

Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans

**Martin Kitchener, Micky Willmott, Marshall Alameida & Charlene Harrington
UCSF National Center for Personal Assistance Services**

Updated January 2005

This report provides state-by-state information on two of the major issues that have arisen from the 1999 Olmstead Supreme Court judgment. The first table provides information on the formal strategies (Olmstead Plans) that states have developed in response to the Olmstead ruling. The second table presents a summary of community integration lawsuits related to Olmstead. The primary aim is to present a summary of information that is accessible to the public, consumers, advocates, researchers and professionals. More detail about activities in each state and specific themes (e.g., legal issues) are available from the references provided in this introduction and in the two tables.

The following paragraphs provide a brief introduction to the tables by outlining the nature and significance of the Olmstead decision, and the content of the tables. Complimentary information about other state initiatives to develop community-based services (such as funding for state plans) is provided in the HCBS section of this website.

What is Olmstead?

Olmstead is used here to describe the 1999 Supreme Court judgment in the case *Olmstead v. L.C.*¹ The case was brought on behalf of two women in Georgia (known as L.C. and E.W.) who have developmental disabilities and were also diagnosed with mental illness (schizophrenia and personality disorder respectively). They were voluntarily admitted to Georgia Regional Hospital for treatment in a psychiatric unit.² After some time, they indicated their preference for discharge and the professionals working with them assessed that they were ready to move into a community setting with appropriate support. However, they were not successfully discharged from hospital and in 1995, this lawsuit was brought and was eventually heard by the Supreme Court.² The Supreme Court ruled that, under Title II of the Americans with Disabilities Act (ADA, 1990) the women had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalization was discriminatory and violated the ADA.

Why is Olmstead important?

The Olmstead ruling provides an important clarification about how states should ensure compliance with the ADA. Because the ADA applies to all public bodies and the use of public funds, it has implications for the way that states provide publicly funded Medicaid services to people with disabilities.³ That is to say, Olmstead confirmed that states have to ensure that Medicaid-eligible persons do not experience discrimination by being institutionalized when they could be served in a more integrated (community) setting.³

The Supreme Court made limited recommendations for how states might ensure compliance with the ADA and Olmstead. This indicated that states should make

‘reasonable accommodations’ to their long-term care programs and that this is demonstrated by ‘comprehensive, effectively working plans’ to increase community integration and reduce institutionalization and waiting lists that move at a ‘reasonable pace’.⁴ By and large, lower courts have decided that “evidence of active engagement and slow progress” towards more community-integrated long-term care systems satisfies the ADA.³

To help states comply with Olmstead, the Federal government issued guidance based on the opinions given by the judges in making their decision. It has also provided ongoing policy guidance encouraging review and development of state LTC policy (e.g. Olmstead plans – see below), promotes increased use of existing policy options for HCBS (e.g. encouraging states to apply for HCBS waivers) and announces amendments to Medicaid rules enabling more flexibility in Medicaid HCBS (e.g. ability to provide retainers to personal assistants).⁵ Whilst the Federal Government’s commitment to new initiatives (e.g., the New Freedom Initiative)^a has been welcomed, it has been criticized on two counts; (1) a lack of an overall national policy framework for community integration of people with disabilities, and (2) inadequate stimulation of change in the long-term care system to eliminate unnecessary institutionalization of disabled people.⁶

The Olmstead ruling stimulated lawsuits raising similar issues in other states on behalf of people who are institutionalized or at risk of institutionalization because of a lack of community-based services. These lawsuits often invoke two different sets of Federal laws; (1) civil rights laws⁷ (including the ADA, Olmstead ruling and the Rehabilitation Services Act 1973, upon which the ADA is based) and (2) Medicaid law. (These types of cases are the described in Table 2). The ruling also led to complaints against states being filed with the Department of Justice regarding community integration.^{8,9} One study found that as of May 2004, an estimated 627 Olmstead-related complaints had been filed against state agencies claiming that people had not received services in the most integrated settings.³

Given the importance of personal assistance services in supporting the community integration of people with disabilities, the Center for Personal Assistance Services tracks these lawsuits and strategic developments (e.g. state Olmstead plans) following the Olmstead decision.

