

**OLMSTEAD ENFORCEMENT UPDATE: USING THE
ADA TO PROMOTE COMMUNITY INTEGRATION**

HEARING

OF THE

**COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS**

UNITED STATES SENATE

ONE HUNDRED TWELFTH CONGRESS

SECOND SESSION

ON

**EXAMINING AN UPDATE ON OLMSTEAD ENFORCEMENT, FOCUSING ON
USING THE AMERICANS WITH DISABILITIES ACT TO PROMOTE COM-
MUNITY INTEGRATION**

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JUNE 21, 2012
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OLMSTEAD ENFORCEMENT UPDATE: USING THE ADA TO PROMOTE COMMUNITY INTE- GRATION

THURSDAY, JUNE 21, 2012

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

The committee met, pursuant to notice, at 9:29 a.m. in room SD-430, Dirksen Senate Office Building, Hon. Tom Harkin, chairman of the committee, presiding.

Present: Senators Harkin, Franken, and Enzi.

OPENING STATEMENT OF SENATOR HARKIN

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

I apologize to everyone, but because of votes on the floor, we had to move this up half an hour. The first vote is at 11:00, so we will have to close this down right around 11:10 or 11:15 so I can make that first vote. Then we just have a whole bunch of votes after that, so we will not be able to come back. I am going to ask everyone to cut their statements short, so we can at least have some discussion between now and 11 o'clock.

The title of this hearing is, "Olmstead Enforcement Update: Using the ADA to Promote Community Integration." This hearing follows up on a similar hearing that we held in 2010.

Tomorrow, we mark the 13th anniversary of the U.S. Supreme Court's landmark decision in *Olmstead*, holding that the civil rights of people with significant disabilities are violated when people are unnecessarily segregated from the rest of society. The *Olmstead* decision was a critical step forward for our Nation, following in the tradition of cases like "*Brown v. Board of Education*."

When Congress passed the ADA 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 *Olmstead*, the Court held that unnecessary institutionalization of individuals with disabilities constitutes discrimination, and that the two women plaintiffs had a right to be provided community-based options.

We will hear today from leaders at the Department of Justice, and the Department of Health and Human Services; also a panel that includes officials from Delaware and Alabama. And a long-time self-advocate leader from the District of Columbia who will speak from personal experiences about life in an institution and contrast that with his life living in the community.

I yield to Senator Enzi. I cut my statement short because we only have an hour and a half this morning.

OPENING STATEMENT OF SENATOR ENZI

Senator ENZI. I know and I appreciate it.

I appreciate the passion that you have for this, and the enthusiasm, and the great panels we are going to have today.

The CHAIRMAN. I appreciate that very much.

I want to publicly thank Senator Enzi for all of his great work in this area too. This has been a great non-partisan, bi-partisan issue ever since ADA, and we approach it in that same pattern again today.

Our first panel is Mr. Tom Perez, Assistant Attorney General for Civil Rights in the U.S. Department of Justice. He has spent his entire career in public service, first as a career attorney at the Civil Rights Division, and then as Assistant Attorney General for Civil Rights at the Justice Department, and later as Director of the Office for Civil Rights at the U.S. Department of Health and Human Services. He is no stranger up here. He was Special Counsel to the late Senator Edward Kennedy, who was a former Chair, along with Senator Enzi of this committee.

Joining Mr. Perez on the first panel is Mr. Henry Claypool, Principal Deputy Administrator of the Administration for Community Living at the U.S. Department of Health and Human Services, a senior advisor to the Secretary on disability policy. Again, long experience; 25 years of experience developing and implementing disability policy at the Federal, State, and local levels.

All of your statements will be made a part of the record in their entirety, and so we will start with Mr. Perez and Mr. Claypool. If you could sum it up in 5 to 7 minutes, I would sure appreciate it.

Mr. PEREZ. I sure will.

The CHAIRMAN. Tom, welcome back.

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

Mr. PEREZ. It is an honor to be here, Mr. Chairman and Senator Enzi.

It is an honor to be here with both of you, and with this committee, and with my friend and colleague, Henry Claypool, and Secretary Landgraf, and other leaders throughout the country.

The Court's ruling in *Olmstead* has often been called the "*Brown v. Board*" of the disability rights movement. As you know, as you just stated, the Supreme Court in *Olmstead* recognized for the first time that the civil rights for people with disabilities are violated when they are unnecessarily segregated from the rest of society.

When I became Assistant Attorney General, I identified *Olmstead* enforcement as one of our top priorities. Consistent with

the administration's "Year of Community Living," in the last 3 years the Division has been at the forefront of ADA enforcement involving the unjustified isolation of people with disabilities, and taken an active role in more than 40 cases in 25 different States.

We have also significantly expanded our collaborations with other Federal agencies including HHS and my friend Henry, the Department of Housing and Urban Development, and the Department of Labor. I met with Seth Harris, literally a week ago, to talk about supported employment, an issue, I know, that is near and dear to your heart. Partnerships with our colleagues across agencies, stovepipe implosion, I call it. It is critical because they reflect the lessons we have learned from the past.

Merely moving people out of institutions is not enough; people must have access to the support of employment, services, and housing that will enable them to be safe and succeed in the community. In addition, the community will be a realistic alternative only if people with disabilities, and their family, can feel confident that the transition will be safe and that the supports necessary to survive are, indeed, available. Our agreements, therefore, call for discharge planning, transition processes that provide opportunities to thoroughly explore community placements and to connect with other families whose loved ones have also transitioned to the community.

Throughout our *Olmstead* work, we helped States comply, not only with their legal obligations under the ADA, but also with their fiscal obligations to taxpayers by moving them from expensive institutional care to more cost-effective community-based services. Secretary Landgraf has been in the forefront of that movement in Delaware, as well as Governor McDonnell in Virginia and former Governor Perdue in Georgia. And equally importantly, *Olmstead* implementation serves the State's moral compact with people with disabilities to ensure that they can live their highest and best uses of their talents, and realize all of their dreams and hopes.

We have used a variety of different tools in our *Olmstead* work including reaching system-wide settlement agreements to expand community opportunities for thousands of people in several States; filing statements of interest to help develop the law; suing States when necessary to ensure *Olmstead* enforcement; and developing guidance and a Web site on *Olmstead* enforcement to help people understand their rights and obligations.

We have engaged in the work on behalf of people with a variety of disabilities including developmental disabilities, intellectual disabilities, mental illness, and physical disabilities, and on behalf of both adults and children.

This work assists people unnecessarily segregated in institutions as well as those at-risk of institutionalization. We have challenged unlawful segregation in a wide array of settings including State-run facilities, private-run facilities such as nursing homes, and board and care homes, and nonresidential settings.

Most recently in Virginia, we entered into a landmark settlement to shift Virginia's developmental disability system from one heavily reliant on large, expensive State-run institutions to one focused on safe, individualized, and cost-effective community-based services

that promote integration, independence, and full participation by people with disabilities in community life.

I again applaud Governor McDonnell. He was a very critical partner in this effort to ensure not only compliance with the ADA, but ensuring that we do so in a way that is cost-effective, and addresses the moral compacts that I mentioned before.

We spent a lot of time in that process consulting with the community, because it is important to involve the community in this effort, to hear their voice, and to make sure that their voice is indeed heard and reflected in our agreements. There are many other places, as I noted, where we are doing significant *Olmstead* work and where such work is necessary.

In October 2010, we reached a very comprehensive agreement with Georgia and former Governor Sonny Perdue, and I applaud him. I went down personally and met with him. I applaud him for his leadership so that we could help many people with developmental disabilities and mental illness to ensure that they can live in the most integrated setting.

As you will hear from Secretary Landgraf, in July 2011, we reached a similarly comprehensive agreement with Delaware to transform the State's mental health systems.

Our allies include sheriffs because all too many States—I was with the major county sheriffs last week, and the Sheriff in Tulsa, OK said, "I run the largest mental health facility in the State of Oklahoma, and that is the county jail." All too frequently, county jails have become repositories for people who do not have criminal justice needs, but have mental health needs, but we do not have community infrastructure to deal with it. And that is an issue that I spent literally almost the entirety of my meeting with the sheriffs discussing. In Georgia, the county sheriffs were very helpful in building this new infrastructure, and elsewhere they have been exceedingly helpful. And so, we continue to do this work across the country.

We have filed suits, recently, in New Hampshire to address, again, the unnecessary institutionalization of people with mental health needs. We are working now with the States of Mississippi and North Carolina to, hopefully, come up with collaborative solutions to these issues because these efforts will continue to be dynamic. They will continue to be ongoing. We learn from every case that we do and we try to do the next case that much better.

We are working on the issues of supportive employment. We filed, as you may be aware, Mr. Chairman, a statement of interest in Oregon involving private plaintiffs who asserted that *Olmstead* applies to where individuals seek integrated, supported employment services but, regrettably, they are being unnecessarily placed in other services that are not the highest and best uses of their talents. And as we know, *Olmstead* is more than simply where you live, it is also how you live, and that is what we are working on.

In the end, Mr. Chairman, this is about people. And I have had the privilege of meeting with, and helping, people with disabilities and their families. And the sentence I remember the most from all of my conversations was a person with a disability who was able to move into the community who said, quite simply yet eloquently, "Thank you for giving me back my life." That is what this is about.

It is not a partisan issue. It never has been, never will be. It is about giving people back their lives, and about informed choice, and that is what *Olmstead* is about. That is what it will continue to be.

Thank you for this opportunity to shine a light on our work, and this important issue, and the work that lies ahead.

[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 about implementation of the Supreme Court's landmark *Olmstead v. L.C.* decision. The Court's ruling has often and properly been called the *Brown v. Board of Education* of the disability rights movement.

As the 13th anniversary of the *Olmstead* decision approaches, I am pleased to testify today about the Civil Rights Division's *Olmstead* enforcement work and about the Department's active role in ensuring that people with disabilities can realize their full potential. As you know, in *Olmstead*, the Supreme Court recognized for the first time that the civil rights of people with disabilities are violated when they are unnecessarily segregated from the rest of society. 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.

The *Olmstead* decision was heralded as the impetus to finally move individuals with disabilities out of the shadows, and to facilitate their full integration into the mainstream of American life. Over the several years following the decision, through advocacy and policy and programmatic changes at the State and Federal level, there was some progress toward this goal. But the hoped-for sea change in the lives of people with disabilities has not come to fruition. More than a decade after *Olmstead*, many individuals across the country who *can* live in the community and *want* to live in the community remain unnecessarily institutionalized.

For that reason, when I became Assistant Attorney General in 2009, I identified enforcement of the *Olmstead* decision as one of the Division's top priorities. In the last 3 years, the Division has been involved in more than 40 matters in 25 States. We have also significantly expanded our collaborations with other Federal agencies, including the Departments of Health and Human Services (HHS), Housing and Urban Development and Labor, recognizing that community integration can only be successful if people have access to necessary community services and housing. Through our *Olmstead* work, we help States comply, not only with their legal obligations under the ADA, but also with their fiscal obligations to taxpayers, by moving from expensive institutional care to more cost-effective community-based services that allow the State to leverage Federal dollars most effectively. As importantly, *Olmstead* implementation serves States' broader interest in serving people with disabilities in the way most conducive to independence and full participation in community life.

The Division's *Olmstead* enforcement efforts have been driven by three goals: (1) people with disabilities should have opportunities to live life like people without disabilities; (2) people with disabilities should have opportunities for true integration, independence, recovery, choice and self-determination in all aspects of life including where they live, spend their days, work, or participate in their community; and (3) people with disabilities should receive quality services that meet their individual needs. We have learned many important lessons from the past. Chief among them is that it is not enough to move people out of institutions; we must ensure that individuals have the support and services that they need to lead successful lives in the community.

We have used a variety of different tools in our *Olmstead* work, including reaching system-wide settlement agreements to expand community opportunities for thousands of people in several States; filing statements of interest in private litigation when questions arise regarding the ADA's legal requirements when necessary, bringing suit in court against noncompliant States and other public entities; and developing guidance documents and a Web site on *Olmstead* enforcement to help people understand their rights and to help public entities understand and implement their obligations. We have engaged in work on behalf of persons with a variety of disabilities, including developmental disabilities, intellectual disabilities, mental ill-

ness, and physical disabilities, and on behalf of both adults and children. This work assists people unnecessarily segregated in institutions as well as those at risk of segregation. We have challenged unlawful segregation in a wide range of settings, including State-run institutions, privately run institutions, such as nursing homes and board and care homes, and other non-residential settings.

MATTERS REGARDING STATE-RUN INSTITUTIONS

The initial focus of our *Olmstead* work was on States that unnecessarily segregate individuals in public institutions or that place people at risk of entering public institutions. Our work focuses, not just on getting people out of these facilities, but also on the systemic reforms needed to ensure that public agencies do not put people at risk of unnecessary institutionalization.

Most recently, in Virginia we entered into a landmark settlement, to resolve the Department's finding that Virginia's system for serving people with intellectual and developmental disabilities violates the ADA by placing people in or at-risk of unnecessary institutionalization. The agreement will shift Virginia's developmental disabilities system from one heavily reliant on large, expensive, State-run institutions to one focused on safe, individualized, and cost-effective community-based services that promote integration, independence and full participation by people with disabilities in community life. The agreement expands and strengthens every aspect of the Commonwealth's system of serving people with intellectual and developmental disabilities in integrated settings, and it does so through a number of services and supports.

Among other things, the settlement agreement:

- Adds thousands of new Medicaid Home and Community Based Waiver slots for individuals to transition to the community from State-run and privately run institutions and for people on wait lists for community services;
- Creates a new family support program to help care for persons with disabilities in their own homes or a family members' home to prevent their unnecessary institutionalization;
- Requires the development of a comprehensive crisis system that will help divert individuals from unnecessary institutionalization;
- Provides for an integrated housing fund because we recognize that housing is a critical barrier to giving full force to the *Olmstead* decision;
- Requires the development and implementation of an Employment First Policy, prioritizing integrated, competitive-wage supported employment and the expansion of integrated employment and day activities; and
- Requires the development of a robust and comprehensive community quality assurance system.

Throughout the investigation that led to the Virginia settlement, we met with stakeholders across the Commonwealth, to learn their views about what was and was not working for people with developmental disabilities. We heard their problems and concerns, and ideas for addressing them, as well as their successes. We heard from families who were barely hanging on while their loved ones sat on long wait lists for community services and from self-advocates wanting more opportunities to work and live independently. We also heard from the families of persons now living in institutional settings who worried whether the needs of their loved ones could ever safely be met in community settings. We took these perspectives to heart, and incorporated them into our agreement.

These stakeholder views have been shared, not only with the Department, but also with the Federal judge who is considering whether to permanently approve the agreement. In responding to the Court's invitation to submit comments on the agreement, several hundred Virginians movingly described the real-life impact of the shortcomings in the Commonwealth's current developmental disability service system, and explained why transformation of that system is so important. Some of these individuals also submitted affidavits supporting the agreement.

For example, a single mother who is caring for a pre-adolescent son with severe autism, developmental and behavioral needs, and who faces an 8-year waiting list for home and community-based waiver services, told the Court that she is "overwhelmed by the thought of the years ahead" and not sure how she can continue to care for her family without the types of behavioral supports provided by the Virginia agreement. This woman wrote that receiving waiver supports would "dramatically improve" her well-being, the well-being of her son, and the well-being of his non-disabled brother. The parents of a 21-year-old with multiple disabilities who has always lived at home expressed their gratitude for recently received waiver services that allowed them to avoid institutionalization and to continue to allow their son to "enjoy his life to the fullest." These parents urged the Court to approve the Agree-

ment for the benefit of many other families who “desperately” need services but do not currently have them. Another parent, whose 6-year-old daughter is one of approximately 7,000 individuals on a wait list for waiver services, described her joy in seeing that her child “thrives in the community” and her hope that her daughter can live in the community as an adult. She added, however, that at present, her family and many others “live in crisis” waiting for needed services.

I have also spoken with a number of parents of people living in the Commonwealth’s training centers and they were very concerned, as they wondered what sort of quality control would be in place if or when their child moved into a decentralized setting in the community. I respect this concern. The *Olmstead* decision recognized that people with disabilities will move to appropriate community-based settings if they do not oppose such placement. For too long, people with disabilities have not been given meaningful choices or appropriate information to make informed choices about community services. Moving to the community will not be a realistic option for persons with disabilities if they and their families do not believe that the transition will be made in a thoughtful, respectful manner, and if they cannot feel confident that persons with disabilities will have the support needed to be safe and to thrive in the community. That is why the Virginia agreement includes a discharge planning process that includes family and community providers, and provides the opportunity to thoroughly explore community alternatives. Our consideration of the concerns expressed by family members is one of the reasons why the Virginia agreement includes enhanced protections for any person transitioning from a training center to the community.

The requirements in the Virginia agreement build and expand upon settlements we’ve reached in the past. For example, in October 2010, the Department, the HHS Office for Civil Rights, and Georgia reached a comprehensive, court-enforceable agreement regarding the Georgia system for serving people with developmental disabilities and mental illness. As a result of the agreement, Georgia is putting into place community-based services and supports for more than 1,000 individuals with developmental disabilities and expanding home and community-based waivers for individuals transitioning out of the State’s developmental disabilities facilities and for people who are at risk of institutionalization. The State is also developing services and supports for more than 9,000 people with mental illness.

In the first year of the agreement, Georgia provided supported housing to more than 100 individuals with mental illness, and will provide the same supports for an additional 400 individuals with mental illness this year. The State increased its existing community services to 20 Assertive Community Treatment (ACT) teams; two intensive case management teams; two community support teams; and maintained a crisis hotline, case management services, five crisis stabilization units, and peer support services. One State psychiatric hospital was closed, and the State negotiated agreements for the provision of services in community hospitals. Among the individuals who benefit from these actions is a man with a mental health diagnosis had been chronically homeless and was living in a tent. Initially, the ACT team worked with this man to find temporary housing at an extended stay hotel. Once his housing voucher was approved, the ACT team helped him search for a suitable apartment until he chose one he liked and moved in. He continues to live this stable environment.

For individuals with developmental disabilities, since signing the agreement, Georgia has ceased admissions to its State hospitals, transitioned 247 people out of these hospitals, funded an additional 100 community waivers, and created six mobile crisis teams and five crisis respite homes. The State provided family supports to 450 families of individuals with developmental disabilities this fiscal year. These changes helped a 9-year-old with developmental disabilities, who had spent her entire life living in one of the State hospitals, to move to the community. As a result of the agreement, this child is now living in a host home with a family and a nurse who is available to provide 24-hour-a-day care; in the fall, she will attend a new school where she will have the opportunity to relate to other children her age.

In July 2011, we signed a comprehensive agreement with Delaware to transform that State’s mental health system. Over the next 5 years, Delaware will prevent unnecessary hospitalization by expanding and deepening its crisis services, including a hotline, crisis walk-in centers, mobile crisis teams, crisis apartments and short-term crisis stabilization programs. Delaware will also provide community treatment teams and case management to individuals living in the community who need intensive levels of support. Our agreement also provides for scattered-site supported housing for everyone in the agreement’s target population who needs it. Finally, Delaware will offer supports to enable persons with mental illness to lead integrated daily lives, including supported employment, rehabilitation services and peer and family supports. I’m pleased to report that Delaware is well on the way to meeting

the agreement's July 2012 compliance benchmarks, including for crisis services, treatment, family support, supported housing and supported employment.

In a recent Delaware monitoring visit, a Civil Rights Division attorney met with several people who, as a result of the agreement, have moved from Delaware's State psychiatric hospital into their own apartments in the past year. These individuals include a formerly homeless woman; a man who had many years of involvement with the criminal justice system; and a long-term psychiatric hospital resident. Our attorney also met a 21-year-old woman who, due to recently enhanced peer counseling, is now preparing to move from the State hospital to her own apartment in the community. These individuals described the positive change that our agreement had made in their lives. They said:

"It's one more day closer to Christmas;"

"I'm no longer invisible, people see you and say hi to you;"

"Independence means being able to accept friendship from other people;"

"I now have the right to just live and the freedom to open and close doors;"
and

"Thank you for giving me back my life."

There are so many other places where we are doing significant *Olmstead* work and where such work is necessary. In December 2011, we issued findings that the State of Mississippi is violating the ADA and *Olmstead* in the operation of its mental health and developmental disabilities system. We are currently negotiating with Mississippi to change its service delivery system from one that unnecessarily institutionalizes thousands of adults and children to one that provides real opportunities to people unnecessarily institutionalized or at risk of unnecessary institutionalization. In New Hampshire, we issued findings in April 2011 that New Hampshire unnecessarily segregates individuals with mental illness in institutional settings and places individuals with mental illness living in the community at serious risk of institutionalization. We recently intervened in private *Olmstead* litigation to address these violations.

MATTERS REGARDING PRIVATELY OWNED SEGREGATED SETTINGS

States' *Olmstead* obligations are not limited to people who are forced to live in publicly run institutions. As many States have been decreasing their reliance on publicly run institutions, we have seen more and more individuals with disabilities inappropriately segregated by States in privately owned or operated institutions, including nursing homes. We have been very active in *Olmstead* enforcement in this area. For example, in July 2011, the Division moved to intervene in private litigation filed on behalf of a class of approximately 4,000 individuals with developmental disabilities in or at risk of entering nursing facilities in Texas. Many of the class members had lived in the community successfully, but ended up in a nursing home because of the way the State administers its program of services for individuals with developmental disabilities.

Additionally, after a lengthy investigation of North Carolina's mental health service system, the Division issued a findings letter in July 2011 concluding that the State is violating *Olmstead* by administering its system in a manner that unnecessarily segregates persons with mental illness in large, privately owned adult care homes. The Department recommended that the State implement certain remedial measures, including the development of scattered site-supported housing and the provision of adequate, community-based support services for people with mental illness who are unnecessarily institutionalized, or at risk of unnecessary institutionalization, in adult care homes. Currently, the Department is negotiating with North Carolina to resolve these findings.

The Division also continues its participation in *Disability Advocates, Inc. v. Cuomo*, a case in which a Federal court in New York found, after a trial, that New York discriminates against persons with mental illness by operating its mental health service system in a manner that confines them to large, for-profit adult homes, when they could and want to receive services in community settings. After the Second Circuit vacated the trial court's decision on jurisdictional grounds, the Division is considering its options for how to proceed in the case and, as with any case, seeks to resolve the case without resorting to litigation.

In other instances, we have learned of States that are segregating children in private nursing homes, depriving them of the opportunity to live with their families and in the community. In Virginia, we learned of almost 200 such children in private nursing homes and private developmental disability facilities, and our agreement provides community relief for them. We currently have an investigation in another State regarding children with physical and developmental disabilities in or at risk of entering nursing homes. We also have an open investigation into whether

a State is unnecessarily placing people with physical disabilities at risk of being forced into nursing homes.

STATEMENTS OF INTEREST

The work I have described above is in addition to the Division's participation in dozens of private lawsuits concerning the right of persons with disabilities to receive services in the most integrated setting appropriate to their needs. We have filed briefs in 27 other matters in 17 States supporting private litigation regarding people who are unjustifiably confined to institutions or at risk of being segregated in an institutional setting unnecessarily.

GUIDANCE AND WEB SITE

The Department also has developed resources to help people to understand their rights and to help States understand and implement their obligations. In June 2011, we issued the Division's first technical assistance document on *Olmstead* enforcement. In this document, we describe the requirements of the ADA's integration mandate and provide a series of questions and answers on a range of topics. Among other things, this document makes clear the Department's view that both the mandate of *Olmstead* and the appropriate remedy to unnecessary segregation apply to the full range of settings in which individuals with disabilities live, work, and receive services. We also have a Web site dedicated to *Olmstead* enforcement, which includes links to settlements, briefs, findings letters, and other materials.

INTERAGENCY COLLABORATION

In 2009, on the 10th anniversary of the *Olmstead* decision, President Obama launched the "Year of Community Living" directing all relevant Federal agencies, including the Departments of Justice, Health and Human Services, and Housing and Urban Development ("HUD"), to work together to make the promise of *Olmstead* a reality for Americans with disabilities. We have embraced this directive and worked in partnership with HHS, HUD, the Department of Labor, and other agencies that have primary responsibility for programs that are essential to community integration.

We have worked with HHS, particularly the Centers for Medicare and Medicaid Services and the Substance Abuse and Mental Health Services Administration, to aid States in making the systemic changes necessary to provide community-based services to individuals who would be in, or at risk of, institutional placement. We have also worked with the HHS Office for Civil Rights (OCR) in matters where we have a shared enforcement interest. For example, in Georgia, the State failed to comply with a voluntary resolution agreement between OCR and the State to resolve longstanding *Olmstead* complaints and DOJ worked with OCR and the State to achieve a comprehensive, court-enforceable settlement. DOJ is currently investigating a matter in another State where OCR was unable to secure voluntary compliance. Moreover, as evident from the relief we sought in Virginia, Delaware, Georgia and other cases, we know that the lack of affordable housing is one of the biggest barriers to community living. So, we have been working with HUD to help identify for States Federal resources for affordable integrated housing.

We have also collaborated with HHS and HUD on policy development, and we continue to work with HHS, including its newly aligned Administration for Community Living, and HUD to develop and disseminate policies that can promote integration in a consistent and comprehensive way.

ONGOING AND FUTURE WORK

The Department's *Olmstead* enforcement activities are dynamic and ongoing. We have several ongoing investigations, and are addressing new issues, including: the segregation of children with disabilities, people with disabilities inappropriately in nursing homes, and the segregation of people with disabilities in day-time activities, including segregated work. With regard to employment, the Division has expanded its *Olmstead* work to look beyond just *where* people live to examine *how* people live and spend their days. Simply moving someone from an institution to a community-based residence does not achieve community integration under *Olmstead* if that person is still denied meaningful integrated ways to spend their day and is denied the opportunity to do what so many people do—pursue competitive employment in the community. And so, in a Federal case in Oregon, we recently filed an *amicus brief* supporting private plaintiffs who asserted that *Olmstead* applies to a situation in which individuals seek integrated supported employment services but are instead placed by the State in employment settings in which they have little or no oppor-

tunity to interact with non-disabled workers or to learn valuable skills that would assist them in working in competitive employment. In addition, our settlement agreements in Virginia and Georgia require the States to expand supported employment opportunities for individuals receiving services under those agreements; and our findings letters in Mississippi and New Hampshire noted a lack of integrated day opportunities, including supported employment opportunities, for individuals receiving services in the State.

