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**Olmstead v L.C.:
Implications for Older Persons
with Mental and Physical Disabilities**

by

Sara Rosenbaum, J.D.

**Hirsh Professor, Health Law and Policy
The George Washington University
School of Public Health and Health Services**

Mary Jo Gibson, PPI Project Manager

The Public Policy Institute, formed in 1985, is part of Public Affairs at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This paper represents part of that effort.

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AARP, 601 E Street N.W., Washington, DC 20049

<http://research.aarp.org>

FOREWORD

Throughout the United States, AARP volunteers and staff have sought for many years to expand choice in the provision of publicly supported long-term care as well as to expand home and community-based services. In June 1999, the Supreme Court ruled that states' unnecessary placement of persons with physical and mental disabilities into institutions for care violates Title II of the Americans With Disabilities Act (*Olmstead v L.C. ex. rel. Zimring*). In the case of publicly administered programs, the Court's decision has far-reaching implications for states, which are now being asked to demonstrate that persons with disabilities are being served in the most integrated community setting appropriate to their needs. Because the Americans with Disabilities Act (ADA) has no age limits, the *Olmstead* case has many implications for older persons who are themselves disabled or who have family members who are disabled.

To understand the potential effect of this important Supreme Court decision, and the opportunities and challenges that it presents, AARP sought legal analysis from Sara Rosenbaum, a nationally recognized Medicaid scholar. She is the Harold and Jane Hirsh Professor of Health Law and Policy at George Washington University. The purpose of this issue paper is to describe the Supreme Court's landmark *Olmstead* decision and to analyze its implications for persons with physical and mental disabilities, with a particular focus on older persons, and the state programs that serve them.

This analysis reinforces the importance of consumer participation in state planning efforts to implement the *Olmstead* decision.

Jo Ann Lamphere
Senior Policy Advisor
Public Policy Institute

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EXECUTIVE SUMMARY

BACKGROUND

The Supreme Court's 1999 decision in *Olmstead v. L.C. ex. Rel. Zimring (Olmstead)* arose under the federal Americans with Disabilities Act (ADA). The ADA, among its provisions, prohibits public programs and public entities from discriminating against persons with disabilities. The ADA requires public agencies to make "reasonable modifications" necessary to avoid discrimination as long as the modifications do not amount to "fundamental alterations."

The *Olmstead* case was brought by plaintiffs who had been diagnosed with both mental retardation and mental illness. Treated in institutions, they remained institutionalized even after their conditions had stabilized and their own treating providers had concluded that their needs could be appropriately met in a community program. However, the state had failed to fund sufficient community services to make community placement possible. Plaintiffs sued the state in federal court under the ADA.

Olmstead's central holding is that the ADA prohibits states from unnecessarily institutionalizing persons with disabilities and from failing to serve them in the most integrated setting appropriate to their needs if the provision of community services represents a reasonable accommodation and not a fundamental alteration of public programs.

The decision directly affects the Medicaid program because it focuses on the obligations of states toward persons with disabilities under the ADA in relation to their health budgets, which in turn are heavily funded by Medicaid. It also describes the steps states must take to eliminate institutional bias from public programs. Because the ADA has no age limits, the case has as many implications for older persons with disabilities as for younger persons with disabilities, a crucial factor that must be kept in mind as states implement the decision and plan for greater levels of community care.

PURPOSE

This issue paper analyzes the *Olmstead* decision and considers its implications for persons with physical and mental disabilities, with a particular focus on older persons.

METHODOLOGY

The *Olmstead* standards are discussed, along with relevant rulings in subsequent cases and a joint policy statement issued in early 2000 by the Department of Health and Human Services (HHS), Health Care Financing Administration (HCFA), and the Office for Civil Rights (OCR). Implications for Medicaid policy are identified.

PRINCIPAL FINDINGS

1. While *Olmstead* does not directly require a state to alter the basic design of its Medicaid and other programs, the decision appears to require reasonable alterations in the existing design where unnecessary institutionalization and segregation of persons with disabilities are present. To elaborate:
 - The ADA’s anti-discrimination provisions prohibit states from placing persons with disabilities in inappropriate institutional placements and require that they make reasonable modifications to their existing programs to avoid such a result. While the particular disabilities experienced by the plaintiffs were mental disabilities, the decision is not confined to a particular type of disability or institution.
 - To accommodate community placement, a state needs to make reasonable accommodations but does not need to make “fundamental alterations” in its services or programs. The state bears the burden of proof in showing that a modification is a fundamental alteration.
 - Judicial decisions to date suggest that the failure to adequately fund an existing Medicaid program (e.g., unfunded home and community care waiver slots) violates both the ADA and Medicaid requirements.
2. A state must take affirmative steps to put the *Olmstead* holding into action. The heart of the decision is found in the Court’s statement that the standard of reasonable modifications would be met if 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.”
3. State and federal court cases and decisions interpreting *Olmstead* in the first year after its issuance indicate that:
 - *Olmstead* does not require that states add Medicaid coverage for services and benefits that are necessary for community care but that the state does not already provide.
 - However, arbitrary *expenditure caps on covered home and community services* that, when surpassed, result in institutionalization or re-institutionalization, would violate the ADA. Thus, a state plan that fails to adequately fund covered services (e.g., a waiting list) or that sets an upper limit of, for example, 90 percent of the average per capita cost of institutional care on Medicaid expenditures for community services, violates *Olmstead*. *The presumption is in favor of community care*. Thus, *it is the state*, not the individual *that bears the burden of proof*. A state must be able to show that additional services would amount to a fundamental alteration and may not require an individual to prove that community care is reasonable.

