

medicaid
and the uninsured

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THE OLMSTEAD DECISION: IMPLICATIONS FOR MEDICAID

In June 1999, the Supreme Court ruled in *Olmstead v L.C.* that states were required to provide services to persons with disabilities in community settings rather than institutions, if certain conditions are met. This Policy Brief provides an overview of the *Olmstead* case, including the facts, the court ruling, and the disposition of the case. Further, the brief describes the issues surrounding implementation and the implications this ruling could have on state Medicaid programs.

OVERVIEW

Olmstead v L.C. ex. rel. Zimring is a landmark ruling, which held that the Americans with Disabilities Act (ADA) prohibition against discrimination in the administration of public programs prohibits states from unnecessarily institutionalizing persons with disabilities as a condition of receipt of publicly assisted medical care. The *Olmstead* decision also held that a state can be required to provide community-based services to individuals for whom institutional care is inappropriate, if such services represent a reasonable accommodation and do not require the state to “fundamentally alter” its public programs. Federal and state officials are now deeply enmeshed in the task of translating this broad ruling into workable standards for measuring what constitutes adequate state performance.¹

It is important to stress that *Olmstead* is not a Medicaid case; the decision alters neither the individual entitlement nor states’ basic legal obligations. The ruling construes the requirements of the ADA; indeed, the Court dismissed as irrelevant to its ruling assertions by the states’ lawyers that Medicaid favored the financing of institutional care.²

Nonetheless, the decision heavily implicates Medicaid. *Olmstead* concerns the obligations of states toward persons with disabilities under the ADA in relation to the *entire fabric and structure* of state health budgets and describes the remedial steps that states must take to eliminate institutional bias from their public spending. Because Medicaid is such an important source of financing for both institutional and community-based services for persons with disabilities, the focus on Medicaid 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 of*, rather than required by, the decision.³

Moreover, the impact of *Olmstead* will be felt nationally, and not simply because the decision was issued by the Supreme Court. While the case arose as a result of the institutionalization of two women in a single state, as of January, 2000, the Director of the HHS Office for Civil Rights reported that his office had received some 30 ADA complaints by persons with disabilities who alleged discrimination in the provision of health services on the basis of unnecessary institutionalization. Thus, every state is involved in post-*Olmstead* planning.

The *Olmstead* ruling is complex and raises many complicated issues of enforcement, as do all desegregation cases. In a sense, the decision can be thought of as a *Brown v Board of Education* for institutionalized persons with disabilities. Writing for the Court, Justice Ginsburg articulated what is essentially an “all deliberate speed” standard for measuring the appropriateness of the state’s response in developing community care services for persons who have been inappropriately placed in medical institutions. While the decision provides limited but a crucial amount of guidance regarding the circumstances under which this “deliberate speed” standard has been met, it also recognizes a series of important interests that must be taken into account in measuring what constitutes adequate movement on the part of states. It is the balancing of these interests in the formation of remedial plans that will prove to be of critical importance in the coming years.

THE FACTS

Olmstead involved two women, L.C. and E.W.. Both had mental retardation and mental illness: L.C. had also been diagnosed with schizophrenia, and E. W., with a personality disorder. Both women had been treated in institutions and remained there even after their conditions had stabilized and treating providers had concluded that their needs could be “met appropriately in one of the community-based programs the State supported.”⁴ The women could not obtain care in a community setting, however. The facts of the case indicated that the state agreed to furnish the care only through its Medicaid home and community waiver program but in fact was operating the program at only a third of its federally approved size (approximately 700 placements available out of 2100 approved placement slots, a fact specifically noted by the Court in dismissing the state’s assertions regarding Medicaid’s institutional bias). 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 attempted to discharge at least one of the plaintiffs to a homeless shelter and then subsequently rescinded the order.

COURT RULING

At issue in the case were the regulations that implement Title II of the ADA and that require states to operate public programs in a non-discriminatory fashion and to furnish services in the most integrated setting.⁵ The central question raised was “whether the proscription against discrimination [under Title II] may require placement of persons with mental disabilities in community settings rather than institutions.”⁶ The answer, according to the Court, was a “qualified yes”:⁷

The Court first held that “unjustified institutional isolation of persons with disabilities is a form of discrimination,”⁸ noting the history of institutionalization as a means of segregating and demeaning persons with serious disabilities, as well as the stigma that flows from being restricted in the receipt of public assistance to institutional status. In describing the stigma that flows from this type of treatment, the Court specifically drew a parallel to race discrimination, suggesting at least that it views discrimination against persons with disabilities as raising the same fundamental level of Constitutional concern that arises in cases alleging racial discrimination.⁹