As I consider the Department's *Olmstead* accomplishments to date, and our plans for the future, I continue to take inspiration from people with disabilities, their families and their caregivers. These individuals express the harm of segregation and the value of integration more eloquently than any lawyer's brief ever could. They are the heroes of this civil rights movement. And so, I end this testimony with the words of a family member who wrote urging the Court to approve our Virginia agreement. This woman, who initially raised her son at home, very reluctantly sent him to a State institution for lack of community alternatives, and most recently has seen him make great strides upon returning to community living, told the Court:

"In my view, it is good for all of us to be able to see that people with disabilities are a part of our society and belong to us. We can respect them, admire them, interact with them, have admiration and compassion for some of the challenges they face—and we can be inspired. People with disabilities are part of us—and should not be put in isolation, unseen and unappreciated."

The Department of Justice will continue to do all we can to ensure that our *Olmstead* enforcement lives up to these words.

Thank you.

The CHAIRMAN. Thank you very much, Mr. Perez, for a very profound statement.

Now, we will turn to Henry Claypool.

STATEMENT OF HENRY CLAYPOOL, PRINCIPAL DEPUTY ADMINISTRATOR, ADMINISTRATION FOR COMMUNITY LIVING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Mr. CLAYPOOL. Chairman Harkin and Ranking Member Enzi, thank you for the opportunity to testify before you today.

Chairman Harkin, I would be remiss if I did not take this opportunity to acknowledge your leadership in protecting the rights of Americans with disabilities to live independently in their communities.

I would also like to recognize my colleague, Tom Perez, when the *Olmstead* decision was handed down, he served as the Director of the Office of Civil Rights at HHS. Today, he leads the Nation's *Olmstead* enforcement efforts at DOJ, and it is a privilege to testify with him today.

In 1995, with the State of Georgia refusing to allow two women to live and receive services in the community, Lois Curtis filed suit under the name "*Olmstead v. LC*." The Supreme Court ruled on the case in 1999 and today, Lois rents her own home, lives a meaningful life as a valued member of her community.

Recognizing that there is still much work to be done, and in his first months in office, and on the 10th anniversary of the *Olmstead* decision, President Obama sought to invigorate enforcement of *Olmstead* by announcing the "Year of Community Living." This initiative established critical partnerships between HHS, HUD, and DOJ and it sparked new activities to help individuals with disabilities transition from institutions to the community.

In addition to DOJ's enforcement efforts that Tom just outlined, HHS and HUD have developed an unprecedented partnership to address one of today's most significant barriers to living in the

community: the lack of accessible and affordable housing for people with significant disabilities.

Under the leadership of Secretaries Sebelius and Donovan, the HUD—HHS partnership has begun to change how housing and health care agencies view their relationship with regard to the needs of individuals with disabilities. In the initial year of the partnership, 5,300 housing vouchers were issued to people with disabilities that rely on supportive services. This includes nearly 1,000 vouchers that were coordinating rental assistance with the long-term services and support that people need to live in the community.

HHS has also worked closely with HUD to improve integration in the Section 811 program. Just last month, HUD announced a new funding opportunity under this program that now limits the number of apartments that can be exclusively set aside for people with disabilities to a maximum of 25 percent. This is a fundamental shift in housing policy at HUD, bringing a key program into alignment with the principles of the ADA, and promoting efforts for Medicare to serve people in the most integrated setting.

On March 23, 2010, President Obama signed the Affordable Care Act which set forth numerous protections for all Americans including people with disabilities, and fills in an important piece of the ADA by addressing health care discrimination, and improving affordability.

Of note, the law strengthens the Money Follows the Person program which provides States Federal support to help institutionalized individuals get out and return to their community by expanding the MFP program through 2016, and investing an additional \$2.25 billion in the program. The success of the MFP program can be understood through the story of Quentin Hammond.

Quentin had a brain injury as an infant, and was placed in a nursing home for the first 6 years of his life. Thanks to the tireless advocacy of his mother, Quentin was able to leave the nursing home and move home with his mother and brother. Through the Money Follows the Person program, Quentin is receiving necessary services and supports to live at home, and today attends school.

And thanks to your leadership again, Chairman Harkin, States have another incentive to reduce the institutional bias in Medicaid. The Community First Choice option, as you know, this program includes Federal Medicaid support for States that choose to offer new personal attendant benefit to beneficiaries who would otherwise face institutional placement. We anticipate several States will adopt this option, helping beneficiaries avoid unwanted institutions and bolstering State resources.

In keeping with the integration mandate of the Americans with Disabilities Act, and as required by the *Olmstead* decision, these critical provisions of the health care law provide new ways to serve people in home and community-based settings.

The President's "Year of Community Living," critical health care improvements thanks to the Affordable Care Act, and the need to continue to transform our health care delivery system have all culminated in Secretary Sebelius's creation of the Administration for Community Living. This new agency creates a home within HHS for aging and disability policy and programs. Many in the aging

and disability community have an extraordinary reliance on health care and long-term services. Among other activities, the Administration for Community Living will work closely with CMS to improve coordination of health care services with the essential long-term services and supports that help people live in the community.

We are excited about this new agency and the emphasis it places on policies that support community living and community integration. We look forward to working with all stakeholders, including Congress, in our commitment to ending the very discrimination that Lois Curtis experienced in Georgia more than 13 years ago.

Thank you, again, for inviting me to testify today, and I look forward to answering any questions.

[The prepared statement of Mr. Claypool follows:]

PREPARED STATEMENT OF HENRY CLAYPOOL

Chairman Harkin, Ranking Member Enzi and members of the committee, thank you for the opportunity to testify this morning on the Supreme Court's *Olmstead* decision, and the Department of Health and Human Services' (HHS) commitment to ensuring that individuals with disabilities can live and participate fully in their communities with access to the services and supports they need.

Chairman Harkin, I would be remiss if I did not take this opportunity to acknowledge your leadership in protecting the rights of, and advocating for increased opportunities for, Americans with disabilities to live as valued and contributing members of their communities. Not only did you author the Americans with Disabilities Act (ADA) and serve as its chief sponsor in the Senate, but today—almost 22 years later—you continue to offer unwavering support to ensure that Americans with disabilities have full access to society, including the right to live independently in their own communities.

I would also like to take a moment to recognize my colleague, Tom Perez. When the *Olmstead* decision was handed down, he was serving as the Director of the Office on Civil Rights at HHS, and helped issue the Department's first guidance to State Medicaid directors on how to make State programs responsive to and comply with *Olmstead*. Today, as Assistant Attorney General for Civil Rights at the Department of Justice (DOJ), he continues to place a high priority on *Olmstead* enforcement, among the many other important civil rights matters at DOJ. Thank you, Tom. It is a pleasure to testify here with you today.

In 1999, the Supreme Court determined in its *Olmstead* ruling that under the ADA, it is discrimination to unnecessarily institutionalize a person with a disability who chooses to live in the community with the proper services and supports, and does not oppose community placement; taking into account the resources available to the State. This Administration has made significant strides, as well as key investments, toward the day that all Americans with disabilities can live in a home of their choosing, accessing the services and supports they need and experiencing the dignity and respect that comes with the opportunity to fully participate in all aspects of our communities.

Before I share with you some of the key investments and achievements the Department of Health and Human Services has made in recent years to ensure that individuals with disabilities can achieve their right to live fulfilling, healthy lives in the community, I first want to take a moment and recognize where we started.

In 1967, the number of individuals with intellectual and developmental disabilities living in institutions reached the peak of nearly 195,000 on an average day.¹ While that number had dropped to about 60,000² by the mid-1990s, there were still many individuals—including Lois Curtis and Elaine Wilson—who were living in institutions and wanted to live freely in their communities. In 1995, with the State of Georgia refusing to allow the women to live and receive services in a more integrated, community-based setting, Lois and Elaine filed suit, under the name *Olmstead v. LC and EW*. Today, Lois rents her own home and is finally able to live a meaningful life, contributing as a member of society through creating and selling art.

¹ Statistic comes from <http://rtc.umn.edu/docs/risp2010.pdf>, p. 12.

² Statistic comes from <http://rtc.umn.edu/docs/risp2010.pdf>, p. 12.

YEAR OF COMMUNITY LIVING

Recognizing that there is still much work to be done, in his first months of office President Obama sought to focus on the goals of the *Olmstead* decision by announcing the “Year of Community Living.” Announced on the 10th anniversary of the decision, this initiative established critical partnerships between three Departments of the Federal Government and has sparked new activity to help individuals with disabilities transition from institutions into the community. Specifically, in this signature disability initiative, the President called for an unprecedented partnership between HHS and the Department of Housing and Urban Development (HUD) to address one of the most significant barriers to living in integrated settings: accessible and affordable housing for those living with a disability who want to live in the community.

Under the leadership and direction of Secretary Sebelius and Secretary Donovan, our agencies meet regularly to identify and implement strategies that address the coordination of long-term services and supports with accessible and affordable housing, particularly for individuals at risk of institutionalization. In the initial year of the partnership between HHS and HUD, the coordination of \$40 million in Section 8 housing choice vouchers made it possible for 5,300 people with disabilities, who rely on supportive services to live in the community, to access affordable housing across the country. This includes nearly 1,000 vouchers designated for individuals transitioning to community-based services and supports through the Federal Money Follows the Person program.

The awarding of nearly 1,000 vouchers was a deliberate effort by HHS and HUD to coordinate rental assistance, health care and other supportive services to support to this population and help States comply with *Olmstead*. For States that are actively working to comply with *Olmstead* and re-balance their Medicaid long-term services and supports programs to increase the emphasis on providing services in home and community-based settings instead of institutional settings, the lack of affordable and accessible housing remains a significant barrier to people with disabilities seeking to realize their right to live in the most integrated setting. The HHS-HUD partnership has begun to change how the housing and health care agencies at the State and Federal level view their relationship with regard to the needs of individuals with disabilities—a population they are both charged with serving.

We have seen how this type of partnership and innovation affects individual lives. Three years ago, a mother of two named Sonia was crossing the street when a car hit her, put her in a coma for 5 months, and left her with the left side of her body paralyzed and in a nursing home separated from her children. Last June, she received a housing voucher and services under the Money Follows the Person program, allowing her to return home. Today she can support and play with her children, go to job training, and participate in her community.

Moreover, HHS has also worked closely with HUD to implement changes to improve integration of HUD’s Section 811 Program, which is designed to develop and subsidize rental housing for very low-income adults with disabilities. Last month, HUD announced a new \$85 million funding opportunity under the Section 811 program for State housing agencies that meet new eligibility criteria, including having a partnership with a State health and human services agency and Medicaid agency, to provide essential supports and services that help people live in integrated settings in the community. This funding opportunity works to align critical health and housing services, and aims to assure integration by setting the number of apartments that can be exclusively set aside for people with disabilities at 25 percent. This is a fundamental shift in housing policy at HUD and brings the Section 811 program into alignment with the principles of the Americans with Disabilities Act and promotes Medicaid efforts to serve people in the most integrated setting appropriate to their needs.

The reinvigoration of the efforts by the Department of Justice to enforce the *Olmstead* decision was the other component of the President’s “Year of Community Living.” The testimony of Assistant Attorney General Perez outlines the steps taken by DOJ to ensure that States understand how they can comply with the ADA when they use Medicaid to provide long-term services and supports. HHS has worked closely with DOJ on matters related to *Olmstead*. Specifically, HHS’ Office for Civil Rights (OCR) partners with DOJ to enforce the ADA and the *Olmstead* decision. For example, in 2008, OCR entered into a voluntary resolution agreement with the State of Georgia to resolve *Olmstead* complaints regarding the State’s mental health and developmental disabilities systems. The State failed to comply with the agreement and DOJ initiated litigation. In October 2010, OCR, DOJ and the State of Georgia signed a comprehensive settlement agreement that will ensure that thousands of people with disabilities will receive community services instead of institu-

tional care. OCR continues to resolve *Olmstead* complaints, often working with people with disabilities, families, advocates, State agency officials, and other HHS agencies to ensure that individuals can remain in the community without risk of institutionalization and have the opportunity to transition to the community from an institutional setting.

To organize and coordinate efforts at HHS related to the President's "Year of Community Living," Secretary Sebelius created the Community Living Initiative. This facilitated a cross-agency workgroup that met to discuss key issues related to community living and the infrastructure of the home and community-based services delivery system. Along with access to affordable housing, the initiative addressed the needs of the workforce that provides community-based services and supports, providing new opportunities to make community-based services available under the Medicaid program, and explored how gathering better data related to disability could enhance the quality of these home and community-based services. Historically, the approach to defining home and community-based services has been exclusively focused on defining services and settings against the framing of "not an institutional setting" instead of defining the positive and necessary elements that create a home in the community. The cross-agency workgroup's work on person-centered planning and self-direction was incorporated into the Community First-Choice and the 1915(i) State Plan Home and Community-Based Services rulemaking, which has helped inform the agency's current effort to define the locations in which Medicaid recipients are receiving coverage for home and community-based services.

Finally, in addition to the Community Living Initiative, Secretary Sebelius formed an HHS Coordinating Council, bringing together multiple HHS agencies and offices and asking them to coordinate their efforts to build and strengthen home and community-based services. Workgroups have been formed to address issues such as affordable housing, building the home and community-based workforce, improving employment supports, and enhancing access to services. Discussions in these intra-departmental conversations inform HHS' work internally and its engagements with other agencies that are part of the Community Living Initiative.

AFFORDABLE CARE ACT

On March 23, 2010, President Obama signed the Affordable Care Act, which set forth numerous protections for all Americans, including people with disabilities, filling in an important piece of the ADA by addressing healthcare discrimination and improving access and affordability.

Thanks to the new healthcare law, people like Tina from Michigan have more control and access over their healthcare. Tina has epilepsy that requires consistent monitoring and care. After graduating from college at the age of 22, Tina could find a job, but she couldn't find health insurance except for a very limited policy that did not meet her needs. Now, because of the Affordable Care Act, Tina—who is now 24 years old—can stay on her family's health insurance plan until she is 26, which not only provides great coverage but also includes the doctors who know her, understand her epilepsy, and whom she trusts.

Moreover, starting in 2014, Tina and other people with disabilities will be protected by the law's prohibition on some insurance companies' egregious practices of denying benefits or charging more to any person based on their medical history. For children younger than age 19, the law has already gone into effect, and insurance companies can no longer discriminate and deny coverage based upon pre-existing conditions for children and youth.

Not only does the Affordable Care Act expand access to health coverage, but also it expands affordability for many low-income individuals, including many people with disabilities. Specifically, starting in 2014 the new health care law includes a Medicaid program expansion that will reach more Americans, including some people with disabilities. This expansion will cover many low-income people with disabilities who do not currently meet the Social Security Administration's definition of disability.

Another critical aspect of the Affordable Care Act are the provisions that address long-term services and supports, including re-balancing Medicaid investments from institutions to home and community-based services. Specifically, the law strengthens the Money Follows the Person (MFP) program, which provides States significant Federal support to help institutionalized individuals get out of their institutions and return to their homes or other community settings, which in almost all cases substantially improves their quality of life. By extending MFP through 2016 and investing an additional \$2.25 billion in funding, the program will build on its successes to date, which in the past 5 years has helped 20,000 individuals leave institutions for the community. Today, 43 States and the District of Columbia are participating

in MFP, and the renewed commitment toward MFP in the Affordable Care Act means that thousands more can leave institutions and live where they want with the services that they need.

The successes of this program can be understood through the story of Quentin Hammond. After a traumatic brain injury as an infant, Quentin lived in a nursing home for the first 6 years of his life, where he was not engaged at his fullest potential. He was misdiagnosed as being blind and non-responsive. However, thanks to the Money Follows the Person program and the tireless advocacy of his mom, Quentin was able to leave the nursing home and move home with his mom and little brother, receiving the necessary services and supports so that he got the same high-level of care. Quentin now attends school and is learning to communicate. His quality of life has improved tremendously.

This critical choice to be able to live in one's own home, and have access to the medical services and supports they need, are the exact kinds of rights that the Affordable Care Act gives Americans, especially Americans with disabilities.

In addition to strengthening the Money Follows the Person program, the Affordable Care Act gives new incentives for States to offer home and community-based long-term services and supports as an alternative to institutions. Under the Balancing Incentive Program, \$3 billion in enhanced Federal Medicaid matching funds are available to States that make structural reforms to increase nursing home diversions and access to non-institutional long-term services and supports. In March 2012, New Hampshire and Maryland were the first States to receive this new funding; and Georgia, Iowa, Mississippi, and Missouri have all since been approved to participate in the program as well.

States have an additional incentive to reduce the institutional bias in Medicaid through the Community First-Choice program, which increases Federal Medicaid support for States that choose to provide home and community-based attendant services to Medicaid beneficiaries otherwise facing institutional placement. In addition to receiving a broad range of services, Community First-Choice recipients must have their self-determination supported through the opportunity to develop a person-centered plan that allows the individual to determine how services are provided. The Community First-Choice benefit will further assist Medicaid beneficiaries in avoiding unwanted institutional placement while at the same time providing States with more resources to support this work.

Finally, the Affordable Care Act makes investments to integrate care delivery under Medicaid and Medicare for dual eligibles. Often, people with disabilities are beneficiaries under both programs, creating the need for care coordination and management across these two programs. Done right, the integration of these two programs can improve access to essential health care services and promote enhanced access to long-term services and supports, which can help avoid unnecessary hospitalization and institutionalization for people with disabilities, and at the same time lowering costs to our Nation's healthcare delivery system.

In keeping with the integration mandate of the Americans with Disabilities Act, and as required by the *Olmstead* decision, these critical provisions of the health care law provide new ways to serve more people in home and community-based settings.

ADMINISTRATION FOR COMMUNITY LIVING

The President's Year of Community Living, the Secretary's Community Living Initiative, critical improvements thanks to the Affordable Care Act, and the pressing need to continue to transform our health care delivery systems, have all culminated in Secretary Sebelius' creation of the Administration for Community Living.

Today, I serve as the Principal Deputy Administrator of the Administration for Community Living, as well as Senior Advisor to the Secretary for Disability Policy. Kathy Greenlee maintains her role as Assistant Secretary for Aging, while also serving as the Administrator of the new agency.

The establishment of the Administration for Community Living creates a single agency charged with developing policies and improving supports for seniors and people with disabilities by bringing together the key organizations and offices focused upon these populations. The agency builds upon this Administration's work to promote the goals of the Americans with Disabilities Act: to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities. We are committed to improving the broad range of supports that individuals may need, focusing on populations that have an extraordinary reliance on health care and long-term services and supports. Ultimately, the integration of the health care system and the long-term services and supports systems is essential to the health and well-being of millions of Americans with disabilities and seniors that have functional support needs.

The Department's efforts to better align the Medicare and Medicaid programs hold great promise to improve the health of those eligible for both programs, such as younger adults with disabilities and seniors who have chronic health conditions and functional support needs. To that end, the Administration for Community Living will work closely with the Centers for Medicare & Medicaid Services to advance its alignment efforts directed to the population jointly served by the two agencies. The potential for better coordination of health care and crucial community-based services and supports will be an area of emphasis for the new agency.

We realize that we are serving diverse populations, including frail elders, individuals with physical disabilities, and those with intellectual and developmental disabilities across the life-span. Representing the voice of each of the populations served is core to the work of the entities coming together under the Administration for Community Living. This will continue with an increased strength through a unified mission while still acknowledging the unique needs and attributes of each group. However, these communities share a common vision—that all Americans should have the right to live in a home of their choosing, with people whom they care about, that is integrated into a community that values their participation and their contributions—and the Administration for Community Living will work to support that vision.

We also know that community living relates to more than where people live. Integration requires the availability of appropriate supports including opportunities in health care, housing, employment, education, childcare, and social participation for people with disabilities and older Americans. The Administration for Community Living will take a holistic approach to meeting the community living needs of people with disabilities and older Americans.

We are excited about this realignment and the renewed focus the development of the Administration for Community Living has placed on community living and community integration at HHS and across the Administration. At the Department of Health and Human Services, we look forward to working internally, with other agencies across the Administration, with Congress, and with the public at large to advance policies that support community living and ensure that those who have been harmed by discrimination, like Lois Curtis, can pursue their passions living in the community.

Thank you again for inviting me to testify and at this time I would be happy to address any questions.

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

Both of you, thank you for your long-time leadership on this issue. You have just been, both been, stalwarts and I cannot thank you enough.

We will start a 5-minute round of questions here. Mr. Perez, you mentioned about the sheriff saying the jails are now our mental health places. I have had the same thing happen to me in Iowa, too; come to me saying, "You have got to do something, because there are people here that should not be in the jail." They need to be out in the community, they need supportive services, but they just do not have the wherewithal to do that. We are getting a lot of input, I know, from our law enforcement people around the country on this.

But there are a couple of questions I want to ask both of you. First of all, two parts. No. 1, it just frustrates me to no end that I keep hearing from parents who have children or young adults with disabilities. They want them in community settings. They want to get them out of an institution, but they are worried about, "What happens when I die?" They are worried about the long term. They might see it now but, "Can you guarantee me that this is going to be there 20 years from now?" that type of thing.

Please address that issue, give me some idea of what things do we need to do, to put in place the structures that will meet the test of time.

The second part of the question is that you both alluded to the stovepipes that are out there. I think Mr. Perez made that state-

ment “stovepipes”. This new Administration for Community Living is crossing over into different agencies, and one of the things you are talking about is affordable housing which is critical—critical—for people with disabilities.

Talk a little bit about, both of you, this long-term plan and how we set structures in place. And second, how satisfied are you with the fact that you are now getting into different agencies, HUD and everybody else, working together on housing and supportive services; those two elements.

Mr. PEREZ. I think as to your first question, Mr. Chairman, it is so important to learn from the past.

The institutionalization movement of the 1970s, the profound mistake that was made was opening the doors of institutions when the community infrastructure did not exist. And as a result, when you hear the sheriffs in Wyoming and in Iowa telling you that, “My facility is the largest mental health facility in my area,” that is because we did not plan for it as a Nation and as communities.

If you look at our agreements—and Secretary Landgraf can talk about it in the mental health context, as well as the witness from Alabama—we are building community infrastructure, assertive community treatment teams, crisis intervention, a short-term bed so that if an officer encounters a person who is clearly in crisis, the choices are not simply the emergency room or the jail. You have these other options in place in the community.

Having that robust infrastructure in place is, I think, a key to addressing the question I hear so often from parents, “I am 70 years old and my son, or daughter, or niece, or nephew, is 48. I am not going to be around forever. What is going to happen with them?” I think we owe it to them to build that community infrastructure. I think we know a lot about what that infrastructure needs to have.

And if you look at the building blocks of our agreements in Virginia, and Delaware, and elsewhere, Georgia, what you will see is what we spent in Virginia, we spent 5 months talking about quality assurance, because if I cannot look you in the eye as a government official and say, “Your loved one is going to be cared for in a safe environment,” then I have no business being in this business. That is what we have spent so much time working on. And you see there are all sorts of quality assurance mechanisms built-in to our agreements because we have to make sure we have that infrastructure.

Governor Perdue in Georgia, invested something like \$500 million over the course of a few years in a tough fiscal environment because they recognized that you have to think long term when you are thinking about these issues.

I think we have a blueprint that can work, that learns from our mistakes, and can move forward.

As to your second question, I am a firm believer that the most vexing public policy questions that we confront here at the Federal level are those through which unprecedented levels of interagency collaboration are required. If you help a person with a disability get a job, but then they lose the health insurance that they have been getting, it is a Pyrrhic victory. We have to have one agency talking to the other.

If we help a person get into a community-based setting, but we cannot insure that the housing and the transportation is there so they can get to a job, then we have not—they are all links on a chain, and every link has to be there.

That is why, for instance, in the employment setting, an issue I know is one of many that is near and dear to your heart, we met literally within the last 2 weeks—convened by Deputy Secretary Harris—HHS, DOJ, DOL, and the EEOC to talk about: how can we ensure that integrated supportive employment becomes the norm and sheltered work-shops become increasingly the exception? Because that is what the integration mandate is about; it is not just where you live, it is how you live.

I think those stovepipe implosion initiatives are beginning to bear fruit, and I hope they will continue because that is how you solve these problems. You do not just sit here at the Department of Justice and figure out, how do you sue them? You have to figure out, how do you solve them?

We have had many willing Governors, and I want to underscore that. I mean, I have great respect for the leadership of Governor McDonnell on this issue in Virginia, for Governor Perdue in Georgia, for Governor Markell in Delaware. They all came to the table in good faith. And they recognized in Delaware that spending \$200,000 of State-only dollars to treat someone in a State institution, no Federal reimbursement, is not cost-effective among other things, aside from not the best way to do it.

I think we can do it. I think we have a blueprint. I think we are implementing blueprints and we are learning from those blueprints. We learn from our mistakes and we try to get better.

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

Mr. Claypool, anything to add? My time has run out.

Mr. CLAYPOOL. I think your questions are very poignant and in some way, they are almost answered together.

But the infrastructure, I think the record is replete with our efforts to make investments in the home and community-based delivery system. They are bipartisan and they extend back to the *Olmstead* decision. You have Money Follows the Person passing with the Deficit Reduction Act in 2005. You see it again affirmed in the Affordable Care Act and the investments made there.

So there is clearly an effort to move the Medicaid program in this direction toward building the community-based infrastructure that Tom has mentioned, and really making some solid investment so that people can lead quality lives there. We continue to push forward on those efforts with these investments.

But really the second part of your question about the partnerships that we have are critical to making sure that the quality experience that people have living in the community is held up. Without HUD and HHS working together and better understanding how the programs can synchronize with each other to support an individual, we will not get there. But as we can see, the stovepipe implosion is already underway. These barriers are breaking down, and I just do not think we can turn back.

It is becoming increasingly apparent that the individuals that are relying on HUD services, especially those with disabilities, often have supportive services needs. And finding new ways for

housers to understand how they can work with partners in health care agencies is just essential.

And to that end, we have been working with CMS to make sure that we are holding forums across the country where we can really introduce, not just at the Federal level the HUD staff to the HHS staff, but at the State and local level, building these partnerships to make sure that these two are working together and making sure that there is an infrastructure available to support people. And that it is a quality infrastructure, and that we need not look to institutional settings to reassure family members that this is their only alternative.

Senator ENZI. Thank you, Mr. Chairman.

Mr. Perez, the Department of Justice's oversight and enforcement efforts seem largely focused on the States' Medicaid program.

Are you investigating the enforcement of the *Olmstead* compliance beyond the Medicaid program, for example, meeting with Medicare or with the Veteran's Affairs program?

Mr. PEREZ. Our enforcement program certainly overlaps significantly with Medicaid because many of the populations at risk are receiving Medicaid dollars, but it is certainly not limited to that.

We have actually begun a number of conversations with the Department of Veterans Affairs because we have many service members with disabilities returning home, and we want to make sure that they, too, receive care and treatment in the most integrated setting appropriate to their needs.

In addition, we have cases involving nursing homes. We have a case in Texas involving people in nursing homes, so our focus has really been expansive. We have a lot of cases in the developmental disability setting, in the mental illness setting, but we also have cases involving nursing home care.

