Attachment 10
Using the Olmstead Decision as an Advocacy Tool for Your Clients[1]

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Like most NAELA members, I frequently hear from my clients, "Do whatever it takes to keep me out of a nursing home." Further, I often am requested to draft an estate plan, and particularly a special needs trust, to protect a client's family member with a disability, that will prevent the beneficiary from being "placed" into a group home or institution against his or her will. Responding to this increasing demand for access to quality long-term care services in the least restrictive setting is a complex legal challenge. We must be able to respond creatively.

This is not a new issue for our clients. As identified in the excellent *NAELA White Paper on Reforming the Delivery, Accessibility and Financing of Long-Term Care in the United States*:

The current system in our country for addressing long-term care is a non-system, a hodgepodge of services that fails to meet the needs of the elderly and disabled in the variety of long-term care settings. It is economically inefficient and it fails to assure the quality of services which are provided.

The *White Paper* asserts that, "The time has come for the citizens and government of the United States to address the issues of the delivery, accessibility and financing of long-term care in our Country." Unfortunately, little progress has been made towards the reforms urged by our organization. So how do we respond to the requests and needs of our clients in the meantime? Be creative. This article will provide an overview of the Supreme Court's decision in Olmstead vs. L. C., 527 US 581 (1999), and outline how it may be creatively used as an advocacy tool on behalf of our clients.

The Decision

This landmark 1999 Supreme Court decision, built upon the promises made in the Americans with Disabilities Act almost a decade earlier, held that "unjustified isolation" of individuals with disabilities "is properly regarded as discrimination based on disability, as it perpetuates negative stereotypes and severely restricts and infringes upon the everyday life activities of individuals with disabilities."[1] Consequently, states must place individuals in community settings rather than in institutions when:

[T]he states' treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.[2]

The plaintiffs in the case, L. C. and E. W., are young women with developmental disabilities. When their suit was filed against the state of Georgia, they were receiving treatment in a state psychiatric hospital. Their treating physicians agreed with the ladies that a community-based setting for their services would better meet their needs than the hospital setting. The ladies sued for violation of Title II of the ADA, which covers " public services furnished by governmental entities."[3]

The decision did not create an *absolute* right to be placed into the community, irrespective of costs or other factors. The court clearly recognized that a state's obligation to provide care and treatment for individuals with disabilities is limited by its available resources and its obligation to, "maintain a range of facilities and to administer services with an even hand."[4] The justices also recognized that states must address difficult policy issues, such as the increased overall expenses, that result from the need to continue operating partially-full institutions, while at the same time funding community services at an appropriate level.[5]

The ADA only requires "reasonable accommodations." Therefore, the court determined that states did not need to make any modifications that would fundamentally alter the nature of the program or service provided.[6] As a result, a state can raise a "fundamental alteration" defense by demonstrating that, "immediate relief for the plaintiffs would be inequitable given the responsibility the state has undertaken for the care and treatment of a large and diverse population of person with mental disabilities."[7] The state could justisfy this defense and be in compliance with the ADA by demonstrating that it has a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting

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1. 527 U.S. 581 (1999) at 597. The ADA's definition of disability is broad and includes any physical or mental impairment, "that significantly limits one or more of the major life activities," including ones ability to care for their self. A.D.A. §12102 (2). Some advocates were originally concerned that this decision would not apply to elders, however this broad definition addresses the issue. See also, GAO Testimony Before The Special Committee on Aging, US Senate, on Long-Term Care by Karen G. Allen, 9/24/2001, GAO-01-1187T, page 5.
2. Id. at 587.
3. A.D.A. §§12131-12165. Many of the advocacy suggestions in this article pertain to Medicaid services as the "public services" at issue. This decision also applies to state or local "governmental services." Therefore if you practice in a state like Michigan (my home) where the provision of Long-Term Care Services occurs through contract from the State to County and/or private providers, the ADA and this decision still apply.
4. Id. at 605.
5. Id. at 604.
6. 28 C. F. R. §35.130 (b)(7)(2001); Id. at 603-604.
7. Olmstead, 527 U.S. at 604. Again note that the ADA is not limited to people with mental disabilities. Commentators read this decision to apply to any qualified person with a disability under the broad ADA definition of disability. See also *The Olmstead Decision: Consumer Rights to and Opportunities for Nursing Home Alternatives*, by Hollis Turnbeam, Consultant to the Nat. Ombudsman Resource Center. Oct. 2001. www.ltcombudsman.org.

