

# Position Statement 25: Community Inclusion after Olmstead

## Policy

In 1999, the U.S. Supreme Court issued its landmark decision in *Olmstead v. L.C. (Olmstead)*,<sup>1</sup> ruling that unjustified segregation of people with mental disabilities constitutes unlawful discrimination under the Americans with Disabilities Act (ADA). MHA strongly supports the enforcement of the principle of community inclusion articulated in the *Olmstead* decision. Deinstitutionalization is not enough, and de-facto segregation on the streets and in single room occupancy flophouses – often referred to as “dumping” -- is not a solution. Robust community-based treatment resources, peer support, and a continuum of crisis care options to resolve danger to self or others without coercion must be understood as bedrock requirements of community inclusion.<sup>2</sup>

## Background

The human story behind the *Olmstead* decision is compelling, documenting recovery through community inclusion. The story begins with two women, Lois Curtis and Elaine Wilson, who had mental illness and developmental disabilities, and were voluntarily admitted to the psychiatric unit in the Georgia Regional Hospital. Following the women's medical treatment there, mental health professionals stated that each was ready to move to a community-based program. However, the women remained confined in the institution, each for several years after the initial treatment was concluded. They filed suit under the Americans with Disabilities Act (ADA) for release from the hospital. The Supreme Court decided under Title II of the ADA that mental illness is a form of disability and therefore covered under the ADA, and that unjustified institutional isolation of a person with a disability is a form of discrimination because it "...perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." The court added, "Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Both plaintiffs had spent most of their lives in the revolving door, in and out of institutions. Then, as the case worked its way through the courts, both plaintiffs were provided supportive housing in the community where they blossomed. Elaine Wilson died in 2005, but she enjoyed eight years with a host family in the community before she died. With the support of a job coach, she presented the story of her life and her lawsuit at several conferences and to university classes. Lois Curtis continues to thrive in her community, [winning recognition as a folk artist](#).<sup>3</sup> Both plaintiffs were able to establish normal and regular relationships with their own families.

The *Olmstead* decision is enforced through enthusiastic and determined grassroots and other advocacy efforts, asserting the ADA integration rights of individuals in state and private, publicly-funded institutions, nursing facilities, and other segregated settings. Judicial enforcement is pursued through private ADA litigation, and the Department of Health and Human Services (HHS) is mandated to assist in enforcement through its programs, especially the Office of Civil Rights (OCR) and the Substance Abuse and Mental Health Administration (SAMHSA). The OCR website is a helpful point of departure:

<http://www.hhs.gov/ocr/civilrights/understanding/disability/serviceolmstead/>

According to HHS, the ADA has been significant in promoting community inclusion:

- Individuals who had been institutionalized for decades are now receiving services in their community.
- Individuals who lost their housing and/or community-based supportive services when they were forced to enter institutions due to an acute health care problem have had the needed services provided or restored.
- Individuals with disabilities are able to access home and community-based services through Medicaid "Waiver" programs.
- Increased hours of personal care and assistance are being provided to individuals who require additional services to remain in the community.
- Individuals with disabilities now have greater control over their community-based care and services.
- Individuals' needs are met by providing reasonable accommodations in their communities, and not by moving to a more restrictive setting.

The Department of Justice (DOJ) has regulatory and litigation authority to implement the ADA, and its regulations were sustained in *Olmstead*. In interpreting the ADA, the Court relied on the "integration mandate"—a regulation issued by the U.S. Department of Justice requiring public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). The Court also relied on a regulation requiring public entities to make "reasonable modifications" to avoid discrimination on the basis of disability. Since 2009, the DOJ has engaged in active enforcement of the *Olmstead* principles in deinstitutionalizing state mental health systems for persons with mental illness and developmental disabilities. The DOJ website documents these efforts:

<http://www.ada.gov/olmstead/>

The decision established that discrimination occurs whenever a person with a disability is segregated despite the reasonable determination of professionals that community placement is appropriate, the person is not opposed to such placement, and community placement can be reasonably accommodated. At this point, the state is obligated to provide the needed supports and services to enable the person with the disability to receive services in the most integrated setting appropriate to the individual.