I am really glad, Senator Enzi, that you brought up the VA issue because we really want to make sure that our vets returning home who have serious disabilities are, indeed, treated in the most integrated setting. That is certainly an area of renewed focus in the last year.

Senator ENZI. So that is a relatively new initiative, then?

Mr. PEREZ. I would agree with that.

Senator ENZI. And you mentioned Virginia, and Delaware, and Georgia frequently.

Mr. PEREZ. Yes.

Senator ENZI. How did you decide to concentrate on those States?

Mr. PEREZ. Well, in all of those States, we had information that led us to be very concerned that there were violations. They are not the only States where we have concerns.

As I mentioned, we have been involved in one way, shape, or form in about 25 States in about 40 different matters. We have attempted in our work to come up with some evidence-based metrics to determine which States are unduly institutionally reliant, and Mississippi is an example.

Mississippi is one of the most institutionally reliant States in the country, and I would observe that they are a State that is probably leaving, as much as anyone, the most Federal dollars on the table because they are eligible for a number of enhanced matches under Medicaid given the nature of the populations that they are serving,

and other indices. When we looked at that and saw the level of unnecessary institutionalization, that was certainly what brought us into the State of Mississippi.

Senator ENZI. So they have been passing up on some resources.

Mr. PEREZ. They sure have.

Senator ENZI. What kind of limitations are there on State resources that you are running into?

Mr. PEREZ. Certainly State budget limitations are undeniably an issue that we confront from time to time.

What we want to make sure, and what we have done working with States, is to make sure that they are making individualized determinations, as opposed to kind of blanket, across-the-board cuts because many of the cuts, aside from implicating the ADA potentially, can be actually cutting off your nose to spite your face.

By that I mean if someone is in a community, is receiving community services which are undeniably less expensive and you cut those services, and then that person goes into an institution, you are going to be on the hook for far more dollars. We really try to work hard to educate and prevent.

And in the budget context, we really tried to do just that because some of the proposed cuts have been—I can understand why; the necessities. I worked in State government. I worked in local government. I have an acute appreciation for the budget woes, but you need a scalpel not a sledgehammer, and sometimes the use of a sledgehammer not only has perverse fiscal impact by making it more expensive, but it can have ADA implications.

Senator ENZI. Yes. I would followup more on that, but now I want to ask Mr. Claypool.

You have been working with this consolidation of the Administration on Aging and the Office of Disability Administration into a single new agency, and the supports go well beyond health care. You mentioned appropriate housing, I think you mentioned employment education, meaningful relationships, and social participation.

How are you specifically engaging with HUD, and other agencies, to support that goal for enforcement?

Mr. CLAYPOOL. Thank you for the question.

The Secretary has just created the Administration for Community Living, so I will not have a full answer to the extent of which partnerships that we will develop over time, but I certainly can identify some really solid starting points.

One of them, and just in terms of, you have acknowledged that the aging and disability agencies are coming together within the Department, and that is an important first step, making sure that we are looking at the needs of people with disabilities, as well as older Americans when we address issues like access to transportation. It is critical that we view these together, and that we look for opportunities to move forward where the needs are the same. Of course, we see that in housing as well.

You have mentioned the VA, and I thought this might be an opportunity to highlight one of the initiatives that the Administration for Community Living has already released.

We have created a partnership with HHS and with the VA where basically in our partnership with CMS, we are creating an en-

hanced front door to Medicaid long-term care services. Making sure that people understand what their options are when they are looking for these long-term care services, so that people do not unnecessarily end up in a nursing home, and part of this new initiative involves a collaboration with the VA.

We are working with them, and they are working closely at the State and local level with the aging infrastructure, with the area agencies on aging, to provide a new service, which is called VA's Home and Community Based Services Delivery System. It basically allows vets that would otherwise have to rely on an agency or perhaps even an institution for the long-term services and the supports they need to hire whomever they choose. It might be a family member, it might be someone in their community to provide those types of basic, personal supports that they need in their home, allowing the vet to really return right back to the environment where they can best pursue their rehabilitation and community integration.

It is partnerships like these that are really essential to making sure that the Administration for Community Living realizes its very ambitious goal of living up to the values of the ADA, and the important principle of community integration.

Senator ENZI. Thanks to both of you.

Mr. PEREZ. Thank you both.

The CHAIRMAN. Thank you both very much.

A lot of different streams are starting to come together. Last year, the U.S. Chamber of Commerce made a commitment to work with all their member companies in the United States to increase employment of people with disabilities by 1 million by 2015. So that is happening.

There are interesting things happening in the private sector. We had a meeting in Connecticut a couple of weeks ago. It was fantastic. It was sponsored by Walgreens; the CEO was there. We had the CEOs of other large corporations—UPS, Lowe's, OfficeMax, a lot of different companies were there—and we got to see, firsthand, people with disabilities working in competitive employment.

Now this is happening in the private sector because Walgreens has shown that people with disabilities can work alongside people without disabilities, you cannot tell who is who and which is which. And it is not that they are doing it out of some goodness of their heart. They are doing it because it helps their bottom line, and these people are more productive. They show up to work on time, they do their jobs, and so I see this now starting to spread around the country.

What we have to be prepared for is the other elements of transportation, housing, some supportive services for people like that. Then they can get into competitive employment. So I see these things kind of coming together. I would hate to see the private sector moving ahead on this, hiring people with disabilities, but the people with disabilities cannot get to work, or they have some element of their life that will not permit them to get to work because they need something in the morning to get them going, or something like that, some intervention to help them get to work, or after work, or something like that.

Again, I think we are at a point now where all of this is kind of coming together, and that is why I like this idea of breaking down the stovepipes, working with HUD, working with all these different people, working with State Governors to help put these things in place so that we have a fully integrated system.

I did not mean to go off so long, but Senator Franken is here. Did you want to have a question?

[Inaudible.]

Thank you both very much. We will now call our second panel.

Our first witness is Rita Landgraf, currently Secretary of the Delaware Department of Health and Social Services. For more than 30 years as the executive director of the ARC of Delaware, and the National Alliance on Mental Illness in Delaware, and president of AARP Delaware, she has been a leader on disability, health care, and aging issues.

Our second witness is Zelia Baugh. Miss Baugh is the commissioner of the Alabama Department of Mental Health. Commissioner Baugh has led Alabama's efforts on *Olmstead* compliance by increasing community-based options for individuals who were at institutional settings, and focusing on home and community-based services. And we have heard a lot about the good work that is being done in Alabama.

Our final witness is Mr. Ricardo Thornton. Mr. Thornton is a former resident of Forest Haven, which was the District of Columbia's institution for people with developmental disabilities. Since leaving there, Mr. Thornton has been a strong advocate for increasing home and community-based opportunities for people with disabilities. He speaks internationally on deinstitutionalization, advocacy, human rights, and Special Olympics, and is a mentor and advocate for people with disabilities in the District. He is married, and is a father and a grandfather.

Welcome to you all. Your statements will be made a part of the record in their entirety. We will go from left to right. If you could sum it up in 5 to 7 minutes, I would appreciate it.

Miss Landgraf, please proceed.

**STATEMENT OF RITA M. LANDGRAF, SECRETARY, DELAWARE
DEPARTMENT OF HEALTH AND SOCIAL SERVICES, NEW CAS-
TLE, DE**

Ms. LANDGRAF. Thank you, Mr. Chairman and Ranking Member Enzi.

I am so honored to testify before you today about the progress being made on advancing community inclusion for individuals with disabilities.

My role in public service is mainly due to my role as a lifelong advocate in the area of disabilities, health care, and senior issues. As you heard, as former executive director of the ARC of Delaware, as executive director of the National Alliance on Mental Illness in Delaware, and as president of AARP in Delaware, I do not believe it is enough for us to be in mere compliance with the Americans with Disabilities Act and the *Olmstead* ruling, but we as State leaders must embrace the intent of the law beyond the compliance, and embed inclusion and the benefits of diversity as a core value. We must engage our partners across the Federal, State, and local

government, and be inclusive of individuals with disabilities as we develop best practice policy and implementation.

This is not merely meeting the objectives of enforcement or a settlement agreement. It is about systemic reform that enables services to meet the desires of the market, to live ordinary lives with identified support. Our State and Federal systems need to ensure that our services adhere to these goals that many of us take for granted.

We know that States, CMS, and disability advocates are beginning to evolve to a new understanding of the *Olmstead* community integration mandate. The fundamental question is how government resources can support a quality of life for people with significant disabilities, eligible for Medicaid funding that enhances full community participation, independent living, and economic self-sufficiency.

Today in Delaware, it is a value that we are committed to extending across the State through meaningful systemic reform that promotes integration of individuals with disabilities in our society. Our Governor, Governor Jack Markell, is committed to this priority bringing the full weight of his office and the political will to accomplish this restructuring. However, the Delaware system has not evolved dramatically since the passage of ADA in 1990 and since the 1999 reaffirmation of the integration mandate by the *Olmstead* ruling.

For decades in Delaware, the State has had an over-reliance on facility-based care and options within community have been limited to mid- to small-group living homes. Far too many individuals were placed in institutions and remained there for extended periods. Since 2009 under the Markell administration, we have focused on shifting our resources and our delivery strategy to a community first focus. Communities should be the norm, not the exception.

The level of reform Delaware is addressing for individuals with serious, persistent mental illness is seen by us as the prototype for all with disabilities and the aging population in need of supports. It begins with a simple, but powerful expectation: individuals with disabilities can live in their own home, have meaningful employment, and be ordinary Delawareans. They may require some level of support, but those supports need to be provided that effectively foster independence and fully engaged participation in society.

A pivotal benchmark for Delaware to excel in our commitment to meaningful reform is the July 6, 2011 settlement agreement between the State and the U.S. Department of Justice which resolved a 3-year investigation of the Delaware Psychiatric Center. More importantly, the agreement became the blueprint for how Delaware will provide mental health services for individuals with severe and persistent mental illness and, indeed, creates the prototype for systemic reform across government.

In order to comply with the agreement, the State must prevent unnecessary institutionalization by offering agreed upon community-based services to the target population with serious, persistent mental illness who are at the highest risk of institutionalization. And we are engaging in the development of upgraded community supports and services. We want to make our State a leader in mental health services, and the U.S. DOJ shares our vision.

Given our State's fiscal challenges, the need for smarter budgeting, smarter spending, and smarter management that must take center stage if we are to achieve meaningful integration, we need to embrace the philosophy of community-based living. But without the re-balancing and flexibility of our funding system, the system will remain vulnerable to stagnation and erosion.

The Department is focused on the development of a quality assurance program that incentivizes payments based on outcomes as they relate to the promises of *Olmstead* and the ADA, and not funds for sheer volume. As a State, we are focused not only on supporting individuals moving out of the Delaware Psychiatric Center and into the community, but are actively assessing all within our State facilities, and asking if they want to return to their communities, and we are assisting them in doing so.

The underlying support for full community participation must be a focus on financial capability and advancing economic self-sufficiency. The *Olmstead* community integration mandate compels us to attack poverty and financial instability through financial coaching as part of an individual's Medicaid support plan. In Delaware, we use our government infrastructure to reset the focus to change thinking and behavior about financial capability through an integrated system of supports that enhance financial empowerment, skills, and outcomes.

I believe we also need ADA—Olmstead Ambassadors throughout the States to promote the premise behind the civil rights movement, and institute a broad education campaign. States must incorporate this awareness throughout their delivery system and in all areas of the cabinet to fully support the civil rights of individuals with disabilities as a core value.

In closing, permit me to share with you my early lesson on inclusion. My path here today began when I was 12 years old when a young neighbor, Mike, who had an intellectual disability ventured out into our community to befriend us. What Mike wanted was to be included with his peers and be a part of our group. What he encountered was ridicule at his expense. The memory still weighs heavy on my mind and my heart. I did not tease Mike, but I did nothing to stop the others.

That haunting look on Mike's face changed my life forever, and I committed myself to working toward a system that educates and promotes diversity and inclusion. Mike on the red bike taught me my first lesson on the value of inclusion. I saw Mike a few years back and he told me that he now drives a car, works at a farmer's market, and is married. He is an ordinary Delawarean, a full community member, and he was smiling broadly. I told him that he was also a great teacher. Individuals with disabilities are our greatest teacher. We need to listen.

Thank you for the opportunity to testify, and I look forward to your questions.

[The prepared statement of Ms. Landgraf follows:]

PREPARED STATEMENT OF RITA M. LANDGRAF

SUMMARY

Mr. Chairman and members of the committee, I am honored to testify before you today about the progress being made on advancing community inclusion for individ-

uals with disabilities. My name is Rita Landgraf and I am the Cabinet Secretary for the Delaware Department of Health and Social Services or DHSS. My role in public service is mainly due to my role as a lifelong advocate in the areas of disability, health care and senior issues, including as the former executive director of The Arc of Delaware and the National Alliance on Mental Illness in Delaware, and president of AARP Delaware.

I do not believe, it is enough for us to be in mere compliance with the Americans with Disabilities Act and the *Olmstead* ruling, but we, as State leaders, must embrace the intent of the law beyond the compliance and embed inclusion and the benefits of diversity as a core value. We must engage our partners across the Federal, State and local governments, and be inclusive of individuals with disabilities as we develop best practice policy and implementation. This is not merely meeting the objectives of enforcement or a settlement agreement. It is about systemic reform that enables services to meet the desires of the market to live ordinary lives with identified supports. Our State and Federal systems need to ensure that our services adhere to these goals that many of us take for granted.

We know that States, CMS, and disability advocates are beginning to evolve to a new understanding of the “Olmstead Community Integration Mandate.” The fundamental question is about “how government resources can support a quality of life for people with significant disabilities (eligible for Medicaid funding) that enhances full community participation, independent living and economic self-sufficiency.”

Today, in Delaware, it is a value that we are committed to extending across the State through meaningful systemic reform that promotes integration of individuals with disabilities in our society. Our Governor, Governor Jack Markell, is committed to this priority, bringing the full weight of his office and the political will to accomplish this restructuring. However, the Delaware system has not evolved dramatically since the passage of ADA in 1990 and since the 1999 reaffirmation of the Integration Mandate by the *Olmstead* ruling.

For decades in Delaware, the State has had an overreliance on facility-based care and options within the community have been limited to mid- to small-group living homes. Far too many individuals were placed in institutions and remained there for extended periods. Since 2009, under the Markell administration, we have focused on shifting our resources and our delivery strategy to a community-first focus. Community should be the norm not the exception. The level of reform, Delaware is addressing for individuals with serious persistent mental illness is seen, by us, as the prototype for all with disabilities and the aging population in need of supports. It begins with a simple, but powerful expectation:

Individuals with disabilities can live in their own home, have meaningful employment and be ordinary Delawareans. They may require some level of support, but those supports need to be provided that effectively foster independence and fully engage participation in society.

A pivotal benchmark for Delaware to excel in our commitment to meaningful reform is the July 6, 2011, settlement agreement between the State and the U.S. Department of Justice which resolved a 3-year investigation of the Delaware Psychiatric Center. More importantly, the agreement became the blueprint for how Delaware would provide mental health services to individuals with severe and persistent mental illness, and creates the prototype for systemic reform across the government, in support of all individuals with disabilities.

In order to comply with the agreement, the State must prevent unnecessary institutionalization by offering agreed upon community-based services to the target population, a subset of individuals with SPMI (serious, persistent mental illness) who are at the highest risk of unnecessary institutionalization and the development of upgraded community supports and services. We want to make this State a leader in mental health services, and the USDOJ shares that vision.

Given the fiscal challenges, the need for smarter budgeting, smarter spending, and smarter management must take center stage if we are to achieve meaningful integration. We need to embrace the philosophy of community-based living, but without the re-balancing and flexibility of the funding system, the system will remain vulnerable to stagnation and erosion. DHSS is focused on the development of a quality assurance program that incentivizes based on outcomes as they relate to the promises of *Olmstead* /ADA and not funds for volume. As a State, we are focused not only on supporting individuals moving out of DPC and into the community, but are actively assessing all within our State facilities and asking if they want to return to their community and are assisting them to do so.

The underlying support for full community participation must be a focus on financial capability and advancing “economic self-sufficiency.” The Olmstead Community Integration Mandate compels us to attack poverty and financial instability through financial coaching as part of an individual’s Medicaid support plan. In Delaware, we

will use our government infrastructure to reset the focus to change thinking and behavior about financial capability through an integrated system of supports that enhance financial empowerment skills and outcomes.

I believe we need ADA/Olmstead Ambassadors throughout the States to promote the premise behind the civil rights movement and institute a broad education campaign. States must incorporate this awareness throughout the delivery system and in all areas of the Cabinet to fully support the civil rights of individuals with disabilities as a core value.

In closing, permit me to share with you my early lesson on inclusion:

My path here today began when I was 12 years old, when a young neighbor Mike who had an intellectual disability, ventured out into our community to befriend us. What Mike wanted was to be included with his peers and be a part of our group. What he encountered was ridicule at his expense. The memory still weighs heavy on my mind and heart. I didn't tease Mike, but I did nothing to stop the others. That haunting look on Mike's face changed my life, and I committed myself to working toward a system that educates and promotes diversity and inclusion. Mike on the red bike taught me my first lesson on the value of inclusion. I saw Mike a few years back and he told me that he now drives a car, works at a farmer's market and is married. He is an ordinary Delawarean, a full participating community member and was smiling broadly. I told him that he was also a great teacher.

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

Mr. Chairman and members of the committee, I am honored to testify before you today about the progress being made on advancing community inclusion for individuals with disabilities. My name is Rita Landgraf and I am the Cabinet Secretary for the Delaware Department of Health and Social Services or DHSS. DHSS is the largest State agency, employing over 4,000 individuals in a wide range of public service jobs. Our department includes 12 divisions, which provide services in the areas of public health, social services, substance abuse and mental health, child support, developmental disabilities, long-term care, visual impairment, aging and adults with physical disabilities, and Medicaid and medical assistance. The Department includes four long-term care facilities and the State's only psychiatric hospital, the Delaware Psychiatric Center.

Our Department's mission is to improve the quality of life for Delaware's citizens by promoting good health and well-being, fostering self-sufficiency, and protecting vulnerable populations.

My role in public service was mainly due to my role as a life-long advocate in the areas of disability, health care and senior issues, including as the former executive director of The Arc of Delaware and the National Alliance on Mental Illness in Delaware, and president of AARP Delaware. I am a firm believer in the Supreme Court's *Olmstead* decision and the Americans with Disabilities Act. In other words, I am a believer that individuals with disabilities have the same rights as all citizens to live in community and it is our responsibility, in the public sector, to provide supports to enable them to exercise that right in a meaningful and purposeful way.

I do not believe, it is enough for us to be in mere compliance with the ADA—Integration Mandate and *Olmstead*, but we, as State leaders, must embrace the intent of the law beyond the compliance and embed inclusion and the benefits of diversity as a core value. We must engage our partners across the Federal, State and local governments, and be inclusive of individuals with disabilities as we develop best practice policy and implementation. This is not merely meeting the objectives of enforcement or a settlement agreement; it is about systemic reform that enables services to meet the desires of the market to live ordinary lives with identified supports. It means embracing and embedding the ADA purpose statement (section 12101 (a) (8)):

The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

Our State and Federal systems need to ensure that our services adhere to these goals that many of us take for granted.

I. DELAWARE'S EXPERIENCE WITH COMMUNITY INTEGRATION OF PEOPLE WITH DISABILITIES AND THE OLMSTEAD DECISION

We know that States, CMS, and disability advocates are beginning to evolve to a new understanding of the "Olmstead Community Integration Mandate". The fun-

damental question is about “how government resources can support a quality of life for people with significant disabilities (eligible for Medicaid funding) that enhances full community participation, independent living and economic self-sufficiency?”

Today, in Delaware, it is a value that we are committed to extending across the State through meaningful systemic reform that promotes integration of individuals with disabilities in our society. Our Governor, Governor Jack Markell, is committed to this priority, bringing the full weight of his office and the political will to accomplish this restructuring. However, the Delaware system has not evolved dramatically since the passage of ADA in 1990 and since the 1999 reaffirmation of the Integration Mandate by the *Olmstead* ruling.

Unfortunately, for decades in Delaware, the State has had an over reliance on facility-based care and options within community have been limited to mid- to small-group living homes. Far too many individuals were placed in institutions and remained there for extended periods. Delaware’s institutional bias has been significant. For our State, an AARP survey found that 87 percent of the State’s long-term care funds for aging and physical disability services is spent on care at facilities, compared to the national rate of 66 percent. When the developmental disabilities population is included, Delaware does fair better in meeting the national average, but this was a result of litigation action by The Arc against the State in 2002. The 2002 litigation did indeed impact the delivery of services to those with developmental disabilities and enhanced community supports, but did not promote systemic reform across government. Since 2009, under the Markell administration, we have focused on shifting our resources and our delivery strategy to a community first focus. Individuals with disabilities should not have to prove that they are worthy of community. We ask that of no other population cohort and community should be the norm not the exception. The level of reform Delaware is addressing for individuals with serious persistent mental illness is seen, by us, as the proto-type for all with disabilities and the aging population in need of supports. It begins with a simple, but powerful expectation:

Individuals with disabilities can live in their own home, have meaningful employment and be ordinary Delawareans. They may require some level of support, but those supports need to be provided that effectively foster independence and fully engage participation in society. This is the norm for individuals without disabilities.

A pivotal benchmark for Delaware to excel in our commitment to meaningful reform is the July 6, 2011 settlement agreement between the State and the U.S. Department of Justice which resolved a 3-year investigation of the Delaware Psychiatric Center.

More importantly, the agreement became the blueprint for how Delaware would provide mental health services to individuals with severe and persistent mental illness, and creates the prototype for systemic reform across the government, in support of all individuals with disabilities.

II. CREATING SYSTEMS THAT WILL MAKE OLMSTEAD A REALITY

In order to comply with the agreement, the State must prevent unnecessary institutionalization by offering agreed upon community-based services to the target population. The target population is a subset of individuals with SPMI (serious, persistent mental illness) who are at the highest risk of unnecessary institutionalization. The agreed upon plan requires Delaware to move individuals from Delaware Psychiatric Center (DPC) into the community and for upgraded community supports and services. Our discussions with the USDOJ impressed upon them that we share their vision for improved mental health services in this State. The USDOJ findings made clear what we already knew, what we knew we needed to do and where we were already headed, which was to stop the historical over reliance on institutionalization and moving to more community-integrated and compassionate care. I believe this is an agreement that reflects where we want to take this State. We want to make this State a leader in mental health services, and the USDOJ shares that vision.

The agreement is a multi-year commitment to provide improved mental health services in Delaware. To the USDOJ, it may be about ensuring we’re complying with the Americans with Disabilities Act. But to us, it is about providing services to our neighbors, our family members, and our friends who have persistent mental health issues but who can, with the right support, be full participating, thriving members of our communities. More importantly, this agreement is the blueprint for how we are going to provide mental health services to persons with severe and persistent mental illness in this State. It will also set the direction for how we re-tool our system for all with disabilities. It is an approach based on providing services

to people in the community, so that we can achieve better outcomes for persons with mental illness, and we can do so in a manner that protects their independence and sense of community.

III. HOW THE STATE IS ADVANCING THE REFORM ON THE GROUND

I now wish to focus on how the State is innovating practices to accelerate building a recovery-based, community-robust system of care. DHSS created a new Request for Proposal (RFP) directed toward facilitating the discharge of individuals who have been institutionalized at DPC, most from 6 to more than 15 years. The RFP developed a “case rate” for each individual at DPC and these will be bundled into a total amount that will represent that provider’s budget for this work. The provider will be expected to provide every service and support required for each of these individuals with the exception of significant physical health care emergencies. This rate is now a comprehensive rate that allows for all inclusive care and will incentivize the provider to support the individual within the least restrictive environment and will provide the funds to enhance the community level of support. The focus of our 5 year plan is:

- Establishment of community-based programs and use of DPC as an acute mental health hospital for stabilization as a hospital would be for individuals with a physical health crisis.
- Establishment of Individualized Recovery Plans, inclusive of the individual’s dreams.
- Expansion of the crisis hotline to 24–7.
- Expansion of Mobile crisis teams that can respond **across the State** within an hour’s timeframe.
- Development of a new crisis walk-in center in our rural county and crisis stabilization beds throughout the State in typical apartment settings.
- Expanded consumer run drop-in centers.
- Peer-to-peer counseling. The successful implementation of a Peer Support Specialist program at DPC to work with the DPC Recovery Teams and the Community providers to model individualized treatment and recovery planning strategies.
- Effective July 1, Medicaid will reimburse for telemedicine services—this is extremely important in our rural locations, inclusive of:
 - Consultations, office or outpatient visits,
 - Psychotherapy,
 - Medication management,
 - Psychiatric interview or examination, and
 - State Rental Assistance Program (SRAP).—Bridge financing via vouchers and connections with typical landlords. Delaware developed the State Rental Assistance Program (SRAP) to serve low-income Delawareans who require affordable housing and supportive services to live safely and independently in the community. At DHSS, we are referring individuals from DPC and from other State-run nursing facilities to the Delaware State Housing Authority for rental housing vouchers. One of the most difficult things for individuals who have been in an institution for a long period is affording a place to live. SRAP provides that necessary foundation in making that transition. DHSS has created a Housing Team made up of individuals from within our disability divisions that are dedicated to becoming housing support experts to continue to assist in supporting individuals locate the housing of their choice as well as working with our State Housing Authority and municipalities to expand the integrated housing for individuals with disabilities.

Given the fiscal challenges, the need for smarter budgeting, smarter spending, and smarter management must take center stage if we are to achieve meaningful integration. We need to embrace the philosophy of community-based living but without the re-balancing and flexibility of the funding system, the system will remain vulnerable to stagnation and erosion. Most States have funding aligned with infrastructure, in personnel, buildings that are growing older and in repair, rather than funding the individual based on their individualized plan and integrating with the natural environment. Inclusion allows for leveraging of resources both paid and natural. So we can leverage our existing resources both fiscal and human with a focus on community. We are shifting resources out of the facilities and promoting a community-based system of support. DHSS is focused on the development of a quality assurance program that incentivizes based on outcomes as they relate to the promises of *Olmstead*/ADA and not funds for volume. If we evaluate based on the ADA and individuals achievements, we are placing a monetary value on the ADA principle. Some refer to this as re-balancing or re-tooling, regardless of the term, it is

an effort to resource the community and leverage both funding and resources throughout and across the government.

