OLMSTEAD: Reclaiming Institutionalized Lives

(Abridged Version)

National Council on Disability

September 29, 2003

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

***Olmstead*: Reclaiming Institutionalized Lives (Abridged Version)**

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

Letter of Transmittal

September 29, 2003

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability is pleased to submit to you this report titled, "*Olmstead*: Reclaiming Institutionalized Lives." Under its Congressional mandate, the National Council on Disability is charged with the responsibility to gather information on the implementation, effectiveness, and impact of federal laws, policies, programs, and initiatives that affect 54 million Americans with disabilities. This report measures progress to date in the implementation of the landmark U.S. Supreme Court decision in *Olmstead v. L.C.* and related Federal and State Government initiatives.

In February 2001, you announced the New Freedom Initiative (NFI), a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in community life. In your NFI, you committed your Administration to pursuing the swift implementation of the *Olmstead* decision and supporting the most integrated community-based settings for individuals with disabilities.

Overall, varying degrees of progress have occurred in the implementation of the *Olmstead* decision. However, given the many areas where progress has not yet been achieved and in recognition of the relatively brief time since the decision was rendered and governmental initiatives were undertaken, further efforts clearly are necessary to increase public awareness of *Olmstead*, provide education and clarification regarding the applications and implications of the decision to relevant entities, and provide resources necessary both to encourage and to ensure effective adherence to both the spirit and intent of *Olmstead*.

In support of the NFI and to progress in the implementation of the *Olmstead* decision, I pledge our support to your Administration's commitment to ensuring that equality of opportunity, full participation, independent living, and economic self-sufficiency become realities in the lives of Americans with disabilities. Under your leadership, I remain confident that we can continue to build an America where all citizens live independent lives in the community of their choice.

Sincerely,

Lex Frieden

Lex Frieden
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Free our people, free our people,

free our people.

—Supporters of MiCASSA

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Acknowledgments

This report is issued in recognition of the victims of unnecessary institutionalization; our nation must not rest until it has delivered on the promise of freedom for all. The National Council on Disability expresses its appreciation to Judith Gran, Esq., with the Public Interest Law Center of Philadelphia, for drafting this report with the assistance of Max Lapertosa, Esq., and Ruthie Beckwith.

Contents

Executive Summary

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, on the states' experiences in the planning and implementation of the *Olmstead* decision.

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.

I.

Barriers to Community Integration in the United States

1. What Is "The Most Integrated Setting"? Views of Persons with Disabilities

> [P]eople with disabilities have the same rights as other citizens to freedom, equality, equal protection under the law, and control over their own lives. These rights must be honored if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.[1]

In our interviews with informants with disabilities and their advocates, we asked what the person considered "the most integrated setting" for persons with disabilities. Almost without exception, the interviewees responded by naming the qualities that make home living meaningful and satisfying to the individual. Only two respondents named a type of program, such as a supported living arrangement or a two-person home. Response patterns were similar across all categories of disability.

The most common response was that the most integrated setting is "a place where the person exercises choice and control," including choice of service providers: "What people themselves want! ... Self-determination is essential. People decide for themselves what they want and need."[2] A variation on this response was, "Whatever the person considers most integrated." The second most common response was, "A home of one's own shared with persons whom one has chosen to live with," or where one lives alone. The third most common response emphasized that home living for persons with disabilities should be like home living for other community members. Integration is "living in the community with everyone else like everyone else."[3] Several

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[1] The Seattle 2000 Declaration on Self-Determination and Individualized Funding.

[2] Interview with Judi Chamberlin, August 3, 2001.

[3] Interview with Melvin Guzman, August 7, 2001.

respondents defined community integration as the result of participation in community activities or of the assumption by persons with disabilities of leadership roles in the community. And finally, one respondent defined community integration as affording opportunities for privacy, unlike an institution.

Similarly, when interviewees were asked what people with disabilities need to live in the most integrated setting, they responded, almost universally, not by listing formal services but by identifying ordinary human needs. Again, response patterns were similar across all disability groups. The most common response was that support depends on the person, must be defined by and tailored to the individual, and may change over time. The second most common response was that people need friendships, emotional support, and networks of friends, family, and mentors. Education, participation in community activities, and transportation were mentioned by a number of respondents. The only services that were listed were personal assistance, communication (for a person with autism), and case management (by one person); however, this latter response was offset by two respondents who stated emphatically that caseworkers and case managers were *not* helpful to persons with disabilities.

Every person we interviewed who was affiliated with a disability organization stated that the organization had a position on the right to live in the community. Organizational positions on community living varied little from one disability group to another. Some stated that the right to live in the community is "absolute," and others that closure of institutions is their organization's highest priority. The following were other common positions:

- Everyone has the right to live in the community with support.
- People should live independently, not in a nursing home.
- We support the right to choose.
- We support self-determination.
- We support inclusive communities.

2. The Extent of Unnecessary Institutionalization in the United States

Measured by our respondents' views of the most integrated setting, the number of people with disabilities who currently are denied the opportunity to live in the most integrated setting is large indeed. That number includes many people who live in group homes and other small congregate settings as well as those who live in large congregate facilities. However, applying a more modest definition of "the most integrated setting" as a living arrangement other than an institution, the number of unnecessarily institutionalized persons in the United States is daunting.

(a) Residents of Developmental Disabilities Institutions

In 2000, approximately 106,000 persons lived in state-operated and private Intermediate Care Facilities for persons with Mental Retardation (ICFs/MR) with seven or more beds. In addition, nearly 35,000 people with developmental disabilities lived in nursing facilities.[4] For how many of these persons is a large ICF/MR or a nursing facility the most integrated setting? Although formal assessment data are lacking, it is possible to conclude from the studies of other institutional residents who have moved to the community that nearly all could receive the support they need in a small home in the community. During the past 20 years, a large body of research has documented the outcomes for people with developmental disabilities moving from

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[4] David L. Braddock, unpublished data for 2000 from the State of the States in Developmental Disabilities Project, Coleman Institute for Cognitive Disabilities and the Department of Psychiatry, University of Colorado. See also C. Harrington et al., *1997 State Data Book on Long Term Care: Program and Market Characteristics* (University of California at San Francisco, 1999) at 3.

institutions to the community. These studies "strongly suggest that people with all levels of developmental disability would enjoy better lives in community-based settings."[5]

The first systematic analysis of the impact of deinstitutionalization, the Pennhurst Longitudinal Study, tracked more than 1,100 persons who moved from Pennhurst Center, a developmental disabilities institution in Pennsylvania, under the court's orders and consent decree in *Halderman v. Pennhurst* beginning in 1979. Pennhurst closed in 1987, and virtually every resident moved to the community. Most moved to three-person homes in typical neighborhoods. The study found that as people moved from Pennhurst, they experienced significant gains in skills, personal happiness, family satisfaction, opportunities to participate in community activities, and other indicators of quality of life. In the community, the former Pennhurst residents were "better off in every way that we know how to measure." Moreover, the gains continued even after people had lived in the community for some time.[6]

These findings have been replicated in many other states, in cases in which institutional closure occurred under court order and in voluntary deinstitutionalization efforts.[7] Further, the studies have shown that institutional residents with the most severe disabilities—those with profound retardation—experience the most dramatic gains in quality of life after they move to the

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[5] J. Conroy, *The Hissom Outcomes Study: A Report on Six Years of Movement into Supported Living* (Brief Report Number 1 of a Series on the Well-Being of People With Developmental Disabilities in Oklahoma (Ardmore, PA: The Center for Outcome Analysis, December 1995) at 2.

[6] J. Conroy, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (Ardmore, PA: The Center for Outcome Analysis, 1985).

[7] J. Conroy, *The Hissom Outcomes Study* at 3–4; S. Larson and C. Lakin, Deinstitutionalization of Persons with Mental Retardation: Behavioral Outcomes, 14 *Journal of the Association for Persons with Severe Handicaps* (1989) at 324–332.

community.[8] More recently, studies of former institutional residents who are supported in newer models of services, such as supported living and self-determination, have shown that those persons make even greater gains in skills and experience a dramatically improved quality of life.[9]

(b) Residents of Nursing Facilities

Nationwide, 1,302,315 persons lived in nursing facilities in 1999, a slight decrease since 1993, when 1,305,212 persons lived in such facilities.[10] Expressed as a percentage of U.S. residents ages 65 and older, this figure is the equivalent of 3.7 percent of the elder population.[11] Because occupancy rates in nursing facilities are significantly less than 100 percent (the average occupancy rate was 86 percent in 1997), the number of nursing facility beds is considerably larger than the number of residents. The total number of nursing facility beds in the nation increased from 1.31 million in 1978 to 1.81 million in 1997, and the number of nursing facilities in the nation increased during that period from 14,264 to 17,628.[12]

The Medical Assistance program supports about 1 million of the 1.3 million nursing facility residents. In 2000, approximately 10.9 percent of those persons were under age 65. The cost of

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[8] J.W. Conroy and V.J. Bradley, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (1985) at 332; J. Conroy et al., 1990 Results of the *CARC v. Thorne* Longitudinal Study (The Connecticut Applied Research Project, Report No. 10, 1991).

[9] J. Conroy, *The Hissom Outcomes Study* at 36, 40, 45–46, 55.

[10] C. Harrington et al., *Nursing Facilities, Staffing, Residents, and Facility Deficiencies, 1993 through 1999* (University of California at San Francisco, 2000) at 26.

[11] *Id.*; U.S. Census Bureau (April 2001). Of course, not all nursing facility residents are 65 or older. W. Fox-Grage et al., *Community-Based Long-Term Care* (National Conference of State Legislatures: Promising Practices Issue Brief, 2000) at 1.

[12] C. Harrington et al., *1997 State Data Book on Long Term Care: Program and Market Characteristics* (University of California at San Francisco, 1999) at 2.

nursing facility services accounted for more than 20 percent of all Medicaid expenditures during most of the 1990s and around 60 percent of all long-term expenditures.[13]

Nursing facility placement varies significantly from one state to another. For example, in Arizona, the nursing facility population is the equivalent of 1.1 percent of the population age 65 or older, whereas in Mississippi, the comparable percentage is 4.1 percent. In some states, such as Arizona, Maryland, and New Jersey, the nursing facility population has decreased significantly since 1993. In many others, for example, Illinois, Florida, and Indiana, the nursing facility population has increased.

The Nursing Home Reform Act[14] requires states to screen persons who are being considered for nursing facility placement to ensure that they need the level of nursing care available in such a facility. The purpose of the Act is to divert persons who do not need nursing home care into community-based services. However, the Act does not prevent unnecessary nursing home placement for persons who do need skilled nursing services but could receive those services in the community if services were available.

The great majority of persons age 65 or older, including those with disabilities, do not live in nursing facilities. In fact, more than 90 percent of disabled older people living in the community get most of their everyday care from family caregivers.[15] Nevertheless, Medicaid expenditures for elders are highly skewed toward nursing facility services. In 1995, Medicaid expenditures on long-term care for elderly beneficiaries represented 84.1 percent of the total and home care only

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[13] Department of Health and Human Services, Center for Medicare and Medicaid Services, Letter to State Medicaid Directors, August 13, 2002.

[14] 42 U.S.C. § 1396r(e)(7), enacted as part of the Omnibus Budget Reconciliation Act (OBRA) 1987.

[15] Testimony of Janet Saynor, former Commissioner of Aging, City of New York, National Listening Session (September 5, 2001), PM testimony at 186–87.

10.3 percent.[16] Compared with nursing facility residents' need for community services and the availability of home- and community-based waiver funding for persons with developmental disabilities, the number of elders, adults, and children with physical disabilities and complex health care needs who receive home- and community-based services under the waiver (and who otherwise might have to live in a nursing facility) is relatively modest. According to statistics released by the National Institute on Disability and Rehabilitation Research (NIDRR) in October 2001, 43 home- and community-based waivers for elders with disabilities served a total of 235,215 persons; 27 home- and community-based waivers for persons with physical disabilities served a total of 25,704 persons; 20 home- and community-based waivers for children served a total of 3,072 persons; and 12 home- and community-based waivers for persons with acquired brain injury served a total of 1,373 persons.[17]

How many nursing facility residents could live in the community if services and support were available? Many elders with disabilities, children with complex health care needs, and adults with physical disabilities who live in their own homes and receive support from personal assistants, family, or friends have disabilities just as severe as those of nursing home residents. Data about the disabilities of more than 200,000 persons served by California's In-Home Supportive Services (IHSS) program show that the persons who use consumer-directed funds to pay family members or friends to provide personal assistance tend to have significantly *more* severe disabilities than other persons served by the program.[18] Community-based models of service for persons with complex

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[16] J.M. Wiener and D.G. Stevenson, *Long-Term Care for the Elderly: Profiles of Thirteen States* (Urban Institute, 1998) Table 3.

[17] NIDRR, Medicaid Home and Community Based Services, Disability Statistics Report 16 (October 2001).

[18] L. Polivka and J. Salmon, *The Ethical and Empirical Basis for Consumer-Directed Care for the Frail Elderly: A Guide to State Policy Makers (*Florida Policy Exchange on Aging, 2000).

health needs, for example, persons with end-stage renal disease, have shown that these persons can receive skilled nursing services in their own homes or in a home-like setting.[19]

(c) Residents of Psychiatric Institutions

The Substance Abuse and Mental Health Services Administration (SAMHSA) of HHS estimates that, in 2001, about 58,000 persons with serious mental illness remained institutionalized in state psychiatric hospitals "in large part" because of "persistent clinical, service system, and financial barriers."[20] Little dispute exists that "[m]any thousands more live in nursing homes and others are inappropriately institutionalized in jails."[21] A 1999 U.S. Department of Justice study reported that 284,000 persons incarcerated in local, state, and federal prisons had a mental illness.[22]

Downsizing and closure of state mental health institutions accelerated during the 1990s. Although from 1970 to 1990 the total number of state and country psychiatric beds declined by half, only 14 hospitals were closed. During the 1990s, however, 44 state psychiatric hospitals were closed, and three additional closures were planned.[23]

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[19] Comments by a registered nurse at the National Listening Session, PM testimony at 172–73.

[20] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at i.

[21] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999).

[22] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 8.

[23] National Association of State Mental Health Program Directors Research Institute, "Closing and Reorganizing State Psychiatric Hospitals: 2000" (August 10, 2000).

Data on use of mental health services by race and ethnicity reveal that African-Americans are significantly more likely than whites to be institutionalized in psychiatric hospitals and to be subject to repeat admissions after discharge. At the same time, African-Americans are significantly underrepresented in outpatient treatment programs, and studies show that they are less likely than whites to receive appropriate treatment and newer medications with fewer side effects.[24]

How many people with psychiatric disabilities are inappropriately institutionalized? Although people with serious mental illnesses may need short-term hospitalization at times, from the experience of state hospital closures[25] and the outcomes of consumer-directed services and certain intensive case management models, most people with mental illnesses who might otherwise be confined in state psychiatric hospitals[26] clearly can be supported in their own homes in the community.

(d) Other Institutions, Including Board and Care Facilities, Shelter Facilities

In 1990, the states reported a total of 514,749 licensed board and care beds serving adults and elders in 35,171 board and care homes. By 1997, these figures had increased to 827,584 beds in 49,913 board and care facilities, but the increase is considered to be due in part to more complete reporting from the states. The average number of board and care beds per facility was 16.6 in

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[24] Department of Health and Human Services, *Mental Health: Culture, Race and Ethnicity* (2001) at 63–64, 67. This study also found that mental health service systems “fail[…] to provide for the vast majority of Latinos in need of care.” *Id.* at 146.

[25] See, e.g., the placement of residents of Haverford State Hospital described in *Kathleen S. v. Department of Public Welfare,* 10 F.Supp. 2d 476 (E.D. Pa. 1998) and 1999 U.S. Dist. LEXIS 19498 (E.D. Pa.).

[26] Federal/Provincial/Territorial Advisory Network on Mental Health, *Review of Best Practice in Mental Health Reform* (1997) at 7, 79.

1997.[27] Because residents of board and care homes by definition require a lower "level of care" than nursing facility residents (that is, they do not qualify for nursing facility services on the basis of the intensity of services they require), they are by definition less disabled than residents of nursing facilities. If most nursing facility residents could live in their own homes and communities with support, then, *a fortiori,* most residents of board and care facilities could live in the community.

3. Barriers to Community Integration

It is beyond question that hundreds of thousands of unnecessarily institutionalized persons with disabilities are kept in isolated living situations by systemic barriers that include the very human service systems that are charged with providing appropriate services to them. As the self-advocates who gathered at the 2000 Conference on Self-Determination stated in the declaration that emerged from the conference,

> Citizens who have disabilities experience oppression in many aspects of their lives. The causes of oppression include poverty, other people's attitudes, and the systems of publicly and privately funded support services, comprising –
>
> laws, policies and regulations;
>
> state and private sector funding bodies;
>
> agencies which provide services.
>
> These systems operate in ways that deny control to those they are intended to serve. Without accountability to those who require their assistance, these systems decide how, where and with whom people shall live and spend their days. While this situation persists, people of many nations will not be able to exercise their rights or fully participate in their communities.[28]

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[27] C. Harrington et al., *1997 State Data Book on Long Term Care: Program and Market Characteristics* (University of California at San Francisco, 1999) at 3.

[28] The Seattle 2000 Declaration on Self-Determination and Individualized Funding.

The persons with disabilities whom we interviewed were asked to identify the barriers to community integration for persons with disabilities. We weighted these barriers by the importance that individual respondents gave to the barrier when they listed more than one, which shows that lack of affordable and accessible housing was perceived as the biggest barrier. The result was the same for persons with physical, developmental, and psychiatric disabilities. The barriers that respondents identified are listed here in order of rank:

Affordable and accessible housing (38)
Quality support staff (35)
Parent/guardian opposition (30)
Lack of affordable and accessible transportation (28)
Lack of adequate medical or dental care (26)
Neighborhood opposition (23)
Lack of jobs and job training (14)
Lack of residential services (11)
Lack of day services (8)

Other barriers mentioned by respondents were lack of social networks and friends; the need to learn skills; and political issues, such as state employees' need to keep their jobs and absence of crisis intervention.

No respondent with physical or psychiatric disabilities mentioned lack of day programs as a barrier, and respondents with developmental disabilities ranked it low. Housing, quality (or well-paid) support staff, and lack of access to medical and dental services were ranked high as barriers by persons in all disability groups. Parent/guardian opposition and neighborhood opposition were ranked high by persons with developmental disabilities, but not by persons with physical or psychiatric disabilities. Persons with psychiatric disabilities perceived lack of access to medical care as an important barrier.[29]

The experience reported by the people with disabilities whom we interviewed is amply validated by the literature on obstacles to community integration.

(a) Lack of Affordable or Physically Accessible Housing

It is little wonder that persons with disabilities and disability rights advocates identify lack of affordable or physically accessible housing as the single biggest barrier to community integration. Persons with disabilities are disproportionately poor, especially the persons who are most likely to be affected by the *Olmstead* decision, who rely on Supplemental Security Income (SSI) and other government benefits.

> For low-income people with disabilities, affordable housing means subsidized housing that is either developed or rented through government housing programs. Because most funding for these programs comes directly or indirectly from the U.S. Department of Housing and Urban Development (HUD), there are potentially significant implications for federal housing policies and programs in the *Olmstead* decision. Thus far, however, the affordable housing issues raised by the *Olmstead* decision have received scant attention.[30]

Nationally, SSI benefits are equal to only 18.5 percent of the one-person median household income. The result is no housing market anywhere in the country in which SSI beneficiaries—who numbered more than 3.5 million adults with disabilities in 2000—can afford

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[29] See interview with Debra Delman, who noted that people using public mental health service die 10 to 20 years earlier than others. Consumers and survivors have found that some physicians tend to regard their psychiatric disabilities as primary and do not pay adequate attention to signs of physical illness.

[30] Technical Assistance Collaborative and Consortium for Citizens with Disabilities (CCD) Housing Task Force, 12 Opening Doors (December, 2000) at 1.

decent housing with their monthly income of about $512 without government subsidies.[31] Thus, access by people with disabilities to a fair share of the approximately $7 billion in federal housing subsidy programs is vital to their ability to afford decent and accessible housing in their own communities and neighborhoods.

The unmet housing needs of persons with disabilities, however, cannot be attributed to poverty alone. HUD data show that people with disabilities between the ages of 18 and 62 make up more than 25 percent of the 4.9 million households with the "worst case" housing needs, yet these persons represent only about 13 percent of the households that currently receive federal housing assistance. From 1997 to 1999, the number of households with "worst case" housing needs declined by 8 percent, probably as a result of economic prosperity, and the decline occurred in every group eligible for federal housing assistance *except* persons with disabilities. Indeed, housing needs among persons with disabilities may have *increased* during this period.[32]

A report published by the Technical Assistance Collaborative, Inc. (TAC), and the Consortium for Citizens with Disabilities (CCD) Housing Task Force identified the following barriers to expanding housing opportunities for persons with disabilities:

- State and local officials do not give a high priority to the housing needs of persons with disabilities.
- Most Public Housing Authorities (PHAs) do not give a high priority to the housing needs of persons with disabilities.
- Most disability organizations have not established relationships or partnerships with affordable housing providers and funding sources.

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[31] A. O'Hara and E. Miller, *Priced Out in 2000: The Crisis Continues* (Boston, MA: The Technical Assistance Collaborative and Consortium for Citizens with Disabilities (CCD) Housing Task Force, 2001) at 10; *see also* Technical Assistance Collaborative and CCD Housing Task Force, 12 Opening Doors (December, 2000) at 4.

[32] A. O'Hara and E. Miller, *Priced Out in 2000: The Crisis Continues* (2001) at 7.

- The disability community's knowledge of the key federal housing programs and policies that can assist persons with disabilities is very limited.
- The disability community has limited knowledge of Fannie Mae housing programs targeted to persons with disabilities.
- Many disability organizations do not understand how participation in HUD's Consolidated Pan process can help expand homeownership and rental housing for persons with disabilities.
- Most homeownership coalitions serving persons with disabilities have achieved only modest results, as measured by the number of persons who have become homeowners.
- Disability organizations need more housing knowledge, housing capacity, and technical assistance to expand access to affordable housing.[33]

The effect of these barriers is that people with disabilities are cut off disproportionately from access to the billions of dollars in federal housing assistance for persons with low incomes.

Federal housing assistance is provided in accordance with three housing plans required by HUD that are prepared at the state and local level subject to HUD approval: (1) the Consolidated Plan, or ConPlan; (2) the Public Housing Agency Plan, or PHA plan; and (3) the Continuum of Care Plan for homeless assistance. Although these plans are developed separately, the activities to be funded through the PHA Plan and the Continuum of Care Plan must be consistent with the housing needs and strategies identified in the ConPlan.

The ConPlan is a comprehensive, long-range plan for development of affordable housing for low- and moderate-income households in states and local communities that receive funds from

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[33] A. O'Hara and E. Miller, *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities* (Boston, MA: The Technical Assistance Collaborative and CCD Housing Task Force, 2000) at 2–3.

HUD. It must describe housing needs, market conditions, and housing strategies and set forth an action plan for the use of federal housing funds. It specifies how the state or locality will spend the money provided through the four principal federal housing subsidy programs, the Community Development Block Grant (CDBG), the Home Investment Partnership Program (HOME), the Emergency Shelter Grant program, and the Housing Opportunities for Persons with AIDS program. The plan must quantify the need for supportive housing for persons with disabilities and other support needs. However, because meaningful participation by the disability community is poor and the disability community is not adequately represented during the development of these plans, people with disabilities are not receiving their "fair share" of the federal housing resources that these plans control. Further, because state and local officials have considerable discretion in developing a ConPlan, HUD will not necessarily reject a plan simply because it does not address the housing needs of people with disabilities.[34] And finally, even if the ConPlan accurately identifies local housing needs, including those of persons with disabilities, state and local officials are not required actually to spend the money to address those needs. HUD can withhold block grant funds if a Conplan is not based on a thorough review of local housing needs, but then only to require revision of the plan.[35]

Advocates of people with disabilities report that "most ConPlans do not accurately describe the housing needs of people who may be living in state institutions or facilities or who are at risk of institutionalization," that "housing strategies adopted in most ConPlans do not typically target federal housing funding to people with disabilities who are waiting to leave institutional settings," and that little meaningful consultation has occurred between health and human services agencies and housing officials about the housing policy issues raised by Olmstead or the housing resources

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[34] *Id.* at 7.

[35] S. Crowley, "Implementing *Olmstead* Through Housing Advocacy at the Local, State, and Federal Levels," *The NIMBY Report* (Spring 2002) at 26.

that could be made available to create more community-based housing for persons who are unnecessarily institutionalized.[36]

The “meaningless compliance” inherent in the ConPlan process was identified as one of HUD’s management problems in the President’s Management Agenda developed by the Office of Management and Budget (OMB) for FY 2002. OMB directed HUD to work with local stakeholders to streamline the ConPlan, making it more results-oriented and useful to communities. In 2002, HUD convened a ConPlan Improvement Initiative, a series of workgroups with stakeholder representation, including that of people with disabilities, to examine how the ConPlan can better be linked to other federally mandated plans for transportation or human services, how goals should be determined, and how results will be measured.[37]As of March 2003, the process is far from complete.

The ADA community integration mandate-and the extreme poverty of people receiving SSI benefits-should compel government housing officials to target an equitable share of ConPlan funding to people with disabilities.[38] That equitable share should include a fair share of the funds available through the HOME program, which can be used to fund the acquisition, rehabilitation, or new construction of housing for people with disabilities and to fund two-year rental assistance subsidies for persons leaving institutions. The manner in which HOME funds are used is decided through the ConPlan process.[39]

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[36] Technical Assistance Collaborative and Consortium for Citizens with Disabilities (CCD) Housing Task Force, 12 Opening Doors (December 2000) at 8.

[37] S. Crowley, *supra*, at 28–29. HUD, ConPlan Improvement Initiative, at www.hud.gov.

[38] *Id.* at 8.

[39] *Id.* at 8–9.

The Section 8 program (renamed the Housing Choice Voucher Program in 1998, but still known by its more familiar name), which provides rental vouchers for people with the lowest incomes, including SSI beneficiaries and currently assists more than 1.4 million households nationwide, is controlled by PHAs. These PHAs have authority to decide how public housing and Section 8 vouchers should be used in their communities, pursuant to a PHA Plan that is submitted to HUD for approval.[40] Section 8 includes programs targeted to people with disabilities. In addition, people with disabilities are also eligible for the general voucher program, known as the "fair share" program. In 2001, Congress appropriated funding for 79,000 new "fair share" vouchers. Beginning in 2000, HUD's "fair share" application process assigns 15 points to any housing authority (thus giving it an advantage in the competitive application process) that agrees that 15 percent or more of the vouchers requested will be used for people with disabilities. In addition, HUD will assign another 5 points if the PHA provides at least 3 percent of the requested Section 8 vouchers to persons who are receiving services under a home- and community-based service waiver.[41] According to an analysis by the Technical Assistance Collaborative (TAC), only 224 of the 499 PHAs that received Section 8 vouchers in 2000 agreed to the set-asides for persons with disabilities; in 2001, the number increased to 422 of 475 PHAs.[42] However, the data collected by TAC show that only 171 of the 475 housing authorities set aside 3 percent of their vouchers for home- and community-based waiver beneficiaries.[43]

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[40] *Id.* at 9; A. O'Hara and E. Miller, *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities* (2000) at 10.

[41] Department of Housing and Urban Development, "HUD Awards $448 million in Housing Assistance Vouchers," press release 01-060 (July 2, 2001); Stephen F. Gold, "Section 8 Vouchers and People with Disabilities: Information Bulletin #3 (July 17, 2001).

[42] Technical Assistance Collaborative, Housing Center for People with Disabilities, "Fair Share Vouchers," http://www.tacinc.org/hc/fairshare.htm.

[43] Technical Assistance Collaborative, Fiscal Year 2001 Fair Share Voucher Awards, http://www.tacinc.org/hc/2001FairShare.pdf.

On October 12, 2000, HUD issued a final regulation enabling Section 8 vouchers to be used for mortgage payments. However, local PHAs are not required to participate in this program. Further, the PHA can choose to make Section 8 homeownership assistance available to any qualified application, or it can limit which families will participate. The inclusion of persons with disabilities in the program will depend significantly, therefore, on advocacy at the local level.[44]

The Section 8 program also includes vouchers targeted specifically to people with disabilities. Before 1992, HUD's Section 202 program required owners of certain HUD-subsidized housing developments to house elderly persons and nonelderly people with disabilities on an equal basis. In 1992, a change in federal law allowed owners to designate these units as "elderly only," and many did. This significantly restricted access by nonelderly people with disabilities to the housing units. Beginning in 1997, Congress has appropriated funding for Section 8 vouchers designated for persons with disabilities to compensate for the loss of housing in projects now designated "elderly only" projects. These vouchers are available to PHAs that document the loss of housing for people with disabilities in their jurisdictions.[45] However, in spite of the fact that the new funding would make up only a fraction of the housing units that have become unavailable to people with disabilities since the "elderly only" provision went into effect, HUD data show that, at most, 10 percent of the PHAs that administer the Section 8 program applied to HUD each year since 1997 to make these vouchers available to people with disabilities. The percentages of PHAs that applied were 9 percent in 1997, 10 percent in 1998, and 8 percent in

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[44] K. Kleinman, "Homeownership and Section 8" (July 16, 2001).

[45] A. O'Hara et al., "What's Wrong with this Picture?" 15 Opening Doors (September, 2001); Technical Assistance Collaborative, Housing Center for People with Disabilities, "Section 8 Housing Choice Vouchers for People with Disabilities," http://www.c-c-d.org/od-Sept01.htm A. O'Hara and E. Miller, *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities* (2000) at 9.

1999.[46] Funding for another 10,000 vouchers has been appropriated since 1997 for the Section 8 Mainstream Program for People with Disabilities.

In 2000, Section 8 programs targeted to people with disabilities provided a total of 8,761 vouchers for people with disabilities (both elderly and nonelderly). Other HUD programs targeted to people with disabilities are the Section 811 Supportive Housing Program, the Section 202 Assisted Living Program (designed to serve frail elderly persons and elderly persons with disabilities), and the Services Coordinators program, which provides funding to owners of private housing developments to hire service coordinators to help persons with disabilities and elders obtain independent living services. Collectively, these programs were funded in 2000 at a total of $271.4 million. In comparison, HUD's largest affordable housing programs—the CDBG, funded at $4.8 billion in 2000, and HOME, funded at 1.6 billion—are potentially available to persons with disabilities but, as discussed above, are not designed to ensure that people with disabilities will, in fact, obtain a fair share of these benefits.[47] A 1999 survey of disability organizations found that very few of these organizations' constituencies had been able to access "generic" affordable housing programs, such as HOME and the CDBG.[48]

The Technical Assistance Collaborative (TAC) and the CCD Housing Task Force have concluded that "[t]he stigma experienced by people with disabilities persists in many communities, and makes accessible or developing affordable housing difficult. Often, PHAs,

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[46] A. O'Hara and E. Miller, *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities* (2000) at 13–14.

[47] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 34. HUD also distributes 60,000 Section 8 vouchers to PHAs that state in their applications that 15 percent or more of the vouchers requested will be used to serve persons with disabilities. *Id.*

[48] A. O'Hara and E. Miller, *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities* (2000) at 18.

housing developers and city officials would rather avoid serving people with disabilities than face the possible controversy."[49] This conclusion is echoed by a Substance Abuse and Mental Health Services Administration (SAMHSA) report that "in spite of the passage of the Fair Housing Amendments Act (FHAA) of 1988 [extending protection from discrimination in housing to people with disabilities], discrimination against people with mental illnesses is perhaps most prevalent when it comes to housing."[50] A further barrier to housing for persons with mental health disabilities is the perception that those persons need supervision and 'round-the-clock support from on-site staff. In fact, "the overwhelming majority of people with mental illnesses can live in their own homes."[51]

(b) Lack of Jobs, Job Training, and Supported Employment

Unemployment rates for persons with significant disabilities are high and have not appreciably diminished since 1990, when the ADA was enacted. The Surgeon General reports that the unemployment rate for persons with significant psychiatric disabilities is around 90 percent.[52]

Related to the lack of meaningful employment experienced by far too many people with disabilities is the failure of the federal Vocational Rehabilitation (VR) program to adequately serve people with mental disabilities. That program, which provides approximately $2.5 billion annually to the states to provide job training for persons with disabilities who seek to enter or re-enter the work

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[49] *Id.* at 9.

[50] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 31.

