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***Olmstead at Five: Assessing the Impact***

*Prepared by*

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Department of Health Policy

School of Public Health and Health Services

The George Washington University Medical Center

June 2004

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# kaiser commission medicaid and the uninsured

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## Introduction

This paper examines the impact of *Olmstead v. L.C.*<sup>1</sup> five years after the United States Supreme Court's 1999 landmark decision. *Olmstead* established two legal principles fundamental to health policy for persons with disabilities. The first is that the medically unjustifiable institutionalization of persons with disabilities who desire to live in the community violates Title II of the Americans with Disabilities Act (ADA), which applies to publicly funded services. The second is that states have a legal obligation to affirmatively remedy such discriminatory practices through reasonable modifications to public programs and services.

As with so many watershed civil rights cases, *Olmstead* is both profound and ambiguous, raising many questions even as it established broad safeguards for persons with disabilities. In its use of "broad brushstroke" standards, *Olmstead* has left many of the most difficult implementation questions in a health context to the lower courts, as well as to federal and state policymakers. The task of interpretation in the wake of a legal landmark is a difficult one, and change often can be difficult to measure, especially in quantifiable terms.

Yet five years after *Olmstead*, the landscape has indeed shifted in important if subtle ways. Even though progress in adapting health programs to the needs of persons with disabilities may be slow, it is nonetheless evident, not only in the courts but also -- and as importantly -- in emerging federal and state legislative investments in community integration.

This analysis brings together new research with a synthesis of research undertaken over the past five years, the purpose of which was to help policy makers and program administrators understand the meaning of the ADA for health programs in *Olmstead's* aftermath.<sup>2</sup> Part 1 of this paper presents an overview of the ADA and its

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<sup>1</sup> 527 U.S. 581 (1999).

<sup>2</sup> Prior analyses include Burke T. and Rosenbaum S., *The Meaning of Community Integration: Exploring the ADA Legal Standard Within a Broader Social Context*. Center for Health Care Strategies, March 2004 (working draft on file with the authors); Rosenbaum S., Burke T., Teitelbaum J., *The Americans with Disabilities Act and Community Integration: An Update on Fundamental Alteration Litigation*. Center for Health Care Strategies, September 2003; Rosenbaum S., Teitelbaum J., Bartoshesky A., and Stewart A., *Community Integration: The Role of Individual Assessment*. Center for Health Care Strategies, October 2002; Stewart A., Teitelbaum J., and Rosenbaum S., *Implementing Community Integration: A Review of State *Olmstead* Plans*. Center for Health Care Strategies, October 2002; Rosenbaum S., Teitelbaum J., and Stewart A., *The Americans with Disabilities Act and Community Integration: Understanding the Concept of "Fundamental Alteration."* Center for Health Care Strategies, May 2002; Rosenbaum S., Stewart A., and Teitelbaum J., *Defining "Reasonable Pace" in the Post-*Olmstead* Environment*. Center for Health Care Strategies, April 2002; Rosenbaum S., Teitelbaum J., and Stewart A., **Olmstead v. L.C.*: Implications for Medicaid and Other Publicly Funded Health Services*, 12 Health Matrix: Journal of Law-Medicine 1 (Winter 2002); Rosenbaum S., Teitelbaum J., and Stewart A., *An Analysis of *Olmstead* Complaints: Implications for Policy and Long-term Planning*. Center for Health Care Strategies, December 2001; Rosenbaum, S., *The *Olmstead* Decision: Implications for State Health Policy*, 19 Health Affairs 5 (September/October 2000). Note that all of the Center for Health Care Strategies documents noted above are available at <http://www.chcs.org/publications3960/publications.htm>. For a much more in-depth treatment of the nation's response to the *Olmstead* decision, see the National Council on Disability's

community integration structure. It also summarizes the results of research into issues which have been identified by researchers, persons with disabilities, and disability advocates as essential to community integration. Part 2 presents a brief overview of the *Olmstead* decision and the legal framework on which it rested. Part 3 describes *Olmstead's* legacy, both in the courts and in the administration of public programs, with special consideration to Medicaid's role for persons with disabilities and the evolving nature of the program.