State Olmstead Plans and Alternative Strategies (Table 1)

The Olmstead ruling suggested that states demonstrate compliance with the Olmstead decision by producing formal plans for increasing community integration. In 2001, the Centers for Medicare and Medicaid Services (CMS) issued guidance concerning the process and content of this strategic planning initiative. The Olmstead Plans table presents findings from our exploratory study of developments in each state. Further analysis of the Olmstead plans is currently underway and will be posted when complete.

^a The New Freedom Initiative is described in the report *‘Home and Community-Based Services: Federal Funding to States.’* also on this website.

The presented data were collected using secondary sources and internet searches. This method was selected to avoid duplication of existing research and to enable an exploration of the literature that has the similar aim of providing accessible summary information about Olmstead planning. This method is limited because the secondary sources may not provide all the data required to complete the priorities identified in this table. Therefore primary (web-based) research was undertaken and supplemented by direct (email) contact with state officials and reference to the Olmstead plans.

A significant source of summarized information about Olmstead planning across the states is a periodic report published by the National Conference of State Legislatures.¹⁰ The report also analyses themes arising from Olmstead planning across the states. This include significant interstate variation regarding the progress made towards compliance with Olmstead (e.g. just over half the states have developed Olmstead plans).¹¹ Olmstead planning efforts and the impact on state Medicaid programs have also been tracked by advocacy and government agencies.^{12,13,14}

The definition of an Olmstead plan is not clear-cut and some states have (for various reasons) developed alternative approaches to Olmstead planning.¹⁰ Some states have displayed little specific strategic work.¹⁵ One study reports three state strategies to address *Olmstead* compliance: legislative action (policy and budgetary mechanisms for moving money around the system); market-based approaches (consumer information to enable choice and create demand for HCBS); and fiscal and programmatic linkages (e.g. improving co-ordination between services and increasing HCBS capacity).¹⁶

Olmstead and Olmstead-related lawsuits table

The Olmstead judgment raises many complicated legal issues and questions that are not discussed here.^{3,17} However, two key legal concepts mentioned in the table are:

- ‘Fundamental alteration’ and ‘reasonable modification’. Olmstead helped clarify that the ADA (Title II) requires any public body to administer programs to provide services in the most integrated setting appropriate for qualified individuals. In complying with this, public bodies are only required to make ‘reasonable modifications’ to programs (e.g., Medicaid). They are not required to make any changes that would be a ‘fundamental alteration’ of their program. Lawsuits regarding whether the state is making enough effort (e.g., financial and administrative commitment) therefore often include arguments and interpretations of these legal concepts.
- ‘Reasonable promptness’. This concept most often arises in lawsuits where complaints concern waiting lists for Medicaid services. This is because §1902(a)(8) of the Social Security Act requires states to promptly determine the eligibility of people who apply for services. Courts have ruled that this also bars states from putting people on waiting lists without assessing their need. However this concept can have complicated implications when discussed in relation to the concept (under the ADA) of ‘reasonable modification’ and ‘fundamental alteration’.

Two main types of cases are included in the table; these are labeled (1) Olmstead, and (2) Olmstead-Related. Olmstead refers to cases started, decided or closed after Olmstead and primarily about community integration of institutionalized people and/or people at risk of institutionalization. Such cases are most likely to cite a violation of the ADA as the primary complaint. ‘Related’ cases involve issues related to Olmstead but do not satisfy the criteria of an Olmstead case or there is insufficient data in the sources to classify them.¹⁸ No cases that were decided before the enactment of the ADA in 1990 are included though there were community integration-type cases in the 1970s and 1980s.¹⁹

The table content is primarily taken from secondary sources (typically reports or journal articles that describe and/or analyze lawsuits dealing with Medicaid law and ADA). While this method avoids duplication of previous work and collates existing information in an accessible way, there are limitations. In particular, this approach depends on the accuracy of secondary sources concerning Olmstead-type litigation. Also, in instances where details about lawsuits are repeated in several sources, some information about those may not be congruent (e.g., the date the lawsuit was filed). Therefore, a limited amount of (web-based) primary research has been used to clarify information found in the literature. Where specific data has remained unclear, it is indicated on the table (n/a).

