Olmstead Implementation

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SUMMARY

In its 1999 decision in *Olmstead v. L.C.,* the United States Supreme Court found that the institutionalization of persons with disabilities who were ready to return to the community was a violation of Title II of the "Americans with Disabilities Act" (ADA). States have made variable progress on supporting people with disabilities in the most integrated settings possible.

Before the COVID-19 pandemic, several states were in the process of: (1) implementing "*Olmstead* Plans" that expand community-based supports, including new integrated permanent supportive housing opportunities; (2) implementing *Olmstead*-related settlement agreements that require thousands of new integrated permanent supportive housing opportunities to be created in conjunction with the expansion of community-based services and supports; or 3) implementing other related activities, such as Medicaid reform, that will increase access to services and supports intended to assist individuals with disabilities to succeed in integrated, community-based settings. Unfortunately, the pandemic has diverted many states' attention away from *Olmstead* and other federal and state priorities, impacting transitions to integrated community settings.

The pandemic has further reinforced the negative consequences of serving individuals in congregate settings. According to a report published by the Kaiser Family Foundation, as of May 17, 2021, the US has reported over 184,000 COVID-19 deaths among long-term care facility (LTCF) residents and staff, accounting for nearly one-third of all COVID-19 deaths in the US. These data do not reflect the full extent of COVID-19's impact on LTCFs beyond nursing homes, however, as data gaps for settings serving nonelderly people with disabilities are an ongoing challenge. Settings for which data are incomplete include certain institutions, such as intermediate care facilities for people with intellectual or developmental disabilities (ICF/IIDs) and inpatient behavioral health settings, and congregate community-based settings, such as group homes, personal care homes, assisted living facilities (ALFs), and adult day programs.

Residents in facilities that serve a relatively large share of Black and Hispanic residents have been affected disproportionately by the coronavirus. People of color are not only at greater risk for illness due to COVID-19, they are disproportionately hospitalized in psychiatric settings. The disparities that increase COVID-19 risk for people of color generally - homelessness, unstable, low quality, or densely populated housing, concerns about immigration status, language barriers, and closure or underfunding of healthcare facilities that primarily serve minority populations - also increase the likelihood of people of color being incarcerated or arrested, thus compounding the risk of morbidity or mortality from COVID-19.

Although the Trump Administration rescinded guidance on *Olmstead* and employment services, the 2011 DOJ *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.* that defines integrated and segregated settings remains. In June 2020, CMS reminded states that, consistent with the integration mandate, facilities are obligated to offer and provide discharge planning, case management, and transition services, as appropriate, to individuals who are removed from their Medicaid home and community based services during the course of the public health emergency, as well as to individuals with disabilities who may require these services in order to avoid unjustified institutionalization or segregation.

The impact of the pandemic on Olmstead implementation has been a double-edged sword. States have needed to divert their attention and resources from complying with Olmstead

to responding to the public health emergency. However, in response to the impact of the pandemic on the historically under- funded community-based systems that support people with disabilities, the Federal government has allocated unprecedented funding opportunities, increasing states' Community Mental Health and Substance Abuse Prevention and Treatment Block Grant awards, allowing states to expand and enhance their home and community-based services and supports and increasing federal funding to expand and enhance crisis response systems. States and communities have also received considerable funding to increase access to affordable housing. Several states are using these funding opportunities to fulfill their Olmstead obligations.

ADMINISTRATION

The U.S. Department of Justice (DOJ) is the federal agency charged with enforcing ADA and *Olmstead* compliance. Other federal agencies, including HUD and Health and Human Services (HHS), have funding, regulatory, and enforcement roles related to the ADA and *Olmstead*. Protection and Advocacy (P&A) agencies in each state are federally authorized and 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 a violation of Title II of the ADA. In its decision, the 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."

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 on 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 many residents primarily with disabilities, insufficient or inadequate services, restrictions on personal affairs, and housing that is contingent upon compliance with services.

IMPLEMENTATION

Since 1999, states have made variable progress on supporting people with disabilities in the most integrated settings possible. Prior to the pandemic, several states were in the process of: (1) implementing "*Olmstead* Plans" that expand community-based supports, including new integrated permanent supportive housing opportunities; (2) implementing *Olmstead*-related settlement agreements that require thousands of new integrated permanent supportive housing opportunities to be created in conjunction with the expansion of community-based services and supports; or 3) implementing other related activities, such as Medicaid reform, that will increase access to services and supports

intended to assist individuals with disabilities to succeed in integrated, community-based settings. Unfortunately, many states never developed Olmstead plans, have outdated plans, or are doing very little to comply with Olmstead specifically.