The important question in each case is: What segregation is justifiable under the ADA? In the Supreme Court's Syllabus, Justice Ginsburg, joined by Justice O'Connor, Justice Souter, and Justice Breyer (leaving Justice Stevens as the only member of the majority not joining in the *obiter dictum*), concluded that:

The State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless. The reasonable-modifications regulation speaks of "reasonable modifications" to avoid discrimination, and allows States to resist modifications that entail a "fundamental[ly] alter[ation]" of the States' services and programs. If, as the Eleventh Circuit indicated, the expense entailed in placing one or two people in a community-based treatment program is properly measured for reasonableness against the State's entire mental health budget, it is unlikely that a State, relying on the fundamental-alteration defense, could ever prevail. Sensibly construed, the fundamental-alteration component of the reasonable-

modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities. [emphasis supplied]

The ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. Nor is it the ADA's mission to drive States to move institutionalized patients into an inappropriate setting, such as a homeless shelter.... Some individuals...may need institutional care from time to time to stabilize acute psychiatric symptoms. For others, no placement outside the institution may ever be appropriate. To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow. 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 not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met. In such circumstances, a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions.<sup>4</sup>

The emphasis here is on the recognition that unnecessary segregation is impermissible but the state may adjust services over time pursuant to a plan, if there *is* a plan and if it moves people into the community at a reasonable pace.

This language has been the heart of ADA litigation and settlement discussions in the many cases settled since, often with Department of Justice assistance. Phased deinstitutionalization plans have adopted in most states, heeding the advice given in the four-justice dictum. If offered in defense of litigation, such plans must be shown to offer real hope of relief. A showing that resources are gradually being shifted from institutions to the community is not enough. The state must demonstrate active movement of people identified for placement. This position statement celebrates the efforts of civil rights advocates and government agencies, especially the DOJ and the OCR, that have fought to make *Olmstead* a reality – to make services to people with behavioral, developmental, and physical health conditions more user-friendly, more recovery-oriented, more community-based and more integrated and comprehensive. A few of the most recent significant resolved system-wide mental health treatment reform cases (from the DOJ website, [http://www.ada.gov/olmstead/olmstead\\_cases\\_list2.htm#ny](http://www.ada.gov/olmstead/olmstead_cases_list2.htm#ny)), include:

- *Helen L. v. DiDario* -- 46 F. 3d 325 (3d Cir. 1995), a precursor of *Olmstead*, held that Pennsylvania violated the ADA by requiring that the plaintiff receive required care services in the segregated setting of a nursing home rather than through an out-patient attendant care program. That program would allow her to receive those services in her own home where she could reside with her children. The Court observed that:

?"Ironically, DPW assert[ed] a justification of administrative convenience to resist an accommodation which would save an average of \$34,500 per year, would allow Idell S. to live at home with her children, and which would not require a single substantive change in its attendant care or nursing home programs. DPW's resistance to such an accommodation is totally inconsistent with Congress' pronouncement that "[t]he Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, [and] independent living...." 42 U.S.C. §

12101(a)(8). [http://scholar.google.com/scholar\\_case?case=9354469717264660022&hl=en&as\\_sdt=6&as\\_vis=1&oi=scholar](http://scholar.google.com/scholar_case?case=9354469717264660022&hl=en&as_sdt=6&as_vis=1&oi=scholar)

- *U.S. v. Georgia* – 10-CV-249 – (N.D. Ga. 2010)

On October 19, 2010, the DOJ entered into a comprehensive Settlement Agreement with the State of Georgia and Georgia officials, resolving the United States' complaint alleging that individuals with mental illness and developmental disabilities confined in State hospitals were unnecessarily institutionalized and subjected to unconstitutional harm to their lives, health, and safety in violation of the ADA and the U.S. Constitution. This comprehensive, state-wide settlement thoroughly restructured the Georgia mental health and developmental disabilities systems.

