

## **The Olmstead Decision: Consumer Rights to and Opportunities for Nursing Home Alternatives**

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In its landmark decision of June 1999, *Olmstead vs. L.C. and E. W.*, the United States Supreme Court ruled that the Americans with Disabilities Act (ADA) grants consumers new rights to live in something other than an "institution" when health or supportive services are needed. The decision applies to all governmental-funded programs and to all people with disabilities, without regard to age or the kind of disability. And yet, the decision also clearly puts some undefined financial limitations on the responsibilities of states to build and fund non-institutional alternatives. The *Olmstead* decision and resulting guidance from the Department of Health and Human Services (DHHS) construct both a federal legal foundation for nursing home alternatives and a process for the creation of the augmented non-institutional services.

As a result, Long Term Care Ombudsman programs (LTCOP) have new tools to respond to the most frequent complaint of nursing home residents and their families, "I do not want to be here. I want to go home." This short paper is an introduction to the decision and its impact on the rights and options of long term care consumers and how LTCOPs can respond to and maximize this opportunity. Key topics addressed in this paper are:

- The Supreme Court Decision
- Federal Guidance to the States
- Olmstead and Ombudsman Program Services
- Resources

### **The *Olmstead* Supreme Court Decision**

L.C. and E.W. are both young developmentally disable women. In 1995, both were being treated in a state psychiatric hospital even though both young women and their treating physicians said that a community-based setting would be better. The women sued the state of Georgia claiming that the state was violating Title II of the federal ADA that covers "public services furnished by governmental entities." ADA sections 12131-12165. These provisions of the ADA provide that a disabled person, who is otherwise qualified, may not be denied any public benefit, service, or program or discriminated against because of the disability.<sup>1</sup> This language applies to the full range of state health, supportive services, welfare, and housing programs.

The plaintiffs found very strongly worded Congressional findings that introduced the substantive provisions of the ADA. In enacting the ADA, Congress determined, in part, that

(2) historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;

(3) discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization . . . ;

(5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . failure to make modifications to existing facilities and practices, . . . [and] segregation. ADA section 12101(a)(2), (3), (5).

As instructed by Congress, the Department of Justice (DOJ) had issued ADA regulations in 1992.<sup>2</sup> Guided by these congressional findings, the ADA regulations instruct all governmental entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 CFR 35.130(d). When read with the Congressional findings equating discrimination and institutionalization, this regulation clearly calls on governmental programs, particularly Medicaid, to offer nursing home alternatives.

In a 6-3 decision, the U.S. Supreme Court sided with the disabled women and said that “unjustified placement or retention of persons in institutions, severely limiting their exposure to the outside community, constitutes a form of discrimination based on disability prohibited by Title II” of the ADA.

But, the ADA's provisions are not unrestricted, according to DOJ regulations and the Supreme Court. Modifications to governmental policies, practices, or procedures are not required by the ADA if such “modifications would fundamentally alter<sup>3</sup> the nature of the service, program, or activity.” 28 CFR 35.130(b)(7). To help define or find a “fundamental alteration,” the Court orders the lower courts to “consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably.”

Recognizing the complexity and difficulties of redesigning health delivery systems, five of the justices also gave the states time to adapt and build their programs away from discriminatory institutional basis.

To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the court below understood the fundamental-alteration defense to allow. If, for example, the State were to demonstrate that it had **a comprehensive, effectively working plan** for placing **qualified persons** with mental disabilities<sup>4</sup> in less restrictive settings, and **waiting list that moved** at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met. (*Emphasis added.*) *Olmstead* opinion at page 9.

### **Federal guidance to the States**

The federal DHHS has made implementation of the *Olmstead* decision a major policy initiative. An ad hoc workgroup crossing DHHS divisions has been created. Two DHHS divisions have extensive *Olmstead* web pages.<sup>5</sup> Seizing the Supreme Court's language for a state plan as satisfying the “reasonable modification” language, DHHS Secretary Donna Shalala wrote to each governor outlining the federal department's goals and abilities to help the states.