- The decision may lead to the imposition of outer limits on the number of days a state has to put together an appropriate community care program for an individual whom the state's own experts find to be inappropriately institutionalized and who desires community care. The decision also supports orders that specify the number of individuals who will be aided.
 - The individuals protected by the *Olmstead* ruling include not only persons who are in institutions and who could be appropriately cared for in the community but also those persons who reside in the community and who risk institutionalization unless they receive appropriate care.
 - The decision requires states to ensure that nursing home diversion programs properly avert institutionalization for potential residents through the provision of appropriate community care. Thus, while the state need not institute a nursing home diversion program, if it does so it must fully fund the program it offers. Thus, for example, if 500 slots are added to the plan, the state must fund the 500 slots at a reasonable pace.
 - The state can deny the aid only at the point at which the obligation to fund appropriate community services requires a fundamental alteration of a state's program.
4. The January 2000 policy guidance from the Department of Health and Human Services, signed jointly by HCFA and the OCR, sets forth a broad framework for planning and draws a nexus between a state's planning activities and the adjudged sufficiency of a state's response to *Olmstead*. The guidance letter vests considerable discretion in states to define what constitutes a reasonable response to the need to develop community services.
5. Most states can be expected to consider revisions in Medicaid as part of their post-*Olmstead* planning.
- States have a Medicaid obligation that parallels the ADA to ensure that individuals are not being inappropriately placed in institutions.
 - In modifying their public programs to develop appropriate community-based care, states can be expected to turn to Medicaid, which offers a broad array of options for covering individuals with disabilities.

Implications for Older Persons in State Medicaid Programs

In considering the needs of older persons with physical and mental disabilities and the role of Medicaid as part of a state's planning process, it is important to consider each of the elements outlined in the HHS guidance. It is also important to assess the state's Medicaid program design in the case of older beneficiaries in particular. For instance:

- Does the state's Medicaid home and community waiver program reach older

individuals as well as children and young adults?

- Does the state Medicaid plan (or the home and community care waiver program) provide coverage for the types and range of services identified by experts as important to the successful community integration of older persons with disabilities?
- How aggressively does the state screen nursing homes and other institutional residents to determine the appropriateness of their placements?
- In the case of older persons with disabilities who are without access to satisfactory informal caregiver arrangements, what resources are available in addition to their own income (e.g., SSI or Social Security benefits) to help meet the cost of community housing, particularly assisted living arrangements?
- Are older consumers represented in the planning process? Does the process include persons who are knowledgeable about the design of community-based programs and services for older persons with disabilities?

CONCLUSION

Olmstead gives both the federal government and consumers the power to more closely examine state efforts to develop community services for persons with disabilities for whom an institutional placement would be inappropriate.

The ruling is as important to older persons with disabilities as it is to younger individuals, and active involvement in state planning processes is key. Advocates for older persons with disabilities should consult their state protection and advocacy agencies to learn about the process in their states.

INTRODUCTION

This issue paper analyzes the Supreme Court's landmark 1999 decision in *Olmstead v L.C. ex. rel. Zimring* (hereinafter referred to as the *Olmstead* case)¹ and considers its implications for persons with physical and mental disabilities. Because the Americans with Disabilities Act (ADA) has no age limits, the case has as many implications for older persons with disabilities as for younger persons with disabilities, a crucial factor that must be kept in mind as states implement the *Olmstead* decision and plan for greater levels of community care.

Strictly speaking, *Olmstead* is not a Medicaid case; instead, the decision concerns the anti-discrimination requirements of the ADA in the case of publicly administered programs. Nonetheless, the decision directly affects Medicaid. This is because *Olmstead* focuses on the obligations of states toward persons with disabilities under the ADA - in relation to the entire fabric of state health and welfare programs and structure of state health budgets - and describes the remedial steps that are needed to eliminate institutional bias from public programs. Because Medicaid is such an important source of financing for both institutional and community-based services for persons with disabilities, heightened attention on the Medicaid program in the wake of *Olmstead* is an inevitable byproduct of the decision. Thus, how states use Medicaid to advance appropriate community care for persons with disabilities should be thought of as a consequence rather than requirement of the decision. All states currently are involved in post-*Olmstead* planning, and courts are beginning to apply the decision to specific cases involving persons with disabilities who need community care to avoid institutionalization.

This issue paper begins with an overview of the relevant provisions of the ADA. Part 2 examines the decision and the standards it sets forth for measuring whether state programs are in compliance with the law's anti-discrimination prohibition. Part 3 discusses a joint policy statement issued in early 2000 by the federal Health Care Financing Administration (HCFA) and the Department of Health and Human Services (HHS) Office for Civil Rights, which has primary jurisdiction over the ADA. Part 4 discusses the planning process and identifies issues that can be expected to arise as states consider, post-*Olmstead*, the implications for Medicaid and other programs that support community residence.