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 struggling to meet supportive housing compliance targets due to lack of resources for housing assistance and services.

Implementation efforts have largely focused on expanding community living options and services that support transitions to and successful tenancy in community-based housing as opposed 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 unnecessarily segregated in "sheltered workshops" and related day activity service programs.

The pandemic has contributed to housing affordability becoming an even greater barrier for states working to comply with ADA requirements. The cost of housing has sky-rocketed nationwide, both for the cost of home ownership and for rent. Nationally, the cost of rent has increased nearly 20% for a one-bedroom apartment, with all states experiencing an increase in rents. Most people with disabilities living in restrictive settings qualify for federal Supplemental Security Income (SSI) payments that average only 20% of median income nationally. Even prior to the Pandemic the Technical Assistance Collaborative's biannual ***Priced Out*** reports repeatedly demonstrated that in no housing market in the country could an individual on SSI afford the fair market rent. Several states have created or expanded state-funded rental subsidies directly related to their *Olmstead* efforts (see http://www.tacinc.org/knowledge-resources/publications/reports/state-funded-housing-assistance-report/ and https://www.huduser.gov/portal/periodicals/cityscpe/vol20num2/ch4.pdf). These state rental subsidies are typically designed as "bridge" subsidies to help people until a permanent HUD subsidy can be obtained, but often come at the expense of funding that could have been used for other necessary services.

In June of 2013, HUD issued *Olmstead* guidance to provide information on *Olmstead*, to clarify how HUD programs can assist state and local *Olmstead* efforts, and to encourage housing providers to support *Olmstead* implementation by increasing integrated housing opportunities for people with disabilities. HUD's guidance emphasizes that people with disabilities should have choice and self-determination in housing and states that "HUD is committed to offering individuals with disabilities housing options that enable them to make meaningful choices about housing, health care, and long-term services and supports so they can participate fully in community life."

HUD also advises that, "For communities that have historically relied heavily on institutional settings or housing built exclusively and primarily for individuals with disabilities, the need for additional integrated housing options scattered through the community becomes more acute." HUD 504 regulations require that HUD and its grantees/housing providers administer their programs and activities in the most integrated setting appropriate to the needs of individuals covered by the ADA. HUD's guidance does not change the requirements for any existing HUD program, but points out that requests for disability-specific tenant selection "remedial" preferences may be approved by HUD's Office of General Counsel if they are related to *Olmstead* implementation.

OLMSTEAD ACTIVITY IN 2021

Throughout 2021, states worked to rebound from the COVID-19 pandemic, diverting attention and resources away from *Olmstead* and impacting transitions to integrated community settings. This comes at a time when LTCF residents and staff account for nearly one-third of all COVID-19 deaths in the US. These data do not reflect the full extent of COVID-19's impact on LTCFs beyond nursing homes, however, as data gaps for settings serving nonelderly people with disabilities are an ongoing challenge. The pandemic has also amplified historic human resource issues; provider capacity nationwide is strained as direct service workforce shortages have reached crisis proportion. Increased incidents of depression, anxiety and opioid overdoses have resulted in Emergency Department boarding and wait times for community inpatient psychiatric beds. Access to affordable housing units has been severely compromised as a result of well-intended eviction moratoria and federal funding for rental assistance/homelessness prevention.

Despite these exacerbated and newly emerging challenges, *Olmstead* activity did continue in some states through planning (e.g. North Carolina, Minnesota) and settlement agreement implementation. States have continued to provide services under the authority of emergency waivers and state plan amendments from the Center for Medicare and Medicaid Services (CMS) to increase flexibility and coverage of services. Several states have extended waivers allowing, and some have institutionalized, the expanded use of telehealth strategies to maintain access to services, including for transition and tenancy sustaining services. Many providers have resumed some face-to-face service contacts with individuals in community-based settings.

The most promising support for community integration are newly available funding opportunities for states. Enhanced Federal Medical Assistance Percentage (FMAP) is available to expand home and community-based services and to enhance the array of crisis response services, through implementation of 988 and mobile crisis response teams. Section 9817 of the "American Rescue Plan Act" temporarily increases FMAP rates by 10 percentage points for certain Medicaid HCBS expenditures. This federal funding boost can help states increase community-based options for people with disabilities, promoting community inclusion. Through the creation of a nationwide and easy to remember number, 988, the "National Suicide Hotline Designation Act of 2020" sets the stage for a centralized access to behavioral health services. With careful state planning and system expansion, 988 has potential to become the foundation of an effective emergency response system for individuals in behavioral health crisis.

