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## PUBLIC HEALTH | RESEARCH ARTICLE

# State reform and respect for the rights of the disabled people: A reflection on the Olmstead decision the case of New York state

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**Abstract:** Individuals with serious mental illness are often forced to live in institutional settings which limit their freedom and rights to become fully integrated into the community. The *Olmstead v. L.C.*, 527 U.S. 581 (1999) decision ruled that states must provide individuals with disabilities the opportunity to live in the most integrated settings based on their needs. Since that time several lawsuits have been filed on behalf of individuals with disabilities against states for failing to comply with the Olmstead decision. New York State is one such state. The purpose of this paper is to describe the lawsuit which was brought against the state of New York by the Department of Justice on behalf of several individuals with severe mental illness who lived in “adult homes.” The lawsuit was filed against New York State in 2013 for failing to fulfill the promise of the Olmstead decision by not providing these individuals access to housing that would allow them to be fully integrated into communities so as to live productive lives. A brief discussion is provided as to how the case was finally settled and the changes New York State made to ensure that the Olmstead decision would be fully implemented in the future.

### ABOUT THE AUTHORS

Roseanne L. Flores is an Associate Professor in the Department of Psychology at Hunter College and the Graduate Center of the City University of New York. She holds Advanced Certificates in Public Administration and Public Policy and Health Care Policy and Administration both from the CUNY School of Professional Studies. She has published peer-reviewed articles in the areas of education, health disparities, poverty, youth development, and policy. The information in the current article is important for individuals, families, communities, and policy makers who care about ensuring that people with both mental and developmental disabilities have the opportunity and the option to live in the most integrated settings within their community. Funding has often been cited as a barrier for fulfilling the mandate. Going forward in order to protect the rights of individuals with disabilities states will have to ensure that adequate funding is available to support the full implementation of the Olmstead decision.

### PUBLIC INTEREST STATEMENT

Today approximately 20% of adults and 20% of youth ages 13–18 experience some form of mental health condition. Additionally, it has been estimated that over 5 million individuals have some form of developmental disability. Many individuals do not understand their rights under the law to receive services that will allow them to live productive lives within their communities. The lawsuit against *Tommy Olmstead* was filed on behalf of two women, one with a mental illness, and the other with a developmental disability who wanted to live within the community. In 1999 the Supreme Court ruled that *unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act* and therefore it was against the law for states to discriminate against individuals with disabilities. The US Department of Health and Human Services, Office of Civil Rights, helps to ensure the Olmstead decision is enforced.

**Subjects: Health and Social Care; Health & Society; Disability; Public Health Policy and Practice; Health Law and Ethics**

**Keywords: Olmstead legislation; mental health; disabilities; human rights; community integration**

### **1. Introduction**

Today more than one in four individuals, approximately 61.5 million individuals, will suffer from some form of mental illness in any given year (National Alliance on Mental Illness, 2013). Some will live with major depression, some will have co-occurring mental health and addiction disorders, some will suffer from severe mental disorders and either be homeless, possibly become homeless, or live in a shelter, and some will be youth who are part of the juvenile justice system, who have experienced some form of mental health problem prior to becoming a part of the system (National Alliance on Mental Illness, 2013). That said, no matter how these individuals will have come to the attention of the mental health profession, one can be sure that at some point in time they will all have felt isolated, and possibly discriminated against due to the stigma and stereotypes attached to mental illness in the United States. Many will have fallen into a downward spiral of hopelessness and depression. Some may have been placed in an institution where they have become despondent, feeling as if they have lost all of their basic human rights, and knowing deep inside that if they were given a chance, and provided access to housing in the community they could live full and productive lives. Furthermore, many individuals in the United States will also have been diagnosed with some form of developmental disability with to date over 5 million individuals having received such a diagnosis (National Association of Councils on Developmental Disabilities, n.d.). Like many suffering from mental illness, many individuals with developmental disabilities will have been discriminated against because of their disabilities and perhaps excluded from fully participating in society (Keith, Bennetto, & Rogge, 2015).

Moreover, many individuals living with mental illness and developmental disabilities will live in constant fear. They and their families will be afraid to seek the help and support they need for fear of either losing their freedom and becoming isolated, or losing their resources. In essence many of these individuals and their families will remain immobilized because they are unaware of the Olmstead decision which protects their rights. In short, these individuals will needlessly suffer.