In addition to the operational implementation of *Olmstead* and ADA, the Department is engaging in a State public policy review. We have a rather antiquated law relative to detention and commitment which has led to over 3,000 yearly involuntary commitments. That amounts to approximately eight involuntary commitments per day. The State has in the past funded the involuntary commitments but did not fund voluntary commitments. We are working toward revamping the detention law and will require a new credentialed mental health screener, who will be an expert in community-based options and work closely with the emergency doctors, psychiatrists, and others to divert individuals to the most appropriate care level. DHSS is advocating changing how emergency evaluations are conducted, preventing unnecessary encounters with law enforcement and avoiding needless trips to emergency rooms and psychiatric hospitals. Individuals will be encouraged to voluntarily commit, if indeed this is seen as the most appropriate level of care and the State will fund both voluntary and involuntary commitments. A past State practice was to fund only involuntary commitments and many individuals were not even provided an opportunity to voluntarily commit to treatment, which is a huge infraction on their rights and presents a barrier to empowerment. The effort to re-vamp this law has not come without objections from the trial lawyers and a protection and advocacy attorney, since, as a compromise, an immunity clause is in the draft legislation for emergency doctors, psychiatrists and credentialed mental health screeners. It is hard to predict if this policy change will be successful, since it has strong lobbyists on both sides of the argument. However, Bryce Hewlett, executive director of the Delaware Consumers in Recovery Coalition has stated, "any loss of civil rights for any amount of time is unacceptable, but we've decided to support this bill because it takes so many steps in the right direction."

Meaningful reform must evaluate both operational and policy practices must be encompassing across the system, inclusive of the entities that support the typical population and develop procedures that encompass reasonable accommodations beyond structural, tangible accommodations. We need to evaluate accommodations for the class as well as for each individual, to assure equality of opportunity, full participation, independent living and economic self-sufficiency.

IV. A MODEL FOR STATEWIDE REFORM

As a State, we are committed to making the mandate of ADA and *Olmstead* a reality. As a State, we are not only focused on supporting individuals moving out of DPC and into the community, but are actively accessing all within our State facilities and asking if they want to return to their community and are assisting them to do so. DHSS is working with an independent agency to perform this assessment and providing education to the residents on ADA and *Olmstead*. We also continue to assist individuals in their desire to move from institutional settings to the community under the Medicaid Money Follows the Person program and our Journeys program. In addition we are working with hospitals and have created a diversion team that provides support to any entity that is evaluating a long-term care need. Our goal is a community first approach to care and returning individuals to their home environments or providing supports within the least restrictive environment. This recently developed service is the Care Transitions Program, and falls under the umbrella of the Delaware Aging and Disability Resource Center (ADRC). The program extends community living for individuals who are in the community or in the hospital and are seeking admission to one of the State long-term care facilities.

The goal of the Care Transitions Program is to: (1) extend community living for individuals who are at high risk for nursing home placement by mitigating immediate risks and stressors that are prompting a move to a nursing home; (2) create a flexible spending pool to facilitate access to services and products. We initiated the diversion teams in February 2011 and since that time, 86 percent of those referred to facility-based care have been diverted back into the community with appropriate supports. It is anticipated that this percentage will increase as we evaluate those situations that were not able to be diverted and initiate a community-based structure to address these issues, especially if we find they are common across the population requiring facility-based care.

The Money Follows the Person Demonstration (MFP) "Finding A Way Home" Program, is a special project funded by the Federal Government and the Delaware Department of Health and Social Services (DHSS) Division of Medicaid and Medical Assistance (DMMA). The MFP Program is available to assist eligible individuals that choose to participate in moving from an eligible Long Term Care (LTC) facility, (nursing home, Intermediate Care Facility for Developmental Disabil-

ities ICF/DD) to an eligible residence in the community with available community services and supports.

The Nursing Home Transition Program is State-funded and the overall goal of the program is to identify, inform and assist nursing home residents, who are not Medicaid-eligible, who want to move to a community-based setting. The program offers individualized case management to accomplish this goal. To date, both of these programs have supported 177 individuals in facility-based care back into their community. Currently, there are 58 individuals awaiting transition from facility care within the Money Follows the Person program. Currently MFP does not pay for home modifications until a participant is discharged home. This leaves people in a potentially unsafe situation if they cannot get in and out of the home without a ramp or other modifications. This also socially isolates people as they cannot leave their home for church, shopping, employment or other community outings.

In our Medicaid program, we are changing the manner in which we deliver services to our long-term care population and those eligible for both Medicaid. Individuals in need of long-term care services require the greatest level of care and, therefore, are the most costly to serve. On April 1, 2011, we began utilizing an integrated long-term care approach that enhances and builds community supports and options, fully develops a continuum of available services, and so better contains cost while providing the market with what they desire. More importantly, it will more effectively support participants' desire to remain in the community. As the leader in the department, I have a standing monthly meeting with our Managed Care Providers and the Medicaid leadership to ensure that the purpose of the program is to develop enhanced community options and not merely for cost containment. I continue to outreach to the advocacy and consumer organizations to ensure that the program is indeed creating a community-based system of support and wish to ensure this is successful for those who access the system.

In the area of substance abuse, mental health, disability and aging, we know that the market is in need of service and support enhancements that promote community-based care. We are also working on measures that would divert individuals from prematurely entering facility-based care through a more comprehensive universal effort in effective discharge planning, practice and the creation of State diversion teams that work with hospitals, Adult Protective Services and others who have a need for support but may not require a 24-hour residential setting. These situations typically led to an automatic referral to a facility without evaluating community-based support planning and engaging the State at time of an admission.

In addition, we are working with St. Francis Healthcare, which will open Delaware's first PACE site in fall 2012. This Program for All-Inclusive Care for the Elderly provides site-based comprehensive, coordinated long-term services and supports to Medicaid and Medicare participants who are 55 and older, require a nursing home level of care and are able to live safely in the community. This model of care can be replicated for individuals with disabilities.

The State and the USDOJ also know that for individuals with serious, persistent mental illness, many have found themselves interacting with the criminal justice system. The State has created an across-the-cabinet approach to support those exiting the criminal justice system and providing the support network 6 months prior to any release. Known as the I-Adapt (Individual Assessment and Discharge Planning Team) Coalition consists of the Departments of Correction, Health and Social Services, Labor, Education and the State Housing Authority. The purpose of the I-ADAPT teams is to coordinate local efforts to support individuals exiting the Delaware Correction system and to develop relationships between service providers and government and build sustainable community supports and buy in for the State's reentry efforts.

V. FISCAL SECURITY AND EMPOWERMENT

Up until now, the focus of ADA/Olmstead has primarily been on expanding housing options (home, apartments, and independent living options with necessary supports). However, underlying support for full community participation must be a focus on financial capability and advancing "economic self-sufficiency." Without attacking the underlying issue of poverty, quality of life choices are diminished. We know poverty impacts adversely mental and physical health, limits community participation, and affects adversely self-concept and others' perception of one's status and value. The next generation of innovation has begun in Delaware and also is being initiated in cities such as San Francisco and New York City. It is the design and implementation of financial empowerment strategies embedded in social and human service delivery.

The Olmstead Community Integration Mandate compels us to attack poverty and financial instability through financial coaching as part of an individual's Medicaid support plan. Providing financial education and counseling that explores new options for employment (income production), savings (income preservation), and safeguarding and building assets can give our most vulnerable citizens with disabilities hope and goals that will enhance "fuller community participation."

There is no roadmap out of poverty. However, State Medicaid re-balancing of resources to meet *Olmstead* requirements can use a new lens to design individualized supports for working age adults with significant disabilities. CMS recognizes that community participation must include pathways to advance economic self-sufficiency. Financial coaching and financial empowerment can stabilize individuals and families and raise expectations and results about quality of life experience.

In Delaware, we will use our government infrastructure (Medicaid, Vocational Rehabilitation, Education, Social Services, and Labor) to reset the focus to change thinking and behavior about financial capability through an integrated system of supports that enhance financial empowerment skills and outcomes. We are calling this the \$tand By Me initiative: a partnership between DHSS and the United Way of Delaware. The National Disability Institute is working on site in Delaware to integrate financial empowerment as part of our collective service delivery system.

What separates people with disabilities from the rest of the population is financial security. The majority of individuals with disabilities are of extremely low income which further disenfranchises and disempowers the population.

Traditionally, State programs have provided support for basic needs and emergency services for low-income residents. In recent years, a shift in national perspective has moved leadership in major American cities and the Federal Government to pursue strategies which promote self-sufficiency. By providing low-income Delawareans with the tools and support they need to take charge of their financial lives, the cyclical dependence on benefits will be reduced, which will reduce investments for benefit programs for the State and the negative sense of self created by dependence for the clients.

VI. NEED FOR AN ADA/OLMSTEAD OUTREACH CAMPAIGN

I believe we need ADA/Olmstead Ambassadors throughout the States to promote the premise behind the civil rights movement and institute a broad education campaign. States must incorporate this awareness throughout the delivery system and in all areas of the Cabinet to fully support the civil rights of individuals with disabilities as a core value.

Delaware's Court Monitor, Dr. Robert Bernstein noted the following in his first 6 month report to the Court:

"The Federal laws that are its basis have been around for far longer than the settlement agreement; the ADA was enacted over 20 years ago, and the *Olmstead* decision was rendered over a dozen years ago. Despite the fact that these Federal laws have enormous implications for people with SPMI and for how public mental healthcare is delivered, and notwithstanding numerous trainings by the State over the years, the Monitor found a widespread lack of knowledge about the principles of the ADA, their crucial implications for people with SPMI, and how they relate to public services. Senior staff members have an understanding of the settlement agreement and underlying civil rights laws. However, just a step or two below leadership positions, it is apparent that there is often only a passing familiarity with the ADA, the settlement agreement, and their requirements. This is particularly significant because it is in these settings, rather than in the offices of management, that decisions about services and interventions for specific individuals are made. Perhaps most poignant is that interactions the Monitor has had with consumers suggest that they are unaware of their own civil rights under the ADA, let alone the fact that the State has effected an agreement with DOJ."

"It is obvious that individuals who are charged with implementing the settlement agreement and those who are intended beneficiaries should be well-versed in its requirements. It is also important that for the settlement agreement to represent something beyond a laundry list of prescribed actions, stakeholders need an appreciation of the underlying values. It is the Monitor's impression that a lack of basic knowledge about the ADA and *Olmstead* has sustained providers, courts and others in unquestioningly making decisions that perpetuate segregation, undermine self-sufficiency, and even result in coercive practices."

In closing, permit me to share with you my early lesson on inclusion:

My path here today began when I was 12 years old, when a young neighbor, Mike, who had an intellectual disability, ventured out into our community to

befriend us. What Mike wanted was to be included with his peers and be a part of our group. What he encountered was ridicule at his expense. The memory still weighs heavy on my mind and heart. I didn't tease Mike, but I did nothing to stop the others. That haunting look on Mike's face changed my life forever, and I committed myself to working toward a system that educates and promotes diversity and inclusion. Mike on the red bike taught me my first lesson on the value of inclusion. I saw Mike a few years back and he told me that he now drives a car, works at a farmers market and is married. He is an ordinary Delawarean, a full participating community member and was smiling broadly. I told him that he was also a great teacher.

Thank you for this opportunity to testify and I look forward to your questions. The CHAIRMAN. Thank you very much, Secretary Landgraf. Commissioner Baugh.

**STATEMENT OF ZELIA BAUGH, COMMISSIONER, ALABAMA
DEPARTMENT OF MENTAL HEALTH, MONTGOMERY, AL**

Ms. BAUGH. Thank you. It is an honor to be here today. I really appreciate it, and so does the State of Alabama.

In 1970, there was a landmark case that began in Alabama. It was called the "*Wyatt v. Stickney*" case. That case set the stage for individuals with mental health problems to have access and right to humane treatment. And in the settlement phase, which started in 1999 in Alabama and continued until approximately 2003, certain conditions were set forth in the settlement. As a result of that settlement, the State of Alabama has been committed to community integration of people with all disabilities.

We have systematically downsized our State institutions in the State of Alabama starting in, actually, 2003 with the closure of several developmental disability hospitals, as well as a few State psychiatric hospitals. Last March, Governor Robert Bentley from Alabama and myself made the decision to close the Partlow Developmental Center, which was our last institution for persons with developmental disabilities. We had approximately 151 consumers living in that State institution that the Governor believed wholeheartedly could live in community integrated settings. That was the right thing to do for the patient and the right thing to do for an Alabamian. As a result of that, we closed the Partlow Developmental Center by December 28, 2011.

Since that time, the individuals that we have moved from those facilities have enjoyed integrating into community-based settings. We believe that virtually all people with disabilities, even severe disabilities, can live in their own apartment or home, have a job with employment supports if needed, and be engaged with family, friends, and their community.

We have had success in Alabama. Thousands of people have moved from State institutions to community settings, and people who would otherwise have been served in State facilities are now being served in community settings.

Alabama has made progress in good budget times and in bad budget times. Currently, our State budget is challenged at this moment with the recession that we are in. As a result of that, we have had significant financial cuts made to the Department of Mental Health, as well as other State agencies. And we have deliberately and thoughtfully reallocated funds from institutions to the community as a way to deal with the budget cuts, and also as a way to

move people out of an institutional setting into a community-based setting.

I believe that States can make significant progress in complying with *Olmstead* without huge, new sums of money. In Alabama, we have been able to prove that thus far.

I work for a Republican Governor in a Republican State, and this is a bipartisan effort. Our Governor is very supportive because it is the right thing to do for Alabamians that are living in large institutional settings, and it is also a cost-effective measure for us as well.

It currently costs the State of Alabama \$150,000 per year to keep one patient in a State psychiatric hospital. That is 100 percent State dollars. If we move that individual into a community-based setting, we can keep that individual in a community-based setting for \$60,000 or less per year, and be able to drawdown Federal dollars on top of that. So as you can see, it is not only a good decision clinically for individuals, but it is also a sound business decision in these times of dire fiscal constraints.

For years, the Wyatt case set the agenda in Alabama. Our current efforts have grown out of Alabama's own commitment to community integration. To make *Olmstead* a reality, we have to change the expectations and use funding differently. Alabama uses an individualized service planning process, but our focus is on identifying the services and individual needs to be successful in the community. Funding has to be flexible enough to allow providers to meet identified needs.

Change can be hard when it requires State employees and private providers to behave in new ways. We try to carefully explain our priorities and the reasons for them, and engage stakeholders in planning and give them a stake in our success. We try to build a consensus and move forward.

When we announced our decision to close the Partlow Developmental Center last March, we met a lot of resistance from local legislators, probate judges, as well as the sheriff and police departments. And, in particular, a lot of pushback from family members and loved ones of individuals who were in Partlow because they were concerned about how their loved one would be treated, and the quality of care that is being delivered to those individuals.

We have partnered with the Alabama Disabilities Advocacy Program and we have a very strong partnership with them, and they actually are part of our quality continuum of care as an outside agency making sure that the quality of services delivered to those individuals are of the highest that they can be. So some of our challenges have been stakeholder buy-in from families, communities, legislators, and law enforcement officials.

Appropriate housing and providing networks, especially in cases of behavioral and medical needs, have also been a challenge to make sure that we have the appropriate community-based resources available for an individual to live fully in the community.

Some of the other challenges that we have experienced as part of our downsizing have been the stigmas related to individuals with mental health problems, as well as intellectual disabilities and other developmental disabilities, as well as physical.

We have received a lot of NIMBY behavior from communities when we made the decision to close our Partlow Developmental Center because they did not want individuals in their backyard thinking it would decrease their property values and increase the crime rate, which that can be further from reality for the people that we serve.

Funding has been a challenge as well because when we are thinking creatively and out of the box and, "How can we do this with less?" Or, "How can we maximize other areas of funding?" One of the key opportunities, we believe, to assist us and other States is flexibility in funding, and be able to have those challenges and opportunities with not having to be as tied to one certain location or one certain provider with regards to Federal and/or other State funding, and allow the flexibility.

Our Federal policy level, we are continuing to support and encourage *Olmstead* implementation. Some of the challenges or opportunities that we see is creating incentives, especially through the Medicaid program such as the 1915(i) State plan. We believe that that is giving the State of Alabama an opportunity to be more creative and seek out more Federal dollars, and maximize those dollars to create community settings, expanding technical assistance offered to States.

Again, I want to applaud Mr. Claypool and the other Federal agencies for their cooperation at the Federal level because it does play over into the States and our ability to access resources or best practices from the Federal level.

In closing, I would like to say that this has been an interesting experience, thus far. I was appointed January 2011 when Governor Bentley was sworn into office, and it has been an honor and a privilege to serve with Governor Bentley because he is extremely supportive of inclusion, and giving opportunities for every individual.

I want to leave you with a story of when we closed our Partlow Developmental Center, which we are the first State in the South to close all of our developmental centers.

We moved a gentleman into a two-person home, and he went to church with his caretaker, and he started crying in church. And the caretaker and other church members were concerned about this gentleman, asked him what was wrong, and he said that he was crying because he was happy, because he never thought he would be able to go to church again.

It is the simple things that many of us take for granted that people with disabilities have to struggle to get and to me, that is where the change happens.

Thank you very much.

[The prepared statement of Ms. Baugh follows:]

PREPARED STATEMENT OF ZELIA BAUGH

EXECUTIVE SUMMARY

In 1999, the Alabama Department of Mental Health (ADMH) created a strategic plan that resulted in the settlement of the 30-year-old *Wyatt v. Stickney* lawsuit. That plan became ADMH's designated *Olmstead* plan. Since the implementation of the *Wyatt* settlement agreement, ADMH has further planned and executed numerous major initiatives that effectuate the letter and spirit of *Olmstead*.

Regarding services for people with intellectual disabilities, ADMH settled a waiting list lawsuit by developing more well-defined and noticed due process procedures relating to denials and/or delays in granting eligibility and/or services to people with ID. The settlement supports the proposition that Alabama may cap its home and community-based services waiver programs and operate a waiting list serving applicants by priority based upon their levels of severity and emergent needs. In addition, with the closure of the W.D. Partlow Developmental Center in December 2011, Alabama became the first State in the South to achieve the milestone of closing all public institutions for people with intellectual disabilities and instead serving all eligible individuals in home and community-based waiver services.

ADMH has also enacted a systematic and inclusionary plan to reduce levels of institutional care and expand access to community-based services for individuals with mental illnesses. Through extended-care transitions, acute-care transitions and facility closures, ADMH has demonstrated less reliance upon State psychiatric inpatient services by shifting funding and focus to less costly, but more effective community services and supports. Likewise, funding continues to be dedicated for community integration and service expansion efforts, and the department has worked with other State agencies to expand services. Further efforts to provide a better quality of life in the community for both individuals with mental illnesses and intellectual disabilities include collaborations on several housing and employment initiatives.

ADMH has experienced three main challenges in its efforts to shift services to community settings: securing stakeholder buy-in, identifying and developing resources within provider organizations to serve persons with significant behavioral challenges or multiple medical needs, and negative stigma. While ADMH has developed strategies to overcome these challenges, long-term efforts will be needed to ensure continued success. Additionally, decreased funding to Medicaid, proposed cuts to medication coverage and optional health care services, and more collaboration between Federal and State levels in meeting *Olmstead* goals are areas of great concern and need. Ultimately, ADMH is proud of its large-scale initiative to provide community-based care for Alabamians and ushering in a new era of individuals enjoying inclusive lives in their communities.

INTRODUCTION

In 1999, the Alabama Department of Mental Health (ADMH) created a strategic plan that resulted in the settlement of the (at the time) 30-year-old *Wyatt* lawsuit. That agreement became ADMH's designated *Olmstead* plan. ADMH substantially complied with the provisions of the settlement over a 3-year period, resulting in the end of this landmark lawsuit that, among other things, was a precursor to the Americans with Disabilities Act that was later construed in the *Olmstead* case. Since the implementation of the *Wyatt* settlement agreement, ADMH has further planned and executed numerous major initiatives that effectuate the letter and spirit of *Olmstead*.

For example, among other things, the *Wyatt* settlement required a minimum of 300 beds in extended-care psychiatric hospitals and 300 people residing in developmental centers (intermediate care facilities for people with intellectual disabilities, i.e., ICF/ID) be closed and the individuals placed in community-based settings, respectively. ADMH deliberately did not agree to close any specific facility that it operated. However, as it moved individuals to community-based settings, the department decided on a comprehensive consolidation plan to close three developmental centers, all three nursing homes, co-locate one psychiatric hospital with another, eventually close the relocated hospital and establish community services support teams for ID residents.

PLANS AND INITIATIVES: DIVISION OF DEVELOPMENTAL DISABILITIES

Before the *Wyatt* settlement agreement could be implemented, another lawsuit was filed on behalf of individuals with intellectual disabilities who were already living in community-based settings, but who sought Medicaid home and community-based services waivers. Once *Wyatt* was settled, and after some limited litigation, the department settled this "ID waiting list case" by incorporating more well-defined and noticed due process procedures relating to denials and/or delays in granting eligibility and/or services to people with ID. The settlement supports the proposition that Alabama may cap its home and community-based services waiver programs and operate a waiting list serving applicants by priority based upon their levels of severity and emergent needs, as it has designed.

Recently ADMH assessed the remaining individuals being served at its last intermediate care facility for people with intellectual disabilities (ICF/ID), the W.D.

Partlow Developmental Center, and determined that all of its residents would be better served in more community-integrated environments. Therefore, in March 2011 the current ADMH commissioner, Zelia Baugh, and Governor Robert Bentley decided to close Partlow and instead serve all eligible individuals in home and community-based waiver services throughout Alabama. At the time of the closure announcement, 11 other States had closed all their public institutions for persons with intellectual disabilities, and Alabama became the first State in the South to achieve this milestone when the center officially closed on December 28, 2011.

PLANS AND INITIATIVES: DIVISION OF MENTAL HEALTH & SUBSTANCE ABUSE SERVICES

As a result of the *Wyatt* “right to treatment” litigation and in response to the *Olmstead* “integration mandate,” ADMH’s Division of Mental Health & Substance Abuse Services has been an active participant in Alabama’s systematic and inclusionary plan to reduce levels of institutional care and expand access to community-based services.

Upon the inception of the Home and Community Based Services Expansion Project, ADMH was a member of the *Olmstead* Planning Core Workgroup established by the lead agency, the Alabama Medicaid Agency. The workgroup comprised of State agencies, consumer and advocacy groups, and other stakeholder representatives was charged with designing a 3-year strategic plan for expanding home and community-based services. Through the *Wyatt* settlement agreement, ADMH was required to implement a statewide community education plan, reduce institutional levels and develop more community options. Several workgroups comprised of ADMH administrators and hospital staff, consumer and family members, public and private mental health providers, and advocacy groups were established to form the *Wyatt* Implementation Plan. This *Wyatt* plan and the 3-year *Olmstead* plan converged to create the roadmap to drive a reduction in the use of State psychiatric institutions and expand community service options.

The converged plan supported the implementation of a census reduction model in which the care of individuals housed within the State’s extended-care wards would be transferred to the community provider network. This resulted in a significant expansion of residential services, many of which reflected the development of new “specialty,” and small capacity (three bed) residential models to address the unique needs of extended-care residents, such as medical and forensic needs. Expert training and consultation was also provided through *Olmstead* funds and other funding sources to include deaf interpreter training, person-centered discharge planning and dual diagnosis services.

ADMH has demonstrated less reliance upon State psychiatric inpatient services by shifting funding and focus to less costly, but more effective community services and supports. Strides to better serve consumers outside of inpatient settings have continued beyond those prompted by the *Wyatt* settlement, leading to a statewide reduction in hospital census as well as closures of State psychiatric facilities. As an example, since 1971 the census at Bryce Hospital, Alabama’s oldest psychiatric hospital, has dropped from more than 5,000 patients to less than 240 in 2012. Other activities that have followed *Wyatt* initiatives include:

In 2007 regional planning groups made up of consumers, family members, mental health providers, and other stakeholders developed plans for new services and protocols designed to transfer the acute-care function from State hospital admission units to local community settings. These efforts resulted in a number of residential programs obtaining “designated mental health facility” status (community-based psychiatric units or hospitals that may serve committed patients outside of a State-run institution), the purchase of local inpatient care, increased psychiatric time, development of a Psychiatric Assessment Center in an area of high State hospital admissions and the establishment of mental health service teams consistent with “best practices,” such as Assertive Community Treatment teams, Adult In-Home Intervention teams and Bridge teams.

In fiscal year 2009 extended-care residents at Bryce and Searcy were evaluated to identify needed community services to permit discharge from those hospitals. In addition, residents living in community residential programs for over a year were evaluated to determine services needed to promote independent living in community. The planning process continued into fiscal year 2010 and was incorporated into planning for the sale of Bryce Hospital to the University of Alabama and the subsequent construction of a smaller, state-of-the-art hospital. Final plans were developed and approved by the Bryce Consumer Transitioning Work Group, the Mental Illness Coordinating Subcommittee (both incorporating a wide range of stakeholder representation) and the commissioner.

The community provider network in Alabama's MI Regions 2 and 4 established boards for the purposes of promoting service coordination and monitoring of project goals at a regional level. New services began in June 2010 in Region 2 (north central Alabama in the Bryce Hospital-served area) and in August 2010 in Region 4 (south Alabama in the Searcy Hospital-served area). The plans included the development of a variety of community services such as an increase in permanent supportive housing units; augmenting current residential homes; establishing a Medication, Observation, and Meals (MOM) apartment model; an increase in small capacity (three bed) homes; the utilization of Peer Bridger Teams; an increase in Peer Support Services and the use of flex funds.

Another part of ADMH's plan for consumer independence and inclusion is the closing of two psychiatric hospitals by the end of this calendar year. To prepare for closure at Greil and Searcy Hospitals, a census downsizing has been underway for the past year. While downsizing is a working goal for ADMH, the feat would not be attainable without partnerships the department has made with community-care providers and private healthcare facilities. By closing these hospitals and successfully overseeing all transfers of consumers, ADMH will provide the best health care available and do it in a way that is financially responsible.

Funds continue to be dedicated for community integration and service expansion efforts through block grant dollars, general State funds and other grant resources. Throughout the years, community integration and services expansion have been the focal point of the SAMHSA Block Grant goals and targets for mental health services. The MI Planning Council, which is mandated to approve the Mental Health Block Grant goals, has supported this process, and their guidance has steered enhancements to this process to expand into peer-directed care that is strength-based and person-centered. In fact, over a decade ago, ADMH partnered with the MI Planning Council to apply for the *Olmstead* stipend, which is provided to States on an annual basis. The MI Planning Council established guidelines for the submission and approval process for proposed uses of the stipend. Funding is dedicated to facilitate State's efforts to carry out the values expressed under the *Olmstead* decision of promoting community integration for adults with serious mental illnesses and/or co-occurring substance use disorders and children with serious emotional disturbances.

Additionally, ADMH is currently working with the Alabama Medicaid Agency to expand services through increased rehab options, targeted case management and the 1915-i State plan amendment (SPA). The 1915-i SPA involves needs-based criteria that require an individual to have a variety of risk factors and a functional need for assistance with community living skills, which cannot be met by an outpatient clinical service.

