

medicaid and the uninsured

June 2004

Olmstead v. L.C.: The Interaction of the Americans with Disabilities Act and Medicaid

Five years ago, on June 22, 1999, the United States Supreme Court issued a decision in the case of *Olmstead v. L.C.*, finding that the unjustified institutional isolation of people with disabilities is a violation of the Americans with Disabilities Act of 1990 (ADA).^{1, 2} This decision marked the first time that the Court has interpreted the ADA, the landmark civil rights law for people with disabilities, in a way that directly impacts Medicaid, the national program providing health and long-term services to people with disabilities.

To fall under the protection of the ADA, individuals must:

- 1) have a physical or mental impairment that substantially limits one or more major life activities;
- 2) have a record of such impairment; or,
- 3) be regarded as having such an impairment.

An estimated 54 million people in the United States, or nearly one in five people, have a disability that meets the standard for coverage under the ADA.³

THE AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act (ADA) was enacted by Congress to establish a clear and comprehensive prohibition of discrimination on the basis of disability. The law's stated purpose was to ensure that the federal government plays a central role in enforcing the law's standards on behalf of individuals with disabilities using Congress' authority to enforce the Fourteenth Amendment and to regulate commerce, to address the major areas of discrimination faced daily by people with disabilities (Figure 1).

THE OLMSTEAD CASE

BASIC FACTS: The *Olmstead* case involved two women with mental retardation, Lois Curtis (L.C.) and Elaine Wilson (E.W.). L.C. also has schizophrenia and E.W. has a personality disorder. Both women were Medicaid beneficiaries who had been treated in institutions.

In 1992, L.C. was voluntarily admitted to the Georgia Regional Hospital (GRH) in Atlanta, where she was confined for treatment in a psychiatric unit. By 1993, her psychiatric condition had stabilized and her treatment team determined that her needs could be met in one of the community-based programs the state supported. Despite this evaluation, L.C. remained institutionalized. In May 1995, L.C. filed suit in federal court challenging her continued confinement in a segregated environment. L.C. alleged that the state's failure to place her in a community-based program once her treating professional determined that such placement was appropriate violated Title II of the ADA. In February 1996, the state placed her in a community-based treatment program.

E.W. intervened in the case making an identical claim. E.W. was admitted to GRH in February 1995, and like L.C., E.W. was confined for treatment in a psychiatric unit. In March 1995, GRH sought to discharge E.W. to a homeless shelter, but abandoned that plan after her attorney filed an administrative complaint. By 1996, E.W.'s treating psychiatrist concluded that she could be treated appropriately in a community-based setting.

She remained institutionalized, however, until a few months after the District Court issued its judgment in this case in 1997.

Figure 1

The Four Titles of the ADA

I. Employment

- Requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others.

II. Public Service

- Requires state and local governments to give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities.

III. Public Accommodations and Services Operated by Private Entities

- Requires public accommodations to comply with nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment and comply with other specific requirements such as certain architectural standards and reasonable modifications to policies, practices, and procedures. Public accommodations are private entities who own, lease, or operate facilities such as restaurants, stores, private schools, doctor's offices, etc.

IV. Telecommunications

- Addresses telephone and tv access for people with hearing and speech disabilities; requires closed captioning of federally funded public service announcements.

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THE DECISION: The case was about whether regulations implementing Title II of the ADA that require states to operate public programs in a non-discriminatory fashion and to furnish services in the most integrated setting appropriate to an individual's needs require placement of persons with mental disabilities in community settings rather than institutions. The Court's answer was a "qualified" yes.

The Supreme Court ruled that:

- Unjustified institutional isolation of people with disabilities is a form of discrimination, noting the history of institutionalization as a means of segregating and demeaning persons with serious disabilities.
- States are required to provide community-based services for persons with disabilities otherwise entitled to institutional services when:
 1. the state's treatment professionals reasonably determine that community placement is appropriate;
 2. the person does not oppose such placement; and,
 3. the placement can reasonably be accommodated, taking into account resources available to the state and the needs of others receiving state-supported disability services.
- The "state's responsibility is not boundless", noting that the needs of persons who require institutional services have to be weighed against those who reside in the community. The Court also noted that nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings.
- The ADA's reasonable-modifications standard does not require states to make "fundamental alterations" in its services or programs. The Court specifically stated that in assessing what is a reasonable modification, states can balance the aggregate needs of the population of people with mental disabilities, and are not required to consider the cost of institutional care versus the cost of providing services in the community on an individual basis.
- If a state has a comprehensive, effectively working plan for placing qualified individuals in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by a state's efforts to keep its institutions fully populated, the reasonable-modifications standard would be met.

