabilities. The passage of the ACA provides new and expanded opportunities to serve more individuals in home and community-based settings and adds to the tools already available so States can implement the integration mandate of the ADA as required by the *Olmstead* decision.

As we work within the broad scope of the Community Living initiative and the new authorities provided under the ACA, CMS is also deepening its efforts in this area. On May 20, 2010, CMS issued a letter to all State Medicaid Directors (SMD) to underscore the importance of continuing to make progress consistent with the *Olmstead* decision and to provide States with information on both new and existing tools for community integration and to reiterate our support for community living options for Medicaid beneficiaries living with disabilities. I would like to take this opportunity to discuss several of these existing approaches in more detail and also to touch on exciting new opportunities under the ACA.

#### WAIVER AND STATE PLAN OPTIONS

The core mechanism that States have used to promote access to community-based services and supports for Medicaid beneficiaries is through the Home and Community-Based Services (HCBS) waiver. We are continuously reviewing and assessing our policies and practices to identify ways in which the Medicaid program can assist States in achieving the requirements of the ADA, including assisting States in efforts to serve more individuals in community settings. Forty-eight States are operating over 300 HCBS waivers that serve over a million individuals with disabilities. In 2009, HCBS services under both State plans and waiver programs comprised 45 percent of Medicaid spending on long-term care. This demonstrates impressive growth in community-based options of approximately 13 percent since 2008 alone, while overall spending on community options has tripled since 1999.<sup>4</sup>

We must acknowledge, however, that there are significant disparities across States in the level of investment in community services. The percent of Medicaid long-term care funding directed toward HCBS varies among States from 14 to 75 percent. In addition, the HCBS investment varies significantly among different target populations. The opportunities afforded under the ACA hold great promise for all States to move forward in expanding HCBS options for all individuals with long-term care needs.

The State plan options under Sections 1915(i) and 1915(j) of the Social Security Act (the act) provide States with opportunities to serve individuals in the most inte-

<sup>4</sup>Thomson Reuters analysis of CMS Form 64 Reports, 2010.

grated setting without the requirement of a waiver. Section 1915(i), which permits States to provide HCBS as a State plan option, allows States to serve individuals in the community without linking the benefit to either a current or future need for institutional care. As of today, five States have taken up the 1915(i) State plan option: Iowa, Wisconsin, Washington, Nevada, and Colorado. States have found the section 1915(i) option to have particular promise for improving access to community-based services for individuals with mental and substance use disorders, a group which has been an underrepresented element of previous waiver populations. With the reforms enacted by the ACA, the State plan option offers even greater promise as a tool to prevent institutionalization and to meet mental health service needs in additional States. The ACA has also provided for broader financial eligibility rules and a more expansive array of services.

Section 1915(j) allows States to design self-directed personal assistance or other HCBS for individuals who would otherwise receive State plan personal care or HCBS waiver services. While not changing the services available to individuals, 1915(j) gives States flexibility in offering individuals the opportunity to exercise maximum choice and control over their services. States offering services under 1915(j) authority include: Arkansas, Florida, New Jersey, California, Oregon, Alabama and Texas.

#### MONEY FOLLOWS THE PERSON (MFP) GRANTS

CMS also operates the Medicaid Money Follows the Person (MFP) grant program, which was authorized in the Deficit Reduction Act of 2005. MFP assists States in their efforts to reduce reliance on institutional care, develop community-based long-term care opportunities, and transition individuals living in institutions to community living. MFP provides enhanced Federal matching funds to serve individuals who move from institutional care to community integrated LTC settings. Originally set to expire next year, the MFP program was extended through September 30, 2016 under Section 2403 of the ACA, with an additional appropriation of more than \$2 billion. The ACA also modified the time Medicaid beneficiaries must reside in institutions so those individuals who do not reside in a facility for a long-term stay will qualify for MFP at 3 months rather than 6 months. Now in its third year, the MFP program has made it possible for almost 6,000 people to live more independent lives by providing necessary supports and services in the community. Currently, 29 States and the District of Columbia have MFP programs. The extension and expansion of MFP under the ACA will allow current MFP States to assist more individuals to move to community settings and allow additional States to initiate MFP programs.

We recognize that much more can be done through this demonstration authority to expand its reach to more beneficiaries who could benefit from this approach. The extension and expansion of MFP under the ACA will allow current MFP States to assist more individuals to move to community settings and allow additional States to initiate MFP programs. CMS is finalizing a letter to State Medicaid Directors providing guidance on the MFP extension and expects to announce a new MFP grant solicitation this summer.

#### AGING AND DISABILITY RESOURCE CENTERS (ADRC)

The Aging and Disability Resource Centers (ADRC) program, a collaborative effort of the Administration on Aging (AOA) and CMS, is designed to streamline access to long-term care services and supports. ADRCs play a critical role in supporting health and long-term care reform by improving the ability of State and local governments to effectively manage the system, monitor program quality, and measure the responsiveness of State and local systems of care. ADRCs now operate in at least one community in each of the 50 States and in four Territories. There are currently more than 200 ADRC sites across the Nation. A growing number of ADRCs have Medicaid applications available on the Internet with seven of these allowing consumers to complete and submit the application online. The ACA provides the opportunity for CMS, in collaboration with its HHS partners, to expand the ADRC program and similar models to ensure streamlined access to information and service supports.

The Person-Centered Hospital Discharge Planning Model Grants, created under the ADRC program, provides another avenue to strengthen person-centered planning and community-based long-term care. CMS awarded 10 of these grants between 2008 and 2009, totaling approximately \$12 million. These grants are designed to assist States in developing hospital discharge planning structures and processes that will place greater emphasis on involving consumers and their families in after-care plans, including community-based alternatives to institutional care. Grantee ef-

forts to date include: development of discharge planning checklists; patient and caregiver information kits and hospital staff training webinars; enhancing online resource directories; developing electronic referral, application, and tracking systems; and employing transition coaches to follow-up with individuals once they are discharged from the hospital back into the community.

CMS looks forward to continuing to work closely with the AOA on the expansion of the ADRC program under the provisions of the ACA. Improving the hospital discharge planning process and enhancing community-based long-term care options are essential elements of an effective community-based long-term care system.

#### NEW INFRASTRUCTURE REFORMS

In addition to the initiatives described above, the ACA created new grant funds and enhanced Medicaid financing to support State efforts to create more balanced long-term care services and support systems. The new authorities provided by Congress under the ACA will allow CMS to sustain and expand Federal support for States to provide long-term care services in a community setting.

One provision in the ACA, known as the Community First Choice Option, establishes a new Medicaid State Plan option, effective October 1, 2011, to allow States to cover home and community-based attendant services and supports for individuals with incomes not exceeding 150 percent of the Federal poverty level (FPL) or, if greater, the income level for an individual who has been determined to require an institutional level of care. It also requires States to make such services and supports available to individuals under a person-centered plan of care for purposes of assisting them in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing. States are provided an additional 6 percentage point increase in Federal Medicaid matching funds for services and supports provided to such individuals. This increased match rate is a strong incentive for States to re-orient spending to sustain these programs. Thank you, Mr. Chairman, for your leadership on the Community First Choice Option.

Moreover, we hope that in this time of State budgetary constraints, there will be great interest in the provisions that offer States additional resources to effectuate widespread changes to their long-term care support systems to better serve people with disabilities and chronic conditions. The increased Federal match offered under the Balancing Incentive Program and the Health Home Initiative will not only expand access to key home and community-based services, but also provide incentives for States to build lasting infrastructure to integrate behavioral and physical health, improve care coordination, and offer health promotion services for people with chronic conditions.

#### AVAILABILITY OF TECHNICAL ASSISTANCE

CMS also currently offers a variety of resources for technical assistance to States regarding the design and operation of their Medicaid programs. While we understand that States face unprecedented budget shortfalls, we also recognize that the Medicaid program provides strong partnership opportunities between CMS and States to support community integration for people with disabilities. As part of this partnership, CMS is committed to providing targeted technical assistance to States to help them meet their obligations under the ADA. Specifically, CMS will, at the request of a State, work with the State to identify the Medicaid coverage, reimbursement and service delivery options available to increase a State's system capacity to serve individuals in the community. Technical assistance also can help identify and support development of the strategies States can employ to ensure that services meet the needs and preferences of each individual.

CMS offers technical assistance through a number of vehicles. The National Quality Enterprise (NQE) is designed to assist States in developing and improving the structures to ensure the health and welfare of individuals served through HCBS waivers and State plan options. The NQE, which provides assistance at no cost to States, is a valuable resource that States can use to design and improve their quality improvement systems.

Another source of technical assistance is provided through the MFP Rebalancing Demonstration. This aspect of the MFP demo provides direct technical assistance to participating States to reduce reliance on institutional care while developing community-based long-term care opportunities, enabling the elderly and people with disabilities to fully participate in their communities. In addition, CMS supports the ongoing operation of the National Direct Service Workforce (DSW) Resource Center. The DSW Resource Center supports efforts to improve recruitment and retention of direct service workers who help people with disabilities and older adults to live

independently and with dignity. This Resource Center brings together the Nation's premier resources on the topic of Direct Support Workforce and provides State Medicaid agencies, researchers, policymakers, employers, consumers, direct service professionals, and other State-level government agencies and organizations easy access to information and resources they may need about the direct service workforce. These resources, which include web-based clearinghouses, technical experts, training tools and more, are designed to address the full range of DSW consumer populations.

Additionally, CMS has published a technical assistance guide, entitled *Long Term Services and Supports in a Managed Care Delivery System*, which describes the various Medicaid authorities and structures that States can use to enhance the availability of HCBS within managed care delivery systems. These managed care delivery systems allow for the use of capitation payments with both institutional and HCBS services in a global budget, where the resources available to support an individual can follow the individual wherever they choose to receive their services. CMS is working to ensure that managed care arrangements encompassing long-term services and support include all necessary safeguards and protections to ensure the health and welfare of individuals served.

#### IMPLEMENTATION OF PREADMISSION SCREENING AND RESIDENT REVIEW (PASRR)

Another mechanism currently available to States is the Preadmission Screening and Resident Review (PASRR) process. Congress developed the PASRR program to prevent inappropriate admission and retention of people with mental disabilities in nursing facilities. Under Federal requirements, States must assure that individuals with mental disabilities or developmental disabilities being considered for admission to a nursing facility are evaluated through the PASRR process to determine the most integrated setting that can meet their needs. CMS has established the new National PASRR Technical Assistance Center, which provides technical assistance to States, at no cost, to facilitate this reform activity. PASRR is a powerful tool for diversion from institutions, and the resident review elements of PASRR are important tools to help encourage transitions to the community.

#### ACCESS TO AFFORDABLE HOUSING AS A MEANS TO MAXIMIZE OPPORTUNITIES FOR COMMUNITY LIVING

The lack of accessible and affordable housing continues to be an obstacle to serving individuals in the most integrated setting. As part of the Community Living Initiative, HHS has partnered with HUD to improve access to affordable housing for people with disabilities. HHS and HUD collaborated to provide housing support for non-elderly persons living with disabilities to live productive, independent lives in their communities rather than in institutional settings. HUD is offering approximately \$40 million to public housing authorities across the United States to fund approximately 5,300 Housing Choice Vouchers for non-elderly persons with disabilities, allowing them to live independently. HHS will use its network of State Medicaid agencies and local human service organizations to link eligible families to local housing agencies who will administer voucher distribution.

Of the 5,300 vouchers set aside as part of this program, up to 1,000 will be specifically targeted for non-elderly individuals with disabilities currently living in institutions but who could move into the community with assistance. The remaining 4,300 may be used for this purpose also, but are targeted for use by non-elderly disabled families in the community to allow them to access affordable housing that adequately meets their needs. HUD expects to have funding awards ready before the end of 2010.

#### LOOKING FORWARD

July 26 will mark the 20th anniversary of the enactment of the ADA. Much progress has been made over the past 20 years to improve the quality of life for individuals with disabilities in the United States, but the work remains unfinished. CMS recognizes the significant progress made since the passage of the ADA and the *Olmstead* decision, but we strongly believe that more can be done with the tools provided to us, despite the challenges that Medicaid beneficiaries—who live with disabilities, as well as States—face in the current uncertain economic and fiscal climate. I assure you that CMS will be taking on a leadership role both in implementing the new opportunities provided by the Affordable Care Act, and also in assisting all States in meeting their obligations under the ADA and the *Olmstead* decision. We intend to capitalize on this opportunity by maximizing existing resources and we look forward to working with States and the Congress in the future to con-

tinue the vital work of improving the quality of life for individuals living with disabilities in this country.

The CHAIRMAN. Thank you very much for your statement. Thank you both, and thank you both for your great work in this area.

We'll start a round of 5-minute questions. Now, basically I just want to talk to you both about *Olmstead*. I, like you, Mr. Perez, I just thought this would be sort of self-actuating, that things would just move. And we've watched over the intervening 11 years. On the good side, we have moved ahead. As Ms. Mann said, we're up to about 45 percent now, I think, if I'm not mistaken.

But still there are so many places where—I think you even pointed out in your written testimony, yours maybe or Ms. Mann's—States are still building institutions. They're still investing in building institutions, when clearly the direction is just the opposite. What is it? What has been the biggest obstacles to getting people—we have the Money Follows the Person, and yet—and we know we have good data to show that States really—it's cheaper. It really is more cost-effective to support someone, let's say with 8 hours a day of attendant services, than it is to give them 24 hours a day care in a nursing home, or maybe even 4 to 6 hours. Maybe it's that small intervention even in the workplace.

So from the standpoint of cost effectiveness, forgetting just the humanity side of it, why don't States see this? Why aren't they moving ahead more aggressively? What's been the holdup? I'm just trying to figure this out. What do you see as the biggest holdup in why States haven't moved more aggressively?

Mr. PEREZ. That's the \$64 million question, Mr. Chairman. When I started this job as AAG, we went around and did a lot of listening tours internally and elsewhere and I would ask, "Why are you doing something this way?" And we got the answer, "Because that's how we've always done it." If I were to sit there and look at why we haven't made much progress, it's because that's how it's always been done.

It doesn't have to be that way. I had the privilege of working in the State of Maryland as a State cabinet official. One thing I would observe from that vantage point and from the vantage point at OCR from 10 years ago was that oftentimes when we were doing our work we were introducing various State stove pipes to each other, because in order to effect the systems change that you're describing you need to bring a number of different agencies to the table, both at a Federal level, which we've been doing and I think have been successful at, and equally importantly at the State level.

I won't name the State, but I vividly remember sending a letter out post-*Olmstead* and the decision says the best way to comply is to develop a comprehensive, effectively working plan for moving people with disabilities into the community. And we offered assistance in the development of that plan. When we had that first meeting, we were quite literally introducing State employees to each other.

So the stove piped nature of the delivery of these services often creates barriers to the prompt transformation. Also, all the wonderful programs that Cindy Mann administers are, "waiver programs." So what that means is community is the exception, institutionaliza-

tion is the rule. So that ethic and paradigm has pervaded for a long time.

So because we've always done it like this and because of the structures of State governments, I think it ends up being the way it is, although it's not the way it should be.

The CHAIRMAN. Ms. Mann.

Ms. MANN. Let me offer some additional observations. As you noted, we have not seen a real decrease in the numbers of people in institutions. So States don't see it as necessarily a zero sum game, but as they are increasing home and community-based services they see that they are adding more people to the long-term care system, and I think they are, particularly in these days, very focused on the cost.

So while the per-person cost of serving somebody in the community is certainly less than serving somebody in the institutions, the number of people needing services is growing.

The CHAIRMAN. What we call "the woodwork."

Mr. PEREZ. The woodwork.

Ms. MANN. The woodwork. Now, there is certainly a dispute as to whether that woodwork is really prohibitively expensive over time, that if you work your way through—in fact, you will end up saving dollars, and there are certainly some studies to that effect. But that certainly is the concern, and I would say cost, fear of the cost anyway, is a considerable barrier.

Housing is a real barrier as well. We have certainly seen that in the context of implementing MFP finding and assuring we have appropriate housing available that's affordable for people is a particular problem in rural communities—finding housing that's also attached close enough to transportation options for people.

The CHAIRMAN. And housing that is accessible.

