



# Is Community Care a Civil Right? The Unfolding Saga of the *Olmstead* Decision

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**OVERVIEW** — This paper lays the groundwork for understanding the implications of the historic U.S. Supreme Court decision in the case of *Olmstead v. L.C.*, which has far-reaching consequences for the long-term care of people with disabilities. The paper reviews the critical components influencing the case: the Medicaid program's role in funding community-based long-term care; the Americans with Disabilities Act, which serves as the statutory basis for the decision; and the Court's legal reasoning. Also, the paper describes the federal and state responses to the ruling and concludes with a brief discussion of some legal issues that will be debated in the courts.



ruling is a brief review of Medicaid's evolving role in financing home- and community-based care.

Medicaid is the nation's primary payer of long-term care services, paying 44 percent of such costs in 2000.<sup>3</sup> Twenty-seven percent of that amount pays for services delivered in home- and community-based settings. This represents a four-fold increase in such Medicaid expenditures since 1990. Despite this growth, however, there remains substantial unmet demand, and waiting lists for services are common.<sup>4</sup>

One of the major barriers to enhancing the supply of home and community-based care has been the institutional bias of Medicaid, that is, its historic inclination to cover long-term care services more readily when the beneficiary resides in an institution, such as a nursing home, than when he or she lives at home. When Medicaid was created in the 1960s, the home health care industry was not very developed, and Medicaid's service coverage for long-term care was focused on nursing homes. The only mandatory coverage of long-term care services was for skilled nursing facility care for people age 21 and older, although states had the option of providing some home health services, private-duty services, and rehabilitation services.<sup>5</sup>

There were a few additions to home-based services during the 1970s, such as mandatory coverage of home health services for those entitled to skilled nursing facility services. However, a broad range of home- and community-based services were not added. Policymakers feared runaway costs would result from induced demand, also referred to as the "woodwork effect."<sup>6</sup> Consequently, the vast majority of Medicaid long-term care spending continued to be for nursing home care.<sup>7</sup>

In the late 1970s and early 1980s, a series of demonstrations were conducted to measure whether providing community-based services to a Medicaid beneficiary was less expensive than institutional care.<sup>8</sup> These studies helped generate policymaker interest in using home- and community-based services as a substitute for nursing home care, even before many of these demonstrations were evaluated. In 1981, Congress amended Section 1915 of the Social Security Act, authorizing states, subject to federal approval, to cover home- and community-based services under a waiver program.

Under the Section 1915(c) waiver authority, states could provide home- and community-based services to specific Medicaid populations such as the aged disabled and people with mental retardation or developmental disabilities. The law listed several types of services allowed under a waiver (for example, homemaker, home health aide, and adult day health) but also permitted other services, as long as they were cost-effective and necessary to avoid institutionalization.<sup>9</sup>

The growth of Medicaid home- and community-based care, however, was restrained by waiver policies and procedures to protect against the woodwork effect. First, the population eligible for a waiver was restricted

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by requiring that the person not only needed the care but also, after an assessment, was determined to be at risk for placement in an institution. Second, the maximum number of people that could be placed in a waiver was capped based on a formula (frequently referred to as the “cold bed rule”) that measured bed vacancies in nursing homes. Third, in response to great concern over costs at the federal level, especially within the Office of Management and Budget, the size of the waiver programs and the pace of approvals were restrained.<sup>10</sup>

The major breakthrough came in 1993 when President Clinton announced to the nation’s governors that the Centers for Medicare and Medicaid Services (CMS, then named the Health Care Financing Administration) would provide greater waiver flexibility for states. The next year CMS eliminated the cold bed rule. In its place, CMS substituted a more flexible cost-neutrality requirement, under which states had to demonstrate that aggregate expenditures with the waiver program would not exceed the cost of serving an equivalent group of people in an institution.

The result was a dramatic increase in state spending for home- and community-based services. In 1990, Medicaid spent \$3.9 billion on home and community-based care, representing 13 percent of total Medicaid long-term care spending. By 2000, the amount had increased more than four-fold, to \$18.2 billion, or 27 percent of total Medicaid spending for long-term care.<sup>11</sup> In 1999, 49 states had 212 waivers serving a total of 688,152 people.<sup>12</sup>

Despite these improvements, a number of factors still discourage the growth in Medicaid home- and community-based care. One is a payment policy that does not cover housing or meal costs in the home-based setting, although Medicaid does factor these costs into payments to nursing homes. This distinction furthers the contention that an institutional bias against home- and community-based care still exists.

Another factor is states’ concern over their budget outlays. With Medicaid second only to education as the largest state expenditure, states have moved to control home- and community-based service costs by restricting (by age and conditions) the populations eligible for the services, the number of slots for each waiver, the service cost per person, and the covered services. In addition, states may be cautious in filling all approved slots, preferring to wait until they are confident that sufficient monies are available for the state match.

The cumulative effect of these factors has been numerous waiting lists for waiver programs. For example, one report noted that in the mid-1990s New Hampshire had a waiting list of 325 people; New Mexico, 2,400; Massachusetts, 2,437; Florida, 6,000; and Texas, 17,500.<sup>13</sup> The lists can be so long that some people wait years before receiving services.<sup>14</sup> This shortage of a full array of readily available home- and community-based services created the environment for the *Olmstead* decision.

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## THE AMERICANS WITH DISABILITIES ACT

The second critical component in the *Olmstead* ruling is the Americans with Disabilities Act. A civil rights law administered by the Department of Justice, the ADA was enacted “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”<sup>15</sup> Fifty-four million people are protected by the act,<sup>16</sup> which defines a disability as a physical or mental impairment that substantially limits one or more of the major life activities.<sup>17</sup> (See text box for examples of disabilities protected by the ADA.)

The primary goals of the law are to assure that people with disabilities enjoy the greatest degree of independence possible and to assist in their full participation in the economy and their community. The law provides them legal recourse when they have been subject to discrimination.