1. The Americans with Disabilities Act and Public Programs

Enacted in 1990, the Americans with Disabilities Act (ADA)² represents a landmark advance in civil rights law. Building on earlier protections under §504 of the Rehabilitation Act of 1973 (which applies to federally funded and conducted activities), the ADA extends anti-discrimination protections well beyond prior law, reaching private employment, publicly funded services, and public accommodations, including services

¹ 119 S. Ct. 2176 (1999)

² 42 U.S.C. §12201 et. seq.

operated by private entities.³

The *ADA contains no age limits*. Being considered a “qualified individual” under the ADA, and thus protected by its prohibition against discrimination, turns solely on whether a person has a disability within the meaning of the Act.

The ADA contains a series of titles, each of which establishes different protections. Title I applies to employers and employment-provided benefits. Title II applies to public programs and entities. Title III applies to entities and services that are considered “public accommodations” under the law. Title IV applies to transportation, and Title V contains a series of miscellaneous provisions, including certain protections for insurers, known as the insurance “safe harbor.”⁴

Title II covers “services, programs, and activities provided or made available by public entities, which are defined as state and local governments and departments, agencies, special purpose districts or other instrumentalities of state and local governments.”

The Civil Rights Division within the Department of Justice has primary oversight responsibilities for the ADA.⁵ Within the Department of Health and Human Services, the Office for Civil Rights (OCR) oversees the ADA in the context of health and human services programs. Thus, the policy guidance and directives involving *Olmstead*’s implementation will come from both OCR and HCFA, which administers Medicare and Medicaid. HCFA’s involvement stems from the fact that Medicaid forms the heart of state spending on persons with disabilities. As a result, many Medicaid issues also arise.

The *Olmstead* case involved the meaning of certain federal regulations implementing Title II, which address the meaning of non-discrimination in the context of publicly administered programs. These regulations, excerpts of which are set forth in Appendix A, contain the following crucial elements:

- First, they prohibit discrimination against “qualified persons with disabilities” by public programs;
- Second, they require that public entities “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities;”

³ For a complete review of the ADA, see Sara Rosenbaum and Joel Teitelbaum, “The Americans with Disabilities Act: Implications for Persons with Mental Illness and Addiction Disorders” (prepared for the Substance Abuse and Mental Health Services Administration, 1999). www.samhsa.gov

⁴ In recent years, there has been considerable litigation relating to insurance as an employment benefit and as a public accommodation; much of it also has raised the insurance safe harbor question. Rand Rosenblatt, Sylvia Law, and Sara Rosenbaum, *Law and the American Health Care System* (Foundation Press, NY, NY, 1997; 1999-2000 Supplement) (Ch. 2(F)).

⁵ 28 U.S. C. §35.104 (a).

- Third, they require public entities to 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 demonstrate that making the accommodation would *fundamentally alter* the nature of the service, program, or activity.”⁶

As the regulations indicate, to come within the protections of Title II, an individual must be a “qualified individual” with a “disability.” Under Title II, the term disability has the following meaning:

A physical or mental impairment that substantially limits one or more major life activities ***; a record of such an impairment; or being regarded as having such an impairment.

The phrase to “substantially limit one or more major life activities” means functions such as:

caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.⁷

The phrase “physical or mental impairment” means:

any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: Neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin and endocrine; any mental or psychological disorder such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.⁸

The phrase also includes:

Such contagious and non-contagious diseases and conditions as orthopedic, visual, speech, and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease (whether symptomatic or asymptomatic), tuberculosis, drug addiction, and alcoholism.⁹

⁶ 28 C.F.R. §35.130.

⁷ Id.

⁸ 28 C.F.R. §35.104

⁹ Id. Homosexuality and bisexuality are excluded from the term “physical or mental impairment.” Id. In addition, the term “disability” does not include transvestism, transexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior

While dementia and Alzheimer’s disease are not specifically listed as impairments, as conditions that affect one or more major life activities, they would be considered to fall within the general categories of impairments listed above.

A “qualified” person with a disability is one who, with or without reasonable modifications of rules, policies, or practices, meets the “essential eligibility requirements for the receipt of services”.¹⁰ For purposes of discrimination claims involving state Medicaid programs, courts have held that beneficiaries eligible on the basis of disability are considered “qualified,” because they meet Medicaid eligibility requirements.¹¹

In sum, Title II of the ADA is a broadly conceived remedial law that is designed to reach all public programs, whether or not federally assisted, publicly operated facilities, and private facilities that contract with public agencies. Title II requires public agencies to ensure that their services operate in an equally effective, non-discriminatory manner. They also must operate in the most integrated setting appropriate to the needs of qualified individuals with disabilities. In addition, public entities must make reasonable modifications necessary to avoid discrimination as long as they do not amount to “fundamental alterations.” The term “fundamentally alter” is not defined in the federal regulations. However, the term has been construed to require a showing by the public entity that a requested alteration affects the basic character of the service or program at issue.