EMPLOYMENT & HOUSING PROGRAMS

ADMH's Division of Developmental Disabilities is working with the Alabama Medicaid Agency to propose amendments to its existing HCBS waiver programs to de-emphasize day services and emphasize more supported and integrated work services. ADMH is hopeful that resolution to these amendments can be achieved by summer 2012. Additionally, the Division of Mental Health & Substance Abuse Services is also reviewing ways to shift from day programming to employment services assisting consumers in achieving maximum quality of life, independence and self-worth.

To foster more housing opportunities for people with serious mental illnesses or intellectual disabilities, ADMH embarked upon a 2-year partnership with the Alabama Housing Finance Authority to prioritize portions of housing developments financed through a combination of low-income housing tax credits and the Home Investment Partnership Program. These plans were approved by HUD and netted up to 15 percent of housing units developed through funding from these two programs for the years 2000 and 2001. Under this initiative, people with mental disabilities have a priority for occupancy up to the total of reserved units and when they vacate the premises, that priority remains. If after working with local mental health service providers and ADMH, housing managers cannot find a person with mental disabilities to occupy the premises, other tenants may occupy that small, integrated percentage of these units. ADMH also created a housing consultant/advocate position to assist individuals with issues that may arise with the managers of these units (and others) because of problems they may have with landlords related to their illness or condition. In addition, ADMH is currently working with HUD, AHFA and housing developers on pilot demonstrations to provide more housing options in integrated settings for individuals.

CHALLENGES

ADMH has experienced three main challenges in its efforts to shift services to community settings. The first challenge was securing stakeholder buy-in. While most consumer and advocacy groups supported the idea, much resistance was met from legislators, probate judges and law enforcement. Likewise, some families expressed concern that their relatives could not live and work in the community and that somehow they would be sacrificing safety by not living in a congregate setting. ADMH held regional meetings with these stakeholders to educate them about the closure process and listen to their concerns, and even made changes to meet their needs. Additionally, much effort went into assuring families that their relatives' needs and safety could continue to be met at or above the level of institutional care.

Also challenging was identifying and developing resources within provider organizations to serve persons with significant behavioral challenges or multiple medical needs. ADMH held specialized trainings with interested providers about enhancing their services in order to serve these individuals. However, as institutions have closed and budgets have shrunk, the ability of the State, with its limited resources, to provide ongoing training to provider organizations to assist them with professional growth has been difficult.

A third challenge stems from the negative stigma sometimes directed toward people with mental illnesses and intellectual disabilities. NIMBY-based ("Not In My Backyard") opposition across the State and country, stigmatic language and incorrect assumptions about violent tendencies are all examples of stigma. ADMH believes part of providing quality services to the people it serves includes public education and stigma reduction efforts, and the department regularly implements public education strategies. For individuals with intellectual disabilities, these efforts bring inclusion in the community closer to reality. For those with mental illnesses, giving the facts about these illnesses encourages people to get treatment or help others they know seek treatment. It also enhances long-term recovery, and increases understanding and acceptance from friends, family members, peers and society as a whole.

NEEDS

There is a concern that with decreased funding to Medicaid, there will be a decline in the overall quality of health care available to persons currently served through the HCBS waivers. Individuals already have limited choices in healthcare providers who accept Medicaid. With proposed cuts to providers, their choices could become more limited. Also, with proposed cuts to medication coverage and optional health care services, people's quality of health, safety and well-being could be further complicated.

Additionally, more collaboration between Federal agencies in consolidating and streamlining mandates and access to Federal programs that meet the initiatives of *Olmstead* efforts would be helpful. Currently States have to dedicate extensive resources to seek out Federal grants and programs that would help them meet their *Olmstead* goals. Improved communication between the Federal and State levels could help ensure States meet and exceed these goals.

CLOSE

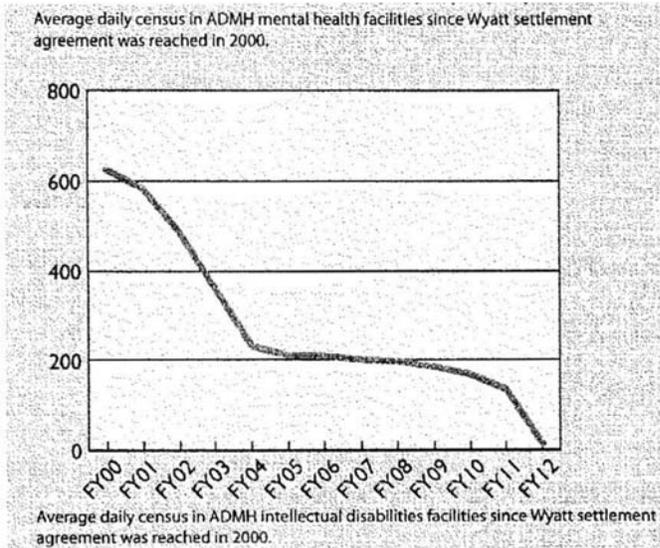
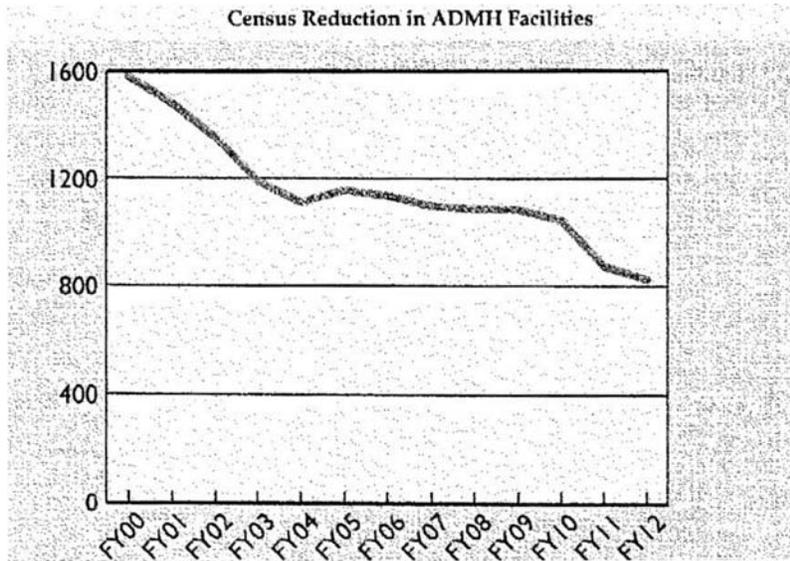
The Alabama Department of Mental Health has launched a large-scale initiative in providing community-based care for Alabamians. Not only has the department enjoyed success, but more importantly, individuals who have transitioned to community-based care have reported being more satisfied with services and more connected with their friends and families. The era of institutionalization is over. Instead, a new era has begun with individuals enjoying inclusive lives in their communities.

ATTACHMENT

ADMH COMMUNITY INTEGRATION TIMELINE

December 2011—W.D. Partlow Developmental Center closed
 July 2009—Alice Kidd Nursing Home closed
 October 2004—Thomasville Mental Health Rehabilitation Center merged with Searcy Hospital
 April 2004—A.P. Brewer-Bayside Developmental Center closed
 January 2004—J.S. Tarwater Developmental Center closed
 December 2003—Wyatt Case closed
 October 2003—Lurleen B. Wallace Developmental Center closed

September 2003—Thomasville Mental Health Rehabilitation Center relocated as a separate entity on the Searcy Hospital campus; S.D. Allen Nursing Home closed
 August 2003—Claudette Box Nursing Home closed
 January 2000—Wyatt settlement agreement
 June 1999—Olmstead decision
 April 1996—Eufala Adolescent Center closed
 November 1996—Glenn Ireland, II Developmental Center closed
 October 1970—Wyatt case filed



The CHAIRMAN. Well, thank you very much, Commissioner Baugh, for a very profound statement.

And now we will turn to Ricardo Thornton. Mr. Thornton, welcome to the committee. Please proceed.

STATEMENT OF RICARDO THORNTON, SR., FORMER RESIDENT OF FOREST HAVEN, WASHINGTON, DC

Mr. THORNTON. Thank you. First let me say, good morning, Senator Harkin. Good morning to you and to the Committee on Health, Education, Labor, and Pensions. I am very excited. I am honored to be here today.

My name is Ricardo Thornton. I am here representing the 92,000 people who are still living in institutions in large public and private facilities. For people with intellectual disabilities and for all of the people like me who used to live in institutions.

With me today is my wife Donna. I lived in institutions all of my childhood. I was a resident of D.C. Village and then in 1996, I went to Forest Haven, the DC institution for people with intellectual disabilities. My wife, my brother, and my sister also lived at Forest Haven.

For many years, no one told me that I had a brother or a sister there. I did not get to think for myself. The staff thought for me. They made decisions for a long time and no one expected anything of me.

At Forest Haven, where I used to go, and like I said, I lived there, went there. I was in a cottage. Each of the cottages had names. If you see the trees, like the oak tree, the maple tree, those types of names. I was at Oak Cottage. And there were lots of guys. I was learning basic skills there.

I have seen lots of abuse. It was sad, but sometimes you have to walk away from it. You could not snitch on them because you would get in trouble, but it was sad to see and it hurts me. And then when I had a relationship with my sister, later on I did have family members who would come out to Forest Haven to visit us, and it was sad to me because they came out, and they would get on the ball field, and say, "We have all this food." And they showed a lot of love, but I had no idea who they were and I considered them as strangers.

Later on, I had developed a better relationship to know who my family was, that was how I got to know my sister Earline and we did a lot of fun stuff there. Unfortunately, she passed at the wrong time, and no one had an explanation on what really happened. She died in a cottage there. And everyone wanted to know what I was going to do next. And all I was told was, "She had a heart attack. Let's leave it at that." Too many incidents like that happened and there are no defense with that.

But the good thing was I promised her before she died that I would advocate, and I would go out and advocate for her and people who cannot advocate for themselves. I will continue to advocate. So I wanted to keep that promise. That is why I am here today at the Senate.

I was very excited to see my wife Donna who also lived there. Donna had a favorite swing that she used when problems were so bad, she would go to her swing and swing. And sometimes she would get into trouble for doing it, and she tells a story about that, but I just thought it was fascinating to see that she had a dream.

And her dream was she wanted to one day get out, get into the community, have a husband, have a beautiful family, and a wonderful life just like everyone else.

We did get out. Forest Haven closed, and I am going to be very brief because of the time, Forest Haven closed and we got out. I moved into my first group home. I was excited. People that left Forest Haven, you know, when you get into the community, we are excited. We cannot wait to see what is next, but to find out that we are winding up in a group home that still has the same institution setting and people did not want us in the neighborhood. You know, they had a lot of resistance to us. So what I did was I went to a hearing.

I remember providers coming together for this big hearing in DC to talk about what is the problem. Why is it that people do not want us in the neighborhood? What is the big problem? And I remember going there, and testifying, and I had invited the council,

“Since you had talked about people with disabilities so bad, I want to invite all of you to come to my wedding. We are going to have a handicapped wedding.”

[Laughter.]

We had a wedding and thanks to the staff at the community, they provided us, got us together with this big program. We had a beautiful wedding. We had the photographer to come out, and it was to show people what people with disabilities can do if you give us a chance to. We had a beautiful wedding.

Later on down the road, we had someone from the “*Washington Post*” who came out. Mike Wallace came out and did an interview, which was really unique. He took a look at the institution where we lived. We showed him some of the real bad things that were happening and we showed him some of the good things that were happening, and he was just so fascinated with that.

I have to say that we are in the community. I work at the Martin Luther King Library downtown. I have been there 35 years now. My wife works at Walter Reed, and she is now working at the Army Medical Center, and she has been there 22 years. My brother now works at Catholic University, and I do not know how many years he has been there, but they are happy, and they are excited about being in the community and learning something new and different.

Many of us, and many of the people that I advocate for, are really against going to workshops. They really want real jobs, real opportunity, to get a feel of something different not just going there doing skills, but they want to use their ability. So we got a chance to do that.

The other thing we have in our community is we are very active in our church. We have a church where many come with disabilities. They play, they sing songs, and they do a lot of fun stuff. They are a part of the community, and I wish you could see the growth. It is there. It is really happening.

And I just have to say, Senator, that disability is not a disability. One of the things I also did was I am very active in Special Olympics. Thanks to Mrs. Shriver, Ted who is no longer here, but those people who inspired us to have Special Olympic competition games. It was not so much about the competition and competing in the

games. Yes, I loved the gold medals, I loved the silver medal, I loved the bronze medal, but the one thing I loved most was I did not have to worry about my label. My label. I was a person, not with a disability, but I was a person who had abilities, and that is what Mrs. Kennedy gave us to look at our abilities to achieve and to reach our goals. And so, I am really thankful for that.

And in closing, it is just saying that I have seen so much growth within our community. I have seen it around the States. I see everybody trying to make changes and to turn things around, but the bottom line is 92,000 people who are still living in institutions. It is time to get them out of there and get into the community, so they can be a part of growth, just like me and my wife Donna.

So Senator, again, I thank you for the opportunity to sit here and speak today. And again, for me, I have a lot of people who gave me support, and believed in me, and my community, for me to achieve the goals I have achieved.

I can go on and on, but I just thank you, Mr. Chairman.
[The prepared statement of Mr. Thornton follows:]

PREPARED STATEMENT OF RICARDO THORNTON, SR.

SUMMARY

With me today is my wife Donna and my son Ricky.

I lived in institutions all of my childhood. I was a resident of first DC Village and then in 1966 I went to Forest Haven, DC's institution for people with intellectual disabilities. My wife, brother, and sister also lived at Forest Haven. My sister died in Forest Haven and is buried there. I advocate on her behalf and on behalf of others who cannot speak for themselves.

In the institution, I didn't get to think for myself. The staff thought for me and made all of my decisions. For a long time, no one expected anything of me. I got to know some good staff and some really bad staff. I witnessed abuse, especially of people with severe disabilities.

I left Forest Haven in 1980. That was a great day! I was in the first group to go out.

After I left Forest Haven, I lived in several group homes. I started to date Donna—and then she proposed to me. People didn't think we should get married but a few people encouraged and believed in us. So we got married, and later we had a beautiful baby boy, our son Ricky. We are very proud of Ricky. He graduated from high school, took a few college courses, is now working part-time, is married, and is the father of a beautiful baby girl.

I have worked at the Martin Luther King Library in DC for 35 years. My wife Donna worked for over 30 years at Walter Reed Medical Center and now works at the Army Medical Center in Bethesda. My brother William works at Catholic University. All of us pay taxes and make a difference on our jobs and in our communities. Donna and I serve on many Boards and committees, and are very active in our church.

When I lived in the institution, no one would have believed that I could have the life I have today. I couldn't always advocate and do what I can do now. I had people who believed in me and who supported me. Some of the best support Donna and I have received has been from friends. When you live in the community, you make friends and they support you. You don't have to depend on staff for all of your support, and you get to support others as well. You develop networks that you could never have in the institution. I've seen this happen for so many people, including people with severe disabilities.

I've seen people with severe disabilities who have grown and accomplished great things given the right support. I hear people say that some people are too disabled to live in the community but I've seen people just like the people still in institutions who do so much better in the community—because no one expects you to do anything in the institution but survive. People need to have high expectations for people with disabilities because then they'll give them opportunities to learn and grow. People don't grow in institutions. There's no such thing as a good institution. Segregating people is always bad, people never grow in those places, and are safer and happier in the community.

We can't go back. We can't go back to a time when people are moved against their will to places where they have no opportunities to learn, grow, and contribute. We need to keep moving forward. Thank you for the opportunity to testify today and for your continued support of people with disabilities.

Good day, Senator Harkin and members of the Senate HELP Committee. My name is Ricardo Thornton. I am here representing the 92,000 people who are still living in institutions and large public and private facilities¹ for people with intellectual disabilities—and for all of the people, like me, who used to live in an institution. With me today is my wife Donna and my son Ricky.

I lived in institutions all of my childhood. I was a resident of first DC Village and then in 1966 I went to Forest Haven, DC's institution for people with intellectual disabilities. My wife, brother and sister also lived at Forest Haven. For many years, no one told me that I had a brother and sister. We weren't told that we were related.

In the institution, I didn't get to think for myself. The staff thought for me and made all of my decisions. For a long time, no one expected anything of me.

I got to know some good staff and some really bad staff. I witnessed abuse, especially of people with severe disabilities.

My sister died in Forest Haven. She is buried at Forest Haven, and I still go back to visit her grave. I promised to advocate on her behalf and on behalf of others who cannot speak for themselves.

I left Forest Haven in 1980 when I was in my early twenties. That was a great day! I was in the first group to go out.

I lived in a few different group homes. Living in the community was a big adjustment. Some people looked at us differently. The community didn't want us there. There was trash in the alley and the neighbors thought we put it there until they saw that we were there cleaning it up. At first, in the group homes, people treated us in some of the same ways as when we were in the institution. I wanted my own bank account but staff didn't want me to manage my own money, so I got in trouble.

While I was living in a group home I started to date Donna—and then she proposed to me. People didn't think we should get married but a few people encouraged and believed in us. So we got married, and invited everyone we knew to the wedding. Later, we had a beautiful baby boy, our son Ricky, 2 lbs 11 oz. We are very proud of Ricky. He graduated from high school, took a few college courses, is now working part-time, is married and is the father of a beautiful baby girl. We were written up in the *Washington Post* and got to be on *60 Minutes*.

When I lived in the institution, no one would have believed that I could have the life I have today—married with a son and granddaughter, a good job for 35 years, a driver's license and car, and opportunities to speak on behalf of Special Olympics International, which has taken me to places like Johannesburg. It's important to have people believe in you and to expect that you're going to succeed. People need to have high expectations for people with disabilities because then they'll give them opportunities to learn and grow. People don't grow in places like Forest Haven and in other institutions.

I have been working at the Martin Luther King Library for 35 years, as an employee of the DC government. I started as a volunteer, then as a part-time worker, and then full-time. My wife Donna worked for over 21 years at Walter Reed Medical Center and is now at the Army Medical Center in Bethesda. My brother William works at Catholic University. All of us pay taxes and make a difference on our jobs and in our communities. Donna and I serve on many Boards and committees to make things better for people with disabilities, and we are very active in our church.

I couldn't always advocate and do what I can do now. I had people who believed in me and who supported me—friends and providers. I've seen people with severe disabilities who have grown and accomplished great things given the right support. For many people, supports come through Medicaid which helps people live in the community and get services such as personal care, transportation, and help learning to do things like plan and manage their household. I hear people say that some people are too disabled to live in the community but I've seen people just like the people still in institutions who do so much better in the community—because no one expects you to do anything in the institution but survive.

¹Public and private residential settings for 16 or more people, including State-operated institutions, private intermediate care facilities, private facilities, and nursing facilities. From Table 5 in Braddock, D., et al. (2012). *The State of the States in Developmental Disabilities 2011*. Boulder, CO: University of Colorado.

I love Special Olympics because they encourage us to focus on our abilities and to show off our abilities, not our disabilities.

Some of the best support Donna and I have received has been from friends. When you live in the community, you make friends and they support you in your advocacy, and in raising your son when you have questions, and when you have to make major decisions in your life. When you live in the community, you don't have to depend on staff for all of your support, and you get to support others as well. You develop networks that you could never have in the institution. I've seen this happen for so many people, including people with severe disabilities.

When I was in Forest Haven, I had a chance to go to the cottage that had the people with the most severe disabilities, who mostly stayed in bed all day. Someone at Forest Haven got a grant so that we went in, gave people musical instruments and played music while they played along. They loved it and never wanted to go back into their beds. When the grant ended, that program ended. If they had lived in the community, their music would not have stopped and wouldn't have depended on a grant.

When I left Forest Haven, I was asked to be on the Mayor's committee that was set up to close it. It was a great day when the last person left Forest Haven in 1991.

What I've seen is that when people are given a chance to grow and contribute, they grow and contribute. We ask that you ensure that people continue to be given chances to have good lives and to grow in their communities with support. I believe that people can do anything if they're given the opportunity and support.

We can't go back. We can't go back to a time when people are moved against their will to places where they have no opportunities to learn, grow and contribute. We need to keep moving forward.

People invested in me and my wife and brother. When we were in the institution, we didn't have a voice. We were thought to be incompetent so no one took the time to teach us things. But people can accomplish great things with support. Having an intellectual disability doesn't limit what you can contribute. Being put in institutions limits what people can do and guarantees that people will be dependent for the rest of their lives.

Anyone can become disabled at any time. We are people just like everyone else. The time needs to be over for people to be sent to institutions because there aren't options in the community or because people think it's cheaper or more protected. It wastes people's lives and, in the long run, keeps them from contributing.

There's no such thing as a good institution. Segregating people is always bad, people never grow in those places, and are safer and happier in the community.

I'm one of many people who could be here today. People sometimes say that I'm not like some of the other people with intellectual disabilities. The only thing that's special about me is that people believed in me and in my potential to learn in spite of my disability, and they took the time to help me learn. Please protect people from places where no one expects anything from them and where they're just kept alive.

We can't go back. It's time to move forward.

Thank you for the opportunity to testify today and for your continued support of people with disabilities.

The CHAIRMAN. You added an exclamation point to this whole hearing. It was great. Thank you very much, Mr. Thornton.

In reading your testimony last night, you did not say this, but I am going to read it. I thought it was very profound. You said, "People need to have high expectations for people with disabilities."

Mr. THORNTON. Absolutely.

The CHAIRMAN. High expectations. High expectations, "Because then it will give them opportunities to learn and grow. People do not grow in institutions."

Mr. THORNTON. No.

The CHAIRMAN. These are your words.

"There is no such thing as a good institution. Segregating people is always bad. People never grow in those places, and are safer and happier in the community."

Those are very profound words.

I am going to ask you the same question I asked Messrs. Perez and Claypool at the beginning. We hear from a lot of families that are concerned. They are in their 60s-70s. They have an adult child

maybe in their 40s–50s. They may be in a community setting now, but what happens to them later on? There is a great concern about the safety and well-being of their family members after they leave an institution.

What do you say to people like that? I mean, your life and what you have done. What about the safety and the well-being of people?

Mr. THORNTON. Well, I think that we should not look at the institution as resolving that. I think that we should not think inside the box, but think outside the box with some positive-ness. Because I think that families need to be assured that their children are safe and that they can grow because they are going to continue to grow with their ability. But if you put them back, look back at the institution or those types of settings, they are not going to grow but so much. So you want to take them out of that and continue to use their ability.

I think that I heard some things about seniors as they get older, the city does not really have a lot for them. But I think that if you have senior citizens beautiful buildings, I am not knocking seniors. I love them. But if you can buildup a beautiful complex building and all this stuff with them, why can't we do it for people with disabilities right here in our community? I mean, we can think outside the box, and I think that will play a very important role.

I do not think institutions are the key. I think nursing homes are not the key. Let them be out. Let them be free. Let them see more and more what the community has to offer, but think outside the box, not in the box.

Thank you. I do not know if that answered the question.

The CHAIRMAN. But that is exactly right. I just have a couple of questions here before my time completely runs out for both Secretary Landgraf and Commissioner Baugh.

Could you please comment on how the implementation of the mental health parity law is impacting *Olmstead* efforts? This is a fairly new law, 3 or 4 years old. Are there things the administration has done or should do on mental health parity that would assist your efforts? So address yourself to mental health parity.

Commissioner Baugh, you spoke about that.

Ms. BAUGH. Yes, sir. Thank you.

I think that the beginnings and the intent of the mental health parity and the law has been very important with regards to *Olmstead* and access to treatment, and treatment being equal.

For example, an individual that has a pancreatitis attack may go into the hospital indefinitely. But if you have a mental health episode, you have to get preapproval and you can only be in there a day or two. And so the intent of the law with access to treatment and equality in treatment has been very profound.

However, the actual implementation of it, I think at least in Alabama, it has been challenging because there has been no clear cut guidance on minimum requirements for States to meet with regards to mental health parity.

For example, you get X-amount of benefits for inpatient stay or different types of things that are important with regards to mental health parity. And even more important with regards to *Olmstead* implementation because right now because of the disparity with insurance coverage, with regards to accessing treatment, still many

people believe the only place you can access adequate treatment is in a large State institution.

And if we are going to truly implement *Olmstead* and truly have integration, then individuals should have choice of care, choice of provider, and choice of treatment. And right now, not having even a baseline minimum standard, I think, is an opportunity that could help many States with the full implementation.

The CHAIRMAN. I thought the one point you made in your statement I wrote down is that you estimated that it cost Alabama \$150,000 per year for an institutionalization, but it cost \$60,000 or less for supportive services in a community.

Has this concept taken hold in Alabama and do people begin to realize that not only do they save money, they make people's lives better?

Ms. BAUGH. It has, and that is a great question, Senator. It has taken hold and it is beginning to take hold.

I failed in my initial summary to say that we are also in the process of closing two more psychiatric hospitals in Alabama by the end of this calendar year. And we are really making not only a clinical case for it being the best treatment, but also a fiscal case. And many people in our State are finally realizing you actually can get more appropriate quality and better treatment at the community, and also it being more cost effective.

Not to negate my employees and our State institutions, they are wonderful, but the nature and the environment that they deliver their care is the issue because when you have a large number of individuals under one or two roofs, and you are trying to get them to take medications or go take their baths. I mean, it is all a schedule. And like you said, nobody is thinking. You do not have to think. The staff did it for you, and is that really the best environment? And in my opinion, it is not, not for long-term care.

The CHAIRMAN. Well, my time has run out. I have some followup questions for Secretary Landgraf. I will do that on the second round.

Senator Enzi.

Senator ENZI. Thank you, Mr. Chairman.

Mr. Thornton, I want to thank you for your testimony. I am impressed with anybody that has had a job for 35 years.

[Laughter.]

Or 22 years, as you have mentioned your wife had, and that was even before the *Olmstead* Act.

How did you come to get that job?

Mr. THORNTON. Well, I was at a special education school. I went to special education, and I went over as a volunteer training, learning skills on how to do shelving of books and stuff. And then later on, they had a backlog. I just showed that I could do more than just do seals all day.

I went there and I got a call to come back. They had a backlog of books, and they needed some help, and I came in as a part-time employee. Then ever since then, I have been there.

And what I do is, I keep the Special Olympics Team. I always say, "Teamwork makes the dream work." So if a part of your team, we are going to make it work, if they just believe it. But now, I

am reaching out for others, hoping they would bring more on. There are a lot of us out there.

Senator ENZI. Well, thank you for all the effort you are doing there.

Mr. THORNTON. Thank you, Senator.

Senator ENZI. One of my favorite people, a librarian in Gillette, WY, is very meticulous in her work, and has never let me put a book back. And she has also been a very loyal employee, and done a great job.

For Secretary Landgraf and Commissioner Baugh, transitioning individuals with disabilities into a community-based setting requires a focus on a full range of services, health care, social services. We mentioned transportation, housing.

