



Olmstead In Massachusetts:

Think Outside the Facility

Outside the Facility....Frederick Law Olmsted

Beginning in 1857 with the design for Central Park in New York City, Frederick Law Olmsted (1822–1903), his sons and successor firm created designs for more than 6,000 landscapes across North America, including Prospect Park in Brooklyn, Boston's Emerald Necklace, Biltmore Estate in Asheville, North Carolina, Mount Royal in Montreal, the grounds of the United States Capitol and the White House, and Washington Park, Jackson Park and the World's Columbian Exposition of 1893 in Chicago.

(Olmsted) believed that parks can bring social improvement by promoting a greater sense of community and providing recreational opportunities, especially in urban environments.

Between 1856 and 1860 he published three volumes of travel accounts and social analysis of the South...he used his literary activities to oppose the westward expansion of slavery and to argue for the abolition of slavery by the southern states.

What is Olmstead?

- ▶ **Olmstead**, or *Olmstead v. LC*, is the name of the most important civil rights decision for people with disabilities in our country's history.
- ▶ Olmstead, the named Defendant in the case, was the Commissioner of the Georgia Department of Human Resources and the named defendant.
- ▶ In 1999, in hearing an appeal on Olmstead, the Supreme Court held that people with disabilities have a **qualified right** to receive state funded supports and services in the community rather than institutions when certain conditions are met.

What is Olmstead? (continued)

The Olmstead decision laid the groundwork for much of the movement of individuals from institution to community.

<https://www.olmsteadrights.org/about-olmstead/>

Current Reality or History?

*“In the approximately ____ since the Supreme Court’s decision in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), regarding the integration mandate of Title II of the Americans with Disabilities Act (ADA), some state and local service systems have begun to provide a greater number of integrated community alternatives to individuals in or at risk of segregation in institutions or other segregated settings; yet, despite these advances, many individuals with disabilities who receive employment and day services that are planned, funded, and administered by state and local governments continue unnecessarily to receive services, and spend the majority of their daytime hours, in segregated settings.”*

Department of Justice, October 31, 2016

Olmstead: Journey to Community



We're not there yet.

However, it's clear that the Olmstead case changed the parameters of the world for people with disabilities and the elderly.

Let's look at how this all came about....

Olmstead v. LC: Highlights

- ▶ “Olmstead” began with Lois Curtis and Elaine Wilson. The women lived in Georgia, and had diagnoses of mental health conditions and intellectual disabilities. Both were engaged in a revolving door – facility to home to facility because they were unable to find treatment and support in the community.
- ▶ The two women asked for help getting treatment in the community; their providers agreed that the women could live in the community with supports.
- ▶ ***However – Ms. Curtis and Ms. Wilson ended up waiting for years for their community-based supports to be set up.***

Olmstead v. LC: Highlights (continued)

- ▶ A lawsuit known as “Olmstead v. L.C.” or “The Olmstead Decision,” was filed on behalf of Lois. Elaine was added to the suit later. The lawsuit asked for community services for the women.
- ▶ In March 1997, Judge Marvin Shoob ruled in favor of the plaintiffs, declaring that the failure of the Georgia Department of Human Resources and Georgia Regional Hospital to:

“...place plaintiffs in an appropriate community-based treatment program violates Title II of the Americans with Disabilities Act”.

The Olmstead Lawsuit

The Georgia Defendants appealed to the Eleventh Circuit Court of Appeals and lost.

They then appealed to the United States Supreme Court.

- ▶ The United States Supreme Court agreed to hear the appeal
- ▶ The case was heard on April 21, 1999, and the decision was announced on June 22, 1999

Olmstead Decision

- ▶ The Court answered with a strong but qualified “yes”, stating that community placement was required:
 - *When treatment professionals determine that community placement is appropriate;*
 - *When the individual does not oppose being served in the community;*
 - *When the placement is a reasonable accommodation when balanced with the needs of others with disabilities.*

Lois Curtis



Photo caption: Lois Curtis with a self-portrait and her portrait of Elaine Wilson. Photo © Robin Rayne Nelson.

Lee: ...Tell me, what do you wish for all the people you've helped move out of the institution to live in their communities?

Lois: I hope they live long lives and have their own place. I hope they make money. I hope they learn every day. I hope they meet new people, celebrate their birthdays, write letters, clean up, go to friends' houses and drink coffee. I hope they have a good breakfast every day, call people on the phone, feel safe.

Lee Sanders is a Career Specialist with Briggs & Associates, Roswell, Georgia. She interviewed Lois Curtis in 2014.