2. The *Olmstead* Decision

The central ruling in the *Olmstead* case is that the ADA prohibits states from: 1) unnecessarily institutionalizing persons with disabilities and 2) failing to serve them in the most integrated setting appropriate to their needs, if the provision of community services represents a reasonable accommodation and not a fundamental alteration of public programs. Thus, while *Olmstead* does not directly require alteration in the design of Medicaid and other programs, the decision appears to require reasonable alterations as a practical matter, in their existing designs where unnecessary institutionalization and segregation of persons with disabilities are present.

The *Olmstead* ruling raises many complicated issues of enforcement, as do all desegregation cases. But in a real sense, the decision can be thought of as a *Brown v Board of Education* for institutionalized persons with disabilities. In *Brown*, the Supreme Court determined that legal segregation by race violated the U.S. Constitution, and ordered the integration of schools. Similarly, in *Olmstead* the Court declared unnecessary institutional segregation to be unlawful discrimination, and ordered integration. Writing for the Court, Justice Ginsburg articulated what is essentially an “all deliberate speed”

disorders, compulsive gambling, kleptomania, pyromania, or psychoactive substance use disorders resulting from current illegal use of drugs. Id.

¹⁰ Id.

¹¹ *Woolfolk v Duncan*, 872 F. Supp. 1381 (E.D. Pa. 1995).

standard (i.e., the *Brown* standard) for eliminating inappropriate institutionalization from the design of state programs. The decision also recognizes a series of important interests that must be taken into account in measuring what constitutes adequate state movement and underscores the need to balance competing interests in a manner that takes the needs of all persons with disabilities into account.

The *Olmstead* plaintiffs had been diagnosed with both mental retardation and mental illness. Treated in institutions, they remained institutionalized even after their conditions had stabilized and their own treating providers had concluded that their needs could be appropriately met in a community program. However, the state had failed to fund sufficient community services to make community placement possible. Among other matters, the Court specifically found that, despite the fact that HCFA had approved more than 2,000 home and community care waiver slots, the state had used only 700. The trial record also indicated that at one point, in response to the lower court ruling to provide services in a community setting, the state had attempted to discharge at least one of the plaintiffs to a homeless shelter.

In considering the case, the Court first had to determine whether the anti-discrimination provisions of the law had been breached. If so, the next step was to fashion the outline of the remedy to be implemented.

The Existence of Discrimination

The Court first held that the law's anti-discrimination provisions prohibited states from placing persons with disabilities in inappropriate institutional placements and required that they make reasonable modifications to their existing programs to avoid such a result. While the particular disabilities experienced by the plaintiffs were mental, the decision is not confined to a particular type of disability or institution.

The Court held that unjustifiable institutionalization of persons with disabilities is a form of discrimination, because it compels persons with disabilities to receive their care in institutions, while persons without disabilities can receive care in community settings:

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 life. *** [C]onfinement in an institution severely diminishes the every day life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. *** *Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, 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 sacrifices. ***¹² (emphasis added)*

The Remedy

Having found the existence of discrimination, the Court then fashioned a broad outline for lower courts to use in fashioning the remedy. In approaching this matter, the Court was mindful of the fact that the “state’s responsibility is not boundless” and that the needs of persons who can receive appropriate care in the community must be weighed against those who require institutional services. The Court also emphasized that “nothing in the ADA *** condones termination of institutional settings for persons unable to handle or benefit from community settings *** [nor] is there any federal requirement that community based treatment be imposed on patients who do not require it.”¹³

The elements of the Court’s remedy are as follows:

- First, a state “generally” may “rely on the reasonable assessments of its own professionals” in determining if individuals are eligible to live in community placements.
- Second, to accommodate community placement, a state needs to make reasonable modifications but does not need to make “fundamental alterations” in its services or programs. Furthermore, in deciding whether a change is reasonable or fundamental, a state may balance the interests of the entire group of persons with disabilities: both individuals for whom community services are appropriate and those for whom institutional placement is appropriate.
- Third, the burden of proof in showing that a modification is “fundamental” rather than “reasonable” lies with the state, and the following factors become relevant: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the State; and how providing services affects the ability of the State to meet the needs of others with disabilities.
- Finally, a state must take affirmative steps to put the holding into action. The heart of the Court’s decision is found in the following passage:

If *** 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.¹⁴ *(emphasis added)*

¹² *Olmstead* at 2187.

¹³ *Id.*

¹⁴ *Id.* at 2188.