## Part 1. Overview

### The Evolution and Meaning of the Americans with Disabilities Act

Enacted in 1990, the ADA represents one of the nation's most important civil rights laws. Its overarching goal is to extend to persons with disabilities the maximum opportunity for community integration across both public and private sectors of society. The reach of the ADA extends far beyond its roots, which can be found in Section 504 of the Rehabilitation Act of 1973.<sup>3</sup> Like the ADA, this earlier legislation prohibits discrimination against otherwise qualified individuals solely on the basis of their disability, but its prohibition is limited to programs and activities receiving "federal financial assistance." Like the ADA, § 504 also mandates certain affirmative forms of conduct in order to alleviate the effects of discrimination.

The ADA builds upon § 504 in several fundamental ways. Like § 504, the ADA applies to "qualified persons" with disabilities, i.e., persons who can perform essential job functions with or without reasonable accommodations, or who meet the essential qualification standards for a program or activity.<sup>4</sup> But the ADA spans all aspects of life, not just federally assisted programs.

Title I of the ADA reaches all facets of employment, from applicant screening and testing to terms of employment and employment-related benefits, including health benefits.<sup>5</sup> Title II covers public services and parallels the provisions of § 504, except that the term "least restrictive alternative" is replaced with the concept of "community integration." Title III applies to places of public accommodation (i.e., privately operated businesses and commercial entities).<sup>6</sup> Title IV covers telecommunications services,

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exceptional report titled "*Olmstead: Reclaiming Institutionalized Lives*," available at <http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm> (August 19, 2003) (accessed June 4, 2004).

<sup>3</sup> 29 U.S.C. § 794.

<sup>4</sup> See *Southeastern Community College v Davis*, 442 U.S. 397 (1979) (applying §504 requirements to a case in which a nursing student who was deaf sought changes in a public university's nursing program in order to accommodate her disability and holding that the ability to hear was so basic to nursing that to require the college to alter its program would amount to a change in the "essential nature" of nursing and nurse training).

<sup>5</sup> Rosenblatt, Law, and Rosenbaum, "Law and the American Health Care System," The Foundation Press, Inc., Westbury, New York (1997).

<sup>6</sup> 42 U.S.C. § 12182(a). Under the ADA, places of public accommodation include the private offices of health care providers, *Bragdon v Abbott*, 524 U.S. 624 (1998), but not the content of private health insurance policies, see e.g., *Doe v Mutual of Omaha Ins. Co.*, 179 F.3d 557 (7th Cir. 1999).

including telephone and television access for people with hearing and speech disabilities.<sup>7</sup> Title V contains miscellaneous provisions including the so-called “insurance safe harbor,” which has been interpreted by most courts as exempting the content of health insurance from the reach of the ADA.<sup>8</sup>

The ADA also parallels § 504 in that it not only prohibits discrimination, but also affirmatively obligates covered entities to undertake the types of reasonable accommodations necessary to make their benefits and services accessible. But the ADA alters the language of § 504 and arguably strengthens it, at least from a rhetorical standpoint. It does so by moving away from the notion of benefits and services in “the least restrictive setting” (the language of § 504) and adopting in its stead the concept of services and benefits in “the most integrated community setting” consistent with an individual’s needs and desires.

This expanded legislative reach and shift in rhetorical structure -- as well as the broad bipartisan support that the ADA’s enactment enjoyed and that the law continues to enjoy -- suggests that the ADA should be understood as more than an important advance in the legal civil rights framework. It also can be understood as a broad statement of national policy regarding the societal importance of integrating persons with disabilities into all aspects of life, not simply those that receive federal assistance as defined in law.

Because *Olmstead* concerned public services, this paper focuses most specifically on Title II of the ADA. Federal regulations implementing Title II define “qualified persons with disabilities” as persons who “meet the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.”<sup>9</sup> Under this rule,

A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability. . . . A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.<sup>10</sup>

Although Title II sweeps broadly, it does operate with certain constraints. The Title II regulations limit the obligations of public entities to remedial activities which are

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<sup>7</sup> 42 U.S.C. § 12184.

