CIVIL RIGHTS AND LONG-TERM CARE: ADVOCACY IN THE WAKE OF *OLMSTEAD V. L.C. EX REL. ZIMRING*

Harriet McBryde Johnson

Lesly Bowers

In a provocative and inspiring article, the authors urge elder law attorneys to join forces with disability rights advocates following a recent decision by the U.S. Supreme Court, which has been hailed as a potentially powerful weapon in the civil rights arena. The Court ruled that states may be required to place persons with disabilities in a community setting versus an institution if certain factors exist. As the population continues to age, the ruling has implications for older Americans who also want to live independently. This is especially true given that so many senior citizens are institutionalized in government-funded facilities. Ms. Johnson and Ms. Bowers aggressively argue that unwanted and unnecessary confinement is wrong at any age, whether it is in an institution for the disabled or a long-term care facility for the elderly. The article concludes by asking elder law attorneys to see the broader civil rights struggle that may lie hidden in their day-to-day client representations.

Harriet McBryde Johnson is a solo practitioner in Charleston, SC, whose practice emphasizes disability issues.

Lesly Bowers is the Managing Attorney for Advocacy for Protection and Advocacy for People with Disabilities, Inc., in Columbia, SC. Both have been active in *Olmstead* advocacy in a variety of contexts.

When the U.S. Supreme Court decided *Olmstead v. L.C.* ex rel. *Zimring*[1] in June 1999, disability rights advocates heralded it as comparable to *Brown v. Board of Education*. Three years later, it sometimes seems like the landmark civil rights case no one knows about. Barely noticed in the mainstream press, off the radar screen for millions who are directly affected, *Olmstead* is nevertheless changing individual lives. It may also be ushering in a quiet revolution in long-term care. It has the potential to transform the social response to people with physical or mental disabilities who need assistance in daily life, including ever-increasing numbers of elderly Americans. These changes necessarily imply new roles and responsibilities for elder law attorneys.

The *Olmstead* case was brought by two Georgia women with cognitive and psychiatric impairments. Following hospitalization in a state psychiatric facility, their acute problems were resolved, and the state's physicians declared them ready to return to the community with appropriate services and supports.[2] However, no community program slot was available, and the women had no choice but to stay in the hospital.[3] The women sued under the Americans with Disabilities Act,[4] claiming that their needless isolation in an institution amounted to disability-based segregation, and segregation is discrimination under the law.[5] They contended that the state had an affirmative duty to serve them in an integrated, community setting.[6] The District Court and the Eleventh Circuit Court of Appeals agreed.[7] On certiorari, the United States Supreme Court ruled:

> [W]e confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State's 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 ac-

1. 527 U.S. 581 (1999).
2. *Id.* at 593.
3. *Id.*
4. 42 U.S.C. §§ 12131–12165 (2000). The Americans with Disabilities Act (ADA) prohibits discrimination by state and local governments in Title II, 42 U.S.C. § 12132.
5. *Olmstead*, 527 U.S. at 594.
6. *Id.*
7. L.C. *by* Zimring v. Olmstead, 138 F.3d 893 (11th Cir. 1998); L.C. *by* Zimring v. Olmstead, 1997 WL 148674 (N.D. Ga. Mar. 26, 1997).

> count the resources available to the State and the needs of others with mental disabilities.[8]

Perhaps the most important aspect of the decision is that it upheld the integration mandate of Justice Department regulations: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[9]

While the ruling is in some respects qualified and narrowly drafted, it has broad implications. Nothing in the decision limits it to younger people, to people with mental impairments, or to large state-owned institutions. Nursing homes isolate people based on disability, just as traditional institutions do.[10] The ruling, therefore, has direct application to seniors placed in Medicaid-funded nursing homes. The basic principle of the "integration mandate" extends to a variety of public and private programs that cluster seniors and restrict their choices based on level or type of impairment, as opposed to their individual needs and desires.

The overwhelming majority of nursing home residents are seniors, but the overwhelming majority of post-*Olmstead* activity has involved other segments of the disabled population. Disability advocates are only beginning to recognize seniors as an underserved part of their constituency. Seniors and their advocates have been equally slow to join disability activists in defining long-term care as a civil rights issue.