[51] *Id.* at 31 (emphasis in original).

[52] United States Department of Health and Human Services, *Mental Health: A Report of the Surgeon General* (1999).

force,[53] is ineffective at helping persons who are or have been institutionalized obtain and sustain mainstream employment. Recent studies have documented the dismal record of state vocational rehabilitation agencies in achieving meaningful employment outcomes for persons with disabilities.[54]

Reasons for the ineffectiveness of VR services for people with mental disabilities include the time-limited nature of those services; the use of "weighted closure" systems that reward counselors for closing cases and create disincentives for serving persons with significant disabilities; the emphasis on disability-determination activities over direct service; the lack of specialized expertise in mental disabilities; the failure to coordinate with mental health/mental retardation and other disability service programs; and the unrealistic funding and durational service limitations that can make it difficult for employment vendors to provide meaningful services to persons with significant disabilities.[55] Advocates echo the conclusion of formal studies that federal regulations governing the VR program "do not match with the individualized employment goals of the program."[56] Employment experts have recommended that more of the funds currently spent on VR services be "reprogrammed" and redirected into programs based on models of supported

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[53] United States Department of Education, "President Bush Requests $56.5 Billion for Department of Education," Press Release (February 4, 2002).

[54] J. Noble et al., *A Legacy of Failure: The Inability of the Federal-State Vocational Rehabilitation System to Serve People With Severe Mental Illnesses* (National Alliance for the Mentally Ill, 1997); J. J. Bevilacqua, "The State Vocational Rehabilitation Agency: A Case for Closure," 10 *J. Disability Policy Studies* 90 (1999); *see* Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 38.

[55] J. Noble et al., *A Legacy of Failure: The Inability of the Federal-State Vocational Rehabilitation System to Serve People With Severe Mental Illnesses* (National Alliance for the Mentally Ill, 1997).

[56] J.R. Harding, National Association of Alcohol, Drugs and Disabilities, Florida Vocational Rehabilitation, National Listening Session, PM testimony at 165–166.

employment, psychosocial rehabilitation, independent living services, and other support services that could enable persons with significant disabilities to succeed in employment.[57]

(c) Disincentives to Work in Public Benefits Programs

Although very many persons with disabilities who receive SSI and Social Security Disability Insurance (SSDI) benefits want to work and would be able to work with appropriate support, relatively few are able to do so because of the disincentives to work created by the eligibility rules for these programs. According to a 1998 study by the General Accounting Office (GAO), only one in 500 SSDI beneficiaries in that year left the rolls by returning to work.[58] These data suggest that it is unrealistic to expect significant numbers of people with disabilities to be able to replace public benefits with income from competitive employment and that the great majority of people with disabilities could benefit from income maintenance programs that make it possible to continue to receive public benefits while receiving additional income from employment.

The Social Security Administration (SSA) reports that the fear of losing health care benefits is the largest barrier preventing people with disabilities from returning to work. Further, the work incentive programs within SSI, SSDI, Medicare, and Medicaid are poorly understood and underused. Increases in income from work may also cause increases in rent under Section 8 housing programs, loss of food stamps, or decreases in public assistance benefits.[59]

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[57] J. Noble et al., *A Legacy of Failure: The Inability of the Federal-State Vocational Rehabilitation System to Serve People With Severe Mental Illnesses* (National Alliance for the Mentally Ill, 1997).

[58] *Social Security Disability Insurance: Multiple Factors Affect Beneficiaries' Ability to Return to Work* (General Accounting Office, GAO-HEHS-98-39, 1998). The same study found that receipt of SSDI benefits was negatively associated with the success of return to work interventions.

[59] 65 Federal Register 105 (May 31, 2000): Cooperative Agreements for Benefits Planning, Assistance, and Outreach Projects; Program Announcement No. SSA-OESP-00-1.

For persons who need personal assistance for work or daily living, the absence of sliding fee scales for personal assistance services is another major disincentive to work because income limits are too low to allow persons with disabilities to be able to pay to replace the services paid for by public benefits. Replacing the current “on/off switch” for eligibility with a sliding fee scale that can accommodate those who can pay privately, those who can pay part of the cost of their services, and those who cannot pay at all is critical.[60]

(d) Shortage of Personal Care Assistance

Until 1980, primarily registered nurses employed by visiting nurses’ associations and public health agencies, as well as family and friends provided support services to people with disabilities in their homes. In the 1980s, changes in Medicare certification and reimbursement policies, the Title XIX home- and community-based waiver amendments of OBRA 1981, and the redefinition of the “homebound” eligibility requirement of Medicare in 1987 led to enormous growth in the number of persons working as personal care assistants.[61] Title XIX funds pay for services by home health aides, defined as “services related to a patient’s physical requirements,” similar to the services that would be performed by a nurse’s aide in a hospital or nursing facility.[62] Home health aides perform such services as homemaking, bathing, feeding, shopping, and assisting consumers with other activities of daily living.

The availability of personal care assistance is vital to enabling persons with disabilities to avoid institutionalization. Personal care assistants enable people with disabilities to accomplish a wide

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[60] B. Kafka, “Home Care and the Disability Community,” *Caring* (July 1998) at 28.

[61] Service Employees International Union, “Home Care Workers: A Briefing Paper” (May 1999) at 2.

[62] Health Care Financing Agency, *State Medicaid Manual,* HCFA Publication 45-4 § 4480, Transmittal No. 67 (April 1995).

range of daily living tasks that they would perform themselves if they did not have a disability, including support with eating, dressing, bathing, grooming, and transferring, as well as health-related tasks, such as medication administration. Personal care assistant jobs are typically entry-level, offer few benefits, often do not even provide reimbursement for travel to clients' homes, and pay an hourly wage that is typically about two or three dollars above the minimum wage.[63]

Because of worker shortages, people with disabilities for whom the state has authorized personal assistance services often do not receive all the hours of service they are entitled to and sometimes fail to receive those services at all. A survey of home care waiver recipients in Minnesota, for example, found that none of the consumers was receiving all the services for which the consumer was authorized.[64]

(e) Low Wages of Support Staff

In 1998, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry reported that 2 million health care paraprofessionals worked in the home care sector, of whom 600,000 were earning wages below the poverty line.[65] A survey of state

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[63] S. Yue, "A Return to Institutionalization Despite Olmstead v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home-and-Community Based Waiver Services," 19 *Law & Ineq. J.* 307, 329–331 (2001).

[64] *Id.* at 333.

[65] President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, *Quality First: Better Health Care for all Americans: Final Report to the President* (May 1998) at 205.

legislative priorities by the National Conference of State Legislatures identified workforce issues, including shortages of personnel, as one of the four highest priorities.[66]

Low wages for direct support staff are the result of low reimbursement rates for personal assistance services by state Medicaid and human services agencies. Low reimbursement rates not only fail to attract adequate numbers of support staff but also affect the competence of the staff who do fill those positions and ensure that those jobs remain entry-level, low-skill, high-turnover jobs.[67]

Wages and benefits in community services are not competitive with jobs requiring comparable education, training, experience, and skill. They are not competitive even with jobs requiring significantly lower education, training, experience, and skill, such as fast food jobs. In many states, wages and benefits for direct care and professional staff in community services are radically lower than those in institutions. For example, in California a 1993 study found that the differential in average direct care staff wages and benefits between institutions and community-based services was 124 percent.[68] A legislative committee in the same state found that "as a result of low rates, vendors are *having extreme difficulty in maintaining existing employees, and in hiring and training new employees*." The subcommittee also found that "staff turnover *results in a lower quality of service and can jeopardize the health and safety of the consumers receiving services*" because "specialized knowledge about consumers and their needs comes from long-term relationships with direct care staff." Further, the subcommittee found, "without these services

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[66] National Conference of State Legislatures, *Health Chairs Project Survey of State Health Priorities for 2001* (2001).

[67] S. Yue, *A Return to Institutionalization Despite Olmstead v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home-and-Community Based Waiver Services,* 19 Law & Ineq. J. 307, 329–332 (2001).

[68] Mitchell et al., *Compensation and Turnover of Direct-Care Staff in Developmental Disabilities Residential Facilities in the United States: Wages and Benefits,* 51 Mental Retardation 429, 433 (Dec. 1993).

many consumers now living in the community would be forced into more restrictive environments."[69]

(f) Service Models and Financing Systems That Limit Self-Determination and Choice

When asked to identify state or federal policies that hinder the ability of persons with disabilities to move into or live in the community, the persons with disabilities whom we interviewed identified the following:

- The institutional bias of Medicaid
- The status of nursing facilities as a required service
- The status of personal care as an optional service
- Intermediate care facilities for the mentally retarded (ICFs/MR)
- Funding that encourages congregating people together
- Funding that encourages investment in "bricks and mortar"
- The mind-set that people have to live in a "program"
- The lack of adequate wages for direct service staff
- That waivers have to be renewed, and institutional services don't
- More dollars going to the institution
- Policies that do not allow paying family members at home, but pay for services in a nursing facility
- VR not being used properly to support persons with severe disabilities.

Many respondents simply identified "funding" as a barrier or cited the imbalance in funding between institutions and community services.

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[69] Senate Budget and Fiscal Review Comm. Subcomm. No. 3 On Health, Human Services, Labor and Veterans Affairs 47 (April 3, 2000) at 477, 48 (emphasis in original).

The programmatic and funding obstacles identified by people with disabilities are well supported in the literature. The Medical Assistance program, Title XIX of the Social Security Act,[70] is the principal source of funding for long-term care services in the United States. Title XIX is a federal program operated by the states to provide medical and rehabilitation services. In 1998, Title XIX financed about 40 percent of the nation's total long-term care spending of $150 billion.[71]

Nursing facility services are a required Title XIX service; all states that accept Medicaid funding are required to provide those services to all eligible persons who request them. Although service in an ICF/MR is an optional state plan service, all the states have elected to provide that service and therefore are obligated to provide services in an ICF/MR to all eligible persons who request them. Unlike personal care, home health services, and home- and community-based waiver services, which the states have great flexibility in designing, the nursing facility and ICF/MR programs require the states to provide 24-hour care according to a detailed set of regulations. Further, the financial eligibility rules for institutional services are far more generous than the requirements for community services. A person can qualify for Medicaid in a nursing home with income up to 300 percent of the federal poverty level. Unless an exception is granted under a waiver, this rule does not apply to people who live in the community. Similarly, spousal deeming of income rules protect the income and assets of the spouse of a nursing facility resident but not the income and assets of the spouse of a person who receives Medicaid services at home. For children placed in institutions, the state may not count the parents' income in determining the child's eligibility, but this is not the case for families who care for their children at home.[72]

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[70] 42 U.S.C. § 1396 et seq.

[71] A.I. Batavia, "A Right to Personal Assistance Services: 'Most Integrated Setting Appropriate' Requirements and the Independent Living Model of Long-Term Care," 27 *Am. J. L. & Med.* 17, 23 (2001).

[72] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (2002) at A-55.

In the 35 states that have exercised the option to cover persons who are "medically needy," that is, to allow persons with high medical expenses to "spend down" periodically to financial eligibility levels, the eligibility requirements for community services are in theory not as onerous. In practice, however, the spend-down limits are often so low that people receiving Medicaid services in the community have insufficient income to cover basic living expenses. In 21 states, the medically needy income level is below the level for SSI benefits (currently about $512 a month for an individual), and seven of those states have levels that are less than 50 percent of the SSI rate. A new federal rule promulgated last year gives spend-down states the option to allow individuals to meet the spend-down level while retaining more of their income for basic necessities, but few states have chosen this option.[73]

As a result of the institutional bias of Title XIX, about three-fourths of Medicaid spending on long-term care is allocated to institutional services. For example, in fiscal year 1998, 58 percent of Medicaid long-term care expenditures were spent on nursing facility services, 17 percent on ICF/MR services, 15 percent on home- and community-based waivers, 6 percent on the personal care option, and 3 percent on home health care. Statistics for 2000 compiled by American Disabled for Attendant Programs Today (ADAPT) from data supplied by the MEDSTAT Group, the Health Care Financing Administration (HCFA) 64 data, Office of State Agency Financial Management, show only two changes in these percentages in 2000, a decrease from 17 to 15 percent for ICF/MR spending and an increase from 15 to 18 percent for spending on home- and community-based waivers. (In June 2001, HCFA changed its name to CMS.) Although Title XIX spending on home- and community-based services increased more than spending on institutional services between 1994 and 1999, from about $8 billion to $16 billion, spending on institutional services increased as well, from about $37 billion to about $46 billion. Medicaid spending on nursing facilities increased from $23.2 billion in 1990 to $44.4 billion in 2000, and the CMS projects that by the year 2001, Medicaid expenditures on nursing facilities will increase to $81.5

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[73] *Id.* at A-57.

billion. Although the percentage of Medicaid funds spent on institutional services varies from state to state, all states except Oregon spent more on institutional services in 1999 than on home- and community-based services.[74]

Some advocates indicated that the current delivery system only intensifies existing unmet needs-needs for long-term care at home and in the community for people with disabilities. A representative of the service provider organization ANCOR echoed the view that persons with disabilities are dependent on "a 40-year-old, outdated, federal long-term support program and financing mechanism, that is ... predicated on a ... statutory institutional bias, making home and community based services an option." This results in "inconsistent and disparate community services, not only between states but within the states."[75]

Similarly, the National Association of State Mental Health Program Directors stated in a letter to the Secretary of Health and Human Services that "certain federal policies actually obstruct the efforts of states, providers, and consumers to enable individuals with mental illnesses to receive effective treatment and participate fully in community living. People with mental illnesses continue to face discrimination and other barriers in federal programs."[76]

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[74] Statistics derived from data on www.hcbs.org and http://cms.hhs.gov/statistics/nhe/historical/ty.asp; K. Kleinmann, "Money to Institutions" (Steve Gold's Treasured Bits of Information News Group Archives, July 16, 2001) (Information compiled by ADAPT from data supplied by The MEDSTAT Group, Inc.; see W. Fox-Grage et al., *Community-Based Long-Term Care* (National Conference of State Legislatures: Promising Practices Issue Brief (2000) at 2. Of total Medicaid expenditures of $180 billion in 1999, about $62 million were allocated to long-term care services. Medicaid pays about two-thirds of the cost of nursing facility services and a similar proportion of long-term care spending for mental retardation and developmental disabilities services.

[75] Testimony of American Network of Community Options and Resources (ANCOR), National Listening Session, PM testimony at 192–93.

[76] Letter from Barry S. Kast and Robert W. Glover, National Association of State Mental Health Program Directors, to Tommy Thompson, May 18, 2001, at 1.

Title XIX Waivers and Optional Services: The Personal Care Option, Rehabilitation Option, Targeted Case Management Option, Home- and Community-Based Waivers, and Demonstration Waivers. These provisions of Title XIX offer states the option to fund home- and community-based services with Medicaid dollars. Especially in the case of the home- and community-based waiver, they afford enough flexibility to fund relatively innovative service models, such as self-determination and consumer-directed personal assistance. However, unlike services in a nursing facility that are required of any state that participates in Title XIX, these services do not have to be provided unless the state elects to do so. Thus, the availability of these services varies from one state to another, and the type of services that are funded also varies, sometimes dramatically.

The personal care option can be used to support a person with disabilities in any setting, including the person's own home. However, because Title XIX dollars cannot be used to pay family members for providing personal care or other services, states must receive a research and demonstration waiver to support programs that allow payments to spouses and family members.[77]

The rehabilitation option can be used to fund various types of rehabilitative services for people with mental illnesses. According to 1998 data collected by the Bazelon Center for Mental Health Law, all but 10 states had elected to cover psychiatric rehabilitation services under this option. However, states that do provide the rehabilitation option often use a restricted definition of those activities.[78]

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[77] For examples of projects funded with Section 1115 research and demonstration waivers, see http://www.hcbs.org/promising_practices.

[78] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 6. The 11 states that have not opted to provide rehabilitation services are Connecticut, Georgia, Idaho, Indiana, Iowa, Kentucky, Montana, Nevada, New Jersey, and Utah.

The targeted case management option is one of the most flexible options available under Title XIX. The option can be targeted to a specific population, such as persons who are “chronically mentally ill,” and does not have to be offered statewide. However, 23 states do *not* target intensive case management services to adults with mental illness.[79]

Although the Title XIX home- and community-based services waiver—created by an amendment to the Social Security Act in 1981[80] —allows states great flexibility in supporting people with disabilities in the community, it has not leveled the playing field between institutional and community services, let alone eradicated the institutional bias within Title XIX. Because state governments do not recognize home- and community-based waiver services as an entitlement, as they do with nursing facility and ICF/MR services, waiting lists for waiver services are large in many states.[81]

Further, the waiver is used much more extensively for some groups of people with disabilities than for others. According to statistics released by the NIDRR in October 2001, there were 75 home- and community-based waivers for persons with mental retardation or developmental disabilities, serving a total of 216,570 persons in 1997.[82] However, only two states had obtained home- and community-based waivers for persons with mental illnesses in 1997, serving a total of

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[79] *Id.* at 6. The 23 states are Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Nebraska, Nevada, New Mexico, Oregon, South Carolina, Tennessee, Utah, and Washington.

[80] 42 U.S.C. 1396n(c).

[81] Gary Smith, in *Closing the Gap—Addressing the Needs of People with Developmental Disabilities Waiting for Supports* (National Association of State Directors of Developmental Disabilities Services, 1999), estimates that between 80,000 and 200,000 persons with developmental disabilities are on waiting lists for home- and community-based services or experience significant delays in receiving those services.

[82] NIDRR, *Medicaid Home and Community Based Services,* Disability Statistics Report 16 (October 2001).

626 persons.[83] By 2001, only two more mental health waivers had been granted.[84] The waiver is not often used to provide home- and community-based services to persons with serious mental illness. Only Colorado has a home- and community-based waiver focusing specifically on persons with serious mental illness. Colorado's mental health waiver serves adults who would otherwise be in a nursing facility, and most are older than 60.[85] As of 1999, only three states had obtained home- and community-based waivers for children with mental health needs and two more had applied.[86]

Under a rule dating from the origins of the Medicaid program, Title XIX reimbursement is not available for services in psychiatric institutions or Institutions for Mental Diseases (IMDs) for persons between the ages of 22 and 64. The IMD exclusion poses a barrier to the development of community mental health services under home- and community-based services waivers authorized by Section 1915(c) of the Social Security Act, 42 U.S.C. § 1396n(c) because the exclusion effectively bars the granting of waivers to serve persons who absent the waiver would require services in an IMD, unless those persons are also eligible for services in a nursing facility. To obtain a 1915(c) waiver, states must demonstrate that the Title XIX expenditures on waiver services will offset the Title XIX dollars that otherwise would be spent on institutional services. Thus, because no Title XIX funds are available for services for adults under 64 in mental hospitals, the option is extremely difficult to use to enable adults with mental illness to

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[83] *Id.*

[84] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 52.

[85] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 8.

[86] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 9.

move from hospitals or specialized nursing homes that are considered IMDs.[87] he statute has also been interpreted to prevent states from using Title XIX expenditures in Residential Treatment Facilities (RTFs) as a cost offset for home- and community-based waivers to serve children in community settings.[88] Because group homes for 16 or fewer persons are not considered IMDs under Title XIX, however, states may bill Medicaid under 42 U.S.C. § 1396a(i) for group home staff and other mental health services provided to group home residents.[89] States may also fund mental health and substance abuse services under the Section 1915(b) waiver, which allows states to waive Medicaid's freedom of choice provisions and require Medicaid beneficiaries to receive services through a managed care plan. Most states use Section 1915(b) only to fund acute mental health and substance abuse services; a few, such as Colorado, have used it to fund long-term services for persons with significant or persistent mental illness.[90]

Although the IMD exclusion prevents federal funds from being used for home- and community-based waiver services to adults with mental illnesses, repealing the exclusion would merely create another incentive for institutionalization. Opponents of repealing the exclusion point out that little evidence exists that states would request home- and community-based waivers for IMD residents if the exclusion did not exist. For example, as of 2001, only three

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[87] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 7.

[88] G. Smith, et al., *Understanding Medicaid Home and Community Services: A Primer* (2000) at 182.

[89] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 7.

[90] G. Smith et al., *Understanding Medicaid Home and Community Services: A Primer* (2000) at 182.

states had home- and community-based waivers for children and one had a waiver for adults who would be eligible for funding in an IMD.[91]

Mental Health Block Grant. The Mental Health Block Grant (MHBG) is the principal federal program designed to support community-based public mental health services and reduce reliance on expensive hospitalization. The program is flexible enough to fund a broad range of services, including respite for families and services to children whose parents have psychiatric disabilities. However, the Administration has proposed to fund the MHBG at the same level in FY 2002 as was available in FY 2001.[92] This continues a pattern of significant decline in the amount of the block grant in real dollars, from more than $250 million in 1981 to less than $100 million in 1998.[93]

The Child Health Insurance Program (CHIP). CHIP, enacted under the Balanced Budget Act of 1997,[94] provides insurance coverage for health care, including mental health services, for children in low-income families who were not, at the time of the statute's enactment, eligible for Medicaid under their state's eligibility rules. States can include CHIP-eligible children as an eligible group under Medicaid, create a separate health program for them, or both. The first option provides the most complete coverage, but only 23 states have adopted it.[95]

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[91] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 52.

[92] Letter from Barry S. Kast and Robert W. Glover, National Association of State Mental Health Program Directors, to Tommy Thompson, August 27, 2001 at 2.

[93] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 12.

[94] P.L. 105-33, 111 Stat. 251 (1997), title IV, subtitle J.

[95] Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 10.

Barriers within Medicare. The Medicare program, which provides health care benefits to older adults and persons with disabilities who receive benefits under the SSDI program, requires higher copayments (50% compared with 20%) and limitations on reimbursement for mental health services than for other health services, including for those who receive disability payments under the SSDI program.[96] The absence of prescription drug coverage under Medicare is a serious problem for mental health consumers who require medication as "a first-line defense against disabling symptoms."[97] Medicare provides no coverage for other services that are extremely important to persons with serious mental illness, including case management and psychosocial rehabilitation.

(g) Lack of Affordable or Physically Accessible Transportation

Some advocates consider lack of accessible transportation the single largest barrier to the inclusion of persons with disabilities in society because it prevents persons with disabilities from holding jobs, voting, accessing education or medical care, or participating in ordinary community activities.[98]

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[96] Lack of parity in private insurance coverage (in lifetime limits, copayments, and deductibles) for physical health and mental health conditions also affects the ability of mental health consumers to obtain services and support. About half the states have adopted some form of parity legislation. "Report from Financing Plank," National Summit of Mental Health Consumers and Survivors (August 26–29) at 6.

[97] Letter from Barry S. Kast and Robert W. Glover, National Association of State Mental Health Program Directors, to Tommy Thompson, May 18, 2001 at 3; Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 10.

[98] J.R. Harding, National Association of Alcohol, Drugs and Disabilities, Florida Vocational Rehabilitation, National Listening Session, PM testimony at 165–66.

(h) State Legislative Appropriations

State appropriations for mental health services (not including the federal Medicaid match that may be available for some services) have declined by 7 percent since 1990 and are significantly lower today than they were in 1955, when mental health services consisted primarily of custodial care. Spending fell from $16.5 billion to $11.5 billion in 1997 dollars, adjusted for inflation and population.[99] State appropriations for mental health services have fallen in relation to total state spending, state spending on health and welfare, and state spending on corrections. From 1990 to 1997, the proportion of all state spending allocated to mental health services fell from 2.12 to 1.81 percent, a decline of 13 percent. [100]

4. Resources and Services Models That Facilitate Community Integration

(a) General

We asked the persons with disabilities whom we interviewed, "What policies could the states enact that would help people who do not need to be institutionalized live in the community?" The responses strongly and consistently favored self-determination and consumer-directed models of service. The respondents showed an awareness of how federal housing programs need to change to foster community integration, as well as the obvious changes that need to occur in the Title XIX program. Many people from all disability groups urged the passage of MiCASSA. Our respondents also advocated better information and training for people with disabilities and support and funding for self-advocacy. The responses include the following:

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[99] Bazelon Center for Mental Health Law, Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses (1999) at 11–12.

[100] *Id.*

- Fund self-advocacy and add self-advocacy organizations to the “Big 3” [Administration on Developmental Disabilities] programs [the University Affiliated Programs, the Protection and Advocacy systems, and the Developmental Disabilities Planning Councils]
- Get rid of red tape; change Medical Assistance (MA) rules and guidelines
- Pass MiCASSA
- Make self-determination federal law
- Set aside Section 8 vouchers for people who are ready to leave nursing homes
- Tie a rent subsidy program to persons leaving institutions
- Shift Section 811, which traditionally has been a project-based funding source, to individual vouchers
- Assist people to live in homes with support staff
- Stop putting money into institutions and instead put it into housing.
- Provide essential therapies and communication
- Change professional and bureaucratic attitudes
- Provide more direct information sessions for people with disabilities to learn their rights
- Train people in institutions to learn how to live in the community; have “buddy systems”
- Provide more home-based programs
- Provide vouchers for homeownership
- Provide peer support
- Have flexible emergency response systems
- Provide vouchers for homeownership
- Provide better salaries for personal assistance providers
- Eliminate programs’ institutional bias
- Provide more supported-living apartments
- Have better pay for front-line staff

- Have mandatory training for staff to overcome the outdated attitude that "I'm here to take care of you"
- Have more flexibility with waivers
- Provide equitable support for people with disabilities entering the workforce
- Allow people to earn higher wages without influencing benefits
- Give money to people and allow them to use it for support from family and friends, not agencies
- Provide education to communities that it is okay to be different

Our respondents' emphasis on flexible funding and on self-determination, choice, and control over how service dollars are spent are reflected in service models based on self-determination, consumer direction, and direct control of service dollars. These models are not necessarily new-the Centers for Independent Living (CILs) and the mental health consumer/survivors' self-help movement have been providing consumer-controlled services for the past two decades. Indeed, most of these service models are strongly supported by scientific studies of their outcomes for consumers.

(b) Consumer-Directed Personal Assistance Services

Most personal assistance services provided through publicly funded programs have been provided through private service provider agencies. The "agency model" has the following features: (1) care delivered through a provider agency by caregivers who are supervised by medical professionals; (2) case management to coordinate services; and (3) public regulation of providers to ensure quality. Case managers or other professional staff members of the agency make important service delivery decisions.[101] Thus, agency-delivered services tend to diminish, rather than enhance, control by

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[101] A.I. Batavia, "A Right to Personal Assistance Services: 'Most Integrated Setting Appropriate' Requirements and the Independent Living Model of Long-Term Care," 27 *Am. J. L. & Med.* 17, 18 (2001).

disabled individuals over their lives. Yet there is evidence that being able to make personal choices regarding one's own life promotes health, well-being, and personal satisfaction.[102] The success of consumer-directed personal assistance services, which place decisions about service delivery squarely in the hands of the consumer, is therefore not surprising.[103]

Consumer-directed programs permit consumers to have a direct employer-employee relationship with their personal assistants. Health care professionals do not supervise the assistants. The consumer advertises for assistants and interviews, hires, trains, supervises, and, if necessary, fires them.[104]

Many variations on this concept can be funded under existing Medicaid law and regulations.[105] The California In-Home Supportive Services (IHSS) program, which serves more than 200,000 consumers, of whom about half are 65 and older, is the largest and oldest consumer-directed care program in the United States. The program allows payments to a wide range of caregivers, including family and agency-managed caregivers. An evaluation of the IHSS program in the late 1990s showed that the consumers in the program who selected consumer-directed services had

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[102] M. Kapp, *Health Care in the Marketplace: Implications for Decisionally Impaired Consumers and their Surrogates and Advocates,* 24 S. Ill. U. Law J. 28 (1999); J. Mattson-Prince, *A Rational Approach To Long-Term Care: Comparing The Independent Living Model With Agency-Based Care For Persons With High Spinal Cord Injuries,* Spinal Cord 326, 330 (1997); M. A. Nosek, *Personal Assistance: Its Effect on the Long-term Health of a Rehabilitation Hospital Population,* 74 Arch. Phys. Med. Rehab. 127, 130 (1993).

[103] See, e.g., P. Doty et al., "Consumer-Directed Models of Personal Care: Lessons from Medicaid," 74 *Milbank Q*. 377, 395 (1996).

[104] A.I. Batavia, "A Right to Personal Assistance Services: 'Most Integrated Setting Appropriate' Requirements and the Independent Living Model of Long-Term Care," 27 *Am. J. L. & Med.* 17, 18–19 (2001).

[105] Fox-Grage et al., "Community-Based Long-Term Care" (National Conference of State Legislatures Promising Practices Issue Brief, 2000).

significantly greater levels of disability than the consumers who selected provider or agency-managed services. The consumer-directed model yielded superior results in satisfaction with services, empowerment, and quality of life. Yet the consumer-directed model was significantly more cost-effective than the agency-managed model, costing about 50 percent less for persons with similar disabilities. No evidence was found that consumer-directed services were less safe than agency-managed services. The survey gave no support to the view that consumer-directed services should be limited to those consumers, primarily younger adults, who are considered capable of hiring, firing, and giving direction to their personal assistants.[106]

Demonstration programs supported by HHS under Section 1115 research and demonstration waivers take the concept further by placing cash to pay for services directly into the hands of consumers. For example, the Cash and Counseling Demonstration cosponsored by The Robert Wood Johnson Foundation and HHS provides consumers with a monthly allowance or budget based on what Medicaid otherwise would have paid to the beneficiary's regular service providers. Participants in the program develop their own care plans and may spend their allowances as they choose, as long as the services they purchase are related to their needs. The "counseling" part of the program provides counselors to explain tax, labor, and other rules and help consumers with paperwork.[107] Each participant in the program receives a cash allowance based on the number of hours of personal assistance services required and the number of hours of services actually delivered. Program participants can hire family, friends, professionals, or neighbors as personal assistants.[108]

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[106] L. Polivka and J. Salmon, *The Ethical and Empirical Basis for Consumer-Directed Care for the Frail Elderly: A Guide to State Policy Makers* (Florida Policy Exchange on Aging, 2000).

[107] Fox-Grage et al., "Community-Based Long-Term Care" (National Conference of State Legislatures Promising Practices Issue Brief, 2000) at 6.

[108] Fox-Grage et al., "Community-Based Long-Term Care" (National Conference of State Legislatures Promising Practices Issue Brief, 2000) at 6.

Arkansas is providing cash allowances and counseling to 2,242 persons under a demonstration waiver. People who are eligible for Title XIX personal care services are randomly assigned to a treatment group and a control group. The control group receives personal care through a provider agency; the treatment group receives a monthly cash allowance and services to help them use the allowance. Persons with cognitive impairments are eligible for the program. Early data indicate the treatment group participants have less nursing home use than the control group. At the beginning of the program, the state conducted systematic outreach to eligible persons, including a letter from the governor to all persons receiving personal care.[109] Similar programs have been initiated by Florida for 2,847 persons, including 1,000 children,[110] and by New Jersey.[111]

In a similar program in Oregon, the state agency deposits money electronically in the participant's bank account every month. The monthly allocation is based on an assessment of the person's functional status. CILs and Senior Services Centers provide training and technical assistance to participants. To conduct payroll tasks, either the participant or a designated surrogate must pass an exam. If the person or surrogate does not pass the exam, a fiscal intermediary is assigned to conduct payroll functions.[112]

Initial research on cash and counseling programs demonstrates a high level of satisfaction with cash and counseling programs. More than 80 percent of the participants in programs that have been evaluated reported that their quality of life had improved, whereas none considered that it

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[109] Independent Choices—the Arkansas Cash and Counseling Demonstration, http://www hcbs.org/promising_practices.htm/AR_CashAllowance.ref.pdf.

[110] http://www.hcbs.org/promising_practices.htm/FL_CashAllowance.ref.pdf.

[111] http://www. hcbs.org/promising_practices.htm/NJ_CashAllowance.ref.pdf.