Ms. MANN. Housing that is accessible, that's right, and that allows somebody to participate in community life, so that it's not isolated housing, but housing that allows people to get connected to the job and be connected to their families.

We have some workforce issues, and I think the new Affordable Care Act gives us some new tools and some new focus on workforce issues. But we need to do more in that area as well.

I will underscore I think, though, where Tom went, which is that it can be done, it has been done. It is not easy, but with persistence, with just clear leadership, I think we have seen many States lead the way. So we're very much interested in—it is not impossible at all. It is, in fact, very possible and we need to lead the way.

The CHAIRMAN. I'd be interested, and I'm sure I speak for Senator Enzi too, that we'd be interested in seeing those States that have really done this, have done a good job. How have they done this and could they be a template for others? So if you have examples, we'd like to see them.

Senator Enzi.

Senator ENZI. Thank you, Mr. Chairman. That's exactly the question I wanted to start off with.

First I wanted to thank both of our witnesses for their tremendous enthusiasm and knowledge. But I wanted to see if either of you could name a few States that we should be looking at as shin-

ing examples of the *Olmstead* implementation, and what do you think makes those States successful?

Ms. MANN. There are a couple States that come to mind. Oregon has been a real leader in this area. Minnesota's been a real leader in this area—just random States I picked.

[Laughter.]

But it's absolutely true. And it is not an overnight occurrence. These are States that have struggled for the last decade, through good times and in bad, and been very determined that this is the direction that they're going in.

I think it also underscores the point you both made and that Tom made as well, that it is a bipartisan commitment, but it takes a real commitment to think about the housing issues, to think about the workforce issues, and to decide this is the direction we're going to go to have a clear goal in mind and to get there.

We'd be happy also to provide some case studies. We've certainly been doing this in the context of providing technical assistance to States, here's what's been working, here's what's not been working. To get States together and share their experiences has also been a very powerful approach to move other States forward.

Mr. PEREZ. I agree with everything that Cindy said. I would note that oftentimes what we see is that there are States who are successful moving certain populations of people with disabilities. For instance, some States have been very successful in moving people with developmental disabilities into community-based settings.

But oftentimes what we'll look at, if we look at other sub-populations of people with disabilities who can live in the community, that program is more problematic in terms of moving people out. My friendly amendment to your question, Senator, would be to not only look in the aggregate at what States are doing, but then to disaggregate so that we understand some of the work that's being done with sub-populations, recognizing that sometimes it has the consequence of making the waiting list longer for other people with different forms of disability.

I would note finally also that we both had the privilege in former lives to work with the Kaiser Commission on Medicaid and the Uninsured, which is a nonpartisan group, with Senator Durenberger, Senator Mathias, and others. They have done a fair amount of research in this area taking a look at the world of waivers and the world of post-*Olmstead*. They did a hearing, *Olmstead at Five*, in the Senate 6 years ago, and they are a very good treasure trove for that sort of information.

Senator ENZI. Thank you.

Ms. Mann, I'd ask for you, if you have a document that you could share on that, what's been working and what hasn't, that would be very helpful in our deliberations.

I'm from Wyoming, which is definitely a rural State. We only have 14 towns where the population exceeds the elevation. Our biggest city is 52,000. Is there a difference in the rural States? I think that to some degree they have more of a sense of community, like to keep the people close at hand, and may be able to service them better that way. But is there any particular assistance that you give to rural States in implementing this *Olmstead* when they have these capacity barriers?



Ms. MANN. I think there are some particular issues that rural communities face. We have several technical assistance providers that we work with under contract, and one in particular focuses on those sets of issues. One of the things that we're working on going forward is to get some peer States together to talk about what's working and what's not. We actually have heard from States and think that there is reason to pull some of the rural States together so that they can exchange information.

I think some of the workforce issues and the housing issues that we've talked about are just exacerbated often in rural communities. At the same time, as you said, there's a real strong sense of community. One of the things that I think the Affordable Care Act and other options that we have available to us allows us to work on more is family caregiving. So there are also solutions and opportunities that I think are particularly appropriate and suited for rural communities.

Senator ENZI. Thank you. My time has run out. I will be submitting some questions in writing that I hope you'll answer, because I am interested in any shining examples as well and what might have caused those, as well as a number of other questions.

Ms. MANN. We'd be glad to respond. Thank you.

Senator ENZI. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Enzi.

I have in order Senator Merkley, Senator Franken, and Senator Hagan. So Senator Merkley, I understand Oregon has done a pretty good job.

#### STATEMENT OF SENATOR MERKLEY

Senator MERKLEY. Thank you, Mr. Chair.

Indeed, the ability to continue aging in place has been a huge emphasis in Oregon. We have one program called Operation Independence, which is aimed exactly at this issue, and a number of other approaches.

Thank you both for your testimony. Ms. Mann, there are certain assumptions we have about the higher quality of life one has in their own setting and some of the challenges in an institutional setting. Those might be disorientation, self-esteem, sense of purpose, depression, abandonment, and—maybe on the medical side—greater risk of infections.

But are these comprehensively measured. Can you point to any studies that really allow us to get a handle on the disparity of quality of life between an institutional setting and an in-community setting?

Ms. MANN. We can certainly look into that. We are doing a couple of things along those lines. First of all, we listen a lot to our partners in the community and what they tell us. So I think in some respects they're our best evidence, and the experiences, for example, like the gentlemen that Mr. Perez noted before who had been in an institution and those who had not.

We are looking at and developing what the hallmarks are of community living. We've put out an ANPRM to try and get public comments about what it means to be in community living, can you have those hallmarks of community living in different kinds of set-

tings, what kinds of settings, can you have it in a group home, does it need to be in your own apartment?

These are all difficult questions, not black and white questions. So we're really reaching out to a very wide range of stakeholders to help us think exactly those questions through.

I just wanted to note that certainly some people need to have some care in a nursing home setting. In the context of our survey and certification work on the quality of care in nursing homes, we are also trying to bring in a sense of quality of life and examine what's going on inside the nursing home as well.

Mr. PEREZ. I would note, Senator, in connection with our work under the Civil Rights of Institutionalized Persons Act we've had a number of cases with specific institutions where one of the metrics we were measuring was life expectancy of people in that institution. In one case in particular, which doesn't need to be named, but we measured life expectancy in that institution against similar institutions and it was considerably lower.

That's obviously not the only metric, but it was an important metric to demonstrate the challenges that were rising to the level of violation.

Senator MERKLEY. Thank you both. I think as we seek to encourage more States to be aggressive in this area having those type of metrics will help people get their hands around it. Certainly the other side of it is the testimony of individuals and that's extraordinarily powerful in favor of community living.

An issue, Mr. Perez, that you raised was that of States being concerned about the cost. Now, in many cases it's just a lot less expensive to have someone housed in a community setting, but not always. But how does one get their hands around that issue of cost in terms of the infrastructure and the services and so on and so forth, and are there rare situations where it is a lot more expensive to have a program that's in the community, and how does one address that in the context of the Olmstead Act?

Mr. PEREZ. There's an ample evidence base demonstrating that it is cost-effective for people with disabilities to live in community-based settings. There have been a host of studies. Cindy and Mr. Chairman talked before about the woodwork effect, which is I think that parade of horrors that concerns States. I think there is a robust evidence base demonstrating that that is more of a hype than it is a reality.

Under the *Olmstead* decision and the ADA itself, the legal question presented would be whether moving in this direction would constitute, "fundamental alteration." I don't believe it would. Quite the contrary. And we have been working hard to demonstrate that this is not only humane treatment and ensuring compliance with the ADA, but it's in your enlightened economic self-interest.

The challenge is that you have to look at this from a long-term perspective, the long-term investments of your resources. All too frequently right now, with the constraints that confront States, long-term thinking is sometimes a little elusive.

Senator MERKLEY. Well, thank you both very much for the work you're doing. Tremendous.

The CHAIRMAN. Thank you, Senator Merkley.  
Senator Franken.

## STATEMENT OF SENATOR FRANKEN

Senator FRANKEN. Thank you, Mr. Chairman, for calling this hearing.

A couple years ago I went to a teachers meeting and I was there to find out about education issues. But a teacher came up to me and was really panicked. She said that her brother, who had been in a group home for 20 years or so, was getting kicked out of his group home. He had developmental, mental issues or emotional issues, and this was his home—he lived in a group home, I think with four people.

What happened in Minnesota—which you say does this well and maybe compared to other States we do—is they were de-funding this. So I decided to find out more about it. What I learned was that to some extent we were taking people out of group homes that the State was paying for, counties were paying for, and moving them. Again, this is someone who is very delicate and vulnerable, and taking them out of a place that he had lived for 20 years. This was why this woman was panicked.

What I found out about it was that they were de-funding programs and that private operators of group homes were taking over, and that they were spending less money. The way they would spend less money is to pay less for care and give shorter hours to the people taking care of those most vulnerable of our citizens. These are great people who do this, who take care of these people, and they don't do it for the money, but the people I met do it because they love doing it and it gives meaning to their lives.

I heard that the private owners of these group homes were saying, "OK, we don't need anyone to stay over at night," and they reduced people's hours and they reduced the care, and they were doing this to make money.

I guess my question is, Ms. Mann, what can you tell me about private companies that cut corners and how patients suffer? What are we doing on this front? And Mr. Perez, you can answer me as well.

Ms. MANN. Well, I think there are corners being cut in lots of different places. My first reaction to this story is how awful it is to be that person and to be that person's family and to be out of control, not being able to make that decision about what goes on in the most important aspects of their life.

I think one of the really important ways in which we have to rethink how we're approaching the care and support that we're providing for people living with disabilities is to give them back an ability to control and make their own decisions to the fullest extent possible.

We have seen a lot of cutbacks. We have seen cutbacks going on at the State level. We've had cutbacks going on in individual provider levels. Personal care attendant services is one area where we've seen cutbacks because of State budget cuts.

Generally—

Senator FRANKEN. I'm sorry, but do you have any comments in particular about private companies?

Ms. MANN. About private?

Senator FRANKEN. Yes.

Ms. MANN. Generally it would be, at least under the law—now, whether or not that was actually what was happening—it would be the State that would decide whether or not there's a different standard that the provider is putting into place. Now, we all know that in real life different providers apply a standard in different ways. So then the question is how aggressively is the State overseeing its different providers to see that there's an evenhanded application of the rules.

Senator FRANKEN. Mr. Perez, has this been a subject that you've run into at all?

Mr. PEREZ. We had a case in the District of Columbia that we were involved in involving a private facility and we argued to the court—it was an ADA case—that the ADA required the private provider to take steps to ensure the safety of the individual who was residing in the group home. So we actually did get involved in that particular case.

Senator FRANKEN. That's one case, but I'm saying that as—well, my time is up.

Mr. PEREZ. It's an absolute concern, Senator, and as we move people into community-based settings and we build the community infrastructure, we are ever mindful of the need to be equally vigilant about oversight, because part of the answer perhaps to Mr. Chairman's question before of why don't they do this more quickly is because it's easier to oversee one facility in the eyes of some States than to have people going into 16 community-based settings, go to one place with 150 people as opposed to 20 places with 8 people.

Senator FRANKEN. I'm going to end here, but I just wanted to tell this story, because this is one family and one person, but I wanted people to understand what this means to one person and one family.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Franken. Well, the story of one person and one family, you can multiply that a million times, and that's what's happening around the country.

Well, we just have to renew our efforts in this area. But before I dismiss this panel, I wanted to ask this panel one thing—oh, I'm sorry. Senator Hagan. I'm sorry. My gosh, I'm getting involved in my own thinking here.

Sorry, Senator Hagan.

#### STATEMENT OF SENATOR HAGAN

Senator HAGAN. You're the chairman. That's OK with me.

But thank you, Mr. Chairman. I did want to say, this is the first time I've seen Mr. Perez since a very, very cold morning in February, I think it was 7 a.m., when—

Mr. PEREZ. Greensboro.

Senator HAGAN [continuing]. For the Civil Rights Division of the Attorney General's Office, he helped me and several others cut the ribbon on the Woolworth's restaurant which is now a civil rights museum, where the Greensboro Four, the four young men from North Carolina A&T, began the sit-in movement at the lunch counter. So that was a very, very cold morning and it was certainly a great day in my State.

Mr. PEREZ. That was 10 or 15 years of your leadership in getting that done. So I want to commend you for your leadership.

Senator HAGAN. It was a great day.

And I thank you for this hearing. Mr. Perez, in your testimony you mentioned a young man named Paul Boyd who has had to remain in an institution because of long waiting lists he faces to access services. I think he wants to go get a master's degree and has issues with transportation and night classes, ET cetera. But we need to ensure that people like this young man have access to community care programs so that they can be productive members of society.

I was wondering, toward that end, have there been any analysis of the cost of providing community care compared to the increased productivity among those who are disabled but still able to work?

Mr. PEREZ. There have been and there again is a robust evidence base demonstrating that community-based care is cost-effective, that you can do it and actually save States money in the long run. And that doesn't even take into account then the additions to the Federal treasury from having people with disabilities—and the unemployment rate, as you know, for people with disabilities is north of 50 percent nationally, and having more people employed means we have more people paying into our tax base.

It's very compelling, the cost-effectiveness argument that can be made.

Senator HAGAN. To date have there been any analyses done on the costs and benefits of the Money Follows the Person demonstrations?

Ms. MANN. Yes. There's been an evaluation and we can provide you and your office with the evaluation and what we've learned so far. We are constantly re-looking with our States at what's working and what's not and trying to look for improvements. We've seen pretty slow startup numbers in Money Follows the Person, but our numbers in 2010 are much stronger relative to any of the prior 3 years, and we're really hopeful that the extension will build on the base that's been provided and the learnings that have occurred, so that we can really grow that progress by leaps and bounds over the next period of time.

Senator HAGAN. Do you have any examples, one example that you can address on that, as to how that works?

Ms. MANN. How the Money Follows works?

Senator HAGAN. Yes.

Ms. MANN. States get grants and there's enhanced match for some services. It's 100 percent paid for by the Federal Government, and it allows the State to set up systems, infrastructures, to bring in peer supports, whatever may be necessary to help transition people from an institution into the community.

Then the grant also allows them to pay for the community-based services for the first 365 days after they've transitioned out of the community. So it's setting up a care plan, making sure that the services are available in the community, setting up the community setting, making sure that the person has the services they need.

Then some of the rub comes in, because of what happens after the 365 days.

Senator HAGAN. That was my next question. After the next year, with the States having extreme budget problems that everybody's in right now—

Ms. MANN. That's right, and that's where we've had problems.

Senator HAGAN. That's a stumbling block.

Ms. MANN. That's correct.

Senator HAGAN. Well, Ms. Mann, in your testimony you mentioned that there are still over 1.6 million Americans receiving services in institutions. That certainly seems like quite a huge number. Of those 1.6 million Americans, how many do you estimate are on community-based living waiting lists?

Ms. MANN. Waiting lists? We don't really know. Some States don't create waiting lists. Some States have waiting lists for certain—as Mr. Perez was talking about before, there is different waivers for different types of disabilities, so that if a State doesn't run a home and community-based waiver for your type of disability in an institution, you may not be on a waiting list even though you are waiting.

So it is hard to get a real accurate sense of the need from just looking at the waiting lists. I think some of what the Office of Civil Rights is doing in terms of its work inside institutions to be able to identify what portion of the people in the institutions want to be and believe they can live their lives productively outside of the institution is one of the most direct ways we have of really measuring that.

Mr. PEREZ. The assessments haven't always been done, and so that's why it's difficult to quantify the percentage of people in that broader figure. Olmstead talks about having an assessment done by a treatment professional and part of our work is to ensure that those assessments are, in fact, being done and that they're done by a qualified treatment professional.

Ms. MANN. That's certainly part of what Money Follows the Person looks at and encourages.

Senator HAGAN. You also mentioned in your testimony that CMS works with States to provide technical assistance to meet community-based requirements. Can you tell me what some of the technical assistance provisions are?

Ms. MANN. We have a number of different contracts that we work with, that we have working with States. Our staff will work tirelessly with a State that comes in and says: "I'm thinking of moving in this direction;" "I'm stuck," or "I've gone in this way and I've had a problem," or "DOJ is after me, what should I do," whatever the circumstances might be.