For disability rights activists, *Olmstead* is one event in a struggle that is now in its fourth decade. The struggle is for a world in which people with even the most severe disabilities are able to choose where, how, and with whom they live.[11] Among the movement's leadership are people who use power wheelchairs, mechanical ventilation, and

8. *Olmstead*, 527 U.S. at 587.

9. 28 C.F.R. § 35.130(d) (1998).

10. In fact, what is now the *Olmstead* theory was first advanced in a Third Circuit case, *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir.), *cert. denied*, 516 U.S. 813 (1995), that involved a physically disabled woman placed in a private nursing home while she waited for in-home services under Medicaid. *Id*. As in *Olmstead*, the state conceded that Helen L.'s needs could be met at home, but cited budgetary constraints. The Third Circuit rejected this argument, noting that the state as a whole is subject to the ADA, and the state controls its budget. *Id*.

11. For comprehensive discussions of disability rights and an argument for a new paradigm for disability policy, see MARTA RUSSELL, BEYOND RAMPS: DISABILITY AT THE END OF THE SOCIAL CONTRACT (1998), and Robert Silverstein, *Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy*, 85 IOWA L. REV. 1691 (2000).

feeding tubes. Their experience illustrates that the services typically provided in nursing homes and other institutions can be provided in the community—and often at lower cost. The critical difference between some people who enjoy freedom and others who languish in institutions is not physical or mental functioning, but where the money is spent.[12] In terms of personal autonomy and freedom of movement, nursing home residents are political prisoners: they are where they are because of political decisions. While the movement's focus and driving energy has typically been on younger people, its analysis applies without regard to age. Unwanted, unnecessary confinement is just as wrong—and just as illegal—at age eighty as at age twenty-five.

The disability rights perspective offers a host of opportunities for the elderly and their advocates to work toward a world in which no one is ever institutionalized simply because that is what the government will fund. At both federal and state levels, advocates are litigating, lobbying, planning, and making policy.

At the federal level, efforts are underway to remove the institutional bias in government funding and to enhance the flexibility and effectiveness of community services. The following initiatives are among the most important:

1. The Centers for Medicare and Medicaid Services (CMS), formerly known as the Health Care Financing Administration, is reviewing policies and procedures and responding to advocates' concerns about state administration of Medicaid and Medicare. Under both Presidents Clinton and Bush, the agency has been moving incrementally toward greater flexibility and consumer control in long-term care services.[13] To a limited extent, it is putting its money where its mouth is by offering grant funding for *Olmstead* planning, innovative demon-

12. A comparison is often made between Ed Roberts and Larry McAffee, both quadriplegics requiring mechanical ventilation. McAffee, shunted between hospitals and nursing homes by Georgia Medicaid, became a "cause celebre" for the right to die. Roberts fought for the right to get personal assistance in the community and became a founder of the independent living movement and eventually director of rehabilitation services for the state of California. Both stories are told in JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1993).

13. *See, e.g.*, Ctrs. for Medicare & Medicaid Servs., *ADA/Olmstead Decision State Medicaid Director Letters*, *at* http://www.cms.hhs.gov/olmstead/smdltrs.asp (last modified May 9, 2002**)** [hereinafter *Director Letters*].

stration projects, and facilitating the transition from institutions to the community.

2. Legislation has been introduced to eliminate the requirement that an individual be "home-bound" to qualify for in-home services under Medicare.[14] This legislation reflects a new understanding that no one should be confined to the house when they could be freed by the right technology, accessible construction, and services. Despite their limitations, Medicare in-home services can make a real contribution in preventing caregiver burnout and supplementing self-pay resources.[15]

3. The Medicaid Community Attendant Services and Supports Act, known as "MiCassa," has been pushed by the disability rights movement in every session of Congress for about a decade.[16] It is again pending.[17] Under current Medicaid law, every state is required to fund institutional services, but in-home services are entirely optional.[18] Seventy-seven percent of Medicaid long-term care dollars go to institutional services;[19] Medicaid is the primary funder of nursing homes.[20] MiCassa would create a national program of in-home services and would allow Medicaid-eligible individuals, or their representatives, to choose where they receive their services and supports.[21] MiCassa has faced stiff opposition from the nursing home industry, but that has not deterred the disability rights movement. Passing MiCassa is now the single national goal for American Disabled for Attendant Programs Today (ADAPT), the grassroots organization that

14. H.R. 1490, 107th Cong. (2002); S. 2085, 107th Cong. (2002).

15. The Medicaid statute does not have a home-bound requirement, but prior to *Olmstead* many state Medicaid plans imposed one. CMS has notified Medicaid Directors that it considers this inconsistent with *Olmstead*. *Director Letters*, *supra* note 13, Letter No. 3.