[112] http://www.cms.hhs.gov/medicaid/promisingpractices/orca.pdf.

had diminished. Satisfaction with the availability and flexibility of assistance was extremely high (95%).[113]

(c) Centers for Independent Living

The CILs, funded under Title VII, Part C, of the Rehabilitation Act of 1973, *as amended*, have been highly successful in assisting persons with significant physical disabilities to leave nursing facilities and in diverting nursing facility admissions. The National Council on Independent Living (NCIL) claims that in 1999, the most recent year for which figures are available, the CILs assisted 2,300 persons with disabilities to leave nursing facilities and kept almost 15,000 from being forced into nursing facilities, for an average cost of $643 per person in federal dollars. However, funding for the CILs grew by only $10 million in FY 2001.[114]

(d) Consumer-Controlled Agency Models

Advocates for persons with physical disabilities recognize that a consumer-controlled agency model is an appropriate choice for some consumers who may prefer to work with an agency that handles the administrative work of providing home and community support services. In the consumer-controlled agency model, the consumer would exercise maximum control over selecting, managing, and dismissing attendants, although in most cases the attendants would be employed by the agency and the agency would provide a pool of attendants from whom the consumer could select. The consumer could, if desired, become his or her own fiscal agent. Although the agency might determine the number of hours of service a consumer would receive on the basis of a functional assessment, the consumer would decide when, where, how, and at

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[113] Fox-Grage et al., “Community-Based Long-Term Care” (National Conference of State Legislatures Promising Practices Issue Brief, 2000) at 6.

[114] Testimony of Marcie Roth, NCIL, National Listening Session, PM testimony at 180–81.

what times the services would be delivered. Services would include nonmedical support in instrumental activities of daily living. Unlicensed attendants would be allowed to perform health-related tasks through delegation or assignment. Training on attendant management would be available to consumers who desire it. Services would be available to those who can pay privately, those who can pay for some of the costs, and those whose incomes do not allow them to pay the costs at all.[115]

(e) Family Support

Family support is a familiar concept from developmental disabilities services, where experience has shown that modest, inexpensive home-based support services can enable people with significant disabilities to live at home with their families and avoid placement in an institution or group home. Some family support programs, such as those in Michigan, pay a monthly stipend to the family to spend as it chooses. These programs have been effective and are highly valued by families. Similarly, modest support services, such as respite care, support groups, training, education, and help in accessing existing community services can significantly enhance the ability of families to continue to care for elderly relatives at home and lessen the time spent in more expensive residential services, such as nursing facilities.[116]

(f) Consumer-Operated Programs

A list of essential community services for people with mental illnesses developed by the Surgeon General in 1999 includes the following:

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[115] *See e.g.*, B. Kafka, "Home Care and the Disability Community," *Caring* (July, 1998) at 28.

[116] Testimony of Janet Saynor, former Commissioner of Aging, City of New York, National Listening Session, PM testimony at 186–87.

- Case management
- Assertive community treatment
- Psychosocial rehabilitation services
- Community alternatives for crisis care
- Services for co-occurring substance abuse and serious mental illness
- Consumer self-help, consumer-operated programs, consumer advocacy
- Family self-help and advocacy
- Housing
- Income, education, and employment
- Health care
- Integrated service systems[117]

Mental health consumers have emphasized the benefits of consumer-directed initiatives. The National Summit of Mental Health Consumers and Survivors held in Portland, Oregon, in August 1999 identified a number of alternatives to traditional mental health services whose common characteristic is that they are consumer-operated and -directed and provide peer-to-peer support. Those services include the following:

- Peer counseling
- Employment assistance
- Drop-in centers
- Wilderness camping
- Housing assistance
- Holistic and herbal medicine
- Spirituality

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[117] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at ii.

The group agreed that the function of these services is "to provide inspiration, hope, and personal experience to peers, provide education and training, and an array of consumer-run services in safe, coercion-free environments, as an integral part of a full system of resources."[118] The group recommended that the program and staff certification and credentialing standards for these programs should be designed by consumers for consumers on the basis of their unique experience, knowledge, and research and integrated into the publicly funded system of services.[119] Participants in the summit agreed emphatically that forced treatment, including involuntary outpatient treatment, is ineffective, drives people away from voluntary treatment, and would not be necessary if there were appropriate community services available.[120]

The principles of service articulated by the National Summit echo the principles outlined in a 1992 report of the Federal Task Force on Homelessness and Severe Mental Illness and are based on research and practice:

- Access, empowerment, and responsibility. Mental health consumers should be empowered to gain access to mainstream resources, and their dignity must be respected.
- Diversity and flexibility. Services should be culturally competent, individualized, and sufficiently flexible to respond to changing needs and preferences.
- Peer, family, and natural supports. Consumers and their allies must engage in planning, delivery, monitoring, and evaluation of services.
- Local, state, and federal participation. Services should be organized locally but

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[118] "Report From the Alternative Services Plank," National Summit of Mental Health Consumers and Survivors (August 16-29, 1999) at 1–2.

[119] *Id.*

[120] "Report from Force and Coercion Plank," National Summit of Mental Health Consumers and Survivors (August 26–29, 1999) at 1.

> coordinated at the state level and supported with leadership and appropriate fiscal incentives at the federal level.[121]

The effectiveness of consumer-directed initiatives at reducing hospitalization of persons with mental illnesses is strongly supported by a small but growing body of research. For example, a large-scale multimethod study of Consumer/Survivor Development Initiative (CSDI) projects in Canada in 1995 found that average inpatient use declined from 48 days to four days. Admissions to hospitals for psychiatric treatment dropped from a mean of three admissions to a mean of 0.6 admissions. Another Canadian study published in 1995 found that nearly 60 percent of the participants in a self-help group had not been rehospitalized and that those who had experienced a significant reduction in hospital days. A much earlier study in New York in 1984 found that persons discharged from psychiatric hospitals who were randomly assigned to participate in a self-help program required half as much rehospitalization 10 months after discharge as a comparable group who did not participate in the self-help program.[122]

Drop-in centers are one of the most widespread service models created by the mental health consumer movement. The drop-in center was conceived as a way to meet the need for a safe place for people moving from state mental health institutions to find companionship, feel welcome, and gain acceptance. Staffed entirely by consumers, drop-in centers may provide advocacy-training, skills training, and information about housing, benefits, and other issues of interest to consumers as well as social programs. Drop-in centers, such as the program operated by AD Lib Inc., an Independent Living Center in Pittsfield, Massachusetts, have developed into

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[121] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 12.

[122] Federal/Provincial/Territorial Advisory Network on Mental Health, Review of Best Practice in Mental Health Reform (1997) at 77–79.

true cross-disability programs whose members include persons with physical disabilities, psychiatric disabilities, retardation, chemical dependency, and learning disabilities.[123]

(g) Self-determination

Self-determination is a model in which persons with disabilities and a circle of support control the funds that pay for their own services, either directly or through a fiscal intermediary. The use of fiscal intermediaries allows self-determination programs to use Medicaid funding without a research and demonstration waiver. Self-determination, a term that originated in the developmental disabilities service system in Monadnock, New Hampshire in the early 1990s, was an effort to answer the question, "How would a system of supports look if people with disabilities and their circle of friends, or network, were truly in charge of their own services, if they achieved self- determination?"[124] The Monadnock model, which has been replicated in many states under the National Self-Determination Initiative supported by The Robert Wood Johnson Foundation, is based on four fundamental principles:

Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than to purchase a program;

Authority: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;

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[123] "Changing Attitudes of People with Chronic Mental Illness," in B. O'Day, *Issues in Rural Independence: Revisited* (2001) at 5.

[124] T. Nerney et al., *An Affirmation of Community: A Revolution of Vision and Goals*. Creating a Community to Support All People Including Those With Disabilities. Durham, NH: University of New Hampshire Institute on Disability 5 (1995).

Support: The arranging of resources and personnel—both formal and informal—that will assist an individual with a disability to live a life in the community rich in community association and contribution; and

Responsibility: The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development, and general caring for others in the community, as well as accountability for spending public dollars in ways that is life enhancing for persons with disabilities.[125]

Evaluations of self-determination programs, including the evaluation of the original Monadnock project, have been highly positive. The persons supported in the program experienced significant gains in self-determination, quality of life, personal satisfaction, improvement in challenging behavior and vocational behavior, and individualized practices in the home.[126]

(h) Supported Employment

Successful employment programs combine education, rapid placement in a real job setting ("place, then train"), strong support from a job coach or other employment specialist to adapt to and sustain the job, and support on and off the job from friends, peers, and coworkers.[127]

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[125] T. Nerney and D. Shumway, (1996). *Beyond Managed Care: Self-Determination for People with Disabilities*, at 4–5 (University of New Hampshire, Institute on Disabilities, Durham, NH, 1996).

[126] J. Conroy and A. Yuskauskas, Independent Evaluation of the Monadnock Self-Determination Project (1997).

[127] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 38.

Research has shown improved vocational outcomes from supported employment to people with significant disabilities who traditionally have not worked in real jobs.[128]

Innovative approaches to the employment of persons with mental illnesses include New York's practice of making available, through a request for proposals process, a portion of the savings from discharging persons from psychiatric institutions to the counties. Counties have responded by creating employment programs, including supported employment and clubhouse models. In Florida, a consortium of behavioral health provides job training, placement, and post-employment support with a combination of mental health and labor department funds.[129]

(i) Intensive Case Management

Research suggests that intensive case management, including the programs known as Assertive Community Treatment (ACT) and Assertive Case Management (ACM),[130] is consistently superior to traditional case management in reducing inpatient stays among persons with serious

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[128] A.F. Lehman and D.M. Steinwachs, "The Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations," http://www.ahcpr.gov/clinic/schzrec1.htm, Recommendation 28; Conroy, The Hissom Outcomes Study.

[129] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 39.

[130] In 1999, Sally Richardson, the director of Medicaid services for HCFA, issued a letter to State Medicaid Directors informing them that ACT and ACM can be supported under existing Medicaid rules. Richardson emphasized that "consumer participation in program design and the development of operational policies is especially key in the successful implementation of ACT programs." As of 1999, 33 states provided ACT programs. It is unknown how many of those programs were developed with consumer participation. Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses* (1999) at 7.

mental illness.[131] Indeed, the evidence of outcomes of traditional case management, in which the case manager assesses needs and deficits and refers the person to services, has been so negative that the model is not recommended as "best practice."[132] Intensive case management combines high frequency of contact, small caseloads, proactive outreach to consumers, 24-hour availability, and supporting consumers where they live rather than in an office-based practice. ACT, a descendent of the Training in Community Living model developed by Leonard Stein in Madison, Wisconsin, in the 1970s provides all these features of intensive case management along with a multidisciplinary team approach in which case management is provided by teams of psychiatrists, social workers, nurses, vocational specialists, and other professionals.

Research has shown that intensive case management methods are effective in reducing hospitalization and achieving cost savings, even taking into account the cost of intensive case management and reduced caseloads. For example, a 1993 longitudinal study that tracked people who had been discharged from a state hospital and received ACT using a team approach found a 28 percent decrease in hospital bed days used by the participants by the third year of the study and an "impressive" cost savings for the target area. A 1993 study of the results of an ACT program developed for consumers in a rural community found significant reduction in hospital admissions and length of hospital stay and a 52 percent reduction in the annual cost per person, taking into account the costs of hospitalization, the costs of traditional services, and the costs of the ACT program. Using a powerful research design, a Canadian study in 1996 found more striking results. In that study, all persons referred to a psychiatric hospital during a 12-month period were randomly assigned either to an assertive community rehabilitation program using a team approach modeled on ACT or to a hospital-based case management program. The mean

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[131] A.F. Lehman and D.M. Steinwachs, "The Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations," http://www.ahcpr.gov/clinic/schzrec1.htm, Recommendation 29.

[132] Federal/Provincial/Territorial Advisory Network on Mental Health, Review of Best Practice in Mental Health Reform (1997) at 4.

number of hospital days for the experimental group was 39 compared to 256 for the control group. In each month of the study, more and more of the consumers in the treatment group were living in the community, and they scored higher on objective measures of quality of life.[133]

Mental health consumers advocate strongly that using ACT and Program of Assertive Community Treatment (PACT) services to force consumers into involuntary outpatient treatment should never be done, because forced treatment is ineffective, drives people away from voluntary treatment, and would not be necessary if there were appropriate community services available.[134] It is possible, and certainly preferable, to provide the benefits of ACT on a voluntary basis.

(j) MiCASSA

The Medicaid Community-based Attendant Services and Supports Act (MiCASSA), introduced but not yet enacted in the past several Congresses and supported overwhelmingly by the disability rights movement, is important to note here because it would end the institutional bias of Title XIX by allowing individuals eligible for nursing facility or ICF/MR services the election to receive community-based attendant services and support. Services covered by the Act would include assistance with activities of daily living, including personal care, household chores, shopping, managing finances, using the telephone, participating in community activities, supervision, and teaching community living skills. MiCASSA services would require the following:

- They would be provided in the most integrated setting appropriate to the needs of the individual.

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[133] Federal/Provincial/Territorial Advisory Network on Mental Health, Review of Best Practice in Mental Health Reform (1997) at 7.

[134] "Report from Force and Coercion Plank," National Summit of Mental Health Consumers and Survivors (August 26–29, 1999) at 1.

- They would be based on functional need, rather than diagnosis or age.
- They would be provided in home or community settings, including school, work, recreation, or religious settings.
- They would be selected, managed, and controlled by the consumer of the services.
- They would be supplemented with backup and emergency attendant services.
- They would be furnished according to a service plan agreed to by the consumer.
- They would be accompanied by voluntary training on selecting, managing, and dismissing attendants.

MiCASSA would allow consumers to choose among various consumer-controlled service delivery models, including vouchers, direct cash payments, fiscal agents, and agency providers.

A person unable to direct his or her own care may be assisted by an authorized representative. The bill would also cover transition costs from a nursing facility or ICF/MR to a home setting; for example, it would cover rent and utility deposits, bedding, basic kitchen supplies, and other necessities and would allow an enhanced federal match of up to 90 percent for persons whose costs exceed 150 percent of average nursing home costs.[135] The IMD exclusion would not create a barrier to eligibility for persons with mental illnesses.

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[135] From summary developed by ADAPT, http://www.adapt.org/casa/summary.htm.

II.

The *Olmstead* Decision

In *Olmstead v. L.C.,*[136] the U.S. Supreme Court, in interpreting the ADA[137] and its implementing regulation 28 C.F.R. § 41.51(d),[138] held that "[u]njustified isolation ... is properly regarded as discrimination based on disability."[139] The logical consequence, the Court held, is that in appropriate circumstances, "proscription of discrimination may require placement of persons with mental disabilities in community settings rather than institutions."[140] Those circumstances exist, the Court further held, when the institutionalized person is "qualified" to live in a community setting "with or without reasonable modifications" to the government entity's rules, policies, or practices."[141]

Olmstead v. L.C. was brought in U.S. District Court in Georgia on May 11, 1995, by Lois Curtis,[142] a woman with disabilities who was institutionalized at Georgia Regional Hospital at

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[136] 527 U.S. 581 (1999).

[137] 42 U.S.C. § 12132.

[138] 28 C.F.R. § 35.130(d).

[139] 527 U.S. at 597.

[140] 527 U.S. at 587.

[141] 527 U.S. at 602, *quoting* 42 U.S.C. 12131(2), which defines "qualified individuals with a disability" as persons with disabilities who "with or without reasonable modifications to rules, policies, or practices, ... meet the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity."

[142] Although the plaintiffs' initials were used throughout the court proceedings and appeals, they have chosen to use their full names in the coverage of the case in the media and the disability rights movement. *See*, *e.g.*, Freedom Clearinghouse, "Lois Curtis, Elaine Wilson: Faces of Freedom," http://www.freedomclearinghouse.org; Liberty Resources Advocacy, "Integration Not Segregation Means Real Choice," http://www.libertyresources.org/advocacy/choice.html.

Atlanta (GRH-A), a state mental hospital.[143] Ms. Curtis challenged her continued confinement in the institution despite the professional judgment of her psychiatric treatment team that she no longer required inpatient treatment but instead needed community residential and habilitation services.[144] Ms. Curtis alleged violations of her rights under the Due Process clause of the Fourteenth Amendment and Title II of the ADA.[145] She sought declaratory relief and an injunction releasing her from GRH-A and providing her with appropriate treatment by qualified professionals.[146] A consent order entered in July 1995 discharged Ms. Curtis to a state institution for persons with retardation, from which she was discharged in February 1996 to a community support program known as "Nyasha Hands." However, the transfer did not resolve the case because Ms. Curtis contended that she was not receiving appropriate services to support her in the community.[147] Meanwhile, Elaine Wilson, who was also confined at GRH-A and whose claims were similar to those raised by Ms. Curtis, was granted leave to intervene in the case.[148] Both plaintiffs and defendants filed motions for summary judgment, asking the court to decide the case on the uncontested facts.[149]

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[143] *L.C. by Zimring v. Olmstead,* 1997 U.S. Dist. LEXIS 3540 (N.D. Ga. 1997).

[144] 1997 U.S. Dist. LEXIS 3540 *3.

[145] *Id.* *3.

[146] *Id.*

[147] 1997 U.S. Dist. LEXIS 3540 *3–4. Due to a funding problem, Ms. Curtis did not receive the services that were to be provided in the community setting for several months. However, this was evidently resolved by the time the district court decided the case. 1997 U.S. Dist. LEXIS 3540 *7.

[148] Both Ms. Curtis and Ms. Wilson have retardation and mental health diagnoses. 1997 U.S. Dist. LEXIS 3540 *2–4.

[149] 1997 U.S. Dist. LEXIS 3540 *4. Ms. Wilson also asked for a preliminary injunction, but the Court deferred ruling on this motion until after the motions for summary judgment were decided.

The defendants claimed that Ms. Curtis' claims were moot because she was already receiving services in a community setting. They argued that they had not violated Ms. Wilson's rights because she was denied community placement because of inadequate funding, not because of discrimination based on her disability. They further argued that they had not violated Ms. Wilson's rights under the Due Process clause because the decision to treat her at GRH-A was based on the exercise of professional judgment.[150]

The district court held, first, that Ms. Curtis' claims were not moot, although she was now receiving the services she sought in the community, because her claims were "capable of repetition, yet evading review."[151] The court therefore reached the merits of both plaintiffs' claims.

Reciting the familiar standard for proving discrimination under the ADA, the district court stated that to prove a violation of Title II of the Act, the plaintiffs must show (1) that they are "qualified individual[s] with a disability"; (2) that they were excluded from participation in or denied the benefits of a public entity's services or programs or were otherwise discriminated against; and (3) that such discrimination was "by reason of" their disability.[152] Applying the standard, the court found that "there is no dispute that plaintiffs are qualified individuals with a disability" and that they could be placed in the community. The defendants disputed whether Ms. Wilson should live in the community, but the court held that "the qualified experts [were] unanimous" in their opinion that she could.[153]

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[150] 1997 U.S. Dist. LEXIS 3540 *5.

[151] 1997 U.S. Dist. LEXIS 3540 *7, *citing Sultenfuss v. Snow*, 35 F.3d 1494, 1498 n. 5 (11th Cir. 1994) and *Vitek v. Jones*, 445 U.S. 480, 487 (1980).

[152] 1997 U.S. Dist. LEXIS 3540 *8, *citing Concerned Parents to Save Dreher Park Center v. City of West Palm Beach*, 846 F.Supp. 986, 990 (S.D. Fla. 1994).

[153] *Id.*

The defendants next argued that the two women were denied community services because of inadequate funding and therefore that the plaintiffs had failed to prove that they had been discriminated against by reason of their disability. The court rejected this contention and held that "under the ADA, unnecessary institutional segregation of the disabled constitutes discrimination per se, which cannot be justified by a lack of funding."[154]

The district court based its holding on an analysis of the text of the statute, its legislative history, and the Title II regulation promulgated by the U.S. Attorney General. The court found that the statute made clear, in 42 U.S.C. § 12101(a)(2), (3), and (5), that "segregation" of persons with disabilities is a form of discrimination that Congress intended to eliminate.[155] The court also found that the legislative history of the ADA is "replete" with statements reflecting Congress' intent to prohibit unnecessary segregation.[156] Finally, the court held that the Title II regulation stating "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" "plainly" prohibits discrimination.[157] The court also noted that the regulation requires public entities to make reasonable modifications in existing programs to avoid discrimination: "A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can

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[154] 1997 U.S. Dist. LEXIS 3540 *9.

[155] *Id.* The Preamble to the ADA states, "The Congress finds that 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 serious and pervasive social problems."

[156] *Id.*, *citing,* as an example, 135 Cong. Rec. 19803 (statement of Senator Harkin, floor manager for the ADA).

[157] *Id., quoting* 28 C.F.R. § 35.130(d). The court noted that the Appendix to the Title II regulation explains that "the most integrated setting appropriate" is "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." 28 C.F.R. Pt. 35, App. A.

demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."[158]

Although the defendants claimed that all available funds were being used to provide services to other persons with disabilities, the district court held that it would not "fundamentally alter" the defendants' services. The court based its holding on the following factors: First, the defendants had existing programs that provided services to persons like the plaintiffs. Second, it was undisputed that the defendants could provide services to the plaintiffs at "considerably less cost" than in the institution.[159] The court granted summary judgment for the plaintiffs—including a declaratory relief—and ordered the defendants to place Elaine Wilson in the community and provide Lois Curtis with "all appropriate services necessary" to maintain her placement in the community.[160]

On appeal, the Court of Appeals for the Eleventh Circuit affirmed[161] the district court's judgment that the defendants had discriminated against the plaintiffs "by confining them in a segregated institution rather than an integrated community-based program." However, the court of appeals remanded the case to the district court for further findings concerning the state's defense that providing community services to the plaintiffs would "fundamentally alter" the nature of the states' services.[162]

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[158] *Id., quoting* 28 C.F.R. § 35.130(b).

[159] 1997 U.S. Dist. LEXIS 3540 *12.

[160] 1997 U.S. Dist. LEXIS 3540 *12–13. The court denied as moot the plaintiffs' remaining claims under the Fourteenth Amendment.

[161] *L.C. by Zimring v. Olmstead,* 138 F.3d 893 (11th Cir. 1998).

[162] 138 F.3d at 895. The court of appeals also affirmed that neither plaintiff's claim was moot, noting that Ms. Curtis' community placement had been unstable at times and therefore the case was capable of repetition yet evading review. *Id.*

As it had in the district court, the state contended that the plaintiffs had not been denied community placement because of their disability. The state argued that the ADA requires a comparison of its treatment of persons with disabilities as against that of persons without disabilities and that Ms. Curtis and Ms. Wilson had not shown that they had been denied community services that were available to persons without disabilities. In short, the state argued, "Title II of the ADA affords protection to individuals with disabilities who receive public services designed only for individuals with disabilities."[163]

The court rejected this argument summarily. First, the court reasoned that the state had to concede that the plaintiffs were confined at GRH-A because of their disabilities. Second, the court reasoned that the state had pointed to no legal authority that supported its reading of Title II; rather, the overwhelming authority in "the plain language of Title II of the ADA, its legislative history, the Attorney General's Title II regulations, and the Justice Department's consistent interpretation of those regulations" supported Ms. Curtis' and Ms. Wilson's position.[164]

The court of appeals considered first the proper interpretation of the regulations promulgated by the Attorney General to implement Title II of the ADA and noted that because Congress entrusted this task to the Attorney General and directed him to define the discrimination prohibited by Title II, the regulation must be "given controlling weight unless they are arbitrary, capricious, or manifestly contrary to the statute."[165] Not only does the regulation require that services be administered in the most integrated setting but also the Attorney General had consistently adopted the interpretation that the most integrated setting was one that "enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible,"

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[163] 138 F.3d at 896.

[164] *Id.*

[165] *Id., citing Chevron, U.S.A., Inc. v. NRDC, Inc.,* 467 U.S. 837, 844 (1984) and other authority.

both in the Appendix to the regulation itself and in the decision to "participat[e] in this and similar litigation."[166] Thus, the court held, institutional confinement of a person with disabilities who can live in the community violated "the core principle underlying the ADA's integration mandate" because the opportunity to interact with nondisabled persons is present in only limited circumstances in a state institution, such as GRH-A.

Having found that the district court had properly interpreted the regulation, the court of appeals then considered the validity of the regulation, that is, whether the integration regulation was "manifestly contrary" to the statute. The court found that it was fully consistent with the statute because, in enacting the ADA, Congress had directed the Attorney General to promulgate regulations consistent with the coordination regulations promulgated to implement Section 504 of the Rehabilitation Act of 1973,[167] which contain an integration mandate essentially identical to the language of 28 C.F.R. § 35.130(d). The 504 regulations require recipients of federal funds to "administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons."[168] In effect, the court of appeals held, Congress "ratified" and

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[166] 138 F.3d at 8897, *citing* 28 C.F.R. Appendix A at 478.

[167] The mandate to promulgate regulations consistent with Section 504, 29 U.S.C. § 794 is at 42 U.S.C. § 12134(b). The integration provision of the § 504 coordination regulation is at 28 C.F.R. § 41.51(d). The court of appeals noted that Congress made a considered choice to require consistency with the coordination regulations rather than other 504 regulations that appear to require a less demanding standard for including persons with disabilities in the most integrated setting.

[168] Congress also mandated that the Attorney General promulgate regulations that are consistent with other titles of the ADA, and the integration regulation of Title II is completely consistent with the provisions of Title III of the ADA, 42 U.S.C. § 12182(b)(1)(B), which requires places of public accommodation to provide goods and services to persons with disabilities "in the most integrated setting appropriate to the needs of the individual."

voiced its approval of the Section 504 coordination regulations, and this ratification was therefore binding on the court.[169]

Like the district court, the court of appeals held that the regulation's consistency with the statute was demonstrated by the plain language of the Congressional findings and by the ADA's legislative history. Both demonstrate that "Congress ought to eliminate the segregation of individuals with disabilities in passing the ADA."[170]

The court rejected the state's argument that the plaintiffs were not discriminated against "by reason of [their] disability" because they sought services that were not provided to persons without disabilities. "Underlying the ADA's prohibitions is the notion that individuals with disabilities must be accorded reasonable accommodations *not* offered to other persons in order to ensure that individuals with disabilities enjoy 'equality of opportunity, full participation, independent living, and economic self-sufficiency.'"[171] Thus, no showing of differential treatment is required.[172] Indeed, the court found that the state's "indifference to [the plaintiffs'] needs—manifested by their refusal to place them in the community while recognizing the propriety of such a placement—is exactly the kind of conduct that the ADA was designed to prevent." Plainly, the ADA was designed to eliminate discrimination against persons with disabilities that was "the product, not of invidious animus, but rather of thoughtlessness and indifference."[173] Having rejected all the state's arguments that the plain language of the integration regulation need not be followed, the court of appeals held that "[t]he State's failure to

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[169] 138 F.3d at 898.

[170] *Id.*, *citing* the legislative history extensively.

[171] 138 F.3d at 899, *quoting* 42 U.S.C. § 12101(a)(8).

[172] 138 F.3d at 900.

[173] 138 F.3d at 901.

place L.C. and E.W. in the community thus falls squarely within the ADA's ban on disability-based discrimination."[174]

Next, the court of appeals considered and rejected the state's argument that lack of funds is a nondiscriminatory reason not to provide services in the most integrated setting. This, the court said, would excuse noncompliance with the assertion that the state lacked the money to comply.[175]

The court of appeals limited its holding, however, by stating, in dicta, that where the "individual's treating professionals" did not find that a community-based program was appropriate, "nothing in the ADA requires the deinstitutionalization of the patient." The court gave no reason why the opinions of the treating professionals, who, in the case of a person confined in a state institution, would probably be state employees, should be conclusive. Of course, this principle had no application to Lois Curtis or Elaine Wilson because, as the court of appeals found when it upheld the district court's grant of summary judgment on this point, all the experts agreed unanimously that they belonged in the community.[176]

The court of appeals departed from the district court in its holding that although lack of funds is not a *nondiscriminatory reason* not to provide community services to a qualified person, lack of available funding might nevertheless provide a *defense* to the plaintiffs' ADA claims. The court found that the district court erred in failing to consider whether providing community services to Ms. Curtis and Ms. Wilson would require additional expenditures. The court of appeals held that the important consideration was not whether a community program would be more expensive than an institutional program, but whether the additional expenditures, if any, required to serve

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[174] *Id.*

[175] 138 F.3d at 902.

[176] 138 F.3d at 903.

the plaintiffs in the community and still pay its fixed overhead costs at the institution would "fundamentally alter the services [the state] provides."[177] Thus, while the district court looked at only the *comparative cost* of each individual's program in the community and the institution, the court of appeals looked at the *marginal cost* to the state of serving two additional persons in the community. The court of appeals also held that the court should consider the "demands" of the state's mental health budget and methods available to the state of reducing the burden to the state of the additional marginal cost, such as transferring funds from an institutional budget line to a community budget line. The court of appeals remanded the case to the district court to consider these factors.[178]

The state petitioned for certiorari, which was granted because of the importance of the issues in the case "to the states and affected individuals."[179] Shortly thereafter, the district court issued a decision concluding that the additional cost to the state of providing community services to the two plaintiffs was not unreasonable in relation to the state's overall mental health budget. The state also appealed that holding to the court of appeals.[180]

The Supreme Court affirmed that part of the Eleventh Circuit's decision holding that unnecessary segregation is a form of discrimination based on disability that is prohibited by the ADA. However, the Court rejected the court of appeals' interpretation of the state's "fundamental alteration" defense to a claim for community placement.

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[177] 138 F.3d at 905.

[178] *Id.*

[179] 527 U.S. at 596.

[180] 527 U.S. at 596 n. 7.

The majority opinion for the Court was delivered by Justice Ginsburg and joined by Justices O'Connor, Souter, and Breyer. Justice Stevens joined Parts I, II, and III-A of Justice Ginsburg's opinion, but did not join Part III-B, which sets forth the parameters for the fundamental alteration defense. Justice Kennedy concurred only in the judgment and wrote a separate opinion. Justices Thomas wrote a dissenting opinion that Justices Scalia and Rehnquist joined. In a part of her opinion joined by Justices O'Connor, Souter, and Breyer, but not by Justice Stevens, Justice Ginsburg wrote that the court must consider not merely the marginal cost of serving two additional persons in the community but also "the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably."[181] Because only four Justices signed that part of Justice Ginsburg's opinion that addresses the fundamental alteration defense, it is important to analyze the three concurring opinions to determine what, precisely, the Court held concerning that defense.

Part III-A of the opinion for the Court, joined by five Justices, examined whether "undue institutionalization qualifies as discrimination 'by reason of disability,'" and held that it did. The Court's analysis is similar to that of the Court of Appeals. First, the Court recognized that the Department of Justice consistently had advocated, as a litigant and amicus curiae in deinstitutionalization cases, that unnecessary institutionalization is discrimination within the meaning of the ADA and Section 504.[182] Although the Court did not find it necessary to accord the views of the Department of Justice the high degree of deference required by *Chevron v.*

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[181] 527 U.S. 597. Sections I and II of Justice Ginsburg's opinion summarize the history of the case and its statutory and regulatory context. The holding, joined by five Justices, arguably the only clear holding of the Court in *Olmstead v. L.C.,* is set forth in Section III-A.

[182] 527 U.S. at 598.

NRDC,[183] it found that it was appropriate to look to the views of the Department of Justice of "guidance."[184]

The Court next rejected the contention that "discrimination" requires "uneven treatment of similarly situated individuals," or that the plaintiffs' claims should be rejected because they had identified no "comparison class" of persons receiving differential treatment. In an important affirmation of Congress' intent, the Court stated, "We are satisfied that Congress had a more comprehensive view of the concept of discrimination advanced in the ADA."[185]

The Court recognized that the ADA was the culmination of a succession of Acts of Congress that were designed "to secure opportunities for people with developmental disabilities to enjoy the benefits of community living."[186] In the Congressional findings that accompanied the ADA, Congress "explicitly identified unjustified 'segregation' of persons with disabilities as a 'form of segregation.'"[187]

The Court noted, "Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments." One is that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community

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[183] *See supra,* n. 30 and accompanying text.

[184] 527 U.S. at 598.

[185] *Id.*

[186] 527 U.S. at 599.

[187] 527 U.S. at 600. The Court reconciled the divergent court opinions interpreting the integration language in the Section 504 regulations by noting that Section 504 "contains no express recognition that isolation or segregation of persons with disabilities is a form of discrimination."

life." The second is that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[188] In recognizing the Congressional judgment that unnecessary segregation is discrimination, the Court acknowledged Congress' authority to make that judgment—a judgment by which courts must abide—and, at the same time, affirmed its reasonableness and its grounding in everyday experience.

The Court next turned to the question of how individuals who are "qualified" for community living should be identified. The Court held that both state officials and courts "generally" may rely on "the reasonable assessments of its own professionals" when they determine that an individual "meets the essential eligibility requirements for a community program."[189] The Court was careful *not* to say, as the court of appeals had, that "nothing in the ADA requires" the state to place persons with disabilities in the community in cases in which the state's own professionals have not recommended community placement.[190] Plainly, the Court left open the possibility that the assessments of the state's professionals might not be "reasonable," that they might not make such assessments, and that assessments by state professionals are not the only way for courts to determine whether an institutionalized person can meet the essential eligibility requirements for community services.

