

Department of Justice

STATEMENT

OF

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BEFORE THE SENATE COMMITTEE ON HEALTH, EDUCATION, LABOR & PENSIONS UNITED STATES SENATE

ENTITLED:

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

PRESENTED ON JUNE 21, 2012

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 thirteenth 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 <u>can</u> live in the community and <u>want to</u> 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 three 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 website 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 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 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 waitlists 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 waitlists 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 eight-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 Agreement for the benefit of many other families who "desperately" need services but do not currently have them. Another parent, whose six-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 five 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 of 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 Website

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 website dedicated to *Olmstead* enforcement, which includes links to settlements, briefs, findings letters, and other materials.

Interagency Collaboration

In 2009, on the tenth 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 opportunity 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.