*** 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. *** Second, 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. ***¹⁰

The Court then reached the more difficult part of the decision: articulating the remedy. In approaching the issue of what was necessary to rectify this type of discrimination, the Court was mindful of the fact that the “state’s responsibility is not boundless”¹¹ and that the needs of persons who required institutional services had to be weighed against those of persons who could reside in community settings. The Court also emphasized that “nothing in the ADA *** condones termination of institutional settings for persons unable to handle or benefit from community settings *** [n]or is there any federal requirement that community based treatment be imposed on patients who do not require it.”¹² The Court further emphasized that its decision was not meant to trigger inappropriate de-institutionalization, nor should be read as condoning placement in inappropriate settings (at one point the state of Georgia had prescribed discharge to a homeless shelter as its “treatment” for one of the plaintiffs; the “treatment plan” was later rescinded).

The Court then turned to the considerations that weighed in its decision regarding what constituted an appropriate remedy. First, it held that the state could “generally” “rely on the reasonable assessments of its own professionals” in determining if individuals were eligible to live in community placements,¹³ noting that without such an assessment it would be “inappropriate” to de-institutionalize a patient. Second, it held that under the reasonable

modifications standard that applies to publicly assisted programs, the state's duty was not to make "fundamental alterations in its services or programs but only those modifications that would be needed to avoid discrimination."

Third, the Court recognized that the needs of each individual for who community care was appropriate did not need to be considered in isolation. It specifically left open to states a "fundamental alterations" defense that would allow them to balance the *aggregate* needs of individuals in need of community services with those of other persons, rather than the more limited, *individual-specific* balancing test favored by the plaintiffs, which would have considered only the cost of institutional care for an individual against the cost of caring for the person in a community setting.¹⁴

*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.***¹⁵*

DISPOSITION OF THE OLMSTEAD CASE

Following the Court's ruling, the case was returned to trial court for a determination by the judge regarding the reasonableness of the state's plan in light of the standards set forth in the opinion. Because of the complex factual issues that arise in determining whether a state's desegregation plan is reasonable and consistent with broad overarching standards that are themselves relatively ambiguous, it may take a considerable amount of time before the first post-ruling decision regarding the reasonableness of a state's plan occurs. In the meantime, the HHS Office for Civil Rights is attempting to negotiate settlements in the large number of *Olmstead* cases that have been filed, while the Health Care Financing Administration (HCFA) is attempting to provide guidance and technical assistance regarding the extent to which Medicaid funds can be used to design community services.

IMPLEMENTATION OF OLMSTEAD

HCFA/OCR GUIDANCE

In their recent letter to state Medicaid directors, HCFA and the Office for Civil Rights provide limited guidance regarding whether and how they will measure compliance with the decision.¹⁶ The letter urges states to develop "comprehensive effectively working plans for placing qualified persons with disabilities in the most integrated setting appropriate" and to maintain a "waiting list that moves at a reasonable pace." In short, the letter repeats the decision itself, without shedding further light on the precise elements of the "working plan", the process by which such working plan is to be devised, or what is meant by a waiting list that moves at a reasonable pace.

Most fundamentally perhaps, the letter does not address the question of when modifications will be considered “reasonable” and when they will be considered “fundamental.” Would adding services to a state’s Medicaid plan in order to strengthen community programs be considered a “fundamental” alteration? Would additional state expenditures aimed at utilizing all federally approved community service waiver slots be considered to be a fundamental alteration?¹⁷ Indeed, it is unclear what the frame of reference will be for measuring reasonable versus fundamental. Is it a state’s Medicaid long term care budget? Its long term care budget for community services? The entire state Medicaid budget? The entire state investment in health services? The Court’s focus on the state’s entire pattern of public expenditures rather than only its Medicaid program would seem to argue for the latter, in which case, the expansion of home and community expenditures under Medicaid would represent only a modest proportion of state spending. But the decision really offers no answer to this question.

The State Medicaid Directors’ letter does not explore these matters. As noted, the letter does clarify that the plan must be devised to consider the needs of all persons with disabilities, not merely those with mental disabilities. However, the letter does not address the myriad issues that will arise in how the Department, in its oversight of both the ADA and Medicaid, will measure state compliance, nor does it address the data that will be required in order to document state action. This failure to set standards or the means for measuring their compliance is consistent with nearly a decade of federal response to the political pressures of federalism, with extensive discretion left to states to determine what is meant by compliance with federal legal requirements and how that compliance will be demonstrated.¹⁸ It also underscores the critical role played by courts in discrimination cases such as *Olmstead* in which federal oversight and enforcement agencies effectively elect not to set compliance standards (perhaps out of fear of being unable to defend them) and in effect relinquish control over the setting of standards to lower courts faced with the implementation of the remedial order.