Key Implications of the Case

Olmstead rests on a set of legal and structural underpinnings that will be critical in the implementation and enforcement phase:

- First, an ADA violation may be established if it can be shown that benefit design choices in public programs unreasonably limit access to community services and force persons with disabilities either to forego appropriate care or to be inappropriately institutionalized.
- Second, states have an affirmative obligation to make reasonable modifications in the design of their publicly funded health programs to eliminate discrimination and provide necessary care for inappropriately institutionalized persons in community-based, integrated settings.
- Third, to demonstrate compliance with the Act, a state must demonstrate that it has a “comprehensive, effectively working plan” for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.
- Fourth, in developing such a plan, the cost of furnishing community care to individuals who need it, as weighed against the resources of the state and the needs of persons who require institutional care, all are relevant. In the end, however, the state must be able to demonstrate reasonable movement toward appropriate de-institutionalization.
- Fifth, whether a change is a “reasonable modification” or a “fundamental alteration” is factual and will turn on whether the reform that is sought changes the basic structure of the state’s programs for persons with disabilities. Whether or not the total spending required to implement modifications is more than the amount previously spent on the population in the aggregate would not appear to be an alteration that changes the basic structure of a state’s programs. On the other hand, a proposed modification that literally closes an institution or terminates one or more classes of services (such as inpatient care) probably would constitute a “fundamental alteration.”
- Sixth, Medicaid should be viewed simply as part of a state’s overall public program design. A state may, but is not required to, modify the design of its Medicaid programs to eliminate “institutional bias.” The state could elect to fund additional community services for persons with disabilities entirely with state or local funds or through the use of alternative federal funding sources.
- Finally, the decision of whether to receive care in integrated settings when both inpatient and community care are reasonable and feasible is one that is up to the individual.

Post-*Olmstead* Court Decisions: The Courts Begin to Apply the Principles of the Case

In recent months, several courts have begun to consider cases involving persons with disabilities who challenged either an inappropriate institutional placement or their state's refusal to provide a sufficient level of community care to allow them to maintain residence in a community.¹⁵ Taken together, these cases, which afford very early but important insights into the practical meaning of the *Olmstead* decision, appear to set forth the following additional points:

- *Olmstead* does not require that states add Medicaid coverage for services and benefits that are necessary for community care but that the state does not already provide.
- However, arbitrary *expenditure caps on covered home and community services* that, when surpassed, result in institutionalization or re-institutionalization, would violate the ADA. Thus, a state plan that fails to adequately fund covered services (e.g., a waiting list) or that sets an upper limit of, for example, 90 percent of the average per capita cost of institutional care on Medicaid expenditures for community services, violates *Olmstead*. *The presumption is in favor of community care. Thus, it is the state, not the individual that bears the burden of proof.* A state must be able to show that additional services would amount to a fundamental alteration and may not require an individual to prove that community care is reasonable. Furthermore, the mere fact that a state might have to spend an additional amount for services that are already covered by Medicaid to avert institutional care does not amount to a fundamental alteration.
- The decision may lead to the imposition of outer limits on the number of days a state has to put together an appropriate community care program for an individual whom the state's own experts find to be inappropriately institutionalized and who desires community care. The decision also supports orders that specify the number of individuals who will be aided.
- The individuals protected by the *Olmstead* ruling include not only persons who are in institutions and who could be appropriately cared for in the community but also those persons who reside in the community and who risk institutionalization unless they receive appropriate care.
- The decision requires states to ensure that nursing home diversion programs properly avert institutionalization for potential residents through providing appropriate community care. Thus, while the state need not institute a nursing home diversion

¹⁵ *Benjamin v Ohl* (Court order, March 2000 implementing consent decree); *Rodriguez v City of New York* 197 F. 3d 611; *Rolland v Cellucci* (Ct. Order, January 10, 2000) (D. Mass.); *Kathleen S. v Broderick* (Ct. Order, Dec. 23, 1999) (E.D. Pa.); *Sanon v Wing* (New York Supreme Court, Feb. 25, 2000). The Sanon decision specifically involved elderly patients residing in their homes and in need of a range of in-home nursing and personal care services.

program, if it does so it must fully fund the program it offers. Thus, for example, if 500 slots are added to the plan, the state must fund the 500 slots at a reasonable pace.

- The state can deny the aid only at the point at which the obligation to fund appropriate community services requires a fundamental alteration of a state's program.

A series of decisions related to Medicaid coverage for persons with disabilities sheds additional light on the meaning of *Olmstead*. Taken together, they indicate that a state need not amend its Medicaid plan to add coverage for previously uncovered services that might be necessary for community placements. At the same time however, the cases also imply that a state must fully fund up to reasonable coverage levels the benefits and services that are listed in its state plan. Furthermore, a state cannot refuse to spend more than a flat, fixed amount per individual for covered services and claim that such additional expenditures up to a reasonable coverage level amount to a fundamental alteration.

The prohibition on arbitrary and unreasonable individual per capita waiver slot limits is as important as the prohibition against unfunded aggregate waiver slots. Federal law conditions the granting of home and community care waivers on a state's ability to show that "the average per capita expenditure *estimated* by the state in any fiscal year for medical assistance with respect to [individuals covered by the waiver] does not exceed 100 percent of the average per capita expenditure that the state reasonably estimates would have been made in the fiscal year for institutional care if the waiver had not been granted."¹⁶ But at least some states appear to be setting their community care spending levels well below the 100 percent threshold, even though federal law prohibits the Secretary from terminating a waiver because the state's *actual* expenditures exceeded its estimates.¹⁷ Moreover, even if a state could argue that exceeding the statutory cap in a specific case would amount to a fundamental alteration because the state would lose its *waiver* program, no such defense would be available in cases in which the necessary services are covered as *state plan* benefit and thus are not subject to the upper expenditure rules of the waiver program.¹⁸

Post-*Olmstead*, cases and settlements seem to suggest that an effectively working plan that moves at a reasonable pace can include time limits on how long a time is reasonable, how many people must be aided, and who bears the burden of proving that aid to any specific member of the group would result in a "fundamental alteration" of the state's program. For example, several recent decisions and settlements place a 90-day outer limit on waiting times.