The opening provisions of the act identify as a form of discrimination the keeping of people in institutions and the failure to make modifications to existing programs and practices to end isolation from the community.<sup>19</sup> The specific ADA section that serves as the basis for the *Olmstead* case is Title II, which sets forth requirements for public entities, including state government and health care services that are funded and administered by state agencies.<sup>20</sup> Title II prohibits people with disabilities from being “excluded from participation in or...denied the benefits of the services, programs, or activities of a public entity, or...subjected to discrimination by any such entity.”<sup>21</sup> These prohibitions in the ADA provided the legal basis for people with disabilities to sue states.

Under the authority of the ADA, the Department of Justice promulgated Title II regulations, two of which are important in the Court’s *Olmstead* decision. The first, sometimes referred to as the “integration regulation,” requires a state to administer services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>22</sup> The most integrated setting is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”<sup>23</sup>

The second key regulation, sometimes referred to as the “reasonable-modifications regulation,” says a state “shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the [state] can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.” Requiring significant new expenditures or immediately closing institutions can be considered fundamental alterations in the nature of a program.

The combination of the two regulations results in a mandate that has some caveats: a state must provide services to people with disabilities in an integrated community setting unless it can prove that the act of compliance would be so great that it constitutes a fundamental alteration.<sup>24</sup> While these two regulations had been in place for years, the

## Disabilities Covered by the ADA

To allow for the future inclusion of currently unrecognized conditions, the statutory language is nonspecific. The regulations nonetheless provide many illustrative examples when defining impairments and limits of major life activities that can result in disability.

■ A “physical or mental impairment” includes any physiological condition, cosmetic disfigurement, or anatomical loss affecting one or more of the body systems. It includes any mental or psychological disorder such as mental retardation, organic brain syndrome, emotional or mental illnesses, and learning disabilities.

■ In defining “substantially limits one or more major life activity,” the regulations include activities such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.<sup>18</sup>

Supreme Court had not handed down a Title II ruling on them until it agreed to hear the *Olmstead* case, which involved two people seeking community-based placement.

## THE FACTS OF THE CASE

Despite the complexity of the *Olmstead* decision, the specifics of the case are straightforward. Two residents of Georgia Regional Hospital in Atlanta (GRHA), a state psychiatric hospital, sought placements in the community.<sup>25</sup> One had a diagnosis of a developmental disability (DD) and the other of mental retardation (MR). Both had co-occurring mental illnesses and histories of treatment in institutional settings. When their conditions had stabilized, they sought placement in a community setting. The GRHA treatment professionals agreed that the needs of these residents could be met in a community-based program. And Georgia had slots available under a Medicaid home- and community-based services waiver for people with MR/DD. Nonetheless, the plaintiffs remained institutionalized well after their request for community placement.

They filed a suit against the Georgia Department of Human Resources, then led by Commissioner Tommy Olmstead. The suit alleged that the state's failure to discharge them to a community-care residential program was a form of discrimination prohibited by the ADA.

The first court to hear the case, a district court, ruled that the state violated the ADA by segregating the plaintiffs in an institution rather than placing them in an integrated setting under the state's community-based services program. The 11<sup>th</sup> U.S. Circuit Court of Appeals agreed that the plaintiffs were protected by the ADA and had been victims of discrimination. The state appealed the rulings and the U.S. Supreme Court agreed to hear the case.

## THE SUPREME COURT DECISION

### ADA-Prohibited Discrimination

The Supreme Court agreed with the lower courts' judgements that the plaintiffs were protected by the ADA and had been subjected to state discrimination by being kept in an institutional setting. The decision that the plaintiffs were victims of discrimination is significant in and of itself, for it rejected the method commonly used by the Supreme Court in determining discrimination.

In the past, courts have often determined whether there is discrimination by comparing two classes to see if one group (or class) of people received preference over the other (for example, black persons and white persons, males and females, or aged and nonaged). This common method of determining discrimination set an impossibly high standard for the disabled because it would require evidence that the nondisabled persons

were receiving services that the disabled did not receive. Since the nondisabled did not need the types of services the disabled needed, it was very difficult to demonstrate discrimination.

The majority opinion recognized that discrimination could also occur within a class, such as people with disabilities (that is, the denial of services to one group of people with disabilities but not to another).<sup>26</sup> This new method enables a person with disabilities not in a waiver program to prove discrimination when similarly disabled persons are receiving community-based services under a Medicaid waiver.

### **Rights of People with Disabilities to Community Services: The Qualified Yes**

The Court then ruled that the ADA regulation mandating that services be administered in the most integrated setting can be used by people with disabilities to demand placement in a community setting. People with disabilities were handed a new tool that greatly enhanced their ability to obtain services in a home setting.

At the same time, however, the Court noted that the requirement to provide community services is not absolute. The Court ruled that, before requiring a state to transfer people with disabilities to a community setting, three conditions must be met: (a) "the State's treatment professionals have determined that community placement is appropriate," (b) "the transfer from institutional care to a less restrictive setting is not opposed by the affected individual," and (c) "the placement can be reasonably accommodated [by the state], taking into account the resources available to the State and the needs of others with mental disabilities."<sup>27</sup>

The first two conditions of the judgement protect the patient. The Court wanted to avoid creating an incentive for states simply to empty their hospitals to save money. In a concurring opinion, Justices Anthony Kennedy and Stephen Breyer noted that past attempts at deinstitutionalizing the mentally ill had a "dark side," in which a massive depopulation of mental hospitals overwhelmed the limited capacity of community providers, often leading to little or no treatment and a life of homelessness.<sup>28</sup> And the majority opinion noted that patients cannot be transferred without their approval, because there are not "any federal requirements that community-based treatment be imposed on patients who do not desire it."<sup>29</sup>

The third condition of the judgement, "placement can be reasonably accommodated," provides some protection for the state. The Court opinion notes that the state's obligation to provide services in an integrated (that is, community) setting to people with disabilities is "not boundless." Although a significant portion of the majority opinion focused on this issue, determining the reasonableness of a proposed state action or inaction has proved to be one of the most problematic

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aspects of the Court's guidance. Despite the Court's best efforts, reasonable accommodation has been a source of contention in the subsequent federal court lawsuits between advocates and states.