More than 40 years ago, states began to shift persons with mental illness and other disabilities from large and often inhumane institutions housing to smaller and more community-based settings. *Olmstead* merely clarifies the legal basis under the ADA for ensuring access to alternative community services.

MEDICAID COVERAGE AND FINANCING FOR LONG-TERM SERVICES AND SUPPORTS

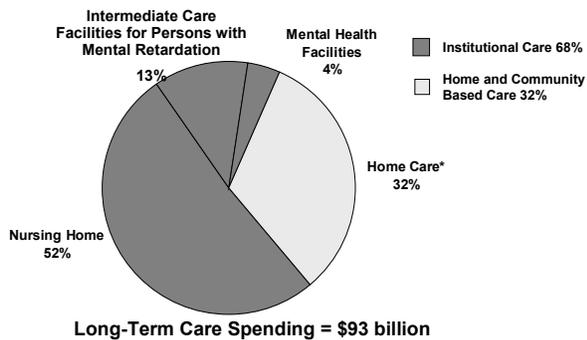
Medicaid is affected by the *Olmstead* decision because it is the major source of public financing for long-term services and supports for people with disabilities. In 2002, Medicaid provided coverage to more than 8 million non-elderly people with disabilities and an additional 5 million seniors, many of whom have disabilities.⁴ In contrast to the ADA's definition of disability which is purposefully broad to protect all people with disabilities who could face discrimination, Medicaid eligibility is limited to low-income individuals who are so severely disabled that they are unable to work as a result of a physical or mental impairment that is expected to result in death or to continue for at least 12 months. There is a modified definition of disability for children. As a result, people with disabilities who are eligible for Medicaid are generally very poor. Seventy-eight percent of Medicaid beneficiaries with disabilities qualify through SSI, which provides income up to 74% of the poverty level (\$564/month in 2004).

Long-term services and supports that people with disabilities depend on to function are not medically-oriented services, but rather assist individuals with very personal and often private activities, such as bathing and dressing, getting out of bed, toileting, preparing meals, and managing finances. This includes a range of activities to enable individuals to participate in their communities, and other supports, such as therapy services and durable medical equipment (DME), designed to maximize cognitive and physical performance and support independence.

Historically, Medicaid covered only institutional long-term care services, but over the past two decades, the proportion of long-term care financing directed to community-based services and the number of persons receiving services in the community has grown considerably. Nonetheless, the majority (68%) of Medicaid long-term service spending remains institutionally-based, while only 32% of Medicaid long-term services spending is directed to the community (Figure 2).⁵ Nearly 1.5 million people with disabilities and seniors receive institutional services under Medicaid and just over 2 million receive services in their homes or communities.

Figure 2

Medicaid Spending on Long-Term Services, by Type of Service, 2002



Long-Term Care Spending = \$93 billion

*Home care includes home health services, personal care, targeted case management, hospice, home- and community-based care for the functionally disabled, and services provided through HCBS waivers.
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 Source: Urban Institute estimates based on CMS (Form 64) data, for the KCMU.

The Medicaid law requires state Medicaid programs to provide institutional services to all eligible individuals as a mandatory benefit, and permits (but does not require) states to make services available in the community as an optional benefit. This is called Medicaid's institutional bias. However, there are three ways state Medicaid programs can provide home and community-based services: 1) through the home health benefit; 2) through one of several optional state plan services; and 3) through home and community-based services waivers.

Home health is a mandatory benefit that historically has emphasized the provision of skilled, medically-oriented services in the home. States have the discretion to cover a number of therapeutic services, but access can be greatly restricted through level of care requirements.

In addition to the home health benefit, state Medicaid programs can offer services, such as personal care, rehabilitation services, private duty nursing, physical therapy, occupational therapy, and transportation services, through state plan amendments. States that choose to provide these services must make them available on a statewide basis to all beneficiaries for whom they are medically necessary.

States can also provide community-based services through 1915(c) home and community-based services (HCBS) waivers that allow states to target specific populations and geographic locations. Every state has at least one HCBS waiver, except for Arizona, which provides similar types of services through an 1115 waiver. Unlike mandatory or optional state plan services, HCBS waivers can have capped enrollment and must be budget neutral. As a result, waiting lists for HCBS waivers are long, and in some cases persons can be forced to wait for

several years. In 2002, at least 150,000 people with disabilities were on HCBS waiver waiting lists.⁶

THE IMPACT OF THE *OLMSTEAD* DECISION ON MEDICAID

Olmstead is not a case based on the Medicaid law. Rather, *Olmstead* established that state Medicaid programs must operate in ways that comply with the ADA.

