Olmstead Implementation

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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). Since *Olmstead*, states have made different amounts of progress on supporting people with disabilities in the most integrated settings possible.

Before the declaration of a public health emergency (PHE) due to the COVID-19 pandemic in 2020, several states were in the process of implementing "*Olmstead* Plans," *Olmstead*-related settlement agreements, or other related activities — such as Medicaid reform — that would improve access to services and supports intended to assist individuals with disabilities to succeed in integrated, community-based settings. The PHE exacerbated existing service and housing challenges. Unfortunately, state social service systems are still struggling with issues related to increased need for mental health and substance use disorder treatment, workforce shortages, and lack of affordable housing.

Community integration for people with disabilities requires the creation of comprehensive community-based systems of care. National efforts to strengthen and expand behavioral health crisis services continued in 2023, as well as additional investments in Certified Community Behavioral Health Care Clinics (CCBHCs) and the Community Mental Health Services Block Grants (MHBG) program. An increasing number of states are pursuing coverage of housing related supports and services under Medicaid, as well as other opportunities within Medicaid to expand mobile crisis services and address Social Determinants of Health (SDOH). These efforts should, in theory, help to create more comprehensive community-based systems and reduce unnecessary hospitalizations. Many states are using resources to expand permanent supportive housing, which is an evidence-based intervention for supporting people with disabilities with affordable housing and voluntary services in the community. In addition to permanent supportive housing, services such as case management, outpatient treatment, Assertive Community Treatment (ACT), Peer Support, psychiatric rehab, and supported employment help to prevent unnecessary inpatient admissions and avoid homelessness for people with psychiatric disabilities.

Despite these gains, an inadequate workforce, diminished access to support services, and lack of affordable housing units are resulting in some states continued or increased reliance on more institutional and restrictive, congregate community-based settings.

This article will describe the above investments and issues in more detail; highlight the current landscape of *Olmstead* implementation and recent *Olmstead* activity; and offer a forecast and possible action steps for 2024.

ADMINISTRATION

DOJ is the federal agency charged with enforcing ADA and Olmstead compliance. Other federal agencies, including the U.S. Department of Housing and Urban Development (HUD) and the Health and Human Services (HHS) department, hold funding, regulatory, and enforcement roles related to the ADA and Olmstead. Protection and Advocacy (P&A) agencies 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.

HISTORY

In its 1999 decision in Olmstead v. L.C., the

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 ADA. The court said 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."

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 substance use disorders), has resulted in the trans-institutionalization of people with psychiatric conditions in prisons and jails.

IMPLEMENTATION

Since 1999, states have made varied amounts of progress on supporting people with disabilities in the most integrated settings possible. 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 reform, that will increase access to services and supports intended to help individuals with disabilities to succeed in integrated, community-based settings. Unfortunately, many states never developed plans, have outdated plans, or are doing very little to comply with *Olmstead* specifically.

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 that Statement are the definitions for integrated and segregated settings that remain in place today. Guidance issued in June 2020 by the federal Centers for Medicare and Medicaid Services (CMS) advised states of their ongoing responsibility "for compliance with the integration mandate of Title II of the [Americans with Disabilities Act] and the 1999 *Olmstead* v. *L.C.* decision to avoid subjecting persons with disabilities to unjustified institutionalization or segregation."

DOJ defines 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."

States with *Olmstead* litigation or settlement agreements, as well as states trying to comply with *Olmstead* through proactive strategies, are working to expand access to integrated permanent supportive housing opportunities for people with significant and long-term disabilities. *Olmstead*-related settlement agreements typically require significant numbers of new permanent supportive housing opportunities. It is important to note, however, that prior to the pandemic, several of these states were already struggling to meet supportive housing compliance targets due to lack of resources for housing assistance and services. Now, states are faced with even greater challenges due to the direct services workforce crisis and unprecedented increases in rental costs.

Implementation efforts have largely focused on expanding community living options and services that support transitions to, and successful tenancy in, community-based housing, with less attention paid to integrated employment or other activities. Several *Olmstead* plans do address competitive, integrated employment, and there have been limited actions on employment in some states such as Rhode Island and Oregon regarding persons with intellectual and developmental disabilities who have been unnecessarily segregated in "sheltered workshops" and day activity service programs. Supported employment is an evidence-based approach to vocational rehabilitation for people with serious psychiatric disorders and is often paired with permanent supportive housing to promote sustained housing stability in the community. In October 2023, the DOJ issued updated guidance regarding the *Olmstead* integration mandates application to employment.