In addition, the "American Rescue Plan Act of 2021" (ARPA) provides a state Medicaid option, through state plan amendment or waiver, for community mobile crisis intervention services for five years. It further incentivizes state participation with an 85% enhanced federal matching rate for the first three years of qualifying services. Every state received an increase in its Substance Abuse Prevention and Treatment Block Grant and the Community Mental Health Services Block Grant awards, to be expended by 2025.

FORECAST FOR 2022

Emerging from the COVID-19 pandemic has been a primary focus for the Biden Administration and for states as federal and state agencies work to mitigate the stress of the virus on healthcare systems, increase vaccination rates, and push economic recovery. State budgets have received significant federal relief to mitigate the economic impact of the pandemic, however budget cuts to critical housing and services that support people with disabilities in integrated community settings could still be on the horizon, including critical supports that facilitate transitions from institutional settings.

The potential expansion of home and community-based services and a more robust crisis response have the potential to reduce reliance on institutional and congregate care settings; however, realizing this potential will require 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.

The Biden Administration has given indications of its intent to reinvigorate *Olmstead* activity, recently appointing Jennifer Mathis, Director of Policy & Legal Advocacy at the Bazelon Center for Mental Health Law & Deputy Legal Director, as a Deputy Assistant Attorney General at the U.S. Department of Justice's Civil Rights Division, where she will help lead its disability rights work. Advocates should make the case that supporting people with disabilities in integrated community settings is important public policy and aligns well with COVID mitigation and recovery plans. Stakeholders should continue to educate elected officials and policy makers on their obligations under the ADA and *Olmstead*. States and other public entities are legally obligated to ensure that all individuals with disabilities have the civil right to live and work in integrated, community-based settings.

On the positive side, several states continue *Olmstead*-related planning, and several continue to implement *Olmstead* settlement agreements that should result in additional community living opportunities despite state budgets. Among these include Louisiana, Minnesota, New York, and North Carolina. Many states have also made modifications to service delivery to sustain access. Telehealth has become an important tool to provide treatment and support services to people with disabilities, and several states have extended waivers allowing for, and some have institutionalized, the expanded use of telehealth.

STAKEHOLDER ACTIONS WITH POLICY MAKERS

Mental health and substance use funding administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) provided an additional $5 billion each for the Substance Abuse Prevention and Treatment Block Grant and the Community Mental Health Services Block Grant, to be expended by 2025. Stakeholders should advocate for these funds to be directed to filling gaps in community-based services and supports to both divert and transition individuals from institutional and congregate care settings.

States are faced with decisions about service waivers and flexibilities adopted during the Pandemic. Oregon and Massachusetts held listening sessions with providers, insurers, and consumers to get feedback on the state's regulatory approach to the ongoing use of telehealth.19 Through this monitoring, regulators learned that the changes succeeded in expanding use of telemedicine. For behavioral health, a few noted the benefits of

telemedicine, which appeared to produce more visits overall and fewer missed appointments. Advocates should inform policymakers about their perspectives on the ongoing role of telehealth in the behavioral health system.

According to the NLIHC, advocates and congressional leaders have secured nearly $85 billion in emergency housing and homelessness assistance since the start of the pandemic through the "American Rescue Plan Act", the December "COVID-19 relief bill", and the "CARES Act." They are now committed to ensuring emergency rental assistance (ERA) and other resources reach the lowest-income and most marginalized people.

Stakeholders must advocate for disparities in access to healthcare, housing, education and employment to be addressed in order to reduce psychiatric hospitalizations and incarceration in jails and prisons.

Finally, advocates should advise states to assess their progress with meeting the Integration Mandate, and to reenergize *Olmstead* planning and implementation if warranted. COVID-19 has dramatically exposed system failures, inadequate disability supports, and racial inequities. Yet the pandemic has also helped to propel large-scale policy changes and federal investments in housing and human services. Stakeholders should advocate for states and communities across the nation to reach across differences and programs to coordinate efforts and maximize the use of these resources. Stakeholders should advocate for states to leverage American Rescue Plan resources and other federal funds to ensure that more people have a safe, stable place to live with the services and supports they want and need to remain stably housed.

FOR MORE INFORMATION

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