Olmstead Implementation

Alicia Woodsby, M.S.W., Senior Associate; Lisa Sloane, M.P.A., Director; and Arvind Sooknanan, Associate, Technical Assistance Collaborative, Inc.

Summary

In its 1999 *Olmstead v. L.C.* decision, the United States Supreme Court found that the institutionalization of persons with disabilities who were ready to return to the community was in violation of Title II of the "Americans with Disabilities Act" (ADA). The ruling affirmed that the unjustified segregation of individuals with disabilities constitutes discrimination under the ADA. In the ADA's integration mandate: https://ecfr.io/Title-28/Section-35.130, public entities such as state and local governments are required to "administer services, programs, and activities in the most integrated setting appropriate to the needs of the qualified individuals with disabilities." The decision's legacy continues to shape the landscape of disability rights and community integration, and the year 2024 marked significant activity in advancing these goals.

Community integration for people with disabilities requires comprehensive community-based systems of care and affordable housing options. Significant investments in community-based services and affordable housing by the Biden Administration continued in 2024. The Administration also made meaningful regulatory updates that further reinforced the integration mandate. The U.S. Department of Justice (DOJ) initiated and continued several investigations, issued findings letters, and secured *Olmstead* settlement agreements. Progress at the state level included settlement agreement implementation, *Olmstead* planning, and actions undertaken by local protection and advocacy organizations (P&As) and other legal advocacy groups.

Despite these achievements, challenges persist. Access to affordable housing and to adequate housing assistance remains at a critically low level relative to demand. The nationwide workforce shortage in the disability services sector continues to pose a significant hurdle, with many states struggling to recruit and retain direct support professionals. Low wages and demanding work conditions contribute to high turnover rates, negatively affecting both the continuity and quality of care.

Further, the Supreme Court's 2024 decision in *Grants Pass v. Johnson*: https://n.pr/4iQ2PPP increases the risk of institutionalization for people with disabilities who are experiencing homelessness. This misguided decision disproportionately affects those who have mental illness, substance use disorders (SUDs), and other disabilities, and especially people of color who live with these conditions. The decision is already having a devastating impact in communities across the nation, as states have begun to enact camping bans and "homeless sweeps" leading to unnecessary arrests and imprisonment; several cities have also enacted laws or begun enforcement. These actions deter efforts to apply proven solutions like providing stable housing and community-based supports for mental health and substance use needs.

Additionally, systemic barriers such as lengthy waiting lists for services and bureaucratic complexities continue to impede progress. Advocacy groups pushed for streamlined processes and more funding to reduce waiting times and improve service delivery. The federal government's role in addressing these challenges was pivotal in 2024, as several policies and regulations strengthened the call for *Olmstead* compliance.

Administration

DOJ is the federal agency charged with enforcing ADA and *Olmstead* compliance. Other federal agencies, including the departments of

Housing and Urban Development (HUD) and Health and Human Services (HHS), hold funding, regulatory, and enforcement roles related to the ADA and *Olmstead*. P&As in each state are federally authorized and also have legal, administrative, and other appropriate remedies to protect and advocate for the rights of individuals with disabilities. Other legal groups, such as the Bazelon Center for Mental Health Law, the Center for Public Representation, and the American Civil Liberties Union have been able to represent plaintiffs in *Olmstead* cases.

History

In its 1999 decision in *Olmstead v. L.C.*: https://supreme.justia.com/cases/federal/us/527/581/, the Supreme Court found that indiscriminate institutional 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. The court also found that confinement in an institution severely diminishes everyday life activities, including "family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." To comply with the ADA's integration mandate, public entities must reasonably modify their policies, procedures, and practices when necessary to avoid discrimination.

The court was careful to say that the responsibility of states to provide health care in the community was "not boundless." States were not required to close institutions, nor were they to use homeless shelters as community placements. The court said that compliance with the ADA could be achieved if a state could demonstrate that it had a "comprehensive and effectively working plan" for assisting people living in "restrictive settings," including a waiting list that moved at a "reasonable pace not controlled by the state's endeavors to keep its institutions fully populated."