One of the things that we did in our May 20 letter to State Medicaid directors is to try and remind them that there is really a wide array of options, so that on a piece of paper they can see those options, and then to invite them to work with us, in some cases to work with our contractors, to think about what are the options that are most viable for them, given their particular circumstances.

Senator HAGAN. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Hagan. Again, I apologize. I guess I was just thinking about one question I wanted to ask Ms. Mann before you left.

Do you think the 6 percent is going to be enough? I'm talking about the Community First Choice Option beginning October 2011. We wrestled with that and I don't know if you have any feel for it. But what do you think? Do you think that 6 percent bump-up in FMAP will be enticing enough?

Ms. MANN. I'm optimistic that it will be. It's certainly not an insignificant bump-up for States, Senator. We've heard some really positive reactions from States. I think time will tell and it depends how long this period of economic downturn continues. But at least it's getting people's attention, let's put it that way. They're noticing that it's there and see it as an important part of helping them move forward, and whether it proves to be sufficient, we'll certainly be watching that closely and wanting to work closely with you about what we're seeing.

The CHAIRMAN. Great.

Tom, have you got any last comments?

Mr. PEREZ. Thank you for your leadership. Civil rights is about persistence and you're one of the most persistent leaders I have ever met, Mr. Chairman.

The CHAIRMAN. I'll return the compliment. I thank you and Ms. Mann both for your aggressive championing of people with disabilities in all aspects. I just can't thank you enough.

Mr. PEREZ. Thank you.

The CHAIRMAN. I appreciate it.

Ms. MANN. Thank you.

The CHAIRMAN. We'll call our second panel. Our first witness is Robert Bernstein. Dr. Bernstein is Executive Director of the Bazelon Center for Mental Health Law in Washington, DC. A nationally recognized expert on public mental health, he was the architect of an innovative system serving people with persistent mental illnesses in integrated community-based settings.

He holds a doctorate in psychology and is also an experienced clinician. He has served as an expert for the U.S. Department of Justice and State protection and advocacy agencies. Dr. Bernstein joined the Bazelon Center in 1997.

Our second witness is Jeffrey Knight. Mr. Knight is an individual with a disability who is a current beneficiary of a home and community-based waiver, as well as the Money Follows the Person Rebalancing Initiative in the State of Maryland.

Mr. Knight was born in Virginia and graduated from Warren County High School. After graduation he lived on his own, supporting himself at the age of 18. He worked for over 11 years for Fort Detrick in Frederick, MD. Over 2 years ago, Mr. Knight entered the hospital because of seizures. He eventually was placed in a nursing facility. He lived at Citizens Nursing Home, a county-owned facility. During his 2 years in the nursing facility he sought help to return to the community and he fought hard to leave the facility and gain back his freedom.

On October 1, 2009, he was able to leave the nursing home through the use of a Medicaid waiver and the Money Follows the Person program in Maryland. He is currently living in the community and enjoying the opportunities of community life.

I might just note that he began with 16 hours of personal assistance per day and now he's down to 8 hours, and he's become a self-advocate, as I'm sure we'll hear here pretty soon.

The third witness is Nancy Thaler, Executive Director of the National Association of State Directors of Developmental Disabilities Services, which serves 50 States and the District of Columbia, and keeps State leaders informed about Federal policy and service innovations. Ms. Thaler began her career in 1971 working in nonprofit agencies, developing community services for children and adults with developmental disabilities.

Joining the Pennsylvania State Government in 1987, she managed a system of institutional and community services for over 80,000 individuals. Ms. Thaler's leadership enabled the expansion of community services for Pennsylvanians with disabilities, resulting in a 50 percent reduction of the institutional population during her tenure. Fantastic.

Then last we have Kelly Buckland, Executive Director of the National Council on Independent Living (NCIL), which we all know as "Nickel." Mr. Buckland has been actively involved in disability issues since 1979. He started his career as an employee for Idaho's protection and advocacy system. He served for over 20 years as the Executive Director of the Boise Center for Independent Living and the Idaho State Independent Living Council.

Mr. Buckland has served on the NCIL Governing Board since 1998, as vice president from 2001 to 2005, and as president from 2005 to 2009. He has been honored with numerous State and national awards, graduated from Boise State University with a B.A. in social work, and, most important of all, earned his master's degree in rehabilitation counseling from Drake University in Des Moines, IA.

Welcome, all of you, to this panel. As I said for the first one, your statements will be made part of the record in their entirety. I'd ask if you might just—and we'll just go from left to right—just sum up in 5 minutes or so your main points, so we can engage you in a conversation.

Mr. Bernstein, welcome and again congratulations to you and the Bazelon Center for all the great work you've done.

**STATEMENT OF ROBERT BERNSTEIN, Ph.D., EXECUTIVE DIRECTOR, BAZELON CENTER FOR MENTAL HEALTH LAW**

Mr. BERNSTEIN. Thank you very much, Mr. Chairman, and thank all members of the committee for allowing me to testify today. I'm pleased to testify about the Americans With Disabilities Act, legislation that is crucially important to people with mental illness. My name is Robert Bernstein and I'm President and Director of the Bazelon Center for Mental Health Law, which has been advocating for the rights and social inclusion of people with mental illness for almost 4 decades.

I began my work as a psychologist in public mental health, where I learned firsthand how law and policy define or foreclose opportunities for people with serious mental illness, particularly those who rely on public assistance.

From the ADA's inception, the Bazelon Center has worked to make sure that its protections include people with mental disabil-



ities, and we continue to advocate in the courts, with legislative bodies, and with Federal and local agencies to ensure that it has its intended impact. No group of disabled Americans has been subjected to more harmful and enduring discrimination than people with serious mental illness. Hundreds of thousands of these Americans were once physically segregated behind the locked doors of State hospitals based on fear, disdain, or the perception that there were no viable alternatives. In many ways, sadly, as you heard earlier, this history remains with us today, in nursing homes, board-and-care facilities, and jails across the Nation.

The ADA for us represents a very ordinary vision, but one that dramatically departs from this history, a vision that people with serious mental illness may have homes they can call their own and participate in society as neighbors, friends, and co-workers, and that they be judged as individuals, untarnished by shaming stereotypes.

Of course, the bold act of Congress, for which we're eternally grateful, even when bolstered by the U.S. Supreme Court's landmark *Olmstead*, does not instantly reverse discrimination that is embedded in society and reflected in its institutions. But on this 20th anniversary of the ADA's enactment, I'm happy to report that we have at least begun to think about mental disability and the role of public systems in very different ways.

Nationally, we see examples of programs demonstrating that people with serious mental illness, even those who have been institutionalized for many, many years, can recover, live in their own homes, outside of psychiatric ghettos, and not be regarded as "ex-mental patients." Scattered-site supportive housing is a powerful model that the Bazelon Center is strongly endorsing. Through local programs providing flexible, individualized services and supports to people in their own homes, individuals who were once consigned to isolated custodial settings now fulfill the vision of the ADA.

Generally, as you've heard, this is achieved at costs that are lower than or, at most, equal to institutional care. These individuals not only realize their personal dreams, but by example demonstrate that the ambitious goals of the ADA are achievable even among a group as derided as people with serious mental illness.

Our challenge today is not so much know-how or even demonstrating cost neutrality, as it is deconstructing the systemic barriers and vested interests that sustain segregation and low expectations. Large State hospitals may be relics of the past, but many people with serious mental illness remain on the margins of society because supportive housing and other good programs are in short supply. Often, access to these programs is targeted to groups that have been visibly failed by human services systems, people with frequent hospitalizations or those who are homeless or incarcerated, for instance. However, many more people with serious mental illness languish in archaic facilities such as nursing homes, group homes, and the infamous adult homes in New York City that a Federal court recently declared in violation of the ADA.

Such facilities may be physically located in communities, but they are not at all what one would consider homes. The residents remain isolated from community life and they have no privacy, no meaningful personal choice, and no hope for something better.

Their rights under the ADA notwithstanding, individuals living in these settings are often mischaracterized by public systems as successfully placed because they are no longer in hospitals. And, in the absence of litigation, they are no one's priority.

For this reason, the Bazelon Center is working closely with the U.S. Department of Justice toward vigorous enforcement of *Olmstead* and to ensure that its benefits extend to all people with serious mental illness, including those who remain hidden on the sidelines. We are also working closely with the Centers for Medicare and Medicaid Services to extend to people with serious mental illness initiatives such as Money Follows the Person, that have promoted *Olmstead* for other disability groups, but have rarely reached people with serious mental illness.

We are grateful for support from SAMHSA that allows us to provide technical assistance to States around *Olmstead* implementation, and one potential source of funding for the services we seek is the SAMHSA mental health block grant, which needs to be restructured to be more targeted and to focus more directly on the ADA as a priority.

Last year on the tenth anniversary of the U.S. Supreme Court's decision, the Bazelon Center issued a call to action titled "Still Waiting—The Unfulfilled Promise of *Olmstead*." I provided your staff with copies of this. In this report, we decried the slow progress toward integration and listed many opportunities for Federal, State, and local action.

Fulfillment of this promise is important to all of us, not only because it will represent a more just society, but also because America will fully benefit from the now-unrealized contributions of people with mental illness.

Thank you for this opportunity to testify. I look forward to your questions.

[The prepared statement of Mr. Bernstein follows:]

PREPARED STATEMENT OF ROBERT BERNSTEIN, PH.D.

Mr. Chairman and members of the committee, I am pleased to testify before you today about the Americans with Disabilities Act (ADA), legislation that is crucially important to people who have mental illness. My name is Robert Bernstein and I am the president and director of the Bazelon Center for Mental Health Law, which has advocated for the rights and social inclusion of people with mental disabilities for almost four decades. I began my work as a psychologist in public mental health, where I learned first-hand how law and policy define—or foreclose—opportunities for people with mental illness, particularly those who must rely on public systems.

From the ADA's inception, the Bazelon Center has worked to make sure that its protection include people with mental disabilities, and we continue to advocate in the courts, with legislative bodies, and with Federal and local agencies to ensure that it has its intended impact. No group of disabled Americans has been subjected to more harmful and enduring discrimination than people with serious mental illness. Hundreds of thousands of these Americans were once physically segregated behind the locked doors of huge abusive State hospitals, based on fear, disdain or the perception that there were no viable alternatives. In many ways, that history remains alive—in nursing homes, board-and-care facilities and jails across the Nation.

The ADA represents a very ordinary vision, but one that dramatically departs from this history: A vision that people with serious mental illness have homes they can call their own and participate in society as neighbors, friends and co-workers, and that they are judged as individuals, untarnished by shaming stereotypes. Recognizing the harmful effects of ingrained discrimination and inaction—or even resistance—by States to the reforms demanded by the ADA, the Bazelon Center played an important role in defending the law's "integration mandate" when *Olmstead* came before the Supreme Court. Gleaning the essence of the ADA and the larger

civil rights movement for people with mental illness, the Supreme Court found in *Olmstead* that “Unjustified isolation . . . is properly regarded as discrimination based on disability.”<sup>1</sup> Without question, the marginal social status of many individuals who have serious mental illness is the product of such discrimination. Further, the Supreme Court affirmed that public systems’ unnecessary consignment of people with mental illness to institutional living, “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participation in community life.”<sup>2</sup>

Of course, a bold act of Congress—even when bolstered by a landmark Supreme Court decision—does not instantly reverse discrimination that is embedded in society and reflected in institutions. But on this 20th anniversary of the ADA’s enactment, I am happy to report that we have at last begun to think in very different ways about mental disability and the proper role of public systems. Recovery and hope have replaced containment as the new focus of public mental health services.<sup>3</sup> And nationwide, we see many examples of programs demonstrating that people with serious mental illness can recover, live in their own homes outside of psychiatric ghettos and not be regarded as “ex-mental patients.” Scattered-site supportive housing is a powerful model that the Bazelon Center is promoting to support successful community membership among people with serious mental illness.<sup>4</sup> Through local programs providing flexible, individualized services and supports to people in their own homes, individuals who were once relegated to isolated custodial settings now fulfill the vision of the ADA. These individuals not only realize their personal dreams but, by example, demonstrate that the ambitious goals of the ADA are achievable, even among a group as derided as people with serious mental illness. And as we have seen in New York, where the Department of Justice has joined the Bazelon Center and local advocates in litigation to allow residents of archaic adult homes to live in scattered-site supportive housing, the very individuals who were once confined in these settings are reaching back to assist their peers in re-entering community life.<sup>5</sup>

Ironically, these positive outcomes in supportive housing can be achieved at costs that are lower than, or at most equal to, institutional care. The cost of serving a person in supportive housing is half the cost of a shelter, a quarter the cost of being in prison and a tenth the cost of a State psychiatric hospital bed.<sup>6</sup> And supportive housing is not unique in this regard. For instance:

- Investments in treatment and parole services could save States \$4.1 billion. For example, every dollar spent on community-based drug treatment avoids \$18 in State spending.<sup>7</sup>
- An in-home crisis intervention program for psychiatric patients found that nearly 81 percent could be treated at home and that patients who received home care were less likely to be re-admitted to the hospital. Considering that the average 2007 Medicare payment was \$137 for a home health day versus \$1,447 for a hospital day and \$325 in a skilled nursing facility, the home-care option can produce significant savings.<sup>8</sup>
- Systems of care for children reduce inpatient hospital days, saving an average \$2,777 per child, and arrest rates, for average per-child savings of \$784. Multi-systemic therapy for high-risk youth saves more than \$31,661 in subsequent costs to the criminal justice system, while multidimensional treatment foster care for troubled youth saves \$43.70 in residential treatment costs for every dollar spent.<sup>9</sup>

<sup>1</sup> *Olmstead v. LC*, No 98–536 (U.S. Sup Ct, June 22, 1999).

<sup>2</sup> *Ibid.*

<sup>3</sup> New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America*. Final Report. DHHHS Pub. No. SMA–03–3832. Rockville, MD: 2003.

<sup>4</sup> See [http://bazelon.org.gravitatehosting.com/LinkClick.aspx?fileticket=q6Fsul.6o\\_jw%3d&tabid=241](http://bazelon.org.gravitatehosting.com/LinkClick.aspx?fileticket=q6Fsul.6o_jw%3d&tabid=241).

<sup>5</sup> See <http://bazelon.org.gravitatehosting.com/In-Court/Current-Cases/Disability-Advocates-Inc.-v.-Paterson.aspx>.

<sup>6</sup> Houghton, The New York/New York Agreement Cost Study: The Impact of Supportive Housing on Services Use for Homeless Mentally Ill Individuals, May 2001, 6–7. <http://www.csh.org/index.cfm/?fuseaction=Page.viewPage&pageID=3251>.

<sup>7</sup> Justice Policy Institute, *Pruning Prisons: How Cutting Corrections Can Save Money and Protect Public Safety*, <http://www.justicepolicy.org/content-hmID=1811&smID=1581&ssmID=84.htm>.

<sup>8</sup> Agency for Healthcare Research and Quality, *Home Health’s Ability to Control National Health Care Costs*, <http://www.ahrq.org/download/File/databook/ControlCosts.pdf>.

<sup>9</sup> Daly, R. Mentally Ill Youth Do Best In Community Care Settings, *Psychiatric News*, June 2, 2006; Washington State Institute for Public Policy, *The Comparative Costs and Benefits to Reduce Crime*, 2001, <http://www.wsipp.wa.gov/rptfiles/costbenefit.pdf>.