<sup>8</sup> Rosenblatt, *supra* note 7. The interpretation of the insurance safe harbor has been held to exempt insurance content, even when there no actuarial basis for the discriminatory practice. *Doe*, 179 F.3d 557. In this regard, courts have rejected interpretations of the ADA adopted by the Equal Employment Opportunity Commission and the Department of Justice, which would have exempted insurance limits which single out specific conditions for disparate coverage (e.g., a \$5,000 cap on HIV/AIDS treatment) only if actuarially defensible. *Id.*

<sup>9</sup> 42 U.S.C. § 12131(2). The term “disability” is defined as a “physical or mental impairment that substantially limits one or more of the major life activities of [an] individual; a record of such an impairment; or being regarded as having such an impairment.” 42 U.S.C. § 12102(2). “Major life activities” includes “caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.” 28 C.F.R. § 35.104 (2001).

<sup>10</sup> 28 C.F.R. § 35.130(b)(7), (d)-(e)-1.



considered “reasonable modifications” of programs and thus do not require changes which “fundamentally alter” (i.e., change the essential nature of) a program or service. The question whether a requested change is a reasonable modification or a fundamental alteration is crucial: if a defendant in Title II litigation can offer convincing evidence that a requested change would amount to a fundamental alteration, then a court essentially does not have the power under the law to order the requested change. At the point at which requested changes in programs and services become “fundamental” rather than “reasonable,” the issue becomes one for legislatures, rather than for the courts. Thus, the judicial power to order remedies under Title II reaches its limit at the point that a public entity can demonstrate that making the modifications would fundamentally alter the essential nature of the service, program, or activity.

It is this tension between the goal of community integration on the one hand, and the “fundamental alteration versus reasonable modification” dichotomy on the other, that lies at the heart of much of the ADA litigation that has taken place over the years. Indeed, at its core, *Olmstead* focused on the extent to which states can be made to alter the manner in which they administer public health care programs, including Medicaid. Where changes to Medicaid are considered reasonable program modifications, they can be ordered by courts. Where, however, a requested change is one that would “fundamentally alter” the essential character of a state’s program, its modification becomes a matter of legislative discretion. This is particularly true when new programs are necessary (e.g., creating a new program to refurbish and modify homes for adapted housing for persons with physical disabilities) or programs require modification in overall design (e.g., adding a new and previously uncovered service to a state Medicaid plan). Yet even here, as the post-*Olmstead* cases show, there are no hard and fast rules.

The issue of when the design of a program is considered *discriminatory* is also critical to understanding *Olmstead*. When the barriers to community integration involve facially neutral programs that place an unequal burden on persons with disabilities, the barriers may in fact be real but there may not be what the law would consider “discrimination.” This essential concept was established for public programs -- and specifically for Medicaid -- in *Alexander v. Choate*.<sup>11</sup> The *Choate* case involved Tennessee’s 14-day annual inpatient hospital day limit under the state’s Medicaid program. A group of persons with disabilities sued under § 504 (the ADA’s predecessor statute), arguing that the state had an affirmative obligation to make reasonable modifications in its plan to permit a greater number of days for patients whose underlying disabilities necessitated longer hospital stays. The Supreme Court rejected the notion that public entities were legally obligated to customize facially neutral service designs in order to accommodate persons with disabilities and held that such across-the-board limits were not discriminatory, despite the greater burden they placed on persons with disabilities. *Choate* thus held in essence that across-the-board treatment and coverage norms built into Medicaid plans -- and applied to all beneficiaries with equal force -- do not violate fundamental disability principles by discriminating.

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<sup>11</sup> 469 U.S. 287 (1985).

## Understanding the ADA in the Context of Community Integration Needs

Realizing the broad goals of the ADA involves both reasonable modifications in the manner in which programs are administered, as well as fundamental alterations in the manner in which programs are designed and structured. It also means understanding and appreciating the wide range of programs and services considered relevant to an assessment of community integration policy is essential to implementing reform. Research undertaken by the George Washington University's Department of Health Policy for the Center for Health Care Strategies identified hundreds of studies, research analyses, and other sources of information relevant to community integration.<sup>12</sup> Based on this analysis, researchers developed a Taxonomy of Community Integration, which is summarized in Figure 1 and which contains certain key "domains" of integration. These themes -- housing, jobs and job training (along with education in the case of children), health care, transportation, and personal assistance -- can be thought of as guiding community integration policy making. Many of the legal decisions and legislative initiatives in *Olmstead*'s wake in fact link to one or more of these themes.