The primary source for the data in this table is a cumulative, periodic report published by the Health Services Research Institute.²⁰ The report compiles information about lawsuits regarding Medicaid services for people with developmental and other disabilities. The report categorizes lawsuits into 3 main categories, these are; access to Medicaid HCBS, community placement of institutionalized persons and limitations on Medicaid home and community benefits. It does not analyze the legal implications of the lawsuits. Lawsuits mentioned in this publication were added to a database and supplemental information and data on other lawsuits mentioned elsewhere was added.

Another useful summary is a docket of cases published by the National Association of Protection and Advocacy Services (NAPAS).²¹ This categorizes cases according to 5 population groups, those living in a psychiatric facility, a state ICF/MR facility or in a nursing home, people on waiting lists for community services or people receiving an inadequate amount support in the community.

Whilst some legal implications of Olmstead remain unclear several studies have tracked the implications of Olmstead in state courts,^{22,23} and a recent report contends that “Olmstead’s legacy in the courts has been uneven” and this is largely due to the subjectivity involved in deciding whether changes sought by plaintiffs to a state Medicaid program constitute a ‘fundamental alteration’.³ The reports detailing states’ reaction to Olmstead also provide contextual background on state Medicaid HCBS that lead to lawsuits being brought and the consequences of this litigation.

Key Trends shown by the tables

- The total number of (reported) cases is 141.

- There are 8 states in which no reported lawsuits have been found. These are; Idaho, Iowa, Missouri, North Dakota, South Carolina, South Dakota, Vermont and Wisconsin. One Territory (Guam) has had one lawsuit, as had the District of Columbia.
- The state with the most (reported) lawsuits is Pennsylvania (14), followed by California (13). Of the 14 cases in Pennsylvania, 11 are closed and 2 are open (the status of one is unconfirmed).
- The most common number of (Olmstead and Related) cases per state is 2 (19 states). 9 states have 1 case and 7 states have 3 cases.
- Of the lawsuits reportedly filed after the Olmstead decision (1999), there was a peak of 23 lawsuits filed in 2000, 13 were filed in 2001, 17 in 2002, 16 in 2003 and 3 in 2004.
- Approximately one fifth (25) of the lawsuits are categorized as Olmstead type cases.
- 29 states have published Olmstead plans and 4 states are developing Olmstead plans.
- 14 states have developed alternative responses to Olmstead.

¹ The full Supreme Court judgment, *OLMSTEAD V. L. C.* (98-536) 527 U.S. 581 (1999) 138 F.3d 893, affirmed in part, vacated in part & remanded. At <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>

² Background about the case from the Atlanta Legal Aid Society: <http://www.atlantalegalaid.org>

³ Rosenbaum, S & Teitelbaum, J (2004) *Olmstead at Five: Assessing the Impact* Kaiser Commission on Medicaid and the Uninsured, Washington DC. At <http://www.kff.org>.

⁴ Smith, J.D.E. & Calandrillo, S.P (2001) *Forward to Fundamental Alteration: addressing ADA Title II integration lawsuits after Olmstead v. L.C.* Harvard Journal of Law & Public Policy, vol.24, Summer, 695.

⁵ Rosenbaum, S (2001): *Behavioral Health Issue Brief 17 Federal Implementation Guidelines, and Analysis of Recent Cases regarding Medicaid Coverage of Long Term care services for persons with disabilities.* Center for Health Services Research & Policy, George Washington University, Washington DC.

⁶ Gran, J (2003) *Olmstead: Reclaiming Institutionalized lives* National Council on Disability, Washington DC.

⁷ Information on Federal laws which give rights to people with disabilities, see USDOJ publication (May 2002) 'A Guide to Disability Rights Laws', at: <http://www.ada.gov/cguide.htm>.

