
Olmstead v L.C.:

Implications for Family Caregivers

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INTRODUCTION

In 1999 the United States Supreme Court held in the landmark case *Olmstead v L.C.* that the medically unjustifiable institutionalization of persons with disabilities constitutes a violation of the Americans with Disabilities Act (ADA). It ruled that when a state’s own medical professionals reasonably conclude that an individual is able to reside in the community, the state must make reasonable modifications to furnish community services in the most integrated setting unless the state can prove that to do so would require a fundamental alteration of its program.

The *Olmstead* decision reflects the enormous shift, embodied in the ADA, in how society views persons with disabilities as well as what Americans have come to expect in terms of the integration of persons with disabilities into the broader community. Furthermore, the decision is sweeping in its implications. The terms of the ADA are not limited by age or by type of disability: the law protects persons of any age who meet its functional disability test and who are considered “qualified.”

This Policy Brief provides an overview of the decision and discusses major issues that must be addressed in implementing the *Olmstead* decision, emphasizing the implications for family caregivers. It examines cases filed with

the United States Department of Health and Human Services (HHS) Office for Civil Rights (OCR) to identify the key issues raised by these complaints. The article then turns to HHS efforts to assist states to comply with *Olmstead’s* key holdings and describes the states’ early efforts to implement the decision.

BACKGROUND AND OVERVIEW

The Americans with Disabilities Act (ADA)

Enacted in 1990, the ADA (42 U.S.C. §12201 et seq.) 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 operated by private entities.

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The ADA has *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 and is considered “qualified” within the meaning of the Act to receive its protections.

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 publicly operated and funded programs and entities.
- Title III applies to entities and services that are considered “public accommodations” under the law.
- Title IV applies to transportation.
- Title V contains a series of miscellaneous provisions, including certain protections for insurers, known as the insurance “safe harbor.” (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; Rand Rosenblatt, Sara Rosenbaum and David Frankford, 2001-02 Supplement) (Ch. 2(F)).

Title II covers “services, programs and activities provided or made available by public entities.” These entities are defined as “state and local governments and departments, agencies, special purpose districts or other instrumentalities of state and local governments” (42 U.S.C. 12201).

The OCR within the Department of Justice has primary oversight responsibilities for the ADA. (28 U.S.C. § 35.104[a]). Within HHS, the 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. In addition, the Center for Medicare and Medicaid Services (CMS, formerly known as the Health Care Financing

Administration or HCFA) plays a significant role in implementing the *Olmstead* decision because of the central role that Medicaid plays in financing community-based services for persons with disabilities.

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The heart of the *Olmstead* case involved the meaning of certain federal regulations implementing Title II of the ADA. These address the meaning of non-discrimination in the context of publicly administered programs

and contain the following crucial elements:

- They prohibit discrimination against “qualified persons with disabilities” by public programs.
- They require that public entities “administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”
- 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” (28 C.F.R. §35.130).

As the regulations indicate, in order 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 (id.)

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” (28 C.F.R. §35.104).

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

While dementia and Alzheimer’s disease are not specifically listed impairments, as conditions that affect one or more major life activities they presumably 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” (Id.). For purposes of discrimination claims involving health care and other services furnished under public programs, courts have held that beneficiaries are considered “qualified” when they meet program eligibility requirements (*Woolfolk v Duncan*, 872 Supp. 1381 [E.D. Pa 1995]). Thus for example, a Medicaid beneficiary would be considered “otherwise qualified” in a situation where the beneficiary alleges that he or she is being discriminated against in the state’s failure to provide covered services. (See, e.g., *Rodriguez v City of New York* 197 F. 3d 611 (1999); cert. den. 121 S. Ct.156 (2000), which held that an agency’s failure to cover personal patient safety monitoring as a separately covered service under the state plan but only as a procedure incidental to actual physical assistance did not constitute discrimination under Title II of the ADA.)

In 2001, the Supreme Court clarified the meaning of the phrase “fundamentally alter” a program or service. In *PGA Tours v Martin* the Court interpreted the term in an ADA Title III context (but in this respect, as well as others, Titles II and III are parallel) as meaning a proposed change that alters an “essential aspect” of the service or provides a person with a disability with a competitive advantage in participation in the activity that is not available to persons who are not disabled. (*P.G.A. Tour v Martin* 2001 Westlaw 567717). The *Martin* case concerned whether a public accommodation (a professional golf tournament) had to reasonably modify its rules

to permit play by a golfer with a disability that prevented extensive walking.