Our challenge today is not so much demonstrating that we know how to assist people with serious mental illness in realizing their rights under the ADA, or even in demonstrating that the outcomes we seek are fiscally sound. Much more at the forefront of our advocacy in pursuit of community integration for people with serious mental illness is the task of deconstructing the systemic barriers and challenging the vested interests that sustain segregation and low expectations. Large State hospitals may be relics of the past, but many people with serious mental illness remain on the margins of society because supportive housing and other good programs are in short supply. Often, access to these programs is targeted to groups that have been visibly failed by human service systems—people with frequent hospitalizations, or those who are homeless or incarcerated, for instance. However, many more people with serious mental illness languish in archaic facilities, such as nursing homes, group homes and the infamous “adult homes” in New York City that a Federal court recently declared in violation of the ADA.<sup>10</sup>

Such facilities may be physically located in communities—and some even have the physical appearance of houses—but they are not at all what one would consider homes. The residents remain isolated from community life and they have no privacy, no meaningful personal choice, and no hope for something better. They often live with assigned roommates and may receive visitors only at defined times and in defined areas of the facility. The rights of these individuals under the ADA notwithstanding, people living in these settings have been mischaracterized by public systems as “successfully placed” because they are no longer in hospitals. Ironically, even as they face dire budgetary cuts, States continue to waste money by consigning people with mental illnesses to such institutional settings, often pressured by profit-making providers. While the annual cost of housing someone in these places may range \$60,000 or more, it costs only \$22,500 a year to provide independent housing with a full range of supportive services for a person with a serious mental illness—and this in New York City, one of the Nation’s highest housing markets.<sup>11</sup> As documented by the media nearly every day, public mental health systems, instead of shifting to such cost-effective (and *Olmstead*-compliant) approaches, continue to struggle.

This is not to suggest that public mental health is adequately resourced—in part reflecting public attitudes about people with serious mental illness, State mental health systems were never adequately funded to achieve the basic ambitions of de-institutionalization, let alone the goal of recovery. And growth in States’ mental health spending (even during times when State coffers were flush) has lagged far behind that for other State agencies, representing about half of the growth in spending within their corrections systems.<sup>12</sup> But even in today’s difficult times, a more rational use of available dollars could very dramatically increase the availability of housing and supportive services that allow people with serious mental illness to realize their rights under the ADA.

Shortly after *Olmstead* was decided, the Bazelon Center issued a report entitled *Disintegrating Systems: The State of States’ Public Mental Health Systems*.<sup>13</sup> In that report, we anonymously quoted the mental health commissioner from a large State who was frustrated at the daunting systemic and political barriers (and, notably, *not* clinical barriers) that would need to be overcome if people with serious mental illness are to realize their rights under *Olmstead*. That State commissioner told the Bazelon Center: “Someone should sue us.”

Three years later, the Bazelon Center issued a statement on the impact of the ADA and the *Olmstead* decision to people with serious mental illness:

Where real progress has occurred, it is largely because States have been sued. Five years after *Olmstead* and 14 years after enactment of the Americans with Disabilities Act, litigation should be unnecessary. Yet it remains the single most effective way to combat the persistent segregation of people with mental illnesses.

It’s past time for *Olmstead* implementation to move out of the courtroom and into America’s communities.<sup>14</sup>

<sup>10</sup> See <http://bazelon.org.gravitatehosting.com/In-Court/Current-Cases/Disability-Advocates-Inc.-v.-Paterson.aspx>.

<sup>11</sup> Bazelon Center for Mental Health Law, *Still Waiting . . . The Unfulfilled Promise of Olmstead. A Call to Action on the 10th Anniversary of the Supreme Court’s Decision*, 2009, <http://bazelon.org.gravitatehosting.com/LinkClick.aspx?fileticket=S5nUuNhJSoM%3d&tabid=104>.

<sup>12</sup> *Ibid.*

<sup>13</sup> Bazelon Center for Mental Health Law, *Disintegrating Systems: The State of States’ Public Mental Health Systems*, 2001.

<sup>14</sup> *Ibid.*

Although the Bazelon Center has a vibrant, longstanding and nationally recognized litigation agenda, it is a sad commentary that, in the face of obvious social, moral and fiscal arguments, we still need to turn to the courts to enforce the basic rights of these Americans. Yet, in the absence of litigation, people with serious mental illness are no one's priority—particularly those who live quiet lives, robbed of hope and isolated in archaic congregate facilities.

For this reason, the Bazelon Center is working closely with the U.S. Department of Justice toward vigorous enforcement of *Olmstead* and to ensure that its benefits extend to all people with serious mental illness, including those who remain hidden on the sidelines. We are also working closely with the Centers for Medicare and Medicaid Services to extend to people with serious mental illness initiatives, such as Money Follows the Person, that have promoted *Olmstead* outcomes for other disability groups. We are grateful for support from the Substance Abuse and Mental Health Services Administration (SAMHSA) that allows us to provide technical assistance to States around *Olmstead* implementation. And one potential source of funding for the services we seek is the SAMHSA Mental Health Block Grant, which needs to be restructured to be more targeted and to focus more directly on the ADA as a priority.

Last year, on the 10th anniversary of the Supreme Court's decision, the Bazelon Center issued a call to action titled *Still Waiting—The Unfulfilled Promise of Olmstead*, in which we decried the slow progress toward integration and listed many opportunities for Federal, State and local action.<sup>15</sup> My testimony today reflects many of the findings from our report. Our recommendations for Federal actions call for Congress and the Federal agencies to carefully consider what we have learned in the 20 years since enactment of the ADA, including our successes, missed opportunities, and understanding of the system dynamics that have stalled progress for people who have serious mental illness.

The recent healthcare reforms enacted by Congress move us significantly forward in expanding access to coverage and addressing mental health as an aspect of overall health, on par with medical and surgical care. The impact of this legislation for people who have mental illness, particularly with regard to their rights under the ADA and *Olmstead*, will be defined in the law's implementation. Among our recommendations for Federal actions, which may be of particular interest to the committee, we urge Congress and the Federal agencies to:

- Include in healthcare reform incentives that adequately address the needs of people with serious mental illnesses. The law requires that the essential benefit include rehabilitation services, but these are not defined. It will be critical for the Department of Health and Human Services (HHS) to define this term so as to include coverage of psychiatric rehabilitation, peer support and case management services.
- Establish linkages between private plans and the public mental health systems. Comprehensive systems that address a person's total health care needs, such as medical homes, need to address mental health issues and specialized medical homes that serve individuals with serious mental illness (such as are authorized as a demonstration of SAMHSA) need to be expanded.
- Pass the Community Choice Act, which would make a package of home- and community-based services a mandatory Medicaid service for individuals who would otherwise be served in institutional settings.
- Amend Medicaid to give States the option to provide home- and community-based services to children with serious mental disorders who are at risk of placement in residential treatment facilities (at this time, these facilities do not qualify as "institutions" under the section 1915(c) authority).

We recommend that CMS, as the agency administering the Medicaid program, should:

- Issue letters to State Medicaid directors highlighting both ways for States to facilitate integration and options for financing services in integrated settings for people with mental illness.
- Clarify that while Medicaid permits States to limit the number of individuals served in waivers, *Olmstead* may require that limits on waiver participation be lifted. CMS should streamline and accelerate the waiver process and condition renewal on States expanding the waiver to cover more people.
- Revamp the Federal rules on rehabilitation services to encourage States to furnish the evidence-based services that have proven effective in helping people with serious disorders to live in the community.
- Encourage the use of homes or homelike settings, by paying for therapeutic foster care for children.

<sup>15</sup> Ibid.

- Accelerate its actions toward aggressive enforcement of current requirements for screening of individuals prior to nursing-home placement. The intent of this underutilized mandate—known as Pre-Admission Screening and Resident Review (PASRR)—is to avoid inappropriate Medicaid expenditures for institutional care and the “dumping” of people with mental illnesses who should be served in their home communities. While pre-dating enactment of the ADA, PASRR should serve as a powerful tool to avert unwarranted institutional segregation.

- Enforce the “IMD” rule that prohibits Medicaid payment for mental health services to people between the ages of 22 and 65 in an “institution for mental diseases”—a facility in which a significant percentage of residents have mental illnesses.

We are heartened by recent actions by CMS and the Department of Housing and Urban Development to promote supportive housing for people with serious mental illness, using HUD funds and Medicaid. In addition, Congress should:

- Enact and fully fund the Melville Supportive Housing Investment Act to improve Section 811 Supportive Housing for Persons with Disabilities. Once the law is enacted, the administration should initiate HUD planning to implement its provisions expeditiously.

- Ensure dedicated support for the National Housing Trust Fund to produce or preserve 1.5 million homes and 200,000 new Housing Choice vouchers per year for the next 10 years. HUD regulations and guidelines for implementation of the Fund must prioritize creation of new affordable supportive housing for people with disabilities who have SSI-level incomes. (In most urban areas, market rent exceeds monthly SSI disability payments).

- Sustain existing supportive housing by renewing with predictability and stability its funding for rent and operating subsidies and services.

- Create incentives within the HOME program to encourage State and local housing officials to prioritize permanent supportive housing. For example, a percentage of HOME funds could be set aside for permanent supportive housing.

- Increase Federal funding for re-entry supportive housing vouchers and services for people with mental illnesses leaving correctional facilities. One way is through creation of a bridge rental-voucher program in which the Justice Department’s Bureau of Justice Assistance awards grants for vouchers to State and local jurisdictions.

- Make clear that States violate *Olmstead* when they direct SSI money to uses that promote segregation of individuals with disabilities in private facilities (including board and care homes).

- Ensure that the Section 8 housing certificates allocated to individuals with disabilities are actually in the hands of such individuals.

We have been working closely with leadership within the Department of Justice (DOJ) and highly commend its increasing attention to the ADA rights of people with serious mental illness. DOJ, in some cases along with other agencies, should:

- Vigorously enforce *Olmstead*, including by filing cases that raise solely *Olmstead* claims.

- Adopt legal positions that would make *Olmstead* enforcement more effective.

The Office of Civil Rights (OCR) of HHS should also enforce *Olmstead* vigorously. OCR should:

- Broaden its enforcement efforts beyond those primarily driven by individual complaints; rather, evidence of systemic issues, including evidence other than complaints, should inform OCR’s activities.

What we conclude is lacking for people with mental illness to fully realize their rights under the ADA and *Olmstead*—and what is urgently needed—is political will. Fulfillment of the promise of the ADA is important to all of us not only because it will represent a more just society, but also because America will fully benefit from the now unrealized contributions of people with mental illness.

Thank you for this opportunity to testify. I look forward to your questions.

The CHAIRMAN. Mr. Bernstein, thank you very much for an excellent statement.

Now we’ll turn to Jeffrey Knight. Mr. Knight, welcome to this committee.

#### STATEMENT OF JEFFREY KNIGHT, FREDERICK, MD

Mr. KNIGHT. Hello, Senator Harkin and committee members. I’m just nervous, this is my first time. Thank you for giving me the op-

portunity, the chance to tell you my story. My name's Jeffrey Knight. I spent 2 years at Citizens Nursing Home. I entered the hospital after having an epileptic seizure and was placed in the nursing home because I could no longer walk.

It took me 2 years to leave the nursing home. At the time I went into the nursing home, I told myself I would get out and would not spend my life there, and I wanted my own apartment and to regain my freedom. Before I went into the nursing home, I lived at home and worked a job for 11 years at Fort Detrick. In the nursing home they treated me like a baby. They tell you when you can eat and when you can sleep and when you can smoke cigarettes and there was no privacy. I didn't worry about those things, but my life in there was spent in a small room, and shared with a stranger, and I wanted to get out because it was better to leave there. I had physical therapy to build my legs up, and am able to walk again. However, they stopped giving me the therapy I needed to walk. They stopped giving me services that I needed to walk and to stay able to walk. Then I was always afraid to walk a short distance. I slipped and fell on the wooden floors. The towels were dirty, and being in the nursing home was disturbing.

In October 2009 I was able to leave the nursing home going into my own apartment. Again, since living at home, I'm able to continue my therapy level and am building my legs up and can one day return to work, which is my biggest goal, and go out to dinner and to my friends' home, and go to picnics.

At the nursing home I felt like I was locked in. I walked around in the nursing home—it was like a cage, you know, living there. It was just a bunch of older people. It wasn't for me. That's what I was trying to say. The place was not for me. It was just older people and I was younger. I'm only 49. There were older people there, and I finally got out.

That's all. Thank you.

[The prepared statement of Mr. Knight follows:]

PREPARED STATEMENT OF JEFFREY KNIGHT

Good Afternoon Senator Harkin, Ranking Member Enzi, and members of the committee. I am Jeffrey Knight. I am a participant of a 1915(c), Home and Community-Based Medicaid waiver and the Money Follows the Person Rebalancing Initiative.

I appreciate this opportunity to discuss my experiences living in a nursing facility and how much it means to me to be given the opportunity to return to the community and live in my own home again. Without Maryland's Money Follows the Person program and the new Money Follows the Person program, I would have never had the opportunity to live in my own home again.

First, let me tell you a little history of Maryland's programs. House bill 752 enacted during the 2002 legislative session, requires social workers in nursing homes to present residents with information about home and community-based services that might help them live in the community. In the 2003 legislative session, lawmakers enacted House bill 478, the Money Follows the Individual Act. The act allowed individuals living in nursing facilities to access a 1915(c) waiver, Medicaid home and community-based waivers known as the Older Adults waiver and the Living at Home waiver. The Older Adults waiver was designed to provide Medicaid plus home and community-based services for individuals age 50 and older. It also includes transitional services such as the first month's rent, electricity, phone, furniture, household supplies, food, etc. for the first month. The financial eligibility requirements allow individuals who were 300 percent of Supplemental Security Income level to access the program. The Living at Home waiver is similar but it is for individuals age 21 through 65. Until 2003, anyone could apply for a waiver whether they were in a nursing home or living in the community, but there was a waiting list. In 2003, both of the waiver programs were closed to community appli-

cants because there weren't any slots available. Maryland began a registry for community applicants. The Money Follows the Person Act made it possible for anyone who resided in a nursing facility to receive a waiver without being on a waiting list or the registry. Currently, the registry has 15,000-plus persons on the list waiting for waivers. There is no such list for nursing home residents. Unfortunately, the only way to get a waiver is to live in a facility and be on long term Medicaid for 30 days. The law prohibits the Department of Health and Mental Hygiene from denying an individual access to HCBS waiver services due to a lack of funding for the program.

Maryland is 1 of 31 states receiving Federal funds from the Centers for Medicare and Medicaid for the Money Follows the Person Demonstration program as a result of the Deficit Reduction Act of 2005. Maryland has developed a Money Follows the Person Demonstration program to re-balance its long-term care costs from institutional care to home and community-based services so the money will follow the person into the community. I am a beneficiary of that effort.

I am 49 years of age. I was born and raised in Front Royal, VA. I graduated from Warrenton High School. After graduating, I moved to Frederick, MD. I have lived in Frederick County for 31 years. I worked at Fort Detrick as a custodian for 11 years. I was born with developmental disabilities, Epilepsy and learning disabilities. I have lived on my own and supported myself since I was 18 years of age.

Two years ago, I entered the hospital because of seizures. As a result, I was placed in a nursing facility for 24/7 care because of my inability to walk. My healthcare providers did not feel because of my disability I was able to care for myself. I lived at Citizens Nursing Home, a county-owned facility. Citizens Nursing facility is no different from other nursing homes. I had a horrible experience living there. It was depressing being in a place that was mostly older people. I had no one to talk to that I could relate with. I didn't like how I was cared for or how others were cared for. They treated me like a baby. They told me when to eat, sleep, and smoke. I had no time that was private or could be on my own. The small space given to me as a bedroom was small and confining. It was more like a hospital room. You have to share it with someone else. You didn't have your own things. There was no privacy, people in and out of your room, all day and all night. Your personal belongings are not safe. Things like electronics, food, and money are stolen. You hear residents screaming all night long. You have to eat what they prepared for you, not what you wanted to eat. I will never eat chicken again for as long as I live. Just to have a hot dog or a hamburger again was a dream come true. It was not clean. The floors and bathrooms had urine all over them. They didn't give you the therapy to get better. I just sat and stagnated, day after day. I had reached my limit and felt that I had to get away from there. I could not take living there any longer. I was totally disgusted with institutional life. So, I contacted the Maryland Disability Law Center (MDLC), the local protection and advocacy organization to find out what my options were. I wanted to go home. They worked with me by advocating getting the Living at Home waiver. The Freedom Center also worked with me to help me gain my freedom back.