The on-going crisis in housing affordability is a challenge for both people with disabilities and for government agencies working to comply with ADA requirements. The cost of housing continues to skyrocket. Although the growth rate slowed in 2023, nationwide, median rents increased by 18% during 2021 and by 25% between January 2021 and June 2022. 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 $983 per month nationally. This amount is only 17.5% of national median income. Santa Cruz-Watsonville Counties in California have the highest ratio of one-bedroom fair market rent to SSI; in these counties, people with disabilities pay 142% of their income for rent. Even in Dallas County, Missouri, the county with the lowest rent to SSI ratio, people with disabilities pay 64% of their income for a one-bedroom unit. HUD would describe all of these households as having Worst Case Housing Needs. Even before the pandemic, the Technical Assistance Collaborative's Priced Out reports repeatedly demonstrate that in no housing market in the country could an individual on SSI

afford the fair market rent.

Many states have created or expanded state-funded rental subsidies directly related to their *Olmstead* efforts. Households with these state or federal housing vouchers continue to have difficulty finding units to rent even with HUD's significant increases in FMRs in recent years. Tight rental market 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. As a result, more national, state, and local resources are being directed toward housing navigation and landlord engagement and recruitment efforts for housing programs serving people with disabilities who are experiencing homelessness.

CMS is also supporting efforts by states to rebalance their health care systems from institutional to community-based care. Many of Medicaid's highest-cost members are individuals with complex and co-occurring health and behavioral health conditions who are experiencing homelessness or housing crises. People with disabilities have historically faced multiple barriers in Medicaid to receiving community-based long-term services and supports, such as inadequate support for self-direction and person-centered planning, lack of housing and transportation, and the lack of a streamlined process for hospital discharges to the community, to name a few. A growing list of states are utilizing Medicaid waivers to provide evidence-based housing supports that improve housing stability and stop the revolving door of emergency departments, hospitalizations, detox, and other acute and crisis services for populations with chronic and disabling conditions.

In 2021, CMS announced a new 1115 demonstration opportunity to cover certain services that address Social Determinant of Health (SDOH), including services that assist individuals to prepare for, move into, and sustain tenancy in permanent supportive housing. For the first time in its history, housing costs, including short-term rental assistance and one-time transition and moving costs (e.g., security deposits), can be considered by CMS under 1115 demonstrations. Furthermore, CMS guidance to state Medicaid agencies promotes partnerships with state and local housing entities, including HUD Homelessness Continuums of Care (CoCs), to coordinate the provision of rental assistance for beneficiaries who are receiving tenancy sustaining services (see https://www.medicaid.gov/sites/default/files/2022-01/sho21001_0.pdf).

To further advance these measures, the Administration recently announced the Housing and Services Partnership Accelerator (HSPA) to support states in their efforts to use new federal resources and opportunities to cover a range of services and supports that help people find, obtain, and maintain their housing. States with an approved section 1115 demonstration or an approved section 1915(i) state plan benefit covering housing-related supports and services for individuals experiencing or at risk of experiencing homelessness were invited to apply for the program to strengthen their state Medicaid agency collaboration with agencies providing housing, aging and disability resources and programs and accelerate and improve their service delivery and effectiveness at reducing avoidable crisis and emergency costs and improving outcomes for Medicaid beneficiaries. The HSPA will run from January through December 2024.

OLMSTEAD ACTIVITY IN 2023

Provider capacity is strained nationwide as direct service workforce shortages continue at crisis proportions. Behavioral health systems are overextended, attempting to respond to the increased demand for treatment and services for people with mental illnesses and substance use disorders (SUDs). As a result, many states are at a crucial point in determining how best to support people with disabilities including a troubling re-emerging interest in returning people to congregate settings as an alternative to individualized housing with voluntary services.

Significant investments in mental health services have continued at the federal level. Funding for

the 988 Suicide and Crisis Lifeline reached nearly $1 billion this year (HHS Announces Additional $200 Million in Funding for 988 Suicide & Crisis Lifeline | HHS.gov). Funded by SAMSHA, 988 offers 24/7 call, text and chat access to trained crisis counselors. It is a national network of over 200 local, independent crisis centers equipped to respond to mental health-related and suicidal crises. There is increasing focus on the larger vision of connecting people from 988 to a range of community-based services, including mobile crisis teams and stabilization centers.

Strengthening and expanding the behavioral health crisis continuum should help to divert more people from entering restrictive, acute care settings if they can be connected to more and better "upstream" services. The "American Rescue Plan Act" (ARPA)-funded mobile crisis response option supports infrastructure for additional crisis services and has been approved in fourteen states to date. Half of all states have expressed the intention to pursue the ARPA community-based mobile crisis services. Workforce shortages, gaps in provider training, lack of technological infrastructure and adequate and sustainable funding were reported as the major barriers to expanding mobile crisis services with workforce shortages rising to the top.

