

## Executive Summary<sup>1</sup>

The extent of unnecessary institutionalization of people with disabilities in the United States is daunting. Research and experience have shown that the great majority of people who live in large congregate settings could be supported safely and effectively and enjoy a higher quality of life in a typical home in the community. Longitudinal studies of community placement document their more favorable outcomes and furthermore establish that persons with significant disabilities benefit the most from community placement. Similarly, comparing residents of nursing facilities with elders, children with complex health needs, and adults with physical disabilities living at home shows that nursing facility residents are not more severely disabled than those who receive support in their own homes. Yet, 106,000 persons with developmental disabilities lived in public and private institutions and more than 1,300,000 elders and persons with disabilities lived in nursing facilities in the year 2000. In addition, data on the outcomes of consumer-directed mental health services and intensive case management models show that most of the 58,000 persons currently confined in psychiatric institutions could be supported in their own homes in the community. The persons who fill the more than 800,000 licensed board and care beds in the United States could also live in the community.

In this report, the National Council on Disability (NCD) assesses the nation's response to the United States Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) that the unjustified institutionalization of people with disabilities is a form of discrimination. NCD's research reports on the extent of unnecessary institutionalization in the United States, the continuing barriers to community placement, and resources and service models that facilitate community integration. NCD examines the Federal Government's implementation efforts and the strategies states and key stakeholders are using to (1) develop consensus on a coordinated action plan, (2) identify and commit the necessary resources for community-based service options, and (3) sustain collaborative action toward creating real choice for people with disabilities living in institutions. NCD collected extensive information, available online in the electronic version of this report at [www.ncd.gov/newsroom/publications/reclaimlives.html](http://www.ncd.gov/newsroom/publications/reclaimlives.html), on the states' experiences in the planning and implementation of the *Olmstead* decision.

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<sup>1</sup>National Council on Disability. (2003, September 29). Executive summary. In *Olmstead: Reclaiming institutionalized lives* [Abridged Version] (pp. 1-8). Washington, D.C.: Author. Available: <http://www.ncd.gov/newsroom/publications/2003/pdf/reclaimabridged.pdf> or <http://www.ncd.gov/newsroom/publications/2003/reclaimabridged.htm>

## The *Olmstead* Decision

In 1999, by a clear majority, the United States Supreme Court held in *Olmstead v. L.C.*, 527 U.S. 581 that, under the Americans with Disabilities Act (ADA), undue institutionalization qualifies as discrimination by reason of disability and that a person with a mental disability is “qualified” for community living 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 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.

Whereas the justices agreed that the state is not required to provide immediate relief in the form of community placement where such relief would represent a “fundamental alteration” of the state’s programs, the majority did not agree on what constitutes a “fundamental alteration.” Only four justices agreed on the interpretation of the fundamental alteration defense set forth in Justice Ginsburg’s opinion: that the defense should be construed to “allow the State to show that, in the allocation of available resources, 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 persons with mental disabilities” (527 U.S. at 604, emphasis added). Justice Ginsburg added that demonstrating that it has “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings” is one method a state may use to show that it already has reasonably modified its programs and that no further alteration is necessary. This statement became the basis for the *Olmstead* planning initiatives.

## Barriers to Community Integration in the United States

Representatives of all disability groups agreed that lack of affordable and accessible housing is the single biggest barrier to community integration in the United States. Persons with disabilities whose incomes depend on government benefits need housing subsidies or shared housing to live in the community. Unfortunately, because of systemic barriers, people with disabilities tend not to receive their fair share of the approximately \$7 billion in federal housing subsidy programs, and the various Section 8 housing subsidy programs targeted to persons with disabilities are funded at a relatively modest amount (\$271 million in 2001) in comparison. An additional barrier is the lack of meaningful collaboration between human services agencies and housing agencies. High unemployment rates for persons with significant disabilities (typically 60 to 90 percent) maintain dependence on public benefits.

Low wages and benefits severely limit the availability of personal assistants and other direct support professionals. In turn, low wages are the result of low reimbursement rates for community services. Lack of quality health care and dependable transportation are also significant barriers.

The institutional bias of the Title XIX (Medicaid) program, in which home- and community-based waiver-funded services and personal care are optional whereas nursing facility services are required and financial eligibility rules for institutional residents are more generous than those for people living in their own homes, greatly compounds the problem. Title XIX waivers have significantly expanded available funding for home- and community-based services but have not leveled the playing field; because state governments do not recognize home- and community-based waiver services as entitlements, waiting lists for waiver services are long in most states. The unavailability of Title XIX reimbursement for services to adults below the age of 65 in Institutions for Mental Diseases (IMDs) poses a significant barrier to the use of home- and community-based waivers to fund community mental health services.

### **Delivering on the Promise**

On June 18, 2001, President George W. Bush, pursuant to his New Freedom Initiative, issued Executive Order No. 13217, committing the Administration to implement the integration mandate of the ADA as interpreted in *Olmstead*. The Executive Order required federal agencies to promote community living for persons with disabilities by providing coordinated technical assistance to states; identifying specific barriers in federal law, regulation, policy, and practice that impede community participation; and enforcing the rights of persons with disabilities. Pursuant to the Executive Order, federal agencies evaluated their own programs to identify barriers and issued their final reports on March 25, 2002.

Altogether, the reports acknowledged the many barriers to community integration of persons with disabilities, including the institutional bias of the Medicaid program, unaffordable and inaccessible housing, a critical shortage of personal assistance and direct support professionals, and the unavailability of supported employment. However, most of the proposed agency actions consisted of technical assistance, training, research, demonstration, policy review, public awareness campaigns, outreach, enforcement of existing regulations, information dissemination, convening of advisory committees, and interagency coordination and collaboration. Systemic solutions, measurable goals, timelines, deliverables, and outcomes were lacking.