### **The Grey Area between "Reasonable Modification" and "Fundamental Alteration"**

In crafting the third condition for requiring community placement, the Court noted that the ADA Title II reasonable-modifications regulation allows a state to discriminate if the proposed modification would fundamentally alter the nature of the program. The next step for the Court was to provide guidance in determining the point at which a proposed modification (for example, a community placement) becomes so extensive or expensive that it constitutes a fundamental alteration in the program and, therefore, relieves the state of the requirement to provide such services.<sup>30</sup>

Determining the appropriate method for considering these costs and the point at which the costs of compliance become too great was the most nettlesome issue for the three courts that ruled on the *Olmstead* case. Each had a different interpretation.

The District Court ruling originally decided that, since the average cost of providing services to the two plaintiffs in a community setting would be less than the average cost of providing services in an institutional setting, the modification was reasonable.<sup>31</sup> The 11<sup>th</sup> Circuit Court of Appeals found that definition of costs too narrow. It said that when looking at the costs of a remedy, the courts should consider "whether the additional expenditures [for home- and community-based services]...would be unreasonable given the demands of the State's mental health budget."<sup>32</sup>

The Supreme Court found both of the lower courts' consideration of costs to be "unacceptable." By limiting the consideration of expense to placing one or two people into a community setting "against the State's entire mental health budget, it is unlikely that a State...could ever prevail." The majority opinion argued that the courts must also consider "the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably."<sup>33</sup> Hence, the Supreme Court included the third prong of its judgement: "taking into account the resources available to the State and the needs of others with mental disabilities."

### **The Court's Example**

The three-pronged judgement, as powerful as it is, is still rather vague and subject to differing interpretations in determining the acceptable cost of compliance. The Court seems to have implicitly acknowledged that developing a single methodology capable of balancing the rights of the disabled and public-sector costs in all states and in all circumstances was futile. In the absence of a methodology, Ginsburg wrote, there were

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alternative ways for a state to demonstrate compliance. She even provided an example, writing that, “if, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings” and “a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated, the reasonable modifications standard would be met.”<sup>34</sup>

This example has become synonymous with the *Olmstead* judgement,<sup>35</sup> serves as the critical pillar in the subsequent CMS guidance, and was instrumental in launching dozens of state task forces and workgroups charged with developing “a comprehensive, effectively working plan.” As noted later, the example may also be an important factor in ensuring that, in the long run, states continually enhance the supply of community-based long-term services.

The *Olmstead* ruling is truly a landmark decision. The ruling that discrimination can occur within a class makes it easier to sue states successfully for providing Medicaid waiver services to some people with disabilities but not others. The decision reinforces the ADA goal of integrating people with disabilities into the community. And it puts states on notice that they will have to justify to the courts a decision to deny a person with a disability from receiving care in a community setting. It is not surprising that the response to the ruling was broad-based and immediate.

## EXECUTIVE BRANCH REACTION

The *Olmstead* ruling elicited a powerful response from federal policymakers in the executive branch. Across two administrations, it has served as the catalyst for a sustained state grant program, an innovative approach to providing state technical assistance, and a broadening of federal agency involvement.

### The Clinton Administration: Swift Response

**Guidance** — The Department of Health and Human Services (DHHS) alerted states about the significance of the *Olmstead* case immediately after the decision was handed down. Six months later, CMS issued guidance suggesting activities that states should be doing to comply with the ADA.<sup>36</sup> In the guidance, a set of six principles was issued (see text box), with each principle including several suggested best practices that states should consider adopting in their plans.

Although the guidance is not legally enforceable as a regulation (only the Department of Justice can issue ADA regulations), CMS stated that a state’s conformance with these principles and practices would be considered by the DHHS Office for Civil Rights when it investigates ADA complaints and conducts ADA compliance reviews.

### DHHS Principles for State Compliance with the ADA

- Develop and implement a comprehensive, effectively working plan.
- Provide an opportunity for the public, including people with disabilities, to be integral participants in the plan.
- Take steps to prevent or correct unjustified institutionalization.
- Ensure the availability of community-integrated services.
- Afford people with disabilities the opportunity to make informed choices.
- Take steps to ensure quality assurance in the delivery of community-based services.

The department also issued revised Medicaid rules to enable more low-income people with disabilities and families with disabled children to obtain Medicaid coverage while living at home.<sup>37</sup> The rule allows a state, under its medically needy program, to disregard portions of a person's income used to pay for food, clothing, or housing. This change helps reduce the institutional bias that lets people living in institutions qualify for Medicaid at higher income levels than if they lived in the community.

**New Grants and Technical Assistance** — The Clinton administration and Congress also authorized \$64 million for three grant programs, under an initiative called Systems Change Grants for Community Living. These grants are to assist states in developing and implementing plans to meet *Olmstead* guidance.<sup>38</sup> The largest program, Real Choice Systems Change, provides states with grant funds to make infrastructure improvements in personal assistance services, quality assurance, consumer-directed care, comprehensive long-term care system reforms, and other similar efforts to assist people with disabilities in receiving quality home-care services.

A second program, Nursing Facility Transition, provides grants to either state agencies or community organizations. The grants support activities to assist in the transition of individuals who are in an institution (or are at risk of requiring a nursing home placement) to a community-integrated living arrangement. The third grants program, Community Integrated Personal Assistance Services and Support, assists in efforts to increase the use of consumer-directed personal care and the availability of personal care workers.

Supplementing the systems change grants is a national technical assistance and evaluation exchange collaborative to help states in implementing their grants and *Olmstead* plans. The collaborative exchange includes two national organizations (Rutgers Center for State Health Policy and Independent Living Research Utilization) that have conducted research and evaluations in the field of home and community care. This exchange includes other organizations and consultants to assist the grantees.<sup>39</sup> As a result of the systems change grants, states have additional resources to commit staff to the issue, interact with their counterparts in other states, and have access to a national network of experts.