Historically, community integration was achieved by moving people out of large, state-run institutions into community settings (deinstitutionalization). In recent years, there has been increasing scrutiny of ways that certain types of large, congregate residential settings in the community are restrictive, have characteristics of an institutional nature, and are inconsistent with the intent of the ADA and *Olmstead*. Such facilities are known by a variety of names, (e.g., adult care homes, residential care facilities, boarding homes, nursing homes, assisted living), but share similar characteristics, including a large number of residents with disabilities, insufficient or inadequate services, restrictions on personal affairs, and housing that is contingent upon compliance with services. Furthermore, the reduction in state hospital beds that began in the 1960s, combined with inadequate investment in comprehensive community-based mental health systems (including treatment for co-occurring mental health and SUDs) and housing options, has resulted in chronic homelessness and the trans-institutionalization of people with psychiatric conditions in prisons and jails.

Implementation

Since 1999, states have made varying amounts of progress on supporting people with disabilities in the most integrated settings possible. Several states are in the process of implementing "Olmstead Plans" that expand community-based supports, including new integrated permanent supportive housing opportunities; implementing *Olmstead*-related settlement agreements that require the creation of thousands of new integrated permanent supportive housing opportunities in conjunction with the expansion of community-based services and supports; or implementing other related activities, such as Medicaid reforms, that will increase access to home and community based services and supports for people with disabilities. Unfortunately, other states never developed plans, are using

outdated plans, or are doing very little specifically to comply with *Olmstead*.

In 2011, DOJ issued the *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.* Included in this statement are the definitions for integrated and segregated settings that remain in place today.

DOJ defines: http://www.ada.gov/olmstead/q&a_olmstead.htm the most integrated setting as:

> "a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible. Integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, just like individuals without disabilities. Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies, and with persons of an individual's choosing; afford individuals choice in their daily life activities; and, provide individuals with disabilities the opportunity to interact with nondisabled persons to the fullest extent possible. Evidence-based practices that provide scattered-site housing with supportive services are examples of integrated settings. By contrast, segregated settings often have qualities of an institutional nature. Segregated settings include, but are not limited to: (1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities."

The ongoing crisis in housing affordability is a challenge both for people with disabilities and for government agencies working to comply with ADA requirements. According to a December 2024 report by the Harvard Joint Center for Housing Studies, the number of cost-burdened renter households has reached a new record high: https://bit.ly/3EEueWC, reflecting an already significant affordability challenge that accelerated during the pandemic. For people with disabilities, the situation is exacerbated: *Deteriorating Rental Affordability: An Update on America's Rental Housing 2024*: https://bit.ly/3EEueWC notes that 60 percent of renter households headed by a person with a disability are cost burdened, 13 percentage points higher than the cost burden share for those without a disability.

Lack of access to affordable housing forces many people with disabilities into costly and segregated nursing facilities, state hospitals, board and care homes, or homelessness. Most people with disabilities living in restrictive settings qualify for federal Supplemental Security Income (SSI) payments that average $1,009 per month nationally. However, this amount is only 17.7% of national median income, putting independent housing out of reach for people whose only income is SSI. Santa Cruz-Watsonville Counties in California have the highest ratio of one-bedroom fair market rent to SSI; in these counties, the average rent for such a unit would require 267% of a person's SSI. Even in Henry County, Alabama, the county with the lowest rent to SSI ratio, people with disabilities must pay 62% of their income for a one-bedroom unit. HUD would describe all of these households as having Worst Case Housing Needs: https://www.huduser.gov/portal/AFWCN.html. Even before the pandemic, the Technical Assistance Collaborative's Priced Out: https://www.tacinc.org/resources/priced-out/ reports repeatedly demonstrated that in no housing market in the country could an individual on SSI afford fair market rent.

Many states have created or expanded state-funded rental subsidies directly related to their

Olmstead efforts. But the upper limit of such subsidies is tied to the federally determined fair market rent for a given area, and many voucher holders continue to have difficulty finding qualifying units — even with HUD's significant recent increases to fair market rent amounts. Tight rental markets and low vacancy rates make it hard to identify landlords willing to take rental subsidies, provide units for supportive housing, or accept referrals for vulnerable people with disabilities in general.