In October 2009, I was finally able to leave. Between MDLC and The Freedom Center, my apartment was found and my services were put in place. The Living at Home waiver vendor, The Coordinating Center, helped me develop a plan of service which cost \$48,229.88 for 6 months. This included 16 hours of care for the first 3 months and 12 hours of care for 3 more months. After 6 months, I was able to get the waiver for a year at a time because my attendant care was reduced to 8 hours per day. I don't need as much care now. The cost of my plan of services now is \$25,094.44. It is much more cost-effective living in my own apartment and that cost is going down allowing Maryland to save even more dollars as a result of the Money Follows the Person Demonstration program. Because of the Medicaid waiver program and Money Follows the Person, I have my own privacy and freedom to come and go as I please I am not locked down like I am in a cage. I get to eat what I want to eat. That first hot dog was the best meal I had ever had. I can eat what I want and when I want to. I am now able to get rehabilitation so I can build my legs up to be able to walk again. I came out of a nursing home using a wheelchair and now, most of the time, I can use just my walker. It is my hope to be able to walk without assistance. My No. 1 goal is to be able to go back to work part time. I can take my medication on my own. I don't have to wait until someone brings it to me. I can visit friends in their homes for the holidays. I can watch TV when I want to. I can watch whatever I want on TV. I really love watching movies either in my bedroom or in my living room. I am able to attend social functions such as picnics and holiday parties. I am, for the last 8 months, enjoying my freedom and being able to control my life in the way I want to. I am at peace. I am becoming a self-advocate and have shown my support by my opposition to Transit budget cuts



which would have affected my paratransit services. I will never go back to a nursing home. I will disappear if someone tries to put me back in a nursing home. I am so strong in wanting to live in the community that it was very hard for me while I waited for everything to be put in place so I could leave. I almost left the nursing home against medical advice. I was ready to leave with or without a waiver. I didn't because I didn't want to jeopardize what I needed in services. My life now is what I want it to be. I am happy and I get much better care than I ever did while in the nursing home. My meals are delicious. And, my apartment is clean. I cannot ever imagine being back in a nursing facility. I am relaxing and enjoying life.

Thank you for allowing me to share my experiences with you and I hope that what I have said will help keep these valuable programs in place and allow others to leave nursing homes and gain their freedom as I have.

The CHAIRMAN. Thank you, Mr. Knight. Thanks for being here and thanks for telling us your story, and your leadership. You're a great example for others.

Mr. KNIGHT. You're welcome.

The CHAIRMAN. A great example.

Mr. KNIGHT. I think they rebuilt it, but the place should be looked at, because when I was there, I mean, for 2 years—at 3 a.m., there were patients in the middle of the hallway laying in their own urine. And the shower was filthy. That's in Maryland, but they've rebuilt it now. So hopefully it's a lot better place.

The CHAIRMAN. No one should be treated like that, no one.

Mr. KNIGHT. No, I know. Thank you.

The CHAIRMAN. Thanks, Mr. Knight.

Ms. Thaler.

**STATEMENT OF NANCY THALER, EXECUTIVE DIRECTOR,  
NATIONAL ASSOCIATION OF STATE DIRECTORS OF DEVELOPMENTAL  
DISABILITIES SERVICES (NASDDDS)**

Ms. THALER. Chairman Harkin, Ranking Member Enzi, and members of the committee, thank you for the opportunity to appear today to talk about the successes and challenges that we've experienced, the States have experienced, in providing community opportunities for individuals with developmental disabilities.

Mr. Perez talked about States having varying experiences depending on the category of people with disabilities. I'm here to talk about people with developmental disabilities, which includes a wide array of disabilities, including autism, Fragile X, and intellectual disabilities. But what people have in common is that they acquire their disability either at birth or in their early childhood years. So their families have been engaged in their disability issues as well.

I'm the Executive Director of the National Association of State Directors of Developmental Disabilities Services. I've been in the field for 40 years in nonprofit agencies and in State and Federal Government. I was for 10 years the Director of the Developmental Disabilities System in Pennsylvania and later worked at CMS, helping them to devise protocols for Federal oversight of home and community-based services.

I also should mention I'm the mom of a 45-year-old son, Aaron, who has developmental disabilities and whom my husband and I liberated from an institution through adoption.

The mission of NASDDDS is to help States develop effective systems for people and their families. We do provide analysis of Federal statutes and regulations. We disseminate information on state-of-the-art programs. We provide a great deal of technical assistance

to our States, including about transferring people from institutions to the community. We are also a forum for the development of State and national policy initiatives.

The States have made dramatic progress in moving from institutions to communities for people with developmental disabilities. The indicators of that progress are: the institutional population has dropped from a high of a quarter of a million people in 1967 to less than 36,000 people today. Of the \$43 billion of State and Federal funds that are invested in the DD system, almost 70 percent is invested in community services. Today there are 10 States and the District of Columbia that have no public institutions and another 12 States with less than 200 people in institutions. We are definitely far down the path of moving toward the community.

How has this success been possible or what have been the drivers of this success? There are about nine of them. First are the parents and advocates who initially in the 1970s outraged about conditions in institutions, fought to reform them and then close them. They later fought then for the right to education, which was adopted in 1975, which has made it possible for all children to go to public school every day. We saw then a precipitous decline in the admissions of children to institutions.

Private nonprofit agencies, fueled with the energy of newly graduated baby boomers in the 1970s, came forward with great creativity to create a wide array of community services. The Department of Justice and the protection and advocacy agencies in States have filed actions to enforce the rights of people with disabilities and they have leveraged change as well.

Medicaid funding and Federal statutes, in particular the Medicaid waiver and Money Follows the Person, have been critical. In fact, transformation of the system toward community services would not have been possible without them.

The expectations of a new generation of families who expect that their children—who have been going to public school—are going to live their entire lives in the community, are leading to new challenges. People want to control their own budgets and make their own decisions about the services they get.

Another factor driving change has been the cost of institutional services, which has become burdensome, at an average cost of \$188,000 a year per person as compared to about \$43,000 for home and community-based services.

Another key factor has been that the States have authority to close institutional beds and institutions because they own them and they run them. They do not have that same authority over privately operated institutions or nursing homes. In order to achieve savings, it is necessary to close beds and move the resources to the community.

Finally, people with developmental disabilities themselves—and Mr. Knight is a great example of that—opportunities to live in the community and work in the community have brought abilities to life. Individuals with developmental disabilities have developed a strong collective voice through self-advocacy and they now speak for themselves very articulately.

There are remaining challenges. One of the largest is the restricted availability of State funding, which has been and continues

to be a barrier to developing community services. While States have embraced the Medicaid waiver, they are still dependent on the availability of State funds to expand services. We certainly would want to express our appreciation for the enhanced Federal financial participation through the ARRA (American Recovery and Reinvestment Act of 2009) legislation, which has, in fact, saved a lot of people by retaining their services.

Another obstacle to continuing the move toward community and moving people out of institutions is certainly opposition from State institution employees, which is not surprising since they have reasonable fears that they will be unable to maintain employment at the same wages and benefits if the institution closes. This challenge is addressed State by State, almost institution by institution.

Opposition from families of those living in institutions is probably the most complex of our challenges. When fears of abuse and neglect and poor quality in community services are addressed adequately, families may still object and feel that their decision should be final.

It would be an easy path to let the issue go for the 36,000 people remaining in institutions, avoiding having to ask families to reconsider a decision they made perhaps 30 or 50 years ago. However, knowing what is possible, knowing how much people improve significantly when they move from the institution to the community, knowing that families overwhelmingly approve of community services once their family member moves, professionals and State agencies cannot just let it go. They are compelled to keep the question open.

Another challenge for States is the waiting lists, which can be characterized as also preventing institutionalization. Almost all States have them and in too many places the death of a caregiver or some crisis is the only way to move to the top of the waiting list. The limited data we have suggests that there are thousands of people waiting. The shortage of State funds restricts growth of community services, a shortage that has become even more severe in the current economic climate.

Then we have the choice paradox. The statutory basis for community services is the right to receive services in an institution. When individuals apply for community services, they must formally opt-out of the institution and affirmatively choose the community. We call this choice. However, we know from the work of Richard Thaler and Cass Sunstein, authors of "Nudge," that when we present individuals with a choice, the decision process can be structured in a way that will influence their choice.

For instance an opt-out decision process is generally recommended for the administration of retirement programs because it results in more people enrolling in retirement programs because they choose not to opt-out. So what is the message in requiring individuals to opt-out of institutional services in order to receive home and community-based services? The message is a mixed one, because it promotes institutions even for those who desire the community. More than one State DD director has identified this quirk in the Medicaid program as problematic.

Finally, I'd like to say that the goal of the DD system is about a lot more than just providing services in the community. It is

about achieving the full participation of people in the life of their community. A real job at competitive wages, membership in civic organizations, knowing their neighbors, and having friends are the real measures of success.

The last thing I'd like to talk about are the apologies that we have seen from States. Recently the State of Minnesota became the sixth State in the Nation to issue a formal apology to people with developmental disabilities for the years of incarceration, abuse, and neglect in State-operated institutions. Those other States are Virginia, Oregon, California, South Carolina, and North Carolina.

Such an apology is an indication of a sea change in attitudes. States are apologizing to a group of people who in recent history were stripped of all their rights, who were denied an education and often medical treatment, who have been sterilized without consent, and were presumed to have nothing to offer society. These apologies, coupled with the almost complete abandonment of the term "mental retardation" from the names of State agencies, are indications that our public systems are about more than providing services; they are about respecting the rights and dignity of people with developmental disabilities and creating opportunities for full participation.

Change has reached all 50 States and the District of Columbia. They are all progressing, each at a different pace, but they are all making progress toward comprehensive systems of community supports and services.

Thank you.

[The prepared statement of Ms. Thaler follows:]

PREPARED STATEMENT OF NANCY THALER

Chairman Harkin, Ranking Member Enzi, members of the committee, thank you for the opportunity to appear today to discuss the successes and challenges States have experienced in providing community opportunities for individuals with developmental disabilities.

I am the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS). I began my career in 1971 working in nonprofit agencies developing community services for children and adults with developmental disabilities. Six years after joining Pennsylvania State government, I was appointed the State's Deputy Secretary for Mental Retardation where, from 1993 to 2003, I managed a system of institutional and community services for over 80,000 individuals. During my tenure as the State director there was significant expansion of community services for Pennsylvanians with disabilities who were on the waiting list for community services, including those living in institutions. During that time, over 2,000 people in institutions were provided with the opportunity for community living, reducing the institutional population by more than 55 percent. From 2003–2005, I served as the Director of Quality Improvement for the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS), Disabled and Elderly Health Programs Group, and was responsible for developing Federal oversight of State-operated Medicaid Home and Community-Based Services Waiver programs. My husband and I are adoptive parents of an adult son with developmental disabilities who spent much of his childhood in an institution and now lives and works in the community.

The National Association of State Directors of Developmental Disabilities Services provides an array of services to developmental disability (DD) agencies in the 50 States and the District of Columbia. The NASDDDS mission is to assist member State agencies in building effective, efficient person-centered systems of services and supports for people with developmental disabilities and their families. NASDDDS strives to provide member State agencies with timely analyses of Federal statutory and regulatory policies that affect people with disabilities; to disseminate information on state-of-the-art programs and service delivery practices; to supply technical

assistance and support to member States; and to offer a forum for the development of State and national policy initiatives.

PROGRESS IN ENSURING COMMUNITY OPPORTUNITIES FOR INDIVIDUALS  
WITH DISABILITIES

In 1967, the number of people with what was then called mental retardation living in large State institutions reached its high point, with 228,500 in large State intellectual/developmental disability (I/DD) institutions and 33,850 in psychiatric institutions. Much has changed since 1967. The most recent national data from 2008 indicates that there were 36,508 in State I/DD institutions—a drop of 194,650 people (84 percent) since 1967; and 767 in psychiatric institutions, a drop of 33,083 people (98 percent).<sup>1</sup>

Between 1967 and the mid-1980s, 5,000 to 10,000 people moved back into the community each year.<sup>2</sup> The civil rights movement that swept the country reached all elements of society, including people living in institutions. Many individuals who learned that they had a right to leave the institution, and had the capacity to do so without special assistance, simply left. The individuals who remained in institutions in the mid-1980s by and large could not leave to live in the community without special assistance.

In 1982 the adoption of the Medicaid Home and Community-Based Services (HCBS) Waiver made that assistance available. Allowing funds that were previously reserved for institutional services to be used for community services enabled State DD departments to build systems of community services that initially supported people leaving institutions and soon expanded to those at risk of institutionalization. For the next two decades, the institutional census continued to drop annually by 4,000 to 5,000 people.

Today, 10 States and the District of Columbia have no institutions for people with developmental disabilities; and 12 States have less than 200 people still living in institutions—Michigan with less than 5 and Minnesota with less than 25. A recent survey conducted by our association found that 67 percent of the States with institutions have plans to downsize or close facilities in the next few years.

By 2006, all but one State was spending more for community services than for institutional services. And, of the approximately 1 million people receiving services, less than 3.6 percent reside in institutions. By 2008, 66 percent of the \$43.83 billion of State and Federal funds that support people with I/DD were committed to community services.<sup>3</sup>

Why has there been such an overwhelming trend toward community services in the developmental disabilities services systems? There are many reasons and there have been many drivers.

KEY FACTORS DRIVING THE DEVELOPMENT OF COMMUNITY SERVICES

**First and Foremost is the Parent/Advocacy Movement.** Outrage at horrific conditions in public institutions in the 1960s and the lack of services for children and adults living with their families in the community fueled simultaneous efforts at: reforming public institutions; establishing a right to education; and creating services for adults living with their families. The thinking quickly evolved—reforming institutions, while important in the short run, was not the final goal. Offering everyone a life in the community became a focus of the advocacy agenda.

By the early 1970s, parents and advocates were experiencing success. Several institutional law suits had been filed resulting in improvements in the institutions as well as expanded opportunities for people to move to the community. Advocacy efforts to achieve the right to education resulted in landmark legislation first in the States, and then at the national level with the adoption of the *Education for All Handicapped Children Act* (Public Law 94–142) in 1975.

**The right to education** profoundly changed the experiences of children with developmental disabilities and the expectations of parents. Prior to the right to education, parents had two choices: to institutionalize their children—something routinely recommended by medical professionals—or to keep their child at home 24 hours-a-day without support or training. Many parents chose to keep their children at home rather than follow the advice of their doctor. But as their children grew,

<sup>1</sup>*Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* Lakin, K.C., Larson, S.A., Salmi, P. & Scott, N.

<sup>2</sup>*Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* Lakin, K.C., Larson, S.A., Salmi, P. & Scott, N.

<sup>3</sup>The State of the States in Developmental Disabilities 2008 Braddock, Hemp, Rizzolo Coleman Institute for Cognitive Disabilities, The University of Colorado.

so too did the stress of being an unsupported care giver. When parents came looking for help, all that States had to offer was the institution. So with grief and often guilt, parents sought admission for their children.

The right to education changed things. When schools opened their doors, admission of children to institutions dropped significantly—and the expectations of families rose just as quickly. If children could live with their families and go to school, then why wouldn't they live their entire life in the community?

**Private nonprofit agencies found in** the baby boomers they hired in the 1970s and 1980s people who were ready and eager to develop community services. Founded by families, faith-based organizations, and community groups, these nonprofits turned a vision into a reality for thousands of people with disabilities. Opening group homes, vocational training programs, and recreational programs they championed the cause of people with intellectual and developmental disabilities and helped them become part of the community.

And as they did so, they built more and more evidence that community living was, in fact, better for people who were once believed to need institutions. It was better for the person—and also better for their families who could now see them more frequently because the group homes were in the family's community rather than far away in a remote part of the State.

**The Department of Justice and Protection and Advocacy** also played a significant role in the shift from institutions to the community. Using the Civil Rights of Institutionalized Persons Act, the Department of Justice conducted investigations and litigation to press for improvements in facilities with the most egregious rights violations. Protection and Advocacy organizations, often contacted by families of those living in institutions, conducted investigations, and initiated litigation when conditions did not improve.

The result of these interventions was increased investment in the institutions to improve conditions, along with agreements to decrease the number of people in the institutions—and in many cases agreements to simply close facilities.

Adoption of the Americans with Disabilities Act (ADA), reinforced by the *Olmstead* decision, provided additional tools for organizations to advocate for community services, and it solidified the right of people to live in the community. The ADA and *Olmstead* are landmark statutes that have validated the values of the DD systems in this country.