ISSUES

Olmstead raises critical issues in implementation:

1. The scope of the decision: all persons with disabilities

Olmstead concerned persons with mental disabilities, and in fact, persons with serious mental disabilities may suffer more significant bias than other persons with disabilities in need of ongoing care. Nonetheless, both HCFA and OCR have made clear that the federal government considers the ruling to cover all persons with disabilities, not just those with serious mental illness.¹⁹

2. The frame of reference: aggregate, rather than individual, needs

As noted, the decision makes clear that courts and other enforcement efforts must examine the aggregate needs of all persons with disabilities, not just those of

particular individuals who at a given time may be inappropriately institutionalized. In essence, the Court recognized that fashioning proper health policy in view of limited resources necessitates consideration of a range of health care needs and an attempt to balance those needs in order to achieve a reasonable outcome. In stressing its concern over the potential for its decision to lead to the inappropriate de-institutionalization of persons who required institutional care, or to spawn a deluge of grossly underfinanced and inadequate “community” programs (such as a discharge to a homeless shelter), the Court effectively sought a balanced and thoughtful approach to the issue of remedies. The test articulated by the Court effectively requires states to be able to show that they are making a reasonable effort to achieve the goals of the ADA while not placing either themselves – and more importantly persons with disabilities — in untenable situations.

3. The range of services implicated: *medical*, not just *Medicaid*, services

As noted, this case is not about the structure of state Medicaid long-term care budgets but rather how states, in budgeting their public programs, avoid institutional bias against persons with disabilities in their administration. A state could decide to develop an *Olmstead* plan without any reference to Medicaid whatsoever, electing instead to finance improved community services entirely out of state and local funds combined with alternative federal resources such as funds allocated under the Mental Health Services Block Grant.

Such a result is unlikely, however, since the cost of providing medical care in community settings is considerable and regardless of any possible institutional bias in Medicaid, the program nonetheless offers numerous options for financing community-based health services both as state plan options and through the use of special federal waivers of otherwise applicable limits on Medicaid funding. Furthermore, to the extent that a state in the face of the *Olmstead* decision fails to make at least those changes in its Medicaid program that would be required to eliminate institutional bias from its services for persons with disabilities, then it presumably could be found ineligible for federal Medicaid funding until it brought its program into compliance with the requirements of the decision.

4. Measuring compliance with *Olmstead*

The decision provides some clues as to how compliance is to be measured. One measurement would be the proportion of persons in institutions for whom a finding of medically appropriate placement does not exist. Another is the length of the waiting list in relation to need and the amount of time spent awaiting community services.²⁰ A third measure might be persons in community placements who are adjudged to be receiving care reasonably appropriate to their needs. A fourth measure would be the proportion of persons for whom a medical need for institutional care exists who are in fact able to obtain services in institutions.

How the courts will decide what is “reasonable” is an extraordinarily factual and state-specific question. The decision does appear to suggest that at some point it is fair for a court to scrutinize the level of resources that states are investing in the development of appropriate community services. In this regard, the revenues received in the recent tobacco litigation settlement, the windfalls from welfare reform, and the overall health of state economies may

become relevant to the decision. Courts historically have been loathe to scrutinize state decisions regarding their dollar expenditure levels, and health services for persons with disabilities compete with many other pressing concerns. At the same time, however, the critical role of *Olmstead* in trying to frame a bottom line for what is “reasonable” under federal law cannot be over-stated.

Rethinking Medicaid in Light of *Olmstead*

Because states are left with enormous discretion in the wake of *Olmstead*, the most compelling issue for future research is how states in fact use the opportunity and responsibility of the decision to rethink and reshape their Medicaid programs, and the process they employ for doing so.

Observers generally agree that *Olmstead* has in fact generated a great deal of thought on the part of states regarding how they use the public resources available to them to provide services and supports to persons with disabilities. Essential to the development of community based services and supports for persons with long term care needs is an overall strategy for managing physical and mental health needs, whether preventive, acute, or ongoing. In a world in which health care and health care financing are fully integrated through organizations that provide and arrange for vertically integrated care, the need grows for the development of “niche” entities able to conform their own activities with other services essential to the proper support of persons with chronic conditions who live in the community.