The Administration continues to support the expansion of Certified Community Behavioral Health Clinics (CCBHCs), which offer community-based mental health and substance use treatment, including crisis services, 24 hours a day, 7 days a week. An additional $127.7 million was awarded by SAMHSA to expand CCBHCs in 2023. CCBHCs have grown from 67 operating in eight states in 2017 to over 500 CCBHCs today. The Community Mental Health Services Block Grant (MHBG) program, which funds comprehensive community mental health services for adults with serious mental illness and children with serious emotional disturbances, also grew in 2023. In August 2023, an additional $59.4 million was awarded to states and territories through the MHBG program as part of the Bipartisan Safer Communities Act (BSCA).

Building a continuum of crisis services and community-based mental health systems is a strategy for reducing emergency rooms visits, criminal justice involvement, and hospitalizations. However, the inadequate workforce, reduced access to support services, and lack of affordable housing units will continue to impact progress on *Olmstead* implementation if not addressed. Despite these challenges, some states have pressed forward with *Olmstead* activity. North Carolina issued a cross-disability *Olmstead* Plan in January 2022 and is moving forward with implementation. Minnesota continued implementing and refining its *Olmstead* Plan and provides accessible performance measures on its webpage. Other states working to comply with settlement agreement implementation, include Georgia, New Hampshire, Louisiana, Illinois and others.

As of May 2023, the U.S Substance Abuse and Mental Health Services Administration (SAMHSA) reports the following active *Olmstead* cases by topic: insufficient transition services for people from unnecessarily restrictive settings (e.g., psychiatric hospitals, adult homes, psychiatric residential treatment facilities, correctional facilities, segregated schools, segregated employment settings, and nursing homes); the provision of non-residential services; issues relevant to specific populations (e.g., children and people involved in the criminal justice system); institutional closure cases alleging a right to institutional care; and cases in which an absence of services in the community creates a risk of institutionalization.

DOJ opened new *Olmstead* investigations in 2023 in Colorado, suing the state of Colorado for unnecessarily segregating adults with physical disabilities, including older adults, in nursing facilities. The DOJ also filed a motion to intervene in Disability Rights California v. Alameda County and a proposed settlement agreement with Alameda County, California, and private plaintiffs to resolve allegations that the county violates Title II of the "Americans with Disabilities Act" (ADA) in its provision

MAJOR TOPICS IN *OLMSTEAD* INQUIRIES/ LAWSUITS AND STATES INVOLVED

Topic	Number of Cases	States Involved
Insufficient Support for Transition		
Psychiatric Hospitals	5	CA, GA, NH, SC, MS
Adult Homes/ Board and Care Homes	4	NY (2), NC, SC
Nursing Homes	3	CT, KS, LA, MO
Subtotal	**12**	
Segregated Non-Residential Services		
Social Services	1	NY
Employment Supports	2	OR, RI
Public Education	2	MA, GA
Subtotal	**5**	
Inadequacy of Community-Based Services for Children and Youth	13	AL, AK, CO, DC, ME, MI, NV, NC, NH, NM, PA, WA, WV
Differential Treatment in Justice Systems		
Post-Release Services	2	NV, NY
`Pre-Release Services	2	CA, CO
Involuntary Confinement	1	MI
Community Crisis Interventions	1	OK
Subtotal	**6**	
Risk of Institutionalization	15	AK, CA, CO, DC, GA, LA, ME, MS, NV, NH, NM, NY, NC, WA, WV
Institutional Closure	1	NY

of mental health services. Specifically, the proposed settlement agreement would resolve the department's findings that Alameda County fails to provide services to qualified individuals with mental health disabilities in the most integrated setting appropriate to their needs. Instead, the department found that the county places too many people with mental illness into institutions such as John George Psychiatric Hospital and other facilities. DOJ also opened an investigation in South Carolina that found the state unnecessarily segregates adults with mental illness in adult care homes.

Stakeholders should be aware of a recent court finding on behalf 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 5th District 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.

In September, 2023, the 5th U.S. Circuit Court of Appeals in New Orleans ruled that the DOJ's claim that adults with serious mental illness in Mississippi were "at risk" of institutionalization was not sufficient to prove discrimination under the "Americans with Disabilities Act," although other federal appeals courts have agreed that people who are "at risk" of unnecessary institutionalization can bring a claim under the ADA. The case could go to the U.S. Supreme

Court, where a judgment in favor of Mississippi could fundamentally alter the authority of the federal government to intervene in similar future cases nationwide.

FORECAST FOR 2024

The expansion of home-and-community-based services and a more robust behavioral health and crisis response are positive investments for reducing reliance on institutional and congregate care settings. However, realizing this potential will continue to be a struggle absent aggressive strategies to address the workforce shortage crisis. Increased funding to states must be passed on through rate increases, and in turn used to raise direct service staff wages, or providers will continue to struggle to maintain staffing to perform this critical work. Wages must be increased equally across systems to avoid disparities in pay and benefits that will cannibalize workers from one system to another. States may also look to expanded employment opportunities for individuals with lived experience and to paying family members as caregivers.