Along with HUD, HHS continues to play an important role in *Olmstead* implementation efforts. For example, SAMHSA funds critical community-based mental health and SUD services through its block grants. The Centers for Medicare and Medicaid Services (CMS), too, plays a significant role in *Olmstead* implementation planning through Medicaid coverage options for community-based behavioral health services. In addition, Medicaid demonstration waivers and options can include evidence-based housing supports to improve housing stability and stop the revolving door of emergency departments, hospitalizations, and other acute and crisis services for populations with chronic and disabling conditions.

Olmstead Activity in 2024

LITIGATION

From 2022 to 2024, the DOJ Civil Rights Division was involved in new *Olmstead*-related litigation in at least 12 states in addition to the numerous active and closed cases filed before 2022. Involvement in these cases ranged from filing a statement of interest where another entity had filed a lawsuit to findings letters and settlement agreements/consent decrees between DOJ and states.

For example, in May 2024, DOJ issued a findings letter to the State of Nebraska: https://bit.ly/4ivdjDG, finding that the state unnecessarily segregated people with serious mental illness (SMI) in assisted living facilities and day program facilities, in violation of the ADA and *Olmstead*. The department found that Nebraska is restricting access to critical community-based services that people with SMI need to live and work in the community. Instead of helping Nebraskans with SMI find jobs, Nebraska relies heavily on segregated day programs that group these individuals together in facilities. People with SMI may spend years in segregated day programs with no path to employment. Instead of being able to live in their own homes, many people with SMI are forced to enter assisted living facilities to get help. Additional DOJ findings in Kentucky: https://bit.ly/4iw8R7K, Oklahoma: https://bit.ly/4iAuiVk, Minneapolis: https://bit.ly/4iu3y8Y, Louisville: https://bit.ly/4jqqBTB, and Memphis: https://bit.ly/4iqhtNb focused on unnecessary institutionalization and discrimination against people with behavioral health disabilities by law enforcement agencies.

In December 2024, DOJ sued the State of South Carolina: https://bit.ly/42Zxd5h for unnecessarily segregating adults with mental illness in adult care homes, in violation of the ADA and *Olmstead*. The lawsuit alleges that South Carolina violates the ADA by failing to provide community-based services to prevent the unnecessary segregation of adults with mental illness in adult care homes. As a result, over a thousand adults with mental illness are segregated in adult care homes for years and more continue to enter these facilities each month.

In November 2024, DOJ secured a settlement agreement to resolve its lawsuit alleging that Colorado: https://bit.ly/3EG0XuJ violated the ADA and *Olmstead* by unnecessarily segregating adults with physical disabilities, including older adults, in nursing facilities. The lawsuit alleged that the state failed to provide adults with physical disabilities with the services they needed to live at home or to avoid moving into a nursing facility. In Colorado, most nursing facility residents and their families are unaware that they can receive services like nursing, per-

sonal care, and housing assistance in the community. As a result, many move into, or remain in, nursing facilities even though they would prefer to live at home. To increase community integration for adults with physical disabilities, the state made significant commitments in the agreement to help thousands of nursing facility residents move back to the community and expand and improve services that help people find and keep affordable, accessible housing in the community, among other commitments.

Nevada: https://bit.ly/3Ry2k1r and North Carolina: https://bit.ly/42LlGp8 also had *Olmstead* activity in 2024. Nevada entered into a settlement agreement with the DOJ to ensure that children with behavioral health disabilities can live in their homes and communities. The settlement agreement with North Carolina was extended, adding a sixth amendment that requires the development and implementation of effective measures to prevent inappropriate institutionalization and the provision of adequate and appropriate public services and supports identified through person-centered planning in the most integrated setting appropriate to meet the needs of individuals with SMI who are in or at risk of entry to an adult care home.

Non-federal advocacy and litigation continue to result in *Olmstead* actions. Massachusetts and the Center for Public Representation settled the *Marsters*: https://bit.ly/4istl1f case, a landmark cross-disability lawsuit that will provide community homes for thousands stuck in nursing facilities. In another example, Disability Rights NJ filed a lawsuit against the Commissioners of the state's departments of Health and Human Services for unlawful abuse, neglect, and segregation in state psychiatric hospitals. Several states, such as North Carolina: https://bit.ly/3SbqC1n, North Dakota: https://bit.ly/3SbqC1n, Massachusetts, Minnesota, and Oklahoma: https://bit.ly/4iyBLUOf, continue to develop and implement Olmstead Plans.