Olmstead Supreme Court Ruling

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 - *When the placement is a reasonable accommodation when balanced with the needs of others with disabilities.*

...When the placement is a reasonable accommodation when balanced with the needs of others with disabilities.

- ▶ The heart of most post-Olmstead litigation.
- ▶ The Court acknowledged that a state might be able to resist some modifications *if the modifications would fundamentally alter services.*



The issue becomes balancing the needs of *SOME* individuals with disabilities against the needs of other individuals with disabilities.

The Olmstead Decision: Implications For Medicaid

Kaiser Family Foundation Report

- ▶ In March 2000, the Kaiser Commission on Medicaid and the Uninsured issued a report. In brief, this stated that:
 - Olmstead was not a Medicaid case; the decision alters neither the individual entitlement nor states' basic legal obligations
 - The ruling lays out the requirements of the ADA with regard to community placement

The Olmstead Decision: Implications For Medicaid

Kaiser Family Foundation Report

The Foundation Report further noted that the Court dismissed as “irrelevant to its ruling” assertions by the states’ lawyers that Medicaid favored the financing of institutional care.

However – the decision implicates Medicaid.

The report suggests that use of Medicaid funding to provide community care for persons with disabilities should be thought of as a consequence of, rather than required by, Olmstead.

<https://kaiserfamilyfoundation.files.wordpress.com/2000/03/2185-the-olmstead-decision-implications-for-medicaid.pdf>

Medicaid and Olmstead

- ▶ Olmstead focused on the setting where services were provided to individuals with disabilities
- ▶ Olmstead doesn't change or interpret Medicaid law
- ▶ Medicaid has leaned, structurally, toward institutional care because state Medicaid programs are obligated to cover nursing facility services
 - HCBS Waivers offered – and continue to offer – an option to move Medicaid services for individuals requiring an institutional level of care into the community

Moving Forward

- ▶ After Olmstead, the lawsuits that followed generally reached written decisions in favor of individuals with disabilities.
- ▶ Courts quickly made clear that Olmstead applied to all state and Medicaid funded institutions, including nursing facilities.
- ▶ *Courts also found that Olmstead applied to individuals living in the community who were at risk of institutionalization.*
- ▶ The United States Justice Department made Olmstead a priority of its Civil Rights division and began to enforce the Supreme Court mandate in state after state after 2009.

Department of Justice & Olmstead

- ▶ **2009:** President Obama issued a proclamation launching the "Year of Community Living,"
- ▶ The Civil Rights Division responded by enforcing, nationwide, the integration mandate of the Department's regulation implementing title II of the ADA.

"The Olmstead ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently."

Barak Obama

DOJ, Civil Rights & Olmstead: Moving Forward

“Olmstead affirmed the rights of Americans with disabilities to live in their communities,” said President Obama. “As we mark the anniversary of this historic civil rights decision, we reaffirm our commitment to fighting discrimination, and to addressing the needs and concerns of those living with disabilities.”

The Department of Justice also continues to enforce the ADA and *Olmstead*. Over the last three years, the Civil Rights Division at the Department has been involved in more than 40 *Olmstead* matters in 25 states.

June 22, 2012, White House Press Release

Administration for Community Living

- ▶ April, 2012: The Department of Health and Human Services (HHS) announced the creation of the **Administration for Community Living** (ACL):
 - The ACL brings together key HHS organizations and offices dedicated to improving the lives of those with functional needs into one coordinated, focused and stronger entity.
 - ACL combined the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities into a single agency
 - ACL will work on increasing access to community supports and achieving full community participation for people with disabilities and seniors.

White House Press Release, June 22, 2012

Why Were State-Specific Olmstead Plans Developed?

In the 1999 Olmstead decision by the Supreme Court, the Court interpreted the Americans with Disabilities Act (ADA) to require states to provide services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”

Additionally, the Court indicated that each state should develop an Olmstead plan to demonstrate efforts to be consistent with the ruling.

Olmstead in Massachusetts

- ▶ Massachusetts developed an Olmstead Plan, beginning in 2007 and publishing in 2008.

“The Commonwealth of Massachusetts is establishing its Community First Olmstead Plan pursuant to a Supreme Court decision compelling states to create meaningful community living plans for people with disabilities and elders....”

- ▶ The plan vision was to:

Empower and support people with disabilities and elders to live with dignity and independence in the community by expanding, strengthening, and integrating systems of community-based long-term supports that are person-centered, high in quality and provide optimal choice.

Massachusetts Olmstead Plan: Community First Goals

- ▶ Help individuals transition from institutional care.
- ▶ Expand access to community-based long-term supports.
- ▶ Improve the capacity and quality of community-based long-term supports.
- ▶ Expand access to affordable and accessible housing and supports.
- ▶ Promote employment of persons with disabilities and elders.
- ▶ Promote awareness of long-term supports.