### Figure 1. Key Community Integration Domains

Consumers and disability advocates consistently cite a handful of domains of community life as the most critical and as measurable starting points from which stakeholders and policymakers can frame the issues to implement effective, fiscally feasible alterations to programs, work settings, etc.:

- 1) Full access to the most appropriate community-based housing;
- 2) Access to and appropriate accommodation for fair participation in the competitive workplace;
- 3) Equal access to local and long-distance public transportation;
- 4) Equal access to healthcare; and
- 5) Appropriate access to personal assistance services.

## **Part 2. The *Olmstead* Decision**

In June 1999, the Supreme Court declared that the medically unnecessary institutionalization of qualified persons with disabilities amounts to discrimination under the ADA. In doing so, the Court rejected the argument that changing Georgia's Medicaid plan to actually fund approved home and community care "waiver slots" would constitute a fundamental alteration of its Medicaid program. The case was brought by two women who were left to live in institutions despite opinions from treating professionals that a community placement was appropriate. Crucial to the case -- and distinguishing it from *Choate* -- was the fact that the state did not administer its Medicaid program "with an even hand," in the words of Justice Ginsberg. Indeed, although the federal Health Care

<sup>12</sup> Stewart A., Cox M., Teitelbaum J., and Rosenbaum S., *Beyond Olmstead and Toward Community Integration: Measuring Progress and Change*, Center for Health Care Strategies, November 2003. See also National Council on Disability, "*Olmstead: Reclaiming Institutionalized Lives*," *supra* note 4.

Financing Administration (HCFA; now the Center for Medicare and Medicaid Services) had approved 2,100 community-based “waiver slots” for Georgia, the state had elected to fund only 700, thereby leaving seriously underfinanced the very portion of its approved plan that arguably would have made community integration feasible. The Court determined that unlike the impartial application of across-the-board limits found in *Choate*, the *Olmstead* situation amounted to biased state plan administration: persons deemed capable of living in the community by the state’s own health professionals nonetheless were consigned to living in an institution, while the state’s approved Medicaid community services program went unfunded in large part.

Finding discrimination was of course only part of the result in *Olmstead*. The further question then became what should be done to remedy the problem. In this regard, the Court offered an approach that can best be termed cautious, but one that is actually not unusual in civil rights cases. Noting that the state was obligated to make reasonable modifications -- but not fundamental alterations -- in its programs, Justice Ginsberg wrote:

To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow. 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>13</sup>

Federal officials, advocates, state officials, and others all seized upon this paragraph as the heart of the remedial portion of the decision. The references to an “effectively working state plan” for placing qualified persons in community settings and a waiting list that operated at a “reasonable pace” rapidly became fundamental jumping-off points for implementation. Unanswered in the decision, though, were many of the questions that have arisen over the ensuing years: When do changes in Medicaid and other public programs amount to “fundamental alterations” and thus lie beyond the purview of courts? What is a “reasonable pace”? How much change is necessary to achieve a lawful level of community integration? Do state planning efforts that involve identification of needs and development of a timetable for meeting those needs in fact expose states to claims that they somehow are failing to make reasonable accommodations? How best can legislatures respond to the needs unearthed by *Olmstead*, particularly long waiting lists of individuals in need of community placements and equally long lists of persons who need community services in order to avoid institutionalization?

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<sup>13</sup> *Olmstead*, 527 U.S. at 605-06.

### **Part 3. *Olmstead*'s Legacy**

#### *Olmstead*'s Legacy in the Courts

Although *Olmstead*'s legacy in the courts has been uneven, this is in large part a function of the fact that determining which requested changes to Medicaid and other public programs and services fall comfortably before the “fundamental alteration” line is an intensely individualized and fact-driven exercise. Nevertheless, certain legal principles and themes can be extracted from *Olmstead*-related judicial decisions to date. In this section, we highlight these themes in four key *Olmstead* areas: reasonable modification vs. fundamental alteration, the meaning of “reasonable pace,” the meaning of “community integration,” and the role of the individual assessment process as it pertains to community integration of disabled individuals.