Although the *Olmstead* decision established that requiring individuals to receive services in segregated institutions is illegal discrimination under the ADA, the Court did not order an immediate end to institutional isolation. The Court's decision did not change the Medicaid law or require an end to the institutional bias.

Following the Supreme Court's *Olmstead* decision, many individuals believed that it would lead to rapid expansion of Medicaid community-based long-term services. This has not happened. In the context of *Olmstead*, the recent state fiscal crisis has meant that states' economic conditions have been a barrier to states implementing their own *Olmstead* compliance plans. Although, the promise of *Olmstead* as a tool for the advancement of the civil rights of people with disabilities in Medicaid has not yet been fully achieved, the *Olmstead* decision has led to important policy responses:

- **Federal Responses:**
 - **State Medicaid Directors Letters:** The Center for Medicaid and State Operations and the Office for Civil Rights issued five joint State Medicaid Directors letters related to the *Olmstead* decision from January 2000 to January 2001.⁷
 - **Real Choice, Systems Change Grants:** Established by Congress in 2000, grants of more than \$158 million have been awarded to states and territories from 2001-2003 to create infrastructure and service options necessary for long-term community integration.⁸
 - **New Freedom Initiative: An Executive Order from the President** requiring all Executive Branch agencies to take steps to comply fully with the requirements of the *Olmstead* decision was issued on June 18, 2001.⁹ As part of the initiative, the Administration has proposed Money Follows the Person legislation that would establish a new federal demonstration program through Medicaid that would provide full federal financing for one year for each person transitioned out of an institution into the community.

- *State Responses*— One way for states to comply with the *Olmstead* decision is to develop a comprehensive state plan to move people from institutions to community-settings. Some states have responded more actively than others. 29 states have issued *Olmstead*-related plans or reports and 10 states have issued or are working on follow-up reports that update, revise and prioritize their original plans.¹⁰

Some examples of state actions to comply with the *Olmstead* decision include Indiana’s plan which assigns recommendations to one of three categories: those that should be implemented quickly with little or no fiscal impact or regulatory requirements; those that should be implemented quickly with fiscal or regulatory changes; and, those that are more costly or difficult to implement. Maine uses pre-admission screening by an independent agency prior to nursing home placement. In addition, North Carolina, Oregon, and Washington have used the proceeds from the sale of state facilities to establish trusts to generate funds for services for people with disabilities.

However, some observers have questioned whether state plans are leading to real improvements in access to community services. The National Council on Disability has identified several issues associated with *Olmstead* implementation. They have noted that state budgets often do not reflect *Olmstead* planning goals and plans do not consistently provide for opportunities for life in the most integrated setting as people with disabilities define “most integrated setting”. In addition, the majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement and few plans identify systemic barriers to community placement.¹¹

- *Disability Community Responses*—People with disabilities have filed *Olmstead*-related complaints when they have not received services in the most appropriate integrated setting. As of May 2004, an estimated 627 *Olmstead*-related complaints have been filed with the HHS Office for Civil Rights (OCR), which has responsibility for enforcing Title II of the ADA and ensuring compliance with the *Olmstead* decision; 459 were resolved or closed and 168 were still open.¹²

Additionally, many people with disabilities have also filed suit against states seeking a court order requiring

enforcement of the *Olmstead* mandate. In some cases, the initiation of a lawsuit has led to the individual and the state signing a settlement agreement which spells out detailed steps the state will take to increase funding for Medicaid home and community-based services. At least 20 such agreements have been signed and a recent review of these settlements indicates that, as a result, hundreds of people with disabilities will begin receiving services in the community.¹³

The disability community has also been active in advocating for programs to assist in transitioning people out of institutions. States such as Texas have implemented programs in response to disability community pressure to allow individuals to use some existing funds that support institutional services to be used instead to provide services in the community.