In sum, the ADA is a broadly conceived remedial law 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 services are furnished in the most integrated setting appropriate to the needs of qualified individuals with disabilities. In addition, the law classifies as discriminatory the failure by public entities and public accommodations to

make reasonable modifications in existing programs and services when such modifications are necessary to afford services or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would

fundamentally alter the nature of the goods and services in question.

The Olmstead Decision

Olmstead v L.C. by Zimring (119 S. Ct. 2176 [1999]) concerned two women with various mental disabilities who resided in a state institution and were unable to secure adequate services to live in the community. In the case, the Supreme Court held that a state violates the ADA when it fails to make reasonable modifications in existing services for persons whom its own health professionals have determined to be capable of community residence. Treated in institutions, the plaintiffs 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. In holding for the

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plaintiffs, the Court specifically found that despite the fact that HCFA had approved more than 2000 home and community care waiver slots, Georgia had used only 700 and had failed to modify its budget to cover additional community services listed under its state plan.

The existence of discrimination. The Court first held that unjustifiable institutionalization of persons with disabilities is a form of discrimination, because it compels them to receive their care in institutions, while persons without disabilities 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,” the Court ruled. “Confinement 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* (Olmstead at 2187, emphasis added).

The remedy. Having found the existence of discrimination, the Court then set forth a framework for lower courts to use in fashioning remedies. The “state’s responsibility is not boundless” and the State must weigh the needs of persons who can receive appropriate care in the community 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” (id.). The Court then outlined the elements of a remedy:

- ♦ 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 accommodations to --but not “fundamental alterations” in -- its services and programs. Furthermore, in deciding whether a change is reasonable or fundamental, a court must consider the interests of the entire group of persons with disabilities: individuals for whom community services are appropriate and those for whom institutional placement is appropriate.
- ♦ Third, the state has the burden of proof as to whether a proposed modification amounts to a fundamental alteration. In deciding the question, several factors are 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 state’s ability to meet the needs of others with disabilities who need institutional care.
- ♦ 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 (Id. at 2188, emphasis added).

IMPLICATIONS OF OLMSTEAD FOR
FAMILY CAREGIVERS

In essence, *Olmstead* requires that states plan for and undertake two basic reforms:

- ♦ The broad and complex task of restructuring existing programs and services in order to promote community integration.
- ♦ The establishment of an individualized assessment process to design community placements.

At the same time, the decision leaves many questions to be addressed. Undoubtedly federal, state and local government agencies, service providers, affected individuals, families, advocates and entire communities have many years of implementation work ahead.

Restructuring Existing Programs for Community Integration

Determining how *Olmstead* affects the daily lives of family caregivers is not easy. Sweeping decisions such as this one often take years to “filter through” the health and social service systems because of difficulties interpreting the full meaning of the decision and the complexities of modifying the ongoing operations of public programs to achieve consistency with the goal of maximum integration.

Family caregivers may find it useful to focus on two levels of public response:

- ♦ The broader process of state planning and program redesign.
- ♦ The use of the individualized assessment process to respond to individual needs and achieve the program and service modifications for integration and community residence.

Of particular concern to family caregivers may be:

- ♦ The ability of programs to pay families to provide support and assistance normally furnished by agencies and unrelated assistants.
- ♦ The extent to which Medicaid eligibility is restructured to permit eligibility in home and community residential settings.
- ♦ How the *Olmstead* decision specifically affects individuals with Alzheimer’s disease and other forms of dementia, which make community and home residential arrangements particularly complex to achieve.
- ♦ How *Olmstead* will assist aging parents caring for adult children with mental retardation and developmental disabilities.
- ♦ Whether, instead of aiding families, *Olmstead* creates the potential to force families to furnish inadequately supported in-home care in lieu of other forms of assistance.

Because the ADA applies to all individuals with disabilities without regard to age or

underlying condition, planning, assessment and service modification must be structured to address the needs of all individuals with disabilities, not just adults with retardation or physical disabilities. Using *Olmstead* to change public programs (such as allowing payment of family members for care otherwise furnished by unrelated individuals) will turn on whether such a shift constitutes a fundamental alteration or merely a reasonable modification. The Court's 2001 decision in *PGA v Martin* addressed the meaning of the term "fundamental alteration," but how that term will be applied in the case of public programs is unclear. A state might be expected to adopt a reasonable modification (for example, paying family members where such payments are lawful, the family member is found capable of carrying out the tasks and the service recipient in fact desires to receive care from a family member). Matters of high importance to family caregivers must be examined in light of the protections articulated in *Olmstead*, that is, discrimination exists when a public agency or program refuses to adopt reasonable modifications that would achieve integration more fully.

