Where We are on the Twentieth Anniversary of *Olmstead v. L.C.*

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Our nation has a dark history of treatment of individuals with disabilities. Not long ago, states prevented people with disabilities from marrying, working in competitive jobs, and attending public schools. Individuals with disabilities were forced to live in isolated, long-term institutions away from their families and communities. Society's focus first shifted to the rights of persons with disabilities in the 1960s civil rights era with the beginning of the Independent Living Movement (ILM), which promoted removal of barriers and acquisition of adaptive skills.[1] Section 504 of the Rehabilitation Act of 1973 was one of the first federal civil rights laws to prohibit unnecessary segregation and offer protection for people with disabilities.[2] Shortly thereafter, the Civil Rights of Institutionalized Persons Act (CRIPA) of 1980 enabled the Department of Justice to protect the rights of institutionalized individuals.[3] The move toward community integration gained impetus with the passage of the landmark civil rights legislation, the Americans with Disabilities Act (ADA) of 1990.[4] The ADA prohibits the unnecessary segregation of people with disabilities and guarantees their right to live, work, and be served in the least restrictive setting. The U.S. Supreme Court solidified this right in the 1999 watershed decision, *Olmstead v. L.C.*[5] *Olmstead* brought with it the promise of community living and integration in society. So where are we today? Have we achieved that utopian state where people with disabilities live and work on the same footing as those without? Are they afforded the same opportunities to grow and prosper as those without? Has the promise of integration made by *Olmstead* been realized? On the twentieth anniversary of *Olmstead*, we review the progress our nation has made in the last two decades in improving the quality of life of persons with disabilities and highlight the challenges faced by states in achieving true integration.

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The ADA and *Olmstead v. L.C.*

Within the broad legislation of the ADA, Title II codifies the right of individuals with disabilities to receive services in the most integrated setting. Title II describes this as "no qualified individual with a disability shall, by reason of such disability, be excluded from participating in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[4] This integration mandate requires public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[6] "The most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible."[7] To achieve this, Title II mandates that "reasonable modifications" be made to programs so that individuals with disabilities can receive services in the most integrated setting possible. But no modification is required to a state's programs "if the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."[1] Despite the integration mandate of Title II, institu-

tional segregation of individuals with disabilities continued. This persistent segregation was addressed in 1999 by the Supreme Court in *Olmstead v. L.C.*[5]

Olmstead centered on two Georgia women with developmental disabilities and comorbid psychiatric disorders who were voluntarily admitted to a state psychiatric hospital. They filed a lawsuit claiming that the state's failure to place them in the community after their treating physicians deemed it appropriate violated Title II of the ADA. The Court explained that "unjustified institutional isolation of persons with disabilities is a form of discrimination" forbidden by the ADA because institutional placement "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life" and "severely diminishes the everyday life activities of individuals" (Ref. 5, pp 600–601). Therefore, the Court held that public entities are required to provide community-based services to persons with disabilities when such services are appropriate; the individuals with disabilities do not oppose community-based treatment; and community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity (Ref. 5, p 607). Because Title II mandates "reasonable modifications" to public programs but not "fundamental alterations," the Court opted for an approach that can be thought of as slow but steady progress toward deinstitutionalization.[8] The Court illustrated this by noting that, "if, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace [. . .], the reasonable-modifications standard would be met" (Ref. 5, pp 605–606).

The First 10 Years After *Olmstead*

Following *Olmstead*, the Clinton and Bush administrations developed initiatives to further deinstitutionalization. President Bush launched The New Freedom Initiative in 2001 to remove barriers to community living for people with disabilities and to implement *Olmstead*.[9] Numerous lawsuits filed in the wake of the *Olmstead* opinion forced states to grapple with the tension between Title II and *Olmstead* over what is a reasonable modification to a public program versus a fundamental alteration. In the two years after *Olmstead*, fifteen states also had lawsuits regarding waiting list concerns, including what is a reasonable pace for a waiting list to move as described in *Olmstead*.[10] By 2003, 42 states had created a legislative Olmstead committee or task force.