Principles of Massachusetts Olmstead Planning

- ▶ People with disabilities and elders should have access to community living opportunities and supports;
- ▶ The principle of “community first” should shape state elder and disability policy development and funding decisions;
- ▶ A full range of long-term supports, including home and community-based care, housing, employment opportunities, as well as nursing facility services are needed;
- ▶ Choice, accessibility, quality, and person-centered planning should be the goals in developing long-term supports;
- ▶ Systems of community-based care and support must be strengthened, expanded and integrated to ensure access and efficiency;
- ▶ Public and private mechanisms of financing long-term care and support must be expanded;
- ▶ Long-term supports developed under this plan must address the diversity of individuals with disabilities and elders in terms of race, ethnicity, language, ability to communicate, sexual orientation, and geography.

Community First: Building Community Systems

- ▶ Implement Community Options Counseling and Aging and Disability Resource Consortium (ADRC) model
- ▶ Launch a 1115 Waiver (Community First)
- ▶ Hutchinson and Rolland plus the new waiver seen as building system capacity while transitioning individuals from facilities
- ▶ Implement a Personal Care Attendant Workgroup to identify and implement ways to improve the MassHealth (Medicaid) PCA program
- ▶ Increase transportation options and resources
- ▶ Hold to a core principle of consumer choice
- ▶ Improve coordination of long-term supports within affordable housing
- ▶ Improve access to gainful employment for elders and individuals with disabilities

The Massachusetts Landscape.....

Massachusetts Olmstead Plan Revision: Just Beginning

Money Follows the Person (1915 (c) Waivers

Second Hutchinson Settlement

Money Follows the Person Demonstration

Community First: Massachusetts Olmstead Plan

Acquired Brain Injury Waivers (1915(c) HCBS Waivers

Hutchinson vs. Patrick

Rolland vs. Cellucci

Boulet vs. Cellucci

Olmstead decision

...Changes Following Olmstead

- ▶ In Massachusetts, several challenges to the availability of community-based services followed Olmstead.
 - **1999:** Boulet vs. Cellucci, held that the issue of long waiting lists for Medicaid funded services must be addressed
 - **2000:** Rolland vs. Patrick, settlement requiring the transition of over 1225 individuals with I/DD in nursing facilities into the community

Following Olmstead (continued)

- **2008:** Rolland v. Patrick, Federal court approves second settlement agreement
- **2008:** Hutchinson v. Patrick, Federal court approves first settlement requiring the transition of over 1,000 individuals with brain injury in nursing facilities into the community
- **2012:** Hutchinson v. Patrick, Federal court approves second settlement
- **2013:** Rolland v. Cellucci, closed after the plaintiffs agreed that the state fulfilled its obligations under the last of two settlements reached in the case

Let's take A Closer Look...



Massachusetts following Olmstead

"I feel like I am part of the community again...."

Cathy Hutchinson

Massachusetts: Boulet

“As Ed approached the age of 40, and we were both approaching 70, we found it harder than ever to care for him all the time - day and night - when he had severe seizures. We all needed a better living situation than Mom and Dad could provide, but there weren't any affordable or adequate alternatives.”

Mary Ann Boulet, mother of Edmund Boulet

Boulet v. Patrick

From Institution to....Waiting List

In Massachusetts, a series of consent decrees began the process of closing the state facilities for individuals with intellectual disabilities. These began to close in 1992. However, there was a long waiting list for community services. Families like the Boulet family waited....and waited.

In 1996, funding was obtained from the Joseph P. Kennedy, Jr. Foundation to support the establishment of Family to Family (intended) to address this Waiting List. 250 parents (were surveyed) to identify needs and hear what families were looking for. Only four said they would consider an institutional setting.

<http://thearcofmass.org/wp-content/uploads/2014/02/History-Book.pdf>

Boulet et al. v. Celluci filed

In 1999, with the leadership of The Arc, eight parents filed a Class Action suit in federal court on behalf of these waiting list families. Neil V. McKittrick of Hill and Barlow agreed to take on the case on a pro bono basis and Edmund Boulet became the lead plaintiff in what would become known as the Boulet lawsuit.

“I will certify a class somewhat narrower than that which plaintiffs propose and I will grant the plaintiffs' motion for partial summary judgment specifically declaring their entitlement within 90 days to residential habitation services in a group home setting....”