It seems that most of the funding historically available to States for implementing this comes from the Medicaid program and, of course, the Medicaid program has a required match. Has this presented an obstacle for your State in transitioning people with disabilities to this fully integrated community-based setting? And what can we do to better accommodate that range of facilities and services?

Ms. LANDGRAF. Thank you, Senator. That is a great question.

I am very fortunate because the Medicaid program falls under my leadership at the Department of Health and Social Services. In addition, all disability services are under our Department, so we kind of break down those silos in that it falls within our Department. And our Medicaid program, actually, we see that as an opportunity to advance inclusion for individuals with disabilities, and it is how we utilize that funding. I believe the Commissioner and I both agree that we need that flexibility.

And relative to Medicaid funding, we need to approach it on an individualized fashion. Whatever individuals will require in order to be included within their communities, the funding should follow that individual, Money Follows the Person, which enables us to actually transition individuals out of long-term care facilities is a first step relative to that level of flexibility.

But we also have to encourage that level of flexibility across, what I call, across the cabinet. Housing becomes very critical. We now, along with our State housing authority, have a voucher program called the State Rental Assistance Program. When I talked a little bit about in my testimony, people with disabilities have a further disadvantage in that they are of extreme poverty level which means if they are to exit or if they are to maintain a high quality level of life within the community, they need to be financially empowered in order to succeed in that.

So we want to use all our Government funding in a way that it supports people on an individualized fashion across that domain, not just relative to Medicaid, but also there are other Federal and State programs that will afford them that access.

Senator ENZI. Thank you.

Commissioner Baugh.

Ms. BAUGH. I think the challenge for Alabama right now is coming up with the match money for Medicaid. I think that we are applying for many grants through the Affordable Care Act that is going to assist us with the 90/10 match for the next 2 to 3 years.

However after that, looking at sustainability is where we have great concern.

With regards to match money, we would be happy to take any match money, Senator, you would like to send our way.

[Laughter.]

Although in this fiscal environment, I am not sure that that is an option. However, it does present a challenge when you look at sustainability long term.

Senator ENZI. Thank you, and my time is almost up.

The CHAIRMAN. Thank you very much, Senator Enzi.

Senator Franken.

Senator FRANKEN. Thank you, Mr. Chairman.

Secretary Landgraf, Minnesota has a very sophisticated home and community-based system to support seniors and people with disabilities.

In Minnesota, people who receive homecare are protected by a “Homecare Bill of Rights,” that guarantees that they will have the same right to information, and protections against abuse and neglect, as people who live in nursing homes do, but unfortunately, this is not the case everywhere.

We know that it is better for everyone—for patients, for families, and for the Federal budget—when our loved ones can get the care that they need at home instead of in a hospital. And I think you will agree that no one should have to worry that they will not receive the same quality of services in their communities as they would in a nursing home or a hospital. And that is why I introduced my Home Care Consumer Bill of Rights Act which would require all States to develop similar protections for seniors who receive homecare. But I wonder if these protections are needed for people with disabilities who are under 65 and opt to receive community-based services and support.

So my question is: Is there more we should be doing to provide people with disabilities the information they need to make sure that they can make informed choices when they receive community-based care?

Ms. LANDGRAF. I will give you a resounding “yes,” to that.

I think, in Delaware we have expanded our long-term care ombudsman program, which is an advocacy and independent advocacy program that goes into those particular facilities. We have expanded that into the community now for that very reason, and it is inclusive, not only of our senior population, but also of individuals with disabilities.

The issue we have is that we need to apply more resources in that area. So individuals have an advocate that is independent from the system that they can work with as well, and I think education at any level. I mean, I think Ricardo is an extreme example of independence and that Ricardo’s level of education and empowerment shows that he is a full participating member of our society, and he can speak out not only for himself, but for others.

I believe that inclusion, too, actually protects people more so than segregation because we build those natural supports. And we, as a society, have a tendency to actually look out for one another when we build relationships with one another, and that happens in the community.

So I believe the protections that you are working toward for our senior population should, indeed, also include those with disabilities.

Senator FRANKEN. Thank you.

Commissioner Baugh, you mentioned that you have had some challenges implementing the 2008 mental health parity law.

What could the Federal Government do to help you fully implement this law? Has the fact that the administration has not released a final rule hindered your implementation efforts?

Ms. BAUGH. That is exactly the case, Senator, not having a final rule with very clear cut, basic, federally mandated requirements of minimum coverage that has to be in any kind of parity act has been a huge barrier to implementation. The sooner we are able to have that, I think, the sooner it sets the groundwork, or a framework, for individuals to be able to access treatment in settings other than in a large State institution.

To me, that is a huge step in the direction toward integration, full integration, having choice of care, choice of provider, and appropriate resources.

Senator FRANKEN. Thank you.

Mr. Thornton, thank you for your testimony here today. In your written testimony, you mentioned you have been working at the Martin Luther King Library for 35 years. We have heard from some other panelists about the importance of providing people with disabilities with an opportunity to engage in their community.

Can you discuss what it means having a job for you and a mainstream job, not a work-shop job as you mentioned?

Mr. THORNTON. It means that I am able to reach some goals like purchase an automobile. I want to be part of a community and I can go. We just recently moved into a new home, my wife and I and my son, who is now a daddy himself.

A question asked to him said, "What is it like to have a father and mother who has a disability raise you? What was that like to you?" And he told the person, he said,

"You know what? They were just like anyone else. They loved me. They supported me. They carried me through hard times when I did not understand, they worked for me. And they have a support system in place to help me get along, to get to school."

He graduated from high school, and that is community.

I educate him a lot. He is probably tired of me giving him advice. We talk a lot. But I think just a lot of stuff there and my wife would tell you. She would say, "Oh, Lord, he is going to bore him again. Oh, God." But it was to teach him that just because we have a disability does not mean that we cannot teach you. We go out and find resources that will help us help explain to you what it is that you deal with. He is a lot more comfortable with that and confident.

Educating others is the key. I found in the community, as we educate them and give them stories, that is one of the greatest things we can give—success stories.

Senator FRANKEN. Well, my guess is that you are a wonderful father.

Mr. THORNTON. It is a lot of work, though.

Senator FRANKEN. I know. I know.

The CHAIRMAN. But how is he as a grandfather?

[Laughter.]

Senator FRANKEN. Well, I am hoping—

Mr. THORNTON. Thank you.

Senator FRANKEN. To be one myself. No pressure on my kids.

[Laughter.]

Thank you, Mr. Chairman.

Mr. THORNTON. Thank you.

The CHAIRMAN. Thank you very much, Senator Franken.

Secretary Landgraf, you were present at this full-day session in Connecticut that we had a few weeks ago.

Your Governor was there, Governor Markell, and he is now going to take over the National Governors Association beginning, I think, next month and he was there for the entire day. And he has committed himself as the head of the NGA to focus on employment of people with disabilities through the National Governors Association. Hopefully in the next year we will see more Governors focusing on this in their States, again, at a time when the private sector is now beginning to expand its employment of people with disabilities. I mentioned the Chamber of Commerce and their commitment to this.

I guess what I want you to address yourself to is, I do not need to have a whole encyclopedia, but what are some of the things that you see? You have been on both sides of this issue. You have been an advocate and now you are Secretary, not that you are not an advocate, but you have been on both sides of this.

What is it that we should be thinking about doing here to really help move this along where Governors are now, the private sector, the idea of getting people out of institutions, getting them competitive employment? Give me two or three different things that you would like to see us address ourselves to.

Ms. LANDGRAF. Well and again, I think it is important when we talk about employment that we—I indicated an ADA Ambassador. But one that really can—and all of us should be responsible for that, for educating businesses, for educating ourselves. Public entities are also businesses, so to speak, and we can do a better job at employing individuals with disabilities.

The private sector, what we saw in Connecticut, major corporations are stepping up to the plate, and they see this as a tremendous opportunity for their bottom line. Not necessarily a charity, but they value all employees, including people with disabilities.

I believe at the distribution center that Walgreens has in Connecticut, the story that I found most compelling was relative to their safety as well, because many times employers will believe that it might be unsafe to hire someone with a disability. They are finding just the opposite, especially with individuals who are deaf and hearing impaired and who are their fork-lifters. And they are actually having those who are not deaf and hearing impaired now wear earplugs because they found out that it actually keeps them from being distracted while they are operating the forklift. So again, it was a teachable moment.

So I believe from the employment perspective that we have to work collectively, again, across the Government. We have the Divi-

sion of Vocational Rehabilitation. My Department actually does the follow along services relative-supported employment. From a benefits package, again, that is a good use of our Medicaid dollars to really focus on: how do we utilize those dollars in the best way to enable individuals to become self-sufficient?

Employment is the opportunity to enable individuals to become self-sufficient. It is better for the individuals, and they have some funding, and they have their own power. I believe that money is power and when people are disenfranchised based on poverty it only further challenges the individual. So we, as the public sector, need to focus our programs on empowerment and, again, a meaningful work and a meaningful wage enables people to become empowered.

We need to look at the Medicaid buy-in program because I hear from family members and individuals with significant disabilities that some of their concern in accessing employment is relative to the fact that they might lose their Medicaid benefit. And Medicaid operates a little bit different than other health insurance. Medicaid provides personal attendant services that a private insurer may not provide, so individuals do not want to lose that.

So we need to kind of look at, from a public policy standpoint, both at the Federal level and the State level with the ADA at the top of that list, how do we change that paradigm and benefit to really focus on how do we enable people access to their community's employment, transportation, housing, and health care?

The CHAIRMAN. Very good because my staff just handed me, Andy just handed me this list of the different tools in Medicaid to provide community-based services. There are: one, two, three, four, five, six that I have right here—six different parts of the code.

There is a Medicaid Rehabilitation and Personal Care Option 1396d(a)(13), then there are home community-based waivers section 1396n(c). Is this good? Should this not all be together?

Commissioner Baugh, I see you smiling about that, all the different silos we have here. How do we wade through all of that stuff?

Ms. BAUGH. Well, actually, one of the challenges at the State level is trying to figure out where do you go to get what for this little piece.

The CHAIRMAN. Yes.

Ms. BAUGH. When it could be something more simple, where you go to one place, you get X-amount of money, and this is what you say you are going to accomplish with those dollars, and actually have a level of accountability based on evidence-based outcomes.

The CHAIRMAN. There you go.

Ms. BAUGH. Not only, for the clinical quality, but fiscal quality as well.

The CHAIRMAN. I think we ought to take a look at how we can consolidate some of these things, all these little different lines.

Excuse me, Senator Enzi, do you have any questions?

Senator ENZI. Thank you, Mr. Chairman.

Commissioner Baugh, in your written testimony you called for more collaboration between the Federal agencies, and consolidating and streamlining mandates. I think this fits with what Senator

Harkin was just talking about, access to Federal programs that meet the initiatives of the *Olmstead* efforts.

Can you expand on why this is needed and what we should do from your perspective to increase this collaboration of the Federal agencies?

Ms. BAUGH. Yes, sir, and that is a great question.

Some of the challenges that we face, or currently face as a result of our downsizing efforts, is housing and the lack of housing for individuals that are currently living in institutions. And sometimes, although this is changing now because of the collaboration at the Federal level, sometimes the policies for CMS and Medicaid may conflict with *Olmstead* implementations.

For example, supportive employment would be a good one, integration and support of employment and fully integrating back into society is something that is inherent in *Olmstead*. And you do not want to just move them from one large institution to a mini institution, and let individuals sit there, because you are not integrating, and they are not thriving and becoming part of the community.

Well, if they go into supportive employment or full employment, then they lose their Medicaid or Medicare benefits. And like the Secretary was saying, the benefits for Medicaid and Medicare are different than on other private insurance that provides the supports to allow an individual to work. And so, that would be one example.

Another example would be housing vouchers. Do our State housing people know what the Federal housing authority is doing with regards to housing vouchers? And is there a disparity among States with implementation of HUD vouchers? Is there a disparity among States with regards to implementation, or requirements for grants through CMS or other Federal agencies? So those would be some examples I would use.

Senator ENZI. Secretary Landgraf, would you like to answer that too?

Ms. LANDGRAF. I would like to touch upon the Commissioner's comments relative to housing because it is something we have just come up against in Delaware with our State rental assistance program, and how we are administering that through the housing authority.

We are finding that for people with serious, persistent mental illness, they typically have issues relative to the criminal justice system. It is the nature of the disease. So many times they get caught up in the criminal justice system.

HUD has some requirements relative to who can be housed in Section 8 housing, and if they have a criminal background. And what we are finding with our vouchers, they are asking that everyone that we refer to the voucher program go through a criminal background check and that is very stigmatizing for the population. And we know that mostly individuals will come up with some type of criminal justice activity just by virtue of their disability, of serious persistent mental illness.

So we are relying on the ADA to say, "We need a reasonable accommodation." And that we now at the Department of Health and Social Services will be the one that guarantees to the housing authority that this individual is able to access these vouchers and

rental programs. I believe HUD has a restriction. If you have been engaging in methadone is one area that they will not allow the individual to be housed or if you are a sex offender.

Now we are responsible regardless. So I call those individuals the unacceptable individuals for the vouchers, but then I am guaranteeing to our State housing authority that we have done a level of background. I do not do full criminal background checks, but I rely on my team to validate that the people we are putting in housing are those individuals that will comply to the Section 8 housing code, and then we are responsible for housing the others.

But that is how discrimination sometimes comes down and how these programs actually end up conflicting. But we are making a commitment and I am working this through with the housing authority. But again, I think reasonable accommodation is the key and how we look at reasonable accommodation. I think many States are familiar with reasonable accommodation relative to tangible things like ramps and accessibility from that perspective.

But when you start talking about, at this level, we really need to have that conversation and look at reasonable accommodation as part of the ADA, and enabling people to have access to their communities.

Thank you.

Senator ENZI. Well, you all have given us a lot to think about and I am out of time, but I am going to submit a question to each of you.

Because one of the things I run into in my State, and other places, is people that want something done with employment laws so that they can find the employees that they need. And I ask them a little bit about what type of a job they are talking about. And I say, "Have you ever considered people with a disability?" They say, "What kind of disability?" And we work through that problem a little bit too. And then their final question is, "That would work. Where would I find them?"

I am going to be asking in this written question, which I want you to take some time and think about, how can we have some kind of a clearinghouse so that the people that need the jobs can find the jobs, and the people that need the workers find the workers? And we wind up with this very competitive situation for people with disabilities.

Thank you for your testimony. Appreciate it. I am going to have to run.

The CHAIRMAN. OK. Thank you, Senator Enzi.

I will close up here. I would like to thank all of the witnesses for their testimony and insights on the progress we are making under *Olmstead*. That was the purpose of this hearing—tomorrow is the 13th anniversary—to promote community integration for people with disabilities. We appreciate you making the time in your busy schedules to travel here and share your expertise.

In the past 2 years, we have continued to make significant progress in expanding home and community-based services and supports that allow people with disabilities to live, work, and participate in their communities. To further encourage this progress, Congress has provided States with a variety of tools including the Community First Choice Option to help them comply with

Olmstead, and making it easier for them to provide services for people with disabilities in integrated settings.

Now today, I have instructed the GAO to release a study that I requested on the degree to which States have already taken advantage of, or are planning to use, these new tools for financing home and community-based services and supports that were included in the Affordable Care Act.

Tomorrow, I will send a letter to each Governor reminding them of these tools and asking them to report to me on their State's efforts to implement *Olmstead*, and to share their best practices, and to let me know if there are additional things the Federal Government can do to assist them in their efforts to comply with the ADA's integration mandate.

I just want to point out that the new GAO report says that Mississippi spends the lowest amount of any State on home and community-based services as a percentage of their total Medicaid spending on long-term services, 14.4 percent; the highest was New Mexico at 83 percent; everybody else is in between; and to share best practices.

We all come from different regions of the country. For instance, I am from Iowa. We tend to associate more with Nebraska, and Illinois, and Missouri, the States around us. Here is Alabama doing a very good job, right next door to Mississippi and Louisiana, which are way down there at the bottom. I am hoping your Governor will reach across, and start working that region, and showing people what can be done.

I might add that my charts show me that Alabama and my State of Iowa are pretty close to the same, but we are not the best, but we are doing better. We are somewhere between 25 and 49 percent right now. But I am asking that the GAO release this study today so that people will know where they are.

I really do want Governors to tell us what their best practices are, and to reach across State lines to let others know what they can accomplish.

I thank you all very much for what you are doing.

We will leave the record open for 10 days to allow additional statements, or supplements, to be submitted for the record.

I thank you for coming here early because, I see now, our time has run out, and we have to get over and start voting. So thank you very much.

The committee will stand adjourned.

[Additional material follows.]

ADDITIONAL MATERIAL

PREPARED STATEMENT OF THE NATIONAL DISABILITY RIGHTS NETWORK

The National Disability Rights Network (NDRN) would like to thank Senator Harkin, Senator Enzi and the members of the Senate Committee on Health, Education, Labor, and Pensions for holding a hearing on the topic of enforcement of the U.S. Supreme Court's decision in *Olmstead v. L.C.*¹

NDRN is the national membership organization for the Protection and Advocacy (P&A) System, the nationwide network of congressionally mandated agencies that provide legally based advocacy services to individuals with disabilities. A P&A agency exists in every State, the District of Columbia, Puerto Rico, and territories (Guam, U.S. Virgin Islands, American Samoa, and Northern Marianas Islands). P&A agencies have the authority to provide legal representation and other advocacy services, under Federal statutes, to all people with disabilities. Collectively, the P&A System is the largest provider of legally based advocacy services to persons with disabilities in the United States.

Since the Supreme Court ruling, the P&A System has been a leader in enforcement efforts of *Olmstead v. L.C.* in the United States. The unique role that the P&A System plays in the Federal enforcement scheme was recognized by the 7th Circuit Court of Appeals, which stated in a case involving the Indiana Protection and Advocacy Service (IPAS) that “the special Federal responsibilities it carries out, and the direct Federal funding it receives, IPAS is closer to being a specialized agent of the Federal Government for these purposes than it is to being an ordinary State agency.”² Furthermore, the U.S. Department of Justice has recognized the P&A System has “a central role in ensuring that the rights of individuals with disabilities are protected, including individuals' rights under title II's integration mandate.”³

As the U.S. Department of Justice stated on the 10th anniversary of the *Olmstead* decision, and remains true today, the “the goal of the integration mandate in title II of the Americans with Disabilities Act—to provide individuals with disabilities opportunities to live their lives like individuals without disabilities—has yet to be fully realized.”⁴ In March 2011, President Obama met with Ms. Curtis, who was one of the lead plaintiffs. Ms. Curtis has multiple disabilities, and was finally given the opportunity to live in the community, 11 years after the Supreme Court issued the decision. Today, Ms. Curtis sells artwork and lives in her community.⁵ Unfortunately, not all persons with disabilities are afforded the same opportunity. For example, according to State of the States in Developmental Disabilities (2011), although the number of individuals with developmental disabilities served by public and private institutions for 16 or more people has decreased, 92,300 people remain institutionalized in these facilities.⁶

NDRN is pleased that Disability Rights Oregon (DRO), the Oregon P&A agency, has taken the lead in a recent innovation in the area of enforcement of *Olmstead*, through the class action lawsuit of *Lane, et al. v. Kitzhaber, et al.* CV-00138-ST (D. Or.). DRO argued on behalf of the class plaintiffs that the *Olmstead* decision should be applied when persons with disabilities are unnecessarily segregated in work that denies persons with disabilities the opportunity to interact with persons without disabilities because of the way employment supports are managed and funded in the State. The class plaintiffs were individuals with intellectual or developmental disabilities that live in the community; are eligible for services from the Oregon Department of Human Services; and are able to and would prefer to work in integrated employment opportunities. Although, the court dismissed the complaint with leave to amend it, in the decision, the court held that *Olmstead* applies to the State's provision of integrated employment services (or failure to provide them).

¹ *Olmstead v. L.C.*, 527 U.S. 581 (1999).

² Indiana Protection and Advocacy Services, 603 F.3d 365 (7th Cir. 2010), cert. denied, 563 U.S. 6 (April 25, 2011).

³ U.S. Department of Justice, “Technical Assistance Guide”, available at http://www.ada.gov/olmstead/q&a_olmstead.pdf.

⁴ U.S. Department of Justice, “Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*”, available at http://www.ada.gov/olmstead/q&a_olmstead.htm.

⁵ See U.S. Department of Justice, “On Anniversary of *Olmstead*, Obama administration Re-commits to Assist Americans with Disabilities”, available at <http://www.whitehouse.gov/the-press-office/2011/06/22/anniversary-olmstead-obama-administration-recommits-assist-americans-dis>.

⁶ David Braddock, Richard Hemp, Mary C. Rizzolo, Laura Haffer, & Emily Shea Tanis, THE STATE OF STATE IN DEVELOPMENTAL DISABILITIES 51 (Colo. U. ed., 2011)(1977).

NDRN and the P&As believe that while it is important to continue to focus on the enforcement of *Olmstead* to ensure persons with disabilities are living in the community and not in institutions, part of this enforcement effort must include ensuring that communities are safe and provide the services and supports the person needs as they transition from institutions to community living. During the closing of the last public institution for persons with developmental disabilities in Alabama, the Alabama Disability Advocacy Program (ADAP) took a strong advocacy role in working with the State to ensure that the residents of this institution were transitioned into the community where they were going to receive the services and supports they required, and necessary followup was provided to ensure they were safe and receiving these services and supports once they were living in the community. NDRN commends the partnership between the State and ADAP and would strongly suggest that this community monitoring partnership be continued throughout the country.

Last, NDRN believes it is important in the context of discussing the enforcement of *Olmstead* to address the concerns of some that the concerns and opinions of guardians and family members are not being properly considered in either class action lawsuits or U.S. Department of Justice settlement agreements. Contrary to that opinion, current judicial rules provide opportunities for all parties to have the chance for their voices to be heard in a fair and reasonable manner by providing the ability to intervene in a case action lawsuit as well as the opportunity to have their voices heard at mandatory fairness hearings at the conclusion of litigation. Class-action litigation is a cost-effective way to ensure that a group of individuals that are similarly situated are able to pursue the enforcement or protection of their civil rights. Two recent examples from Illinois and Virginia show that the current rules work in a fair and just manner, and do not require legislative change.⁷

NDRN and the P&A System stands ready to work with Congress and Federal agencies to ensure the strong enforcement of *Olmstead v. L.C.* We would be happy to provide more information about the work that the P&A System has done to advocate for people with disabilities in regards to community integration.

ADAPT COMMUNITY,
JULY 6, 2012.

Health, Education, Labor, and Pensions Committee,
U.S. Senate,
Washington, DC 20510.

DEAR CHAIRMAN HARKIN, RANKING MEMBER ENZI AND MEMBERS of the HELP Committee: ADAPT is a national grass-roots community that organizes disability rights activists to assure the civil and human rights of people with disabilities to live in freedom. We are submitting this written testimony on behalf of the ADAPT Community and the many thousands of people with disabilities who want to have a REAL CHOICE so that they may live full and productive lives in the community.

ADAPT respectfully submits this written testimony in response to the recent committee hearing, "*Olmstead* Enforcement Update: Using the ADA to Promote Community Integration" (June 21, 2012).

The 1999 U.S. Supreme Court Decision in *Olmstead v. L.C. and E.W.* was a landmark decision that recognized the right of people with disabilities to live in the community instead of being locked away in institutions. This decision represents the promise of freedom for Americans with disabilities, but it has become clear that this will be an empty promise without adequate enforcement and CMS policies that require States to implement this decision.

The Supreme Court correctly noted that the:

"[i]nstitutional 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"

and "institutional confinement severely diminishes individuals' everyday life activities." *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 583 (1999). While the Supreme Court's words are powerful, ADAPT believes that the REAL VOICES of people who have been or are still trapped in institutional settings are critical to understanding this issue.

⁷ See *Ligas, et al., v. Hamos, et al.*, No. 05 C 4331 (N.D.I.L. June 15, 2011)(final consent decree), available at http://equipforequality.org/resourcecenter/LigasConsentDecreeSigned_06152011.pdf; *U.S. v. Va.* No. 3:12 CV 059 (E.D. VA, June 2012).

Jeff Arrison, Corning, NY

Jeff was preparing for college when he had a single car accident in 1980. This resulted in him becoming a quadriplegic. From age 20 onward Jeff would pretty much be in Medicaid institutions.

He had been planning on completing his education, getting a job, getting married, and having children. Medicaid institutionalization ended this plan. Although he made over one dozen serious attempts, he never was able to "break free" from Medicaid's grip. Even when his counselor said to him "we will get you out of that nursing home," he remained there.

Jeff knew that he was capable of managing an apartment because for a while he had an apartment of his own from 1981-84. Due to the fact that Social Security and Medicaid and the State of Massachusetts did not live up to their word about available community services, he returned to institutionalization and was never able to "escape" again.

Right now Jeff is institutionalized in Founder's Pavilion Nursing Home, a very inappropriate place for him, but the only place available in his hometown of Corning, NY. He "rots" there with little hope of returning to society.

His day begins at approximately 10:30 (he says any nursing home is pleasant when you are asleep, so he tries to sleep as much as possible.) After getting morning "hygiene" he exists by having lunch (he worked in kitchens before his accident so he knows what kitchens are capable of, this kitchen doesn't even try). Adequate nutrition is maintained by "junk food." After lunch he gets through the afternoon by watching boring television, napping, etc. Keeping him appropriately entertained would be impossible if it were not for his relatives pooling their efforts and purchasing him a computer to keep him busy (when he asked the State to help him finance the computer they said, "No"). Then another meal of inadequate dinner is served. Followed by doing the days business (like correspondence) and more television. This is followed by his evening "hygiene" at approximately 10:30. Then at approximately 1:30 a.m. he goes back to sleep.

He has had to endure such things as broken and dislocated bones, inadequate doctors care, physical "forcing," unpleasant social care, medications that is prescribed or requested being often more than 1-hour late without immediate correction. After many years of non-action about "problems", he has come to the conclusion that Medicaid institutions "just don't care."

Paula Barton, Rochester, NY

My name is Paula Barton. I am a 28-year-old disabled female. After going to emergency with chest pain, I was sent to a nursing home. They told me I could not return to my apartment because I could not get any Nurses Aide service to get me in and out of bed. I was there for 4 months.

During my stay in the nursing home, the experience was not good. Here are some of the reasons why. The hospital was not geared for a young person. I could not move freely and I had to be signed out by a person who was not in a nursing home. I had no independence.

I did have one good experience. The social worker was a young woman. She understood what I was going through. She started a month after I arrived there. Together we found an agency that would give me aide service. I am now home after 4 months. I have 20 hours of aide service and I'm doing very, very well.