To understand how the distinction between fundamental alteration and reasonable modification becomes intensely factual, consider several issues of concern to families:

- ♦ **Medicaid eligibility.** To add new eligibility categories probably would constitute a fundamental alteration of a state plan. It would alter the basic design of the plan and apply to an entire class of eligible persons, not to specific individuals.
- ♦ **Medicaid coverage.** Previous decisions about Medicaid and the ADA suggest that a state can be ordered to expend additional funds to provide prompt coverage for both institutional and community services listed in its plan (*Olmstead* at 2188). But adding coverage where none existed appears to amount to a fundamental alteration although this standard (*Rodriguez v City of New York*) predates the *Martin* decision.

Whether requiring a state to add one or more classes of community services to a state Medicaid plan would be a reasonable modification or a change that alters an "essential aspect" or gives persons with disabilities a competitive advantage (in the quest for Medicaid resources) remains to be determined.

- ♦ **Medicaid service delivery.** Often what is needed is a change in the way in which existing covered services are delivered (for example, allowing non-licensed professionals to deliver personal care services where no special skills and qualifications are needed, altering fee schedules to encourage more participation by providers, allowing coverage for certain services in nontraditional settings, such as in-home therapies). In the context of service delivery, paying family members, if lawful under the statute, probably would be construed as a minor alteration in a state plan's operations, not a fundamental alteration.
- ♦ **Other public programs.** Housing, transportation, employment and social services also are critical to successful community residence. Is requiring a state to establish a new program component a fundamental alteration of an existing program? Examples include adding benefits for persons who need home modifications to a state's existing housing assistance and paying higher voucher rates so that housing benefits include an adaptation component. Is requiring a state to allocate more funds to certain services and away from other services a fundamental alteration? For example, could a state be ordered to downsize its institutions and allocate more long-term care resources toward other services?

The Individual Assessment Process

The Court was clear on the need for an individual assessment process: In deciding whether an individual can reside in a community, a state may rely on the

assessments of its own professionals. In *PGA Tours v Martin* the Court clarified further that deciding whether an alteration is a reasonable modification versus a fundamental alteration turns on the facts of each case. Nevertheless, many important aspects of the assessment process remain unaddressed, and no federal standards have been issued:

- ♦ **Access to the assessment process.** Who is eligible to seek an assessment? For example, only persons currently in institutions? Or persons at risk for inappropriate institutionalization as well? What procedures must states use to publicize the availability of the process and ensure access to it? Can the state use a passive process, i.e., await applications by individuals, or must it engage in “proactive” assessments, e.g., seeking out individuals who may require and want an assessment?
- ♦ **Waiting times and assessment timelines.** How long can individuals be made to wait for an assessment? How long can the assessment process take?
- ♦ **Conducting an assessment.** Who may conduct an assessment, and what professional qualifications must the individual have?
- ♦ **Elements of the assessment process and permissible assessment factors.** What must be covered—what factors are relevant and permissible in light of the ADA objectives—in an assessment? In assessing an individual, for example, can the state weigh the relative costs of community residence and institutional care (say, refuse community care if it costs more than 80% of anticipated institutional costs)? Can existing limits on services be considered, or must the process determine the feasibility of community residence with reasonable accommodations?
- ♦ **Appeals.** Must a written decision follow an assessment, with an opportunity for review? If so, who bears the burden of proof (the state or the individual)? Must the appeals process be capable of hearing new evidence and arguments for or against

community residence? Is the denial of a community placement as “inappropriate” subject to judicial review?

- ♦ **Implementation of assessment.** If community residence is determined to be appropriate, what is the slowest “reasonable pace” that a state can pursue?
- ♦ **Failure of the state assessment process.** At what point do flaws in a state’s own process mean the state may no longer “generally rely” on it? What substitute process then must be used?

Broader Planning Process

The *Olmstead* decision emphasized the importance of an “effectively working” plan for overall implementation. While several states have submitted plans, these tentative documents have not yet been analyzed. Among key questions are how states shape and carry out their planning processes, identify issues to be addressed, develop implementation timetables and cost estimates, and begin the actual implementation schedule.