So why is the Olmstead decision so important? In 1999 the Supreme Court ruled in the *Olmstead v. L.C.*, 527 U.S. 581 decision, that states in accordance with the Americans with Disabilities Act (ADA) were obligated to provide individuals with disabilities services within the most integrated settings based on their needs (Supreme Court of the United States, 1999; New York State, 2013). This landmark decision paved the way to provide individuals with disabilities with the opportunity to live full and productive lives within the community. Since the time the Olmstead decision was issued many lawsuits have been filed on behalf individuals against several states for failing to comply with the decision. One such state was New York State. Like all other states, New York State was bound by the Olmstead decision to provide the residents of New York, diagnosed with mental illness, access to services in the most integrated settings according to their needs. The purpose of the present paper is to briefly describe the case filed by the Department of Justice on behalf of several individuals with severe mental illness living in adult homes against the State of New York and discuss what New York State has done to fully implement and comply with the Olmstead decision since the filing of the lawsuit.

### **2. Overview of the Olmstead vs LC decision**

In 1995 the Atlantic Legal Aid Society filed a lawsuit against Tommy Olmstead the Commissioner of Georgia, on behalf of Lois Curtis and Elaine Wilson who, although deemed competent and well enough to live in the community by healthcare professionals, were nevertheless confined to living in a state psychiatric institution because such community residences were not available (Bazelon Center for Mental Health Law, 2009; Ng, Wong, & Harrington, 2013). Eventually the case went before

the courts and was settled in favor of the plaintiffs with both women being moved to supportive housing, finally able to live full and productive lives in the community. However, the Georgia Department of Human Services was not satisfied with the outcome and they attempted to appeal the decision which had found that the state had violated the American with Disability Act's "integration mandate" by leaving Lois Curtis (LC) and Elaine Wilson (EW) in the hospital way beyond the time deemed necessary by the hospital staff, and thus the case went before the Supreme Court and has since then become the landmark case which we now refer to as *Olmstead vs LC* (Bazelon Center for Mental Health Law, 2009).

As with most legal cases that set a precedent for future legal decisions, the question that arises is why was this case so important for individuals with disabilities? After all didn't the American with Disabilities Act (ADA) protect the rights of disabled persons? Shouldn't their rights have been guaranteed under this Act? In the next section of the paper I will address these questions by: (1) discussing what exactly the integration mandated entailed; (2) who was directly affected by the mandate and how community integration differs for individuals with disabilities; (3) whether the lawsuit was necessary to ensure the rights of individuals with disabilities; (4) consider why after more than a decade states have not fully implemented the *Olmstead* decision; and finally (5) examine how community integration can be achieved in 2017 most effectively?

### **2.1. The integration mandate**

On July 26, 1990 Congress passed the American Disabilities Act. The purpose of the Act was to ban discrimination against disabled persons by providing *comprehensive civil rights protections to individuals with disabilities in the areas of employment, public accommodations, State and local government services, and telecommunications* (American Disability Act, 2010). Congress banned segregation as a blatant form of discrimination (SCOTUS, 1998). In addition, Congress instructed the Attorney General to issue regulations that would ensure that the law would be implemented by states and local governments to ensure that discrimination would be prohibited. One such regulation was the "integration regulation" (SCOTUS, 1998). Under Title II of the Act this regulation stated that

the public entity must administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities, i.e. in a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible, and that persons with disabilities must be provided the option of declining to accept a particular accommodation. (28 CFR Section 35.130 (d))

Today this portion of the Act has become known as the "integration mandate". It is this mandate that the State of Georgia wanted to challenge when it appealed its case to the Supreme Court. In short, Georgia wanted to know if under the law institutional treatment constituted discrimination toward the mentally disabled (American Psychological Association, 1999).

### **2.2. Individuals vs States: Impact of the mandate**

Based on the *Olmstead* Case the outcomes of the ruling directly affected the way that states did business with individuals with disabilities, communities serving such individuals, and professionals and associations providing services to such individuals, for example the American Psychological Association (APA), as well as the individuals themselves. The description for LC was applied to individuals and patients residing in state psychiatric hospitals who might be eligible for community care, individuals residing in nursing homes, as well as individuals who were bounced around from one institution to another due to lack of access to community services (Bazelon Center for Mental Health Law, 1999).

### **2.3. Full community integration and individuals with disabilities**

According to "integration mandate" individuals with disabilities were to be provided with the opportunity to live in a community with nondisabled individuals so as to be able to realize their fullest

potential. The question that arises is what does it mean to have full community integration? Does community integration differ for those with developmental disabilities versus for those experiencing mental health challenges? According to Wong and Solomon (2002) the answer to this question may be yes. These authors suggest that whereas the field of developmental disabilities has often defined integration in terms of the physical integration which focuses on housing and the environment, the notion of full community integration for individuals with psychiatric disabilities should be broadened to include physical, social, and psychological integration, with psychological integration addressing the emotion connection with one's neighbors and the community (Wong & Solomon, 2002). This distinction, although not clearly delineated in the original decision should nevertheless be considered as states continue to update and modify their Olmstead plans for mental health and disability services.