Despite this, the number and rate of people leaving institutions in the decade before *Olmstead* were greater than in the decade after. This deceleration was driven by low rates of deinstitutionalization in a handful of states; by 2008, 52.3 percent of all public institution residents in the United States resided in these few states.[11] Subsequently, in 2009, on the tenth anniversary of *Olmstead*, President Obama launched the Year of Community Living to focus on increasing the availability of community-based care for individuals with disabilities and to direct federal agencies to enforce the civil rights of individuals with disabilities. Since then, the Department of Justice has increasingly championed the enforcement of *Olmstead* across the country.[12]

The Department of Justice has interpreted the ADA to require a state to have an Olmstead Plan in order for the state to claim that any modification would fundamentally alter a program.[13] An Olmstead Plan consists of specific timeframes and measurable goals for the state to provide individuals with disabilities opportunities to live, work, and be served in integrated settings.

Several court cases have demonstrated that a state can reduce its legal exposure by proactively creating an Olmstead Plan.[9] Despite this, not all states have developed Olmstead Plans. Constructing an Olmstead Plan, though, is just a first step. The actual implementation of *Olmstead* is a long, arduous process with many moving parts and hurdles, both logistic and budgetary. To illustrate the complex challenges faced by states in implementing *Olmstead*, we present a case study of Minnesota, our home state, and outline the systemic changes made in Minnesota to meet the mandate of *Olmstead*.

Minnesota Olmstead Plan

Despite a long history of valuing care for individuals with developmental disabilities, Minnesota only created an Olmstead Plan as a result of a 2009 lawsuit, more than a decade after the original *Olmstead* decision. In 2009, families of three residents of a facility for adults with developmental disabilities filed a class action lawsuit against the Minnesota Department of Human Services (DHS), which ran the

facility.[14] They alleged that the facility's inhumane use of restraints violated the Minnesota and U.S. Constitutions and other laws. In 2011, the families and DHS reached a settlement agreement, named the Jensen Settlement Agreement[15] after the lead plaintiff. In accordance with this agreement, the state overhauled direct clinical care for individuals with developmental disabilities, including changing restraint and seclusion policies and training DHS staff in best practices, such as positive behavioral supports, person-centered approaches, and crisis intervention. The agreement led to the closure of the facility that housed the plaintiffs and spurred movement of Minnesotans with developmental disabilities to the least restrictive settings through expansion of community support services.[16] Additionally, the agreement stipulated that individuals with a developmental disability would not be treated at the state psychiatric hospitals unless they also have an acute psychiatric condition. Despite steady progress, community placement of many of these individuals has been challenging due to histories of violence or sexual offenses.[17] The Jensen Settlement Agreement also required that the state develop an Olmstead Plan within 18 months, but due to its expansive scope and extensive revisions, it took the state four years to create with the plan.[18]

Minnesota's Olmstead Plan is a dynamic blueprint designed to achieve 50 measurable goals grouped in four categories: movement of people with disabilities from segregated to integrated settings, movement of individuals from waiting lists, measurement of quality of life, and increases in system capacity and options for integration.[19] In the four years since the creation of Minnesota's Olmstead Plan, the state has moved several thousand people from segregated to integrated settings. Minnesota has also realized the Supreme Court's vision of deinstitutionalization by maintaining "a waiting list that moved at a reasonable pace" (Ref. 5, pp 605–606). There is no longer a waiting list for community housing disability waivers, and fewer people are waiting for developmental disability waivers (Ref. 19, p 5). Quality of life measures still indicate that many people with disabilities do not make their own decisions about various aspects of their care, including who they live with or who their staff are.[20] Because there is still a shortage of community living settings, Minnesota continues to work to increase the system capacity for integration. The Olmstead Plan addresses full integration into the community by addressing not only housing but also employment and education. While Minnesota has made progress with housing integration for individuals with developmental disabilities, there continues to be a need for integrated postsecondary education and employment.