In early 2003, President Bush's Administration announced a five-year program beginning in FY 2004, the "Money Follows the Individual" Rebalancing Demonstration, to enable people with disabilities to move from institutions to the community. The program would provide 100 percent federal funding for home- and community-based waiver services for one year for a person leaving an institution, after which the state would agree to continue to provide services for the person at the regular Medicaid matching rate.

### **The States' Response**

After *Olmstead* was decided, the Department of Health and Human Services (HHS) provided guidance to the states concerning the development of "comprehensive, effectively working plans" in increasing community placements. In addition, *Olmstead* stakeholders concluded that state implementation plans could have value both as an organizing tool for achieving deinstitutionalization and as a method to persuade states to commit to numerical targets, timelines, and allocation of resources. Although the experiences of states and stakeholders in implementing *Olmstead* varied widely, NCD's evaluative study documents some key overarching findings, including the following:

- Plans do not consistently provide for opportunities for life in the most integrated setting as people with disabilities define "the most integrated setting."
- The majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement.
- Few plans identify systemic barriers to community placement or state action steps to remove them and few plans contain timelines and targets for community placement.
- State budgets often do not reflect *Olmstead* planning goals.

### **Lessons Learned: Good Practice in Community Services and What Works**

The following are some of the many examples suggested by this report of promising practices in the design, delivery, and financing of community services.

- **Good practice in *Olmstead* planning.** Indiana's recent plan assigns each recommendation to one of three categories: those that should be implemented quickly and with little or no fiscal impact or regulatory requirements; those that should be implemented quickly but have a fiscal impact or require regulatory changes; and those that are more complex, costly, or difficult and will require

more time to develop and implement. Indiana's plan should serve as a model for other states. Nevada's *Olmstead* plan is commendable for its candid analysis of the state's compliance with *Olmstead*.

- **Overcoming incentives to unnecessary institutionalization.** Methods include Maine's use of pre-admission screening by an independent agency prior to nursing facility placement, Minnesota's legislation encouraging nursing facility operators to take beds out of service, and Washington's system for tracking reduction targets for nursing facility placements.
- **Identification and transition of people with disabilities from institutions.** In Colorado and Kansas, disability rights advocates are doing the work of identifying people in nursing facilities who could move to more integrated settings.
- **Use of trusts and fine funds to finance transition costs and start-up of community services.** A creative and underappreciated set of strategies for financing transition costs, providing "bridge funding," and funding new community services involves the creation of trusts and fine funds dedicated to the needs of people with disabilities. North Carolina, Oregon, and Washington have used the proceeds from the sale of state facilities to establish trusts to generate funds for people with disabilities.
- **Housing strategies.** Commendably, and in large part because of the influence of the technical assistance provided by the Department of Health and Human Services' (HHS') Office of Civil Rights (OCR), the more recently developed plans tend to reflect the input of housing agencies. Provisions for requiring universal design in new units that state housing agencies fund or finance; ensuring that all existing publicly financed housing has completed Section 504/ADA self-evaluations; conducting utilization reviews to ensure that targeted Section 8 programs are fully used; and including home modifications and home repair in the services provided under home- and community-based waivers and independent living programs are examples of housing-related recommendations in state *Olmstead* plans.
- **Single point-of-entry systems.** Single point-of-entry systems have the potential to reduce unnecessary institutionalization by providing easier access to a wider array of community services. Single point-of-entry systems that separate "assessment" and "service brokerage" from "service provision" are also responsive to the Centers for Medicare and Medicaid Services (CMS) findings in a number of states that Medicaid beneficiaries' right to choose among qualified providers was violated.

- **Beyond institutional closure: Increasing community integration.** Developmental disabilities services in Vermont and New Hampshire show that, more than placement in a residence outside an institution, “the most integrated setting” is a continuous process of increasing community inclusion. These states’ service systems have progressed far beyond institutional closure and are eliminating group homes in favor of living in a companion home or a home of one’s own and working at a real job with support.
- **Self-determination.** Self-determination and consumer-directed service models have been so broadly tested and practiced that they have emerged as fundamental principles in human services.

## Recommendations

On the basis of its research, NCD recommendations for the Federal Government include the following:

- HHS and CMS should provide more explicit guidance on implementation of *Olmstead v. L.C.*
- CMS should determine whether the states are adequately identifying residents of Medicaid-funded and -certified facilities that can handle and benefit from community living.
- HHS should refocus its Real Choice Systems Change grant program as a true system-change project by shifting from funding demonstration projects to funding change that affects entire service systems.
- HHS should require the states to identify all institutionalized persons in the state and their need for community services.
- CMS should use its waiver approval authority to require the states to minimize “institutional bias” in the choice between institutional and home- and community-based waiver services.
- HHS should provide federal financial assistance to states to provide small grants to people with disabilities for transition costs from institutions to community.

## Conclusion

The *Olmstead* decision has become a powerful impetus for a national effort to increase community-based alternatives and eliminate unjustified institutional placements. Ultimately, only comprehensive amendments to Title XIX of the Social Security Act, similar to the amendments proposed in MiCASSA (the Medicaid Community-based Attendant Services and Supports Act), will overcome the institutional bias within

the Medicaid program. In the meantime, however, federal agencies have many measures, short of a thorough revision of Title XIX, they can and should undertake. We must continue to empower *Olmstead* stakeholders in their state “systems change activities,” that is, in their efforts to redesign the state service systems to enhance choice, independence, self-determination, and community integration. Our nation will be much more prosperous when it makes real the right of people with disabilities to live in the most integrated setting.