CHALLENGES TO ENDING MEDICAID’S INSTITUTIONAL BIAS

There is broad consensus that greater access to home and community-based services should be available under Medicaid. In most cases (although not all), it is cheaper, on an individual basis, to serve individuals in the community. However, in the absence of new resources, barriers to the full community integration of people with disabilities include:

- *Financial Constraints on Medicaid*— Ending the institutional bias by creating a new entitlement to community living services has the potential to incur substantial new costs for federal and state governments. Some policymakers fear that a new entitlement to community-based services could result in unpredictable and potentially large number of additional people with disabilities currently relying on family members and other informal caregivers enrolling in Medicaid if more community-based services became available.
- *Affordable Housing*—Low-income people with disabilities receiving Medicaid rely on government assistance in obtaining affordable and accessible housing. Medicaid funds generally cannot be used for housing, and there are currently inadequate resources to ensure access to appropriate housing through Section 8 and other subsidy programs.

- *Labor Shortages*—There is a shortage of direct care workers who are trained and willing to provide community-based personal assistance and other long-term services. This results from low wages, poor or limited benefits, and limited career advancement opportunities.
- *Political Pressure*—Institutions are often large employers, especially in small towns where shifting resources from institutions to the community could lead to lost jobs and an economic drain for the community. The nursing home industry and organized labor are both politically powerful lobbies that have worked against de-institutionalization efforts in the past.

CONCLUSION

Despite significant changes in public attitudes toward people with disabilities, people with disabilities have not yet achieved full equality. Hundreds of thousands of people with disabilities could live in the community, with the proper long-term services and supports, but are segregated in an institution as their only option for receiving assistance with core activities of everyday living. Efforts to end the Medicaid institutional bias and to create meaningful and affordable opportunities to receive community-based long-term services outside of Medicaid are currently at the forefront of the civil rights movement for people with disabilities.

The *Olmstead* decision is important because of its core finding that institutional isolation is discriminatory and illegal under the ADA. While measurable improvements over the last five years to eliminate waiting lists for waiver services and expand access to community-based long-term services have not been as rapid as expected, the decision provides a legal rationale—and a moral authority for federal and state Medicaid policy making to support the full integration of people with disabilities into American society.

¹ *Olmstead v L.C.*, 119 S. Ct. 212187 (1999).

² P. L. 101-336, The Americans with Disabilities Act of 1990.

³ National Council on Disability

⁴ Kaiser Commission estimates based on CBO and OMB data, 2004

⁵ Urban Institute estimates based on data from CMS (Form 64), for the KCMU.

⁶ Heidi Reester, Raad Missmar, and Anne Tumlinson, *Recent Growth in Medicaid Home and Community-Based Service Waivers*, prepared for the Kaiser Commission on Medicaid and the Uninsured, April 2004.

⁷ CMS, <http://www.cms.hhs.gov/olmstead/smdltrs.asp>.

⁸ *The New Freedom Initiative: A Progress Report*, The White House, March 2004.

⁹ Executive Order 13217.

¹⁰ Wendy Fox-Grage, Barbara Coleman, and Donna Folkemer, *The States' Response to the Olmstead Decision: A 2003 Update*, NCSL, February 2004.

¹¹ *Olmstead: Reclaiming Institutionalized Lives*, National Council on Disability, September 29, 2003.

¹² HHS Office for Civil Rights.

¹³ Gary Smith, *Litigation Concerning Home and Community Based Services for People with Disabilities*, Human Services Research Institute, April 2004.

Addendum: The Need for Civil Rights Protections for People with Disabilities

Throughout our country's history, people with disabilities have advocated for greater involvement in the lives of their communities. Popular views of disability have also evolved substantially (Exhibit 1). Fourteen years ago, Congress enacted the ADA and five years ago, the United States Supreme Court issued the *Olmstead* decision. These actions by Congress and the Supreme Court, while meaningful, are just recent chapters in a longer movement by people with disabilities to fully participate in society.

Civil rights protections are important for people with disabilities. In the absence of such protections, they face isolation and segregation. Civil rights laws help to ensure that individuals with disabilities are able to participate fully in all aspects of life in the community, whether it is voting, receiving a public education in a non-restrictive environment, accessing communications, (such as using the telephone or watching television) or accessing transportation systems (including flying on commercial airlines, taking public transportation, or using a taxicab) (Exhibit 2). Civil rights laws have also made the physical environment more accessible to people with disabilities.

Exhibit 1

EVOLVING VIEWS OF DISABILITY

Colonial America—People with disabilities were viewed primarily in terms of their dependency. For people with no family support, colonial governments established “poor laws” which provided subsistence to people who were poor, elderly, or had disabilities.