The unwinding of Medicaid's pandemic-related continuous enrollment guarantee was in effect through January 11, 2023. By November, over ten million people had been disenrolled from Medicaid coverage. More than seventy percent are estimated to have lost coverage due to procedural reasons, such as missing forms or inaccurate mailing addresses. While the federal government is working to address erroneous coverage loss, the gaps in coverage could impact health and behavioral health care access and outcomes for people with disabilities.

Stakeholders should also be aware of the CMS proposed rule to improve access to and quality of Home and Community-Based Services (HCBS) posted in 2023. If finalized, the new provisions will ensure important safeguards are in place for beneficiaries who receive HCBS through Medicaid. HCBS are critical for progress toward community integration for people with disabilities and achieving compliance with the ADA and *Olmstead* obligations. Policy and advocacy organizations across the nation are voicing concerns that many provisions in the proposed rule will not apply to Medicaid State plan mental health rehabilitative services, the option through which most Medicaid enrollees receive community mental health services and are calling for the Administration to finalize the rule with proposed changes that extend the protections to mental health rehabilitative services.

Some states will continue *Olmstead*-related planning, and others will continue to implement *Olmstead* settlement agreements that should result in additional community living opportunities despite state budget limitations. Such states include Louisiana, New York, North Carolina, and Georgia. Many states have also made modifications to service delivery to improve access to community-based care. For example, institutionalizing the use of telehealth to serve as an important tool to provide treatment and support services to people with disabilities. A growing number of states have submitted new and amended 1115 Medicaid waivers to address social determinants of health, including stable housing.

The expansion of voluntary community-based crisis services could further divert people from more restrictive settings, but access to upstream services, such as permanent supportive housing, case management, outpatient treatment, and supported employment, will be needed. Stakeholders should continue advocating for these funds to be directed toward gaps in community-based services and supports. This chapter identifies strategies for states to reinvigorate 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*.

STAKEHOLDER ACTIONS WITH POLICYMAKERS

Advocates should educate policy makers on *Olmstead*, integrated settings, and the case for affordable housing. There is increasing interest

by policy makers in some states to create new institutional capacity and forced treatment options in response to the highly visible problem of homelessness, as well as incarceration, of people with behavioral health conditions and other disabilities.

Though states have already determined how they will use increased allocations to the Substance Abuse Prevention and Treatment Block Grant and the MHBG awards, which must be expended by 2025, stakeholders should continue advocating for these funds to be directed to filling gaps in community-based services and supports to both divert and transition individuals from institutional and other segregated care settings.

Paramount to successful tenure in integrated housing is access to flexible and intensive support services. Advocates should learn about the opportunities afforded to states in using Medicaid programs, such as 1115 demonstration waivers to address social determinants of health and monitor the demonstrated outcomes. The Administration initially approved four 1115 waivers in AR, AZ, MA, and OR with SDOH provisions. Now seventeen states have 1115 SDOH provisions that include housing supports (CA, UT, AZ, NM, AR, IL, FL, RI, VA, MD, VT, MA, HI, NC, OR, NJ, WA), and several other states with pending applications (ME, NY, WV, MT). California's CalAIM initiative is receiving national attention for the massive transformation of its Medicaid program to cover non-traditional services that address social determinants of health like food and housing.

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.

In addition, the *Olmstead* planning lens requires intentional state efforts to address the ongoing overrepresentation of individuals with mental health and co-occurring mental illness and SUDs in the criminal justice system, along with equity strategies for people with disabilities from racially and ethnically diverse communities. In a recent groundbreaking development, CMS issued guidance on a new Medicaid Reentry Section 1115 Demonstration Opportunity that allows states to cover a package of pre-release services for up to 90 days prior to an individual's expected release date that could not otherwise be covered by Medicaid. Until this point, Medicaid has prohibited Medicaid payment for most services provided to most people in the care of a state or county carceral facility due to a statutory exclusion. Reentry from the criminal justice system is a critical intervention point. Supporting connections to community-based treatment and services for people with disabilities prior to reentering the community will help to avoid emergency department use, hospitalizations and recidivism, among other health benefits. CA and WA are the first two states to receive approval from CMS for reentry waiver proposals. Stakeholders should ensure that key decision makers in their state are informed of the Medicaid Reentry opportunity and associated benefits to communities, public health and public safety.

June 2023 marked the 33rd anniversary of the ADA. After more than three decades of affording individuals with disabilities the right to live, spend meaningful time and engage in social activities 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.

FOR MORE INFORMATION

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