The agreement requires Georgia to expand community services so that individuals with mental illness and developmental disabilities can receive supports in the most integrated setting appropriate to their needs.<sup>5</sup>

- *U.S. v. Delaware* – 11-CV-591 – (D. Del. 2010)

On July 6, 2011, the DOJ filed in District Court a Complaint and a simultaneous Settlement Agreement resolving its ADA *Olmstead* investigation into whether persons with mental illness in Delaware are being served in the most integrated settings appropriate to their needs and its CRIPA investigation into conditions of confinement at Delaware Psychiatric Center.

The fundamental goals of the Agreement are: to ensure that people who are unnecessarily institutionalized, at the Delaware Psychiatric Center or other inpatient psychiatric facilities, can receive the treatment they need in the community; to ensure that when individuals go into mental health crisis, sufficient resources are available in the community so that they do not need to go unnecessarily to psychiatric hospitals or jails; and to ensure that people with mental illness who are living in the community are not forced to enter institutions because of the lack of stable housing and intensive treatment options in the community.<sup>6</sup>

- *U.S. v. North Carolina* – No. 5:12-CV-557 – (E.D.N.C. 2012)

On August 23, 2012, the DOJ entered a comprehensive, eight-year settlement agreement with the State of North Carolina resolving the Civil Rights Division's ADA *Olmstead* investigation of the State's mental health service system, which currently serves thousands of individuals with mental illness in large adult care homes. The Agreement will expand access to community-based supported housing – integrated housing that promotes inclusion and independence and enables individuals with mental illness to participate fully in community life.<sup>7</sup>

- *Amanda D., et al. v. Hassan, et al.; United States v. New Hampshire*, No. 1:12-CV-53 (SM)

On December 19, 2013, the DOJ, along with a coalition of private plaintiff organizations, entered into a comprehensive Settlement Agreement with the State of New Hampshire that will significantly expand and enhance mental health service capacity in integrated community settings over the next six years. The Agreement is a full consent decree entered by the U.S. District Court for the District of New Hampshire as a Court order on February 12, 2014. The Agreement also provides for regular compliance reviews and public reporting by an independent monitor.

The Agreement will enable a class of thousands of adults with serious mental illness to receive expanded and enhanced services in the community, which will foster their independence and enable them to participate more fully in community life. It will significantly reduce visits to hospital emergency rooms and will avoid unnecessary institutionalization at State mental health facilities, including New Hampshire Hospital (the State's only psychiatric hospital) and the Glenclyff Home (a State-owned and -operated nursing facility for people with mental illness).<sup>8</sup>

- *U.S. v. New York* – 13-CV-4165 – (E.D.N.Y. 2013) (The New York care and boarding homes litigation)

On July 23, 2013, the United States, individual plaintiffs, and the State of New York filed a settlement agreement in the U.S. District Court for the Eastern District of New York. The parties filed an amended settlement agreement on January 30, 2014, and the court approved the settlement agreement on March 17, 2014. The agreement remedies discrimination by the State in the administration of its mental health service system and ensures that individuals with mental illness who reside in 23 large adult homes in New York City receive services in the most integrated setting appropriate to their needs consistent with the ADA and Olmstead. Under the agreement, such individuals will have the opportunity to live and receive services in the community such that they are able to live, work, and participate fully in community life.<sup>9</sup>

Prior to the agreement, the parties litigated these issues in *Disability Advocates v. Paterson*, in the District Court and in the U.S. Court of Appeals for the Second Circuit. In that case, following a trial on the merits, the U.S. District Court for the Eastern District of New York ruled that New York State officials and agencies discriminated against thousands of people with mental illness by administering the State's mental health service system in a manner that segregated them in large, institutional adult homes and denied them the opportunity to receive services in the most integrated setting appropriate to their needs.