¹⁶ §1915(c)(2)(D) of the Social Security Act.

¹⁷ §1915(c)(6) of the Social Security Act.

¹⁸ Unfortunately, however, many individuals are eligible for Medicaid coverage for home and community care services only as a result of a home and community care waiver. The President's FY 2000 budget calls for expanding eligibility for coverage for community care as a state option, but prospects for enactment during 2000 are slim.

3. Recent Guidance from the OCR and HCFA

On January 14th, 2000, the OCR and HCFA released a State Medicaid Directors Letter setting forth the first formal agency guidance in the wake of the *Olmstead* decision.¹⁹ The letter (see key excerpts below) provides a framework against which the agencies will assess state compliance with the ADA and spells out the details of the planning processes that states are expected to be able to demonstrate:

Comprehensive Effectively Working Plans

Principle: Develop and implement a comprehensive, effectively working plan (or plans) for providing services to eligible individuals with disabilities in more integrated, community-based settings. When effectively carrying out this principle:

The State develops a plan or plans to ensure that people with disabilities are served in the most integrated setting appropriate. It considers the extent to which there are programs that can serve as a framework for the development of an effectively working plan. It also considers 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.

The plan ensures the transition of qualified individuals into community-based settings at a reasonable pace. The State identifies improvements that could be made.

The plan ensures that individuals with disabilities benefit from assessments²⁰ to determine how community living might be possible (without limiting consideration to what is currently available in the community). In this process, individuals are provided the opportunity for informed choice.

The plan evaluates the adequacy with which the State is conducting thorough, objective, and periodic reviews of all individuals with disabilities in institutional *settings* (such as State institutions, ICFs/MR, nursing facilities, psychiatric hospitals, and residential service facilities for children) to determine the extent to which they can and should receive services in a more integrated setting.

The plan establishes similar procedures to avoid unjustifiable institutionalization in the first place.

¹⁹ <http://www.hcfa.gov/smd>

²⁰ While the letter does not define the term “assessments,” it implies an individual, face to face, and thorough assessment of health status, health care needs, and ability with various services and supports, to reside in one or more forms of community settings (e.g., the individual’s own home, a group residence, or with family members).

Plan Development and Implementation Process

Principle: Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up. When effectively carrying out this principle:

The State involves people with disabilities (and their representatives, where appropriate) in the plan development and implementation process. It considers what methods could be employed to ensure constructive, ongoing involvement and dialogue.

The State assesses what partnerships are needed to ensure that any plan is comprehensive and works effectively.

Assessments on Behalf of Potentially Eligible Populations

Principle: Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities. When effectively carrying out this principle:

The State has a reliable sense of how many individuals with disabilities are currently institutionalized and are eligible for services in community-based settings. The plan considers what information and data collection systems exist to enable the State to make this determination. Where appropriate, the State considers improvements to data collection systems to enable it to plan adequately to meet needs.

The State evaluates whether existing assessment procedures are adequate to identify institutionalized individuals with disabilities who could benefit from services in a more integrated setting.

The State also evaluates whether existing assessment procedures are adequate to identify individuals in the community who are at risk of placement in an unnecessarily restrictive setting.

The plan ensures that the State can act in a timely and effective manner in response to the findings of any assessment process.

Availability of Community-Integrated Services

Principle: Ensure the availability of community-integrated services. When effectively carrying out this principle:

The plan identifies what community-based services are available in the State.

It assesses the extent to which these programs are able to serve people in the most integrated setting appropriate (as described in the ADA). The State identifies what improvements could be accomplished, including in information systems, to make it an even better system, and how the system might be made comprehensive.

The plan evaluates whether the identified supports and services meet the needs of persons who are likely to require assistance to live in the community.

It identifies what changes could be made to improve the availability, quality, and adequacy of the supports.

The State evaluates whether its system adequately plans for making supports and services available to assist individuals who reside in their own homes with the presence of other family members. It also considers whether its plan is adequate to address the needs of those without family members or other informal caregivers.

The State examines how the identified supports and services integrate the individual into the community.

The State reviews what funding sources are available (both Medicaid and other funding sources) to increase the availability of community-based services. It also considers what efforts are under way to coordinate access to these services. Planners assess the extent to which these funding sources can be organized into a coherent system of long-term care that affords people with reasonable, timely access to community-based services.

Planners also assess how well the current service system works for different groups (e.g., older people with disabilities, people with physical disabilities, developmental disabilities, mental illness, HIV-AIDS, etc.). The assessment includes a review of changes that might be desirable to make services a reality in the most integrated setting appropriate for all populations.

The plan examines the operation of waiting lists, if any, and what might be done to ensure that individuals are able to come off waiting lists and receive needed community services at a reasonable pace.

