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

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This report provides state-by-state information on two of the major issues that have arisen from the 1999 Olmstead Supreme Court.

The report contains two tables and a brief outline of the nature and significance of the Olmstead decision, along with a summary of the table. The first table provides information on the formal strategies (Olmstead Plans) that states 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.

## What is Olmstead?

Olmstead is used here to describe the 1999 Supreme Court judgment in the case Olmstead v. L.C. (US Supreme Court 1999). The case was brought against the Georgia State Commissioner of Human Resources (Tommy Olmstead) on behalf of two women with developmental disabilities (known as L.C. and E.W.) who were diagnosed with mental illness (schizophrenia and personality disorder respectively).[1] They

were voluntarily admitted to Georgia Regional Hospital for treatment in a psychiatric unit (Atlanta Legal Aid Society 2004). 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 the Atlanta Legal Aid Society brought this lawsuit and it was eventually heard by the Supreme Court. 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 comply with Title II of the ADA. The ADA applies to all public bodies and to the use of public funds and therefore has implications for publicly-funded Medicaid services to people with disabilities (Rosenbaum and Teitelbaum 2004). The Olmstead decision confirmed that states must ensure that Medicaid-eligible persons do not experience discrimination by being institutionalized when they could be served in a more integrated (community) setting (Rosenbaum and Teitelbaum 2004). This obligation is sometimes known as the ADA 'integration mandate'.

The Supreme Court made limited recommendations for how states might ensure compliance with the ADA in light of Olmstead. The Court indicated that states should make 'reasonable accommodations' to their long-term care systems, but should not be required to make 'fundamental alterations'. It suggested that compliance might be demonstrated by 'comprehensive, effectively working plans' (Olmstead Plans) to increase community-based services and

reduce institutionalization, and by ensuring that waiting lists for services move at a ‘reasonable pace’ (Smith and Calandrillo 2001). An analysis of rulings in community integration lawsuits after Olmstead has shown that lower courts have generally decided that “evidence of active engagement and slow progress” towards more community-integrated long-term care satisfies the ADA (Rosenbaum and Teitelbaum 2004).

To help states comply with Olmstead, the Federal government issued guidance based on the opinions given by the judges. It has also provided; ongoing policy guidance encouraging review and development of state LTC policy (e.g., Olmstead plans), promoted the increased use of existing policy options for HCBS (e.g., encouraged states to apply for HCBS waivers) and announced rule amendments to enable more flexibility in Medicaid HCBS (e.g., ability to provide retainers to personal assistants) (Rosenbaum 2001). Whilst the Federal Government’s commitment to new initiatives (e.g., the New Freedom Initiative) has been welcomed, it has also 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 (Gran et al 2003).

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 laws (including the ADA, Olmstead ruling and the Rehabilitation Services Act 1973) and (2) Medicaid law (US DOJ 2002). These lawsuits are the described in Table 2.

The ruling also led to complaints against states being filed with the Department of Justice regarding community

integration (Rosenbaum et al 2001, US DOJ 2005). One study found that by May 2004, 627 complaints had been filed against state agencies claiming that people had not received services in the most integrated setting (Rosenbaum and Teitelbaum 2001). In addition, a recent report from the Office of Civil Rights describes community integration complaints from approximately 250 individuals across the nation which it has resolved (OCR, 2005).

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

## State Olmstead Plans and Alternative Strategies (Table 1)

The Olmstead ruling suggested that states demonstrate compliance with the ADA 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. Table 1 (Olmstead Plans) presents findings from our exploratory study of these developments in each state.

The 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 information about Olmstead planning across the states is a periodic report published by the National Conference of State Legislatures (Fox-Grage et al 2004). The report analyses themes arising from Olmstead planning across the states. It found significant interstate variation regarding the progress made towards compliance with Olmstead (e.g. just over half the states have developed Olmstead plans). Olmstead planning efforts and the impact on state Medicaid programs have been tracked by numerous advocacy and government agencies (Musselwhite 2003, Allen 2001).

The definition of an Olmstead plan is not clear-cut and some states have developed alternative approaches to Olmstead planning (Fox-Grage et al 2004). Some states have displayed little specific strategic work. 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 report by Fox-Grage et al (2004). Where states are shown to have Olmstead plans, no further investigation was made into 'alternative' strategies. However, this does not necessarily mean the state does not have alternative strategies. 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) (Crisp et al 2003).

Numerous barriers exist to implementing Olmstead plans and promoting the inclusion of people with disabilities in the community. Financial constraints on Medicaid, the lack of affordable and accessible housing, labor shortage of home care workers and political pressure of institutional care

facilities are some difficulties states may face when implementing their Olmstead plans (Kaiser 2004).

To address some of these concerns, the Robert Wood Johnson Foundation awarded grants to seven states to encourage community integration and identify barriers regarding implementation of their Olmstead plans (Chaney 2003). The grants helped states address the following issues:

- Systemic barriers such as regulatory/financing restrictions and inadequate infrastructure in the areas of housing, workforce, service flexibility, and information management.
- Inadequate public awareness of community-based options.
- Consumer involvement in the design, implementation, and monitoring of state *Olmstead* responses (Chaney 2003).