The Court was equally careful in framing the issue of opposition to placement in the community. Noting that there is "no federal requirement that community-based treatment be imposed on

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[188] 527 U.S. at 600–601. The Court also noted that institutional residents with disabilities are treated differently from other persons in the sense that, to receive needed services, they must "relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice." 527 U.S. at 601.

[189] 527 U.S. at 602.

[190] *See supra,* n. 41 and accompanying text.

patients who do not desire it," the Court held that no genuine dispute existed about Lois Curtis' and Elaine Wilson's eligibility for community services because "the state's own professionals determined that community-based treatment would be appropriate" and "neither woman *opposed* such treatment."[191] The Court did not place the burden on the plaintiffs to affirmatively request community placement or show that she or an authorized representative, such as a guardian, had consented to it.

Part III-B of Justice Ginsburg's opinion, joined by four Justices, rejected the court of appeals' formulation of the fundamental alteration test as the reasonableness of the marginal cost of a handful of additional community placements measured against the state's entire mental health budget. Obviously, the marginal cost will be such a small fraction that "it is unlikely that a state ... could ever prevail" under that test. Justice Ginsburg[192] also rejected the cost-comparison test employed by the district court and expressed her concern that this would lead to overall increases in expenses without enabling the state "'to take advantage of the savings associated with the closure of institutions.'"[193] Rather, she stated, "Sensibly construed, the fundamental-alteration defense would 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."[194]

Justice Ginsburg then invoked the need to provide "a range of facilities," citing the need to provide a high level of support and supervision for those who need it to avoid improperly "dumping" persons with disabilities in homeless shelters and similar inappropriate settings.

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[191] 527 U.S. at 602–603 (emphasis added).

[192] Since this part of the opinion was not the opinion for the Court, it will be referred to as the opinion of Justice Ginsburg.

[193] 527 U.S. at 604, *quoting* Brief for the United States as *Amicus Curiae* at 21.

[194] 527 U.S. at 604 (emphasis added).

Justice Ginsburg suggested that states might need to maintain institutions for some persons. But she drew a remarkable conclusion from these assumptions:

> To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts 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 in less restrictive settings*, and a 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.[195]

This conclusion is remarkable because it seems based on recognition of the relationship between the rights and needs of individuals and the configuration of the state's service system as a whole. Although Justice Ginsburg characterizes her standard as more generous to the state than the court of appeals' standard, in fact, the opposite is probably true under the facts of most deinstitutionalization cases. The "marginal cost" calculation invoked by the court of appeals would tilt in favor of the state when the number of persons with disabilities seeking community placement is large. In contrast, Justice Ginsburg's standard would not require a "fundamental alteration" when large numbers of persons with disabilities are inappropriately placed in institutions. In a case in which the evidence shows that the entire population of a state institution could be relocated to the community where all institutional residents could receive better services at lower cost, it is difficult to see how the state could prove that community placement for all residents represented a "fundamental alteration."

Justice Stevens wrote separately to state his opinion that the court of appeals "appropriately remanded" to the district court for consideration of the state's fundamental alteration defense and that, therefore, the Supreme Court should simply affirm the court of appeals. He noted that the district court, on remand, rejected the state's fundamental alteration defense and stated that if the

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[195] 527 U.S. at 605–606 (emphasis added).

district court were wrong in its conclusion that the state had failed to make out such a defense, then that error should be corrected by the court of appeals or the Supreme Court in reviewing that decision.[196] Justice Stevens did not squarely address the meaning of "fundamental alteration" or the standard for determining when a change in configuration of the defendants' service system might constitute a reasonable modification.

Justice Kennedy also wrote separately and did not join any part of the opinion written by Justice Ginsburg. However, he would have remanded the case to the court of appeals or the district court "to determine in the first instance whether a statutory violation is sufficiently alleged and supported in [the] summary judgment materials and, if not, whether they should be given leave dissenters." Justice Kennedy would have held that discrimination requires "differential treatment vis-a-vis members of a different group on the basis of a statutorily described characteristic," yet he considered that such discrimination might be proved in this case by evidence showing that "a group of mentally disabled persons" unnecessarily receives "psychiatric or other medical services" in an institutional setting when persons with comparable medical problems receive similar services in an integrated setting. Like the court of appeals, he would have held the "comparative costs of treatment" ought not to be used as the standard for determining "undue burden," but did not go on to state a standard other than the view that "the State is entitled to wide discretion in adopting its own systems of cost analysis, and, if it chooses, to allocate health care resources based on fixed and overhead costs for whole institutions and programs."[197]

Justices Thomas, Rehnquist, and Scalia dissented on the ground that, in their view, "discrimination" could not encompass "disparate treatment among members of the *same* protected class."[198]

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[196] 527 U.S. 607, 607–608 (Stevens, J.).

[197] 527 U.S. 615.

[198] 527 U.S. 615, 616 (Thomas, J.) (emphasis in original).

Thus, while a clear majority of the Court held that unnecessary institutionalization of persons with disabilities represents discrimination and that unnecessarily institutionalized persons with disabilities have a right to community placement unless the state can show that community placement would represent an undue burden, only four members of the Court could agree on a single definition of "fundamental alteration." At least five members of the Court agreed, however, that states do not have discretion to keep persons with disabilities unnecessarily institutionalized for unreasonable lengths of time and that the state must at the very least maintain a waiting list that moves at a reasonable pace. The concluding statement of Justice Ginsburg's opinion seems to be a fair statement of the principles on which at least five Justices agreed:

> States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities.[199]

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[199] 547 U.S. at 607.

III.

Case Law Applying and Interpreting *Olmstead* and Other Post-*Olmstead* Case Law Concerning Rights to Community Services

1. Introduction: The Role of Disability Rights Advocates in Defining the Requirements for Effective *Olmstead* Implementation

In the plurality opinion in *Olmstead v. L.C.*, the existence of a "comprehensive, effectively working plan" that enables waiting lists for community services to move at a reasonable pace is framed as a defense to an ADA claim, not as an affirmative obligation on the part of the states. However, some disability rights advocates concluded after *Olmstead* was decided that a plan could have value both as an organizing tool and as a device to force states to commit to numerical targets, timelines, and allocation of resources.

One of the earliest responses to *Olmstead* came from then-HHS Secretary Donna Shalala in a speech on July 28, 1999, to the National Conference of State Legislatures. Secretary Shalala reminded the Conference that *Olmstead* requires states "to move at a reasonable pace to provide community-based alternatives" and that states can meet this obligation by having comprehensive plans. The Secretary offered HHS' support and technical assistance "[t]o build better systems of supports enabling people with disabilities to live life to the fullest."[200]

Just a few days before the Secretary's speech, at a conference in Bethesda, Maryland, advocates took the first steps toward operationalizing the *Olmstead* comprehensive planning requirement. The conference, titled "Personal Assistance Services: A New Millennium," was held on July 23–25, 1999, and cosponsored by United Cerebral Palsy, Independent Living Research

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[200] Remarks by Donna E. Shalala, HHS Secretary, National Conference of State Legislatures, Indianapolis, Indiana (July 28, 1999).

Utilization, the National Council on the Aging, ADAPT, and the World Institute on Disability. It brought together about 120 disability rights activists, leaders of advocacy organizations, and policymakers. A goal of the conference was to create a unified vision for personal assistance services across all disability constituencies and to develop action plans to expand and improve personal assistance services in the new millennium. The conference's Litigation Group focused its discussion on *Olmstead* implementation.[201]

The members of the Litigation Group concluded that every state should have a comprehensive implementation plan and advocates should not wait for HHS to require one. Energized by their success in persuading state governors and attorneys general to remove their states' names from an amicus brief in *Olmstead v. L.C.* in support of the state of Georgia,[202] the advocates affirmed that the organizing effort showed the value of setting deadlines and set July 26, 2000, as the date by which they expected states to have a plan in place. Conference participants agreed to go back to their own states, convene the key players (Independent Living Councils, Developmental Disabilities Councils, Protection and Advocacy agencies, self-advocacy groups, mental health consumer groups, nursing facility family and resident councils, volunteers, and ombudspersons), hold an initial meeting by September 1, 1999, and make contact with state Medicaid officials by October 1, 1999. The conference participants agreed that the National Association of Protection and Advocacy Systems (NAPAS) would draft an outline of the key elements of a state plan that would be disseminated widely among advocates around the nation.

Accordingly, in October 1999, NAPAS published a "Template of Key Elements Which Must be Considered When Developing a Comprehensive, Effectively Working State Plan For Moving

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[201] Research and Training Center on Personal Assistance Services, "Personal Assistance Services: A New Millennium," A Report on the Conference Held July 23–25, 1999.

[202] Center for an Accessible Society, "The Supreme Court Upholds ADA "Integration Mandate" in *Olmstead* Decision" (n.d.). http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm.

People Out of Institutions and Into Appropriate Community Settings.” Reasoning that a “comprehensive” plan must be one that addresses the need for community services of all persons who are unnecessarily institutionalized or at risk of institutionalization, NAPAS recommended the following:

- States’ planning for *Olmstead* implementation include all stakeholders.
- States should assess institutionalized persons’ need for community services.
- States should develop community services and improve the infrastructure of the community system.
- States should develop transition services.
- States should develop tracking systems to monitor individual progress.
- *Olmstead* implementation plans should contain measurable goals and time frames tied to resource allocation.
- Implementation plans should provide for quality assurance and resource development.[203]

Similarly, ADAPT integrated *Olmstead* implementation into its Campaign for Real Choice, a systematic advocacy effort to support passage of MiCASSA, and developed a checklist, similar to the NAPAS template, against which states’ *Olmstead* implementation efforts could be measured. The following were ADAPT’s conditions:

- The state should create a “Most Integrated Setting” committee to develop a community integration plan to implement the *Olmstead* decision. The committee majority should be people with disabilities and their family members and advocates.

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[203] NAPAS, Template of Key Elements (October 12, 1999).

- The community integration plan should include assurances that all individuals applying for support services will receive information on ALL home and community services options.
- A “reasonable pace” should be no longer than 90 days.
- States should contract with advocacy groups throughout the state to identify all individuals who want to get out of nursing homes and other institutions and (1) develop information on home and community options, and (2) go into the nursing homes and other institutions to inform people of their home and community service options.
- The plan should contain timetables for getting people out; expanding service capacity by increasing waivers, Personal Care option, or other programs; development of new services, such as Medicaid waivers and Personal Care option.
- The HCFA and OCR regional managers should ensure that *Olmstead* implementation will occur.[204]

Against these standards, advocates scrutinized their own states’ planning processes and found them woefully lacking.[205] In addition to advocating with officials in their own states, disability

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[204] ADAPT, Campaign for Real Choice, Most Integrated Setting, “ADAPT’s Response to Olmstead” (n.d.).

[205] For example, in September 1999, the Disability Policy Consortium, a coalition of disability organizations in Texas, attended the presentation of the Texas Health and Human Services Commission’s draft Plan to Expand Opportunities for Texans with Disabilities and almost immediately began to negotiate changes in the plan to conform to the requirements of *Olmstead.* The Consortium urged that the plan (1) include people with disabilities residing in *all* institutions, including nursing facilities, state hospitals, and public and private ICF/MR facilities; (2) prescribe meaningful identification procedures for people with disabilities in nursing homes and private ICF/MR facilities and modify, where necessary, the current identification practices in state schools and state hospitals; (3) contain clear timeframes for the community integration of people in nursing homes, state hospitals, and public and private ICF/MR facilities; (4) appoint people with disabilities, families of people with disabilities, and advocacy organizations to positions on an oversight committee whose role would be to ensure that people who want

rights advocates also urged state and federal officials to collaborate with the disability community to develop action plans to transition people from institutions to community living.[206]

2. The Federal Response: The HHS *Olmstead* Policy Letters

On January 14, 2000, as a result of extensive discussions and meetings among the Secretary of HHS, the Director of HHS OCR, and the disability community, HHS issued guidance on *Olmstead* implementation planning that was remarkably similar to the guidelines already established by disability rights advocates. The Secretary of HHS sent a letter to every state governor emphasizing the import of the *Olmstead* decision for persons with disabilities who are unnecessarily institutionalized. The letter encouraged the states to develop and implement "comprehensive, effectively working plans" as suggested by the Supreme Court to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs. On the same day, HHS wrote to state Medicaid directors encouraging them to work with state human service agencies to foster the integration of persons with disabilities into community life, promote equal opportunity, and maximize individual choice. The agency's guidelines had much in common with the guidelines previously developed by advocates.

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community services are identified and enabled to move from institution to community in accordance with specific timeframes, recommend service enhancement and expansion, identify barriers to community services and solutions, evaluate the integration implementation process, and develop recommendations for funding; and (5) recognize the role of people with disabilities in designing and choosing their own support services. Memorandum from Disability Policy Consortium to Don Gilbert, Commissioner (October 5, 1999).

[206] For example, on October 6, 1999, the Texas Disability Policy Consortium sponsored a conference on the implications of the *Olmstead* decision at which approximately 165 consumers, advocates, and state agency personnel discussed *Olmstead* implementation with Tom Perez, director of HHS OCR, and Ralph Rouse, regional manager, Region VI, HHS. *See also* Statewide Independent Living Councils (SILC) Congress Resolution #10 (January 6, 2000), calling on states to work with disability advocates to develop plans for transition to community living.

The HHS letter defined a "comprehensive, effectively working plan" in clear, operational terms. In developing such a plan, the state should consider—

- the extent to which existing programs can serve as a framework for developing services;
- the level of awareness and agreement among stakeholders and decisionmakers regarding the elements needed to create an effective system; and
- how this foundation can be strengthened.

A plan for providing services to persons with disabilities in more integrated community settings should—

- ensure that qualified persons with disabilities transition to the community;
- ensure that the transition moves at a reasonable pace; and
- identify improvements that can be made to support people with disabilities in the community.

The planning process must ensure that persons with disabilities—

- receive assessments to determine how community living might be possible;
- are assessed for their ability to benefit from community living without limiting consideration to what is currently available in the community; and
- are provided the opportunity for informed choice.

The plan should examine the adequacy of the state's current periodic reviews of institutional residents to determine whether they are—

- thorough;
- objective;
- conducted for residents of all institutional settings, including ICFs/MR, nursing facilities, psychiatric hospitals, and residential service facilities for children; and
- adequate to determine whether institutional residents can be served in a more integrated setting.

The plan should establish similar procedures for persons who may be at risk of unjustifiable institutionalization. In the plan development process, the state should—

- involve people with disabilities;
- employ methods that ensure constructive, ongoing involvement and dialogue; and
- establish partnerships with stakeholders to ensure that plans are comprehensive and work effectively.

To remedy unjustified institutionalization, the state needs—

- a reliable sense of how many people with disabilities are currently institutionalized and eligible for services in community-based settings;
- adequate information and data systems about institutionalization and eligibility; and
- a willingness to make improvements to data collection systems when necessary.

The state needs to look closely at existing assessment procedures and whether they are—

- adequate to identify institutionalized persons with disabilities who could benefit from services in a more integrated setting; and

- adequate to identify individuals in the community who are at risk of placement in an unnecessarily restrictive setting.

The plan should ensure that the state could respond to assessment findings in a manner that is timely and effective.

To ensure the availability of community-integrated services to persons who are unnecessarily institutionalized, the plan should—

- identify what community-based services are available in the state;
- assess the extent to which these programs are able to serve people with disabilities in the most integrated setting appropriate;
- identify the improvements that can be made in existing services;
- consider how the system might be made more comprehensive;
- evaluate whether the identified supports and services meet the needs of people who are likely to require assistance to live in the community; and
- identify the changes that could improve the availability, quality, and adequacy of the supports.

The plan should look at people who are at risk of unjustified institutionalization and—

- evaluate whether the system adequately plans for supporting people who live at home with family; and
- consider whether the plan is adequate to address the needs of people without family or other informal caregivers.

The plan should look at the real-world outcomes of supports and services and how they actually help integrate people with disabilities into the community.

The state should look at funding for the plan; specifically, it should—

- review the funding sources available under Medicaid and other sources to increase the availability of community-based services;
- consider what efforts are underway to coordinate access to these services; and
- assess the feasibility of organizing these funding sources into a coherent system of long-term care.

Planners should assess—

- how well the current system works;
- how it works for different groups (e.g., elders with disabilities or persons with physical disabilities, developmental disabilities, or HIV/AIDS); and
- the changes needed to make services in the most integrated setting a reality for all populations.

The plan should examine what can be done to ensure that people waiting for services—

- are able to move off waiting lists;
- receive needed community services; and
- receive needed services at a reasonable pace.

Plans should honor the principle of informed choice by—

- providing opportunities for informed choice;
- providing choices both to persons with disabilities and their representatives; and
- addressing the information, education, and referral systems needed to ensure informed choice.

Finally, the plan should address the infrastructure changes that may be needed to support implementation of the plan. Planners should—

- evaluate effective quality assurance systems for community services; and
- consider the planning, contracting, and management infrastructure that will enable placement in the most integrated setting to become the norm.[207]

Subsequently, HHS issued other policy clarifications to assist states in placing institutionalized Medicaid beneficiaries in more integrated settings. HHS' *Olmstead* Update No. 2, issued on July 25, 2000, answered a number of questions the agency had received from states and the disability community. In this memo, HHS affirmed its willingness to provide technical assistance to promise effective implementation of its policy of facilitating the provision of services in the most integrated setting and to provide federal financial participation to states to design and administer *Olmstead* plans. HHS announced that it was reviewing its own policies, programs, statutes, and regulations to "identify ways to enhance and improve the availability of community-based services." The memo clarified the role of *Olmstead* planning in resolving OCR complaints:

> Where States or other "respondents" (entities against which OCR has received complaints) engage in planning processes in good faith and at a reasonable pace, OCR may determine it is possible to allow plan development to proceed in lieu of investigation. Where a State or other respondent evinces no intent to undertake planning, or where delays in doing so evidence a lack of good faith, or where States or other respondents utterly fail to involve stakeholders in plan development, OCR may determine it necessary to commence a full-blown investigation. Following investigation, if a violation is found and no resolution is reached, cases may be referred to DOJ for litigation.[208]

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[207] HHS Letter to State Medicaid Directors, January 14, 2000.

[208] http://www.cms.hhs.gov/states/letters/snd72500.asp.

HHS clarified that in the context of a complaint investigation in which plan development seems an appropriate remedy, OCR "typically" would ask the state to demonstrate the pace at which services to persons with disabilities would be provided in the most integrated setting. HHS also clarified that *Olmstead* applies to all qualified individuals with a disability who are covered by the ADA, including elders and children with disabilities and persons with a history of substance abuse, and made clear that unjustified segregation would violate not only the ADA but also Section 504 of the Rehabilitation Act of 1973.

In *Olmstead* Update No. 3, issued on July 25, 2000, CMS issued a number of policy clarifications, most concerning Medicaid coverage of waiver services, including case management, environmental modifications, personal assistance, "nurse-delegated" services, and services provided out of state. CMS also clarified that the Medicare "homebound" requirement does not apply to Medicaid home health services.[209]

In *Olmstead* Update No. 4, issued on January 10, 2001, CMS clarified some of the boundaries of the state's obligations to provide services under the home- and community-based waiver and the relationship between the state's obligations under Medicaid and its obligations under the ADA and *Olmstead*. The agency's interpretations of the state's obligations under the waiver and its

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[209] HHS Letter to State Medicaid Directors, July 25, 2000. *See* Smith, et al., *Understanding Medicaid Home and Community Services: A Primer* (2000) at 54 (it is not necessary for Medicaid beneficiaries to meet the *Medicare* requirement of being homebound to receive home health services under *Medicaid*). Although Medicaid home health recipients need not be homebound to receive home health services, CMS regulations require that home health services be provided in the home. A federal appeals court has held that the HHS regulation limiting Medicaid coverage to home health care services provided at the recipient's place of residence is an unreasonable, arbitrary, and capricious interpretation of the statute establishing home health care as mandatory and affirmed a district court order permanently enjoining state and HHS officials from denying Medicaid funding to members of the plaintiffs' class for medically necessary home health nursing services outside their residences. *Skubel v. Fuoroli*, 113 F.3d 330 (2d Cir. 1997).

obligation to provide services with “reasonable promptness” have important implications for *Olmstead* implementation.

Update No. 4 clarified that whereas a state may set a limit on the number of persons who may receive services under a home- and community-based services waiver, this does not limit its obligation to serve people with disabilities in the most integrated setting nor to provide a safe harbor: “If other laws (e.g., ADA) require the State to serve more people, the State may do so using non-Medicaid funds or may request an increase in the number of people permitted under the HCBS [home- and community-based services] waiver.” States may request a waiver amendment to increase the number of persons served at any time. The amendment is usually retroactive to the first day of the waiver year in which the request was submitted.[210]

Update No. 4 clarified the relationship between the number of waiver slots requested and the program’s funding appropriation. CMS stated that it has allowed states to limit the number of people to be served to a number derived from the amount of money the legislature has made available and the corresponding federal match, but only if the application so informs the agency. The state must inform CMS of any limit on the number of persons served derived from a fiscal appropriation made subsequent to the submission of the waiver application.[211]

Update No. 4 clarified that once enrolled in the waiver, the person cannot be denied a needed service that is covered by the waiver, and states are not allowed to place a limit on the number of enrollees permitted access to different waiver services. Although CMS did not set guidelines in this letter for “reasonable promptness” in the provision of waiver services, the agency indicated

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[210] HHS Letter to State Medicaid Directors, January 10, 2001, [1] at 4–5.

[211] *Id.* at 5.

that, in its view, "reasonableness" would vary with the urgency of the person's need for the service at issue.[212]

The letter addressed the important question of how CMS will review states' limits on the amount, duration, and scope of waiver services. The agency stated that it would ask "whether the amount, duration and scope of all the services offered through the waiver (together with the State's Medicaid plan and other services available to waiver enrollees) is sufficient to achieve the purpose of the waiver as a community alternative to institutionalization." In sum, the "sufficiency" question may be answered only by "a three-way review" of the needs of the target group, the services available to that group under the Medicaid State plan and other relevant entitlement programs, and the type and extent of waiver services.[213] The message to states that CMS will examine the adequacy of waiver services to meet the needs of the proposed beneficiaries is a powerful one given the current propensity of some states to seek approval for multiple waivers, each with a different service mix and cost cap.

While acknowledging that states generally have discretion to amend a home- and community-based waiver to reduce the total number of persons who may be served under the waiver, CMS informed the states that it would take certain "special considerations" into account in reviewing a request for a waiver amendment. First, if the number of waiver eligibles is "a material item in any ongoing legal proceeding" or investigation, the state should notify CMS and the court (in the case of a pending lawsuit) and the HHS OCR (in the case of a civil rights investigation) of the state's request for a waiver amendment.[214] Second, the state must assure CMS that "the health,

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[212] *Id.* at 5–6.

[213] *Id.* at 7.

[214] Because the courts have held that persons with disabilities eligible for home- and community-based waiver services have an entitlement to those services up to the number of persons the state has applied to serve in the waiver, that limit, or "cap," will frequently be a "material item" in litigation. The requirement that states inform the court where such an action is

welfare *and rights* of all individuals already enrolled in the waiver" will be protected, including the right to live in the most integrated setting. The state can accomplish this by assuring HCFA that no one will be removed from the waiver or inappropriately institutionalized or that persons removed from the waiver program will receive community services through other programs.[215]

CMS clarified that states have some flexibility in defining targeting criteria as long as the waiver is limited to one of the three subgroups defined in the statute (aged or disabled, developmentally disabled, and mentally ill), thus encouraging states to broaden the populations served in their waivers.[216] Finally, CMS clarified that waiver services may not be used to deny or limit services that are available under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) children's health care program, a Medicaid entitlement.

Olmstead Update No. 5, also dated January 10, 2001, is an announcement of the system-change grants, described as additional tools to improve state long-term care systems "so as to fulfill the promise of the ADA."[217] The concept of system-change grants was borrowed from a provision in MiCASSA that would allow states to receive grants for Real Choice Systems Change Initiatives to help the states change the institutional focus of their long-term care systems and refocus those

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pending is taken from *Boulet v. Cellucci,* 107 F.Supp. 2d 61, 70 (D. Mass. 2000), where the defendants amended their waiver to lower the number of persons who could receive waiver services without notifying the court.

[215] *Id.* at 8 (emphasis added).

[216] *Id.* at 9.

[217] HHS Letter to State Medicaid Directors, January 10, 2001 [2] at 1.

systems on community services and supports.[218] The system-change grants have emerged as the Federal Government's most significant *Olmstead* implementation effort to date.

Three types of grants are available. The first type is the Real Choice Systems Change grants, which are designed to help states work in partnership with their disability and aging communities to enable people with disabilities or chronic illness to live "fuller, more self-directed lives." Fifty million dollars was available to the states under this program in 2001–2002.[219]

HHS also announced that it would allocate $12 to $15 million in Nursing Facility Transition grants and Access Housing grants to enable people of all ages who live in nursing homes to make a successful transition to community living. The agency has notified states that, to receive grant awards, state Medicaid agencies should work in partnership with state and local housing authorities to make full use of all applicable HUD programs that benefit low-income elderly individuals and those with disabilities.[220]

CMS also announced that it would award $5 million to $8 million in state infrastructure grants to help states develop or improve community-based attendant service systems that offer individuals

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[218] At the time *Olmstead* was decided, the disability rights movement was engaged in intensive advocacy for passage of the Medicaid Community Attendant Services and Supports Act (MiCASSA). An earlier version of MiCASSA was introduced in the 105th Congress but did not pass; in the 106th Congress, MiCASSA was introduced on November 16, 1999, as S. 1935. MiCASSA was reintroduced in the 107th Congress on August 1, 2001, as S. 2198.

[219] HHS Letter to State Medicaid Directors, January 10, 2001 [2] at 2.

[220] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 14. In a related initiative, the U.S. Department of Housing and Urban Development (HUD) announced that it would make up to 400 Section 8 vouchers available for use by eligible nonelderly individuals with a disability who make the transition from a nursing facility to the community. States may apply for both the state program grant and the Section 8 rent vouchers as part of a single application, or they may apply for just one of the two programs.

with disabilities maximum control. The goal of this program is to create systems that support self-determination for people with disabilities. Eligible activities, for example, will include training consumers to recruit and supervise personal care attendants and to understand their fiscal and legal responsibilities as employers.[221]

Thirty-seven states received grants during the first round of this initiative. Of the $70 million available for the program, about $64 million was allocated to grantees.[222] In 2002, another $55 million was made available.[223] Although the amounts allocated under the grants have been small, typically $2 million or less for Real Choice Systems Change grants and less than $1 million for the other grant categories, the grants are unique in requiring states to work directly with the disability community. CMS notified applicants that it expects "continuous and active involvement of consumers in project design, implementation, and evaluation."[224] Five grants were awarded to partnerships between states and Independent Living Centers to transition nursing facility residents to the community, and Centers for Independent Living (CILs) play a direct role in implementing other states' Nursing Facility Transition grants.[225]

In a letter to the governors of the states on August 12, 2002, HHS Secretary Tommy Thompson urged continued efforts to overcome the institutional bias in Medicaid programs. Secretary

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[221] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 14.

[222] CMS, "Systems Change Grants for Community Living," www.cms.hhs.gov/systemschange/.

[223] HHS, "Administration Announces Steps to Promote Community Living for People with Disabilities," News Release (May 25, 2002).

[224] HHS, "Overview of FY 2002 Systems Change Grants Award Process," http://www.cms.hhs.gov/systemschange/2002over.pdf.

[225] 67 Federal Register 20791 (April 26, 2002). *See* the state-by-state descriptions of the grant projects at www.hcbs.org.

Thompson noted that states already have many affordable community-based options for serving people with disabilities, and he pointed to a new Web site identifying promising practices.

"The President's New Freedom Initiative builds on our partnership to assure Medicaid-eligible individuals with disabilities are served in the most appropriate setting according to their own needs and preferences," Secretary Thompson wrote in his August 12, 2002, letter to the governors. "We believe there is a tremendous opportunity to serve people who meet nursing facility levels of care in their own homes or other community residential settings without increasing costs." Secretary Thompson noted that a number of states have already developed and implemented programs that serve individuals in community settings rather than institutions, including diversion programs to keep people in the community, transition programs to move individuals from institutional settings to community placements, and program models in which "the money follows the person" to ensure stability for beneficiaries living in the community.

On August 13, 2002, HHS wrote a letter to state Medicaid directors echoing Secretary Thompson's recommendations and noting a number of promising practices employed by the states that have facilitated the movement of institutional residents to the community and enhanced opportunities for community integration:

> [T]he Center for Medicaid and State Operations believes there is tremendous potential to serve people who meet nursing facility level of care in private homes or in community residential settings that would be more acceptable to the beneficiary, *without increasing costs to the states*.
>
> Many states have engaged in activities and developed programs that serve persons in the most appropriate community setting rather than in an institution. These programs and activities, *developed under existing authority*, have included diversion programs to maintain people in the community, transition programs to actively move individuals from institutional settings to alternative community

> placements, and program models in which the 'money follows the person' to assure stability of community living.[226]

In other words, HHS informed the states that by using existing federal funding sources appropriately, they could support nursing facility residents in the community without incurring additional costs. In a time of fiscal scarcity and draconian state budget cuts, the significance of this message cannot be overstated. Further, HHS affirmed the principle of "the money follows the person," so movement from institutions need not be contingent on the infusion of new funding sources.

The following are examples of the promising practices to which HHS drew the states' attention:

- The Colorado "Fast Track" program, which provides on-site assessment for waiver services and Medicaid eligibility determination within a hospital setting to divert hospital discharges from nursing facility placement.
- Texas's Rider 37, a state law providing that as individuals "relocate from nursing facilities to community care, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services."
- Florida's Long-Term Care Community Diversion Project, a pilot project in four counties, in which managed care organizations (MCOs) are paid a capitated rate to provide all Medicaid services, including both home- and community-based services and nursing facility services, to eligible elders so that the MCO has a strong incentive to reduce nursing home placements.
- New Jersey's Community Choice Initiative, in which 40 state employees are exclusively dedicated to informing nursing home residents and persons in hospitals awaiting nursing facility admission about home- and community-based services and housing alternatives.

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[226] HHS, Letter to State Medicaid Directors, August 13, 2002.

- Utah's program in which representatives from Area Agencies on Aging (AAAs) and CILs visit nursing facilities every six months to conduct on-site resident education about home- and community-based long-term care programs, conduct one-on-one follow-up interviews for interested residents, and, on request, perform needs assessments to determine if the person's needs could be met using available community resources.
- Vermont's new waiting list policy for home- and community-based services, which gives priority to nursing home residents, hospital patients awaiting nursing home placement, and people residing at home who are at great risk of institutionalization.
- Washington's post-eligibility treatment of income rules that allow Medicaid-supported nursing facility residents to use their own income for up to six months—up to 100 percent of the poverty level—to make rent, mortgage, utility, and other payments to maintain their home in the community. Nursing facility residents moving to the community can receive a one-time payment of up to $800 of state-only funds to pay for rent, security deposits, utilities, household goods, assistive technology, furniture, or home modifications.
- Wisconsin's state fund that enables people moving from nursing facilities to bypass county waiting lists.[227]

In the August 13 letter, HHS also informed the states that an evaluation was underway of the Real Choice Systems Change grants. In the meantime, however, the agency summarized some of the lessons learned from the states' experience with the grants:

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[227] *Id.*

- Staff who work with nursing facility residents to facilitate transition for them should be hired specifically for this purpose and should be highly dedicated to the challenge; people who have lived in institutional settings are especially effective.
- To establish a community residence for people leaving nursing facilities, flexible funding should be made available to be used for security deposits, utility setup, moving expenses, furnishings, and other necessary expenses.
- Nursing facility transition programs should be closely coordinated with community-based services programs.
- Transition program staff should work with public housing authorities and private landlords.
- Transition programs should implement aggressive outreach efforts to notify nursing facility residents of the opportunities for receiving assistance with moving back to community life.
- Nursing facility residents should take an active role in planning their own return to community life.[228]

HHS has made $50 million available to assist states to develop and improve home- and community-based services and planning for *Olmstead* implementation. Initial awards of $50,000 were made to all states and territories requesting one. These start-up funds will help pay for the planning and public-private partnerships and task forces to advise the states on how to increase services and supports to people with disabilities.