#### **2.4. Necessity of the lawsuit**

For all individuals with disabilities the *Olmstead Case* opened the door for them to finally be treated with respect and dignity. While the American with Disabilities Act had already mandated that persons with disabilities should not be discriminated against, the Olmstead Case became the hallmark case for finally holding states and other local entities accountable for implementing and adhering to the ADA, which is why it became thought of as the *Brown vs the Board of Education* for individuals with disabilities (Bazelon Center for Mental Health Law, 2009). The case was critical because up until that time no one had ever held states accountable for discriminating against the disabled. What the Olmstead ruling solidified for individuals with disabilities was first, that they had the power and the right to sue states who did not have their best interest at heart and second, that they had the right to live in community housing that was best suited to their health and well-being (Carlson & Coffey, 2010). Moreover, the Olmstead ruling helped reshape the perceptions of policy makers, communities, the public and all other stakeholders by reaffirming the rights of persons with disabilities to be fully integrated into society (Carlson & Coffey, 2010). Thus, in the eyes of individuals with disabilities and the friends of these individuals this ruling was too long in coming and a much welcomed outcome.

#### **2.5. Barriers to implementation of olmstead decision**

With the successful ruling for individuals in the Olmstead Case one would have thought that states would immediately have begun to move individuals who qualified, and wanted to live in the community, into community supported housing, but that was not to be the case. Many states cited several major challenges which they argued prevented them from fully implementing the decision. For example, several states claimed they would incur increased costs if they were forced to fully implement the community integration mandate (Snyder-Hegener, 2012). In addition, they maintained that by expanding home and community-based services they would be forced to place an undue burden on the current workforce, a workforce that was already underpaid and overworked (Snyder-Hegener, 2012). Furthermore, states said that the rapid expansion and opening of integrated community-based housing might have unintended consequences, such as the lowering of the quality of care that individuals with disabilities currently received. For example, they argued that although an individual might be deemed fit to live in community-based housing, the actual services that they required might not be readily available in the community, thereby leading to the overall lowering of the quality of care they would actually receive (Snyder-Hegener, 2012). In short, many states did not fully implement the Olmstead decision because they claimed that while they ultimately wanted to serve the needs of all of their citizens, the actual implementation of the decision posed a great many challenges for them. They based their inability to fully implement the decision had still on the Court's ruling *that placement for services was not without limits and that accommodations would need to be based on the resources available to the state and the needs of others with mental disabilities* (Desonia, 2003).

Since the passing of the legislation in 1999 many lawsuits have been brought against states for failing to implement the Olmstead decision. In 2009 the Case of Olmstead vs LC celebrated its 10th year anniversary. Again up until that time the decision had still not been fully implemented, with states still claiming that given their budgetary constraints they were unable to provide the kind of

community supportive housing that individuals with disabilities required. They argued that this in part was due to the lack of an adequate supply of housing and funding (Bazelon Center for Mental Health Law, 2009). That said, based on the evidence these claims were found to be unsubstantiated. In essence the data demonstrated that the cost of housing someone with a disability in the community actually saved the state money because the actual cost of living in the community was substantially below the cost of institutionalization (Bazelon Center for Mental Health Law, 2009). Moreover, whereas states could have shifted some of their Medicaid funding away from long term institutional care to home and community based services, many did not often leaving many individuals on waiting lists for years (Musumeci & Claypool, 2014). Recent research has demonstrated that not only are non-institutional settings less costly but they also provide a better quality of life for individuals living with a disability (Espinosa, 2015). Thus based on the above mentioned evidence, evidence which supports the integration of individuals with disabilities into community-based supportive housing, the question arises as to what can be done to ensure that states implement the Olmstead decision to its fullest extent? In the next section, I will attempt to address this question by providing an overview of how New York State (2013) initially failed to implement the Olmstead decision by discriminating against individuals with mental health challenges by segregating them into institution like homes and denying them their rights to live in fully integrated communities. The section will also address the progress New York has made since the signing of the settlement agreement in 2013 to ensure that individuals with disabilities receive the services they need in the most integrated settings.