Informed Choice

Principle: Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings. When carrying out this principle:

The plan ensures that individuals who may be eligible to receive services in more integrated community-based settings (and their representatives, where

appropriate) are given the opportunity to make informed choices regarding whether - and how - their needs can best be met.

Planners address what information, education, and referral systems would be useful to ensure that people with disabilities receive the information necessary to make informed choices.

Implications for State and Community Infrastructure

Principle: Take steps to ensure that quality assurance, quality improvement, and sound management support implementation of the plan. When effectively carrying out this principle:

Planners evaluate how quality assurance and quality improvement can be conducted effectively as more people with disabilities live in community settings.

The State also examines *how it can best manage the overall system of health and long-term care so that placement in the most integrated setting appropriate becomes the norm. (emphasis added)* It considers what planning, contracting, and management infrastructure might be necessary to achieve this result at the State and the community level.

The OCR/HCFA letter sets forth a broad framework for planning and draws a nexus between a state's planning activities and the adjudged sufficiency of a state's response to *Olmstead*. But it neither requires planning as a condition of federal financial participation in programs such as Medicaid, nor does it indicate how the government will measure the reasonableness of actual performance. The letter thus vests considerable discretion in states to define what constitutes a reasonable response to the need to develop community service.

Despite these limitations, the letter clarifies several matters:

- First, the needs of persons with disabilities *of all ages* must be considered in the planning process;
- Second, the needs of both physically and mentally disabled persons must be considered;
- Third, the needs of persons both residing in institutions and living in the community and at risk for institutionalization because of inadequate services must be considered.
- Fourth, the department (HHS) will seek active community involvement by affected individuals as well as all agencies and programs whose activities are

implicated by the decision. In other words, the planning process must include more than Medicaid.

- Fifth, the department will examine for compliance not only with the broad prescriptions of the decision, but also with relevant Medicaid requirements including those related to avoiding inappropriate institutionalization of persons who can live in communities.

4. Issues in Planning

In General

Many states are now actively engaged in post-*Olmstead* planning.²¹ A number of advocacy organizations have developed planning tools that identify the basic financial, health care, housing, social support, transportation, and other resources that individuals will need to be able to reside successfully in communities, as well as potential sources of funding for meeting these needs.²² According to these organizations, an effective planning effort for implementing *Olmstead* should contain the following elements:

- Movement should be expeditious to ensure that individuals in need of community services receive the supports they need in a reasonable time period.
- Family involvement, as well as involvement by individuals who need the services, is essential.
- The planning process must consider the needs of all persons who require community placements, not just a subset, and must have an effective means for identifying the total population in inappropriate institutional placement or at risk for institutionalization.
- The plan must identify clearly the resources that will be needed and contain provisions for actively seeking the necessary funding.
- The plan must contain a mechanism for ongoing monitoring to ensure reasonable movement into appropriate settings.
- The plan must have a mechanism for overseeing the quality of community care.²³

²¹ The National Association of Protection and Advocacy Systems (NAPAS) regularly updates state planning activities and state-level developments. See www.protectionandadvocacy.org. Also extremely helpful is information on state developments put out by the Judge David Bazelon Center on Mental Health Law, www.bazelon.org.

²² See Judge David Bazelon Center, *Under Court Order* (Washington D.C. October, 1999), www.bazelon.org/undctord.

²³ *Id.*

As part of its post-*Olmstead* planning, most states can be expected to consider revising Medicaid. As the OCR/HCFR letter makes clear, states have a Medicaid obligation that parallels the ADA to ensure that individuals are not being inappropriately placed in institutions. In modifying their public programs to develop appropriate community-based care, states also can be expected to turn to Medicaid, which offers a broad array of options for coverage of individuals with disabilities.

Medicaid

Medicaid is an extraordinarily important source of coverage for persons who report having limitations in major life activities. In 1997, nearly 7 million persons were enrolled in Medicaid on the basis of disability.²⁴ This group, which consisted of one million children²⁵ and more than five million non-elderly adults, comprised nearly 17 percent of the Medicaid beneficiary population.²⁶ Twenty percent of individuals with disabilities report having Medicaid coverage, while only 54 percent report having any private coverage.²⁷ In addition to non-elderly persons with disabilities, 4.1 million elderly persons received Medicaid in 1997;²⁸ over 90 percent of these individuals received Medicare as well. Among individuals dually eligible for Medicare and Medicaid, about 30 percent have limitations in two or more activities of daily living (ADLs). This concept parallels the “limitations on significant life activities” test that, as noted above, defines whether an impairment is in fact disabling under the ADA. More than 40 percent of Medicare/Medicaid enrollees have cognitive impairments.²⁹ In addition, 25 percent of dual eligibles reside in nursing facilities.³⁰ According to another estimate, 41 percent of all persons dually eligible for Medicare and Medicaid and over age 65 report that they need help from another person to perform one or more ADL.³¹

Medicaid permits, but does not require, providing long-term care services to individuals in community settings. Medicaid “waiver” programs permit provision of home- and community-based services to individuals who are eligible for Medicaid’s

²⁴ The Medicaid definition of disability is far stricter than that used under the ADA and entails a demonstration of an inability to engage in substantial gainful activity, a showing that is not required to establish disability under the ADA.