REVIEW OF ADMINISTRATIVE COMPLAINTS FILED WITH HHS/OCR

In 2000, the George Washington University School of Public Health, Center for Health Services Research and Policy, undertook a review and typology of more than 200 administrative complaints filed nationwide with OCR during, just before, and after the Supreme Court’s decision (Rosenbaum and Stewart, 2001). The purpose was to gain a better understanding of the issues and needs of the “*Olmstead* class” for broader planning. All complaints were read and their elements were captured anonymously using an instrument developed for capturing important information about each case. Conducted with the support of OCR and the Center for Health Care Strategies in Princeton, New Jersey, this review will be updated periodically as more complaints are filed and resolved. The analysis of complaints sheds important light on issues germane to broader planning and to

the design of the individual assessment process.

While the complaints cannot be considered representative of the children and adults who have disabilities under the ADA and who are at risk for unnecessary institutionalization, they shed valuable light on the nature of the problem. As of June 2001, approximately 275 complaints had been filed with OCR. From the 216 that had sufficient detail for analysis comes this picture:

- ◆ Complainants live in all regions of the U.S., with particular concentration in HHS Regions I through VI (73% or 158 complaints). (Boston is Region I; New York; II; Philadelphia, III; Atlanta, IV; Chicago, V, Dallas, VI; Kansas City, VII; Denver, VIII; San Francisco, IX; and Seattle, X). The issue of inappropriate institutionalization that initially gave rise to *Olmstead* in Georgia is widespread.
- ◆ Individuals were the most frequent complainants (43%), followed by advocacy groups (33%) and family members (16%).
- ◆ Of the complaints with enough information to draw conclusions, one quarter involved adults ages 22-50, 9% involved adults ages 51-64, 5% elderly persons and 14% children and adolescents.
- ◆ Two out of three complaints involved institutionalized persons, with the remainder involving community residents. Among institutionalized complainants, more than two-thirds resided in nursing or psychiatric facilities, with nursing facilities dominant, suggesting that the primary diagnosis was not usually mental illness. Among children, hospital and psychiatric facility residence were more common.

“...complainants are of all ages and from all regions of the country, have significant levels of both physical and mental disabilities and have a heavy need for housing and in-home services.”

- ◆ Among community complainants, half resided with their families, a third lived without a family and the remainder of living situations could not be ascertained.
- ◆ Physical disability was most dominant among adults; among children under 21, mental illness was more dominant. Numerous complainants (18%) reported at least two classes of disabilities (i.e., mental illness, mental retardation/developmental disabilities, and

physical disabilities). Housing and in-home care dominated the service requests (60% together). Inadequate current service levels accounted for 15 percent. Housing requests were more common for

children under 21 than for adults ages 21-64 (28% versus 16% of all requests) suggesting that significant numbers of children had been removed from their homes or had families who could not house them.

In sum, complainants are of all ages and from all regions of the country, have significant levels of both physical and mental disabilities and have a heavy need for housing and in-home services. Many are on the verge of institutionalization. Among the two-thirds who already were in institutions, adults mainly lived in nursing facilities, while children were in hospitals and psychiatric facilities. Planning for adults seems to require creating more community housing and supports for persons with physical disabilities, while planning for children may entail more community residential programs for children with mental disabilities.

FEDERAL PLANNING GUIDANCE
AND STATE EFFORTS

Federal Planning Guidance

On January 14, 2001, OCR and HCFA issued joint guidance to assist states develop their broad based planning efforts

(www.ocr.gov/olmstead). This guidance provides a framework for planning, covering:

- ♦ Comprehensive effectively working plans.
- ♦ Plan development and implementation process.
- ♦ Assessments on behalf of potentially eligible populations.
- ♦ Availability of community-integrated services.
- ♦ Informed choice.
- ♦ Implications for state and community infrastructure.

“Anecdotal evidence from advocates and state websites suggests that most states are moving ahead with planning, either through executive order or legislation, and that in general states’ planning efforts are broad based in their involvement of community stakeholders, public agencies and programs.”

Presidential Executive Order and Followup Activities

On June 18, 2001, President Bush issued Executive Order 13217 affirming the United States’ commitment to community-based

alternatives and programs that foster independence and participation in the community. The order reiterates the ADA’s integration mandate, the controlling nature of the *Olmstead* decision and the need for “swift implementation” of the decision by all federal agencies. Expressly identified were the Attorney General and four Departments: Health and Human Services, Housing and Urban Development, Education and Labor. Agencies have been directed 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 persons with disabilities.” Notice of the review process and invitations to comment appeared in the July 27, 2001 *Federal Register* as part of HHS’s new freedom initiative.