**Our country's progress . . . reflects a shared belief that no person should have to live in a nursing home or other institution if he or she can live in his or her community. The recent Supreme Court decision in Olmstead v. L.C. affirms this shared value, by finding**

**that unnecessary institutionalization of individuals with disabilities is discrimination under the Americans with Disabilities Act (ADA). In the decision, the Court explained that a State may be able to meet its obligation under the ADA by having comprehensive, effectively working plans ensuring that individuals with disabilities receive services in the most integrated setting appropriate to their needs.**

**We encourage you to develop and implement such plans, and to involve individuals with disabilities and other stakeholders in the process of design and implementation. This Department stands ready to assist you in these efforts. (*Emphasis added.*) January 14, 2000, letter from Secretary Shalala to each state Governor.**

On the same day, the CMS (Center for Medicare and Medicaid--*Formerly HCFA*) and the Office of Civil Rights (OCR) within DHHS sent letters to state Medicaid Directors.<sup>6</sup> The letter again calls on the federal and state governments to work together to "enable individuals with disabilities to live in the most integrated setting appropriate to their needs." The letters suggested "framework" re-enforces several points:

- A state with a "comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated" will likely be able to demonstrate compliance with Title II of the ADA.
- The OCR within DHHS will be evaluating state efforts to comply with the ADA and the Olmstead decision. OCR's work will be in both "compliance reviews" and responsive to any individual complaints filed with the agency about the failure of the state to provide services in the most integrated setting.
- A state will likely be seen in ADA compliance if it is developing a plan to create more community-based options.
- In addition to planning for increased community services, "states must also be responsive to institutionalized individuals whom request their situations be reviewed to determine if a community setting is appropriate."
- One clear message sent in the CMS (Center for Medicare and Medicaid--*Formerly HCFA*)/OCR January letter is that the "best" planning process within a state "actively involve(s) people with disabilities, and where appropriate, their family members or representatives, in design, development, and implementation."

Through an "Initial Technical Assistance Recommendation" attachment to the January 14<sup>th</sup> letter, CMS (Center for Medicare and Medicaid--*Formerly HCFA*) and OCR give specific, detailed principles and guidance to the states on how to plan for community-based services in a most integrated setting.<sup>7</sup> The six principles outlined by DHHS include:

- Comprehensive, effectively **working plan(s)** that analyze existing programs as a framework for growth, "awareness and agreement among stakeholders and decision-makers" about the elements of an effective system, and evaluating the adequacy of the current periodic reviews of consumers such as the PASARR process,<sup>8</sup> and finally how to avoid unjustifiable institutional placements in the first place.
- Plan development and implementation that **involve people with disabilities** (and their representatives, where appropriate) using methods that are constructive and ongoing.

- Create **assessment processes** for potentially eligible populations that prevent or correct current and future unjustified institutional placements including the collection of baseline data about the numbers of people being served who could be served in community-based settings and evaluation of the state's ability to respond in a timely, effective manner to the findings of an assessment.
- Ensure the **availability of community-integrated services** that meet the needs of people with disabilities and their support systems by evaluating the available funding sources and their coordination, the current operation of waiting lists, and how well the current service system works for different consumer groups.
- Furnish consumers and their families the opportunity, information, and referral systems to make **informed choices** regarding how their needs can best be met in community or institutional settings.
- Ensure that **quality** assurance, quality improvement, and sound management are parts of the plan's implementation.

Since January 2001, DHHS has also made a substantial financial commitment to the states for their ADA and Olmstead compliance efforts. Over \$70 million in five separate grant processes, including a \$50,000 "starter grant" for each state, has been created. The larger design, demonstration, and evaluation grant applications for "systems changes" are due in July 2001. Only states may apply but the state has to develop the work in tandem with a consumer task force. For more detailed information on the DHHS grant specifications, go to <http://www.hcfa.gov/medicaid/systemschange/default.htm>.

### **Olmstead and Ombudsman Program Services**

The *Olmstead* decision and resulting guidance from DHHS construct a federal legal foundation for the creation of nursing home alternatives, a process for building an expanded non-institutional service system, and new advocacy avenues to serve nursing home residents and other long term care consumers. LTCOPs have new tools to help each resident who wants a less restrictive place to live and receive services. The decision supplies the program, through a state initiated Olmstead planning process, a forum to work with consumers and other advocates to create a long term care system that works.