### **The Bush Administration: Renewed Energy**

The availability of the systems change grants was announced less than two weeks before the change of administrations in January 2001. Given the transition, there was a risk that the momentum built by the Court ruling, CMS guidance, and the unveiling of the new grant program could dissipate while the new administration devoted its energy to assuming the reins of power and filling its agency positions. That did not happen.

On February 1, 2001, President Bush announced the New Freedom Initiative, a multi-agency effort to improve access to community living and the economic status of persons with disabilities.<sup>40</sup> Affirming his strong

support of the ADA, the president said that the swift implementation of the *Olmstead* ruling was a priority of the administration.

On February 25, 2001, the new DHHS secretary, Tommy Thompson, announced before the nation's governors the availability of a \$50,000 "starter grant" to promote state plan development of the systems change grant program. This effort, with a streamlined application process, was designed to engage as many states as possible in developing comprehensive efforts to comply with *Olmstead*. All 48 states that requested a starter, or planning, grant received one.<sup>41</sup> In September 2001, CMS announced that 31 states and one territory were subsequently awarded one or more grants under the Systems Change Grants for Community Living program.

On June 18, 2001, Bush followed up his February announcement of the New Freedom Initiative with an executive order, *Community-Based Alternatives for Individuals with Disabilities*.<sup>42</sup> The order directed several federal agencies with responsibilities for serving people with disabilities to work cooperatively in ensuring that the *Olmstead* decision is implemented in a timely manner.<sup>43</sup> Each department was instructed to work with states in complying with the ADA and to evaluate its policies, programs, statutes and regulations to identify any that needed revision to improve the availability of community-based services. DHHS was charged with coordinating this effort.

On March 25, 2002, Thompson announced that \$55 million in new funding was available under the Systems Change Grants for Community Living program.<sup>44</sup> By September 2002, 48 states, the District of Columbia, and two territories had received at least one grant under the systems change grants program. The technical assistance collaborative also received supplemental funding. In February 2003, Congress approved the DHHS request for an additional \$40 million to fund more systems change grants. An identical amount to fund more grants has been proposed in the fiscal year 2004 budget.

Also on March 25, 2002, DHHS released a 437-page New Freedom Initiative report, "Delivering on the Promise."<sup>45</sup> The report includes hundreds of recommended actions for federal agencies in removing policy and regulatory barriers that impede people with disabilities from living in the community and thriving economically. During the summer of 2002 the president appointed the New Freedom Commission on Mental Health. In September of 2002, a new Office of Disability was created within the DHHS Office of the Secretary and assigned the responsibility for departmental coordination of *Olmstead* compliance. Additional federal activities on this front include the awarding of grants by DHHS' Substance Abuse and Mental Health Services Administration, the Department of Labor and, the Department of Education to assist with *Olmstead* implementation.<sup>46</sup>

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## STATES' RESPONSES

State reaction to the *Olmstead* ruling was also swift and broad in scope. By the end of 2000, 37 states had task forces or work groups to develop comprehensive plans or significant papers that could serve as blueprints of change.<sup>47</sup> The size and representativeness of these work groups was extensive. The few states that did not initiate specific *Olmstead* planning activities argued they were already implementing efforts to improve the availability of community-based services. For example, Vermont has no institution for people with developmental disabilities, and all nursing home residents have been assessed for community-based services. Oregon has a six-year plan to eliminate a waiting list of 5,000 individuals desiring services under a home- and community-based waiver.<sup>48</sup> Nonetheless, these two states were among the 48 that received systems change grants.

A review of the state plans and papers issued either in final or draft form found several common, long-standing barriers to complying with the *Olmstead* ruling—barriers that are difficult and often expensive to surmount (see text box). Compounding these obstacles is the current state fiscal crisis. Recent shortfalls have constrained the growth in resources available for financing expansions in Medicaid services, including home- and community-based services, and have likely diverted the attention of Medicaid long-term care staff toward the immediate need to contain Medicaid costs. In light of such difficult barriers and a tight fiscal environment, implementation of *Olmstead* might be expected to grind to a halt in virtually all states.

In fact, while states' progress in complying with the *Olmstead* decision may have slowed somewhat compared to the initial burst of activity, planning and design activity continues. One reason for this continued activity has been the systems change grants. The combination of grant funds and the existence of a technical collaborative has enabled fiscally stressed states to maintain some staff time devoted to *Olmstead* and have the access to a national network of expert assistance necessary to design and implement.<sup>49</sup>

Another force behind continued state activity has been the pressure created by the legal challenges filed by people with disabilities. These cases constitute the next stage in *Olmstead* implementation. They will be instrumental in deciding how many people will be protected by the ADA and in which settings (for example, only institutional or also the community). They will also determine how quickly people with disabilities will receive home-care services.

## IMPLEMENTATION: DISTRICT COURT RULINGS

Care must be taken when examining the many *Olmstead*-related court cases, for very few have completed the trial phase, much less been subjected to review by the appellate courts. While it is tempting to select

## State-Identified Needs

- Affordable and accessible housing.
- Transportation (nonmedical).
- Assessment tools to identify people's needs.
- Information tools to link people with services.
- Data systems to monitor quality and track people at risk.
- Adequate staffing.
- Education and outreach.
- Availability of funded Medicaid waivers.

cases that may serve as precedents, such an effort is fraught with peril.<sup>50</sup> Each case has unique circumstances that may mitigate its likelihood of serving as a precedent. Successfully picking the “right one” is unlikely. This predicament is exacerbated by the relative dearth of precise guidance from the regulations issued under Title II of the ADA and the absence of case law regarding fundamental alteration within the context of community-based care.<sup>51</sup> It will take years for the key issues to wend their way through the courts before case law is built and precedents handed down.

Nonetheless, looking at the *Olmstead* decision and a few key rulings by the district courts does reveal some of the emerging policy issues courts will struggle with in the coming years:

- Will the courts interpret broadly who is covered by the *Olmstead* ruling?
- Will courts require home placements when waiver slots are available, as in the original *Olmstead* case?
- After existing waiver slots are filled, will the courts require states to expand their waiver programs, resulting in sustained long-term expansion of home care services?