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[228] *Id.*

3. Other HHS Initiatives

(a) Office for Civil Rights

Since *Olmstead* was decided, OCR has investigated hundreds of complaints filed by persons with disabilities alleging that they are inappropriately institutionalized or at serious risk of institutionalization. An analysis of 334 complaints filed with OCR found that more than half—55 percent—were filed by persons with physical disabilities, 23 percent by persons with developmental disabilities, and 22 percent by persons with mental illnesses. (These categories overlapped because some complainants had more than one diagnosis.) In 44 cases, the complainants were of school age. Nursing facilities were the most common residential setting where complainants lived, accounting for 60 percent of all complaints. Another 30 percent of complaints were filed by residents of psychiatric institutions.[229]

OCR representatives have participated in the *Olmstead* advocacy training sponsored by HHS, CMS, and the Department of Education (ED); met with state officials to explain the legal basis for *Olmstead* planning and implementation; and provided significant technical assistance to the states, including assistance in *Olmstead* planning and application of HHS standards to state *Olmstead* plans.[230]

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[229] S. Rosenbaum et al., "An Analysis of *Olmstead* Complaints: Implications for Policy and Long-Term Planning" (Center for Health Care Strategies, Inc. Consumer Action Series Working Paper 2,5,6, December, 2001).

[230] Interview with Tony Records, October 6, 2002.

(b) Advocacy Training and Technical Assistance

In 2001, HHS, CMS, and ED funded a national conference of experts and a series of regional training conferences titled "Disability Advocacy in a Post-*Olmstead* Environment." The trainings were designed primarily to prepare disability rights advocates to advance implementation of the *Olmstead* decision within each state. Secondary audiences included legislators, governors' office representatives, and other state officials. The training was designed and delivered by Independent Living Research Utilization (ILRU) and the Brain Injury Association, Inc. (BIA), and training topics included the *Olmstead* decision, consumer direction, personal assistance services, Medicaid policy and practices, related state laws, *Olmstead* plans, related services and benefits, and exemplary programs and strategies for *Olmstead* implementation. Each state could send to the training up to eight participants who had to be nominated by disability leaders and demonstrate that they had the backing of a disability advocacy organization, such as a CIL. In the second year of the *Olmstead* project, the core group of participants trained in the first year will receive additional technical assistance and problem-solving support from experts to assist those participants in implementing the *Olmstead* decision in each state.[231] From the experience of *Olmstead* implementation at the state level, advocates who have participated in the *Olmstead* trainings clearly are well equipped to critique their states' planning efforts and propose constructive alternatives.[232]

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[231] U.S. Department of Education, *Self-Evaluation to Promote Community Living for People with Disabilities* (2002) at 3; Independent Living Resource Utilization, Olmstead Resources, http://www.ilru.org/olmstead/. The training curriculum is available at http://www.ilru.org/olmstead/publication/manual.htm. IRLU NetWork (March 2001).

[232] *See* Chapter VI of this report.

4. Substance Abuse and Mental Health Services Administration (SAMHSA) Initiatives

On December 14, 2000, SAMHSA's Center for Mental Health Services (CMHS) sponsored a meeting of 40 federal agencies, national mental advocacy organizations, consumer groups, and private sector companies to establish a National Coalition to be composed of representatives of the Departments of Labor, Health and Human Services, Housing and Urban Development, Education, Justice, Transportation, and Veterans Affairs; the Social Security Administration (SSA); and the President's Task Force on Employment of Adults with Disabilities, along with community leaders from dozens of national organizations, "to promote community-based care for persons with mental illness in accordance with *Olmstead v. L.C.*" The Coalition proposed to lead the development of similar coalitions at the state level that, in turn, would aid in the design and development of comprehensive community mental health service plans." CMHS committed $6.3 million to help develop the statewide coalitions, provide training, and support an *Olmstead* coordinator in each state.[233]

As of June 2001, 43 states had received grants of $20,000 to support state coalitions and *Olmstead* coordinators.[234] The National Coalition, now called the National and Statewide Coalitions to Promise Community-Based Care, provides technical assistance to state *Olmstead* Coalitions through a team of national consultants. The impact of the *Olmstead* Coalitions is

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[233] "National Coalition Formed to Promote Community-based Care for Persons With Mental Illness under Landmark Supreme Court Decision," http://www.samhsa.gov/news/newsreleases/001214Onrolmstead.htm.

[234] Home and Community-Based Services Resource Network, "A Compendium of Current Federal Initiatives in Response to the Olmstead Decision" (July 10, 2001) at 28. *See* Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001).

apparent at the state level, where several of the Coalitions have persuaded reluctant state governments to address *Olmstead* implementation in more meaningful form.[235]

SAMSHA is also conducting a $20 million study to determine the effectiveness of mental health service consumer-oriented programs as an adjunct to traditional mental health services.[236] Other SAMHSA activities include convening technical assistance conferences and meetings on employment of persons with psychiatric disabilities, involuntary treatment, and electro-convulsive therapy and establishing a CMHS National Advisory Council Subcommittee on Consumer/Survivor Issues.[237]

(a) Administration on Aging

In February 2001, the Administration on Aging launched a National Family Caregiver Support Program funded at $125 million. States can use this program to support elders who are not eligible for Medicaid.

5. Housing Initiatives

Without affordable and accessible housing, large numbers of persons with disabilities who are unnecessarily institutionalized will be unable to move to the community. Yet, unlike HHS, which began working with state Medicaid agencies shortly after *Olmstead* was decided to assist them in

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[235] *See* Chapter VI of this report.

[236] U.S. Department of Health and Human Services, “HHS Announces Efforts to Implement Community-Based Alternatives for Individuals With Disabilities,” News Release, June 19, 2001.

[237] Home and Community-Based Services Resource Network, “A Compendium of Current Federal Initiatives in Response to the Olmstead Decision” (July 10, 2001) at 28–29.

incorporating the integration mandate into their delivery of services to persons with disabilities, HUD has not played an active role in fostering *Olmstead* implementation.[238]

HUD did, however, launch two initiatives in 2001 to expand housing opportunities for persons with disabilities: the Section 8 Homeownership Voucher Pilot Program for Disabled Families[239] and the Project Access Demonstration.[240] As implemented by HUD, the Homeownership Voucher Pilot is targeted to persons with disabilities with incomes up to 99 percent of the median income in the area. To be eligible, a household must have an annual income of at least $10,000. Thus, the program targets persons with disabilities who have higher household incomes; the income requirements would have precluded the two plaintiffs in *Olmstead v. L.C.* from participating in this project. The impact of this promising practice is also limited by the fact that local public housing authorities (PHAs) are not required to participate nor to include persons with disabilities in the home ownership program.[241]

The second project, called Project Access, initially provided 400 rental vouchers in 11 states and a projected 2,000 at full implementation that are being distributed in collaboration with HHS to connect people moving from nursing facilities to the community with Medicaid-funded services. HUD provides rental vouchers and technical assistance, and HHS will use Nursing Home

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[238] *See* Technical Assistance Collaborative and Consortium for Citizens with Disabilities Housing Task Force, 12 OPENING DOORS (December, 2000) at 1–2.

[239] On December 27, 2000, the American Homeownership and Economic Opportunity Act of 2000 was enacted. This statute permits Section 8 voucher recipients with disabilities to use up to a year's worth of vouchers to finance the down payment on a home. Regulations were published in the Federal Register on June 22, 2001.

[240] U.S. Department of Housing and Urban Development, "President's Executive Order Launches Independent Living and Homeownership Program for Disabled," News Release (June 19, 2001).

[241] B. O'Day, *Issues in Rural Independence: Revisited* (2001) at 12.

Transition grants or other Medicaid funds to assist people moving from nursing facilities to the community. Some disability organizations were concerned that this program actually took resources from another program at HUD that was serving people with disabilities[242] and that it would "direct Section 8 vouchers to a number of settings that fly in the face of the inclusion mandate of the ADA, such as assisted living and residential 'facilities.'"[243]

6. The Work Incentives Improvement Act

Although not a direct response to *Olmstead*, the Work Incentives Improvement Act was enacted to overcome a barrier to community integration: the loss of public health benefits for Medicaid beneficiaries who wish to return to work. The Act provides that persons receiving SSDI and Medicare benefits who return to work can receive up to six additional years of Medicare benefits. States also have the option to amend their Title XIX state plans to offer Medicaid coverage to persons who, but for their income and resource levels, would be eligible to receive SSI. In return, the state may apply a sliding-scale premium for Medicaid-funded health care services. This should allow persons receiving Medicaid benefits to continue their general Medicaid coverage and to continue to receive whatever services they are receiving under a waiver program. States may also offer Medicaid coverage to individuals with a medically improved disability who lose Medicaid coverage because they no longer meet the definition of disability.

The Work Incentives Improvement Act provides a voucher from the Social Security Administration—called a "ticket to work"—that Medicaid beneficiaries can use to shop for a program from approved providers. Providers will be paid, not on a fee-for-service basis, but for documented outcomes for the person with disabilities. Providers also will be paid an incentive in

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[242] Andrew Sperling, Deputy Executive Director for Policy, National Alliance for the Mentally Ill, National Listening Session, PM testimony at 190–91.

[243] Consortium of Citizens with Disabilities (CCD) Housing Task Force, Non-Support Letter to HUD, February 19, 2001.

the form of a percentage of the federal benefits the person would have been paid, as long as the person they are serving maintains employment. However, providers will not be paid until the person leaves the Social Security rolls. Since the number of SSI and SSDI beneficiaries who find it possible to leave the rolls altogether is very small, providers of employment-related services may be reluctant to risk failure by serving persons with more significant disabilities.[244] State Vocational Rehabilitation (VR) agencies may participate in the Ticket to Work program as an employment network. If the VR agency is the designated employment network and has written agreements with providers in the network to provide vocational services, providers can at least be assured of payment for their services. However, VR participation is optional.

7. The Executive Order

During his presidential campaign, George W. Bush promised that if he were elected, he would issue an Executive Order committing his Administration to implementation of the *Olmstead* decision.[245] After his election, President Bush announced the New Freedom Initiative on February 1, 2000, and repeated his commitment to sign an order that *Olmstead* be fully implemented.[246] When the order had not been signed more than three months later, advocates held a demonstration in Washington, D.C., to press the point. Less than an hour after the demonstration began, some advocacy representatives were invited to meet with the director of the President's Domestic Policy Council and were informed that the Executive Order would be

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[244] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 21.

[245] George W. Bush, "New Freedom Initiative" (speech delivered in Portland, Maine, June 15, 2000).

[246] George W. Bush, "Remarks by the President in Announcement of New Freedom Initiative" (White House, February 1, 2001). The Initiative contains five components: increasing access to assistive technology and universal design technologies; expanding educational opportunities; promoting homeownership; integrating Americans with disabilities into the workforce; and promoting full access to community life.

completed and signed within 30 days. Accordingly, President Bush issued Executive Order No. 13217, “Community-Based Alternatives for Individuals with Disabilities,” on June 18, 2001. The Order asserted the Administration’s commitment to implementation of the integration imperative of the ADA as interpreted by the Supreme Court in *Olmstead v. L.C.*

The Order affirmed the commitment of the government of the United States to five fundamental principles concerning the right of persons with disabilities to live in the community:

1. Community-based alternatives for individuals with disabilities advance the best interests of Americans.

2. Community-based alternatives should foster independence and participation in the community for persons with disabilities.

3. Unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by Title II of the ADA and must be avoided by states unless doing so would fundamentally alter the nature of the service, program, or activity.

4. The Supreme Court in *Olmstead* construed the ADA to require states to place individuals with disabilities in community settings, rather than institutions, whenever treatment professionals determine that such treatment is appropriate, the affected individuals do not oppose community placement, and the state can reasonably accommodate the placement given the resources available to the state and the needs of others with disabilities.

5. The Federal Government must assist states and localities to implement swiftly the *Olmstead* decision to ensure all Americans have the opportunity to live close to

> their families and friends, to live more independently, to engage in productive employment, and to participate in community life.

The Executive Order requires federal agencies to promote community living for persons with disabilities by (1) providing coordinated technical assistance to states; (2) identifying specific barriers in federal law, regulation, policy, and practice that impede community participation; and (3) enforcing the rights of persons with disabilities. Specifically, the Order requires federal agencies to collaborate to ensure that the *Olmstead* mandate is implemented in a timely manner. Agencies that work with states are to help states assess their compliance with *Olmstead* and ensure that federal resources are used in the most effective manner to support the goals of the ADA.

The Order directs federal agencies to "evaluate the policies, programs, statutes, and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities." The purpose of the review is to identify affected populations, improve information about community support, and remove barriers to community placement. The review must include consumers, advocacy organizations, and service providers.

Finally, the Order directs the Attorney General and the Secretary of HHS to "fully enforce Title II of the ADA." The agencies are encouraged to work cooperatively with states and to use alternative dispute resolution procedures.

Following the Executive Order, the Administration carried out an extensive public comment process to assist the agencies in conducting their self-evaluations. The public comment process was led by HHS through the new Interagency Council on Community Living and launched in an open letter from Secretary of HHS Thompson to all interested parties inviting their input. The agencies gathered information from the public for their self-evaluations through written comments, a national teleconference held on August 15, 2001, a National Listening Session held on September 5, 2001, and studies and policy research. More than 800 individuals and organizations provided comment.

In HHS, Deputy Secretary Claude Allen convened a department-wide task force known as the New Freedom Initiative Group. Each of HHS' 17 component offices appointed a senior-level manager and a key staff person to the group. The Deputy Secretary then directed all HHS components to conduct separate self-evaluations. Each component was asked to look at its policies, programs, statutes, and regulations and respond to two questions:

1. Does any policy, program, statute, or regulation inhibit the ability of individuals with disabilities to live in the community?

2. Can any of these be revised or modified to improve the availability of community-based services for people with disabilities?[247]

The group met biweekly to review and analyze policies, program administration, laws, regulations, program guidance documents, data systems, research, budget and program planning documents, information about past and current component activities, contract documents, and human resource materials.[248]

On December 21, 2001, HHS issued a preliminary report on its own actions and those of the Departments of Labor, Education, Housing and Urban Development, Justice, Transportation, and Veterans Affairs; the Office of Personnel Management (OPM); and the Social Security Administration (SSA) to fulfill the mandate of the Executive Order. The preliminary report

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[247] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at A-51.

[248] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at A-51–52.

identified barriers to community integration and described the agencies' proposed solutions.[249] The agencies' final, more detailed reports were released on March 25, 2002.[250] The final reports contained few changes from the preliminary report.

8. Actions and Proposed Actions by Federal Agencies, as Reported in "Delivering on the Promise"

(a) Health Care Structure and Financing

The report acknowledged the institutional bias of the Medical Assistance Program, in which 73 percent of Medicaid long-term care funding goes to pay for institutional care and only 27 percent toward home- and community-based services. However, the principal action proposed to address this systemic barrier was the creation of a Medicaid Community Services Reform Task Force within HHS to advise on removing barriers to community integration. HHS did promise a "coordinated package of regulatory or potential legislative improvements" to reduce barriers to community living and institutional biases in the Title XIX program, but although the proposed changes would result in marginal improvement, they would not squarely address the disproportionate funding of institutional services by Medicaid. HHS proposed to do the following:

- Make home- and community-based waiver renewal less burdensome by removing the requirement that states seek renewal of a Section 1915(c) waiver unless CMS requests renewal because of performance problems.

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[249] U.S. Department of Health and Human Services, *Delivering on the Promise: Preliminary Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration* (December 21, 2001).

[250] U.S. Department of Health and Human Services, "Compilation of Individual Federal Agency Reports to Eliminate Barriers and Promote Community Integration," May 9, 2002, http://www.hhs.gov/newfreedom/final/.

- Clarify that one-time costs of transition to a community residence may be covered under a home- and community-based services waiver, including such costs as security deposits, initial furnishings, and utility and telephone setup fees and deposits. HHS also promised to allow Durable Medical Equipment, prosthetics, orthotics, and supplies to be furnished to skilled nursing facility residents prior to discharge.
- Clarify that the need for “active treatment” is distinct from level of care and not required to qualify for services under a home- and community-based mentally retarded/developmental disability services waiver.
- Allow states to tighten institutional eligibility for hospitals and ICFs/MR without simultaneously narrowing home- and community-based waiver services eligibility
- Allow states to restrict the disregard of income or resources to people who are eligible for home- and community-based waiver services without applying the disregard to an entire eligibility group, thus giving the state more flexibility in administering its Medicaid program.
- Provide guidance to the states to ensure continuity of health coverage for Medicaid-eligible persons in Institutions for Mental Diseases (IMDs) or correctional facilities to ensure that states do not let those persons’ Medicaid eligibility lapse merely because federal financial participation under Medicaid is not available in those facilities.[251]

HHS also promised to establish a time-limited advisory committee, the Medicaid Community Services Reform Task Force, to be composed of representatives of “all age and target groups within the disability community,” organizational representatives, and government associations to “advise CMS on other actions that may be advisable to remove barriers and promote community

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[251] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March, 2002) at III-25–26.

living." The role of the Task Force would be to consider improvements to state plan services; consider when family caregivers, spouses, and children would be cost-effective; improve coordination between state Title XIX agencies and other agencies; improve methods of contracting for services and service delivery to promote person-centered planning, peer mentoring, support coordination, individualized budgeting, and consumer direction of services. Not included in its charge was consideration of statutory changes that would remove the Title XIX institutional bias.[252]

To consumers of mental health services, HHS promised to "issue technical assistance and guidance to improve states' understanding of their existing options" under Medicaid waivers.[253] Of course, these options are limited to waiver services for children and adults older than 64 because younger adults cannot be served in the home- and community-based waiver. Nor did the report address the lack of Medicaid funding for home- and community-based long-term support for people with mental illness. In a 2001 report addressing barriers to community integration for persons with mental illness, SAMHSA had recommended establishing such an option,[254] but this recommendation was ignored.

On a subject of great concern to persons with significant disabilities for whom state Nurse Practice Acts are a barrier to receiving health-related services in the community, HHS promised to "work with states to advance methods" under which delegation of nursing tasks under Medicaid can be achieved, a commitment that stops short of removing the barrier itself.[255]

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[252] *Id.* at III-27–28.

[253] *Id.* at III-28.

[254] Bianco et al., *Overcoming Barriers to Community Integration for Persons with Mental Illness* (SAMHSA, 2001) at 32–33.

[255] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March, 2002) at III-29. Nurse Practice Acts

HHS promised to provide simplified model waivers to permit states to offer self-directed services and support for informal caregivers, and it also promised to seek authorization from Congress to conduct a 10-year demonstration of respite services for family caregivers.[256] On May 9, 2002, CMS released two template applications that states may use to simplify their requests for § 1115 demonstration waivers to provide consumer and family-directed services. Because CMS was already granting § 1115 applications for self-determination waivers, the templates do not create a new program or benefit but merely streamline the application process.[257]

HHS proposed a statutory change to create a state option enabling presumptive Medicaid eligibility for people determined to need a nursing facility or ICF/MR level of care who are being discharged from hospitals or other institutions to the community. Another statutory improvement would authorize a 10-year home- and community-based services demonstration as an alternative to Medicaid-funded psychiatric residential treatment centers for children.

HHS also promised to establish an Office on Disability and Community Integration. The agency proposed to develop a strategy for addressing quality-of-care issues in home- and community-based services that includes establishing defined expectations for home- and community-based services, assisting states to use results of HHS quality reviews of community placements,

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require that certain nursing tasks, such as catheter insertion or ventilator and tracheostomy management, be performed by a registered nurse, which significantly raises the cost of home- and community-based personal assistance services and reduces the number of people with disabilities who can be served under home- and community-based waivers. In states such as Kansas, in which Nurse Practice Acts have been amended to allow "delegation" of nursing tasks to personal assistants, people with significant health care needs are able to direct their own services in the community at a substantial savings to the state. Mary Johnson, "In Thrall to the Medical Model," *Ragged Edge* (January–February, 1999).

[256] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at III-35–36.

[257] HHS Letter to State Medicaid Directors, May 9, 2002.

providing technical assistance to states and HHS regional staff in effective systems design or quality improvement strategies, and implementing new quality assurance and improvement systems suited for in-home services.

HHS promised to review the discharge planning policies of institutions participating in Medicare and Medical Assistance to ensure that these institutions provide more effective discharge planning for adequate and appropriate community-based care.

HHS also promised that a plan to achieve appropriate community-based services for youth with special health care needs would be developed and implemented. The only increased funding for community services HHS promised was the initial $70 million in Systems Change grants for community living plus an additional $55 million to be allocated in FY 2002.

The HHS report acknowledged in written comments and at the National Listening Session, "Institutional bias in Medicaid was identified as a major barrier by HHS components and all stakeholder groups including state and local governments." Of the groups that commented, approximately 35 percent of the consumers, 45 percent of the providers, 52 percent of the advocacy organizations, and 75 percent of the governmental interests identified Medicaid structure and financing as a major barrier to community living.[258] HHS framed the solutions it proposed in the March 2002 report as measures to address the institutional bias of Medicaid. However, those recommendations plainly ignored the root cause of the institutional bias: the fact that participating states are *required* to provide nursing facility services and, for states that have opted into the ICF/MR program—as all the states have—institutional services for persons with developmental disabilities. The states are given broad discretion to design the home- and community-based services and personal care services they will provide, and indeed they have discretion as to whether to provide those services at all. HHS also did not propose to eliminate or

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[258] *Id.* at A-53–54.

reduce the differences in eligibility requirements for institutional and community services that create an incentive for institutionalization. In the report, the Administration did not commit to seeking the statutory change in Title XIX that will be necessary to remove these barriers. The closest it came was the weak promise that "CMS will work with states and other stakeholders to consider statutory changes to establish a state plan option for comprehensive HCBS."[259]

(b) Housing

The final report acknowledged that federal housing programs have many barriers to community integration of persons with disabilities including the following:

- Insufficient supply of affordable and accessible housing.
- The status of private housing providers as "contractors" rather than "recipients" of federal funds so they are not required to ensure the accessibility of their services.
- HUD 504 regulations on homeownership that are ignored by HUD offices because they refer only to programs that no longer exist.
- Lack of full use of the Federal Housing Administration's (FHA's) Title I and 203(k) programs to finance accessibility modifications because eligibility for these programs requires that rehabilitation costs be at least $5,000.
- Lack of flexibility within the Section 811 Supportive Housing program to develop more integrated housing with fewer supportive services.
- Unavailability of funds for move-in expenses, deposits, and household items for Section 8 voucher recipients.
- Absence of data collection requirements that would enable HUD's Office of Public and Indian Housing to know whether vouchers targeted for persons with disabilities under the Mainstream, Certain Developments, Designated Housing,

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[259] *Id.* at III-30.

and targeted Fair Share vouchers, in fact, have been issued to families with disabilities.

- Failure of some PHAs to request an adequate number of vouchers to meet the housing needs of nonelderly disabled families or to designate accessible units as "elderly only."
- Shortage of "visitable" units in public housing developments caused by lack of technical knowledge on the part of PHAs and their engineering and architectural consultants.
- Lack of enforcement of Section 504 and the Fair Housing Act of 1988 at the design review stage of construction of new public housing to ensure accessibility.[260]

Apart from a commitment to update the HUD Section 504 regulation and to require a standardized certification on construction drawings for federally funded public housing projects of the number and percentage of accessible units meeting Section 504 and Fair Housing Act requirements as well as a proposal to amend Section 811, the actions the federal agencies proposed to address these barriers consist primarily of information and technical assistance to PHAs and seem unlikely to result in a significant expansion of affordable housing.

The HUD report does not mention the Section 232 program, by which HUD guarantees loans to nursing facilities, assisted living facilities, and other congregate facilities. According to a report from ADAPT, HUD paid out $174 million in 2001 for defaulted loans to nursing facilities and $27.6 million to assisted living facilities, some very large in size. Rather than foreclose on the properties and sell them, HUD set up a workgroup with the American Health Care Association and other "stakeholders" to study the problem.[261]

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[260] U.S. Department of Housing and Urban Development, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at 7–14.

[261] ADAPT, "Another HUD Outrage: Over $200 Million Spent on Nursing Home Developers in 2001" (June 1, 2002). Nursing and assisted living facilities with a minimum of 20

To expand the use of Section 8 vouchers, HUD promised to provide technical assistance to local PHAs and "strongly encourage" them to consult with disability organizations. HUD also promised to issue notices to PHAs and to Community Development Block Grant (CDBG) grantees explaining the implications of the *Olmstead* decision. HUD promised to work with the Department of Justice (DOJ) on investigations and enforcement of developers' obligations under the accessibility provisions of the Fair Housing Act. (No private right of action exists under these provisions, and thus the United States is responsible for enforcing them.) Actions proposed by other federal agencies (the Departments of Labor, Education, Justice, and Health and Human Services) consisted primarily of interagency collaboration to identify strategies to increase access to housing by people with disabilities.

(c) Personal Assistance, Direct Care Services, and Community Workers

The reports acknowledged that very low pay and lack of benefits has caused the critical shortage of personal assistants and community care workers. The principal response, however, was the proposal of the Department of Labor (DOL) to develop a cross-agency/cross-department federal plan "to increase the availability and quality of personal assistants, and to identify options for the education, training and career advancement for personal assistants and other direct care staff and community service workers." DOL also promised to establish an online registry and to assess the impact on the availability of personal assistance services of the exemptions within the Fair Labor Standards Act's (FLSA's) minimum wage and overtime exemptions for companionship and live-in services.[262] Although an online registry and repeal of the companionship exemption in the

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beds are eligible under the Federal Housing Administration (FHA) Section 232 program for loans for new construction or substantial rehabilitation. Section 232 loans offer lower interest rates than conventional mortgages, and can include funds used to market the facility to prospective residents in the mortgage amount. "Securing FHA Loans," *Provider* (January 1998).

[262] U.S. Department of Labor, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at III-B.

FLSA will be helpful, these actions fall far short of addressing the extremely low pay of personal assistants, which is the acknowledged cause of the labor problem.

HHS promised to address workforce shortages by initiating a national demonstration to test the impact of better coordination with the Temporary Assistance for Needy Families (TANF) program and the availability of vouchers for workers to purchase affordable group health coverage. HHS also promised to make available to states a coherent body of information about methods to address worker shortage issues, research these issues, and collaborate with foundations, the private sector, the DOL, and other agencies to "formulate a comprehensive approach to the worker issue."[263] These actions, again, do not directly address the pay issue.

ED's Rehabilitation Services Administration (RSA) promised to explore how funds for personal assistance services could become more "consumer driven." Because the concept of consumer-driven personal assistance services has already been widely demonstrated and evaluated and is being funded with Medicaid dollars, this exploration seems unlikely to result in change.

(d) Caregiver and Family Support

HHS promised to provide states with a simplified model waiver form for caregiver support and to seek authority to conduct a national respite care demonstrations for caregivers of adults and children.[264]

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[263] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at III-33–34.

[264] *Id.* at III-38.

(e) Transportation

The Department of Transportation (DOT) promised to renew its FY 2002 budget request, which was not funded, for $145 million to establish two grant programs to promote innovative transportation solutions for people with disabilities. These programs would fund community-based organizations, nonprofits, and transportation providers to expand transportation options. DOT also stated that it is considering a number of proposed regulations to enhance the accessibility of aircraft and the safety standards for motor vehicles.[265]

DOT and several other federal agencies (DOL, ED, DOJ, and HHS) promised to collaborate with other agencies to encourage integration of transportation and other services. DOT promised to revitalize the joint DOT/HHS Council on Access and Mobility,[266] and DOJ promised to look for opportunities to participate as an amicus curiae in private lawsuits concerning accessible transportation.

(f) Employment

DOL acknowledged the "urgent need to increase the availability of customized employment" (i.e., supported employment) to enable people with significant disabilities to work. To that end, DOL promised to initiate an Olmstead Community Employment Initiative, a coordinated strategy to "ensure that all DOL policies and activities fully address the employment and training needs of people with disabilities who are at risk of institutionalization" or are moving from institutions to the community. DOL also promised to award Olmstead Community Employment Planning and Implementation grants to states that include an employment focus for people with disabilities in

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[265] U.S. Department of Transportation, Self-Evaluation to Promote Community Living for People with Disabilities (March 2002) at 31.

[266] *Id.* at 36–38.

their *Olmstead* state plans and activities and that coordinate “employment and related supports” at the state and local level. The grantees will be consortia of nonprofit advocacy or service agencies and Local Workforce Investment Boards; their activities will focus on increased capacity, coordination, and feedback to DOL on effective *Olmstead* implementation strategies. However, the administration requested only $8.3 million to fund these grants in FY 2002. The FY 2002 budget also proposes an additional $6 million to expand the Customized Employment Grant initiative from seven to 17 sites. These amounts are minuscule in comparison with the funding for traditional VR services.[267]

Additional DOL activities promised in the preliminary and final reports included research and demonstration of promising practices to increase employment and successful transition from school to work, the convening of a Youth Advisory Committee, training and technical assistance, and expansion of grants to enable Local Workforce Investment Boards to systematically review their policies. DOL promised to develop and implement an action plan to promote self-employment and small business development among people with disabilities, including those who wish to return to their communities from institutions.[268]

The RSA of ED promised assistance and coordination to help state VR agencies improve transition from school to work. RSA also promised to enforce actively the VR regulation that eliminates extended evaluation as a final employment outcome and to ensure that an employment outcome is counted only for a person with a disability who is working in an integrated setting in the community. However, fundamental reform of the VR program to address the barriers it presents to persons with significant disabilities who seek employment were not addressed.

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[267] U.S. Department of Labor, Self-Evaluation to Promote Community Living for People with Disabilities (March 2002) at III-8–13.

[268] *Id.* at III-14–23.

HHS promised to work with other federal agencies to develop strategies on employment issues. OPM proposed to disseminate information about hiring, retaining, and working with persons with disabilities and to facilitate "telework." OPM also proposed to revise its guidelines to make it easier for persons with disabilities to apply for federal employment.

The Social Security Administration (SSA), the agency responsible for implementing the Ticket to Work and Self-Sufficiency Program, promised aggressive implementation of that program. SSA also promised to expand its corps of employment support representatives specially trained to both assist SSDI and SSI beneficiaries to work and conduct research and demonstration projects to encourage employment of persons receiving SSDI and SSI.

(g) Veterans

The Department of Veterans Affairs (VA) promised to consider expanding its authority to pay for assisted living or board and care home services after the evaluation of a pilot program authorized by P.L. 106-117 for VA-paid assisted living. Currently, this is the only exception to the statutory rule that allows VA to pay only for nursing facility services. VA also promised to require its outpatient clinics to submit plans for the provision of mental health services. At present, some clinics do not offer basic mental health services. VA also promised to evaluate and consider expanding its adult day care, homemaker, and health aide program and to reduce its backlog of more than 661,000 claims.

(h) Education

ED and DOL made several commitments designed to improve educational outcomes for students and adults with disabilities by disseminating information, providing technical assistance and training, and enforcing transition planning requirements. Of greatest relevance to *Olmstead* implementation is the commitment of the ED to consider amendment of the provision of the Carl

D. Perkins Vocational and Technical Education Act that allows vocational education funds to support state institutions for persons with disabilities.

(i) Access to Technology

DOL, ED, and HHS all promised to take steps to improve the availability, affordability, and accessibility of technology to people with disabilities. Except for DOL's commitment to expand its DisabilityDirect.gov Web site to provide employment information, the agencies' promises had little specificity beyond a commitment to plan.

(j) Accountability and Legal Compliance

DOJ, ED, DOL, HHS, and HUD all committed to increased enforcement, monitoring, and review of the implementation of federal legal mandates that protect persons with disabilities, including the ADA and, specifically, *Olmstead*-related claims, the Fair Housing Act, the Civil Rights of Institutionalized Persons Act (CRIPA), the Vocational Rehabilitation Act, and the Workforce Investment Act. The agencies also committed to provide technical assistance and information dissemination to enhance implementation of these federal statutes.

(k) Public Awareness, Outreach, and Partnerships

DOJ, ED, DOL, HHS, and HUD committed to conduct public awareness campaigns, education, training, outreach, and listening sessions and to develop informational materials, public service announcements, and improved lines of communication with people with disabilities all for the purpose of enhancing awareness of the rights of persons with disabilities, in particular, the rights articulated in the *Olmstead* decision. Of note is HHS's commitment to establish a Disability Advisory Committee that includes all the constituencies described in Executive Order 13217 to review and advise HHS on the implementation of solutions to the problem of unnecessary institutionalization and to provide information and advice to HHS on community integration issues.[269]

(l) Income Supports

The SSA committed to provide enhanced training to SSA staff, disability examiners, and administrative law judges in *Olmstead*-related issues.