For the individual nursing home resident who wants a less restrictive place to live and receive services, two options are now clearly available to help meet that desire. In its 1/14/00 letter to state Medicaid directors, CMS/OCR explained that a state must be "responsive" to a nursing home resident who asks for a review to determine if a community setting is appropriate. An LTCOP should assist a resident or family is seeking that review. If the state is "unresponsive," an individual can also file a complaint with the regional OCR office that the state has failed to comply with Title II of the ADA.<sup>9</sup>

Similarly, any disabled person, particularly those dependent upon Medicaid, facing placement in a nursing home from home, hospital, board and care home, or assisted living ought to be able to use the same two options, state review and OCR complaint, to seek community services instead of nursing home care.

Moreover, many states are in a formal Olmstead planning process to create a long term care system that works for consumers.<sup>10</sup> These states have taken seriously the Court's suggestion of a credible state planning process coupled with moving waiting lists will be

viewed as ADA compliance by both OCR and federal courts. A new state system can strengthen the state's home and community-based waiver services, help elders remain in board and care/assisted living with Medicaid funding or expand respite beyond a weekday, 9 to 5 service.

Some states began this process quickly while others have not yet taken action responding to the Olmstead decision. A handful of states is challenging the Supreme Court decision and the federal law.<sup>11</sup> A first step for state Ombudsmen would be to determine what action - if any - has begun within the state. Contacts with the state's Medicaid agency and the disability community will probably be the most fruitful along with visits to the websites noted in this paper.

Disability advocates suggest that the process begin with a letter from consumers to the state's Medicaid director asking that planning begin following the DHHS guidance.<sup>12</sup> Such a letter from the aging and disability communities jointly would be a powerful beginning to reform. Under its federal Older Americans Act responsibilities to "represent the interests of residents before governmental agencies" and to "analyze, comment on, and monitor the development of implementation of federal and state" laws and governmental policies affecting the health, safety, welfare and rights of residents"<sup>13</sup>, the LTCOP could facilitate such an effort with leaders of the disability community such as ARC, Centers for Independent Living, Protection and Advocacy Services, United Cerebral Palsy, or others. The Alzheimer's Association, state chapters of the National Council for Senior Citizens, or AARP might also take the lead in facilitating the joint letter to the state's Medicaid director. Convening the aging and disability communities prior to the formal planning process would also give the affected stakeholders an opportunity to develop suggestions for the how the overall process can best be organized and consensus approaches to fact-finding, decision-making, and system reform.

### **Additional Resources**

The National Ombudsman Resource Center will continue to issue Olmstead Alerts addressing the questions raised by LTCOPs and reporting on the elements of a successful Olmstead plan and its development. In the meantime, there are some valuable materials currently available.

In February, DHHS, CMS, the MedStat Group, and the School of School Work at Boston University put a new website upB [www.hcbs.org](http://www.hcbs.org). This site may be the place to find the most up-to-date releases from DHHS.

AARP's Public Policy Institute has posted a paper on the Olmstead implications for older people with mental and physical disabilities, [http://research.aarp.org/health/2000\\_21\\_disabilities\\_1.html](http://research.aarp.org/health/2000_21_disabilities_1.html). The paper is an excellent explanation of the Court's opinion, ADA requirements, and raises some important initial implementation questions.

The disability community has developed a wealth of helpful advocacy tools available on the Internet. Three, in particular, provide all the basic information needed such as links to information from the Supreme Court and DHHS, updates on what is happening in many states, and detailed suggestions for how to get an Olmstead planning process up and running and producing effective results. First, is a site created by people with disabilities

from a more radical frame of mind, [www.freedomclearinghouse.com](http://www.freedomclearinghouse.com). The site is full of basic organizing and research tools all focused on making the Olmstead planning process credible and productive. While the document is set in a "disability" as opposed to "aging" dialect, its "Blueprint for developing an effective State Plan to implement Olmstead" is an excellent step-by-step guide to putting substance on the principles DHSS laid out for effective planning.