16. *See* Liberty Res., *ADA Victory in Supreme Court*, *at* http://www.libertyresources.org/advocacy/olmstead.html (last visited Nov., 4 2002).

17. S. 1298, 107th Cong. (2001); H.R. 3612, 107th Cong. (2002). As of this writing (Aug. 2002), MiCassa had twelve Senate cosponsors and eighty-four House sponsors, with bipartisan support.

18. LAWRENCE A. FROLIK & RICHARD L. KAPLAN, ELDER LAW IN A NUTSHELL § 5.2 (2d ed. 1999).

19. HEALTH CARE PLANNING ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., A PROFILE OF MEDICINE CHARTBOOK 48 (2000), *at* http://www.cms.hhs.gov/charts/Medicaid/2Tchartbk.pdf (last visited Nov. 4, 2002).

20. KAISER COMM'N ON MEDICAID & THE UNINSURED, THE ROLE OF MEDICAID IN STATE BUDGETS 1 (2001), *at* http://www.kff.org/content/2002/20020918/4024.pdf (last visited Oct. 28, 2002).

21. S. 1298, 107th Cong. (2001).

effectively applied direct action, including civil disobedience, in its successful, twenty-year fight for accessible public transportation.[22]

At the state level, *Olmstead* has spurred activity that varies widely depending on local conditions—and sometimes on the happenstance of the particular interests of the individuals who have jumped into the fray. Although the general public has not paid much attention to *Olmstead*, state lawyers and policy makers have little choice but to recognize a federal civil rights mandate. *Olmstead* gives advocates a hook to attack a broad range of issues. Some examples include the following:

1. In the *Olmstead* decision, the Supreme Court suggested that states adopt "comprehensive, effectively working plans" to ensure that people who are ready and desire to leave institutions are able to do so.[23] The implication that such a plan might offer states a valid litigation defense would normally be expected to spawn a mountain of documents and nothing more. However, with varying degrees of success, advocates have pushed for open processes that genuinely challenge existing systems. Some state officials are learning that the people who use long-term care know something about it; they should be among the "stakeholders" at the table when decisions are made.

2. Advocates are targeting state laws that needlessly restrict the freedom of people with disabilities. In many states, Nurse Practice statutes define virtually any hands-on services provided for pay to a disabled or elderly person as the practice of nursing, requiring licensure.[24] For many, this type of regulation makes effective in-home services unavailable; those who live in a rural area beyond the reach of a nursing agency, or need an attendant for short shifts throughout the day, or have limited self-pay dollars, are simply out of luck. Advocates are therefore calling for statutory exemptions to allow people with disabilities and their surrogates to hire people of their own choice to act at their direction. Thus, the individual, not the nursing profession, "delegates authority" to nonlicensed personnel.[25]

22. ADAPT, *at* http://www.adapt.org/back.htm (last visited Sept. 30, 2002).
23. *Olmstead*, 527 U.S. at 605–06.
24. *See* STATE MEDICAID MANUAL § 4480: PERSONAL CARE SERVICES (2000), *at* http://aspe.hhs.gov/daltcp/reports/primap2.pdf (last visited Sept. 30, 2002).
25. The writers hope they will be forgiven for citing South Carolina's recently enacted Nurse Practice Act amendment, which they believe is currently the most progressive in the nation. H.B. 3817, 2002 Leg., Reg. Sess. (S.C. 2002) (to be codified at S.C. CODE ANN. § 40-33-50(9), (10) (2002)).

3. In some states,[26] advocates have secured passage of legislation that "the money follows the person"—that state funding used to house individuals in nursing homes and institutions must follow them into the community if they choose to leave. It is not clear how these measures are being translated into systems, but given the high cost of institutional confinement, the principle has enormous power.