Implementation of Minnesota's Olmstead Plan since its inception four years ago has not been without challenges. As people with developmental disabilities were treated in large facilities and institutions for years, Minnesota simply did not have the infrastructure to accommodate these individuals in the community. Thus, there is still a shortage of more affordable community housing. While it has been shown that community-based care is more cost-effective than institutional care, creating a new foundation of community-based housing still consumes significant resources.

Recent Enforcement of *Olmstead* in States

Minnesota is not alone in implementing the mandate of *Olmstead* in response to a lawsuit and subsequent settlement agreement. More than a decade after the Court's decision, enforcement of the ADA and *Olmstead* continued across the country due to action from the Department of Justice following an investigation or from lawsuits brought by affected individuals, at times with the Department of Justice joining these lawsuits. For instance, in 2012, eight individuals with developmental disabilities filed a class action lawsuit[21] in the United States District Court for the District of Oregon. The lawsuit alleged that Oregon unnecessarily segregated disabled individuals in sheltered workshops instead of integrated jobs in their communities, in violation of their rights under Title II of the ADA and Section 504 of the Rehabilitation Act. Individuals with disabilities remained in sheltered workshops for an average of 11–12 years and received an average wage of $3.72 per hour. In 2015, Oregon reached a settlement agreement with the Justice Department.[22] Under this agreement, Oregon pledged to provide part- or full-time competitive-wage employment for approximately 7,000 individuals over seven years at facilities where the employee interacts with persons without disabilities. In 2014, a similar settlement agreement was reached in Rhode Island, which also included provisions for access to internships and mentoring programs for students with disabilities.[23]

In 2013, the Department of Justice, along with affected individual plaintiffs, brought complaint against the state of New York in the Eastern District of New York alleging that the state's placement of individuals with mental illness in 23 adult homes in New York City amounted to violation of Title II of the ADA.[24] These adult homes had 120 or more beds and, for the most part, had characteristics of an institution, thereby denying persons with mental illness residing there the opportunity to receive services in the most integrated setting appropriate to their needs. A settlement agreement was reached between the parties in 2014.[25] Under this agreement, New York effectively agreed to provide 2,000 community-based, scattered-site supported housing units over the next five years to all eligible people with serious mental illness who are unnecessarily segregated in these adult homes and who wish to live in supported housing.

In 2018, in response to a Department of Justice investigation, the State of Louisiana reached an agreement whereby it agreed to an intensified transition of individuals with mental health disabilities residing in the state's nursing home facilities to home- and community-based services and community-based mental health services, including supportive housing, assertive community treatment, substance use disorder services, and crisis services with individualized service planning.[26]

The above examples are a small sample of disability rights lawsuits decided in the last decade from across the country. They demonstrate the wide spectrum of ages, disabilities, and settings in which the protections guaranteed under *Olmstead* and the ADA are applicable. In all, there have been more than 50 lawsuits in over 25 states in the last decade that have led to the enforcement of the reasonable accommodation and integration provisions of *Olmstead*, with litigation currently underway in Georgia, Florida, Mississippi, and elsewhere.[27]

What Have We Learned?