Stakeholders should be aware of a September 2023 federal court finding on behalf of the State of Mississippi that could affect *Olmstead* enforcement in the future. Following a trial in 2019, a federal judge ruled in favor of DOJ that Mississippi was in violation of Title II of the ADA. In 2022, Mississippi's Solicitor General filed an appeal with the court, arguing that "The remedies provided under Title II are to persons," and that alleged violation would need to be on behalf of an individual, not a class action filed by the United States. The 5th U.S. Circuit Court of Appeals in New Orleans ruled that the DOJ's claim that adults with SMI in Mississippi were "at risk" of institutionalization was not sufficient to prove discrimination under the ADA, although other federal appeals courts have agreed that people who are "at risk" of unnecessary institutionalization can bring a claim under the ADA. It remains uncertain what additional actions, if any, will take place on this case.

FUNDING AND PROGRAMS

A notable accomplishment was the increased investment in home- and community-based services (HCBS). Many states allocated substantial funding to expand HCBS programs, enabling more individuals to transition from institutional settings to community living. These services included personal care assistance, transportation support, and employment training programs designed to foster independence and inclusion. States such as California, Minnesota, and Virginia led the way, demonstrating innovative approaches to integrating technology and telehealth services to support individuals in their homes.

The Biden Administration administered $240 million in awards to develop and expand mental health and SUD services in more than 400 community health centers across the country, and dedicated close to $70 million in grant funding to expand the mental health workforce and support the behavioral health needs of

underserved communities. Two years into the implementation: https://bit.ly/4iyvYPd of the 988 Suicide and Crisis Lifeline, call volume, state investments, mobile crisis and short-term crisis stabilization services, technology and infrastructure, and specialized services have all continued to expand. The Biden Administration also continued to make significant investments in affordable integrated housing for people with disabilities, including $138.5 million in grants for more than a dozen state housing agencies to expand the supply of housing and supportive services for low-income persons with disabilities through HUD's Section 811 Project Rental Assistance (PRA) for Persons with Disabilities program: https://bit.ly/4lLpvTT (affordable housing resources are covered in Chapters 4 and 5). In 2024, several states continued work to implement approved Medicaid 1115 demonstration waivers or state plan options including pre-tenancy and tenancy-sustaining support services and other housing benefits aimed at supporting the transition to housing and ongoing housing stability for people with disabilities and other complex conditions experiencing or at risk of homelessness.

Noteworthy efforts were made to ensure that *Olmstead* implementation benefited individuals with disabilities across diverse racial, ethnic, and socioeconomic backgrounds. For example, culturally competent outreach programs were developed to engage communities that had traditionally faced barriers to accessing services. In states like New York and Texas, multilingual resources and staff training initiatives helped bridge communication gaps and foster trust within diverse communities.

As the year concluded, success stories from individuals who transitioned to community living highlighted the transformative impact of these initiatives. For instance, in Illinois, a pilot program supported 200 individuals in moving from nursing facilities to independent living arrangements, with 95% reporting improved quality of life and increased satisfaction with their autonomy.

REGULATIONS

HHS took several steps to reinforce the importance of *Olmstead* through rules and regulations: https://bit.ly/4itPgoM. In the past year, HHS codified the requirement to provide services in the most integrated setting in the Section 504 regulations, clarified that the *Olmstead* mandate applies to insurers in Section 1557 and will be enforced, and improved access to HCBS by finalizing the Medicaid Access Rule: https://go.cms.gov/3RxtVzO.