#### Reasonable Modification vs. Fundamental Alteration

Since *Olmstead* was decided, numerous lower courts have attempted to distinguish, in the context of health and human services, between requested changes that are reasonable and those that are “fundamental” in nature and thus immune from judicial intervention. Courts have tended to view the reasonable modification/fundamental alteration issue through two prisms: lawsuits in which an individual alleges that the program’s eligibility criteria themselves are discriminatory, and those involving persons who are eligible for services but claim that a program is being administered in a discriminatory fashion.

*Eligibility criteria:* Persons with disabilities might seek the broadening of a community care waiver program to recognize additional groups of persons (e.g., expanding a Medicaid community care waiver program to include persons with mental disabilities as well as the frail elderly). Such cases might fail, since changes in basic eligibility criteria appear to lie beyond the furthest reaches of disability law.<sup>14</sup> Furthermore, eligibility criteria that are essential to the very nature of a program (i.e., being over age 65) would be deemed beyond the reach of the courts.<sup>15</sup> Whether a change in eligibility criteria is fundamental or reasonable turns on the facts of a given case. Relevant evidence includes:

- whether the change effects the very nature and purpose of the program or activity or merely a peripheral function;
- the degree to which the program already has waived its own rules;
- the number of individuals previously not deemed qualified who would be permitted to participate; and
- whether the program’s purposes can be achieved through means that are not so exclusionary.<sup>16</sup>

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<sup>14</sup> See, e.g., *Rodriguez v City of New York*, 197 F.3d 611 (1999), cert. den. 531 U.S. 864 (2000).

<sup>15</sup> *PGA Tour, Inc. v. Martin*, 532 U.S. 661 (2001).

<sup>16</sup> See Jefferson Smith and Steve Calandrillo, “Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits after *Olmstead v L.C.*,” 24 Harv. Jour. Law & Policy 695, 727 (Summer 2001);

*Services for eligible persons:* In the second category of cases (those in which individuals are already eligible for the services complained of), the critical issue appears to be whether a court views the limits as an across-the-board matter of design (as in *Choate*) or as a discriminatory method of administration, as in *Olmstead*. Here the cases are quite varied and, again, turn heavily on the facts. In *Rodriguez v. New York*,<sup>17</sup> the U.S. Court of Appeals for the Second Circuit rejected a request by persons with mental disabilities to cover cueing services under Medicaid. This service is essential to the rehabilitation and independence of persons with disabilities, and such services were covered for persons with physical disabilities as an incident to physical care in the home. Because persons with mental disabilities needed no physical assistance, however, the state refused to cover the service as an independent benefit. Rather than viewing the case as uneven administration, the Second Circuit construed the limit as one of coverage design, and dismissed the case.

In *Townsend v. Quasim*<sup>18</sup> and *Fisher v. Oklahoma Healthcare Authority*,<sup>19</sup> however, the outcome was quite different. In *Quasim*, a group of medically needy Medicaid recipients sued the state of Washington under the ADA over its refusal to continue home care services for them as a result of minor changes in program income. Because of a slight monthly increase in his Social Security benefits (about \$35.00), the plaintiff class representative, an elderly man with multiple impairments, was converted from categorically needy to medically needy status under the state plan. The reclassification had absolutely no bearing on his ability to afford care or benefit (or not) from community services. Unfortunately for him, however, the state medically needy program did not cover community residential long-term care, but was instead restricted to long-term care in nursing facilities. The plaintiff thus was literally threatened with the loss of a community placement and subsequent institutionalization as a result of this long-term care service distinction.

Rather than defining the case as one about coverage of procedures, the Ninth Circuit Court of Appeals defined the litigation as one concerning how the state administered its long term care program under Medicaid. In other words, the court refused to define the case as a coverage case and instead recast it as a case of discriminatory administration:

Characterizing community-based provision of services as a new program of services not currently provided by the state fails to account for the fact that the state is already providing those very same services. If services were determined to constitute distinct programs based solely on the location in which they were provided, *Olmstead* and the integration regulation would be effectively gutted. . . *Olmstead* did not regard the

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Southeastern Community College v Davis, 442 U.S. 397 (1979); Easley v. Snider, 36 F.3d 297 (3rd Cir. 1994); PGA Tour, Inc. v. Martin, 532 U.S. 661 (2001).