The courts’ rulings on the range of individuals covered by *Olmstead* will have a major impact on both people with disabilities and state and federal budgets. Since the *Olmstead* plaintiffs had developmental disabilities and were residing in a state psychiatric hospital, the Supreme Court’s majority opinion considered its decision within the context of mental disabilities, state mental health budgets, and state psychiatric institutions. The ADA, however, covers people with all types of disabilities—physical as well as mental; it also covers people living in other types of institutions, such as nursing homes, and those living in the community.

### Estimates of the Number of People Affected by *Olmstead*

Currently, there is no reliable estimate for the number of people who may benefit from the ruling. There are approximately 34 million people with severe disabilities and 10.4 million people with disabilities so severe that they need some level of personal assistance.<sup>52</sup> The General Accounting Office (GAO), which has a more conservative approach to the disability numbers, estimates that there are 2.3 million adults with severe disabilities living in the community who need considerable assistance from another person.<sup>53</sup> And, it estimates, there are approximately 1.8 million people with disabilities that are living in institutions (that is, nursing facilities, institutions for the mentally retarded and developmentally disabled, and state or county facilities for the mentally ill).

The GAO did not relate these figures to the number of people to whom *Olmstead* may apply. It concluded that there was too much uncertainty

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about the widely varying population of people with disabilities, the settings in which they are receiving services, and their true risk of institutionalization to make such an estimate. Thus, one must look elsewhere to provide some illumination of who may potentially benefit from the ruling.

The conditions of people with disabilities seeking remedies in the courts are similar to those of the *Olmstead* plaintiffs. The most extensive and frequently updated listing of *Olmstead*-related lawsuits is by Human Services Research Institute (HSRI). In 10 states, the plaintiffs have a developmental disability or are mentally retarded, are residing in institutions, and are seeking community placements.<sup>54</sup> If this trend is to continue, the reach of *Olmstead* will still be important but limited in scope.

However, there is the potential for greater pressure in broadening the scope of *Olmstead*. Four other cases have at least some plaintiffs who have physical disabilities. The most recent is a Georgia case filed on January 31, 2003; in *Birdsong et al. v. Perdue*, a class action complaint has been filed on behalf of individuals with physical disabilities who reside in nursing homes or are at risk of nursing home placement.<sup>55</sup> The suit alleges that Georgia has made no significant effort to expand home- and community-based services since the *Olmstead* decision.

Another study by the Center for Health Services Research and Policy at the George Washington University supports the argument that pressure is building for a broader scope of *Olmstead*. The study examined the characteristics of people who have filed a Title II ADA-related complaint with the DHHS Office of Civil Rights (OCR) and found that many differed from those of the plaintiffs in *Olmstead* and *Olmstead*-related lawsuits.<sup>56</sup> For example, 50 percent of those who filed an OCR complaint were people with physical disabilities.<sup>57</sup> In terms of living arrangements, 42 percent were in nursing homes, and 30 percent were residing in the community (most of them living with families).<sup>58</sup>

One substantial subgroup of people with disabilities does not constitute a significant proportion in either study—people with disabilities who are age 65 and older. This is surprising because aging advocates played an active role in many of the state *Olmstead* workgroups. However, no conclusions can be drawn from the HSRI and OCR studies since their methodologies may underestimate the true involvement of the aged in *Olmstead*-related efforts.<sup>59</sup> If the aged disabled increase their participation in future legal cases, *Olmstead* could have a larger impact.

### **The Short Term: Placement in Home- and Community-Based Services Waivers Programs**

A second critical issue courts will grapple with is whether to require the states to place people in existing home- and community-based services waiver programs. In the *Olmstead* case, Georgia had vacant slots under a waiver program that fit the needs of the plaintiffs. The

waiver slots were vacant because the state had not allocated state funding. A question the district courts are facing, but few have decided, is whether fulfilling a request for a placement is a reasonable modification when slots are available.

In post-*Olmstead* settlement agreements, many states are filling vacant slots and expanding their home- and community-based services waiver programs to include more slots. Over a five-year period, Massachusetts will extend community services to an additional 375 to 400 people per year.<sup>60</sup> Hawaii has agreed to increase the number of waiver slots by 70 percent over a three-year period. Louisiana, Washington, and West Virginia have also signed agreements to expand the number of waiver slots.

Not all states, however, are filling vacant slots. In response to the state fiscal crisis, Michigan and Idaho proposed reducing the number of filled waiver slots. Michigan's proposal is being challenged in court. In one district case, *Benjamin v. Ohl*, the federal district court instructed the state that it "will have to show more than that the state has not appropriated enough funding."<sup>61</sup>

### The Long Run: Expansion Potential for Community-Based Services

A third critical question that courts will need to address in determining whether states' efforts meet the reasonable-modifications standard involves what to do when a state's waiver slots are filled: Will courts require states to obtain new waivers or will they be allowed to have their waiting lists grow? One interpretation is that instructing the state to expand its waiver program would constitute a "fundamental alteration," since it might require the state to reallocate budget funds from a disability program to finance a waiver expansion.<sup>62</sup> This could violate Ginsburg's admonition that states "mete out services with an even hand."

It is not clear how the courts will rule on this issue. As noted, in response to *Olmstead*-related lawsuits, several states have signed settlement agreements expanding the number of waiver slots. But those settlements were signed between February 2000 and August 2001, when state budgets were in good shape.<sup>63</sup> No similarly broad agreements have been crafted since then.

One case, *Arc of Washington State v. Lyle Quasima*, did touch on this issue. The federal district judge made a summary ruling dismissing the case. The dismissal was based on the finding that the ADA cannot serve as the basis for ordering a state to increase its limit on the number of individuals who receive waiver services. Doing so would require the state to make a "fundamental alteration" in its services.<sup>64</sup> This case, however, eventually resulted in a settlement agreement signed in April 2001.

If other courts hand down decisions that adopt the argument of the judge in *Arc of Washington v. Lyle Quasima*, a deterrent for expanding the supply

**Between February 2000 and August 2001, when state budgets were in good shape, several states signed settlement agreements expanding the number of waiver slots.**

of home- and community-based services could be created. States, knowing that obtaining more waiver slots will place them under great legal pressure to fill them immediately, may decide not to request additional slots.