Forecast for 2025

Policies favored by the incoming presidential administration and 119th Congress could bring substantial threats to programs and funding and put people with disabilities at risk of placement in segregated settings. Further, concerns by the new administration regarding the role of DOJ and its enforcement of the ADA could limit the ability of DOJ to enforce the ADA to the extent that it has done in recent years. Proposals calling for massive cuts to Medicaid have been well documented, including proposals such as block granting the Medicaid program, adding work requirements, per capita caps, cutting the Federal Medical Assistance Percentage (FMAP), and repealing enrollee protections, among others. Potential threats to approved and pending Medicaid waivers with Health-Related Social Needs (HRSN) benefits, including housing, may also be on the horizon. Medicaid covers over 70 million people and is the largest payer of long-term services: https://healthlaw.org/wp-content/uploads/2024/09/01-PMF-MedicaidServices-9.3.24.pdf and supports (LTSS) across the nation with over 6 million recipients of this care.

Severe cuts would be detrimental to state budgets and leave states with no options other than cutting enrollment, optional services, or provider rates. The impact on the workforce, service options, and people in need would be devastating and unwind decades of work to rebalance LTSS from costly, segregated institu-

tional settings to home- and community-based care. The expiration of "American Rescue Plan Act" (ARPA) funding for HCBS and potential loss of momentum on the expansion of Certified Community Behavioral Health Clinics (CCBHCs) could also negatively impact access to and capacity of community behavioral health services.

The incoming Administration has described plans for addressing homelessness that would negatively impact *Olmstead* efforts on a variety of fronts, from preventing use of the successful Housing First approach, to forced treatment, to warehousing of people experiencing homelessness in federally operated facilities. In 2025, more states and communities will likely use the Grants Pass decision to justify criminalization of people experiencing homelessness, which will divert essential resources and attention away from proven, long-term solutions such as the expansion of supportive housing and comprehensive community-based continuums of care. This trend will also result in further trans-institutionalization of people with disabilities.

On a positive note, bipartisan support for the Medicaid Reentry: https://bit.ly/4IMFC3k Section 1115 Demonstration Opportunity bodes well for more states be able to apply and allow coverage for a package of pre-release services for up to 90 days prior to an individual's expected release from incarceration. These are services that could not otherwise be covered by Medicaid that support connections to community-based treatment and services for people prior to reentering the community to avoid emergency department use, hospitalizations, and recidivism, among other health benefits. Based on the overrepresentation of individuals with mental illness and SUDs in the criminal justice system, the Demonstrations are an important tool for community integration, as well as an equity strategy for people with disabilities from racially and ethnically diverse communities.

Stakeholder Actions with Policymakers

Advocates should educate policymakers on *Olmstead*, integrated settings, and the case for affordable and permanent supportive housing. It's important to make the case for expanding voluntary community-based crisis services to further divert people from more restrictive settings, while at the same time ensuring access to upstream services such as permanent supportive housing, case management, outpatient treatment, and supported employment.

Advocates will need to strengthen their efforts at the state and local levels. State and local governments will bear the brunt of cuts to Medicaid, community-based services, and affordable housing, and will need help in communicating this fact to federal agencies and their federal representatives. State and local governments will also need advocacy against camping bans, "homeless sweeps," and other ways of criminalizing homelessness. Partnering with state and local officials to advance effective alternatives to criminalization will be critical.

Stakeholders should ensure that key decision-makers in their state are informed of the threats to Medicaid, and need to advocate strongly against any cuts. Key decision-makers should also be made aware of the Medicaid Reentry opportunity and its associated benefits to communities, public health, and public safety.

Stakeholders must press policymakers and funders to pursue any and all remedies to address the direct care workforce crisis. Funding is one important tool, as long as increases are passed along to the direct care workers. Additional approaches to pursue include providing increased training and supervision to staff, establishing pathways for career advancement, expanding job opportunities for people with lived experience, paying family members as caregivers, and expanding the use of technology to alleviate the strain on staff resources, among others.

June 2024 marked the 34th anniversary of the ADA. After more than three decades of affording individuals with disabilities the right to live and engage as fully included members of the community, we cannot allow current challenges, no matter how great, to drive states back to relying on institutional and segregated settings.

This chapter identifies strategies for states focused on their community-based services. Chapter 4 identifies strategies to increase access to rental assistance for people with disabilities. These strategies are essential for states to fulfill their responsibilities under *Olmstead*.

For More Information

Technical Assistance Collaborative, Inc. (TAC), 617-266-5657, www.tacinc.org.