²⁵ The number of children eligible for Medicaid on the basis of disability has probably dropped significantly since this time as a result of restrictions on SSI benefits for children enacted as part of the Personal Responsibility and Work Opportunity Act of 1996. Sara Rosenbaum and Julie Darnell, *An Analysis of the Medicaid and Health Provisions of the Personal Responsibility and Work Opportunity Act of 1996* (Kaiser Commission on Medicaid and the Uninsured, Washington D.C., 1997)

²⁶ Andy Schneider, Victoria Strohmeier and Risa Ellberger, *Medicaid Eligibility for Persons with Disabilities* (Kaiser Commission on Medicaid and the Uninsured, Washington D.C., July, 1999) (Figure 3)

²⁷ *Id.* (Figure 1)

²⁸ *Id.* (Figure 3)

²⁹ Ellen O’Brien, Diane Rowland, and Patricia Keenan, *Medicare and Medicaid for the Elderly and Disabled Poor* (Kaiser Commission on Medicaid and the Uninsured, Washington, D.C., May, 1999)

³⁰ *Id.*

³¹ AARP Public Policy Institute, using the Medicare Benefits Model, version 3.0, 1995 data. Limitations in ADLs are more narrowly defined in this estimate: the person requires help from another person to perform a daily activity.

institutional services.³² Furthermore, through its waiver provisions as well as through the basic state plan function, Medicaid can be used to cover a broad range of services in the community including personal care, attendants, case management, services of clinics and day-treatment programs, and other services whose purpose is to avert unnecessary institutionalization and promote community integration. It is important to stress that although nursing home benefits are mandatory and community services are optional, once a state adds community services to its Medicaid plan the benefits become part of the individual entitlement and subject to all state plan requirements related to reasonableness and promptness of services.

In considering the needs of older persons with physical and mental disabilities and the role of Medicaid as part of a state's planning process, it is important to consider each of the elements outlined in the OCR/HHS planning process. It is also important to assess the state's Medicaid program design in the case of older beneficiaries:

- Does the state's Medicaid home and community waiver program reach older individuals as well as children and young adults? How many placements are there in relationship to the estimated need for community services among state residents, and how are placements allocated among different age groups and groups of persons with disabilities (i.e., physical versus mental disabilities)?
- Does the state Medicaid plan (or the home and community care waiver program) provide coverage for the types and range of services identified by experts as important to the successful community integration of older persons with disabilities?
- How aggressively does the state screen nursing home and other institutional residents to determine the appropriateness of their placements? What types of community services are available, and how are beneficiaries and families counseled regarding their options? What case planning services are available?
- With the important exception of coverage for group living arrangements for 16 residents or fewer, Medicaid does not pay room and board costs other than in large medical institutions. In the case of older persons with disabilities who are without access to satisfactory informal caregiver arrangements, what resources are available in addition to their own income (e.g., SSI or Social Security benefits) to help meet the cost of community housing, particularly assisted living arrangements?
- Are older consumers represented in the planning process? Does the process include persons who are knowledgeable about the design of community-based programs and services for older persons with disabilities?

³² Id. Figure 6.

CONCLUSION

The *Olmstead* decision can be expected to act as a catalyst for the development of community based systems of care for persons with disabilities in the coming years. In implementing the decision, states will be expected to demonstrate that they have effective plans for integrating persons with disabilities into the community. While the decision places important limitations on the extent of state obligations, it also makes clear that states have an obligation to ensure that they do not force persons with disabilities to choose between inappropriate institutional care or inadequate or no care.

In essence, *Olmstead* gives both the federal government - and as importantly, beneficiaries themselves - the power to more closely examine state efforts to develop community services for persons with disabilities for whom an institutional placement would be inappropriate. The ruling is as important to older persons with disabilities as it is to younger individuals, and active involvement in state planning processes is key. While most states are in the early planning stage, work has been done by advocates and protection and advocacy systems to identify the key elements in planning. Advocates for older persons with disabilities should consult their state protection and advocacy agencies to learn about the process in their states.

Appendix A:

Relevant Excerpts from Federal Regulations Implementing Title II of the Americans With Disabilities Act

28 C.F.R. §35.130

(a) no *qualified individual with a disability* shall * * * be subjected to discrimination by any public entity.

(b) (1) a public entity, in providing any *** benefit or service, may not * * *

(ii) afford a qualified individual with a disability with a *** service that is not equal to that afforded others;

(iii) provide a qualified individual with a disability with [a] *** service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others;

(iv) provide different or separate *** services to individuals with disabilities *** unless such action is necessary to provide qualified individuals with *** services that are as effective as those provided to others; * * *

(3) a public entity may not, directly or through contractual *** arrangements, utilize criteria or methods of administration

(i) that have the effect of subjecting qualified individuals with disabilities to discrimination * * *; * * *

(7) 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 demonstrate that making the accommodation would fundamentally alter the nature of the service, program, or activity.

(8) a public entity shall not impose or apply eligibility criteria that screen out *** an individual with a disability *** from fully and equally enjoying any service, program or activity, unless such criteria can be shown to be necessary for the provision of the service, program or activity being offered. ***

(d) A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.