- *M.R. v. Dreyfus* – 663 F. 3d 1100 (9<sup>th</sup> Cir. 2011)

In a suit brought on behalf of approximately 45,000 individuals with disabilities who receive personal care services through Washington State's Medicaid program, a 9th Circuit panel determined that across the board state budget cuts that reduced in-home care hours by 10 percent violated the ADA. The Ninth Circuit reversed the judgment of the district court and granted injunctive relief with respect to the named plaintiffs, finding that plaintiffs had demonstrated that the State's cuts placed them at serious risk of institutionalization in violation of the

ADA. [http://scholar.google.com/scholar\\_case?case=5879426322966814266&hl=en&as\\_sdt=6&as\\_vis=1&oi=scholar](http://scholar.google.com/scholar_case?case=5879426322966814266&hl=en&as_sdt=6&as_vis=1&oi=scholar)

## Call To Action

- Affiliates and advocates have long advocated for deinstitutionalization of state mental hospitals, and many have participated in DOJ audits and remedial activities, implementing Olmstead. The challenge now is to promote more effective community integration, including positive social interactions and support, especially of peers, access to meaningful work, and promotion of spiritual, religious, cultural and recreational opportunities. Part of providing services in the most integrated setting is providing services early and effectively so that a person avoids exclusion from the community

altogether. A mix of universal and targeted early intervention and prevention services integrated into schools and communities ([#B4Stage4](#)), would assure that care would truly be given in the most integrated setting possible.

- MHA is committed to protecting the gains made under the ADA in reforming state mental health systems. MHA and its affiliates should oppose legislative efforts to undermine Olmstead or to roll back gains made under the ADA for people with mental health conditions. MHA and its affiliates should likewise support proactive legislation in all states to advance community inclusion and integration of services, without waiting for additional courts to compel states to do what NY, DE, PA, NH, GA, and others are now having to do.
- MHA and its affiliates should advocate for universal prevention services and targeted early intervention services in schools and in primary care, as well as an effective continuum of care. These are essential to avoid segregation caused by failure to address mental health and substance use treatment needs before symptoms become more serious.
- MHA and its affiliates should educate the public concerning the parallel issue of transinstitutionalization (e.g. over-incarceration of consumers)
- MHA and its affiliates should ensure that community inclusion is promoted and measured as an outcome by providers, peers, and administrators of mental health care systems.
- To make community inclusion successful, MHA and its affiliates should prioritize public education and outreach to help communities become more welcoming of consumers and facilitative of their recovery.

## Effective Period

This policy was adopted by the Mental Health America Board of Directors on March 7, 2015. It is reviewed as required by the Mental Health America Public Policy Committee.

Expiration: December 31, 2020

1. *Olmstead v. L. C.* (98-536) 527 U.S. 581 (1999) <http://www.law.cornell.edu/supct/html/98-536.ZS.html>

2. [See MHA Position Statement 22, Involuntary Treatment](#)

3. <http://www.whitehouse.gov/blog/2011/06/22/olmstead-champion-meets-president>

4. *Olmstead v. L. C.* (98-536) 527 U.S. 581, \_\_\_ (1999).

5. Specifically, for individuals with developmental disabilities, the agreement provides that Georgia will cease all admissions to the State-operated institutions; transition all individuals to the most integrated setting appropriate to their needs by July 1, 2015; create more than 1100 home and community-based waivers to serve individuals in the community; serve those



receiving waivers in their own home or their family's home consistent with the individual's informed choice; and provide family supports, mobile crisis teams, and crisis respite homes.