Boulet Settlement

- ▶ Boulet et al v. Cellucci was settled in December, 2000
- ▶ The settlement agreement included 2,437 people then on a DDS waiting list, but not those that were wait listed after July 14, 2000
- ▶ The agreement committed the state to spending nearly \$126 million between FYs 2001-02 and 2005-06 to:
 - Provide out-of-home placements to the people it covered
 - Interim services while they waited.

Boulet Settlement (continued)

- ▶ The agreement requires the governor to ask the legislature for the agreed-upon funds each year. If the legislature does not appropriate the requested amount in a particular year, the following year the governor must ask for that year's required funds plus the gap in the previous year's appropriation.

<https://www.cga.ct.gov/2003/olrdata/ph/rpt/2003-R-0382.htm>

Coming Home:

Rolland and Hutchinson

Rolland v. Cellucci

Massachusetts: Rolland vs. Cellucci

- ▶ Named after lead plaintiff Loretta Rolland. Paul Cellucci, the named defendant, was the Governor of Massachusetts.
- ▶ Rolland was a class action case brought on behalf of almost 2000 persons with intellectual and developmental disabilities placed in nursing facilities.
- ▶ The initial Settlement Agreement of 1999 required:
 - Provide community placement to 1100 persons
 - Provide specialized services and active treatment to class members while they remain in a nursing facility.
- ▶ After several findings of noncompliance with the terms of the settlement, the district court adopted CMS' active treatment standards, appointed a court monitor, and approved a detailed monitoring protocol.

Active Treatment Standards

- ▶ Comprehensive Functional Assessment
 - Specific developmental strengths, including individual preferences;
 - Specific functional and adaptive social skills the individual needs to acquire;
 - Presenting disabilities and when possible their causes; and
 - Need for services without regard to their availability.
- ▶ Individual Program Plan
- ▶ Program Implementation
- ▶ Program Documentation
- ▶ Program Monitoring

https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR_Glossary.pdf

Rolland vs. Cellucci

- ▶ In 2007, the plaintiffs returned to court, stating that active treatment was not being provided, nor was adequate placement.
- ▶ The Commonwealth entered into a new Settlement Agreement on Active Treatment in 2007 which resulted in community placements for an additional 650 class members.
- ▶ Many of the plaintiffs did not need skilled nursing care, but help with basic daily activities, according to the suit. The case also said most plaintiffs were not receiving required services to help them live more independently.
- ▶ Case dismissed in May 2013, after a finding of substantial compliance with both Settlement Agreements.

Loretta Rolland



Loretta Rolland moved out of a nursing facility in 2002.

She is shown here as she leaves U. S. Federal Court in Springfield Wednesday with her brother Alfred Rolland, left, of Springfield and her sister, Claire Harris, right, of Chicopee.

Hutchinson v. Patrick

Hutchinson vs. Patrick

“The brain injuries experienced by these individuals are profound and life changing, but they need not result in a lifetime of institutional care. ...these individuals need “family relations, social contacts, work options, economic, independence, educational advancement and cultural enrichment.”

Olmstead v. L.C., 527 U.S.581, 600 (1999)

“Their medical and rehabilitative needs can best be met in community settings, which have been demonstrated to improve skills, promote rehabilitative goals, and facilitate independence for persons with brain injuries and other severe disabilities. These individuals are entitled to receive services in the most integrated setting appropriate for their needs...”

Attorneys for the Plaintiffs

Hutchinson vs. Patrick

- ▶ Five named plaintiffs, the Brain Injury Association of MA and Stavros Center for Independent Living sued the Commonwealth for community-based, individualized care.
- ▶ On June 2, 2008, a landmark settlement was reached that enabled individuals with acquired brain injuries to move out of nursing facilities and into the community.

Massachusetts: Hutchinson vs. Patrick



“I lived in nursing home for 15 years. I feel very happy and satisfied to hear of how this has helped other people in the hope to have all states to follow suit. I just love it. I feel like I am part of the community again, the privacy back is wonderful I have my life back.....”

Coming Home



Cathy Hutchinson still lives in the home she moved into as part of the ABI-Residential Habilitation waiver.

Acquired Brain Injury Waivers

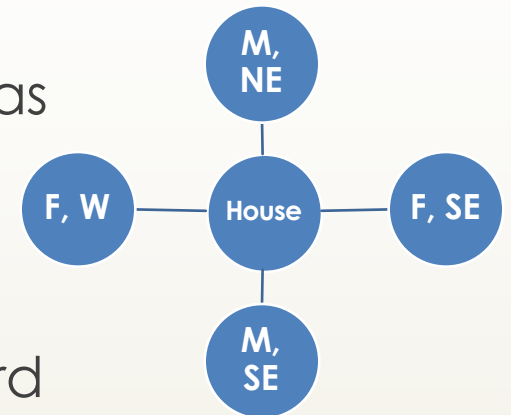
- ▶ As part of the Settlement, the Commonwealth agreed to apply for HCBS waivers
- ▶ An application was submitted to Centers for Medicare and Medicaid for two HCBS 1915(c) waivers
 - Acquired Brain Injury Residential Habilitation, or ABI-RH
 - Acquired Brain Injury Non-Residential Habilitation, or ABI-N).
- ▶ The applications were approved, and these opened on May 1, 2010.