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list that moves at a reasonable pace not controlled by the state's endeavors to keep their institutions fully populated."[8]

The Court did not define "effectively working," "reasonable pace" or "waiting list." It is unclear exactly how states can comply with the requirements of this well-balanced decision. It is especially confusing when attempting to determine the exact scope of the states' obligations to provide community based services under the Medicaid Act in order to be in compliance with this decision and the ADA. The Department of Health and Human Services has made implementing the decision, and providing guidance to the states, a priority. The Centers for Medicare and Medicaid Services (formerly known as HCFA) issued letters for the State Medicaid Directors/and governors. These letters provide guidance to the States and advocates.[9] I urge you to read them, and use them in your advocacy efforts.

Litigation over these issues, aimed at securing prompt access to Medicaid Home and Community Services for people with disabilities, continues.[10] It continues in a tradition of protecting people with disabilities from the horrors of the past by encouraging states to provide for increased demand for Medicaid Home and Community Based Services.

Medicaid is the dominant "public service" supporting long-term care, accounting for about 44 percent of the $134 billion spent nationally for these services in 1999.[11] Traditionally, it paid for services that were primarily provided in nursing homes or institutions, and billed as a medical service. While Medicaid spending for home and community based services is growing, these services are optional benefits. A state does not have to provide them. Once a state does elect to provide a service under a home and community based waiver, "that service becomes part of the state Medicaid plan and is subject to the requirements of the federal law," which includes the "reasonable promptness" standard of the Medicaid statute.[12]

The grim reality is that in most states the demand for community based services far exceeds what is available.[13] The people on waiting lists for such services may be people living in institutions and/or nursing homes who want to move to a less restrictive setting or they may be people who need access to community based services to prevent admission to a nursing home, institution, or group home.

The Olmstead decision makes it clear that it is no longer acceptable for states to allow folks to wait for services needed to live in the least restrictive setting. The states need to address this critical shortfall in "public services" to comply with the ADA and the Olmstead decision. As of September 2001, an estimated 40 states and the District of Columbia have task forces focused on developing "effectively working plans." Unfortunately, not all states are so involved. According to the National Conference of State Legislatures (NCSL), which is tracking the states' efforts, the following states are not developing plans: Michigan, Minnesota, Nebraska, New York, Oregon. Rhode Island, South Dakota, Tennessee, Vermont, and Virgina. With no "effectively working plan" these states arguably would have no "fundamental alteration" defense to an ADA claim.

Although most NAELA members will not be involved in the massive litigation likely to be brought against the states (and which is likely to continue for years to come), we may be able to assist in assuring that key stakeholders participate in the development of states' "effectively working plan," and in measuring the movement of the waiting lists. Consider the following as examples of Olmstead advocacy that we can use as tools for our clients:

Example 1: *A person living in a nursing home, institution, or group home who wants to move to a less restrictive setting and receive services in the less restrictive setting.*

Olmstead Advocacy: In the January 14, 2000 letter to State Medicaid Directors, HCFA/OCR explained that a state must be responsive to a resident who asks for a review to determine if a community setting is appropriate. Practitioners can assist the individual or his or her family in requesting the review and/or securing second opinions and can obtain the relevant files. There may already be assessments stating community placement is appropriate. If the state is unresponsive, the individual can file an OCR complaint stating that the state has failed to comply with Title II of the ADA.[14] Further, if the individual is a Medicaid beneficiary, the assessment may be a covered service. Therefore, a lack of response could be a denial of a Medicaid service, without proper notice as required by due process. I like to call this a "non-denial" denial. A Medicaid Fair Hearing should be requested, and document how many times, when, and by whom the services were requested. Also, file complaints under any applicable state civil rights or mental health rights statutes as well. The more individuals or agencies looking at this the better.

Example 2: *A Person with a disability, who also is a recipient Medicaid Home and Community Based Waiver,*

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8. Id. at 605-606.
9. http://www.hcfa.gov/Medicaid/Olmstead/olmshome.htm.
10. *Status Report: Litigation Concerning Medicaid Services for Person with Developmental Disabilities*, by: Gary A Smith, November 8, 2001 garsh@han.org; and Implementing Olmstead v. L. C. by Melody M. Kubo, 23 U. Haw. L. Rev. 731.
11. GAO Testimony Before The Special Committee on Aging, US Senate, on Long-Term Care by Karen G. Allen, 9/24/2001, GAO-01-1167T, page 11.
12. 42 C. F. R. §435.930 (a). (b). 2001. Doe v. Chiles, 136 F.3d 709, 714 (11th Cir. 1998).
13. GAO Testimony Before The Special Committee on Aging, US Senate, on Long-Term Care by Karen G. Allen, 9/24/2001, GAO-01-1167T, page16.
14. Instructions on how to file an Olmstead complaint with OCR can be found at the following website under Olmstead v. L. C. Resources for Advocates, www.protectionandadvocacy.com

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needs an increase in covered services to either avoid placement in a more restrictive setting or a move to a less restrictive setting even if the increased total cost of services as requested would be less than the costs of a more restrictive alternative.