For individuals with mental illness, the agreement provides that Georgia will serve in the community 9,000 individuals with serious and persistent mental illness who are currently served in State Hospitals; frequently readmitted to State Hospitals; frequently seen in emergency rooms; chronically homeless; and/or being released from jails or prisons. Services will be provided through a combination of 22 Assertive Community Treatment teams, 8 Community Support teams, 14 Intensive Case Management teams, 45 Case Management service providers, 6 Crisis Services Centers, 3 additional Crisis Stabilization Programs, community-based psychiatric beds, mobile crisis teams, crisis apartments, a crisis hotline, supported housing, supported employment, and peer support services. The agreement also provides for a State-wide quality management system for community services and names an Independent Reviewer to assess the State's compliance with the agreement.

6. Pursuant to the Agreement, Delaware will create a comprehensive community crisis system to serve as the front door to the state's mental health system including a crisis hotline, mobile crisis teams able to reach someone anywhere in the state within one hour, 2 walk-in crisis centers, and short term crisis stabilization units. The agreement also commits the state to providing intensive community-based treatment through 11 Assertive Community Treatment (ACT) teams, 4 intensive case management teams, and 25 targeted case managers. The State will offer at least 650 housing vouchers or subsidies to allow people to obtain stable, integrated housing. Finally, the State will develop evidence-based supported employment services for 1100 people, rehabilitation services including substance abuse and educational services to 1100 people, and family and peer support services to 1000 people. The Agreement requires Delaware to establish a statewide quality management system reflecting qualitative and quantitative measures and provides for an independent monitor with capacity to hire staff to assist in the implementation and to conduct compliance reviews.

7. Pursuant to the Agreement, North Carolina will provide community-based supported housing to 3,000 individuals who currently reside in, or are at risk of entry into, adult care homes. A person-centered discharge planning process is designed to ensure individuals are able to transition successfully to community-based settings, while a pre-admission screening process will prevent more individuals from being unnecessarily institutionalized. The Agreement will also ensure that thousands of people with mental illness have access to critical community-based mental health services such as Assertive Community Treatment (ACT) teams, and will expand integrated employment opportunities for individuals with mental illness by providing supported employment services to 2,500 individuals. The Agreement also requires development of a crisis service system that offers timely and accessible services and supports in the least restrictive setting, including mobile crisis teams, walk-in crisis clinics, short-term community hospital beds, and 24/7 crisis hotlines.

8. The Agreement requires the State, for the first time, to create mobile crisis teams in the most populated areas of the State and to create crisis apartments to help support team efforts at avoiding hospitalization or institutionalization. The Agreement also requires the State to make enhanced Assertive Community Treatment ("ACT") team services available statewide, such that the mental health system can provide ACT to at least 1,500 people at any given time. The Agreement requires the State to provide scattered-site, permanent, supported housing to hundreds of additional people throughout the state; the State will also create special residential community settings to address the needs of persons with complex health care issues who have had difficulty accessing sufficient community services in the past. The State will also deliver

additional and enhanced supported employment services, consistent with the Dartmouth evidence-based model, to hundreds of new recipients throughout the state.

9. The Agreement will transform New York's mental health system to ensure that individuals with serious mental illness who reside in 23 large, privately owned institutional settings known as adult homes in New York City are provided the opportunity to receive the community-based services and housing that will enable them to live, work, and participate fully in community life.

The Agreement provides community-based, scattered-site supported housing to all eligible people with serious mental illness who are unnecessarily segregated in these adult homes and who wish to live in supported housing. Supported housing is scattered-site apartments for which the State provides rental assistance and housing-related support services. Residents will have access to flexible services to support them as needed and desired. The State will create at least 2,000 supported housing units and will continue to create additional units to ensure that all eligible adult home residents who want to move to supported housing have the opportunity to do so.

Every adult home resident who moves to supported housing will also get the community-based mental health services he or she needs to succeed in supported housing, including Assertive Community Treatment (ACT) teams, crisis services, personal care assistance, assistance with taking medication, and care coordination. The State will also implement a person-centered planning process to help people transition into the community.