Acquired Brain Injury Waivers

- ▶ The new waivers were targeted specifically to support discharge of individuals with acquired brain injury from nursing facilities and rehabilitation hospitals.
- ▶ Case Management, the Provider Network, Eligibility and application processing were all managed by the University of Massachusetts Medical School, Disability and Community Services (U Mass)
- ▶ MRC provided operations support and oversight for MassHealth.

What Happened to the Hutchinson Settlement?

- ▶ Slots were hard to fill, particularly ABI-N
- ▶ With no history and experience, there was considerable caution used in determining eligibility for the waivers
- ▶ Because slots filled slowly, it was very hard to group individuals together into one residential program
- ▶ Placement was therefore a slow process



Hutchinson 2013: Settlement Terms

- ▶ In 2013, the Plaintiffs requested that the Settlement Agreement of 2008 be revisited
- ▶ An Amended Settlement Agreement was reached in 2013
- ▶ The current Settlement Agreement ends on June 30, 2019, if it is agreed that the Commonwealth has met the terms of the Settlement.

Hutchinson 2013: Settlement Terms (continued)

- ▶ The agreement included:
 - Application for two new HCBS waivers:
 - ✓ Moving Forward Plan Residential Supports (MFP-RS)*
 - ✓ Moving Forward Plan Community Living (MFP-CL)*
 - Application for Money Follows the Person Demonstration

*The MFP waivers were renamed in September, 2017 to Moving Forward Plan (Residential and Community Living)

Hutchinson 2013: Settlement Terms (continued)

- ▶ A 1915 (b) waiver allowing MFP participants access to behavioral health services was applied for and approved.
- ▶ MassHealth delegated responsibility for Outreach to individuals with ABI in facilities to the Transition Entities (ASAPs and ILCs)

MFP Demonstration Grant

- ▶ The MFP Demonstration Grant allowed Massachusetts to:
 - Expand its existing commitment to support community living for frail elders and people with disabilities across their lifespan;
 - Provided Massachusetts with an increased rate of federal funding to increase the use of home and community based services, ensure quality assurance and quality improvement; and

MFP Demonstration Grant

- ▶ Transition Entities (the Aging Services Access Points (ASAPs) and Independent Living Centers (ILCs)) enrolled people in SNFs into the MFP Demonstration and helped them apply for waivers
- ▶ Transition Entities initially carried out the Outreach responsibilities MassHealth had accepted as part of the second Hutchinson Settlement

Hutchinson 2013: Other Settlement Terms

- ▶ The settlement agreement also delineates specific numbers of ABI residential and non – residential slots per year. These numbers can be increased based on demand (if slot availability was exhausted early in the waiver year)
- ▶ Settlement terms also required outreach to seek out SNF residents with ABI if ABI slots weren't filled in year 4 of the settlement.

Hutchinson 2013: Other Settlement Terms

- ▶ Waiver responsibilities were divided:
 - Application management, initial eligibility and provider network retained by U Mass Medical School
 - Residential waivers (ABI-RH & MFP-RS) operated by DDS
 - Community waivers (ABI-N & MFP-CL) operated by MRC

Hutchinson Outreach

- ▶ In August 2017, the two state agencies operating the waivers assumed responsibility for outreach to skilled nursing facilities
- ▶ This included establishment of a Family-to-Family/Peer-to-Peer program to support potential applicants in understanding and applying for the waivers
- ▶ Today, we have a 75-person team including case managers, supervisors and managers visiting approximately 400 facilities each quarter.

Hutchinson Today (continued)

- ▶ We've worked with about 35 Peer Mentors and families to help them prepare for supporting applicants
- ▶ We've created short videos of several of the Peer Mentors
- ▶ Our Stakeholder group has provided valuable feedback on how to best reach out to applicants
- ▶ We've developed and provided training to staff who support the Peer Mentors

Hutchinson Today

- ▶ We've developed and provided training to the state agency staff who are reaching out to the SNFs
- ▶ We've developed and provided training to the SNF staff to help them to understand the vast potential of the waivers to support people in the community

Stephon: I've been Waiting to Tell My Story



Where is Hutchinson Today?

Come back
And
ask us in 2 years!!