If this disincentive were to occur, *Olmstead* could slow the expansion of new waiver slots—the exact opposite of what advocates are seeking. The overall effect of *Olmstead* could simply be a short-term spurt in funding unfilled home- and community-based service waiver slots, followed by slow growth thereafter. However, adopting the scenario in Ginsburg’s two-part example—an effective plan and a waiting list moving at a reasonable pace—could lead to a quite different conclusion.

For a state to demonstrate it has met the first criterion in the example—a “comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings”—implies that it must be making continued progress in improving the availability of community placements. The district courts will have to rule on what constitutes such a plan. Although there is no systematic report on the implementation status of state plans, one study of plans in 14 states found that their implementation would put those states in compliance with the *Olmstead* decision.<sup>65</sup> In only one case (*Arc of Delaware v. Meconi*), which has yet to go to trial, has the plaintiff argued that the state’s plan is inadequate.<sup>66</sup>

Determining whether a state is conforming to the second part of the Court’s example—“a waiting list that moved at a reasonable pace”—is more problematic: A state may have a difficult time arguing it is complying with Title II of the ADA if the waiting list for waiver slots remains static or moves very slowly. While no decisions based on the ADA have focused exclusively on what constitutes a reasonable pace, a set of court cases focused on Medicaid waiting lists could provide precedents for defining it.<sup>67</sup>

Under Medicaid law, services are to be provided with “reasonable promptness.” In a watershed decision, the 11<sup>th</sup> Circuit Court of Appeals ruled federal Medicaid law does not allow a state to wait-list individuals for ICF/MR (intermediate care facilities for the mentally retarded) waiver services indefinitely.<sup>68</sup> While reasonable promptness has not been precisely defined, there appears to be a growing consensus among some courts that frequent waiting periods of “many years are outside of the zone of reasonableness.”<sup>69</sup> Thus, in the longer term, the Ginsburg example may provide people with disabilities additional support in challenging states that hope to be in compliance simply by filling vacant waiver slots without ever expanding their waiver programs.

## AN EVOLVING POLICY DRAMA

At this point, *Olmstead* has raised many more issues than it has answered. That should not be surprising, since, despite being handed down almost four years ago, *Olmstead* is still in the preliminary stages of implementation.

And following the progress of *Olmstead* will be frustrating. Unlike other major policy actions, such as new federal legislation, there are no clearly stated objectives, budgets, or timetables to guide and measure implementation. The pace of implementation will fluctuate, undergoing both periods of intense activity, such as the year following the Supreme Court decision, and phases, like the present, of slower progress. The timing of subsequent court decisions will be unpredictable and sporadic, resulting in piecemeal clarification.

Future periods of increased activity will likely result from key court decisions, especially at the appellate and, possibly, at the Supreme Court levels.<sup>70</sup> Numerous court decisions will have to be made before sufficient case law is built clarifying who is covered under *Olmstead*, where the boundary lays between a reasonable accommodation and a fundamental alteration, when a waiting list is moving at a reasonable pace, and what constitutes an effectively working state plan. Given the glacial pace of the legal process, therefore, it will be years before the full impact of *Olmstead* is known.

Care must be taken in estimating the power of *Olmstead* to effect change. Regardless of future court decisions, there are still many issues impeding the expansion of home- and community-based long-term services that are not addressed by *Olmstead*. It does not increase the workforce needed to deliver more services, nor does it create an oversight system assuring that the community-based services delivered are of high quality. A number of questions are yet to be answered if home- and community-based care are to be expanded:

- How can the true extent of the “woodwork effect” on the demand for services in the community setting be determined?
- Will the federal government provide states additional assistance in meeting their obligations?
- Will the New Freedom Initiative, including the systems change grants, be able to meet the high expectations for removing barriers to community care at the federal and state levels?
- Are there other state financing strategies that can be developed to fund an increase in services?

Although *Olmstead* is not the solution to bridging the large gap between demand and supply for home- and community-based services, it does apply additional pressure on state and federal policymakers to address these issues. And it adds another stakeholder in the process—judges who will be determining whether the pace of implementation is adequate.

How powerful this force will be is yet to be determined. Nonetheless, the ruling has served as a catalyst for state and federal government activity. It has empowered people with disabilities, particularly those residing in institutions, with legal recourse to obtain home- and community-based services. And the Court’s opinion has set into motion

**Given the glacial pace of the legal process, it will be years before the full impact of *Olmstead* is known.**

a new expectation for community-based services that will be hard to ignore. Long-term care policymakers will find it difficult not to make some accommodation to this ruling today and in the years to come.