1820s—State and local governments began constructing large almshouses in which people who were poor, old, sick, disabled, or simply idle drifters, were given a disciplined daily regimen and an exacting routine.

1830s—States began to erect asylums for people who were mentally ill. The insane asylums were designed to “cure” people who were mentally ill by depriving them of stimulus or emotion.

Late 1800s—Despite various reform movements during the 1800s, by the end of the 1800s, people with disabilities were living in yet more almshouses, which they shared with abandoned children, drifters, petty criminals, and a growing number of poor immigrants.

Although people with disabilities may have received pity or compassion, the assumption was that they were “unable to function” in society. People with a range of medical conditions or impairments who were able to function in society despite their medical conditions were not considered disabled. Since people with disabilities were unable to function in society, individuals were to be pitied, excluded, and/or cared for outside of the mainstream of society.

End of World War I—A new approach to disability emerged that focused on work rehabilitation. In 1918, Congress enacted the Smith-Sears Veteran's Rehabilitation Act. Two years later, Congress enacted the Smith-Fess Act, which extended vocational rehabilitation programs to civilians with physical disabilities.

1950s—For persons who could not be rehabilitated into the workforce, the government began providing income support to people with disabilities through the enactment of the Social Security Disability Insurance (SSDI) program in 1956.

1960s—The medical, rehabilitation and support models of disability began to be challenged as the civil rights movements for African Americans and women gathered momentum. During this time, people with disabilities started an “independent living” movement demanding more autonomy in their lives, as well as rejecting society's attitudes of pity, charity, and rehabilitation.

1970s—In 1972, Congress established the Supplemental Security Income (SSI) for providing income support to low-income people with disabilities. Unlike SSDI, eligibility for SSI is not tied to past employment.

In 1973, Congress enacted the Rehabilitation Act requiring executive branch departments to develop an affirmative action program for the hiring, placement, and advancement of people with disabilities. The Act also included an explicit anti-discrimination prohibition on the basis of disability for programs receiving federal financial assistance.

1990s—Congress enacted the Americans with Disabilities Act in 1990 establishing a comprehensive prohibition of discrimination on the basis of disability.

Source: Chai Feldblum, “Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What We Can Do About It?,” *Berkeley Journal of Employment and Labor Law*, 2000.

DISABILITY-RELATED CIVIL RIGHTS LAWS

Americans with Disabilities Act of 1990 (ADA): Provides a comprehensive prohibition of discrimination on the basis of disability in the areas of employment, public services, public accommodations and services operated by public entities, and telecommunications. (P.L. 101-336)

Air Carrier Access Act of 1986: Prohibits discrimination in air transportation by domestic and foreign carriers against qualified individuals with physical or mental impairments. (P.L. 99-435)

Architectural Barriers Act of 1968: Requires that buildings and facilities that are designed, constructed, or altered with federal funds, or leased by a federal agency must comply with federal standards for physical accessibility. (P.L. 90-480)

Civil Rights of Institutionalized Persons Act (1980): Authorizes the U.S. Attorney General to investigate conditions of confinement at state and local government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and institutions for persons with psychiatric or developmental disabilities. (P.L. 96-247)

Fair Housing Amendments Act of 1988: The Fair Housing Act, as amended in 1988, prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin. Its coverage includes private housing, housing that receives federal financial assistance, and state and local government housing. (P.L. 90-284)

Individuals with Disabilities Education Act Amendments of 1997: Requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. (P.L. 105-17)

National Voter Registration Act of 1993: Known as the "Motor Voter Act", it makes it easier for all Americans to exercise their fundamental right to vote. Requires all offices of state-funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing forms, and to transmit completed forms to the appropriate state official. (P.L. 103-31)

Rehabilitation Act Amendments of 1998: Prohibits discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in employment practices of federal contractors. (P.L. 106-246)

Telecommunications Act of 1996: Requires manufacturers of telecommunications equipment and providers of telecommunication services to ensure that such equipment and services are accessible to and usable by persons with disabilities, if readily achievable. (P.L. 104-104)

Voting Accessibility for the Elderly and Handicapped Act of 1984: Generally requires polling places across the country to be physically accessible to people with disabilities for federal elections and requires polling places to make available voting aids, such as telecommunications devices for the deaf (TDDs) and teletypewriters (TTYs). Where no accessible location is available, an alternate means of casting a ballot on the day of the election must be provided. (P.L. 98-435)

Source: *A Guide to Disability Rights Laws*, U.S. Department of Justice, May 2002.

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