Federal Funding and Technical Resources

The federal government has been vigorous in encouraging active planning and efforts to stimulate additional community resources . (See State Medicaid Directors Letter, Jan. 10, 2001, www.hcfa.gov/medicaid/smdl and www.hcfa.gov/medicaid/realchoice.) Of specific interest are:

- ♦ The Real Choice Systems Change grants program. This program initially provided states with small “starter grants” and has been followed by a \$50 million grant program whose goal is to implement improvements in the provision of home and community services.
- ♦ The Nursing Home Transitions/Access Housing 2001 Grants, whose purpose is to

- assist individuals in making the transition from nursing homes to communities.
- ♦ Systems Improvement Technical Assistance Grants.
- ♦ Community Based Personal Assistance Grants.
- ♦ Medicaid Infrastructure Grants for Employment of People with a Disability.
- ♦ Demonstration to Maintain Independence.

HHS also has formed a Working Group for ADA/Olmstead to develop federal policy and to respond to policy questions. (Interested persons can contact ADA/Olmstead@HCFA.gov.)

State Efforts

Anecdotal evidence from advocates and state websites suggests that most states are moving ahead with planning, either through executive order or legislation, and that in general states' planning efforts are broad based in their involvement of community stakeholders, public agencies and programs. States seem to understand the nature of the reforms needed to realize change, as well as the range of individuals whose concerns and needs should be heard through the planning process. Whether the planning process reflects the full range of issues raised by the decision and highlighted by the federal guidance is unclear. Moreover, it is not known whether states have implemented the individual assessment process and if so, for which individuals.

The George Washington University School of Public Health and Health Services, in its research support to OCR and implementing states, has developed a research template to identify state plans that appear to capture the elements of the federal guidance. Information will be disseminated as it becomes available. Particularly valuable websites for tracking state implementation of *Olmstead* are:

- ♦ The David Bazelon Center's www.bazelon.org
- ♦ The National Association of Protection and Advocacy Systems www.protectionandadvocacy.com.
- ♦ The National Conference of State Legislators www.ncsl.org.

“The Olmstead decision represents a fundamental shift in the legal and social framework for measuring how public agencies spend public resources in serving persons with disabilities.”

In addition, a number of states have posted their state plans at their state websites. Finally, families may wish to consult with the OCR in their HHS region to determine where

their state stands with respect to planning and implementation of the decision and to identify contact persons.

CONCLUSION

The *Olmstead* decision represents a fundamental shift in the legal and social framework for measuring how public agencies spend public resources in serving persons with disabilities. The case stands for the proposition that unnecessary institutionalization and failure to make reasonable modifications in public services to accommodate community residence constitute legal discrimination under the ADA.

The case calls for two levels of implementation. The first is broad planning to redesign existing programs and services to meet the needs of persons with disabilities. The second is an individualized assessment process. This assessment must consider the situation of qualified persons who need services in order to reside in the community and to avert unnecessary institutionalization. Complaints filed with HHS/OCR suggest that these persons span all ages and types of disabilities and are in particularly great need of in-home medical, health and support services as well as housing. Broad planning

efforts appear to be well under way, but less is known about states' progress in establishing and structuring their individualized assessment programs.

Family caregivers need to be involved in both dimensions of change. In virtually every state there are active *Olmstead* planning efforts in which families can become involved.

Organizations that may be able to provide information about planning efforts include state protection and advocacy (P and A) agencies; state chapters of such organizations as Family Voices, AARP and other consumer organizations; and the state Governor's Office.

The individualized assessment process is the dimension that raises more immediate concerns. An individualized assessment process may be housed in a single comprehensive service agency. Or it may be scattered across agencies, e.g., the state Medicaid agency (for persons residing in Medicaid facilities), the mental health agency (for residents of mental illness institutions), the Medicaid program (for persons who need home care), the public housing agency (for persons who need public housing). Who is in charge of designing and overseeing the process is unclear, although presumably this flows from the broader planning process. It is also unclear what happens if states fail to establish these processes or limit them to certain classes of individuals or residential settings.

While much is not yet known about the scope or timeline for *Olmstead* implementation, it is known that the decision has had a profound impact on how public policymakers understand the ADA and its protections for persons with disabilities. It is equally clear that while the process may take a long time, the decision will permanently alter the care landscape for persons with disabilities because it is grounded in the ADA, a sweeping law. Finally, family involvement in the implementation of *Olmstead* is central to

creating community services for persons with disabilities.

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