(m) Gathering, Assessment, and Use of Data

DOJ, ED, DOL, HHS, and HUD made numerous commitments to collect data on the unmet needs of persons with disabilities, on efforts to meet those needs, on compliance with federal requirements, on promising practices, and on use of federal programs designed to assist persons with disabilities.

(n) Cross-Agency Collaboration and Coordination

Finally, DOJ, ED, DOL, HHS, and HUD made commitments to collaborate in workgroups and other partnerships to enhance access to housing, employment, and transportation. Of note was HHS's proposal that the Interagency Council on Community Living convened by Secretary Thompson in July 2001 be authorized permanently and that the Council develop a strategic interagency plan to expand and promote home- and community-based services and to address housing, workers with disabilities, the long-term care workforce, assistance technology, transportation, and education.

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[269] U.S. Department of Health and Human Services, *Self-Evaluation to Promote Community Living for People with Disabilities* (March 2002) at III-41.

9. Conclusion

A comparison of the barriers to community integration identified by people with disabilities in Chapter II with the actions proposed by federal agencies in "Delivering on the Promise" shows that major barriers, including the institutional bias of Medicaid funding, the severe shortage of affordable housing, and the low wages of personal assistants and direct support staff, will scarcely be affected by the proposed actions of the federal agencies. Whereas many of the actions proposed by the agencies will be helpful to people with disabilities and to states seeking to implement the *Olmstead* mandate, most of these activities seem likely to have only a marginal impact on service systems for people with disabilities. In many cases, the agencies' proposed actions consisted of further demonstration of consumer-directed approaches to services whose efficacy has already been quite thoroughly demonstrated.

In early 2003, the Bush Administration announced a five-year program beginning in 2004—the "Money Follows the Individual" Rebalancing Demonstration—to enable people with disabilities to move from institutions to the community. The program would provide for one-year 100 percent federal funding for home- and community-based waiver services 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 Administration will seek $350 million to fund the program in 2004, with $1.75 in proposed funding over a five-year period[270].

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[270] U.S. Department of Health and Human Services, "President Will Propose $1.75 Billion Program to Help Transition Americans with Disabilities from Institutions to Community Living," News Release (January 23, 2003).

IV.

The States' Response to *Olmstead v. L.C.*

This chapter summarizes the states' overall progress in responding to *Olmstead v. L.C.* by analyzing the following on a state-by-state basis: the planning process; the progress the state has made in community integration since *Olmstead v. L.C.* was decided; and state "systems change" activities, that is, efforts to redesign the state service systems to enhance choice, independence, self-determination, and community integration. Collectively, these activities are indicators of the states' overall compliance with *Olmstead*. More extensive information on the states' experiences in the planning and implementation of the *Olmstead* decision is available in the electronic version of this report that is online at www.ncd.gov.

Alabama is drafting an *Olmstead* plan, and the state has agreed to extend to nursing facility residents and those at risk of institutionalization the assessment procedures developed in a 2000 settlement agreement in the long-running *Wyatt* litigation. However, neither the planning process nor Alabama's systems change grants address the most significant barrier in the state's long-term care system—the state's failure to make more than modest use of federal funding opportunities for community services.

Alaska has not formed an *Olmstead* planning group. Although the state's institutional populations are small, the state has not responded to *Olmstead* by reducing institutional populations; indeed, the trend is in the opposite direction.

Arizona is moving toward becoming an institution-free state. The vast majority—94 percent—of the state's developmental disability long-term care funds are dedicated to home- and community-based waiver services. Lack of providers and services in rural areas and lack of specialized providers even in urban areas are the most significant barriers to community integration.

Arizona's ratio of nursing facility beds to total population also is low, about half the national average. Lack of affordable, accessible housing is a significant barrier to moving out of a nursing facility; Maricopa County reports a two- to three-year wait for Section 8 housing.

Arizona uses a wide variety of Medicaid options to serve persons with mental illness, including COBRA case management, the clinic option, the rehabilitation option, and the personal care option. The rate of long-term institutionalization in psychiatric hospitals is relatively low.

Arizona's *Olmstead* plan was released on August 27, 2001, and authored by the state Medicaid agency, the Department of Health Services, and the Department of Economic Security. The plan cites *Olmstead* planning as the state's initiative. Each of the three agencies produced a draft in its own area; the state then sought comments on the plan and, to that end, convened four regional stakeholder meetings in August 2000.

While the Arizona plan identifies some systemic barriers to community integration, it also has deficiencies. It lacks timelines, outcome benchmarks, or analysis of underlying problems. It does not commit to any specific plan for assessing nursing facility residents. It does not attend to the needs to expand housing and transportation services, a striking omission because both are major barriers to community integration.

Because the plan lacks timelines or targets and focuses on marginal improvements in the community service system, it is not surprising that state officials report that their efforts to implement the plan are on target.

Arkansas released a draft plan on October 14, 2002. It contains no timelines or numerical targets. Its only provision relevant to deinstitutionalization is to interview a random sample of about 300 persons living in Arkansas' nursing facilities and ICFs/MR to identify individuals who would prefer to live in the community. These persons will then be referred to entities that can help them transition. The results of the survey will be used to determine whether a statistically significant percentage of institutional residents would choose to live in the community and whether an assessment of all institutional residents for their desire to move would be "cost-effective." This process will drastically limit the number of persons who will have opportunities to move to the community, especially from the Human Development Centers (the developmental disabilities institutions) and is inconsistent with *Olmstead's* mandate to identify *all* persons who can handle and benefit from community placement, not simply those who can express an affirmative desire to do so.

Although **California** represented to the National Council of State Legislatures in 2001 that its Long Term Care Council was serving as an *Olmstead* task force, the state, in fact, did not begin to develop an *Olmstead* plan until a cross-disability *Olmstead* coalition used pressure from litigation and from the legislature to force the state to begin planning in earnest. The state is now working on an *Olmstead* plan.

In **Colorado**, four state agencies are developing their own *Olmstead* plans, which are to be combined into a single plan.

Connecticut's *Olmstead* planning process grew out of a long-term care planning process established by the legislature, housed in the state Medicaid agency, and intended to focus on the needs of elders. After the *Olmstead* decision came down, the agency broadened the planning committee by adding an advisory group, the Community Options Task Force, which included representatives of a broad spectrum of disability groups. The role of the Task Force was to provide advice to the long-term care planning committee and help develop an *Olmstead* plan. In 2002, the long-term care planning committee published a document titled "Choices are for Everyone." Funding for numerical targets and the many ambitious proposals to remove barriers to community integration suggested by members of the Community Options Task Force are not reflected in the plan because the Long Term Care Planning Committee refused to set measurable goals for community integration. Accordingly, the Community Options Task Force produced a Supplementary Report of its own that it presented to the governor.

Delaware's governor issued an executive order in May 2000 directing the state human services agency to develop an *Olmstead* plan. A change in administration derailed the plan, but advocates bypassed the administration in July 2002 by persuading the legislature to create a commission by House Resolution to assess and make recommendations on community-based alternatives for persons with disabilities. The state agency issued a hastily thrown-together document in October 2002, proposing to place a small number of residents of the state's developmental disabilities institution in the community, but lacking any placement goals or estimates of the number of persons with disabilities or elders who could leave institutions for the community. In March 2003, the legislative Commission issued a report criticizing the dearth of community services in the state.

The **District of Columbia** does not have an *Olmstead* plan.

Although **Florida's** institutional populations are large, they are around the national average measured on a per capita basis. The state maintains a large capacity of expensive psychiatric hospital beds. In the past 10 years, nursing home bed capacity has expanded significantly, whereas community services have not developed as extensively.

Florida has not developed a formal *Olmstead* plan. Although Governor Jeb Bush has made expansion of community developmental disability services a priority, by early 2002 the waiting list of developmental disability services had grown to nearly 6,000 persons. In July 2002, a state-organized coalition of officials and advocates, the Real Choices Coalition, published the Real Choices Partnership Work Plan for streamlining access to home- and community-based waivers and reviewing the progress of waiting lists. The document does not specify when a report will be completed or whether state agencies will be obligated to follow its recommendations.

Georgia has been engaged in *Olmstead* planning since 1999, and its Planning Committee issued a Final Report and Recommendations in November 2001. However, the planning process is continuing. The Planning Committee set four goals: (1) transitioning people from institutions to the community; (2) diverting people presenting in the community from institutions; (3) building system and provider capacity; and (4) gaining commitment from the state to provide the resources needed to implement the plan. The plan is remarkably faithful to *Olmstead*; for example, the Planning Committee has recommended that the "universe" of people potential appropriate for community services be identified and that persons living in institutions receive one-on-one education and outreach from people who have been institutionalized themselves.

In **Hawaii**, an *Olmstead* planning process was established by resolution of the state legislature and resulted in a five-year strategic plan to enhance services and support for people with developmental disabilities. The plan was also intended to respond to *Makin v. Cayetano*, a lawsuit on behalf of persons with developmental disabilities waiting for services. The plan does not address other populations.

Idaho is developing a plan to enhance its community service system but has not set a target date for plan completion.

Illinois is a heavily institutional state, ranking higher than all but five other states in its rate of institutionalization of persons with developmental disabilities in public and private facilities. For all persons with disabilities, nursing facilities are a major source of treatment and care; nearly three times as many persons live in nursing facilities as receive services under the home- and community-based waiver, and twice as many people with developmental disabilities live in ICFs/MR as live in home- and community-based programs. The state's Medicaid expenditures are heavily slanted toward institutional spending, and Illinois is one of the lowest-ranking states in the nation in Medicaid spending for home- and community-based services. Illinois also spends a significant amount of state funds that could be matched with federal reimbursement, but the state has declined to request that.

The initiative for *Olmstead* planning in Illinois began with enactment of HR 765 by the state legislature. The Act directed the Illinois Department of Human Services to ensure that services are provided in the most integrated setting. HHS established a Steering Committee of 224 stakeholders in six working groups. The Committee released a report in December 2000, emphasizing it was not a "comprehensive, effectively working plan" but merely the first step in the process.

The Steering Committee report, though comprehensive and thoughtful, is missing a commitment from the state. The Financing Work Group documented underuse of waiver slots and recommended expansion of Illinois' seven waiver programs, removal of such barriers as financial eligibility requirements that limit participation, and assessment of people waiting for services. Other workgroups recommended increasing consumer choice of services, pursuing funding alternatives to promote integrated housing, removing institutional bias from state funding and payment systems, ensuring that money follows the individual and that transitional services are available for people who want to leave institutions, and pursuing best practices, such as self-determination and cash and counseling.

Using the Steering Committee report as a guide, Illinois released its "Community Living and Disabilities Plan" in April 2002, containing submissions from the state agencies responsible for disability services, housing, and Medicaid. The plan is not a plan but merely a defense of existing policies and practices. It contains no analysis of Illinois' compliance with *Olmstead* or of the actions that would be needed to achieve compliance. It is devoid of plans to reduce unnecessary institutionalization and proposes only about 200 community placements for the coming year, including emergency placements. Rather than analyze the need for additional community services, the Illinois plan defines the need in terms of the state's level of effort. It is not responsive to the Steering Committee recommendations and does not acknowledge the barriers to community integration identified by the Steering Committee.

Indiana published the first edition of an *Olmstead* plan on June 1, 2001, articulating six progressive policy directives but providing extremely modest targets for reducing institutional populations. The plan contains no provision for assessing institutional residents. Reaction in public meetings around the state was highly critical of the plan. However, the Governor's Commission on Home- and Community-Based Services, appointed in July 2002, has made an exemplary effort to identify urgent needs for systemic change that can be addressed in the short term with little fiscal impact. In December 2002, the Commission published sixteen short-term recommendations addressing systemic barriers that in many state *Olmstead* planning efforts would simply be identified for further study and analysis. The Commission's effort to prioritize activities that could begin immediately and at little short-term cost is exemplary and should serve as a model for other states.

Iowa's *Olmstead* plan, published in July 2001, commits the state to a relatively small number of significant initiatives that have the potential significantly to restructure the state's service delivery systems: "Money Follows the Person," "No Discrimination Because of Severity of Disability," "Home Health Services Designed to Support Independence," and "Support the Use of Paraprofessionals to Provide Comprehensive Personal Attendant Services."

Kansas does not have an *Olmstead* planning process. However, in 2000, two state agencies formed a cooperative project with ADAPT, called "Operation Escape," in which ADAPT would design a program (with state agency approval) of information and referral. Members of ADAPT would go into facilities to provide information about services, assistance with moving out, advocacy, and follow-up. Thus far, the state's planning efforts have not determined how many people are unnecessarily institutionalized nor set measurable targets for community placement.

Kentucky's final *Olmstead* plan was published on December 11, 2002. It contains goals designed to ensure that people with disabilities are evaluated and determined eligible to receive services in the most integrated setting. The plan states that "Individuals with disabilities currently living in institutional settings who desire community services and for who[m] the treatment team has concluded that community placement is appropriate will be identified and plans will be developed as soon as is practicable and funds are available." The qualification that the person must "desire" community services and that transition plans will not be developed until "funds are available" are inconsistent with *Olmstead.*

In **Louisiana**, state officials originally had chosen not to develop an *Olmstead* plan. However, the advocacy of a cross-disability coalition called LaPOP and a meeting with representatives of the Office of Civil Rights attended by about 25 representatives of the disability community caused them to reconsider. As a result of LaPOP's advocacy, legislation was passed in 2001 establishing the Disability Services and Supports System Planning; however, no formal plan has been produced.

Maine's *Olmstead* planning process has been unusually broad and inclusive. In response to the first CMS letter, Commissioner Concannon of the Maine Department of Human Services, with the approval of the governor, invited several other state commissioners to develop a common response to the *Olmstead* decision. The workgroup was charged with answering the question, "How do we eliminate altogether the unnecessary institutionalization of persons with disabilities (in both state and private institutions)?" The group has made recommendations. Although they are not final, it appears that the workgroup has essentially put off to another day its original goal to identify "the number of waiting lists, the number of people on each list, what services they need in order to move to a less restrictive setting and a schedule for when those needs will be met."

In **Maryland**, former Governor Glendening issued an executive order on July 25, 2002, creating a Community Access Steering Committee (CASC) charged with developing "a comprehensive plan to expand community access opportunities for a broad spectrum of individuals with disabilities." A year later, the CASC issued recommendations to the governor. Shortly thereafter, a broad coalition of disability organizations published a response to the CASC report. The coalition charged, "The report does not move a single person nearer to freedom than they were prior to July 25, 2000, when the Governor issued his Executive Order." The governor's 2003 budget requested funding for only a handful of the CASC's recommendations. Maryland's new governor, Bob Ehrlich, has promised a radically different approach. A bill requiring that money follow the person has been introduced in the state legislature and passed the House in March 2003.

In **Massachusetts**, after advocates for elders and persons with disabilities charged that the state was doing little or nothing to respond to *Olmstead*, the governor established an *Olmstead* Advisory Group and directed that an *Olmstead* plan be developed by an interagency Steering Committee and an Interagency Leadership Team composed of the secretaries or commissioners of several departments. On July 31, 2002, the first phase of the *Olmstead* plan, called Enhancing Community Based Services, was released. The document is basically a "plan to plan," although it does outline steps that are logical and consistent with the HHS guidelines. For example, the plan calls for an inventory of people in institutions, to identify everyone who is in an institution or at risk of institutional placement and to determine how many people would like to leave the institution or could leave if they had adequate support and if funds could be redirected toward their support. The next phase of the planning process is to develop a budget proposal for the coming fiscal year.

Michigan is one of the most advanced of the large states in community integration. Apart from the large number of persons with developmental disabilities in nursing facilities, nearly every person in the state with developmental disabilities receiving out-of-home care is served in a community-based setting. However, Michigan's spending on nursing facility services is substantial, and the number of nursing facility beds per 1,000 people in the state significantly exceeds the national average.

Michigan has not developed a formal *Olmstead* plan. In June 2000 the Department of Community Health issued a report titled "Long Term Care Innovations: Challenges and Solutions." The workgroup that produced the plan consisted of state officials; no one from the disability community participated. The report does not purport to be an *Olmstead* plan, but it does reference *Olmstead,* and some of its recommendations are relevant to *Olmstead* compliance, for example, its endorsement of person-centered planning, community integration, and measures to improve recruitment and retention of direct care staff. However, the recommendations are fairly general and nonspecific.

Although **Minnesota** is not developing an *Olmstead* plan designated as such, the Department of Human Services produced a report to the Minnesota legislature in February 2002 that addressed several *Olmstead* themes, though only in the context of services for elders. The report, "Keeping the Vision: Report to the Minnesota Legislature, Progress in Reshaping Long-Term Care in Minnesota," was a response to long-term care legislation enacted in 2001, the purpose of which was to reduce the state's reliance on institutional services and expand the availability of home- and community-based options.

Mississippi's service systems are characterized by a heavy institutional bias and low level of fiscal effort for community services. In developmental disabilities, Mississippi ranks 47th in the nation in community fiscal effort and 50th in the nation in its use of the home- and community-based waiver. Between 1990 and 2000, the number of persons with developmental disabilities living in congregate settings actually increased by almost 30 percent. Community services rely heavily on large, state-operated group homes. Mental health services are also heavily institutional and coercive. Prior to development of the state's *Olmstead* plan, Mississippi offered few services for elders and persons with physical disabilities other than nursing facility care, and spending per elderly beneficiary for long-term care was the lowest in the nation. People waiting for services under the Aged and Disabled waiver are placed on waiting lists simply to be evaluated. In the five years prior to *Olmstead* plan development, Medicaid expenditures on nursing facilities rose by 42 percent and Medicaid home care expenditures declined by 22 percent. Unlike most states in which housing is the biggest barrier to community integration, Mississippi stakeholders view lack of transportation as the major barrier.

In June 2000, the governor appointed the Division of Medicaid as the lead agency for *Olmstead* planning with the participation of other state agencies. Eventually, consumers and other stakeholders were invited to join the discussions under the rubric of a coalition called Mississippi Access to Care. The stakeholder group was relatively inclusive, although elders were underrepresented.

The coalition collected data for the planning effort by distributing a statewide survey to identify needs and services available and by holding a series of public meetings. Although advocates did not regard the input process as particularly effective, it was used to develop common themes—consumer education, database development, housing, population identification, simplification and standardization, transition, and transportation—that formed the basis for workgroups to develop the plan.

In March 2001, the legislature formalized the planning process by enacting legislation that mandates the development of a comprehensive plan. The act requires that the plan include an estimate of the number of people who need services, the appropriations that will be necessary to provide these services, and a goal that the state will have community services available to all persons with disabilities for whom those services are required.

The plan was submitted to the state legislature in September 2001. A unique feature of the plan, and the reason it is widely considered an exemplar for other states, is that implementation of each planning goal is costed out over a 10-year period so that the plan can be incorporated into budgets and legislative appropriations. The plan also includes numerical targets for increasing the number of persons served in the community, although it is impossible to tell whether the increase would meet the demand for home- and community-based services among persons who are institutionalized. The plan combines goals for the creation of community services with goals for meeting the state's obligations under a variety of federal statutes that have only a tangential relationship to *Olmstead.*

As of March 2003, the Mississippi plan has not been implemented. Nonimplementation is attributed to shortfalls in the state Medicaid budget. However, even the provisions in the plan that would not require additional funding, such as the single point-of-entry requirement, are not being implemented.

The plan does not identify cost savings that could be achieved by reducing institutionalization, nor does it call for redirecting funds from nursing facilities. Advocates have called the document a "bricks and mortar" plan—a plan to build new facilities. It contains no requirement that people who could handle and benefit from community living be identified, let alone that they be able to move to the community at a reasonable pace. The planning group was unable to reach consensus on the changes in assessments of institutional residents that would need to occur to achieve compliance with *Olmstead*. Rather than a goal of identifying all institutional residents who could handle and benefit from community living, the plan proposes only to "advise" nursing facility residents of the availability of community services. The needs of persons with mental illness are virtually unaddressed in the plan. The plan does contain promising strategies for increasing the supply of accessible, affordable housing, for example, training case managers in housing facilitation and adding home modifications to the menu of waiver services.

In May 2002, the Mississippi Coalition of Disabilities filed a lawsuit, *Billy A. v. Lewis-Payton,* on behalf of persons segregated in nursing facilities who could be living in the community if they had adequate support. That this lawsuit was necessary shows that even an *Olmstead* plan that is widely regarded as "the best of the best" cannot succeed in the absence of resolve on the part of the state to ensure that waiting lists do in fact move at a reasonable pace.

Missouri's *Olmstead* plan is widely regarded as a model. The plan describes existing programs, participants, and existing funding; discusses and makes recommendations concerning development of outcome assessment tools; identifies the number of institutionalized people with disabilities in the state; and identifies the number of waiting lists for services, identifies the number of people on them, and analyzes the pace at which the lists move. It examines whether the available information on community services is adequate for people to make informed choices. The plan recommends changes in Missouri's service system in seven areas: consumer-directed personal care assistance, housing, interagency coordination, Medicaid services, funding mechanisms, transportation, and employment opportunities for people with disabilities. Specific recommendations include increasing availability of personal care assistant services and increasing their wages and increasing funding for accessible, affordable housing. The plan contains timelines for various actions and agencies responsible for those actions during fiscal years 2001 and 2002. However, in some respects, the plan fell short of recommendations made by advocates, including the proposal that by December 1, 2000, assessments would be completed and the state would have a list of the names and locations of persons who want to move to the community and the specific types of support, in hours and funding sources, they need to live in the community. The final plan does not require that institutional residents who could move from institutions actually be identified and provided with opportunities to move.

In response to *Olmstead*, the **Montana** Department of Public Health and Human Services has issued two task force reports, one from the Senior and Long Term Care Division, the other from the Disability Services Division. The former plan has a goal to "increase availability of all community services" and an objective of developing a legislative proposal to increase funding for community services, but it sets no goals and contains no specific proposal for increased funding. The Disability Services Division's Biennial Work Place for 2001–2003 calls for developing up to three new community residential homes to allow 12 persons to move from Montana's developmental disabilities institutions. The plan suggests that more than 12 persons have been recommended for community placement but acknowledges that the state agency "does not have adequate appropriations from the 2001 Legislature by which to initiate an expansion of community service opportunities."

Nebraska does not have an *Olmstead* planning process or task force.

During the 1990s, **Nevada** was the fastest-growing state in the nation, yet spent relatively little on disability services. Out-of-home placement rates are low, and a significant number of nursing home and ICF/MR residents are in out-of-state placements.

Nevada's *Olmstead* planning process began with a legislative mandate enacted in July 2001, followed by public hearings on how the plan should be developed. Compared with *Olmstead* planning committees in other states, Nevada's contained few state officials. Instead, Nevada relied heavily on expert national consultants.

The *Nevada Strategic Plan for People with Disabilities* is comprehensive and paints an in-depth, if bleak, analysis of Nevada's current compliance with *Olmstead*. The plan finds that Nevada has undercounted the number of people waiting for services and that more and more people are exiting special education that will need services. To avoid unnecessary institutionalization, the plan recommends setting neutral assessment, allowing money to follow the person, and ensuring that any Medicaid-funded nursing facility resident be eligible for state-funded community services.

New Hampshire was the first state in the nation, in 1991, to close its state developmental disabilities institution, and it has continued to make progress toward community integration since that time. The self-determination model pioneered by Monadnock Developmental Services has been adopted statewide, giving consumers control—with the assistance of circles of support and fiscal intermediaries—of the Medicaid dollars that fund their services. The number of nursing facility residents is slowly decreasing, but the state is still well above average in the number of nursing facility residents as a percentage of all persons age 65 and older.

New Hampshire has assertively applied for federal grant programs to transition nursing facility residents to the community. At the same time, however, by restricting the cost of home-based care to one-third the average cost of home-based care and by requiring separate budget line-items for nursing facility and home-based care, a state law enacted in 1998 presents significant barriers to nursing facility residents who wish to move to the community.

New Hampshire does not have a formal *Olmstead* planning process. Legislation enacted in 2002 established a legislative committee to review community services for elders and persons with disabilities.

The impetus for **New Jersey's** *Olmstead* planning process came from New Jersey Protection and Advocacy, Inc., which convened an ADA coalition composed of 90 organizations and developed a set of principles for an *Olmstead* plan. The coalition persuaded Governor Whitman and the New Jersey Department of Human Services (DHS) to convene an *Olmstead* Stakeholder's Task Force in November 2000. However, the plan drafted by DHS does not include the action steps proposed by the Coalition for identifying institutionalized persons who would like to live in the community, the costs associated with institutional living, the services that currently exist, and the recommended changes, nor does the plan contain measurable outcomes, target dates, or provisions for monitoring and quality assurance. Predating *Olmstead*, DHS conducted another planning effort, Redirection II, to improve mental health services both in institutions and the community. As a result of independent assessments, the planning group concluded that 388 persons could be receiving services and support in alternative settings and that the hospital beds currently being used to house these persons could eventually be taken off-line. Unfortunately, however, the plan contemplates that at least some of the 388 persons would move to nursing facilities, residential health care facilities, and group homes. Redirection II was not coordinated with development of the *Olmstead* plan, although it does contain many elements of an *Olmstead* plan.

In **New Mexico**, the state senate requested that the state Department of Health and the Human Services Department develop an *Olmstead* plan and recommended that the state's plan include assessing people who are at risk of institutionalization and addressing systemic and infrastructure barriers to community living, including the personal care attendant and nursing aide shortage and the lack of accessible, affordable community-based housing. In the next legislative session, the state senate again passed a resolution that a task force be created under the direction of the Governor's Committee on the Concerns of the Handicapped to develop a comprehensive, coordinated state plan in response to *Olmstead* and to report its findings to the Legislative Finance Committee in October 2002. In response, the Department of Health and the Human Services Department held an *Olmstead* meeting where, according to advocates, they simply stated what they were doing. In June 2002, an official of the Long Term Care Division of the New Mexico Department of Health reported that the Department had decided that it "has no *Olmstead* exposure because the DOH was far ahead of *Olmstead* with respect to community-based care" yet acknowledged that the state does not have adequate community services for persons with chronic mental illness.

New York has radically reduced the number of persons with developmental disabilities living in state institutions, but this has not always been matched by the development of community services. The number of nursing facility beds has grown steadily, and the number of persons with developmental disabilities housed in nursing facilities has grown significantly since 1996. Large group homes are so common that only 39 percent of people with developmental disabilities live in homes of six or under, and the number of people waiting for services is large. On the other hand, New York has a large and well-resourced personal care program compared with those of other states, and New York leads the nation in drawing down the most Medicaid dollars as a percentage of its total community spending. But it has not fully addressed the scarcity of accessible, affordable housing.

New York has not yet developed an *Olmstead* plan, although in September 2002, the governor signed into law a bill to establish a Most Integrated Setting Program. The act requires the Department of Health to identify nursing facility residents who could live in a “most integrated setting” and calls for a coordinating council composed, in part, of people with disabilities. The bill was introduced in February 2001 but was not passed by the legislature until June 2002, when hundreds of advocates from ADAPT orchestrated a sit-in to bring the bill out of committee and to a vote. Even then, it took three more months and another sit-in before it was signed into law. The act has not been implemented, and the governor has introduced a bill that would weaken the Most Integrated Setting legislation by weakening the role of the coordinating counsel, the data collection requirements, and the implementation mandates.

North Carolina began to develop its *Olmstead* plan in 2000. Concurrently, the state engaged in another planning process. The core of the state’s draft *Olmstead* plan is a process for identifying current institutional residents for potential community placement. Once identified, an individualized plan will be developed for each individual. Unfortunately, the process for identifying institutional residents for community placement in the North Carolina plan is thoroughly inconsistent with *Olmstead* and with North Carolina’s own extensive experience with implementation of a pre-*Olmstead* class action suit, *Thomas S. v. Flaherty*, because the plan provides that assessment for transition will occur only *after* the person has expressed a preference for community placement.

In **North Dakota**, after HHS issued its first letter to state Medicaid directors, the director of the Department of Human Services appointed an internal workgroup to review the *Olmstead* decision and recommend further action. People with disabilities were not included but formed their own workgroup. The internal workgroup issued a White Paper that was intended not as a plan but as a set of recommendations for further action. In August 2001, the governor issued an executive order establishing an *Olmstead* commission to develop a plan to include representatives of the disability groups that had asked to participate; however, only three advocates actually were appointed. In 2002, the Commission held focus groups sessions around the state.

Ohio's plan is widely regarded as a model for other states. Planning began in June 2000, when Governor Taft instructed his Office of Budget and Management to coordinate a review of state service systems with other state agencies. The resulting plan was published on February 28, 2001. It addresses most of the components of *Olmstead* planning recommended by HHS. Despite its strengths, however, the plan does not address the pace of transition from institutions to community living or off waiting lists, does not set timelines for movement, and does not look at the adequacy of the state's current system of assessing institutional residents.

In **Oklahoma**, in February 2000, the Oklahoma Health Care Authority (OHCA) began a series of public meetings and workgroup meetings to obtain stakeholders' views of the service delivery system and identify where "reasonable modifications" to existing programs were needed and could be made. Following the first two *Olmstead* public meetings, an *Olmstead* Work Group began meeting monthly at OHCA. The Summary Report of the Working Group, even in its fourth draft, is little more than a "plan to plan." It became clear to the consumers and advocates in the workgroup that the planning process had progressed as far as it could go without a much more substantial commitment from the state. Advocates next obtained a legislative mandate for *Olmstead* planning, which became law in May 2002, and planning began again. Legislation authorizes planning to continue until 2005, with annual reports on the planning group's progress.

In **Oregon**, the strongest impetus for *Olmstead* planning came from mental health advocates, and the resulting plan—the Oregon *Olmstead* Workgroup's report—although limited to a small number of mental health consumers, is a model *Olmstead* plan in many significant respects. It identifies with specificity the people recommended for placement and the services they will need in the community, examines the adequacy of the discharge process, considers the adequacy of existing services and the changes needed to make those services responsive to the needs of consumers, and projects the costs that will be associated with transition.

In **Pennsylvania**, 16 advocacy organizations joined in a letter of March 21, 2000, to the Secretary of Public Welfare urging her to develop and implement an *Olmstead* plan to provide effective community-based services to people remaining in state developmental disabilities institutions; to continue planning for community mental illness services with additional input from consumers and family members; and to convene a nursing facility planning process with significant, diverse consumer involvement. The signatories were an unusually broad coalition of disability and elders' organizations. The advocates convened a meeting in April 2000 to discuss how the process for developing community services for nursing facility residents should proceed. However, the request was ignored, and no *Olmstead* planning has occurred.

Rhode Island does not have a comprehensive *Olmstead* planning process, although it did obtain a grant from SAMHSA to develop a plan to move children with mental illness to less restrictive settings. The planning process was carried out by a consumer organization, the Parent Support Network of Rhode Island, under contract with the state Department of Children, Youth and Families (DCYF). Although DCYF has not issued the plan, an intergovernmental task force chaired by two legislators—the Ideal System of Care Committee—published a plan in April 2002 to reform children's services more generally over the next five years.

In **South Carolina**, Governor Hodges issued an executive order in November 2000 establishing the South Carolina Home and Community-Based Services Task Force and charging it with developing a comprehensive, effectively working plan for compliance with *Olmstead.* The Task Force was to conduct a review of all services available to people with "physical, mental or developmental disabilities" in South Carolina, analyze their availability and efficacy, identify affected populations, improve the flow of information about support services in the community, and remove barriers that impeded community inclusion. The Task Force was to ensure the involvement of consumers, families, providers, and advocates and submit a report to the governor with specific recommendations for improvements in services and a timeline for implementation. A Task Force of 33 members issued a report in August 2001. Although the report lists the home- and community-based services available to people with disabilities in South Carolina and the numbers of persons waiting for services (but only for those services that maintained waiting lists), it does not really analyze the extent to which those services could be used to get people out of institutions. The plan commits the state to the principles of choice and self-determination, autonomy and consumer direction, flexibility, cultural sensitivity, empowerment, community integration, and access to activities and resources available to all. The plan sets a goal that all persons living in institutions who have indicated their desire to do so move to a community setting. Of course, this alone is insufficient. The plan recommends an independent assessment process but does not specify the number of residents who could move to other settings.

South Dakota is not conducting any *Olmstead*-related activities.

Tennessee does not have a formal *Olmstead* plan. The Tennessee *Olmstead* Coalition, a broad-based advocacy coalition has outlined the necessary components of a plan, organized planning workgroups and developed a comprehensive set of tasks needed to complete the plan. The Coalition has done an excellent job of organizing community support for *Olmstead* planning. However, the Coalition's efforts have not been supported by the state, and without a working relationship with the state agencies with access to data or authority to collect it, it has been virtually impossible for the Coalition to collect the data needed to meet its own ambitious planning goals.