4. With so many states in budget crises, *Olmstead* advocates need to fight to preserve such community services as are currently funded. In most states, *Olmstead* compliance will require significant new funding as well. While advocates are convinced that, in the long-term, home services cost less than institutional services, an initial investment of new funding is needed to build a service infrastructure. Elders and their advocates need to be involved to ensure that the diverse needs and desires of this population are not overlooked in the competition for scarce resources. Their participation in large numbers would also lend strength to a movement to increase the size of the pie for all disabled Americans, whatever their age.

5. Post-*Olmstead* litigation has been filed or is in the works to challenge myriad state practices, including excessively long waiting lists for community services, failure to identify and assess institutional residents who want to return to the community, failure to have effective working plans, and denials of due process.[27]

Elder law attorneys, elder rights organizations, and senior activists should be full partners in these ongoing efforts. As needed, they should also challenge disability advocates to do a better job representing elders' interests and including elders' perspectives. The first step is to make contact.

---

26. H.B. 1111, 90th Gen. Assem., 2d Reg. Sess. § 11.445 (Mo. 2000).

> Provided that an individual eligible for or receiving nursing home care must be given the opportunity to have those Medicaid dollars follow them into the community and choose the personal care option in the community that best meets the individuals' needs. . . . And further provided that individuals eligible for the Medicaid Personal Care Option must be allowed to choose, from among all the options, that option that best meets their need; and also be allowed to have their Medicaid funds follow them to whichever option they choose.

Id.

27. For a sampling of litigation and other *Olmstead* information, see the web site of the National Association of Protection and Advocacy Systems (NAPAS), *at* http://www.protectionandadvocacy.com (last visited Nov. 4, 2002) or Bazelon Center for Mental Health Law, *at* http://www.bazelon.org (last visited Nov. 4, 2002).

Who is doing what varies from state to state. In every state, there is a federally funded protection and advocacy system, which offers free legal representation and advocacy for people with disabilities, regardless of age. Most of these are involved with *Olmstead* advocacy.[28] Each state also has an Independent Living Council and a network of community-based, consumer-controlled independent living centers, all charged with the central mission of enabling people with disabilities to live as they choose, with whatever services or supports they need.[29]

In helping individual clients and families make informed choices within the current system, elder law attorneys have performed valuable services. Too often, however, the focus has been on funding institutionalization, selecting a "good" institution, and preserving assets. In the post-*Olmstead* climate, much more should be expected.

When a client comes to discuss nursing home placement, the first question should be, "Is that where you really want to live?" If the answer is no, the lawyer should work aggressively to prevent unwanted confinement. The lawyer should not stereotype clients by assuming that certain impairments or functional losses make institutionalization a necessity. Instead, the discussion should be based on an individualized inquiry. What is the client unable to do in daily life? What is causing difficulty? What is putting the client at risk? What services, technologies, or other modifications would enable the client to perform tasks or have tasks performed? How can risks be eliminated or reduced? For risks that cannot be eliminated, is the client capable of understanding and assuming risk? What are the costs? What resources are available?

A great deal of information specifically targeted to seniors is available through community-based aging networks and traditional service providers. However, independent living centers and other organizations not specific to aging may turn out to be the source for getting ramps built on homes, locating simple off-the-shelf consumer electronic solutions, finding personal assistants, and other disability support.

28. Contact information by state is available through NAPAS, *supra* note 27.

29. Contact information is available through the Independent Living Research Utilization Project at the Baylor College of Medicine, Houston, Texas, *at* http://www.ilru.org (last visited Nov. 4, 2002). For additional information about independent living, see http://www.ncil.org (last visited Nov. 4, 2002), the web site of the National Council on Independent Living.

In some situations, the lawyer will be able to refer the client to community-based services that are already in place. However, when such services are denied or unavailable—when the state requires nursing home admission as a condition for getting the help clients need—elder law attorneys should consider the *Olmstead* implications. What seemed to be a lifelong care-planning project may prove to be a civil rights case instead.

By reframing an individual problem as a civil rights issue, elder law attorneys can build a bridge between individual client representation and the broader struggle for justice and civil rights. As the population ages and the incidence of severe disability increases, this broader struggle stands to benefit, directly or indirectly, every member of society.