**Medicaid Funding and Federal Statutes.** Statutes, regulations, funding, and technical assistance all play an important role in assisting States to make community opportunities available for people in institutions and on waiting lists.

The Developmental Disabilities Act, the Americans with Disability Act, the Individuals with Disability Education Act, amendments to Title XIX of the Social Security Act, and so many other statutes have opened doors and served as vehicles for States to provide services in the community. Most recently new Medicaid State plan options and Money Follows the Person grants have provided States with even more tools.

New Medicaid options have enabled States to expand services. While many States already had programs providing community services to individuals with developmental disabilities, usually called "family supports," the advent in 1982 of the 1915(c) Home and Community-Based Services (HCBS) Medicaid waiver program meant the availability of Federal funds to support individuals in the community—and this drove rapid expansion of such programs. Allowing States to waive comparability (i.e., target specific populations) and to include a diverse set of non-medical supports and services in their 1915(c) programs gave them the opportunity to innovate and to build systems of support around the specific needs of individuals. Paradoxically, allowing States to cap the number of waiver participants has played a key role in the robust growth of the program, as States have been able to expand their community infrastructure, develop a broad array of services and the capacity to provide them, and build expertise in serving individuals with developmental disabilities in the community, while retaining the tools they need to manage financial risk and ensure the survival of HCBS programs. Because of this freedom to innovate, States have become experts at serving individuals in the community who not long ago would have been considered impossible to serve outside of an institution.

Money Follows the Person (MFP) grants are assisting 27 of the 30 grant States to move people with developmental disabilities out of institutions and into the community. The grants are directly focused on a key barrier States have faced to rebalancing their systems of long-term supports and services. While we know that serving individuals in the community rather than in institutions is ultimately more cost-effective, the up-front transition costs involved in moving individuals into the community can often act as a deterrent to State efforts. The CMS implementation of MFP focused on effective transition procedures and used, as one measure of suc-

cess, the rate of return to facilities. The increased appropriation in the Patient Protection and Affordable Care Act (PPACA) will allow more States, and more individuals currently residing in institutions, to benefit from this valuable program.

The recent addition of the 1915(i) State plan option for HCBS, the Community First Choice Option, and enhanced Federal Financial Participation (FFP) for those States whose investment in community services is less than 50 percent are all examples of recent Federal initiatives aimed at giving States more opportunities to provide services to individuals in community settings.

The Centers for Medicare and Medicaid Services (CMS) has partnered with State agencies to explore ways in which CMS can assist States in advancing community services. The willingness of CMS leadership to meet regularly with the national associations representing various State agencies and to fund technical assistance to States is particularly noteworthy.

**A new generation of families with young children** who have benefited from early intervention services, public education, medical and clinical advances, and more importantly, have raised their children in a world that is more accepting of people with disabilities, a world that sees the value in diversity, a world that can recognize the gifts that each person brings. They are demanding even more change.

Families of young children not only reject institutions, they also reject community models that segregate or isolate their sons and daughters from typical life. They expect their sons and daughters to graduate from school, to get a job, to have meaningful relationships and to participate in the life of their community.

**The cost of institutional services** has also been a factor in the transition from the institution to community services. While the cost of providing services to each individual differs as systems respond to individual needs, in the aggregate, it is far more cost-effective to customize support that builds on each individual's strengths and the natural supports they have in their family and community, than to create a residential model that provides comprehensive services whether an individual needs them or not. In addition, investment in models of service that do not provide an environment where people grow and achieve positive outcomes is questionable public policy.

Cost is a factor because people with developmental disabilities do not enjoy an entitlement to services. Resources used inefficiently add numbers to the waiting list. The meager data on waiting lists indicates that over 100,000 people are waiting to be served.

**State Authority.** The effectiveness with which States have transferred funds from the institutional system to the community is directly related to the fact that States own and operate the institutional facilities and have full authority to determine the number of certified beds and the disposition of resources. However, privately operated ICFs/MR and nursing homes, however, present a challenge to rebalancing the system because States do not have the authority to close beds other than in situations where the facilities or the providers do not meet certification standards.

**And most importantly, people with intellectual and developmental disabilities** themselves have driven the change. An outgrowth of the movement of people from institutions to the community has been the growth of self-advocacy; i.e., people finding their voice and advocating for themselves. Self-advocates have survived indignities and often abuse in institutions and have demonstrated a level of courage, fortitude, and forgiveness that inspires everyone who hears their stories.

#### CHALLENGES REMAIN

The barriers to creating community opportunities for people who remain in the institutions are the same barriers that have been with States since the 1980s.

**The Availability of State Funding has been and Continues to be a Barrier.** While the Medicaid Home and Community-Based Services Waiver program provides significant Federal funding for services, it does so only on a matching basis—which requires States to fund up to 50 percent of the cost of services, depending on each State's matching rate. The scope of programs competing for resources within each State's budget include education, transportation, and law enforcement, coupled with a constitutional requirement to balance annual budgets that affects the growth rate of Home and Community-Based Services. The current fiscal crisis, which has meant precipitous drops in State revenue, has recently compounded the problem. States have embraced the Medicaid Waiver program because it provides them with tools to manage growth within the confines of the State's economic conditions. During times of economic gains, States will typically expand their waiver programs. Conversely, during times of economic distress, they will curtail growth.

**Opposition from employees** has been a factor in downsizing and closing of institutions. An institution may be the primary employer in a geographical area. In fact, some were established in rural areas many years ago precisely for the purpose of providing employment. Employees often enjoy robust wages and benefits that are difficult to replicate in other fields or in the private sector. It should come as no surprise that employees often oppose the downsizing and closure of facilities and that their opposition includes solicitations of support from legislators in their districts. Strategies used by States to overcome this barrier, such as guaranteeing employment in other State operations or in-State-operated community services, are not always feasible. Each facility closure has been accomplished by employing multiple strategies crafted uniquely for that particular facility.

**Opposition from families** is another challenge—and the most complex one. What we know from 40 years of experience is that people do better in the community than in institutions. No matter their age, they learn new skills, develop new competencies and appear to be much happier. We know this from research which has established that all individuals make gains but those with the most significant disabilities make the most gains after moving to small community residences.<sup>4</sup> But just as importantly, the thousands of provider staff, clinicians, and leaders in our field know this—because they have witnessed it.

We know that, regardless of the intensity of the opposition from families, once the person moves to the community the opposition melts and the family sees the benefits of community living. In fact, rarely has any family member requested the return of their son, daughter, sister or brother to the institution.

Opposition can be based on any number of assumptions. One is that the services in the community will be discontinued over time, leaving the family entirely responsible for providing both support and living arrangements. The fact that the Medicaid Waiver is funded with precisely the same funding sources as the institution—and that most community service systems are now over 50 years old—can assuage some of those fears.

Opposition based on the assumption that their family member can't live in the community can be addressed by taking families to visit community services that support people with the same level of needs as their family member. Arranging meetings for family members with people living in the community can also help to address those fears. In the past it has been said that for every person living in an institution, there is one in the community. Today it would not be an exaggeration to say that for every person living in an institution, there are thousands living in the community.

Opposition based on fear of abuse and neglect requires a frank discussion that acknowledges that abuse and neglect have been serious problems in institutions and can be an equally serious problem in the community. States must explain the processes they have built into community systems to prevent abuse and neglect, to detect it as soon as it occurs, to inform family members and to respond promptly.

The institution is often perceived as better able to provide intense and specialized services. It is important to educate families about the impact of environment and experience on learning and that, while the institution may have specialists, the environment and the routines of the institution lack the real life experiences of daily living. Activities as simple as buying weekly groceries and making meals, going to the bank or post office, taking in a movie, or greeting neighbors are the experiences through which people develop competencies and social skills. The availability of medical services may also be a concern, and can be addressed by involving families in establishing a relationship with medical professionals in the community prior to their family member leaving the facility.

The absence of oversight to assure quality is often incorrectly identified as a weakness in the community system. What is often not recognized is the considerable attention the Centers for Medicare and Medicaid Services and the States have placed on quality assurance. The application States must complete to obtain approval to operate a Home and Community-Based Services Waiver requires States to provide detailed descriptions of provider qualifications, oversight functions, and quality management practices. States are then required to report the findings from their oversight activities on an annual basis and approval to continue to operate a Medicaid Waiver is contingent upon assuring CMS of the health and safety of waiver participants.

Last, there are those who say that families should have absolute authority to make any decisions that affect their family member, and that any government participation constitutes interference with the family relationship. The central question

<sup>4</sup>Bradley, V.J., & Conroy, J.W. *The Pennhurst Longitudinal Study Executive Summary* Philadelphia: Temple University Developmental Disabilities Center, 1985.



that should be the primary focus of both family members and State professionals and the basis for any decisionmaking is “what would benefit the person most?” And, it is this question that drives State agency professionals to continue to create community service opportunities for people living in institutions. Having assisted hundreds of people to move from institutions to the community, having witnessed their growth and development and the satisfaction that families inevitably experience, professionals are bound by professional ethics and compelled by their personal commitment to pursue community options for people living in institutions.

It would be a far easier path to simply let the issue go for the 36,000 people still living in institutions, to avoid asking families to reopen the decision they made to institutionalize their family member 30 or even 50 years ago. But knowing what is possible and what is right, professionals working in State agencies cannot do that.

There is another compelling reason for public officials to stay the course of reducing the number of people in institutions: the need to manage public resources, to manage long-term care systems, in as cost-effective a manner as possible. Large facilities are generally the most costly service model in State systems. States that have significantly reduced the number of people in facilities have made more progress in expanding services for people in the community. Savings from reducing or eliminating the use of the most expensive model of care are an important resource for those on the waiting list.

While opposition can be intense, there are also many stories of family groups working hand-in-hand with States to close institutions and participating actively in the development of community services. The State of Wyoming is a model of what may be one of the best closure processes in the country, and won the NASDDDS Censoni award for outstanding achievement in public services. As is so often true, the story begins with litigation. But the path Wyoming took to respond to that litigation was not to oppose the plaintiffs and argue the case out in court for 10 years, but instead to seize the opportunity to build a robust community service system where there had been none, to serve not only the people from the Wyoming State Training School but also people who were already living in the community with their families and were at risk of institutionalization. Wyoming was among the first States to demonstrate that the thoughtful development of a community system with a wide-range of services eliminates the need for an institution.

**Preventing Institutionalization: The Waiting List Challenge.** There is no entitlement to Home and Community-Based Services and States are restricted in their capacity to expand services. Therefore waiting lists are a reality in most State developmental disability systems. Advocacy efforts, law suits, a booming economy, and funds available from the closure of institutions have allowed many States to expand services for people on the waiting list over the past two decades. But few States have achieved enough growth that important services can be made available promptly to every eligible applicant upon request. Emergencies and crises become the entry point into Home and Community-Based Services systems for many. There is no reliable national data on the number of people waiting for services but we know that in many States the number is in the thousands and the wait can be as long as 10 years. Many States do not maintain a count of people on the waiting list for fear of creating expectations they cannot meet.

The barrier to meeting the needs of people on the waiting list are purely financial. The inability to provide State funds to earn Federal matching dollars controls the pace of growth.

**The Choice Paradox.** The statutory basis for community services is the right to receive services in an institution—an Interim Care Facility for the Mentally Retarded (ICF/MR). When individuals apply for community services, they must first formally “opt-out” of receiving services in an institution and affirmatively choose Home and Community-Based Services. This is called choice. However, we know from the work of Richard H. Thaler and Professor Cass R. Sunstein, authors of *Nudge*, that in presenting individuals with choice, the decision process can be structured in a way that will “influence people’s behavior in order to make their lives longer, healthier and better.” For instance, an “opt-out” decision process is often recommended for the administration of employee retirement programs because it results in more people enrolling in a retirement program which will presumably make their life better when they reach retirement age.

What is the message in requiring individuals to opt-out of institutional services in order to receive Home and Community-Based Services? The message is a mixed one because it promotes the institution even for those who desire and are requesting services in the community. More than one State Developmental Disability Director has identified this “quirk” in the Medicaid program as problematic when promoting Home and Community-Based Services.

THE GOAL OF FULL INCLUSION IN COMMUNITY LIFE THROUGH THE DELIVERY  
OF HIGH QUALITY SERVICES

Creating community opportunities is only a beginning. The goal of our DD services systems is the full participation of people in the life of their community. A real job at competitive wages, membership in civic organizations, knowing the neighbors, and having friends are the real measures of our success.

Services must be designed to do more than maintain people in the community. They must be of high-quality and designed to achieve real life outcomes. People working in developmental disability systems across this country have pioneered strategies to assist people with disabilities to achieve a life of full inclusion and participation in their communities. Individualized planning, supported employment, self-determination, positive behavioral practices, and more recently person-centered planning, individualized budgeting, and consumer-directed services have been adopted by support infrastructures for other populations, including mental health and aging systems.

Measuring quality has been a long standing priority for States. In 1997, NASDDDS launched the National Core Indicators Program (NCI) in partnership with the Human Services Research Institute (HSRI). NCI is a set of system performance indicators organized into domains such as Health, Welfare, and Rights which measure the performance of each State and makes benchmarking between and among States possible.

APOLOGIES

Recently the State of Minnesota became the sixth State in the Nation to issue an apology to people with developmental disabilities for the years of incarceration, abuse, and neglect in State-operated institutions. Such an apology is an indication of a sea change in attitudes. States are apologizing to a group of people who in very recent history were stripped of all rights as citizens, who were denied an education and often medical treatment, who were sterilized without consent and were presumed to have nothing to offer society. These apologies, coupled with the almost complete abandonment of the term "mental retardation" from the names of State agencies are indications that our public systems are about more than providing services; they are about respecting the rights and dignity of people with developmental disabilities and creating opportunities for full participation in community life.

Change has reached all 50 States and the District of Columbia. They are all progressing—each at a different pace—but they are all making progress toward comprehensive systems of community supports and services.

The CHAIRMAN. Thank you very much, Ms. Thaler.

Now we'll wind up with Mr. Buckland. Kelly, welcome. Please proceed.

**STATEMENT OF KELLY BUCKLAND, EXECUTIVE DIRECTOR,  
NATIONAL COUNCIL ON INDEPENDENT LIVING**

Mr. BUCKLAND. Thank you, Senator. It's good to see you again. Mr. Chairman, Ranking Member Enzi and distinguished members of the committee, good afternoon and thank you for the opportunity to speak today on behalf of the National Council on Independent Living. NCIL is the longest running national cross-disability, grass-roots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals, including Centers for Independent Living, Statewide Independent Living Councils, individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

Since its inception, NCIL has carried out its mission by assisting member CILs and SILCs in building their capacity to promote social change, eliminate disability-based discrimination, and create opportunities for people with disabilities to participate in the legislative process to effect change. NCIL promotes a national advocacy

agenda set by its membership and provides input and testimony on national disability policy.

NCIL currently works on a wide array of disability rights issues, including passage of the Community Choice Act, which will provide many people with disabilities the opportunity to choose where and how they receive personal assistance services in their homes and communities.

America is home to 391 centers for independent living, 330 branch offices, and 56 statewide independent living councils. From 2004 to 2008, centers for independent living moved 11,451 people out of nursing homes and other institutions, saving the State and Federal Governments over \$200 million. This last year, 2008 to 2009, they moved out an additional 3,000 people. That makes about 15,000 people they've moved out in that time period.

Centers also provided the core services of advocacy, information and referral, peer support, and independent living skills training to over 3 million individuals with disabilities; and centers attracted over \$618 million through private, State, local, and other sources annually.

In that same time period, centers for independent living provided other services to over 659,000 people with disabilities, including assistance with housing and transportation, personal assistance, employment, and technology.

Here are some examples of how NCIL members assist people with disabilities to live independently in the community. Access Living in Chicago made 61 home modifications and placed 45 people in housing and transitioned 38 people to the community. Independent Living Resources of Greater Birmingham provided 65 home modifications, eliminating barriers to independence. REACH Resources CILs in Texas transitioned 33 nursing home residents, saving the State and Federal Government \$495,000. In Rochester, the Center for Disability Rights and the regional CIL transitioned or diverted 65 individuals, saving New York \$4,041,914. Three Rivers Center for Independent Living in Pennsylvania provided housing services to nearly 400 consumers, reducing homelessness and discrimination. And the ENDependence Center of Northern Virginia persuaded Fairfax County to require grantees to ensure ADA compliance.