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## ENDNOTES

1. Jefferson D. E. Smith and Steve P. Calandrillo, "Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits after *Olmstead v. L.C.*," *Harvard Journal of Law and Public Policy*, Summer 2001.
2. Sara Rosenbaum, "*Olmstead v. L.C.*: Analysis and Implications for Medicaid Policy," working paper, Center for Health Care Strategies, Lawrenceville, New Jersey, May 2000; accessed February 10, 2003, at <http://www.chcs.org/publications/pdf/cas/Olmstead.pdf>.
3. Kathryn G. Allen, "Long-Term Care: Implications of Supreme Court's *Olmstead* Decision Are Still Unfolding" (GAO-01-1167T), testimony before the Special Committee on Aging, U.S. Senate, Washington, D.C., September 24, 2001; accessed March 6, 2003, at <http://www.ohiosilc.org/il/library/medicaid/d011167t.pdf>.
4. Barbara Polister, ed., "Policies and Resources Related to Waiting Lists of Persons with Mental Retardation and Related Developmental Disabilities," University of Minnesota, Minneapolis, June 2002; accessed February 11, 2003 at <http://rtc.umn.edu/pdf/waitlist2002.pdf>.
5. Gary Smith, Janet O'Keeffe, Letty Carpenter, Pamela Doty, Gavin Kennedy, Brian Burwell, Robert Mollica, and Loretta Williams, "Understanding Medicaid Home and Community Services: A Primer," U.S. Department of Health and Human Services, Washington, D.C., October 2000; accessed February 7, 2003, at <http://aspe.hhs.gov/daltcp/reports/primer.htm>.
6. The "woodwork effect" theory is based on the belief that if the states and the federal government were to pay for substantially expanded home-based and community-based care, the many people who currently remain at home or in the community because of the supportive care being provided by family or friends would come forward to claim the expanded benefits. Thus, the savings realized by providing less-expensive, home- and community-based care for persons formerly residing in an institutional setting would be more than offset by the increased number of people who would take advantage of the benefits.
7. For example, in 1980 payments for nursing home care comprised 34 percent of total Medicaid payments, while home health services comprised 1.4 percent. See Congressional Research Service (CRS), *Medicaid Source Book: Background Data and Analysis* (Washington, D.C.: U.S. Government Printing Office, January 1993), Table II-13.
8. Robert Wardwell, Visiting Nurses Associations of America, telephone communication with author, December 3, 2002. Also, a description of those and similar evaluations is available in Pamela Doty, "Cost-Effectiveness of Home and Community-Based Long-Term Care Services," U.S. Department of Health and Human Services, June 2000; accessed February 11, 2003, at <http://aspe.hhs.gov/daltcp/reports/costeff.htm>.
9. Wardwell, telephone communication.
10. Wardwell, telephone communication. An example of the restraint in growth is revealed by a comparison of Medicaid payments. Home health services grew from 1.4 percent of total Medicaid payments in 1980, to 5 percent in 1990. Nursing home payments in 1990 were 27 percent. See CRS, *Medicaid Source Book*.
11. Allen, "Long-Term Care."
12. Allen, "Long-Term Care." The 50th state, Arizona, has a Section 1115 waiver that includes home- and community-based services offered under Section 1915(c).
13. Gary Smith, "Status Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilities," Human Services Research Institute, Portland, Oregon; accessed February 11, 2002, at <http://www.hsri.org/index.asp?id=news>. The waiting

list numbers are from court records. Current information on waiting lists is difficult to obtain, for state reports on waiting lists are sporadic and often incomplete. Also, the presence of a list can be misleading at times. For example, a person may be receiving a variety of home health services but be on a waiting list for a narrow, unmet need, such as a housing modification.

14. Sara Rosenbaum, Alexandra Stewart, and Joel Teitelbaum, "Defining 'Reasonable Pace' In the Post-Olmstead Environment," working paper, Center for Health Care Strategies, Lawrenceville, New Jersey, April 2002; accessed September 22, 2002, at <http://www.chcs.org/publications/pdf/cas/reasonablepace.pdf>.

15. Andrew I. Batavia, "A Right to Personal Assistance Services: 'Most Integrated Setting Appropriate' Requirements and the Independent Living Model of Long-Term Care," *American Journal of Law and Medicine*, 28, no.2 (Spring 2001).

16. President, "New Freedom Initiative," White House, February 1, 2001; accessed April 10, 2002, at <http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html>.

17. Americans with Disabilities Act of 1990, Section 3, Definitions; accessed February 11, 2003, at <http://www.usdoj.gov/crt/ada/pubs/ada.txt>.

18. This information was drawn from the ADA Title II regulations, Section 35.104, Definitions; accessed March 6, 2003, at <http://www.usdoj.gov/crt/ada/reg2.html>. The regulations also list over 18 specific conditions, including diabetes, epilepsy, cancer, hearing impairment, drug addiction and alcoholism.

19. *Olmstead v. L.C.*, 527 U.S. 581 (1999); accessed February 11, 2003, at <http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&navby=case&vol=000&invol=98536>.

20. Rosenbaum, "*Olmstead*: Analysis" Two other Titles of ADA proscribe discriminatory practices in employment (Title I) and public accommodations (Title III). Title I, while not addressed in the *Olmstead* ruling or in this paper, is nonetheless of interest to health policymakers, for it applies to employment-related benefits, such as health coverage.

21. *Olmstead v. L.C.* In the same section the opinion also notes that the statute defines a public entity as "any state or local government," and "any department, agency, [or] special purpose district" of a state or local government. A qualified individual is "an individual with a disability who with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity."

22. *Olmstead v. L.C.*

23. *Olmstead v. L.C.*

24. *Olmstead v. L.C.* The "reasonable-modifications rule" is sometimes referred to in post-*Olmstead* articles as the "fundamental alteration rule."

25. *L.C. v. Olmstead*, U.S. 11th Circuit Court of Appeals, No. 97-8538; accessed March 20, 2002, at <http://laws.lp.findlaw.com/11th/978538OPN.html>. See also *Olmstead v. L.C.*

26. This alternative method of determining discrimination generated a stinging dissent from Justice Clarence Thomas that was joined by Chief Justice William Rehnquist and Justice Antonin Scalia. They argued that "discrimination, as typically understood, requires a showing that a claimant received differential treatment *vis-a-vis* members of a different group on the basis of a statutorily described characteristic."

27. *Olmstead v. L.C.*

28. The facts of the case raised this concern. One of the plaintiffs received a recommendation for a community placement, a homeless shelter. This was quickly rescinded by the state.

29. *Olmstead v. L.C.*

30. Justices Kennedy and Breyer noted in a concurring opinion that the courts must show "appropriate deference to the program funding decisions of state policymakers."