### **3. The case of United States department of justice vs. The state of New York**

The Plaintiff, the United States of America, sued the Defendant for violating Title II of the American Disabilities Act (ADA) of 1990 and section 504 of the Rehabilitation Act and the implementation of their regulations as mandated by *Olmstead vs LC* (1999) to serve the needs of individuals with mental illness by providing them with the “most integrated setting.” The Plaintiff argued that *qualified* individuals with mental illness living in New York City were placed in *impacted* “adult homes,” which did not allow for their full integration into environments that were appropriate to their needs. Furthermore, the Plaintiff argued that adult homes were “highly regimented” and that individuals had limited privacy and little, if any autonomy. Individuals were forced to live exclusively with others with mental illness and they often suffered from abuse and neglect. The Plaintiff argued that Title II of the ADA specifically prohibited isolating persons with disabilities (*Olmstead vs LC*, 1999) and the Rehabilitation Act further mandated that entities receiving federal funds not be allowed to discriminate against individuals with disabilities and must provide them with the most integrated form of care. The Plaintiff further argued that New State was in violation of federal law because of (1) the city’s overreliance on “adult homes, and (2) the city’s status as a recipient of federal funding which prohibits discrimination.

For many years New York State was negligent in its response to the full implementation of the Olmstead decision, however in 2013 the State settled the case with the United States.

#### **3.1. The settlement**

On July 23, 2013 the Department of Justice and New York State reached a landmark settlement in the case of the United States versus the State of New York. Under the settlement, New York State agreed to provide individuals with severe mental illness, living in adult homes, the opportunity to move into more integrated communities that would support them in reaching their full potential and participating community life (United States Department of Justice, 2013).

As part of the settlement the state agreed to provide community-based housing to those who had been inappropriately placed in adult homes. In addition, it agreed that all residents who moved into supportive housing would also have access to the community-based mental health services they needed in order to live productive lives in the community. Some of these services would include access to Assertive Community Treatment (ACT) teams, access to crisis intervention teams, as well as other forms of assistance that would ensure that they were able to thrive in the community setting. Moreover, the state agreed to provide support through “person-centered” planning for those individuals

transitioning into the community from adult homes. The overall purpose of the agreement was to ensure that the quality of care that individuals with disabilities received did not erode over time.

Finally, as part of the settlement the state agreed to be monitored by the United States government to ensure that it was meeting the needs of these individuals and implementing all aspects of the agreement. In 2014 the parties signed an amended agreement which the court signed on March 17, 2014. A second amended agreement was approved by the court on May 18, 2017.

#### **4. Current implementation of the Olmstead legislation in New York state**

In November 2012, Governor Cuomo issued an Executive Order Number 84, which created the Olmstead Development and Implementation Cabinet, hereafter referred to as the Olmstead Cabinet. Under this order the Cabinet was charged with the task of developing a plan that was consistent with Olmstead decision which was to provide individuals with services in the most integrated settings according to their needs. This Cabinet met with over 160 stakeholders to ensure that all voices were heard and that the needs of individuals with disabilities would be heard and ultimately addressed. The results of these known as many meetings resulted in what today is the *Report and Recommendations of the Olmstead Cabinet*. The report recommends the specific action steps that the state must take over the next several years to ensure that New York State is providing the appropriate services for individuals with disabilities in the most integrated settings. The recommendations include: (1) providing assistance for individuals to transition out of segregated institutional settings into integrated community settings; (2) developing new assessment and outcome strategies which will allow the state to examine which services lead to the most cost efficient opportunities that provide people with disabilities access to more successful ways of integrating in the community; and (3) providing supportive mechanisms and enhancing ways that allow individuals with disabilities to smoothly integrate into the community. To reach these benchmarks the state instituted a plan to work with agencies in order to: (1) provide access to housing, (2) provide employment services that would afford opportunities for work that is not degrading, (3) provide access to transportation services that are not dependent on Medicaid, (4) coordinate children's services so as to provide for a smooth transition from childhood into adulthood, (5) work with aging services to ensure that individuals are not needlessly placed in nursing homes, and (6) to work with the criminal justice system to make sure that individuals with disabilities are not needlessly criminalized, and that those who do end up in the system, receive the treatment that they need, so that once they are released they can be fully integrated into the community (New York State Office of People with Disabilities, 2010).

To ensure that that state fully implemented the recommendations, the last section of the report calls for accountability on the part of the state for community integration. The state recognized that in order to protect the rights of disabled persons it must measure the outcomes and be held accountable. To that end Governor Cuomo established the Justice Center to provide oversight and monitoring and to ensure that the rights of disabled persons are respected. In short, the Olmstead Cabinet in working together across organizations, agencies and individuals who represent people with disabilities has produced a comprehensive plan to ensure the full integration of individuals into communities according to their needs. The implementation of this plan will ensure that the settlement reached between the United States on behalf of disabled people and New York State is realized.