On the twentieth anniversary of *Olmstead v. L.C.*, we as a nation have made slow but steady progress toward deinstitutionalization as envisioned by the Supreme Court in its landmark decision. As with other civil rights guaranteed under the law, the Department of Justice has zealously enforced the protections afforded under the ADA, in many instances with broad-based support from the judiciary. And while class action litigation under the aegis of the Department of Justice has spurred this process forward, it often seems not fast enough. A significant challenge that remains in this progress toward community integration is that Medicaid funding, which finances most long-term care for individuals with developmental disabilities, does not fully align with the vision of *Olmstead*. In the last 20 years, the federal government has also provided various incentives to states to shift Medicaid funding from institutional to home- and community-based services (HCBS waivers). In this way, *Olmstead* has served to reposition Medicaid as a tool for community integration rather than one of institutional isolation. In some instances, *Olmstead*'s mandate has even required a public entity to alter cost-effectiveness formulae used to determine whether a service will be covered by Medicaid.[28] As is to be expected, however, the full realization of *Olmstead* also comes with substantial financial cost. Between 1999 and 2009, even as long-term care spending grew at an average annual rate of 6.3 percent, average annual spending on community-based services and supports grew by 11.8 percent (Ref. 8, p 594). In 2009, the nation spent $52 billion on community services financed through Medicaid, while community spending grew from 27 percent of total long-term care spending to 45 percent; that year, over half of all long-term care beneficiaries received care in communities (Ref. 8, p 594). By 2017, this figure had increased to $82.7 billion that benefitted 4.6 million enrollees.[29] Nearly all this spending (93%) went to services that are provided at state option. Medicaid HCBS spending per enrollee averaged just over $17,800 nationally, with more than $44,000 per enrollee spent on people with intellectual or developmental disabilities (Ref. 29, p 1). While Medicaid funding is slowly shifting toward community-based services, the cost of resources needed to fully support the reality of individuals with disabilities living in the community is continually expanding.

Much of the focus of the enforcement of *Olmstead* has been on individuals with disabilities living in the least restrictive setting. Yet true community integration, as envisioned by the Court, is not limited to housing. Individuals with disabilities can live in a community-based home and remain isolated from the immediate community outside their door. Integration of transportation, education, and employment is, according to *Olmstead*,

part of the integration mandate of Title II of the ADA. With the progress of moving individuals with disabilities into community-based housing, enforcement of *Olmstead* has begun to shift toward further social integration, not just physical integration, with Oregon's 2012 settlement being exemplary of such a shift.

The Department of Justice has recently extended its focus of *Olmstead* enforcement to a large public entity that falls under Title II of the ADA, the criminal justice system. Efforts are underway in four key areas: promoting de-escalation in police encounters to reduce the need for force; diversion of individuals with mental illness, when appropriate, from incarceration to community-based treatment; connecting people in jails and prisons to needed services to reintegrate into their communities; and states meeting their ADA obligations to provide sufficient community-based mental health services. The Justice Department has made clear that the ADA applies to arrests and other interactions between police and people with disabilities.[30] Therefore, in promoting de-escalation in police encounters, the Department of Justice has advocated for police departments to have specialized Crisis Intervention Teams or CIT-trained officers respond to situations where individuals' mental illness, disability, or use of drugs or alcohol may impact their behavior. The Justice Department has also provided resources to law enforcement on how to treat justice-involved individuals with mental health conditions. More work is needed, however, to divert individuals with disabilities and mental illness from incarceration to community-based treatment, and sufficient community-based treatment options are needed for this population.[30] This and many similar initiatives have highlighted the shortages of and need for involvement of competent psychiatric professionals, especially forensic psychiatrists, in the areas of education, training, policymaking, advocacy, and direct patient care.

As psychiatrists, we are obligated to advocate for the basic rights of our patients with developmental disabilities across the country. At its core, the principle behind integration of individuals in the community is about person-centered care. Many of our disabled patients who have lived in institutions for most of their lives may have never been given the opportunity to decide for themselves where they want to live. As deinstitutionalization progresses, it is our duty to promote person-centered care for our patients and to advocate and encourage our patients to make individual decisions. While *Olmstead* and the ADA are broad and far-reaching, the vision of *Olmstead* is ultimately realized at the individual level of offering our patients the decision of where to live and work and making it possible for them to thrive in that setting. Perhaps the greatest victory of *Olmstead* is the broader public exposure to the social and moral costs of unnecessary institutionalization. Let us not forget these costs and advocate not only for broad changes in integration but for our individual patients with developmental disabilities.

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