⁸ Rosenbaum, S et al (2001) *An analysis of Olmstead complaints: implications for policy and long-term planning*, Center for Health Care Strategies, Inc.

⁹ US Dept of Justice has responsibility for ensuring enforcement of all 5 titles of the ADA. It publishes a quarterly status report covering its activities regarding ADA enforcement. 'Enforcing the ADA: A Status Report from the Department of justice' at: <http://www.usdoj.gov/crt/ada/statrpt.htm>.

¹⁰ Fox-Grage, W; Folkemer, D; Lewis, J (February 2004) *The States' Response to the Olmstead Decision: how are states complying? A 2003 update* Forum for state Health Policy Leadership, the National Conference of State Legislatures (NCSL), Washington DC.

¹¹ The report and related NCSL work is online at <http://www.ncsl.org/programs/health/oncsrep.htm>

¹² Musselwhite, JC (2003) *Protection and Advocacy Agencies: involvement in deinstitutionalization lawsuits on behalf of individual with developmental disability: Report to the Chairman, subcommittee on oversight and investigations, Committee on Energy and Commerce, House of Representatives.* The General Accounting Office.

¹³ Allen, KG (2001) *Long-Term Care: implications of the Supreme Court's Olmstead Decision are still unfolding: Testimony before the Special Committee on Aging, US Senate.* The General Accounting Office.

¹⁴ Bazelon Center for Mental Health Law <http://www.bazelon.org/issues/disabilityrights/resources/olmstead>

¹⁵ In the table, Olmstead Plans are those that have been specifically developed in response to the Olmstead decision and subsequent guidance. The results have been validated with the NCSL report¹⁰. Where states are shown to have Olmstead plans, no further investigation was made into 'alternative' strategies (denoted by X in the table). However, this does not necessarily mean the state does not have alternative strategies.

¹⁶ Crisp, S; Eiken, S; Gerst, K; Justice, D (2003) *Money Follows the Person and Balancing Long-Term Care Systems: State Examples* Medstat, CMS. At: <http://www.hcbs.org/files/39/1943/mfp92903.pdf>

¹⁷ See Desonia, R (2003) *Is community Care a Civil Right? The unfolding saga of the Olmstead decision - A National Health Policy Forum background paper*. George Washington University, Washington DC.

¹⁸ The primary complaint is likely to be a violation of Medicaid law.

¹⁹ Examples of cases brought in the 1980s are: *Weston v. Wyoming*; *USA v. Oregon*; *Homeward Bound v. The Hissom Memorial Center* (Oklahoma); *Garrity v. Gallen* (New Hampshire) and the Supreme Court case *Alexander v. Choate* (Tennessee, at: <http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=469&invol=287>). Examples of cases brought in the 1970s are; *New York Association for retarded children v. Carey* and *Halderman v. Pennhurst* (Pennsylvania).

²⁰ Smith, G (2004) *Status Report: litigation concerning Home and Community Services for People with Disabilities*. HSRI, Oregon. Regular updates are available from <http://www.hsri.org>.

²¹ Priaulx, E (2004) *Docket of cases related to access to community-based services for people with disabilities*. National Association of Protection and Advocacy Services, Washington DC.

²² Rosenbaum, S; Stewart, A & Teitelbaum, J (2002) *Defining "reasonable pace" in the Post-Olmstead environment*, Center for Health Care Strategies, Inc. Washington, DC. And; Rosenbaum, S; Burke, T & Teitelbaum, J (2002) *The Americans with Disabilities Act and Community integration: an update on "fundamental alteration" litigation*, Center for Health Care Strategies, Inc. Washington, DC

²³ Batavia, A (2001) *A Right to Personal Assistance Services: 'most integrated setting appropriate' requirements and the Independent Living Model of long-term care* in American Journal of Law and Medicine, Boston University School of Law, vol. 27(1) 17-43. And Petrila, J (1999) *The Americans with Disabilities Act and community-based Treatment law in Psychiatric Services*, vol. 50(4) 473-480