Barrie Berliner, Gloversville, NY (Institutionalized for 1 Year)

I, Barrie Berliner, was in a nursing home because I fell off a balcony and the nursing home was not a place for me to spend the rest of my life. With financial supports funded by the Department of Health, I moved into a house with a few housemates where the care is great. I have my own room with my own things, help to cook my own meals and I have all my workout equipment in the living room and it is basically my own home.

At the nursing home, I had room assigned to me and there were elderly people there and it was very regimented. Being a spontaneous person, I couldn't go out with my friends. It was very strict, there were strict rules and I hated it there. I felt almost dead. It was because of the physical therapy at Lexington, I can walk by myself and before, I couldn't walk by myself, I couldn't transfer. I needed a lot of help. Now I need no help. I am so independent. I couldn't even take a shower before. Now, I can take a shower by myself and I can take a shower everyday. Lexington Center has done wonders for me. They've done so much. There is personal help. Instead of being fed, they taught me how to feed myself, which in the long

run, made me feel great. Nobody wants to be fed for the rest of their life. Independence is great.

I am a true testimony of what not living in a nursing home can do for you. Do they want to be waited on or do they want a free independent life? A choice of freedom. This is America.

Marie Brawn, Eastern, KY (*Institutionalized for 20 Years*)

I was born in Eastern, KY in 1953. I have Cerebral Palsy. It affects my limbs and speech. I was institutionalized from age 2 until 27. I will tell you of things that happened to me during this time. I was drugged so I wouldn't talk about what I heard or saw. I saw physical abuse. People were being hit. I went to school wearing dirty clothes. I had to wait a long time for help to the bathroom. I had very little privacy, even when talking on the phone or to my priest.

Some of the aides would make fun of me.

Things are now changed for me. I have been out for 23 years because my second husband got me out after a big fight. He died in 1994 from a heart attack. Then with the assistance of personal attendants, I learned to live on my own. I have a part-time job working for the Salvation Army collecting money. I have a pet cat named Shadow. As a child in an institution, I could never have a pet.

I know a lot of people in institutions who want and need to get out. It would cost the Government less to keep us in the community. I am glad to be out and to have more freedom. I can be my own boss.

Kurt Breslaw, Boulder, CO (*Institutionalized for 15 Years*)

You don't live in a nursing home; you only exist in a nursing home. I love living in my own house. I get better care in my own home than I ever did in the nursing home.

Ella Dil, Gallup, NM (*Institutionalized for 33 Years*)

I went to Los Lunas institution, then to Ft. Stanton institution, then to Santa Rosa group home, then to the MASH group home in Gallup.

I never came home for Christmas or Thanksgiving. I was sad and very scared living in these places. I wanted to be with my family growing up, not in institutions.

I have had my own apartment for years. I live by myself. I pay my own rent and pay for my food, and everything else I want. I work at Subway. I have worked there for many years. Now, I visit with my family on Christmas, Thanksgiving and when I want to on weekends.

Paul Dorenkamp, Chesterfield, MO (*Institutionalized for 2½ Years*)

I have been living with MS for over 10 years. I'm unable to walk and care for myself. When my care became too burdensome for my wife to care for me, I was placed in this nursing home. Since I arrived at this place, I've been sexually and physically abused. My needs and wants are ignored and neglected on a daily basis. I want to go home and live with my family. I want to watch my children grow up, because of the current Medicaid policies I'm trapped and imprisoned in this nursing home.

Katy Hoffman, Denver, CO

I felt bad. I didn't want to be there. I cried all the time. I feel independent being on my own.

Robert Fesel, Robbinsville, NJ (*Institutionalized for 11 years*)

I am a man with Cerebral Palsy. In my life I have lived in a boarding home, a developmental center, and three group homes. I have been restrained, starved, burnt with cigarettes, and abandoned for dead.

I use a wheelchair and I communicate via an electronic language board called a Liberator. Technology has changed my life. I now live in a condominium and work with preschoolers. I work as a volunteer to help other people move out of developmental centers.

I have my freedom.

I ask you if one of your daughters had a disability would you put her in an institution. PLEASE, PLEASE help us get people out of institutions and help get institutions out of our great Nation.

Sheila Dean, Denver, CO (*Institutionalized for 2 Years*)

I was 28 years old in a nursing home, and had a 7-year old son. I got out when I was 30, and I wouldn't trade my freedom for anything!

Nathaniel Gates, Rochester, NY (*Institutionalized for 3 years*)

My name is Nathaniel Gates and I have Multiple Sclerosis. In 1999 while living independently, in Rochester, NY, I found out I needed spinal surgery. After my operation, I was sent to Monroe Community Hospital for rehabilitation. Following my rehab, I waited to return home. I was then told I could not live on my own because I couldn't walk. They told me I was unable to get aides to take care of me through a traditional Home Health Care Agency. For this reason I ended up staying at Monroe Community Hospital for the next 3 years. Living at the hospital was a big disappointment. It was very depressing and I felt the whole world was passing me by.

The Center for Disability Rights has helped me to get an apartment. I have hired my own aides and live independently. I'm happier now and I'm my own boss again. It's like being on top of the world.

Rick James, Denver, CO (*Institutionalized for 5 years*)

It was fucking hell, and it is better in my own home.

Herb Larkins, Philadelphia, PA (*Institutionalized for 5 years*)

I was robbed of my freedom to come and go as I pleased. They took away my dreams and independence and what I was capable of doing. I was robbed of my privacy and my ability to have company when I wanted it. They took away my right to speak up for myself and to speak my mind.

These are the voices and stories of Americans with disabilities who have been forced to give up their freedom and many of their rights in order to get the personal assistance services they need to live. These are the voices that must be heard. While parents and providers may have their points of view, ultimately, the *Olmstead* decision is about these individuals who have been or still are institutionalized. While each of these people have their own individual stories and experiences, they all agree that they would rather be in their own home in the community—like every other American—rather than locked away in institutions.

ADAPT acknowledges the efforts of the Department of Justice under the Obama administration to enforce the *Olmstead* decision, however, we are concerned that *Olmstead* enforcement has been driven by key personnel within the Obama administration and *Olmstead* compliance is being determined on a case-by-case basis. Because compliance is determined on a case-by-case basis, there are no clear benchmarks for States that set the minimum standard for *Olmstead* compliance. Inevitably, the administration will change, and we are concerned that the gains we have made over the past few years will be quickly lost.

ADAPT has developed a list of issues to consider when developing benchmarks for *Olmstead* compliance related to people with disabilities who are institutionalized in nursing facilities or are at imminent risk of institutionalization in nursing facilities.

This list is attached at the end of this testimony. ADAPT acknowledges that minimum standards often become the maximum that can be expected. However, ADAPT believes that there is an even greater risk of allowing *Olmstead* compliance to be defined in the current manner which can continually be reinterpreted. This is particularly concerning in the context of State budget crises and initiatives to limit Federal Medicaid spending. We urge the Office of Health and Human Services to work with the Department of Justice, ADAPT, and other advocates for community living to develop specific benchmarks for *Olmstead* compliance. Once developed, HHS could require States to report on these benchmarks and pursue enforcement with DOJ where needed.

We have also noted that existing enforcement measures have largely focused on individuals with developmental disabilities, intellectual disabilities, and mental health disabilities and the issues of older Americans and Americans with physical disabilities who face institutionalization in nursing facilities have been largely unaddressed. This is due, in large part, to how funding for advocacy and enforcement have been established. Enforcement efforts have been driven by funding for the Protection and Advocacy system which has significant resources devoted to addressing the needs of people with developmental, intellectual and mental health disabilities. This leaves the rights of individuals with disabilities who are locked away

in nursing facilities, or at risk of being forced into nursing facilities, largely unprotected.

This emphasis in enforcement is reflected in the spending patterns of States that have begun to re-balance their systems for serving people with developmental and intellectual disabilities while re-balancing of nursing facility spending with the home and community-based alternatives has significantly lagged. There needs to be a stronger emphasis on *Olmstead* enforcement in this area.

Because traditional enforcement systems have not adequately addressed this issue, Centers for Independent Living have taken on the charge. Unfortunately, we are seeing a recurring trend that the Centers which have worked to enforce the *Olmstead* decision face significant retaliation.

For example, in Rochester, NY, the local Center for Independent Living—the Center for Disability Rights (CDR)—had assisted individuals in filing *Olmstead* complaints because people in nursing facilities were unable to access home and community-based services. Basically, the local county was failing to assess these individuals for services in a timely manner, and people were waiting months in nursing facilities to even be initially assessed for services in the community. Approximately 88 *Olmstead* complaints were filed. In response to this effort, in July 2010, Monroe County abruptly ended its contract with CDR to serve as a fiscal intermediary of Consumer Directed Personal Assistance Services and publicly attacked the organization in the media.

More recently, in Kansas, Centers for Independent Living assisted individuals in filing literally hundreds of *Olmstead* complaints because of the growing waiting list for home and community-based services. Since filing these complaints, the centers have seen the reimbursement rates for Consumer Directed Services slashed and found their credibility under public attack by the State. This has been a statewide response by the State and has affected many independent living centers. Although the disability rights community is becoming increasingly aware of the threat of retaliation against centers that are working to enforce *Olmstead*, there has been little notice of this issue by the U.S. Department of Justice which leaves the retaliation to continue unchecked.

To address these concerns, it is imperative that the Protection and Advocacy network begin to systematically use Protection and Advocacy for Individual Rights funding to address *Olmstead* compliance for older Americans and those with physical disabilities in nursing facilities or at risk of placement in nursing facilities. We also urge the Department of Justice to focus on *Olmstead* enforcement for people with physical disabilities and elderly people who are trapped in or at risk of being forced into nursing facilities. The Department of Justice, perhaps working in conjunction with the Protection and Advocacy system, can make significant progress by focusing on a few high profile nursing facility cases in order to set precedent and send a clear message that people with physical disabilities and the elderly are also covered by *Olmstead*. Additionally, DOJ must begin to address the retaliation that has occurred against Centers for Independent Living that have advocated for *Olmstead* compliance.

Another lesson learned from the Kansas experience is that there is extremely limited enforcement available through Health and Human Services (HHS) and that pursuing enforcement through the HHS Office for Civil Rights actually delays justice for individuals who are institutionalized against their will or face unwanted institutionalization. In Kansas, advocates filed literally hundreds of *Olmstead* complaints with the HHS Office for Civil Rights. Although HHS/OCR tried to address these complaints with the State, the State of Kansas refused to resolve the compliance issues. Although HHS could have withheld Medicaid funding from the State as an enforcement mechanism, it instead referred the case to the Department of Justice. Advocates didn't realize that DOJ could not simply pick up the case where HHS/OCR left off. DOJ is unable to use the investigative work that had previously been done by HHS/OCR. Instead, DOJ is required to do its own investigation. Consequently, the Kansas advocates are now being required to submit even more complaints directly to DOJ and must start the entire process again. This is an incredible waste of time that is delaying justice for Kansans with disabilities who need home and community-based services to live independently.

Although HHS has said that it is unwilling to withhold Medicaid funding from the States as a method to force *Olmstead* compliance, it has in fact done so with Medicaid funding for family planning. When Texas refused to contract with Planned Parenthood, CMS withheld its Medicaid funding for family planning services. Given this precedent, HHS should withhold Medicaid funding for institutional placement if a State is unwilling to provide adequate home and community-based services in compliance with the *Olmstead* decision. CMS has demonstrated that it has the au-

thority to do this. The agency should use this authority to leverage the changes needed to assure *Olmstead* compliance.

In light of the 13th anniversary of the *Olmstead* decision, which determined, in accordance with the Americans with Disabilities Act's integration mandate, that long-term services and supports must be provided "in the most integrated setting appropriate to the needs of qualified individuals with disabilities," it is imperative to take stock of how far we have come and where we need to go.

Since the inception of Medicaid in 1965, there has been an institutional bias: nursing facility services are mandatorily covered while community-based alternatives to institutionalization remain optional. Despite over 20 years of advocacy, this bias remains today. Perhaps the most significant movement forward toward ending the institutional bias in Medicaid, is the creation of the Community First Choice (CFC) Option, which passed as part of the *Affordable Care Act*. We commend Senator Harkin and Senator Schumer for championing this Option and securing its place in the historic healthcare legislation.

The Community First Choice Option is a community-based Medicaid State plan service which includes hands on assistance, safety monitoring, and cueing for assistance with activities of daily living, instrumental activities of daily living, and health-related functions based on functional need, not diagnosis or age. Although not a national mandate, States were given the option to select CFC with the incentive of enhanced Federal assistance. This financial incentive has been the impetus for several States (including California, New York, Maryland, and Alaska, to name a few) to move forward with CFC implementation. If done correctly, CFC will have a significant impact on States' systems for providing Medicaid long-term services systems and could potentially allow millions of Americans with disabilities to avoid unwanted institutionalization or transition out of institutions into the community.

Because it was enacted as an option under the Medicaid State Plan, States must select the option in order to eliminate the institutional bias so there are still significant barriers to full community integration and the promise of the *Olmstead* decision. Perhaps the most significant barrier is the fiscal crises at the State level and the efforts to curtail Federal spending on entitlement programs like Medicaid. As States face unprecedented budget deficits, many are cutting Medicaid home and community-based services. Disability rights advocates continue to propose thoughtful budget solutions that contain Medicaid spending and increase community integration and independence. As an example, advocates in New York offered budget proposals that would advance the *Olmstead* compliance and reduce New York's Medicaid budget by \$1B over 5 years. Yet these proposals are not the solutions States implement. Rather, States all across the country are making drastic cuts to home and community-based services and supports, the very programs that support people with disabilities living independently in the community. At greatest risk are people with the most significant disabilities who are rightfully fearful that they will end up institutionalized when their services are cut.

Where States are not directly cutting services, they are implementing managed care to reduce Medicaid spending. While the potential exists for managed care to more efficiently use existing funds through the coordination of services and supports, advocates worry that this is actually a thinly veiled approach to cutting services. Even though States can use managed care to eliminate the institutional bias, some States may be actually reinforcing that bias because they control access to home and community-based services through managed care but leave institutional placements in the traditional fee-for-service system. With inadequate or poorly structured rates, this approach could lead to people with significant disabilities being forced into institutional placements against their will. HHS is in a position to evaluate the State proposals and assure that States do not force individuals into unwanted institutionalization. Although CMS has the authority to do this, it has not exercised that authority sufficiently and States continue to implement proposals that promote institutionalization with the approval of CMS. It is imperative that CMS acknowledge that States must comply with *Olmstead* as part of their approval process and CMS refuse to authorize proposals that undercut the right of Americans with disabilities to live and receive services and supports in the most integrated setting.

Finally, although CFC creates a system for providing long-term services and supports based on functional need, it is only part of the solution. Despite all of the efforts to make home and community-based services available to individuals with disabilities, institutional placement is still mandatory and home and community-based services are only optional. Despite the Supreme Court's findings that "[i]nstitutional placement . . . perpetuates unwarranted assumptions that [people with disabilities] are incapable or unworthy of participating in community life" and "institutional confinement severely diminishes individuals' everyday life activities" our Nation's Med-

icaid policy still forces Americans with disabilities into institutions. For the promise of Supreme Court's *Olmstead* decision to be real, it is up to Congress and the Administration to end the institutional bias and FREE OUR PEOPLE!

ATTACHMENT

Issues to consider when developing benchmarks for *Olmstead* compliance related to people with disabilities who are institutionalized in nursing facilities or are at imminent risk of institutionalization in nursing facilities.

1. Number of people transitioned out of NH and into HCBS A/D waivers. Has it increased, decreased, remained the same per year?
2. Number of people diverted from entering NH and instead received HCBS A/D services. Has it increased, decreased, remained the same per year?
3. Length of time people wait to transition out of NH. Increased? Decreased? Remain the same?
4. Number of people State *requested* approval to serve in HCBS A/D waivers?¹ Have the numbers increased decreased, remained the same per year?
5. Length of time people wait to receive HCBS to prevent institutionalization NH. Increased? Decreased? Remain the same?
6. Numbers of people *actually served* in HCBS A/D waivers? Have the numbers increased, decreased, remained the same per year?
7. Change in *per capita* expenditures for NH Institutionalization vs. Integrated Community-Based Services for A/D by year?² How do the increases or decreases compare between NH and HCBS?
8. Change in percent of LTC for Institution vs. Integrated in Community? Is there any indication of "re-balancing"?³ How do the increases or decreases compare between NH and HCBS?
9. Change between dollar increases in MA per diem NH payments vs. community MA per diem expenditures? Have the per diem increased, decreased, remained the same per year? How do the increases or decreases compare between NH and HCBS?
10. Does Medicaid agency use MDS data or other mechanism to transition people out of nursing homes who have expressed a desire for integrated placement? Does Medicaid agency identify people in NH who want to leave?
11. Does the Medicaid agency have a process for tracking people who are unable to gain access to HCBS services (e.g., waiting list management and protocols for both people in NH and in the community)?
12. Does the Medicaid agency have a process to update and maintain its waiting list on a timely and periodic basis?
13. Does Medicaid agency have a formal procedure to offer HCBS before people go into NH?
14. How many or percent of people who were admitted to NH with no HCBS services offered before institutional admission?⁴
15. How many or percent of people who were admitted to NH had been offered some HCBS before admission?⁵
16. Has the Medicaid agency developed and implemented a single entry point or one-stop system of access for all [institutional and community-based] MA LTC?
17. Has the Medicaid agency revised and consolidated its MA LTC under the direction of one agency with regards to budgetary, programmatic and oversight responsibility for institutional and HCBS services? If not, does the Medicaid agency have any barriers to transfer MA funds from NH line budget to community line budget? If yes, has Medicaid agency ever done so?
18. Does Medicaid agency have a mechanism to prevent acute care hospitals from discharging people directly into NH?⁶

¹This will require a review of States' waiver applications. If a State has not requested increases in approved waiver "slots," regardless of whether the State either receives funds for these slots or even fills the slots, there will not be increases in people served in the A/D waivers.

²DOJ could use data from fiscal year 2000 as a base and compare to most recent data, fiscal year 2008. Data for these benchmarks is available from Medstat, Kaiser and MDS, and CMS Nursing Home Data Compendium.

³CMS at the time of the MFP wrote that a "measurable benchmark" in re-balancing was "a percentage increase in home and community-based services versus institutional long-term care expenditures under Medicaid for each year of the demonstration program."

⁴MDS (Table AB2) provides data by Medicaid agency re-admissions to NH.

⁵Ditto. This data is important to determine if institutionalization would have occurred if more services had been offered? Whether the number of admissions could be reduced depends in part on the amount of home health services actually received and needed to stay at home.

⁶Ditto.

19. Does the Medicaid agency—as distinguished from the NH—have and use an uniform assessment policy/procedure/form at admission to divert people from institutionalization? Does the Medicaid agency—as distinguished from the NH—have and use an uniform assessment policy/procedure/form at regular intervals during NH residence to determine what services the person may need or request to be integrated in the community?

20. Does the Medicaid agency have a formal procedure to inform MA residents in NH and before admission to NH of both availability of integrated services and to assess specifically what services person might need?

21. Has the Medicaid agency reduced MA expenditure payments? If yes, has Medicaid agency reduced HCBS while leaving NH program expenditures at status quo, increased, or proportionately reduced?

22. Does the Medicaid agency use lack of care for medical tasks as a basis to deny HCBS?

23. Has the Medicaid agency revised its nurse and/or physician delegation/assignment statutes to allow medical and health maintenance tasks (e.g., bowel and bladder care, medication management, trach/vent care) to be performed by qualified unlicensed persons?

24. Does the Medicaid agency use “lack of housing” as a basis to deny HCBS?

25. Has the Medicaid agency developed and implemented relationships with State/local housing departments in order to coordinate LTC and services in affordable and accessible housing? Does the Medicaid agency use “lack of housing” as a basis to deny HCBS?

26. Has the Medicaid agency developed and implemented policies and programs that support informal caregivers and consumer directed care.

27. Does the Medicaid agency use a “too risky” criteria as a reason to deny community services?

28. Does the Medicaid agency require “informal care” as a reason to deny community services?

29. Does the Medicaid agency use an aggregate or individual cost basis in it's A/D waivers? If the latter, does the Medicaid agency provide for reasonable modification in waiver services to meet the needs of people with the most severe disabilities?

30. Is there a process/staff/contract to identify and assist people who are in NH and choose to transition to a community setting.

31. Is there a shortage of community workforce personnel due to low wages/benefits that restricts the States ability to serve people in the community?

32. Is there a rate setting policy that is consistent both for HCBS and NH programs, *i.e.*, higher inflation factor for one vs the other?

33. Do nursing home waiver package of services and/or cost cap meet the needs of people with significant needs who choose to remain in the community?

JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW,
WASHINGTON, DC 20005-5002,
July 6, 2012.

U.S. Senate,
Committee on Health, Education, Labor, and Pensions,
428 Senate Dirksen Office Building,
Washington, DC 20510.

Re: *Olmstead* Enforcement Update: Using the ADA to Promote Community Integration

DEAR CHAIRMAN HARKIN, RANKING MEMBER ENZI AND MEMBERS of the Senate Committee on Health, Education, Labor, and Pensions: The Judge David L. Bazelon Center for Mental Health Law submits this testimony for the record of the June 21, 2012 hearing on *Olmstead* enforcement efforts. The Bazelon Center is a national non-profit organization dedicated to advancing the rights of all individuals with mental illnesses or intellectual disabilities to exercise their own life choices and have access to the resources that enable them to participate fully in their communities.

At the June 21 hearing, Assistant Attorney General for Civil Rights Thomas Perez testified that the Department of Justice has prioritized *Olmstead* enforcement over the last 3 years, becoming involved in more than 40 *Olmstead* matters in 25 States. The Bazelon Center applauds the Department's dedicated effort to achieve increased home- and community-based care for individuals with mental disabilities. This represents an important commitment to end the unnecessary segregation of individuals with disabilities in our country.

Community living improves the lives of people with mental disabilities. It leads to independence; strengthens self-care and social and vocational skills; and correspondingly decreases challenging behaviors. Improved service and treatment approaches allow providers across the country to serve successfully individuals with serious mental illnesses and profound intellectual disabilities—including those with the most complex medical needs and challenging behaviors—in integrated, home- and community-based settings. As detailed in the *amicus brief* submitted by the National Association of State Directors of Developmental Disabilities, the American Association of Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities, and others in support of the Settlement Agreement in *United States v. Virginia*,¹ States have significantly expanded community services, successfully phased out institutions, and safely transitioned residents of large institutions to the community.

Ricardo Thornton, the formerly institutionalized self-advocate who testified before this committee at the June 21 hearing, has made significant and lasting contributions to his community and his country. Individuals without Mr. Thornton's wisdom and skills can also enjoy a safe and fulfilling life in the community. With individually tailored services and person-centered planning, virtually anyone—including those who need round-the-clock care—can live successfully in the community. In fact, more than 1.2 million individuals who qualify for an institutional level of care currently receive services in home- and community-based settings through section 1915(c) waivers, including more than 500,000 individuals with intellectual disabilities.² Unfortunately, however, the majority of Medicaid long-term care dollars is still spent on outdated and unnecessary institutional care, leaving hundreds of thousands of individuals on waiting lists to receive services in integrated, home- and community-based settings.³

Advocates for institutional care have expressed concerns about the Department of Justice's collaboration with States to phaseout institutions in accordance with *Olmstead*. In written testimony submitted to this committee, VOR cites several examples of high-needs individuals whom it believes require "24/7 care." These individuals may in fact need such care, but without question it can be provided in home- and community-based settings. Given our Nation's success in serving individuals with comparably high needs in community settings,⁴ there is every reason to believe that the nine individuals profiled by VOR could be served in a more integrated setting, and that these individuals might experience improvements in their health and behaviors outside of an institutional setting.

It is a tragic reality that individuals with disabilities often become victims of abuse and neglect. Advocates for institutional care frequently cite deplorable instances of abuse and neglect that occur in the community. But abuse and neglect of individuals with disabilities is rampant in institutional settings as well,⁵ and the appropriate response is greater oversight of providers and caregivers regardless of their location. As such, the Department of Justice has taken great care to insist on improved oversight, accountability and quality management in the States where it is working to transition individuals from institutions to integrated settings.

Finally, in its written testimony, VOR calls for a hearing and reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act ("DD Act"), presumably to attempt curtail by amendment the investigation, representation, research and advocacy activities of State Protection & Advocacy organizations (P&As), University Centers of Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), and the Councils on Developmental Disabilities (CCDs). These organizations responsibly and effectively discharge their statutory duties to accomplish the central purpose of the DD Act—to "assure that individuals with de-

¹ See *United States v. Commonwealth of Virginia*, 3:12-cv-00059, Docket No. 52 (April 5, 2012).

² Kaiser Commission on Medicaid and the Uninsured, *Medicaid Home and Community-Based Services: Data Update* 35, Table 4, at <http://www.kff.org/Medicaid/upload/7720-05.pdf> (December 2011).

³ *Id.* at 10. Individuals with intellectual disabilities comprise 63 percent of those on the waiting list for home- and community-based services.

⁴ See Br. for Nat'l Ass'n of State Dir. of Developmental Disabilities, *et al.*, *supra* note 1.

⁵ See, e.g., Danny Hakim, *State Faults Care for the Disabled*, *New York Times*, Mar. 22, 2012, at A1, available at <http://www.nytimes.com/2012/03/22/nyregion/new-york-state-draft-report-finds-needless-risk-in-care-for-the-disabled.html?pagewanted=all> ("At the large institutions overseen by the Office for People With Developmental Disabilities, the report found 119.68 abuse claims for every 100 beds."); Emily Ramshaw & Becca Aaronson, *Despite Reforms, Abuse Continues at Texas Institutions for Disabled*, *The Texas Tribune*, Oct. 23, 2011, available at <http://www.texastribune.org/library/data/abuse-neglect-texas-disabled-institutions/> (citing 2.21 allegations of abuse per resident in 2011 at Texas' 13 residential institutions for individuals with disabilities).

velopmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” 42 U.S.C. § 101(a)(17)(b).

Life in an institution does not permit “inclusion in all facets of community life,” such as social, educational and work activities. In contrast to institutional settings, where residents typically have regimented lives and little opportunity to learn independent living skills, community settings afford individuals the chance to learn to do things for themselves and develop greater independence, as well as the opportunity to make choices about matters such as what they eat, when they get up, how they spend their day, and with whom they spend it.

Given the DD Act’s primary focus on community inclusion, it is well within the authority of the agencies it created to advocate strongly toward this goal. Indeed, the Act charges CCDs to “engage in advocacy, capacity building, and *systemic change activities* that . . . contribute to a . . . comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.” *Id.* at § 101(b)(1) (emphasis added). State P&As are obligated to “protect the legal and human rights of individuals with developmental disabilities” by advocating for community inclusion. *Id.* at § 101(b)(2). And the UCEDDs are required by law “to strengthen and increase the capacity of States and community” to achieve community integration. *Id.* at § 101(b)(3).