Texas has traditionally been a heavily institutional state and one characterized by low levels of Medicaid use and, in particular, low levels of family and in-home support. In 2000, it ranked 48th in the nation in the percentage of persons with developmental disabilities in community residential settings. Persons with physical disabilities fare somewhat better. Whereas more than 87,000 people lived in nursing facilities in Texas in 2000, an equal number received services in Texas's community-based personal care program.

The Texas *Olmstead* plan, *Promoting Independence,* arose from an executive order by then-Governor George W. Bush, directing the Texas Health and Human Services Commission to conduct a comprehensive review of all services to people with disabilities and remove barriers that impeded opportunities for community living. The Texas legislature then passed a bill requiring the development of a comprehensive, effectively working plan consistent with *Olmstead.* The planning group is an interagency task force that includes six advocates as well as eight representatives of state agencies.

The two *Promoting Independence* plans are refreshingly free of platitudes about choice and independence. Instead, most Texas initiatives involve an examination of state funding mechanisms and how they can be modified to encourage community placement.

Two initiatives make Texas unique in *Olmstead* planning. The first, Rider 37, is a modification to Texas's method of funding nursing facilities. It allows the general revenue used to purchase nursing facility services to follow the individual into the community and purchase community services. A parallel initiative, Rider 7, allows the state to establish procedures for controlling the number of Medicaid beds and for the de-certification of unused Medicaid beds. These initiatives alleviate the concern expressed by the Supreme Court in *Olmstead* that states may have to maintain expensive institutional facilities while simultaneously paying to transfer people to the community.

Another unique aspect of Texas' plan is that in includes children in foster care under the rubric of *Olmstead* planning on the ground that "the most integrated setting" for children is a permanent family.

In **Utah**, the *Olmstead* planning process emerged in response to pressure from advocates. It was housed in the Governor's Office of Planning and Budget, the Department of Health, and the Department of Human Services with participation by other agencies (notably, contributions by housing and transportation agencies are not reflected in the plan). The plan, issued on March 26, 2002, addresses services for elders, adults with disabilities, children placed outside their home, people with mental illness, people with developmental disabilities, and youth in corrections facilities.

The most obvious gaps in the Utah plan are its failure to include a census of institutions, to spell out the pace of movement from institutions to community, or to address waiting lists for community services. The plan does not contain measurable goals, timelines, and a list of concrete action steps. Rather, it describes generally the activities the state needs to undertake or continue to improve its service system, for example, "integrate self-determination concepts into the long-term care system." The plan contains no timelines for assessments.

In **Vermont**, a bill was signed into law in June 2002, establishing an *Olmstead* advisory commission in the Agency on Human Services on specifying the Commission's membership. The Commission is to submit a status report on January 1 of each year to the governor and the legislature.

Virginia is one of the last states to begin an *Olmstead* planning process. The state legislature mandated an *Olmstead* Task Force in the 2002 Appropriations Act; the group is to submit its final recommendations to the governor, the chair of the House Appropriations and Senate Finance Committees, and the chair of the Joint Commission on Health Care by August 31, 2003.

The Task Force is organized by disability populations, with a lead agency assigned to each, who will develop population-specific reports and Issues Teams, which will examine broad issues that cut across populations. An impressive range of population groups were proposed, including adults with mental illness; children with emotional disturbance; people with mental retardation; people suffering from substance abuse; people with Alzheimer's/dementia, autism, physical disabilities, developmental disabilities, HIV/AIDS, and brain injuries; and people who are deaf, hard of hearing, or blind. On the basis of stakeholders' identification of cross-cutting issues, seven Issues Teams were organized in the areas of accountability; educating the public, consumers, and families; employment; qualified providers; housing; prevention and transition services; and waivers. By October 2002, when the Task Force chair reported to the House Appropriations Committee on the status of the planning project, 14 state agencies were participating or providing resources to the Task Force, including the Departments of Aging, Health, Housing and Community Development, Medical Assistance, Rehabilitative Services, and the Housing Development Authority. Of note is that representatives of the Office of Civil Rights (OCR) of HHS attended the first meeting of the Task Force and presented OCR's understanding of the elements of a comprehensive *Olmstead* plan.

Washington falls squarely in the middle range of the states in rates of institutionalization and community integration. Unlike most states, however, it maintains a larger Adults with Disabilities waiver program for people with physical disabilities than its mentally retarded/developmentally disabled waiver. Still, Washington ranks 16th among the states in the percentage of citizens with developmental disabilities who are supported in settings of six or fewer persons, and its supported living program exceeds those of most states in size and expenditures. Its rate of institutionalization, including placement in nursing facilities, of persons with developmental disabilities is about average.

During the 1990s, Washington bucked the national trend by decreasing the number of nursing facility beds by about 4 percent. The move to more cost-effective community-based alternatives accelerated after 1994, when voters enacted Initiative 601, which limited annual growth of state expenditures to the combined rate of population growth and inflation. The state responded with a concerted effort to divert and relocate nursing facility residents with annual reduction targets for nursing facility caseloads. Case managers are assigned to specific facilities, assess residents within seven days of their entering a nursing facility, and decide whether the person should be an "active relocation client." Case managers also have a flexible pot of money available from fine monies levied against nursing facilities in a Civil Penalty Fund. Washington is considered a leader among the states in using consumer-directed care.

The state maintains three psychiatric hospitals and has no plans to close them. Washington finances its community mental health services, the Integrated Community Mental Health Program, through a full carve-out, stand-alone mental health and substance abuse Section 1915(b) waiver combined with Title XX block grant and state funds. Fourteen county-based Regional Service Networks (RSNs) serve as Prepaid Health Plans and contract with Community Mental Health Centers for service delivery. The RSNs are designated by state statute as the single point of entry for service delivery. Wide disparity in service existed among the RSNs.

To address lack of coordination between the services delivered by various state agencies, the state has promoted cross system teams and a "No Wrong Door" multiagency case coordination model. In response to the findings of a state legislative audit, Washington is implementing an Enhanced Community Services Project to help consumers with mental illness move to more integrated settings; stakeholders perceive this as a response to a legislative mandate rather than a response to *Olmstead.*

Litigation brought by the state Protection & Advocacy system also has resulted in community placement of institutionalized persons with mental illness.

On March 27, 2000, Governor Gary Locke designated the Department of Social and Health Services as the lead agency for *Olmstead* planning. The planning process was tied to the state biennial budget cycle. The planners envisioned that in each phase, a set of plan activities would be developed, incorporated into the budget process, funded, and implemented. On the one hand, stakeholders criticized this approach as lacking in vision and long-term view. On the other hand, the planning process has been more comprehensive than that of most states (notably, it addresses transportation), and the connection to the budget process has maximized the probability that planning initiatives will be funded.

In the first cycle, the 2001–2003 biennial budgets, a wide variety of state agencies each developed its own *Olmstead* plan. The Division of Developmental Disabilities undertook a survey of people with developmental disabilities to determine eligibility for community services. Unfortunately, this consisted only of asking state institutional residents and their guardians whether they would like to live in the community. Predictably, only 80 out of 1100 surveyed said yes, and, of these, only 60 are actually targeted for community placement. Placing the burden on institutional residents to state a preference affirmatively for community living is inconsistent with *Olmstead*'s requirement that the person not *oppose* community living. The Division also has a plan to identify persons with developmental disabilities who would like to move from nursing facilities. Owing to the present budget situation, however, this plan is unlikely to occur.

The second cycle of *Olmstead* planning concluded in December 2002 with the publication of plans from each of the relevant state agencies.

Because of the state's budget deficit of about $1.5 billion, no substantial new funds for *Olmstead* implementation have been requested in the current planning cycle, and none are expected until 2005.

The Aging and Adult Services Administration has been the most active in plan implementation. Among other initiatives, the agency awarded two contracts for a three-year pilot program to enhance availability and retention of personal assistance workers.

The Division of Mental Health has been allocated almost $14 million to expand community services for people transitioning from state hospitals. Two staff members have been assigned to coordinate the transition process.

A provision in the plan that the Division of Vocational Rehabilitation (DVR) would provide independent living services to 170 additional persons has not been implemented. Instead, DVR has focused on traditional VR services.

Washington has a Nursing Facility Transition grant to support the transition of 300 persons younger than 65 from nursing facilities. The state recognizes that it will not be able to meet this goal because of the absence of support systems for people with complex needs, especially in rural areas, and the nervousness of housing providers, despite the availability of Access 2000 vouchers.

In **West Virginia**, Governor Underwood created an *Olmstead* Task Force by executive order and charged it with identifying all institutionalized persons with disabilities and those at risk of institutionalization, the services they need, and the cost of providing them. A representative of HUD served on the Task Force. The resulting plan submitted on December 17, 2001, is basically a plan to plan. It contains no numeric goals or targets for deinstitutionalization or the creation of community services. As a general outcome, the document proposes that “people who *choose* to transition” from congregate settings may do so, rather than those who are unnecessarily institutionalized. The other general outcomes proposed for the plan focus on the changes in state law, policy, licensing, and certification changes that will be necessary to overcome the remaining institutional bias in the service system. Specific policy changes envisioned by the planners include consumer control of personal assistance; elimination of the “home-bound” requirement; 24-hour, seven-day backup support; changes in Certificate of Need requirements; and opening the system to more providers. The West Virginia plan provides and budgets for a strong infrastructure for *Olmstead* implementation and oversight, including an executive staff member on loan to serve as *Olmstead* director; an administrative assistant; office support; release time for agency and provider staff to serve on the *Olmstead* task force; travel and other compensation for consumers to serve on the Task Force; and a toll-free line answered by the *Olmstead* director and assistant as the “one-stop” point for all *Olmstead*-related information, including community service referrals, *Olmstead* complaints, mediation, and grievance procedures. One of the director’s roles is that of “assisting State agencies to ensure that their budget requests include sufficient funding to allow the State to meet its ADA obligations under the *Olmstead* decision.” The state plans to hire four regional *Olmstead* specialists to respond to local inquiries, conduct training, maintain regional resource databases, and assist in transition and diversion activities and grievance procedure, that is, “any potential service gap that could result in the consumer being returned to or potentially entering a more restrictive placement than that which he/she currently inhabits,” including a service gap that “prevents an individual from moving from an institutional or segregated setting to a community-based setting of his/her choice.” The *Olmstead* Director will receive complaints, acknowledge them within 24 hours, direct them to the appropriate agency, and ensure that they are resolved within 90 days of receipt. The complaint resolution process included provision for appeal and fair hearing.

Wisconsin’s *Olmstead* planning had its origin in systemwide complaints filed with the OCR. In September 2000, after discussions with OCR, the Wisconsin Department of Health and Family Services (DHFS) designated the Wisconsin Council on Long Term Care as the state’s *Olmstead* planning body. Barriers to *Olmstead* planning soon surfaced in the workgroup discussions. Existing assessment tools proved inadequate to identify persons who could handle and benefit from community living, but rather focused on the availability of community support. Existing data were inadequate to estimate the number of people in nursing homes who wanted to move to the community or were appropriate for community living. The Consumer Task Force found it difficult to get adequate representation of consumers. Despite these barriers, the plan for Phase I of the state's *Olmstead* planning efforts was released in January 2002. Although initial plan activities focus on offering institutionalized persons a choice of where to live, the plan's funding goal projects that by July 1, 2007, all persons "who have *not* made an informed choice to *stay* in the institution" (emphasis added) and who "could be served appropriately and cost effectively in the community" will be relocated from institutions. Given the size of Wisconsin's institutional populations, this is perhaps the most ambitious goal set forth in any state *Olmstead* plan to date; significantly, the goal is stated in appropriate *Olmstead* language. However, this goal is not developed in the body of the plan, and the proposed DHFS budget for 2003–2005 does not acknowledge it or reflect even a token effort to implement the goal. The plan's capacity-building strategies are extremely general (e.g., coordination with state housing, transportation, workforce, public instruction, and VR agencies, as well as with agencies that were not at the table during the planning process) and constitute little more than a plan to plan.

Wyoming used the NAPAS template as an outline for its plan; however, the plan is a bare draft that contains neither timelines nor target dates. It does not identify how many persons are on waiting lists for community services; does not examine the adequacy of the state's current assessment process; and does not ensure that all institutional residents will be assessed to determine whether they can handle and benefit from community living. Unique among state *Olmstead* plans, Wyoming's plan contains a relatively thorough section on Acquired Brain Injury. Almost simultaneously with the development of the draft *Olmstead* plan, Wyoming developed a plan for its mental health system that contains much more specific action steps. Unaccountably, there is little integration between the two plans.

V.

Lessons Learned: Good Practice in Community Services and What Works

The states' *Olmstead* planning efforts include many examples of promising practices in the design, delivery, and financing of community services. We hope that policymakers, program administrators, and advocates can make use of these examples in their efforts to make real the right of people with disabilities to live in the most integrated setting. First, we shall single out some examples from the states of exemplary *Olmstead* planning. Next, we shall identify examples of promising practices and strategies for facilitating effective *Olmstead* implementation.

1. Good Practice in *Olmstead* Planning

One of the most effective approaches to *Olmstead* planning we have seen to date is the report of the Governor's Commission on Home and Community-Based Care in Indiana. In this report, the planning group assigned each of its recommendations to one of three categories: (1) those that should be implemented quickly and with little or no fiscal impact or regulatory requirements; (2) those that should be implemented quickly but have a fiscal impact or require regulatory changes; and (3) those that are more complex, costly, or difficult and will require more time to develop and implement. The Commission developed 16 recommendations that are directly responsive to systemic barriers, can be implemented simply and at little or no additional cost, and are judged critical to developing the longer-term recommendations of the planning group.

We agree with the advocates in Maine who urged that planners should focus on the "meat and potatoes" of getting people out of segregated settings and not merely the "dessert and champagne" of improving the existing community system. The Texas *Olmstead* planning process does an admirable job of focusing on this goal, and Georgia's plan also is focused appropriately on the "meat and potatoes." Texas' tracking of the persons who have moved from nursing facilities to the community under Rider 37 also is commendable.

Nevada's *Olmstead* plan is commendable for its candid analysis of the state's compliance with *Olmstead* and for stating at least some of the goals in the plan with sufficient specificity to enable the planning group to evaluate objectively whether the state has followed its recommendations.

Oregon's plan, The *Olmstead* Decision and Adults in Oregon's State Hospitals, is a model *Olmstead* plan in many significant respects. It identifies with specificity the people recommended for community placement and the services they will need in the community, considers the adequacy of existing services and the changes needed to make those services responsive to the needs of consumers, and projects the costs that will be associated with transition.

Maine's *Olmstead* planning process has been unusually broad, inclusive, and well resourced. A wide range of disability groups, program administrators, and services providers has participated in the process, and the state provided funds for staff support from the University of Southern Maine and for workgroup members' travel expenses to the meetings.

A component of the West Virginia plan that deserves to be replicated by other states is the infrastructure for *Olmstead* implementation and oversight for which it provides and budgets. That infrastructure includes an executive staff member on loan to serve as *Olmstead* director; an administrative assistant; office support; release time for agency and provider staff to serve on the *Olmstead* task force; travel and other compensation for consumers to serve on the Task Force; and a toll-free line answered by the *Olmstead* director and assistant as the "one-stop" point for all *Olmstead*-related information, including community service referrals, *Olmstead* complaints, mediation, and grievance procedures. Among the ambitious roles for the director is that of "assisting State agencies to ensure that their budget requests include sufficient funding to allow the State to meet its ADA obligations under the *Olmstead* decision." Equally promising are the state's plans to hire four regional *Olmstead* specialists to respond to local inquiries, conduct training, maintain regional resource databases, and assist in transition and diversion activities and grievance procedures.

Another promising component of the West Virginia plan is its proposed procedure for resolving *Olmstead*-related complaints. An *Olmstead* complaint is "any potential service gap that could result in the consumer being returned to or potentially entering a more restrictive placement than that which he/she currently inhabits," including a service gap that "prevents an individual from moving from an institutional or segregated setting to a community-based setting of his/her choice." The *Olmstead* director will receive complaints, acknowledge them within 24 hours, direct them to the appropriate agency, and ensure that they are resolved within 90 days of receipt. The complaint resolution process included provision for appeal and fair hearing.

The *Olmstead* planning group in Arkansas has made a concerted effort to inform Arkansas of *Olmstead* issues and the planning process, through regional "revival" meetings, newsletters, and Web sites. Advocates in many states have engaged in effective cross-disability coalition building; for example, the Coalition of Californians for *Olmstead* (COCO) has brought together an exceptionally broad cross-disability coalition of consumers and advocates for successful legislative advocacy. The Connecticut *Olmstead* coalition has also brought together different disability constituencies.

Wisconsin's *Olmstead* plan contains a funding goal of transitioning to the community all institutionalized persons "who have not made an informed choice to stay in the institution" and could be served appropriately in community settings. Although the state's current budget does not reflect this goal, the goal is stated in language that is consistent with *Olmstead* and is an example of an appropriate *Olmstead* planning goal.

2. Overcoming Incentives to Unnecessary Institutionalization

Several states have demonstrated methods of overcoming incentives to unnecessary institutionalization. Maine’s use of pre-admission screening prior to nursing facility placement, in which a single independent agency performs the assessments, has helped reduce nursing home utilization.

Minnesota has encouraged the nursing facility industry to reduce the number of nursing facility beds with legislation (enacted in 2000) that allows nursing facility operators to place beds in “layaway” for up to five years, that is, to take them temporarily out of service and have them be treated as though they were unlicensed during that interval. In the first 18 months of the “layaway” program, nursing facility operators took 2,350 nursing facility beds out of service. Legislation enacted in 2001 goes further and established the goal of closing or partially closing up to 5,140 beds during FY 2002 and 2003. This approach has made Minnesota one of the leading states in the nation in the reduction of nursing home beds, with a 9.5 percent reduction from 1996 to 2001.

The state of Washington has reduced its nursing facility population with several strategies. Each of the state’s six regions had an annual reduction target for nursing facility caseloads, and the state tracked these targets monthly. Case managers are assigned to specific nursing facilities, and their responsibilities are limited to assessing and working with clients to be relocated. Within seven days of entering a nursing facility, a resident receives a comprehensive functional assessment using an instrument developed by the state to determine eligibility for all residential settings. The case manager then determines whether the resident should be classified as an “active relocation client.” If so, discussions with the resident about community-based options and preferences begin within two weeks, a timeframe that ensures that the community placement process will begin before the person begins to deteriorate functionally and emotionally.

Ensuring that “the money follows the person” requires a particular set of methods for overcoming institutional bias. Because of fixed costs in many institutional settings and the specific configuration of most federally financed disability services, this is difficult to accomplish for people already living in institutions, but less difficult for people who are not yet institutionalized. Florida is conducting a long-term managed care demonstration project whose goal is to divert elders and people with significant disabilities from nursing facility placement by eliminating financial disincentives to nursing facility use. In this project, the state pays participating HMOs a capitated rate for all Medicaid services, including home- and community-based services and nursing facility services. The HMO is responsible for unlimited nursing facility payments for Medicaid beneficiaries enrolled in the program for as long as the person remains enrolled. As a result, the HMO has a strong incentive to reduce costs by reducing nursing facility usage. The HMOs employ case managers to coordinate acute and long-term care services and offer certain benefits, including partial room and board payments in assisted living facilities, in addition to the services by Medicaid and the state’s home- and community-based waivers. The program appears to have had success in diverting a significantly impaired population from nursing facilities.

Similarly, New Mexico is developing a “global funding” Section 1115 waiver request to CMS, under which Medicaid reimbursement no longer will be tied to nursing facility beds or waiver slots but will be attached to the consumer. Consumers of long-term care services will be able to move from one setting to another without having to go on a waiting list. The waiver will enable the state to finance long-term care services using funds currently identified for Medicaid nursing facilities and home-based care services. The waiver will enable long-term care consumers to receive more cost-effective services because the state spends $39,000 annually for nursing facility services compared with $17,000 for home- and community-based services.

Texas’s Rider 37, a modification to the state’s system of funding nursing facilities is probably the most well-known example of “the money follows the person.” The rider allows “the general revenue used to purchase [nursing facility] services to follow the individual into the community and purchase community services." Similarly, Missouri's H.B. 1111 requires that persons eligible for or receiving nursing home services must be given the opportunity to have Medicaid dollars follow them to the community and choose the personal care option in the community that best meets the person's needs. It states that "individuals eligible for the Medicaid Personal Care Option must be allowed to choose, from among all the options, that option which best meets their need; and also be allowed to have their Medicaid funds follow them to whichever option they choose."

Even before *Olmstead,* South Carolina used a formula for transferring funds from the institutions to the community. State Appropriations Acts gave the Department of Disabilities and Special Needs the authority to retarget resources, realign the workforce, and shift funding from state institutions to local communities. As institutional residents moved to the community, the state negotiated voluntary separation agreements with institutional employees, and those FTEs were then deleted from the institutional budget line and the funds transferred to local disability boards.

In Kentucky, the *Olmstead* planning committee has recommended that all persons who currently live in personal care homes will be transitioned to their own homes, a family care home, or a group home, and that the funds currently used to support them in personal care homes will be reallocated to support people in more community-integrated settings.

3. Identification and Transition of People with Disabilities from Institutions

In Colorado, Atlantis/ADAPT is a subcontractor for Colorado's Nursing Facility Transition grant implementing a project to establish support networks based in Independent Living Centers, inform 1,200 nursing facility residents of their right to receive services in the community, identify barriers to transition, and establish a model transition planning process.

“Operation Escape” is a program developed by ADAPT of Kansas to identify people in nursing facilities who wish to move to the community. ADAPT secured the cooperation of the Kansas Departments of Aging and Social and Rehabilitation Services with this approach, in which members of ADAPT go into facilities to provide information about services, assistance with moving out, advocacy, and follow-up.

4. 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. The North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS) provides “bridge financing” for people leaving the institution for the community through two mechanisms: a MH/DD/SAS Trust Fund and Realignment/Community Capacity Reinvestment. The Trust Fund is a fund designated by the legislature for start-up and short-term operational costs of developing community services, housing, rental deposits, equipment purchases, and other resources for people leaving institutions in the interim before savings are realized through realignment of institutional resources. In the Realignment/Community Capacity Reinvestment strategy, as individuals leave state institutions, the financing of their community services will come directly from the planned redirection of the resources that become available as a result of closing institutional beds. In 2002, the Senate set aside $50 million for the Trust Fund. A budget amendment provided that all proceeds from the sale of the Central North Carolina School for the Deaf would be deposited in the Trust Fund.

Ohio has an administrative rule providing that one-third of the proceeds from the collection of franchise permit fees and penalties paid by nursing facilities and hospitals are to be deposited in a “home and community-based services for the aged fund” and used to fund programs for

Medicaid beneficiaries, including the PASSPORT waiver for persons older than 60 who are at risk of nursing facility placement.

In Oregon, the proceeds from the sale of a state psychiatric facility, Dammasch State Hospital, were placed in a housing trust fund. The Mental Health Alignment Work Group, a planning body formed to redesign Oregon's mental health service system, recommended that these funds be transferred to the Oregon Housing and Community Services Department for leveraging and growth. Similarly, the Delaware Commission on Community-Based Alternatives for Persons with Disabilities has recommended to the Delaware state legislature that the state sell off the land and facilities at Stockley that are not needed and dedicate the proceeds to the improvement and expansion of community-based services.

Case managers in Washington have a flexible pot of money available to facilitate nursing home transition from an unusual source—fine monies levied against nursing facilities for violations of licensing standards. Fine monies are placed in a Civil Penalty Fund and can be used to fund security deposits, utilities, furniture, home modifications, and other housing costs. Case managers have significant flexibility in the use of these funds.

5. Housing Strategies

Housing has been an especially problematic area for *Olmstead* implementation. Commendably, and in large part because of the influence of the technical assistance provided by HHS' OCR, the more recently developed plans tend to reflect the input of housing agencies. The recommendations of Massachusetts' *Olmstead* planning group in the area of housing are thoughtful, concrete, and a good example of the results that can occur when state housing agencies are at the table. Those recommendations include requiring universal design in new units that state housing agencies fund or finance; developing new housing to the greatest degree possible in areas serviced by accessible public transportation or in areas where fundamental amenities are in walking distance; ensuring that all existing publicly financed housing has completed Section 504/ADA self-evaluations; expanding the agency's definition of "homeless" to include persons living in rest homes, rehabilitation facilities, and group homes; conducting utilization reviews to ensure that targeted Section 8 programs are fully used; and researching whether underused housing developments for elders and persons with disabilities can be reconfigured to provide more usable and desirable housing

The strategies for addressing housing needs in Mississippi's *Olmstead* plan are also promising. They include training case managers in housing facilitation; expanding the menu of services under home- and community-based waivers to include home modifications and home repair; expanding home modification and accessibility services under the independent living program; encouraging the Mississippi Development Authority to allocate 5 to 10 percent of all state housing funds granted to cities and counties to be used for people with disabilities; bringing housing agencies (including Rural Development and Regional Housing Authorities) together to educate them on the funding needs of people with disabilities; earmarking 10 percent of Section 8 vouchers for people with disabilities; and increasing funding to cover down payments and closing costs from the Mississippi Development Authority.

New Hampshire has amended its state Section 8 plan to create an immediate highest priority for people coming out of institutions.

6. Single Point-of-Entry Systems

Many states are designing single point-of-entry systems to overcome the barriers to service delivery that are created by fragmented, categorical service systems. At least theoretically, single point-of-entry structures 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

CMS' findings in a number of states that Medicaid beneficiaries' right to choose among qualified providers was violated.

The long-term plan of the North Carolina Department of Health and Human Services, called Blueprint for Change, calls for reorganizing the Department from its present divisional model of "essentially freestanding, single-disability silos" that operate independently of one another to a cross-disability framework that is intended to foster the development of common approaches to similar issues. The area agencies that currently provide services will be reorganized into Local Management Entities that will develop local business plans for development of services and manage a network of providers. To receive public funds, the provider must be a member of the network. Access to the reformed system at the local level will be through a "uniform portal."

New Jersey's Easy Access, Single Entry uses a toll-free caller system that can identify the county from which the call is made and automatically transfer the caller to the single entry office for that county. Callers can obtain information, receive counseling about available public benefits, schedule comprehensive assessments, and arrange for services to be provided.

7. Beyond Institutional Closure: Increasing Community Integration

State service delivery systems vary tremendously around the country, from systems in which institutions provide the only real choice for people with high support needs to systems in which institutions were eliminated more than a decade ago. Developmental disabilities services in Vermont and New Hampshire show that "the most integrated setting" is more than placement in a residence outside an institution but a continuous process of increasing community inclusion.

Since the closure of its state developmental disabilities institution, Vermont has continued to pursue the goal of increasing community integration by reducing the size of community residential settings, expanding supported employment, and phasing out group homes in favor of more normal settings, such as supervised apartments, companion homes, and adult foster homes. From 1993 to 1999, the number of persons in supervised apartments increased by 30 percent and the number of persons in developmental homes increased by more than 80 percent, with corresponding decreases in the number of persons living in staffed group homes and small ICFs/MR. The average size of a community residence is 1.2 persons. Vermont's community service system is unusual in that the "developmental home," which may be either a home in which a person with disabilities lives with a companion or an adult foster home in which the person lives in a pre-existing household, is its primary service model. Benefits of that model include tax-free payments to foster families, which increase substantially the value of the income to host families and the benefit to persons with disabilities of the social networks of the host family.

Vermont uses its home- and community-based waiver to provide services called "flexible supports," a service category approved by CMS in 1998, which include personal support in the home and community, transportation, therapies, crisis services, environmental modifications and equipment, and any other support other than service coordination and supported employment included in the person's plan of care. The state also has a system of cash payments to families. Vermont's use of flexible, individualized services in normal settings is highly cost-effective, and the state does not have lengthy waiting lists.

Similarly, New Hampshire's developmental disabilities service system has progressed far beyond the closure of its state developmental disabilities institution in 1991. The self-determination model pioneered by Monadnock Developmental Services has been adopted statewide. From large group homes and sheltered workshops, consumers have moved to homes of their own, companion homes, and supported employment.

8. Self-Determination

All over the nation, states are adopting the principles of self-determination and consumer-directed services in pilot and demonstration projects, as a service option, or even as a statewide service delivery system. Programs like California's program of In-Home Support Services and Arkansas' Cash and Counseling Demonstration show that people whose disabilities are at least as significant as those of nursing facility residents can live in their own homes, direct their own services, and avoid institutional placement. Iowa's experience shows that consumer-directed personal assistance services can be provided as a state plan service under the personal care option.

We thus conclude this report as it began, with an affirmation of self-determination as an exemplar of the "most integrated setting." The 50 states and the District of Columbia are in vastly different stages of progress toward the most integrated setting, but by 2003, self-determination and consumer-directed services plainly have emerged as the guiding principles for supporting people with disabilities in inclusive communities.

VI.

Conclusions and Recommendations

Conclusions

1. Plans do not consistently provide for opportunities to live in the most integrated setting as people with disabilities define "the most integrated setting."

On the one hand, many state *Olmstead* plans invoke as guiding principles services that were most often cited by people with disabilities as fostering true community integration: highly individualized support that depends on the person, is defined by and tailored to the individual, and may change over time. Many plans call for the development of service models, such as self-determination and consumer-directed services, that correspond to the stated preferences of people with disabilities, especially physical disabilities and developmental disabilities.

However, few *Olmstead* plans explicitly address the creation of opportunities to live in the most integrated setting as the persons with disabilities we interviewed were most likely to define "the most integrated setting," that is, as "a place where the person exercises choice and control." In particular, very few plans call for the development or expansion of the models of consumer-operated services preferred by people with mental illness, such as peer counseling and drop in centers.

2. Few Olmstead plans consider institutional populations other than people in nursing facilities, developmental disabilities institutions, and psychiatric institutions.

The needs of people who live in institutions other than nursing facilities, developmental disabilities institutions, and psychiatric institutions, such as board and care facilities, juvenile facilities, residential treatment facilities, shelters, corrections facilities, and large group homes, are not addressed in most states' *Olmstead* plans. This is all the more remarkable considering that more than 800,000 people with disabilities live in board and care facilities across the United States.

There are exceptions, such as Maine's effort to identify people who are unnecessarily institutionalized in board and care facilities and Iowa's plan to compile a comprehensive list of the Iowans living in residential settings, including residential treatment facilities, corrections facilities, and any other congregate facilities that may be identified. Planning groups in which consumers and advocates were well-represented on the planning committees and that played a leading role in developing the plan were more likely to take a broad look at institutional populations.

3. The needs of people with psychiatric disabilities have not received a fair share of attention in the plans.

The absence of community services clearly has kept thousands of persons with mental illness institutionalized in state psychiatric hospitals, many thousands more live in nursing homes, and others are inappropriately institutionalized in jails. However, people with mental illness have not received their fair share of attention in most states' *Olmstead* plans. Surprisingly, few state plans had made provision for identifying persons with mental illness living in nursing facilities and other institutional settings, where it is unlikely they will receive treatment.

4. People with developmental disabilities have been relatively disadvantaged in the setting of goals for community placement.

This is a surprising conclusion given the relative success that people with developmental disabilities have enjoyed in the past two decades in obtaining well-resourced community services and the fact that the lion's share of state spending on home- and community-based waiver services still is targeted to people with developmental disabilities. Yet in those state *Olmstead* plans where targets exist for people with developmental disabilities to move from institutions to the community, those targets are extremely modest. For example, the *Olmstead* plans of Washington and Texas call for placement of less than 10 percent of the residents of state developmental disabilities institutions. This is ironic indeed, considering that the movement for community integration of people with developmental disabilities is justly considered a success story and studies of the closure of entire institutions documented that virtually everyone with developmental disabilities can live in the community.

In part, the limited numbers of people with developmental disabilities slated to move arises from the states' misinterpretation of the *Olmstead* standard as requiring people with disabilities to express a desire affirmatively to move before they can be considered for community placement. Another cause is the "stakeholder" composition of *Olmstead* planning groups and advisory committees, in which parents, including parents of institutionalized persons with developmental disabilities who oppose community placement, play a significant role.

A related phenomenon is that opposition to deinstitutionalization from parents and guardians has received relatively little attention in *Olmstead* plans, although people with disabilities, especially people with developmental disabilities, regard such opposition as a significant barrier to community integration.