##### **4.1. Moving toward effective integration in 2017**

On March 25, 1966 in an address to the Medical Committee on Human Rights the Reverend Dr. Martin Luther King Jr. in his quest for striving for equality for African-Americans and the poor stated that *Of all the forms of inequality, injustice in health care is the most shocking and inhumane* (Moore, 2013). His outrage was based on the fact that the United States, the wealthiest country in the world at the time, allowed many of her citizens to die and suffer from diseases that had long been eradicated due to a lack of access to adequate health care. This was the same United States that in 1948 under the chairmanship of Eleanor Roosevelt drafted the Universal Declaration of Human Rights which held nation states accountable for the health and well-being of their citizens. This declaration argued that individuals had a right to health and countries had the responsibility to provide it. According to

the Office of the United Nations High Commissioner for Human Rights (2008) while the right to health includes access to adequate health care, it also includes access to other elements in society that allow citizens to enjoy healthy and productive lives. So what about disabled individuals? Should they not enjoy the same rights as the rest of society? According Article 19 of the Convention on the Rights of Persons with Disabilities, individuals with disabilities have the right to live independently and be included in the community. According to *this Convention State Parties must recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community ....* (United Nations, 2006). Thus in keeping with spirit of the Convention on the Rights of Persons with Disabilities, the implementation of the Olmstead legislation is the fulfillment of basic human rights.

In June 2011 on the Anniversary of the Olmstead decision President Obama met with Lois Curtis and pledged his support to ensure that the federal government would do all in its power to ensure that the ruling would be fully implemented. He stated that the Department of Justice had entered into a settlement with the state of Georgia's mental health and disability services and that furthermore the DOJ had continued to pursue cases against other states so as to ensure that community-based housing for those individuals who qualified, and wanted it, would be made available (White House, 2011). In addition, he outlined how in 2009 he started the *Year of Community Living* which provided funds to assist persons with disabilities to live in the community. Furthermore, he stated that as part of that initiative HUD and HHS would provide funding for vouchers to be used in paying for an individual's choice of housing. Additionally he affirmed that with the initiation of the *Money Follows the Person Rebalancing Demonstration Program* states would be encouraged to use the money to help individuals transition smoothly from living in institutions to the community housing (White House, 2011).

On July 22, 2014 the Senate Committee on Foreign Relations voted 12–6 to approve UN Convention on the Rights of Persons with Disability and while the vote did not lead to the United States ratifying the Convention it was a step in the right direction of the country in recognizing the need to protect the universal rights of people with disabilities (United States Senate Committee on Foreign Relations, 2014).

In short, while there is still much work to be done the above mentioned initiatives and the continued fight on the part of the DOJ to ensure full implementation of the ruling is a good next step in making sure that individuals' with disabilities can be fully integrated into the community. While the executive branch of the federal government must continue to play a key role in ensuring that the Olmstead decision is fully implemented and states are held accountable, in no way should the burden of ensuring that the spirit of the decision is implemented be left to the government, for it should be noted that many of the original lawsuits against states were brought about by legal aid groups and other parties (Dinerstein, 2016). Thus, professional associations, researchers, disability and human rights advocates and individuals themselves must be vigilant and hold states accountable. They must advocate for individuals with disabilities and mental illness to have the same rights as all United States citizens, rights that are often violated (Whitley & Henwood, 2014).

## 5. Summary and Conclusions

In summary, the Olmstead decision can truly be lauded as the *Brown of the Board of education* for disabled individuals. As a result of that landmark decision individuals with disabilities are now free to live productive and fulfilling lives; and when their rights are challenged they are now free to hold states accountable for not complying with the law. No longer must they live in fear. No longer must they have their rights abused, and no longer must they feel that they are less than human, something which those who have been oppressed understand. Going forward if we as a nation are to remain a model for the world we must respect the rights of all people, in this case the rights of those with disabilities. As we advocate for health care policy we must remember that Medicaid is critical to fulfilling the Olmstead mandate and advocate for full funding to support long term home and community-based services (Musumeci & Claypool, 2014; The Coalition to Implement Olmstead in New York, 2003; Rosenbaum,

2000). Moreover, as we seek to ensure that disabled individuals are provided with the opportunity to live in the most integrated settings we must examine each state's Olmstead plans to ensure that the built environments not only address the physical aspects of the communities such as housing and transportation (Christensen & Byrne, 2014), but also the social and psychological aspects of community integration (Wong & Solomon, 2002). And finally we must place before us the Convention on the Rights of Disabled Persons and always remember why it was established in the first place, to ensure the dignity and rights of disabled persons so that they, like all people, may live full and productive lives.

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The authors declare no competing interest.

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