The Bazelon Center and its many partners throughout the country have seen first-hand that individuals with mental disabilities, including those with the most complex needs, can live successfully in the community. Care in the most integrated setting appropriate is the right of all people with disabilities. For these reasons, and because such care is cost-effective, allowing States to provide care to more people, we will continue to advocate for the transfer of State and Federal dollars from institutional care toward care in integrated settings, consistent with the Americans with Disabilities Act and the Developmental Disabilities Assistance and Bill of Rights Act.

Thank you for the opportunity to provide testimony on these important issues, and for conducting the recent hearing on *Olmstead* enforcement.

Sincerely,

JENNIFER MATHIS,
JULIA M. GRAFF,
The Judge David L. Bazelon Center For Mental Health Law.

VOR,
June 28, 2012.

DEAR CHAIRMAN HARKIN, RANKING MEMBER ENZI AND MEMBERS of the HELP Committee, VOR respectfully submits this written testimony in response to the recent committee hearing, “*Olmstead* Enforcement Update: Using the ADA to Promote Community Integration” (June 21, 2012).

VOR is a national, nonprofit, advocacy organization representing individuals with intellectual and developmental disabilities (ID/DD) and their families. The vast majority of the people VOR represents are full-grown adults with the mental age of a newborn or 1-year old. They cannot care for themselves, many have never spoken, and they are the most medically fragile of our citizens.

Consistent with *Olmstead* and a myriad of Federal laws, VOR strongly supports a continuum of quality care options to meet the wide range of needs, ranging from family home, own home and other community-based options to Medicaid-licensed facility-based homes (ICFs/MR).

Individuals with ID/DD who rely on ICF/MR care do not have the capabilities of witness Ricardo Thornton, whose accomplishments since moving from Forest Haven Center more than 3 decades ago are impressive and heartwarming. His 34-year career working in the library, his happy marriage, his fatherhood, and his capable self-advocacy are all to be applauded. Years of aggressive deinstitutionalization have led to more appropriate, less-specialized services for former residents like Mr. Thornton. However, other affected individuals, as discussed below, have been met with preventable, predictable tragedy. The Supreme Court, in its *Olmstead* decision, expressly cautioned against interpreting its decision as a deinstitutionalization mandate, predicting such action would harm people:

“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings Nor is there any Federal requirement that

community-based treatment be imposed on patients who do not desire it.”—*Olmstead v. L.C.*, 119 S. Ct. 2176, 2187 (1999). *See also*,

“As already observed [by the majority], the ADA is not reasonably ready to impel States to phaseout institutions, placing patients in need of close care at risk . . . Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing on a case-by-case basis, that setting may be an institution”—[quoting VOR’s *Amici Curiae* brief.]” *Id.* at 2189.

Despite the clarity of the Supreme Court’s holding and its cautionary statement with regard to unjustified *community* placement, Federal and State officials continue to mischaracterize *Olmstead*, treating it as a mandate to close facilities without any regard for how individuals will be served. As indicated in his statement to the HELP committee, Thomas Perez, Assistant Attorney General, Civil Rights Division, Department of Justice, “The Court’s [*Olmstead*] ruling has often and properly been called the *Brown v. Board of Education* of the disability rights movement.” One VOR Board Member responded:

“Appropriate services, supports and placements are individualized and not necessarily ‘equal.’ My children would die if all that was available to them was what everyone else has available. With regard to level of disability, my children were not created equal. They need highly specialized 24/7 care.”

Mr. Thornton does not need 24/7 direct care supports. Imposing such care on him would not be appropriate, cost-effective or even humane. Consider, however, Aaron Underwood. Providing Aaron care “equal” to the supports received by Mr. Thornton would be a death sentence.

“**Aaron** was born 8 weeks prematurely in December 1979. While he survived the birth, the lifelong effects from subarachnoid and pulmonary hemorrhages are devastating. A large portion of his brain was destroyed with the subarachnoid hemorrhage. Aaron is profoundly neurologically impaired to the point that mental retardation is not even an appropriate descriptor. His functional abilities are in the 2–3 month range. Seizures, respiratory insufficiency, frequent pneumonias, cortical blindness, spastic tetraplegia with ever-increasing spasticity are just a few of the daily challenges for his caregivers. Aaron has no purposeful movement and does not reach for nor grasp objects. He will remain in the position he is placed until someone repositions him. He has no bowel or bladder control—undergarments will be required for the rest of his life. An incomplete swallow coupled with frequent aspirations necessitates a feeding tube for all nutrition and medications. He can, and has, choked on his own mucus, cutting off his airway. Aaron is non-mobile and when not in bed is positioned in a custom made wheelchair which accommodates the curvature of his body. Aaron is also non-verbal and cannot communicate his needs. Needs must be anticipated and proactively met.”—(“Meet Aaron Underwood,” 2011 by parents Kevin and Rebecca Underwood)

People with disabilities have wide-ranging, diverse, unequal *needs*. Equal *rights* does not mean that individualized, person-centered, supports are to be ignored. “Equal rights” must relate to access to individually appropriate and necessary supports, no matter the setting.

I. PREDICTABLE TRAGEDIES: THE PRESENT DAY DEINSTITUTIONALIZATION EXPERIMENT

Advocates and policymakers are familiar with the failed deinstitutionalization experiment of persons with mental illness. Homelessness and incarceration, even today, are evidence of our ongoing failure to provide specialized treatment for persons with mental illness. Despite these lessons learned with regard to the mental health community, people with ID/DD continue to suffer from the same failed experiment.

As recently as November 2011, the *New York Times* reported that “One in six of all deaths in State and privately run homes, or more than 1,200 in the past decade, have been attributed to either unnatural or unknown causes”—(November 6, 2011). The *Atlanta Journal-Constitution* found,

“Deficiencies in care, living conditions and recordkeeping have piled up in scores of Georgia personal care homes [35,000 violations], with the State rarely shutting down violators or levying heavy fines [in just 544 cases]”—(May 22, 2012).

A *Miami Herald* investigation found a string of “deaths [that] highlight critical breakdowns in a State enforcement system that has left thousands of people to fend for themselves in dangerous and decrepit conditions”—(May 1, 2011).

These tragedies, which are repeated in more than 25 States,¹ amount to reckless disregard for people with profound ID/DD who have met with tragedy while Federal and State officials figure out what went wrong. Consider these statements during the hearing by Thomas Perez and Zelia Baugh:

“It is so important to learn from the past. The deinstitutionalization movement of the 70’s—the profound mistake that was made was opening the doors of institutions when community infrastructure didn’t exist.”—Thomas Perez, Assistant Attorney General, Civil Rights Division, Department of Justice, June 21, 2012)

“If you look at our [settlement] agreements . . . we are building community infrastructure” so when someone is in crisis there are options other than jail or an emergency room.—(Perez, June 21, 2012)

“ADMH [the Alabama Department of Mental Health] has experienced three main challenges in its efforts to shift services to community settings: securing stakeholder buy-in, identifying and developing resources within provider organizations to serve persons with significant behavioral challenges or multiple medical needs, and negative stigma. While ADMH has developed strategies to overcome these challenges, long-term efforts will be needed to ensure continued success.”—(Zelia Baugh, Commissioner, Alabama Department of Mental Health, June 21, 2012)

A careful reading of these statements signals a profound lapse between the reality of “community integration” and the promise of community living. Time and again, deinstitutionalization is aggressively pursued *before* a “robust community infrastructure,” as described by Tom Perez, is in place. In the context of the mentally ill, Mr. Perez spoke about the support of some sheriffs’ groups for more community placements for people with mental illness to keep them from inappropriate placements in the jails—50 years after some pushed to close all the institutions for people with mental illness. **We must not repeat the same mistake for people with ID/DD.**

Mr. Perez says the Justice Department includes strong quality assurance provisions to prevent repeating this tragic mistake. For example, Justice Department officials have indicated that the proposed settlement agreement in Virginia includes a quality assurance provision modeled on best practices to include crisis centers and more. When pressed by VOR representatives, however, Justice Department officials acknowledged that this model community system is not in place in Virginia or anywhere, but is representative of a compilation of best practices from around the country. VOR and the members we represent do not dispute that is a well-intended plan, but it is only a *plan* and it is not in place for people to evaluate the results. Given the tragedies that have befallen fragile individuals with ID/DD who lack access to highly specialized care in communities around the country, there is little trust that a “robust community infrastructure” will actually materialize.

Consider, for example, Alabama. Partlow ICF/MR closed nearly 2 years ago, yet ADMH is still working on addressing care, safety,² and funding challenges. By Commissioner Baugh’s own admission, short-term funding is not assured (requests are pending), and financial sustainability beyond 2–3 years is of great concern:

“The challenge for Alabama is coming up with the match money for Medicaid. [We have applied for Affordable Care Act grants that would] assist us with a 90/10 match for the next 2–3 years, but after that looking for sustainability is where we have great concern.”—(Zelia Baugh, Commissioner, Alabama Department of Mental Health, June 21, 2012).

The mother of a former Partlow resident, who disputes Commissioner Baugh’s characterization of Partlow’s closure as a “success,” has tried desperately to remain in contact with the families of displaced Partlow residents:

“I am in touch with several parents and the disturbing patterns of abuse and the lack of money for personal needs is so hard to handle. One family must now travel 1½ hours to visit their daughter each day to be sure she is doing well. I know of nine residents who have died and four who are in jail. ADAP [Alabama Disabilities Advocacy Program] is supposed to be monitoring former residents but when I spoke to ADAP they were only aware of 2 deaths, including

¹See, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities, Rev. June 27, 2012 at <http://www.vor.net/images/AbuseandNeglect.pdf>.

²Commissioner Baugh also cites the State’s quality assurance agreement with Alabama Disabilities Advocacy Program (ADAP) as evidence that former Partlow residents are being watched over. Yet, ADAP, which strongly supported closure even while identifying lapses in community care before Partlow closed, received a lucrative (\$42,000) contract to oversee quality *after* it closed.

one individual who died in a nursing home. All former 151 residents were very fragile upon their move from Partlow. Although I have encouraged families to contact ADAP if they have any problems, families don't trust ADAP since they were instrumental in closing Partlow. It seems no one remembers that *Olmstead* stated on page 17 that residents, or their legal guardians, have the final say about the resident being moved to a community setting. We were totally ignored."—(Mother to M.M, former Partlow resident, June 25, 2012).

Unrealistic predictions of cost savings continue to contribute to community failings. We agree with Mr. Perez that "robust community infrastructures" are needed to serve safely and well people with ID/DD who are also multiply disabled, medically fragile or who experience dangerous behavioral conditions.

Significant funding, on par with facility-based care or more, must be in place before transitioning people from facility-based care. "Putting the cart ahead of the horse"—moving people before services are in place with false expectations of cost savings—has resulted in a poorly funded, ill-prepared community infrastructure leading to predictable tragedies and poor outcomes. As evidenced in statements by Mr. Perez and Chairman Harkin, jails continue to be ad hoc "treatment" centers for people with cognitive disabilities in many States who have nowhere else to go. Justice Department settlement agreements require that "robust community infrastructures" be built (in the future) so that, according to Mr. Perez, jails and emergency rooms do not remain the crisis centers of last resort. Yet these same agreements mandate the displacement of a pre-determined number of ICF/MR residents (quotas) per year, without any regard for individual choice or need, as required by *Olmstead* (see e.g., Virginia and Georgia settlement agreements).

VOR appreciates the questions posed by Senator Al Franken, who asked whether people with disabilities who chose home and community-based services should receive the same protections as people who receive facility-based care. The response by Rita Landgraf, Secretary, Delaware Department of Health and Social Services, was a "Resounding yes!" We agree completely.

II. LOOKING AHEAD: OLMSTEAD ENFORCEMENT MUST RESPECT DIFFERENT NEEDS

Until Federal and State officials remove their "rose-colored glasses," tragedies will continue. The people at the center of the deinstitutionalization experiment are profoundly fragile individuals. Their right to receive appropriate and necessary care, based on their individual needs, continues to be ignored, contrary to the letter and spirit of *Olmstead*.

As discussed above, anything less than 24/7 highly specialized services would be a death sentence for some people with ID/DD. There are thousands of people with severe and profound intellectual disabilities who are also medically fragile and have multiple physical disabilities, or who experience significant behavioral challenges that render them dangerous to themselves or others. These individuals, like Aaron whose story was shared previously, are thriving in ICFs/MR, specialized facilities designed to meet their long-term, complex care needs 24/7. Here are a few of their stories³:

- **David** has multiple disabilities including a **profound** level of intellectual disability (ID), total bilateral deafness, cerebral palsy and epilepsy. His teeth lack the normal enamel protective layer. David is 47 and has a mental age of 18 months. He is non-verbal and does not use sign language. He has had a hip replacement and is being treated for osteoporosis. His seizures have been under control with medication for 5 years. He has a history of aspiration pneumonia and has a diagnosis of moderate oropharyngeal dysphagia. Each meal consists of specially prepared blended foods and thickened liquids. David is at a high-risk level for falls, diabetes, choking and dehydration. His bowel movements are monitored to avoid bowel impaction. David requires staff assistance with brushing his teeth, shaving, bathing, toileting, dressing, eating, transferring, and transporting himself. David uses a wheel chair. He can walk with staff assistance using a walker and a gait belt. He requires staff assistance to go from one location to another. He can't perform work activities in active day treatment without hand-over-hand guidance. David is aware of his surroundings. He is able to recognize people who are familiar to him and uses facial expressions (i.e., smiling) to greet others. He enjoys being in an area where other people are moderately active such as in his home living room, traveling in a car or van, or in a mall or store. He enjoys watching people. His only method of communication is through eye contact and smiles. He does not have other communication skills.—(May 2012, by parents D.P. and N.P.).

³ As you read the stories of these individuals, consider how very different their disabilities and support requirements are from self-advocate Ricardo Thornton.

- My son, **Brian**, was expelled from four private facilities (two in Minnesota, two in Wisconsin), which do not have to keep difficult clients. When they expelled Brian because of dangerous aggression, he was sent HOME where we had little children. Out of structure, he broke hundreds of windows (we repaired them every weekend) and injured everyone in the family except the baby who was locked away from him. State-operated ICFs/MR in Illinois and many other States serve people with profound intellectual disabilities, and people with brain injury and physical aggression like Brian, but some even more extreme behaviors like sexual aggression, fire-starting, self-mutilation, etc. The most extreme cases need to have a stable environment and staff who are well-trained and well-paid. Brian who engaged in PICA while he was in and out of settings that could not handle him has had three surgeries to remove pens and pencils which perforated his stomach lining and infected his lungs. At Choate, a State-operated ICF/MR, that behavior was extinguished. Families who have been on the edge between life and death with their loved ones like we have or waiting for release of their severely disabled loved one who was inappropriately thrown into jail—we have those stories as well—do not want another tragedy in their loved ones' lives. What apartment building would be right for Brian and which McDonald's has an application with his name on it?—(May 8, 2012 Letter from mother R.B.)

- **R.S.** suffers from brain damage due to an oxygen deficiency at birth, epilepsy with uncontrolled mixed seizures, profound swallowing problems, brittle bones, optic atrophy with myopia, incontinence, stenosis of his neck and back, peripheral neuropathy and hyper-salivation. R.S. is non-verbal and completely non-ambulatory. He gets all nutrition, hydration and medication via a gastrostomy tube.—(February 11, 2012 Letter from guardian A.S.)

- **S.B.C.** suffered from spinal meningitis when she was 7 weeks old and was left mentally and behaviorally disabled with “explosive-type” outbursts during which she kicks, screams, bites, and throws things requiring her to be separated from others for her safety and that of those around her.—(March 12, 2012 Letter from parents, D.C. and L.C.)

- **K.M.** was born with severe brain damage resulting in many medical issues including a seizure disorder. K.'s father describes his son's intellectual ability as being “that of a new born baby.” He is blind, a quadriplegic with little control of his limbs, and he receives nourishment through a feeding tube.—See, March 9, 2012 Letter from father, D.M.

- **J.K.** has Angelman Syndrome and has the intellectual development of a 6-month to 1-year-old. J.K. is not toilet trained; he is entirely non-verbal; he tends to place everything in his mouth and chew on items that become choking hazards; and, when excited and agitated, he is prone to grab and hold onto whoever is nearby. J.K. has an exceptionally high pain threshold as illustrated by his not showing even a whimper of pain after he broke his collarbone a few years ago. This condition poses a constant risk of accident or medical emergency. His mother described a recent situation in which J.K. ate 11 inches of his quilt, which has since been encased in parachute material, and another incident in which J.K. picked at a sore on his elbow to the point that he pulled tissue out of his arm requiring surgery.—(February 11, 2012 Letter from his mother, J.A.)

- **T.K.**, who has been a resident of SVTC since the 1970s, is classified as moderately retarded with autistic tendencies. Her sister, J., states that T.K. has regularly exhibited violent behavior for most of her adult life including hitting, pushing, biting and breaking things. On one occasion, T.K. tried to put a piece of glass in her sister's eye and, on another occasion, she turned her bed upside down and ripped a water fountain out of the ground.—(March 15, 2012 Letter from sister, J.K.)

- **R.J.** is totally disabled, bed/wheelchair bound, tube fed, spastic with rigid muscles, diapered and medicated for seizures.—(March 17, 2012 Letter from guardian L.J.)

The individuals' profound disabilities and related needs are remarkable, but not unique. Their stories are repeated by the vast majority of families across the country whose loved ones receive life-sustaining supports in licensed Medicaid facility homes.

Mr. Perez and Commissioner Baugh's testimony acknowledged family opposition, characterizing such opposition as a “challenge” to closing ICFs/MR. It's no wonder. The deinstitutionalization experiment has not served people with profound ID/DD very well, nor have Federal and State officials respected families as true partners in policymaking and service decisions. Over and over again we hear, “We were totally ignored.” Promises have simply not met with reality. Inasmuch as it is their loved ones' lives at stake, families are morally driven to challenge these life-threatening proposals.

Still, closure attempts have proceeded in spite of family opposition. Fortunately, some Federal courts have noticed:

“Furthermore, the Petitioners have a significant, protectable interest in receiving the appropriate care of their choice and protecting their rights under the ADA. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 602 (1999) (‘Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it.’).”—(*U.S. v. Virginia, May 9, 2012*)(*Order granting intervention to ICF/MR residents, as represented by their families/legal guardians, over objection of the Justice Department*)

“Most lawsuits are brought by persons who believe their rights have been violated. Not this one . . . All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus, the United States [Department of Justice] is in the odd position of asserting that certain persons’ rights have been and are being violated while those persons—through their parents and guardians—disagree.”—(*U.S. v. Arkansas, June 8, 2011*) (*case dismissed*).

“Thus, the argument made by Arc and the United States regarding the risk of institutionalization fails to account for a key principle in the *Olmstead* decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it.”—(*The Arc of Virginia v. Kaine, December 17, 2009*) (plaintiffs were represented by Virginia’s Protection and Advocacy and supported by the Justice Department as Amicus) (*case dismissed*).

Yet, DOJ persists undeterred and with continued disregard for resident and family input and opposition. As noted in Mr. Perez’s testimony:

“[W]hen I became Assistant Attorney General in 2009, I identified enforcement of the *Olmstead* decision as one of the Division’s top priorities. In the last 3 years, the division has been involved in more than 40 matters in 25 States.”

Ann Knighton, VOR’s president and the president of the East Central Georgia Regional Hospital (Gracewood ICF/MR), was not consulted as a stakeholder with regard to the Justice Department Settlement (October 2010) which calls for the closure of all Georgia ICFs/MR. In response, she stated:

“The United States Department of Justice has undermined the U.S. Supreme Court’s *Olmstead* decision by being forceful and aggressive with regard to community transitions and thereby omitting the element of resident choice, whether that be a community or ICF/MR setting. If everyone is forced to accept community living, then no one has choice.”—(November 30, 2012)

III. VOR URGES THE HELP COMMITTEE TO HOLD HEARINGS AND REAUTHORIZE THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT WHICH HASN’T BEEN REAUTHORIZED IN 12 YEARS

The recent HELP hearing on “*Olmstead* Enforcement Update: Using the ADA to Promote Community Integration” is a perfect prelude to a long-overdue hearing: The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). It has been over a decade since the DD Act was last subjected to congressional scrutiny and reauthorized.

We want to be clear up front. VOR supports reauthorization of the Developmental Disabilities Act. We believe the DD Act programs play an important role in encouraging community integration.

However, we strongly believe that most federally funded DD Act programs, including State DD Councils, State Protection & Advocacy groups, and University Centers of Excellence for People with DD, are harming the very people they are supposed to protect by subscribing to the incorrect notion that the DD Act and the Americans with Disabilities Act (ADA), as interpreted by the *Olmstead* decision, mandate the transition of *all* people from ICFs/MR to alternative settings. P&A, which files class action lawsuits for the sole purpose of forcing “community integration,” are most guilty of operating as though *Olmstead* and the DD Act are mandates to close centers, without regard to resident need and family input. For example:

In a survey of all the people living in a Pennsylvania State operated ICF/MR and their family contacts were asked if they wanted a community placement: 1,013 of the 1,223 family contacts responded to the question and 97.24 percent of them answered “no.” Of the 307 residents who were able to respond to the

question 88.27 percent also answered “no.”—(Source: Survey, completed September 2011, as required by the **P&A-filed Benjamin v. PA Department of Public Welfare** Settlement Agreement. No attempt was made to survey all ICF/MR residents and their families before the settlement agreement).

Coffelt v. Department of Developmental Services was filed 1994 irrespective of the fact that 98 percent of the developmental center family/guardian survey respondents opposed P&A representation of their family members. As a result, two centers closed and 2,500 residents were transferred from developmental centers to community settings, resulted in well-documented higher mortality rates. One peer-reviewed study found risk of mortality to be 82 percent higher in community-based settings. Then, “*Coffelt II*” was filed in 2002. P&A challenged intervention efforts by parent/guardian representatives, arguing,

“As a matter of substantive law, parents and guardians of institutionalized persons have different and potentially conflicting interests on matters pertaining to their child’s or ward’s constitutional or statutory rights to liberty and due process.”

The Court rejected P&A’s challenge.

A survey of family members and guardians of residents in six New Jersey ICFs/MR asked recipients of the survey whether they were happy with the current placement of their loved ones, or would prefer community-based care instead. Sixty-one percent of the families and guardians receiving the survey responded. Ninety-six percent of respondents indicated support of continued ICFs/MR placement. The survey, sponsored by family advocates for residential choice, was an effort to respond to serious flaws in earlier State surveys and studies that have been used to justify downsizing and closure proposals, including a New Jersey P&A lawsuit.

The *Ligas* Federal class action lawsuit was brought in 2005 by Equip for Equality (P&A), against Illinois “on behalf of” 6,000 severely disabled residents who live in the 240 privately operated ICFs/MR with more than nine residents, as well as those living at home with elderly parents awaiting placements. In the first 4 years of the case, families, on behalf of their loved ones, unsuccessfully tried to intervene. As feared, in 2009, after 4 years of litigation, the parties reached a proposed settlement that would have required the State to reduce private “institutional” beds for each community bed it added. In response, more than 2,000 families throughout the State for whom the settlement was supposed to help successfully objected to the settlement.

All three DD Act programs believe that families of ICFs/MR residents need to be “educated” about the community and are spending precious resources on propaganda to prove how successful some transitions are. Families whose children reside in ICF/MR homes do not need to be educated any more than families of those living in the community. They have simply made a choice that is deemed unacceptable to the policies of the DD Act programs, contrary to their authorizing statute and the ADA (*Olmstead*). Their original charge was not to do this type of work but with the long gap in Federal oversight, these programs have wandered off their established path of advocating for people with intellectual disabilities into the role of telling the families and guardians of people with profound intellectual disabilities what is best for their loved ones. The result is to impose new limitations on people with intellectual disabilities rather than to expand those options to the maximum extent possible.

WHAT THE LAW REALLY SAYS: THE DD ACT AND OLMSTEAD

Like *Olmstead* in 1999, the DD Act in its 1993 amendments upheld the rights of individuals with developmental disabilities and their families to be the primary decisionmakers:

“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(1993) (*Findings, Purposes and Policies*)⁴; see also, *Olmstead v. L.C.*,

⁴In 2000, the following language was added to the “primary decisionmaking” clause, further strengthening the right of individuals and their families to choose from among an array of residential options: “. . . , including regarding choosing where the individuals live from available options, . . .”.

119 S. Ct. 2176 (1999) (“the transfer from institutional care to a less restrictive setting is not opposed by the affected individual”).

The “primary decisionmaking” clause was first added to the Act in 1993 due to an amendment by Congressman Henry Waxman. In 1999, the spirit of the clause was embodied in the *Olmstead* decision itself. Both the Act and *Olmstead* recognize that individuals and their families are in the best position to know what is best by way of services, supports and policies. Both the Act and *Olmstead* embrace individuality—recognizing that people with disabilities have very diverse needs.

Both also caution against forcing a community setting on someone who does not desire and could not handle a community setting. The legislative history of the DD Act, as contained in the 1994 Conference Report, is as clear as *Olmstead* on this point:

“First, the goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions.”

* * * * *

“Third, Protection and Advocacy systems established under Part C of the Act shall use the resources made available under this Act in accordance with the purposes and statement of policy set forth in the Act and are authorized to pursue appropriate remedies to address the violation of rights under the laws in all settings, including community and ICF/MR institutions”—[(H. Rep. 103–442 (March 21, 1994)].

The parallels between *Olmstead* and the DD Act are unmistakable. Yet, many DD Act programs continue to work to counter individual and family choice by proactively seeking the elimination of the ICFs/MR option.

IV. CONCLUSION

Contrary to the decision itself, “*Olmstead* enforcement” initiatives impose community placement on individuals, with regard for choice and the fundamental differences between individuals with physical or mild intellectual disabilities and those with profound intellectual disabilities. The ideology which drives the deinstitutionalization experiment (in the name of *Olmstead*) and the resulting outcomes are not critically scrutinized by Congress or the Administration.

The affected individuals and their families deserve a hearing; they deserve a voice. Including family stakeholders in future Senate “*Olmstead* Enforcement” hearings and holding a hearing in conjunction with the DD Act would provide these individuals and their families, as well as other people with intellectual and developmental disabilities and their families, with an opportunity to be heard. Their perspective matters. Choice matters.

Thank you for your consideration. For additional questions, please contact Tamie Hopp, VOR Director of Government Relations & Advocacy, at 605–399–1624 or thopp@vor.net.

Sincerely,

SAM GOLDEN,
Chair, VOR Government Affairs Committee.

PETER KINZLER,
Chair, VOR Legislative Committee.

[Whereupon, at 11:09 a.m., the hearing was adjourned.]

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