



Department of Justice

STATEMENT OF

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BEFORE THE

**COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS
UNITED STATES SENATE**

AT A HEARING ENTITLED

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

PRESENTED

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**Statement of
Thomas E. Perez
Assistant Attorney General
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**Before the
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**At a Hearing Entitled
“The ADA and *Olmstead* Enforcement:
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Good morning Chairman Harkin, Ranking Member Enzi and members of the Committee. Thank you for holding this hearing on the anniversary of the *Olmstead v. L.C. decision*, a ruling that has often been called the *Brown v. Board of Education* of the disability rights movement.

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

But for all of the progress made, I continue to hear about people like Paul Boyd, who I had the opportunity to meet earlier this year while on a trip to Birmingham, Alabama. In 1995, while a sophomore at Troy State University, Paul was injured in an accident that left him paralyzed below the collar bone. Paul eventually returned to college in his hometown of Montevallo, graduating in 2007 with a bachelor of fine arts degree. In December 2006, Paul entered a nursing home, and in his own words, it is “next to impossible” for him to find work that would allow him to live independently. Earlier this year, Paul was accepted to a graduate program at the University of Montevallo to seek his master’s degree in community counseling. However, his classes would be at night, and he is not sure that he will be able to begin the program because of lack of transportation from his facility, which is 13 miles from the University. Paul told us that if he could get out of the nursing facility and receive services in his community in Montevallo, he could easily make it to his classes. In order to live independently, he would need the assistance

of healthcare workers to help him bathe and dress and get into his wheelchair. He would also need assistance with some basic household chores. Montevallo is Paul's hometown, and while he has an extended support network of siblings and friends there, that is not enough, and the community-based services he needs to live independently simply are not available.

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

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

Civil Rights Division Olmstead Enforcement

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

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

In January, the Division filed a motion for immediate relief in a case involving seven state-run psychiatric hospitals in Georgia, including the facility that was at the heart of the Olmstead case more than a decade ago. A year prior to our motion, the Division and the state entered into an agreement to ensure that individuals in the hospitals were served in the most appropriate integrated settings and that unlawful conditions in the hospitals were remedied, but the court had not yet approved the agreement. After monitoring conditions at the hospital, the Division found that hundreds of individuals who could and should be served in the community remained institutionalized. In addition to this unlawful segregation, individuals in the hospitals are exposed to often dangerous conditions.

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

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

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

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

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

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

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

In New York, the Justice Department intervened in *Disability Advocates Inc. v. David A. Paterson, et al.*, a case brought by a protection and advocacy organization to challenge the state's placement of persons with mental disabilities in Adult Homes. The Department filed a brief in support of the advocates' proposed remedial plan to require the state to create 6,000 new community-based placements, and against the state's proposed plan to create approximately 1,000 new placements.

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

Year of Community Living: Administration Efforts

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

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

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

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

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

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

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

Looking Forward

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

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

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

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

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

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