In recent health care reform legislation, NCIL stated its priorities in an effort to integrate the needs of the disability community into the legislation, including language to end the institutional bias in Medicaid. It was our unwavering goal to have the language of the CCA in the final reform bill, and our policy to pursue a compromise only if it became clear that the CCA would not be part of the reform legislation.

Over the course of developing the legislation, it became very clear to us and disability advocates in Washington and throughout the country that we were not going to get CCA into the legislation. Therefore we compromised on including the core principles of CCA into the Community First Choice Act. This was a major step forward to ending institutional bias and NCIL wants to thank you, Mr. Chairman, and all the other members of the committee for your support and hard work to keep it in the legislation. Now it's our responsibility to convince the States to adopt that option.

If adopted by the State, the Community First Choice Option would provide individuals with disabilities who are eligible for nursing homes and other institutions with options to receive community-based services. CFC would support the *Olmstead* decision by giving people the choice to leave facilities and institutions for their own homes and communities. It would also help address State waiting lists for services by providing access to community-based services. The option does not allow caps on the number of individuals served, nor allow waiting lists for these services. Congress provided a significantly enhanced Federal match, or FMAP, as you talked about earlier, Mr. Chairman.

NCIL fully supported the Community First Choice Option as part of the health care reform legislation, but we continue to stand firmly behind efforts to see that the Community Choice Act is passed as a stand-alone bill. We realize the limitations of the CFC, being only an option to States. We also realize that all 50 State governments are different and our brothers and sisters in institutions will not be freed in each and every State.

The CFC will lay down a significant foundation and will move our Nation closer to equality, but the CFC will leave the decision to do the right thing up to States, and many States will fail their constituents.

In fact, NCIL receives reports from centers for independent living and statewide independent living councils from every corner of this country that things are not getting better; in fact, things are getting much more difficult for people with disabilities to get out of institutions and live in the community. States are experiencing the worst economic downturn since the Great Depression and they are being forced to make some very tough decisions regarding their budgets. Unfortunately, this has resulted in many of them significantly cutting their Medicaid budgets. Because of the current institutional bias in the program, most of them are cutting services that support people with disabilities in the community because they believe that they are, "optional."

This is why we will continue to push for the Federal Government to end the institutional bias forever and mandate the States offer the Medicaid program to allow people their choice to get their long-term services and support in their own home or whatever setting they choose. We know that when States make these types of cuts they violate the *Olmstead* decision. However, there has been very little enforcement of *Olmstead* by the Federal Government. It is very encouraging to NCIL to see this Attorney General vigorously going after States that violate the decision.

The budgets that many States set this past winter will go into effect in just a few days. NCIL is concerned that when these budgets go into effect States will be in violation of *Olmstead*, and on this anniversary of the decision NCIL calls on the Federal Government to point these violations out to States and dedicate the necessary resources to enforcement.

Sadly, NCIL's vision of equality has not yet been fully realized. Many people with disabilities remain imprisoned in nursing homes and our civil rights laws have been undermined and devalued. As a membership organization, NCIL needs the support of all of our Nation's advocates in order to achieve our goals and advance the

disability rights movement. We hope the U.S. Senate, the House, and the Administration will join us in our quest.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Buckland follows:]

PREPARED STATEMENT OF KELLY BUCKLAND

Mr. Chairman, Ranking Member Enzi, distinguished members of the committee, good afternoon and thank you for the opportunity to speak today on behalf of the National Council on Independent Living. NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

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Independent Living Resources of Greater Birmingham provided 65 home modifications, eliminating barriers to independence.

REACH Resource CILs in Texas transitioned 33 nursing home residents, saving the State and Federal Government \$495,000.

In Rochester, the Center for Disability Rights and the Regional CIL transitioned/diverted 65 individuals, saving NY \$4,041,914.

Three Rivers CIL in Pennsylvania provided housing services to nearly 400 consumers, reducing homelessness and discrimination.

The ENDEpendence Center of northern Virginia persuaded Fairfax County to require grantees to ensure ADA compliance.

Arizona Bridge to IL received a Community Hero Award from the city of Phoenix for its Home Modification Program.

In the recent health care reform legislation, NCIL clearly stated its priorities in an effort to integrate the needs of the disability community into the legislation, including language to end the institutional bias in Medicaid. It was our unwavering goal to have the language of the CCA in the final reform bill, and our policy to pursue a compromise only if it became very clear that the CCA would not be a part of the reform legislation. Over the course of developing the legislation it became very clear to disability advocates in Washington and throughout the Nation that we would not get CCA into the legislation. Therefore we compromised on including the core principals of CCA into the "Community First Choice Act. This was a major step forward to ending the institutional bias and NCIL thanks each of you for your support and hard work to keep it in the legislation. Now it is our responsibility to convince the States to adopt the option.

If adopted by a State the Community First Choice (CFC) Option would provide individuals with disabilities who are eligible for nursing homes and other institu-

tional settings with options to receive community-based services. CFC would support the *Olmstead* decision by giving people the choice to leave facilities and institutions for their own homes and communities with appropriate, cost-effective services and supports. It would also help address State waiting lists for services by providing access to a community-based benefit within Medicaid. The option does, not allow caps on the number of individuals served, nor allow waiting lists for these services. A significant enhanced Federal Medical Assistance Percentages (FMAP) is provided to encourage States to select this option.

The Community First Choice Option:

- Amends Medicaid to allow State Medicaid plan coverage to: community-based attendant services and supports for certain Medicaid-eligible individuals.

- Services under this option would include services to assist individuals with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands-on assistance, supervision, or cueing. ADLs include eating, toileting, grooming, dressing, bathing, and transferring. IADLs include meal planning and preparation; managing finances; shopping for food, clothing, and other essential items; performing essential household chores; communicating by phone and other media; and traveling around and participating in the community.

- Health-related tasks are defined as those tasks that can be delegated or assigned by licensed health-care professionals under State law to be performed by an attendant. Services also include assistance in learning the skills necessary for the individual to accomplish these tasks him/herself; back-up systems; and voluntary training on selection and management of attendants. Certain expenditures would be excluded, including room and board; services provided under IDEA and the Rehabilitation Act; assistive technology devices and services; durable medical equipment; and home modifications.

- Services must be provided in a home or community setting based on a written plan.

- Services must be made available statewide and must be provided in the most integrated setting appropriate for the individual.

- Services must be provided regardless of age, disability, or type of services needed.

- States will establish and maintain a comprehensive, continuous quality assurance system, including development of requirements for service delivery models; quality assurance to maximize consumer independence and consumer control; and external monitoring; along with other critical State and Federal responsibilities/requirement.

- Service delivery models must include consumer-directed, agency-based, and other models, along with requirements to comply with all Federal and State labor laws.

- States would be required to establish a Development and Implementation Council to work with the State in developing and implementing the State plan amendment necessary in order to provide the services. The majority of Council members must be individuals with disabilities, elderly individuals, and representatives of such individual and must collaborate with, among others, providers and advocates.

- States would cooperate in reporting to Congress.

- CFC services would not affect the States' ability to provide such services under other Medicaid provisions.

- Provision to collect data regarding number of people receiving services, dollars spent, and procedures for consumer control.

NCIL fully supported the CFC as part of the healthcare reform legislation, but we continue to stand firmly behind efforts to see that the Community Choice Act is passed as a stand-alone bill. We realize the limitations of the CFC, being only an option to States. We realize that all 50 State governments are different and our brothers and sisters in institutions will not be freed in every State.

The CFC will lay down a significant foundation, and will move our Nation closer to equality, but the CFC will leave the decision to do the right thing up to States, and many States will fail their constituents.

In fact, NCIL receives reports from CIL's and Statewide Independent Living Councils from every corner of this country that things are not getting better. It is getting much more difficult for people with disabilities to get out of institutions and live in the community. States are experiencing the worst economic downturn since the great depression and they are being forced to make some very tough decisions regarding their budgets. Unfortunately this has resulted in many of them significantly cutting their Medicaid budgets. Because of the current institutional bias in the program, most of them are cutting services that support people with disabilities in the community because they believe that they are "optional."

This is why we will continue to push for the Federal Government to mandate that States that offer the Medicaid program allow people the choice to get their long-term services and supports in their home or whatever setting they choose.

We know that when States make these types of cuts, they violate the *Olmstead* decision, however there has been very little enforcement of *Olmstead* by the Federal Government. It is very encouraging to NCIL to see this Attorney General vigorously going after States that violate the decision.

The budgets that many States set this past winter will go into effect in just a few days. NCIL is concerned that when these budgets go into effect States will be in violation of the *Olmstead* decision, and on this anniversary of the decision, NCIL calls on the Federal Government to point these violations out to States and dedicate the necessary resources to enforcement.

Sadly, NCIL's vision of equality has not yet been fully realized. Many people with disabilities remain imprisoned in nursing homes and our civil rights laws have been undermined and devalued. As a membership organization, NCIL needs the support of all our Nation's advocates in order to achieve our goals and advance the Disability Rights Movement.

We hope the United States Senate, House and Administration will join us in our quest!

The CHAIRMAN. Thank you, Mr. Buckland, and thank all of our panel for great statements, both the verbal and the written statements.

I'll start with Mr. Bernstein. Mr. Bernstein, in your written testimony—and I think you also mentioned it in your verbal statement, about deconstructing the systematic barriers and challenging the vested interests that sustain segregation and low expectations. Talk to me about that. What do you mean by that?

Mr. BERNSTEIN. I'm actually very happy you asked about that, because I'd like to frame it this way. We are very, very pleased that the Department of Justice has joined with the advocacy community and it begins to ask the question first, not what are the conditions in the institution, but why are people here to begin with. When you begin asking that question, it takes you all kinds of places.

What you find out, for instance, is that hospitals remain open because they're big employers and within States there's political pressure for them to remain open unnecessarily and for beds to be filled there. What we find is stories of operators of facilities for people with serious mental illness who troll homeless shelters, because people are treated as commodities and it's a business. What we find is that in some States—in one very large State that I'd prefer not to mention, every year a bill would come up where it's demonstrated that the State could save millions of dollars by moving people out of institutions for mental disease that are privately owned and into integrated programs that are funded by Medicaid, and every year the bill fails.

The industry that profits from dependency and isolation has developed political prowess and they use it. I think as was alluded to earlier, in our view it's the role of government to rise above that and to look out for the best interests of its citizens.

So when I talk about deconstructing systems, that's one piece. The other piece, which is more at a Federal level, is we've heard today about all kinds of wonderful new initiatives that reinforce community living, reinforce choice, personal control, ownership of one's own home, but these are piecemeal solutions. At some point we, as a nation, are going to need to look at what are we paying for and why do we continue to pay for solutions that we know are archaic and segregating. I think those are all pieces that we really don't talk enough about.

The CHAIRMAN. I guess that we started this segregation hundreds of years ago and it just became such an integral part of society that vested interests grew up around it and those vested interests continue on. That's not to say that we haven't made a lot of progress. As Ms. Thaler pointed out, we have made progress in the recent past. But we still have a long way to go and we still don't have, as Mr. Buckland points out, a mandate. It's still sort of up to the States. Maybe yes, maybe no. We have waivers, and we have waiting lists that are so long that people get disappointed waiting on them.

Hanging over all of this, as one who has been sponsoring MICASA for so many years, the mandate part of it, is the budget implications, how much is it going to cost. I've been arguing this for 15 years at least on this aspect, that I think that CBO has it wrong in terms of how they look at it. Who was it who said look at the longer term? If you look at it maybe in 1 year, 2 years, maybe so. But if you look at it in terms of a continuing obligation of our government to do what we said in the ADA and what *Olmstead* said, if we look at it as a continuing obligation over a longer period of time, the economics become on our side, as you might say, much cheaper. As I always say, if you look at the economics, not to say anything about certain quality of life and giving people choices to live independently.

But anyway, about deconstructing the systematic barriers, that's been one of the real tough things in this whole thing. Well, Mr. Knight was a subject of that systematic barrier that Mr. Knight had when he encountered that. Again, you were—was it 2 years you were in, 2 years? Is that right, Mr. Knight?

Mr. KNIGHT. Yes, sir.

The CHAIRMAN. Two years that you kept trying to get out. It took you 2 years.

Mr. KNIGHT. Yes, sir.

The CHAIRMAN. Of constant effort. Well, that just shouldn't be.

Mr. KNIGHT. No.

The CHAIRMAN. Obviously, Mr. Knight is perfectly capable of living in the community, and he's proven that. He worked for many years by himself.

Mr. KNIGHT. Before that I'd lived nearly all my life by myself.

The CHAIRMAN. Exactly, precisely.

So again, you point to these things and you say, "Why can't we finally get over that hurdle?" Well, we are trying with the Community Choice Option, that we've got to get the States to get into. I asked Ms. Mann earlier about the 6 percent bump-up, will that help? We hope that will be sufficient to do that.

I think maybe that, coupled with a new, aggressive role on the part of the Department of Justice to go after those that are not abiding by the *Olmstead* decision, and you get the carrot and the stick. You get the carrot with the 6 percent and you get the stick with maybe the Department of Justice's becoming more active, with the Bazelon Center of course always being actively involved in cases dealing with mental health and disabilities, that perhaps we can see after next year a more rapid deconstruction of this.

Thank you.

Mr. BUCKLAND. Thank you. We're very hopeful.



The CHAIRMAN. We hope. We hope.

Mr. BUCKLAND. The planets are in alignment.

The CHAIRMAN. Pardon?

Mr. BUCKLAND. The planets are in alignment for that.

The CHAIRMAN. Well, I sure hope so. I sure hope so.

Listen, I took more time than I meant to talking rather than asking questions. But Senator Casey is here and I wanted to go to Senator Casey.

#### STATEMENT OF SENATOR CASEY

Senator CASEY. Mr. Chairman, thank you very much for the hearing. I'm sorry I'm late here for the second panel.

I want to first of all commend our chairman for the hearing, but also in a larger sense for what he's been doing all these years on so many issues, and especially those that relate to the subject matter of this hearing. So I want to thank Senator Harkin for that and the work of this committee.

I wanted to start with a question for Nancy Thaler. You worked in Pennsylvania for I guess the Department of Public Welfare for 10 years?

Ms. THALER. Sixteen years.

Senator CASEY. Sixteen, OK. I'll get my math right. One of the main features of your testimony was how to deal with opposition from families and being able to make what has to be a very difficult transition. I know you addressed it in your testimony, but I was struck in the section that begins with opposition from families being another challenge.

You say,

“What we know from 40 years of experience is that people do better in the community than in institutions, no matter their age. They learn new skills, develop new competencies, and appear to be much happier.”

And then you go on from there.

I know you refer to a couple of approaches or strategies that help you do that. Can you highlight those again, because I do remember going back in Pennsylvania—gosh, I don't know what year it was, but 10 or 15 years, where we are, and still are, I guess, all these years later—I can remember this being debated in the 1960s and the early 1970s, going back that far. But that process of de-institutionalization and, even though the evidence was very compelling that it was the best approach for individuals, that families had a hard time with it, and at times our State didn't do a very good job of recognizing that.

You had these horrific situations where people would—I remember one in particular—be put on a bus to be taken out of the institution, and the windows were obscured so that families couldn't see them, and there were State police, and it was a disaster of a process.

I wanted to have you highlight some of the strategies that you know work, so that families can make this transition with at least a lot more peace of mind.

Ms. THALER. The strategies—and there are many of them—work 99 percent of the time. There are instances where no amount of

strategizing or working with families or talking things through will achieve agreement. I think that's the situation that you're referring to.

If we approach families who made a decision 20, 30 years ago with a level of understanding and respect for their pain and anguish and spoke to them from that point of view, we win and earn their trust. Many of those families did not want to put their sons and daughters into institutions and they have a sense of guilt and sorrow and pain over that. When we invite them to consider community placement, we re-open all of that pain up.

The professionals and people who work with families need to first recognize that and take the time that's necessary to win their trust and confidence and then show them, show them how it works, show them where it works, introduce them to other families who are satisfied and happy.