31. *Olmstead v. L.C.*

32. *Olmstead v. L.C.*
33. *Olmstead v. L.C.*
34. *Olmstead v. L.C.*
35. The example's impact is striking, given that it comes from a section of the opinion where there is a plurality of four justices, not a majority.
36. Donna E. Shalala, "Secretary's Letter to Governors on Olmstead Decision," U.S. Department of Health and Human Services, Washington, D.C., January 14, 2000; accessed February 22, 2003, at <http://cms.hhs.gov/states/letters/smd1140b.asp>.
37. U.S. Department of Health and Human Services, "HHS Proposes Changes Allowing States to Expand Medicaid Coverage," press release, October 27, 2000; accessed February 22, 2003, at <http://www.hhs.gov/news/press/2000pres/20001027.html>.
38. Timothy M. Westmoreland, "Olmstead Update No. 5 (New Tools for States)," letter to Medicaid directors, U.S. Department of Health and Human Services, January 10, 2001; accessed February 23, 2003, at <http://cms.hhs.gov/states/letters/smd110a1.pdf>.
39. For more information about the systems change grantees and the Community Living Exchange Collaborative, see Resource Network on Home and Community-Based Services, "Community Living Exchange Collaborative: A National Technical Assistance Program," at [http://www.hcbs.org/exchange\\_collaborative.htm](http://www.hcbs.org/exchange_collaborative.htm).
40. President, "New Freedom Initiative."
41. Only Arizona and South Dakota did not apply.
42. President, Executive Order, "Community-Based Alternatives for Individuals with Disabilities," White House, Office of the Press Secretary, June 19, 2001; accessed February 28, 2002, at <http://www.whitehouse.gov/news/releases/2001/06/20010619.html>.
43. The agencies included the Departments of Health and Human Services, Justice, Education, Labor, and Housing and Urban Development as well as the Social Security Administration. Subsequently, this effort was joined by the Departments of Transportation and Veterans Affairs, along with the U.S. Office of Personnel Management.
44. U.S. Department of Health and Human Services, "Delivering on the Promise—Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration," press release, Washington, D.C., March 25, 2000; accessed June 14, 2002, at <http://www.hhs.gov/news/press/2002pres/20020325.html>
45. U.S. Department of Health and Human Services, "Delivering on the Promise: Self-Evaluation to Promote Community Living for People with Disabilities," report to the president on Executive Order 13217, March 2002; accessed February 11, 2003, at <http://www.hhs.gov/newfreedom/final/hhsfull.html>.
46. Donna Folkemer, National Conference of State Legislatures, telephone communication with author, February 5, 2003.
47. Wendy Fox-Grage, Donna Folkemer, and Kevein Horahan, "The States' Response to the *Olmstead* Decision: A Status Report," National Conference of State Legislatures, March 2001; accessed January 19, 2003, at <http://www.ncsl.org/programs/health/forum/olmsreport2001.pdf>.
48. Fox-Grage, Folkemer, and Horahan, "States' Response."
49. Susan Reinhard, Rutgers Center for State Health Policy, email communication with author, February 11, 2003.
50. In contrast to the executive branch, where regulations and technical assistance are often provided in implementing a new policy or program, the judicial branch does not have a history of legal scholarship explicitly intended to inform advocates and judges of how to deal with future cases. See Smith and Calandrillo, "Forward to Fundamental Alteration."
51. This is in contrast to the more detailed guidelines issued under the employment and public accommodation titles of the ADA. See Smith and Calandrillo, "Forward to Fundamental Alteration."

52. Author's estimates made by extrapolating from the most recent data from the 1997 Survey of Income and Program Participation (SIPP) data to the 2000 Census Bureau estimate of the nation's noninstitutionalized population (273,643,273 people). The SIPP estimates for the percentage of people with varying levels of disability was derived from Jack McNeil, "Americans With Disabilities 1997," *Current Population Reports*, P70-73, U.S. Census Bureau, Department of Commerce, February 2001; accessed March 6, 2003, at <http://www.census.gov/prod/2001pubs/p7073.pdf>. The 2001 noninstitutionalized population estimate was derived from Census Bureau, "Table 1: Total Population in Households and Group Quarters by Sex and Selected Age Groups, for the United States: 2000"; accessed March 6, 2003, at <http://www.census.gov/population/cen2000/grpqr/grpqr01.pdf>.

53. Allen, "Long-Term Care."

54. Smith, "Status Report."

55. Smith, "Status Report."

56. The DHHS OCR is responsible for investigating complaints of discrimination against public entities receiving federal financial assistance for health or human services, such as a state Medicaid agency. Recommendations for enforcement action are forwarded by the DHHS OCR to the Department of Justice.

57. Sara Rosenbaum, Joel Teitelbaum, and Alexander Stewart. "An Analysis of Olmstead Complaints: Implications for Policy and Long Term Planning," Center for Health Care Strategies, Lawrenceville, New Jersey, December 2001; accessed February 12, 2003, at <http://www.chcs.org/publications/pdf/cas/olmsteadcomplaints.pdf>.

58. The author derived the figures from Rosenbaum, "Analysis of Olmstead Complaints."

59. While continually updated, the Health Services Research Institute list on Medicaid litigation focuses on those cases being filed by people with developmental disabilities or mental retardation. The study of complaints filed with the Office of Civil Rights by the Center for Health Services Research and Policy was restricted to those complainants filed by the fall of 2001.

60. Smith, "Status Report."

61. Rosenbaum, "Reasonable Pace."

62. Smith and Calandrillo, "Forward to Fundamental Alteration."

63. Smith, "Status Report."

64. Smith, "Status Report."

65. Alexander Stewart, Joel Teitelbaum, and Sara Rosenbaum, "Implementing Community Integration: A Review of State Olmstead Plans," Center for Health Care Strategies, Lawrenceville, New Jersey, October 2002; accessed December 12, 2002, at <http://www.chcs.org/publications/pdf/cas/stateOlmsteadplans.pdf>.

66. Smith, "Status Report."

67. Smith, "Status Report." In fact, some of the cases are cited by some as violating the ADA, however, many of the cases have been argued and won based on Medicaid statute and not on ADA.

68. Smith, "Status Report."

69. Rosenbaum, "Reasonable Pace."

70. Smith and Calandrillo, "Forward to Fundamental Alteration." In the last decade, the Supreme Court has expanded state government immunity from citizen lawsuits, citing protection by the 11th Amendment of the U.S. Constitution. Every state fighting an *Olmstead* lawsuit has cited protection under the 11th Amendment, although the district courts have usually viewed the argument with skepticism. In early 2003, the Supreme Court accepted another Title II ADA case, *California Medical Board v. Hason*, that may provide a ruling on this issue. A decision will be announced in June of 2003.