The participating states made a number of recommendations at the end of the grant period including the need for workforce development and improved coordination among agencies (Chaney 2003). Authors of the resource paper concluded that while progress is being made, continued efforts and initiatives are necessary for states to fully implement their plans (Chaney 2003). Additional research is ongoing regarding the implementation of Olmstead state plans and the evaluation and measurement of community integration (Stewart et al 2002; Stewart et al 2003).

## Olmstead and Olmstead-related lawsuits (Table 2)

Two main types of cases are included in the table; these are labeled (1) Olmstead, and (2) Related. Lawsuits which are coded 'Olmstead' are those which primarily concern people who are institutionalized or at risk of institutionalization, on the other hand, 'Related' cases do not cite the ADA but may use another law (e.g., Medicaid law, the Rehabilitation Act) to raise issues about HCBS provision and may raise complaints about unnecessary institutionalization (e.g.,

Rosie D. v. Romney in Massachusetts, MA4). Lawsuits which are coded 'Olmstead' have two key features; (1) the case was closed after Olmstead (although they may have been brought before Olmstead was decided) and (2) cites a violation of the ADA Title II. 'Related' cases are those which do not satisfy the criteria of an Olmstead case (or there is insufficient data in the sources to classify them). In addition to ADA claims, the table also indicates those lawsuits which directly considered the provision of PAS.

No lawsuits 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. These cases often alleged violations of the Rehabilitation Act (1973) which is similar to the ADA in that it indicates that people should receive care in the 'least restrictive setting'. An example of a case brought in the 1980s is the Supreme Court case Alexander v. Choate (Tennessee) and an example of two earlier cases in the 1970s are; New York Association for Retarded Children v. Carey and Halderman v. Pennhurst (Pennsylvania). The table does include a case which was brought in the Territory of Guam.

The table content is the result of a two-tiered search; (1) a search of legal, health care and disability literature, and (2) a web-based search for primary data on lawsuits. The searches covered 5 domains: (1) Journals (e.g., Harvard Journal of Law & Public Policy); (2) Databases (e.g., ABI Inform); (3) Authors (e.g., Rosenbaum, Smith); (4) Keywords (e.g., 'Medicaid litigation'); and (5) Organizations (e.g., National Health Law Project, NAPAS). The search for primary data used legal databases (e.g., LexisNexis) and organizations involved in the lawsuits (e.g., Atlanta Legal Aid).

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. 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, (web-based) primary research was used to clarify information found in the literature as well as to identify new information and cases. Where specific data remains 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 (Smith 2006). The report compiles information about lawsuits regarding Medicaid services for people with developmental and other disabilities. The report categorizes lawsuits into three categories; 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.

Another useful summary is a docket of cases published by the National Association of Protection and Advocacy Services (NAPAS) (Priaulx 2004). This categorizes cases according to five population groups; people 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.

The Olmstead judgment raises many complicated legal issues and questions that are not discussed here (see Rosenbaum and Teitelbaum 2005, Desonia 2003). However, two key legal concepts are:

- ‘Fundamental alteration’ and ‘reasonable accommodations’. 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 accommodations’ 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) often include arguments and interpretations of these 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 'reasonable promptness' arguments can have complicated implications when discussed in relation to the ADA concepts of 'reasonable accommodation' and 'fundamental alteration'.

Whilst some legal implications of Olmstead remain unclear several studies have tracked the implications of Olmstead in state courts (Rosenbaum et al 2002, Rosenbaum et al 2002a, Batavia 2001, Petrila 1999). A recent report contends that "Olmstead's legacy in the courts has been uneven" and that this is largely due to the subjectivity involved in deciding whether changes sought by plaintiffs to a state Medicaid program constitute a 'fundamental alteration' (Rosenbaum and Teitelbaum 2004). 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. In a recent report, Enbar and colleagues review the use of litigation across the states, relating this with state efforts to increase deinstitutionalization and community integration of people with developmental disabilities and conclude that "litigation has been used as a catalyst" to stimulate such long-term care reforms (2005).

## Key Trends shown by the tables

- The total number of (reported) cases is 144.
- There are 7 states in which no reported lawsuits have been found (ID, IA, MO, ND, SC, SD and VT). However, Missouri and Wisconsin have both had several complaints raised with the Office of Civil Rights (OCR 2005) and Iowa has also had cases investigated by the Department of Justice. Under the US Department of Justice settlement with Iowa, DHS plans a reduction of 15 beds per year at state institutions (Iowa Real Choices Program 2006).
- 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). 4 of the lawsuits are classified as 'Olmstead' cases.
- There have been 59 'Olmstead' lawsuits (approximately 40% of those identified) in 28 states.
- The most 'Olmstead' lawsuits filed in one year was 16 in 2000, twice as many as in the preceding year.
- Washington has the most 'Olmstead' lawsuits (5), 4 of which are closed. Most states only have one 'Olmstead' lawsuit (12 states).
- At least 14 of the cases found (6 Olmstead, 8 Related) have had an impact on the provision of personal care services in the state.
- By 2006, 30 states had published Olmstead plans and 14 states had developed alternative responses to Olmstead. Eight states (CO, DC, FL, ID, PA, OR, RI, SD) have neither an Olmstead plan or an alternative response to Olmstead.

**1**E.W. died in 2004. (Atlanta Legal Aid Society, at **http://www.atlantalegalaid.org/impact.htm**)

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