Another very helpful website is from the National Association of Protection and Advocacy Systems. It has a large catalogue of information under the heading "Olmstead v. L.C., Resources for Advocates," at its website [www.protectionandadvocacy.com](http://www.protectionandadvocacy.com). The site also has more detailed information about the Olmstead related litigation going on across the country. Included are instructions on how to file a complaint with OCR.

The Bazelon Center for Mental Health Law has completed an analysis of the Olmstead decision's impact of people with mental illnesses. Uniquely, their analysis has a detailed listing of places to look for funding non-nursing home services. The site also has up-to-the-minute analysis of ADA and Olmstead litigation developments. Their work can be found at [www.bazelon.org/lcruling.html](http://www.bazelon.org/lcruling.html).

Finally, the Department of Justice has its own ADA home page with a broad summary of the entire Act and activities across the country, <http://www.usdoj.gov/crt/ada/adahom1.htm>.

## Conclusion

LTC consumers have sought Ombudsman help to find different set of long term care options and services since the program's beginnings. The *Olmstead* decision, built on the ADA, offers an historic opportunity to integrate facility-based long term care with home-based long term care creating a rational system of real consumer choices. The opportunity is too good to miss.

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<sup>1[1]</sup>The ADA's definition of disability is quite broad including any physical or mental impairment "that substantially limits one or more of the major life activities" including the ability to care for yourself. ADA section 12102(2).

<sup>1[2]</sup>The DOJ regulations are patterned on the 20 year old regulations for the section 503 - 505 of the Rehabilitation Act of 1973 which also prohibited discrimination based on disability.

<sup>1[3]</sup>The regulations give no advice on the meaning of "fundamentally alter" and the Supreme Court's decision is not clear. This meaning of this term will be the key to all Olmstead work.

<sup>1[4]</sup>The ADA is not limited to people with mental disabilities. Universally, commentators read the *Olmstead* decision to apply to anyone who meets the broad ADA definition of disability.

<sup>1[5]</sup> [www.hcfa.gov/medicaid/olmstead/olmshome.htm](http://www.hcfa.gov/medicaid/olmstead/olmshome.htm) , the Health Care Financing Administration site and [www.hhs.gov/ocr/mis.htm](http://www.hhs.gov/ocr/mis.htm) , the Office of Civil Rights site.

<sup>1[6]</sup>[www.hcfa.gov/medicaid/letters/smd1140a.htm](http://www.hcfa.gov/medicaid/letters/smd1140a.htm)

<sup>1[7]</sup>*Ibid*. While a summary of the principles and guidance is provided here, you are strongly urged to study the original document and its list of initial planning questions. [www.hcfa.gov/medicaid/letters/smd1140a.htm](http://www.hcfa.gov/medicaid/letters/smd1140a.htm)

<sup>1[8]</sup>PASARR (pre-admission screening and annual resident review) process is a required element of the federal Nursing Home Reform statute. Before admission and annually thereafter, all nursing home residents are to be assessed for mental retardation and mental illness.

<sup>1[9]</sup>Instructions on how to file an Olmstead complaint with OCR can be found at the [www.protectionandadvocacy.com](http://www.protectionandadvocacy.com) website under "Olmstead v. L.C., Resources for Advocates."

<sup>1[10]</sup>It is estimated that as many as 36 states are doing Olmstead planning. The best summary of state Olmstead activity have been completed by the National Conference of State Legislatures. The NCSL has consolidated all their excellent disability related materials on one page at <http://www.ncsl.org/programs/health/disabil.htm> .

<sup>1[11]</sup> One such challenge was the *Garrett* case from Alabama. The Supreme Court's decision did not negatively affect the *Olmstead* ruling. For more information on this case, go to <http://www.bazon.org/garrettcase.html>

<sup>1[12]</sup> A sample letter to the state's Medicaid director can be found at [www.freedomclearinghouse.com](http://www.freedomclearinghouse.com).

<sup>1[13]</sup> Section 712(a)(3)(E)(G)