In the situation you're talking about, one of the things we learned is that the more we could give the families in the process, the more confident they were. So when they could choose which provider, choose what part of town, be involved in identifying the home, even engaged in hiring the staff, their confidence grew, and they turned out to be champions of community services.

But time and respect are important. Oftentimes closures have target dates that truncate the process, which we have to be careful not to do.

Senator CASEY. I know in our State, in Pennsylvania, there are still, by one estimate, as many as over 1,200 people still living in five State-run institutions.

One line from your testimony really struck me as well, about one of the fears that families have is when you move an individual out of an institution there'll be less oversight, which is not an unreasonable or not an illogical conclusion to reach. We all think in terms of oversight being better, I guess, if you have a finite structure or location. That makes sense.

But you say in the testimony, "What is often not recognized is the considerable attention that the Centers for Medicare and Medicaid Services and the States have placed on quality assurance." I think that's an accurate assessment, although we've got to prove it and we've got to be vigilant about it.

Ms. THALER. Yes.

Senator CASEY. I know my time's up, but I do want to thank all of the witnesses for being here. Mr. Knight, thank you for sharing what can only be very personal experiences in your own life.

Mr. KNIGHT. Thank you.

Senator CASEY. Thank you very much.

The CHAIRMAN. Just responding to Senator Casey on the oversight, again what Mr. Knight said in his testimony—I was just reading it again—that the institution that he was in, he said that you didn't have your own things, there was no privacy, your personal belongings are not safe, things like electronics, food and money were stolen, residents screaming all night long, you have to eat what they prepare for you, the floors and bathrooms had urine all over them, ET cetera, ET cetera. So that was institutional care.

Mr. KNIGHT. Now they've rebuilt it.

The CHAIRMAN. Yes?

Mr. KNIGHT. Now they've rebuilt it, so I don't know how it is now. It might be different now.

The CHAIRMAN. It's still not as good as living on your own, though.

Mr. KNIGHT. No. Oh, no.

The CHAIRMAN. Not at all.

Mr. KNIGHT. I'll still live on my own, not in there.

The CHAIRMAN. Absolutely.

Ms. Thaler, one thing I wanted to follow up with you is that I understand there's a trend in some States—and I said that at the earlier panel, but I don't think I followed up on it enough—to build or renovate segregated residential facilities. Is that happening? I need more information on that. Why would that be happening?

I can see the pause, this deconstructing. But to be actually building more facilities—is that happening?

Ms. THALER. Yes. Not in a lot of States, but it is happening in some places. Despite our generally universal understanding that community services are what people want and where people are better off, there continues to be support for institutional services, minimal but some advocacy support, and political support.

So we have a handful of States who have launched the building of buildings on the grounds of State institutions, either new buildings or replacement buildings, oftentimes then administered by the administration that follows them, that are sort of stuck with them. But they're anomalous events in time that have to do with the forces locally that still believe we need institutions.

The CHAIRMAN. Well, I've got to look at that more closely. This just can't be done. I mean, that's absolutely going in the wrong direction, and you just build up a whole new set of things that have to be deconstructed over time.

Ms. THALER. I might add that the Office of Civil Rights and the protection and advocacy agencies have been on this, Mr. Chairman.

The CHAIRMAN. Good. The P and A's are great.

Kelly, every time I see a center for independent living, they're really good. They do good work, and I don't mean just to say that to you, but they get things done. What's so unique about them? Why are they so successful?

Mr. BUCKLAND. Well, Senator, I think it's because they are run by people with disabilities and they've experienced what we just heard from Mr. Knight. I think a lot of people who've worked in centers have gone through very similar experiences and they understand this. That's what I think makes them unique.

But thank you for recognizing that. I appreciate it.

The CHAIRMAN. They do, they just get things done. They're very, very, very good at that.

Now, you do a lot of work with the P and A system, don't you, Mr. Bernstein?

Mr. BERNSTEIN. Yes, we do.

The CHAIRMAN. Do you share Ms. Thaler's opinion of them, that they're very aggressively pursuing some of the—not opinion, her view—that they are aggressively pursuing some of these rebuilding of segregated facilities?

Mr. BERNSTEIN. The P and A's are on it. Like most protection systems, they're very thinly spread and have huge demands on

them. But notwithstanding their efforts and our efforts, one State is building a 620-bed psychiatric hospital right now, and other States are actually declaring parts of existing hospitals to be the community, and they're making community placements that are on the grounds of the hospitals. So there are all kinds of things going on that one wouldn't expect 20 years after the ADA was enacted.

The CHAIRMAN. Is this publicly known, what State? I mean, is it a secret?

Mr. BERNSTEIN. The 620-bed State, Oregon.

The CHAIRMAN. Oregon?

Mr. BERNSTEIN. Yes.

The CHAIRMAN. Well, I just heard that Oregon earlier was one of the good States.

Mr. BERNSTEIN. It is. But part of the issue—and again, this is a conversation we haven't had as a nation. A State legislature can get its arms around building a facility to correct problems in the State. They understand that. To talk about community mental health, where the programs are dispersed and you can't photograph it, it's a harder sell. So I think that's part of the dynamic here.

The CHAIRMAN. It seems odd that I heard earlier that Oregon was one of the leading States in getting people out of institutions, but you tell me Oregon is now building a 620-bed psychiatric hospital.

Mr. BERNSTEIN. And another 300-bed one down the road. Part of this has to do with forensic patients, who really for no good reason get sucked up into the correctional system and then are transferred to mental health.

Let me say, Oregon has a very, very fine community mental health system, but it's a shell of what it used to be. Things are de-funded because of the economic times.

The CHAIRMAN. If they're de-funded, how can they be funding a 620-bed unit? That costs a lot of money.

Mr. BERNSTEIN. It absolutely does.

The CHAIRMAN. Find out for me. Get me some information on this. I wonder if Mr. Merkley knows this. I've got to talk to Senator Merkley about this, because we've discussed other things in terms of community-based services before. So I have to discuss that with him and see what's happening in Oregon.

Has anybody else got anything they want to bring up before I dismiss the panel? Mr. Buckland, anything else?

Mr. BUCKLAND. Well, Mr. Chairman, I too would just like to be one of the people in line to thank you for your leadership on holding the hearing, all the stuff that you've done for people with disabilities in the country. It's much appreciated by all.

The CHAIRMAN. You're kind to say that. I have good people I work with.

Ms. Thaler.

Ms. THALER. I express my appreciation on behalf of all of my members as well.

The CHAIRMAN. Well, thank you very much, Ms. Thaler.

Mr. Knight.

Mr. KNIGHT. No response.

The CHAIRMAN. Just keep on doing good stuff. I hope you get your legs back.

Mr. KNIGHT. Sorry I'm a little nervous, but it's the first time.

The CHAIRMAN. Oh, don't worry about that, not around us anyway.

Mr. KNIGHT. I'll be better next time.

The CHAIRMAN. I hope you get use of your legs back soon so you can get back to work.

Mr. KNIGHT. Oh, yes. I'm working on walking now. I used to be in a wheelchair.

The CHAIRMAN. Good. Good for you. Keep up your good work.

Mr. Bernstein, any last thing?

Mr. BERNSTEIN. Senator, thank you so much for this hearing. But even more so, thank you for all that you do.

The CHAIRMAN. Well, you're nice—you're all nice to say that. I didn't mean to elicit it. I just thought maybe you might have something you wanted to say, some additional input here.

But again, this is an ongoing thing. We've just got to recognize that there's no substitute for independence and for people having their own choice. Every time I bring it up—I say, "Look, if Medicaid money is going out there and a person can get that Medicaid support if they go in the nursing home, shouldn't they be able to get at least that same amount of money if they decide to go someplace else to live?"

Everybody says, yes, that makes sense. I say: "Well, guess what; it isn't happening," and it hasn't happened. But we're trying to get the Community First Choice Option to at least move it ahead a little bit. But as long as I'm here, I'm going to continue to try to get a mandate that Medicaid money has to go to the person; the person himself or herself decides what they want to do with it, where they want to live, and not have to be told that they will get it if they go to a nursing home, if you've got a waiver, if you get on the waiting list; if all the stars, as you say, are in alignment, maybe then you can get that money if you live in the community.

We've got to do away with that. We've got to break that whole system down. I think the most frustrating thing in my job here has been how long it's taken to do that. But we can't give up on it. I know none of you have given up on it and we're not going to give up on that battle either.

Thank you all very much for being here.

The record will stay open for 10 days for Senators to enter any questions to you that they might have.

[Additional material follows.]

## ADDITIONAL MATERIAL

## RESPONSE TO QUESTIONS OF SENATOR ENZI BY CINDY MANN

*Question 1.* Per our discussion at the hearing could you name a few States that Congress should be looking at as shining examples of *Olmstead* implementation? What makes those States successful?

Answer 1. Certain States have created robust home and community-based service (HCBS) delivery systems, and have done a good job at enabling individuals to receive services in the most integrated settings appropriate to their needs. That said, even within States where great strides have been made for some populations, there may be opportunities for improvement in other areas. Some of the hallmarks of strong service delivery systems that seem to best position a State to meet their obligations under the Americans with Disabilities Act (ADA) and the *Olmstead* decision include: the availability of individual budget allocations that enable individuals to freely choose where to receive services; single points of entry to the services of their choice; strong functional, objective assessment tools; person-centered planning processes; and robust service options in the community with significant opportunities for individual control and direction.

*Question 2.* For States that are struggling with implementing the decision why are they struggling? What enforcement action steps can and has your Center taken to help enforce the decision?

Answer 2. Over the last two decades, CMS has worked diligently with our other Federal partners who have responsibility for *Olmstead* enforcement to identify opportunities for the Medicaid program to further support State efforts in implementing the *Olmstead* decision. As noted in our testimony, much progress has been made to date thanks to the leadership provided by this committee and through numerous legislative initiatives. Specific examples include:

- Hundreds of millions of dollars have been provided under the Real Choice Systems Change (RCSC) grants and Ticket to Work and Work Incentives Improvement Act (TWWIIA) to provide States greater capacity to build community-based infrastructure, expand access to community-based services, and foster community integration for individuals with disabilities.

- Dating back to 1999, CMS has issued a series of State Medicaid Director (SMD) letters designed to illuminate Medicaid policies and programs that may contribute to equalizing access to all community and institutional long-term care services. Our most recent SMD letter of May 20, 2010 provided States with information on new tools for community integration available under the Affordable Care Act, reminded States and other key stakeholders of the array of tools already available to serve individuals in the most integrated setting appropriate, and explained opportunities for Federal assistance in overcoming key barriers.

- We have also continued to provide technical assistance to all States as they seek to overcome individual challenges to implementing HCBS options. In addition to the lack of available State resources, challenges often include overcoming barriers related to affordable housing for individuals who may no longer have community ties. States may also experience barriers related to their workforce and provider capacity. As more individuals receive care in HCBS settings, it is imperative that qualified staff and providers are available to provide needed care.

- Additionally, CMS has dedicated significant resources to improving the oversight and monitoring of HCBS waivers nationally. CMS has heightened its expectations of States around quality programs and ensuring the health and welfare of the individuals served. Specifically, CMS requires States to have an operational Quality Improvement Strategy (QIS), and requires detailed information on the methods used by the State to discover, remediate and provide systems improvements to their programs. Through our application and review process, we expect States to identify performance measures to demonstrate their compliance with all statutorily mandated assurances, and to provide data to demonstrate States' efficacy in identifying and fixing problems. We are continually working to ensure that States have the tools and resources to carry their QIS out effectively. We provide robust technical assistance at no cost to States and assist in the design and implementation of their programs. While we work to achieve a collaborative Federal/State relationship, in the event problems within a particular State are identified, CMS requires the State to make changes in its programs to improve quality.

While these efforts have begun to tip the long-term care balance towards community-based services, several statutory and structural barriers impede further progress. For example, while coverage for institutional services is mandatory under Medicaid, coverage for HCBS under the section 1915(c) and section 1915(i) pro-

grams, as well as key Medicaid State plan services, is optional. As such, in times of economic downturn and limited budgets, States may make difficult choices that limit access to these “optional” services. The Affordable Care Act provides new HCBS options for States, which CMS hopes will improve access to HCBS across the country.

*Question 3.* Can you provide data on the cost savings associated with providing community-based services versus institutional care?

Answer 3. There is significant research regarding the efficacy and efficiency of HCBS, particularly in comparison to institutional care. However, given the structural differences in how States implement institutional and HCBS services and in how individuals gain access to these services, a traditional cost-effectiveness analysis has proven challenging to the research community. The nature of the services and their reimbursement structure is fundamentally different across different care settings and even among different populations. As a result, recent studies performed by economists Stephen Kaye and David Grabowski suggest that while making progress in refining cost-effectiveness analysis, CMS must also explore subjective measurements for quality of life and place greater emphasis on consumer choice. In addition, it is difficult to precisely quantify the cost of expanding the entitlement to HCBS services because of the unknown numbers of individuals who may need and avail themselves of HCBS but who would not have availed themselves of institutional nursing facility services. A recent study by Charlene Harrington at the University of California, San Francisco indicates that States with well-developed HCBS programs had lower overall LTC spending, as they were able to reduce institutional utilization over time.

Beyond the question of cost savings, the Administration is committed to providing each individual living with disabilities access to quality long-term services and supports in the most appropriate care setting of his or her choice.

*Question 4.* What would CMS do for rural States, like Wyoming, where we have a housing crisis? While I believe in community-based services, housing is scarce across Wyoming. In mining communities we have 15–20 miners renting two bedroom apartments and taking turns sleeping there on a rotating basis. What assistance does CMS provide for rural States to better implement *Olmstead* when they have capacity barriers?

Answer 4. CMS, through the Medicaid program, can address housing capacity issues through two primary roles. First, CMS supports State efforts to educate and coordinate between the respective systems of a State’s housing and human service agencies. Second, CMS supports resources that link human service and housing agencies with one another for purposes of planning and developing the necessary housing capacity, and/or connecting consumers with the housing and the services and supports they need to live meaningful lives in the community.

In our experience, many human service agencies are not fully aware of the statutory and regulatory authorities, organizational structure, policies, and programs associated with housing resources and organizations. It is equally apparent that housing agencies are not familiar with these elements as they relate to Medicaid or other human service agencies. More opportunities exist for CMS to facilitate better collaboration between housing and human service agencies in order to generate sufficient housing capacity in the community for the elderly and people with disabilities and link these populations with the affordable and accessible housing that does exist.

To that end, we are committed to addressing this issue in a proactive fashion. Shortly after arriving at the Department of Health and Human Services (HHS), Secretary Sebelius announced the Community Living Initiative. As part of this initiative, HHS is working through CMS to implement solutions that address barriers to community living for individuals with disabilities and older Americans. HHS is also partnering with the Department of Housing and Urban Development (HUD) to improve access and affordability of housing for people with disabilities and older Americans with long-term care needs.

On April 7, 2010, HUD issued a \$40 million HUD Notice of Funding Availability (NOFA) that will provide approximately 5,300 Housing Choice Vouchers over 12 months for non-elderly disabled families living in the community or transitioning out of institutional care. CMS will use the network of State Medicaid agencies, in concert with local human service organizations, to link eligible families to local housing agencies which will administer voucher distribution. Of the 5,300 vouchers set aside as part of this program, up to 1,000 will be specifically targeted for non-elderly individuals with disabilities currently living in institutions but who could move into the community with assistance. Local housing agencies will place on their

waiting lists any otherwise eligible individuals transitioning out of institutional care that demonstrate they will receive necessary services, including care/case management services. The remaining 4,300 can be used for this purpose also, but are targeted for use by non-elderly disabled families in the community to allow them to access affordable housing that adequately meets their needs.

Subsequently, on June 22, 2010, CMS announced a technical assistance (TA) contract designed to implement the following concepts:

- Educate housing and human service agencies at the Federal, State, and local levels of government to help each type of agency navigate other organizations to obtain essential resources;
- Provide critical information about the housing and human service sectors that could include relevant Federal statutory and regulatory requirements, and organizational structures, culture, policies and programs;
- Assist State-level housing authorities, Medicaid agencies and population-specific authorities on how and with whom to link to obtain housing and services/supports for consumers; and,
- Assist regions and entities within States to plan, fund and develop housing options for vulnerable populations.

[With that, the committee will stand adjourned.]

