



Testimony of

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“Olmstead Enforcement Update: Using the ADA to Promote Community Integration”

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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 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 tenth 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 rebalance 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 five 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 institutional 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 rebalancing 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 five 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 six 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 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 lifespan. 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.