Olmstead Advocacy: Assist the individual in requesting the service and documenting the need for the increase. If denied, or if not responded to, request a Medicaid Fair Hearing. Medicaid Services must be provided in sufficient amount, duration, and scope to reasonably achieve their purpose.[15] The Home and Community Based Waiver was intended to contain "long term care cost... by providing services to some individuals in less restrictive settings, such as at home or in the community rather than an institution."[16] File an OCR complaint and pursue other state options.

Example 3: *Same facts as in Example 2, except that the amount of the waiver services to keep the person in the less restrictive setting (or to move them there) costs the same or more than the more restrictive alternative.*

Olmstead Advocacy: Request and represent the individual in a Medicaid Fair Hearing, as Olmstead requires that the individual should be able to live in the least restrictive setting for so long as it is reasonably accommodated. A hearing will balance the language in the Olmstead decision with other cases, such as Helen L. v. Di Dario, 46 F. 3d 325 (3rd Cir. 1995), where the court said, "... a lack of funding or other funding constraints would not excuse a state from compliance with the requirements of the ADA." Further, in this case the court determined that providing services through an existing program did not fundamentally alter the nature of the program. File a OCR complaint, and pursue other state options.

Example 4: *Same facts as in examples above, except that the Medicaid beneficiary is also the beneficiary of a special needs trust. The beneficiary wants to remain in the least restrictive setting or move from a more restrictive setting.*

Olmstead Advocacy: Meet with the individual and/or the trustee of the special needs trust to determine the amount of services, and types needed, to be successful. Determine all other sources of support and seek them, i.e., Section 8 Housing, Medicare Services; State plan of Medicaid Services. Then present your request for services in light of available additional resources. The special needs trust could pay for things that the waiver does not cover, for example household furnishings. Notify the public system if the individual is willing to share the home and therefore the costs. Document all efforts to develop this private public partnership. If the request is still denied, appeal through a Medicaid Fair Hearing, file an OCR complaint, and pursue other state options. Remember that the Olmstead decision holds that the less restrictive setting should be provided if it can reasonably be accommodated, taking into account the state's financial circumstances. In this case, the use of the additional resources could be the factor that makes it easy to accommodate the request for community based services.

Example 5: *A client comes in for help in planning for future long-term care needs. In reviewing the facts, it is determined that the individual could stay out of a nursing home with the help of the services under a Home and Community Based Waiver. They apply for a waiver and are informed that there are no slots available.*

Olmstead Advocacy: The Medicaid Statute allows states to limit enrollment and maintain waiting lists for waiver services (states are not required to provide these services, or even to maintain a waiting list). To date, no court has determined whether a state may deny community based services once the state's federally approved population limit for the waiver has been reached or whether a state must seek a waiver program. A test case may be necessary and individuals are forced into restrictive settings by a state's refusal to plan or act.

Therefore, you will need to investigate to determine if your state is holding back waiver slots because they do not have adequate state matching funds. If so, request a Medicaid Fair Hearing, and file an OCR complaint. In Boulet v Cellucci, 107 F.Supp. 2d 61 (D. Mass. 2000) the federal court determined if the eligible individuals are within the population limits of the waiver they are entitled to services within 90 days. This could be especially helpful if your waiver is large. Michigan's waiver covers all individuals with developmental disabilities. Many have been waiting for services for years. We now have the ability through Medicaid Fair Hearings and OCR complaints to secure appropriate services for our client and their family members.

If you determine that waiver eligibility is being limited by your state strictly for financial reasons, or it fails to plan on how to expand their waiver or refuses to apply for one, then systems advocacy, combined with targeted litigation, will be required.

In conclusion, it is clear that we are still very far away from the unified approach to long-term care urged in the *NAELA White Paper*. The Olmstead decision is a tool that we can use in advocating for our clients in the meantime. Use it! I am attempting to collect creative approaches to this problem, so that we can share information and learn from what our members are doing in their states. Feel free to contact me at pdudek@beierhowlett.com.

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15. 42 C.F.R. §440.230

16. HCBS Waiver Program Fact Sheet, page 1 of 2.