5. The majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement.

In *Olmstead v. L.C.,* the Supreme Court held that all people who can handle and benefit from community placement have a right to live in the community, subject only to the states' "fundamental alteration" defense. The Court added that the state had no duty to offer community placement to persons who oppose leaving the institution and may continue to provide them with services in the institution if it chooses to do so. A state may also, consistent with *Olmstead*, decide to close all its institutions and offer services only in the community. However, the Court certainly did not condition the right to live in the most integrated setting on the person's affirmative expression of a desire to move.

Many state *Olmstead* plans provide that the state will identify and support in the community only those institutionalized persons who *choose* to live elsewhere. For example, the plan produced by the Delaware Department of Health and Social Services envisions community placement of only 24 residents of its state developmental disabilities institutions, about 12 percent of the population, who "want" to move. Arkansas' plan proposes to consider for community placement only those persons who "choose to live elsewhere." Even Texas' plan, which is justly considered a model in other respects, envisions community placement only for those who would like to move. Exceptions exist, of course. Georgia's plan is a shining example of a plan that does properly apply the *Olmstead* standard.

To some extent the emphasis in the plans on people who express an affirmative desire to move to the community may reflect the different perspectives of people with physical disabilities and people with developmental disabilities. In the physical disability movement, choice has been used as a sword to free people from institutions. In the movement of people with developmental disabilities, "choice" (usually, the choice of the person's parent or guardian) has been used more often to keep people in institutions rather than to free them.

6. Provisions in state *Olmstead* plans for assessing people with disabilities in institutions to determine if they can handle and benefit from community living are surprisingly limited.

Without the assumption that all or nearly all institutionalized persons with disabilities can handle and benefit from community living, which most state planning groups have not embraced explicitly, identification of institutional residents who can handle and benefit from community living is a vital first step in eliminating unnecessary institutionalization. Even if it is assumed that everyone can live in the community, effective planning requires identification of the support and services people will need in the community so that those services will be ready when the person moves. Thus, an objective assessment process is a critical component of the process of planning for community transition. Most states began the *Olmstead* planning process with little or no data on persons who may meet the conditions for community services described in the *Olmstead* decision. Typically, certain data do exist on the needs of Medicaid-supported applicants for nursing facilities, which are assessed to determine whether they meet the medical criteria for nursing facility placement; however, such assessments do not address whether the person could live in the community. In some state plans, collection of this data is proposed as an implementation activity, for example, development of data systems that can identify and track persons who are affected by the *Olmstead* decision as well as those at risk of unnecessary institutionalization.

Few plans examine the adequacy of existing assessment procedures. In part, this is because few such procedures exist.

7. Few plans contain timelines and targets for community placement.

Setting clear targets for community placement is an essential component of an effective plan. Without knowing what persons will move and what needs they have, developing the community support and services those persons will need in a planned manner or developing budget proposals that reflect the needed funding or transfer of funds to the community is impossible. Yet, few state plans contain numerical community placement goals and timelines.

In some cases, state officials on the planning groups have actively resisted setting numerical targets. For example, in Connecticut, the numerical targets suggested by members of the Community Options Task Force are not reflected in the plan because the Long Term Care Planning Committee refused to set measurable goals for community integration. In Delaware, the *Olmstead* plan developed by the Department of Health and Social Services contains no goals for enabling residents of psychiatric institutions to move to the community. Rather, it simply states that its current process for evaluating people after they are admitted to a psychiatric institution complies with *Olmstead.*

Targets that do exist are typically very modest. For example, Indiana's plan calls for reducing the population of the state psychiatric hospital by 100 and developing community services for 350 institutionalized persons with developmental disabilities (out of a total of nearly 3,500) who have been "targeted for placement" by 2003. The plan does not include the number of persons in need of service, the projected number of individuals to be served, or the funding needed for such services. Timelines are short-term, with most being within the next two years, and most action steps were already in progress before the document was written. The document appears to be more of a status report than a comprehensive plan. Where more substantial targets for developing community services have been set, as in Massachusetts, those targets are commonly required by court orders or consent decrees.

8. Few plans identify systemic barriers to community placement or state action steps to remove them.

Most states have failed to examine barriers to community integration that could be removed quite cost-effectively, for example, differences in coverage of health-related services under state home- and community-based waivers and nursing facilities, which have the effect of driving people into more costly institutional settings as the only way to obtain health services even though they could be provided more cost-effectively in the community. Other examples of barriers to community integration that could be removed cost-effectively are the failure to take advantage of CMS rules that allow coverage of community transition costs under a home- and community-based waiver for months before the actual move or different asset and income rules for Medicaid eligibility in the community and in nursing facilities, respectively, that can lead to loss of Medicaid eligibility for people who move back to the community. Often, barriers that have been identified in the reports of consultants to state agencies or by state agencies themselves are simply not addressed or even acknowledged in the state's *Olmstead* plan.

An exception is the widespread recognition that state Nurse Practice Acts may need to change to allow personal assistants to administer certain medical procedures. This recognition is undoubtedly due to the efforts of the physical disability movement, which successfully has highlighted this issue. However, states need to look much more closely at the configuration of their service delivery systems, their use of available federal financial assistance, and the opportunities available to transfer funding to the community.

If some of the earlier *Olmstead* plans, written before the current state-funding crisis developed, read like a "wish list," some of the later plans read like lists of specific projects rather than a blueprint for systems change. This evolution can be seen in the shift in Arkansas' planning process from the list of 115 recommendations developed in summer 2002 to the relatively limited number of projects set forth in the draft plan produced in fall 2002 and still not connected in any cohesive fashion.

9. In many states, initiatives other than *Olmstead* have been a more significant driving force for system change than the *Olmstead* planning process.

In many states, state and federal initiatives other than *Olmstead* have been a driving force for system change. For example, a number of states have been encouraged by the opportunities presented by Section 1115 demonstration waivers and combined Section 1915(b) and (c) waivers to redesign long-term care programs and develop unified funding streams combining state, federal, and local funding for community and institutional long-term care into a single capitated benefit. This allows states to streamline fragmented and overlapping funding streams and can effectively eliminate institutional bias. A single point of entry for information, pre-admission counseling, and intake is frequently a part of these system redesign efforts.

CMS audits and reviews of state home- and community-based waiver programs that have found noncompliance with Medicaid choice of provider requirements or conflict of interest when a state or local government agency fails to separate assessment from service delivery have provided a significant impetus for change, such as in Pennsylvania. Although such system redesign efforts have the potential to prevent unnecessary institutionalization, advocates have found that they must be especially vigilant to ensure that the needs of people with disabilities are met in the process and that the result is not simply to save money for the state.

In the past two decades, litigation has probably been the most significant force driving states to reconfigure their service delivery systems. In state after state, we found that court orders and consent decrees are a more powerful force driving community placement than the *Olmstead* planning process.

10. State *Olmstead* plans often are not well integrated with the states' other long-term care plans.

In many states, we found a fascinating contrast between the *Olmstead* planning process, in which consumers and advocates tend to be well-represented if not leading members, and concurrent or pre-existing long-term care planning processes in which stakeholders also were represented but that plainly were internal activities of the state agency.

Some states, such as Ohio, used previous long-term care planning as the basis for a later *Olmstead* plan. The problem is that sometimes the earlier plan was not developed to conform to *Olmstead* requirements, leading to a somewhat uneasy mix. In other states, the effect of concurrent but separate planning processes is that the *Olmstead* planning process appears as the public face of the state agency, whereas the internal process is where the "real" decisions and actions take place.

11. Federal initiatives have had a positive impact on the *Olmstead* planning process.

In addition to the HHS letter of January 14, 2000, to state Medicaid directors outlining the criteria for an *Olmstead* plan, the federal initiatives that have had the greatest positive impact on the planning process include the encouragement by the HHS OCR to submit *Olmstead* complaints to OCR and OCR's response to these complaints—advocacy that the states engage in *Olmstead* planning as an alternative to undergoing extensive complaint investigation—and the provision of technical assistance to the states in *Olmstead* planning. In many of the states, the development of an *Olmstead* plan was a direct response to an OCR investigation.

The training program funded by CMS and ED and delivered by the Independent Living Research Utilization (ILRU) and the Brain Injury Association (BIA), Inc., "Disability Advocacy in a post-*Olmstead* Environment," was quite influential in helping form state-level cross-disability *Olmstead* coalitions and arming them with knowledge of how to advocate for an effective *Olmstead* plan. In states as diverse as California and Louisiana, the *Olmstead* coalitions trained by ILRU and BIA have probably been the single most powerful driving force behind the *Olmstead* planning process.

The availability of Real Choice Systems Change grants also has facilitated *Olmstead* planning; more specifically, these grants have encouraged the states to work directly with the disability community. The option of receiving federal funds dedicated to nursing facility transition and other *Olmstead*-related activities has encouraged states to include these activities in their *Olmstead* planning efforts. However, it has proven more difficult to integrate the activities supported by the Real Choice Systems Change grants into states' overall service delivery systems.

In contrast, federal initiatives in the area of housing unfortunately have had little impact on state *Olmstead* plans and it cannot be said that these initiatives have facilitated deinstitutionalization.

12. Advocates have successfully used state legislatures to jump-start the planning process.

Many state *Olmstead* plans have been or are being developed in response to a mandate from the legislature. In a number of states, including California, Delaware, and Oklahoma, advocates have succeeded in persuading the state legislature to start or restart the planning process when the executive branch was unwilling to begin a planning process or take it seriously.

13. Housing, transportation, and educational agencies are seldom meaningful collaborators in the planning process.

Although lack of available, affordable, and accessible housing is almost certainly the most significant barrier to community placement experienced by institutionalized persons with disabilities, relatively few planning groups include representatives of state housing, transportation, and education agencies. The tendency to locate the *Olmstead* planning process in state human service agencies has created a barrier to inclusion of other important agencies. Further, few plans include data on waiting lists for available housing or strategies for overcoming housing shortages.

14. State budgets often do not reflect *Olmstead* planning goals.

In addition to developing an effective *Olmstead* plan, a further challenge to state officials is to ensure that the goals in the plan are reflected in the state budget. Some state planners have avoided this problem by obtaining explicit commitments to link the budget process and the *Olmstead* planning process. For example, Washington's *Olmstead* plan was developed explicitly to serve as the basis for program revision requests in the state budget. A tension may arise between the short-term focus of state budgets and the longer-term focus needed for an effective *Olmstead* plan; however, this tension does not necessarily have to exist, as can be seen by the example of Mississippi's long-term plan that was intended to serve as a guide to budget development as well as service system change. (That plan has run aground because of state budget shortfalls that have eliminated most of the funding for the plan.)

15. In most states, elders and their organizations have not been true collaborators in the planning process.

In most states, the *Olmstead* planning process has been driven by disability organizations. With some significant exceptions, organizations of elders have been relatively less involved. In part this may be traced to the different perspectives the two constituencies bring to the table, with the disability movement focused more on individual rights and freedom from institutional confinement, and elders focused more on long-term care reform.

16. The pace of deinstitutionalization has slowed, not accelerated, since *Olmstead* was decided.

In most states, the pace of deinstitutionalization has slowed since the 1990s. In a significant number of states, populations have remained relatively constant in the past few years, for example, Arkansas, California, Connecticut, and Delaware, where it has been estimated that only about half of one percent of Delaware's institutional population moved to the community in 2002. In some places (for example, Alaska, the District of Columbia, and Idaho), institutional populations actually have increased in the past few years. Medicaid expenditures on nursing facility services have increased significantly in most states from 1996 to 2001, and whereas some of this reflects inflation and the impact of an increasingly older U.S. population, much of the increase can be traced to an oversupply of nursing facility beds and the relative absence of community support and services for elders with significant disabilities.

Recommendations: How the Federal Government Can Facilitate Implementation of *Olmstead v. L.C.*

Ultimately, only comprehensive amendments to Title XIX of the Social Security Act, similar to the amendments proposed in MiCASSA, will overcome the institutional bias within the Medicaid program. We urge the Administration to work collaboratively with the disability community and other stakeholders to craft such legislation. In the meantime, however, short of a thorough revision of Title XIX, federal agencies can and should undertake many measures.

1. NCD recommends that HHS and its CMS provide more explicit guidance on implementation of *Olmstead v. L.C.*

Despite the detailed guidance in the original *Olmstead* letters to the states concerning *Olmstead* planning, the states' implementation record shows that some of the most basic *Olmstead* principles must be reinforced. Few states have attempted to identify those residents of nursing facilities, psychiatric hospitals, or developmental disabilities institutions who could receive services in a community-integrated setting, let alone all persons who are unnecessarily institutionalized. Even fewer have developed, or plan to develop, waiting lists for community services that include people who are unnecessarily institutionalized.

Many states have misinterpreted the Supreme Court's directive on how persons who are *qualified* for community living may be identified. The Court did not place the burden on institutionalized persons with disabilities to request community placement affirmatively, and neither may the states. An active waiting list would include every institutionalized person who can handle and benefit from community placement and does not *oppose* community placement.

Similarly, nothing in the Court's opinion in *Olmstead* allows guardians or other surrogate decisionmakers to decide that an institutionalized person with disabilities is not *qualified* for community placement. The great weight of judicial opinion also makes clear that guardians cannot annul the basic right under the ADA to be free from discrimination. Similarly, the case law makes clear that the right to receive services in the most integrated setting is not limited by a person's competency status under state law. NCD believes that HHS and CMS need to provide guidance to states making clear that they cannot discharge their duties under the integration mandate of the ADA by offering community placement only to those institutional residents whose guardians have requested it or are considered legally competent to request community placement under state law.

CMS has made clear to the states in its *Olmstead* letters that compliance with the requirements of Title XIX of the Social Security Act does not necessarily equal compliance with the ADA. CMS clarified in *Olmstead* Letter 4 that whereas Title XIX allows a state to set a limit on the number of persons who may receive services under a home- and community-based services waiver, such limits do not circumscribe the state's obligation to serve people with disabilities in the most integrated setting nor provide a safe harbor from claims of discrimination. Similarly, CMS needs to make clear to the states in policy directives that a guardian's choice for his or her ward of services available in a nursing facility or an ICF/MR rather than services available under a home- and community-based waiver does not waive the person's rights under the ADA.

Finally, CMS needs to make clear to the states that a comprehensive, effectively working plan must have numerical targets and timelines. Such goals are essential to any plan. Without numbers and timelines, it is impossible to judge whether a waiting list moves at a reasonable pace.

2. **NCD recommends that federal agencies complete the review of their own regulations that they began in response to Executive Order No. 13217 of June 18, 2001, for consistency with the ADA.**

The Executive Order directed federal agencies to "evaluate the policies, programs, statutes and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities." Although the agencies with important roles in *Olmstead* implementation, particularly HHS and HUD, did identify barriers to community integration within their own regulations and policies and HHS, in particular, proposed regulatory changes to remove these barriers, the reports the agencies published in May 2002 were incomplete.

3. **NCD recommends that CMS review its regulations governing admission, discharge, and use control to determine their consistency with the ADA . To the extent CMS determines that those regulations are consistent with the Act, NCD recommends the agency enforce those regulations to assure that the states comply with the ADA in carrying out utilization review and professional review of the appropriateness and quality of care and services furnished to institutionalized recipients of medical assistance. To the extent CMS determines that the regulations are inconsistent, NCD recommends CMS use its rule-making authority to initiate amendments to the regulations.**

Title XIX requires state Medicaid agencies, health agencies, and other agencies with responsibility for services provided in Title XIX certified institutions to screen residents prior to admission and periodically to view the quality and appropriateness of services they receive in those facilities.[271] As applied by the states, those regulations result in admission to nursing facilities and other institutions of many persons who could be supported in community-integrated settings. The regulations also permit the continued institutionalization of many persons who could handle and benefit from community living and do not oppose community placement. In that respect, the regulations permit practices that are inconsistent with *Olmstead*.

CMS regulations require utilization control in Title XIX-certified facilities, in mental hospitals, and for inpatient psychiatric services to persons younger than 21.[272] These regulations require periodic recertification by a health care professional of each resident's continued need for

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[271] 42 U.S.C. §1396a(a)(33)(A).

[272] 42 C.F.R. §§ 456.201; 456.160; 456.360; 456.481.

intermediate care facility services or services in a mental hospital. In practice, these regulations are interpreted to permit continued institutionalization of any person who requires an intermediate care facility level of care or requires the services that an institution for mental diseases is intended to provide. In other words, the regulations have been interpreted to sanction long-term institutionalization of many persons who could receive appropriate community services under a home- and community-based waiver or other funding source of noninstitutional services.

As applied by the states, the Title XIX regulations governing Preadmission Screening and Annual Review of Mentally Ill and Mentally Retarded Individuals who have been admitted to nursing facilities or whose admission is sought to nursing facilities (the PASARR regulations)[273] allow admission to nursing facilities and continued institutionalization of any person with mental illness or developmental disabilities who needs the "level of service" provided by a nursing facility, regardless of the person's ability to handle and benefit from community living. The section governing admission of persons with mental illness or developmental disabilities states, "If the State mental health or mental retardation authority determines that a resident or applicant for admission to a NF [nursing facility] requires an NF level of services, the NF may admit or retain the individual."[274] Thus, the regulation sanctions the unnecessary institutionalization of many persons who could receive services in the community. Data from the states reveal large and, in many cases, growing populations of persons with developmental disabilities in nursing facilities in many states. Data on persons with mental illness are not as readily available, but anecdote suggests that unnecessary institutionalization of persons with mental illness in nursing facilities is also common.

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[273] 42 C.F.R. §§ 483.112, 483.114, 483.126.

[274] 42 C.F.R. § 483.116(a).

In 1991 and 1992, CMS promulgated a regulation governing admission, transfer, and discharge rights in nursing facilities.[275] Although the regulation is technically consistent with *Olmstead,* it should be clarified by interpretive guideline or additional explanatory language that the regulation does not forbid the transfer to appropriate community-based services of nursing facility residents who do not oppose community placement.

The Title XIX regulation governing admissions, transfers, and discharges in ICFs/MR allows admission of persons who require an ICF/MR level of care but does not require facilities or state agencies to consider whether the person could be served in a community integrated setting, such as a home- and community-based waiver program.[276] The regulation has been interpreted to allow admission to a large congregate ICF/MR of any person with developmental disabilities who needs active treatment, whether or not the person needs to be institutionalized to receive active treatment. CMS should clarify it or amend it.

In its self-evaluations, HHS has approached the problems presented by the Title XIX facility admission regulations primarily as eligibility and coverage issues rather than as civil rights issues.[277] In response to the Executive Order, HHS proposed a statutory change that would make it possible for the states to require higher levels of need for nursing facility admission without applying the same standards for home- and community-based waiver recipients. The change would allow states that have tightened or would tighten institutional eligibility for hospitals or Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) to do so, without simultaneously narrowing HCBS [Home- and Community-based Services] waiver eligibility, by

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[275] 42 C.F.R. § 483.12.

[276] 42 C.F.R. § 483.440(b).

[277] *See* S. Rosenbaum et al., Community Integration: The Role of Individual Assessment, Center for Health Care Strategies, Inc. Working Paper (October, 2002) (noting that assessments implicate both coverage and liberty issues).

permitting (but not requiring) the state HCBS program to include levels of care that have been in effect in the state plan on or after passage of 1915(c) of the Social Security Act.[278]

Although the proposed change is a positive development, it does not address the central problem of preventing unnecessary institutionalization, because the ability to handle and benefit from community living cannot be reduced to a level-of-care determination. Research and experience has shown that people whose disabilities would qualify them for a nursing facility level of care under any possible formulation can thrive in the community. It is important, therefore, to unhinge determinations about appropriateness for community placement from level-of-care determinations.

In sum, CMS must thoroughly review these regulations, and, to the extent that they may be interpreted to be consistent with *Olmstead,* it should issue interpretive guidelines clarifying that they do allow continued institutionalization of persons who can handle and benefit from community services and do not oppose community placement. CMS should institute regulatory change of the PASARR regulations and the ICF/MR conditions of participation so that they cannot be used to permit continued unnecessary institutionalization

4. **NCD recommends that CMS enforce the utilization control regulation 42 C.F.R. Part 456 Subpart I governing inspections of care in intermediate care facilities and institutions for mental diseases to require states to identify residents of these facilities who can handle and benefit from community living.**

Title XIX regulation 42 C.F.R. § 456.609 requires inspection of care or utilization review teams to determine annually whether residents of intermediate care facilities and institutions for mental

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[278] U.S. Department of Health and Human Services, *Delivering on the Promise: Self-Evaluation to Promote Community Living for People with Disabilities* at III-26–27.

diseases need to remain in the facility or can receive services elsewhere. The regulation also requires—in 42 C.F.R. § 456.613—that the state take corrective action based on the findings of the teams.[279]

Sections (b) and (c) of the regulation speak directly to unnecessary institutionalization and to the feasibility of providing the person with services in the community. If properly conducted, inspections of care should identify every resident of an ICF or an IMD who is qualified to receive services in the community, that is, everyone who is institutionalized unnecessarily, meaning he or she can handle and benefit from receiving services in the community and does not oppose community placement. CMS should use its leadership and regulatory authority to ensure that states are carrying out their inspection of care obligation in a manner that is consistent with *Olmstead.*

5. NCD recommends that CMS use its existing regulatory authority to require meaningful and valid assessments of nursing facility residents' ability to handle and benefit from community living.

Under Titles XVIII and XIX of the Social Security Act and CMS regulation, the Secretary of HHS must specify a minimum dataset (MDS) of "core elements" to be used by long-term care facilities in conducting comprehensive assessments of residents in long-term care facilities.[280] The assessment instrument used to conduct such assessments must be either the one designated

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[279] 42 C.F.R. § 456.609.

[280] 42 C.F.R. § 483.20.

by CMS[281] or an alternate assessment instrument approved by CMS.[282] The comprehensive assessment of the person's needs must include assessment of the person's "discharge potential."[283] The section of the CMS MDS on "discharge potential" consists of the following items: (a) whether the resident expresses/indicates preference to return to the community; (b) whether the resident has a support person who is positive toward discharge; and (c) whether the stay is projected to be of short duration—discharge projected within 90 days (do not include expected discharge due to death).[284]

This instrument is far too limited to serve as an accurate assessment of nursing facility residents' potential to return to the community. It conditions discharge on expressed preference to return to the community (excluding persons who do not oppose community placement, but are unable to express a preference) and on the attitudes of the person's family and friends, and it suggests that long-term facility residents are less appropriate for discharge than others. This section of the instrument is inconsistent with *Olmstead* and should be revised to eliminate that inconsistency.

In sum, CMS should review its MDS and its criteria for approving alternate assessment instruments to ensure that the instruments are adequate to identify every nursing facility resident that is appropriate for community living.

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[281] The current Resident Assessment Instrument was designated by CMS in September 2000. CMS, State Operations Manual, Appendix R at 3.

[282] 42 C.F.R. § 483.315(a).

[283] 42 C.F.R. § 483.315(b)(1)(xvi).

[284] CMS, Resident Assessment Instrument (RAI) Version 2.0 Manual, Section Q.

6. **NCD recommends that CMS exercise its look-behind authority under 42 U.S.C. 1396a(a)(33)(B) to determine whether the states are adequately identifying residents of Title XIX–certified facilities who can handle and benefit from community living.**

Title XIX of the Social Security Act requires, at Section 1396a(a)(33), that states survey nursing facilities and ICFs/MR to determine their compliance with the conditions for participation of such facilities, that is, their eligibility for federal financial participation. The statute also authorizes "look-behind" inspections by CMS of a facility's compliance:

[I]f the Secretary has cause to question the adequacy of such determinations, the Secretary is authorized to validate State determinations and, on that basis, make independent and binding determinations concerning the extent to which individual institutions and agencies meet the requirements for participation[285]. In the 1980s, in response to Senate hearings that revealed significant noncompliance with the ICF/MR conditions of participation, HCFA conducted hundreds of look-behind inspections of ICFs/MR all over the country and found that noncompliance with the conditions and standards was widespread. CMS should similarly use its authority to determine whether Title XIX–certified institutions are appropriately assessing residents' "discharge potential," that is, their appropriateness for community placement as required by the Title XIX nursing facility standards.

7. **NCD recommends that HHS refocus its Real Choice Systems Change Grant program as a true system-change project by shifting from funding short-term demonstration projects to funding change that affects entire service systems.**

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[285] 42 U.S.C. § 1396a(a)(33)(B).

The Systems Change grants have generated a great deal of *Olmstead*-related activity, and it cannot be questioned that they have had a positive effect. However, in some of the states we looked at in depth, notably Washington and New Hampshire, it has proved difficult to integrate activities funded under a Systems Change grant with other components of the service system. This is inherent in the nature of a temporary, grant-funded project, which provides little incentive for a state to commit to lasting change in return for the grant.

8. NCD recommends that HHS require the states to identify all institutionalized persons in the state and their need for community services.

Whether or not HHS and CMS use their authority in the areas of utilization review, admission and discharge, and assessment as recommended above, HHS must require the states to identify all persons living in institutions (at least, those who are supported by federal public benefits) and their need for community services. Far too few of the states are doing this on their own, and those states that are doing it have generally limited identification to persons in ICFs/MR, psychiatric hospitals, and nursing facilities. Large numbers of people with disabilities and elders living in personal care boarding facilities, children in Residential Treatment Facilities, and people with disabilities in shelters, jails, and prisons are unidentified for the most part. To maximize objectivity and cost-effectiveness, identification and assessment should be carried out by independent agencies under contract with public agencies.

9. NCD recommends that HHS publish data at regular intervals on the number of persons waiting for community services, as well as publish the number of people living in the community and in institutions.

The availability of waiting list data has become a highly sensitive issue in many states because of the existence or threat of litigation. As a result of the prevalence of cases asserting either an *Olmstead* theory or the Title XIX right to receive services with reasonable promptness, states are reluctant to publish or collect data on the number of institutionalized persons who could receive services in the community or the number of persons waiting for services in the community. Some states even deny that a waiting list exists or claim that it is something other than a waiting list, for example, a “registry.” State employees may even be reluctant to assess institutional residents objectively because of the concern about liability under the ADA. HHS could place states and stakeholders alike on a more even footing by requiring that states provide such data and by publishing them.

10. NCD recommends that CMS 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.

Congress may not have intended the “institutional bias” in Title XIX service delivery, but it is pervasive and goes far beyond the difference between mandatory services and waived services. Medicaid recipients who live in nursing facilities or other institutions receive housing, meals, health care, pharmaceuticals, and other goods and services in addition to personal care and nursing services. Recipients of waiver services may not receive these additional services as part of the waiver package, and, in addition, they may be subject to more stringent income limits than institutionalized individuals. States that offer the personal care option may drastically limit the amount of services available (for example, to six hours a day on weekdays and none on weekends), and waivers may not pay for needed prescription medications or specialized therapies. CMS should require states to show in their waiver applications that the array of services in the community is sufficient to allow recipients a genuine choice between institutional and home- and community-based services.

This does not mean that a state would have to offer every conceivable service under a home- and community-based waiver. Other means exist to ensure that the home- and community-based services are not so limited that recipients are forced into nursing facilities. One method is by developing an array of capped waivers designed to support persons with different levels of need, with transfer available from one waiver to another, as the person's needs change. Another method is using the personal care option to provide a basic floor of personal assistance services for all persons with disabilities in the state that need them, with additional services available to the more limited number of persons who need more intensive services. Yet another method is by developing individual budgets for services tied to individualized assessments, as many states now are doing.

11. NCD recommends that CMS enforce the assurances states are required to give in return for funding under the home- and community-based waiver, especially the requirement of 42 C.F.R. § 441.302(d) that Medicaid beneficiaries who are eligible for services in an ICF/MR or nursing facility be notified of the feasible alternatives under the waiver and given the choice of services under the waiver or services in a facility.

We have seen little evidence from the states that the requirement of 42 U.S.C. § 1396n(c)(2) that all Medicaid beneficiaries who are *eligible* for services (including those who are receiving those services and those who have applied for services and been determined to be eligible for an ICF/MR or nursing facility level of care) be given the choice of services under the waiver as well as services in a facility is honored much in practice. This is a fundamental requirement of all home- and community-based waiver programs, and the states are required to give assurances that they will fulfill this condition of waiver funding. CMS should enforce the states' implementation of this requirement, just as it has in recent years actively enforced the choice of provider requirement. To be consistent with *Olmstead,* CMS' interpretation of this statutory requirement should not permit a beneficiary's guardian to choose an institutional setting for a person with disabilities who can handle and benefit from a home- and community-based waiver program and who does not oppose community placement.

12. NCD recommends that ED play a stronger role in *Olmstead* implementation.

The response of ED to *Olmstead*, the Executive Order, and the New Freedom Initiative has been surprisingly weak. The Office of Special Education Programs needs to be much more proactive in addressing the problem of children with disabilities who receive their education in Residential Treatment Facilities and juvenile detention centers, as well as the enormous problem of those who leave school without appropriate transition services that offer the hope of meaningful employment as adults.

The Rehabilitation Services Administration should provide VR funds to the states earmarked for *Olmstead*-related activities, for example, funding the Centers for Independent Living (CILs) to identify people in institutions who wish to move and providing assistance in relocation and diversion. Whereas the partnerships between state agencies and CILs in developing and implementing Real Choice Systems Change grants has been positive, the CILs should have a stable and well-resourced role in *Olmstead* implementation that is not dependent on states to apply for a time-limited grant. Helping people with disabilities to move from nursing homes or to avoid entering them in the first place is what the CILs do better than anyone else, and they do it with tremendous cost-effectiveness.

13. NCD recommends that HHS support and fund Relocation Specialists based in independent advocacy organizations, such as the CILs, People First organizations, or similar advocacy organizations to assist people in moving from institutions and nursing facilities.

Advocates have the skill, the motivation, the community connections, and the ability to provide peer support to people with disabilities moving from nursing facilities. It makes sense and is highly cost-effective to fund advocacy organizations directly to perform this role as an alternative to training agency staff.

14. NCD recommends that the Federal Government support and fund Protection & Advocacy agencies in specific *Olmstead*-related activities.

Historically, advocacy has been one of the most powerful engines for change and community integration for people with disabilities. Just as the Social Security Administration has awarded Work Incentives Assistance Program grants to the designated Protection and Advocacy agencies in each state and territory under the Ticket to Work and Work Incentives Improvement Act of 1999, HHS should award grants to Protection and Advocacy agencies in specific *Olmstead*-related activities. The Protection and Advocacy system already has considerable expertise and skill in advocating for people with disabilities who are unnecessarily institutionalized or at risk of unnecessary institutionalization, and Protection and Advocacy agency staff have been actively involved in *Olmstead* stakeholder groups in nearly all states with *Olmstead* planning groups.

Olmstead-related grant activities could include investigation of *Olmstead*-related complaints; review of states' assessment procedures and identification of persons with disabilities waiting for community services; advocacy; legal representation of people with disabilities who have been denied services in the most integrated setting; and systems advocacy to remove barriers to community integration.

15. NCD recommends that federal agencies provide federal financial assistance to states to provide small grants to people with disabilities for transition costs from institutions to community.

People with disabilities and elders leaving institutions often have little if any savings to pay the cost of setting up a household and to pay rent while waiting to receive housing assistance. The relatively modest amounts involved (usually less than $3,000) can be an unnecessary barrier to community integration. Although CMS has clarified that states may cover one-time transition costs under a home- and community-based services waiver, this option will not cover all one-time transition costs, at least not in the short term, and will not at all cover people who are not eligible for home- and community-based waiver services. Grants to the states, which could be administered through CILs, AAAs, or other agencies that work directly with people leaving institutions for the community, specifically designated for one-time transition costs and temporary rent subsidies are a highly cost-effective way to overcome barriers to community placement.

16. NCD recommends that HUD continue its efforts to simplify the ConPlan process, work to simplify other aspects of federal housing programs, and support focused advocacy and service brokerage for people with disabilities to access federally supported housing programs.

For people with disabilities, housing is the single biggest barrier to community integration and to *Olmstead* implementation. Every stage of the process to secure federal housing assistance--from developing localities' ConPlans and PHA plans to applying for Section 8 vouchers—has complicated, arcane procedures that make it vastly more difficult for people with disabilities to obtain affordable and accessible housing. The state of Mississippi recognized this problem in its *Olmstead* plan, which includes a provision for training case managers in housing facilitation. People with disabilities would benefit greatly from trained advocates who can participate effectively in the ConPlan and PHA planning process and from advocates, services brokers, and case managers who can help them negotiate the process of applying for housing vouchers. Advocates around the country who already are knowledgeable about federal housing programs could conduct the training.

Appendix

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the secretary of education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD’s purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government’s official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the ADA. NCD’s present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of the ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

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