Several studies suggest that states increasingly are extending their managed care initiatives to cover persons with long term health care needs. *Olmstead* may hasten and intensify this trend. At the same time, the evidence also suggests that there are only a limited number of entities with the range of skills, networks, and expertise necessary to deliver this sophisticated form of managed care service. Additionally, relatively little is known regarding how to fashion compensation and incentive arrangements in ways that promote effective services and supports and deter inappropriate care and underservice. Development of such models and techniques is essential if states are to avoid exactly the outcome that the Justices feared: the inappropriate care of persons in communities. Thus, one of *Olmstead*’s most important consequences may be to further stimulate the development of long term, community-based, integrated service approaches for persons with disabilities.

Olmstead also underscores the needs for benchmarks and measures of the reasonableness of investment in community services. In a very real sense, there is virtually no person with a disability who could not, with proper services and supports, live in a community setting. The question is at what point the re-orientation of a state’s health and human services budget to achieve the goals embodied in the ADA so large that it can be classified as a fundamental alteration. States add Medicaid services all the time and shift public spending constantly. Is there no point at which the revision becomes fundamental? If the answer is somehow tied to overall state budgets, then in the current economy is it reasonable to expect therefore that all persons with disabilities will be accommodated in community settings? If not, then how does society draw the line? The Court clearly anticipated that such a point would be

reached and listed a series of markers for setting the parameters of the required response. But these markers are broad, and there are little to no data to measure when they are achieved.

As with all resource allocation decisions in health policy, it is probably safe to say there is no one answer, only a range of answers. Indeed, it may be that the most important single issue in answering what is reasonable is the process that a state uses to reach its answer. If a state planning process sets its services and spending modification limits with minimal involvement of affected parties, and fails to ask the right ethical questions in working through the resolution, the answers that it reaches may in fact be incorrect regardless of what they are. Like so many questions of health ethics in resource allocation, the proper pathway to resolving the quandary of *Olmstead* may lie as much in the process that is used to travel the pathway as in the ultimate answers that are reached. It may be in the articulation of the process that will be used to resolve these questions that the federal government can ultimately make its most important contribution.

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Endnotes

¹See January 14, 2000 State Medicaid Directors letter from Timothy Westmoreland, Director for Medicaid and State Operations and Thomas Perez, Director, Office for Civil Rights, regarding HHS implementation plans. <http://www.hcfa.gov/medicaid/smd1140a.htm>.

² 119 S. Ct. at 2187. Indeed, the Court noted that in recent years, Medicaid has been dramatically altered to expand the options for the treatment of persons in communities and that at the time of the decision, the state had used only 700 of 2100 home and community service waiver slots approved for use by HHS.

³ It should be noted that while *Olmstead* focuses on the ADA, separate provisions in the Medicaid statute would prohibit the expenditure of federal funds on the unnecessary institutionalization, as well as the imposition of unreasonable limitations (such as excessively long waiting periods) on the provision of covered services in community settings. *Benjamin v Ohl* Civ Action No. 3:99-0338 (S.D.W. Va., 1999) and *Cramer v Chiles*, 33 F. Supp. 2d 1342 (E.D. Fl., 1999).

⁴ 119 S. Ct. at 2183

⁵ 28 C.F.R. 35.130

⁶ 119 S. Ct. at 2181

⁷ *Id.*

⁸ *Id.* at 2187

⁹ *Id.* at 2187.

¹⁰ *Id.*

¹¹ *Id.* at 2188

¹² *Id.* at 2187-2188.

¹³ *Id.* at 2188.

¹⁴ *Id.* at 2188-2189.

¹⁵ *Id.* at 2189.

¹⁶ State Medicaid Letter, January 14, 2000. www.hcfa.gov.

¹⁷ The Court's notation, *supra*, regarding the state's failure to use its waiver slots would suggest not, but the discussion on this point certainly is unclear.

¹⁸ For example, in *Madison Hughes v Shalala*, 80 F. 3d 1121 (6th Cir., 1996) the Court of Appeals for the Sixth Circuit held that federal civil rights laws do not require the Secretary of HHS to require the provision of race-based data to demonstrate compliance with the requirements of Title VI. I

¹⁹ State Medicaid Directors Letter, *op. cit.*, p. 2.

²⁰ As the *Benjamin* case, which concerns the need for community placement services underscores, waits of years may not be unusual at this point.

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