<sup>17</sup> 197 F.3d 611 (1999), cert. den. 531 U.S. 864 (2000).

<sup>18</sup> 328 F.3d 511 (9<sup>th</sup> Cir. 2003).

<sup>19</sup> 335 F.3d 1175 (10<sup>th</sup> Cir. 2003).

transfer of services to a community setting, without more, as a fundamental alteration.<sup>20</sup>

In short, in ruling for the plaintiffs on appeal, the court drew a significant distinction between *whether services were offered at all* and the manner in which the state administered its long-term care services. Rather than being guided to specific Medicaid service and benefit definitions, as was the case in *Rodriguez*, the court examined Medicaid services as a “bundle” (i.e., as “long-term care”). In effect, the court stepped back from the specific services and benefits listed in the federal Medicaid statute for federal payment purposes and aggregated services into one generic and conceptual service category for purposes of its ADA analysis. Viewed in this manner, the plaintiff’s case was transformed from one that sought a new benefit (and that thereby would likely have violated the ADA’s fundamental alteration rule, as in *Rodriguez*) to one that merely argued for a reasonable modification in how the state administered its long-term care program.

The type of ADA-driven, rather than Medicaid-driven, analytic approach in *Quasim* garnered support in a subsequent fundamental alteration case, *Fisher v. Oklahoma Health Care Authority*.<sup>21</sup> In *Fisher*, participants receiving Medicaid-financed community-based care challenged under the ADA the state of Oklahoma’s cost-saving attempt to limit their prescription drug benefits to five-per-month, while at the same time providing unlimited drugs to those receiving the same services in a nursing home. Specifically, the plaintiffs claimed that a community care-based limit would essentially force them into an institutional environment, and that the continuation of an unlimited drug benefit would not amount to a fundamental alteration of the Medicaid program. The federal court agreed that the state’s fundamental alteration defense could not stand without more facts, stating “[i]f every alteration in a program or service that required an outlay of funds were tantamount to a fundamental alteration, the ADA’s integration mandate would be hollow indeed . . . . [Plaintiffs] are not demanding a separate service or one not already provided by the state.”<sup>22</sup> Thus, the *Fisher* court also essentially narrowed the state’s use of a fundamental alteration defense by suggesting that such a defense did not exist where a benefit already existed somewhere in a state’s plan. In such a circumstance the court was willing to accept the proposition that claims made by persons with disabilities could be interpreted as a challenge to the manner in which the benefit was being administered, thus bringing the remedy within the court’s reach.

*Rewarding rather than sanctioning states that move slowly toward change*

A powerful theme that emerges from post-*Olmstead* cases is that courts desire to encourage policy change, not unnecessarily insert themselves in the change process. This inclination on courts’ part to defer to change, even when it comes slowly, can be seen in *Williams v Wasserman*.<sup>23</sup> In *Wasserman*, a group of persons with disabilities who had

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<sup>20</sup> *Quasim*, 328 F.3d at 519.

<sup>21</sup> 335 F.3d 1175 (10<sup>th</sup> Cir. 2003).

<sup>22</sup> *Fisher*, 335 F.3d at 1183.

<sup>23</sup> 164 F. Supp.2d 591 (D. Md. 2001).

waited more than 5 years for a community placement sued the state of Maryland, claiming a violation of *Olmstead's* reasonable pace standard.

Rejecting the claim, the court commended the state for its active efforts to increase community integration for severely mentally disabled individuals, which included visible planning and focused attention on the problem of community integration, efforts to secure additional legislative funding for key community services, and other administrative reforms aimed at producing greater community benefits. The court concluded that Maryland's ongoing efforts towards de-institutionalization satisfied the ADA and *Olmstead*, suggesting that what courts desire on the part of states is a dedicated effort to change the landscape for persons with disabilities, even if the pace of change is slower than the need warrants.

This result suggests that states' response to the goal of community integration and the broad "reasonable pace" mandate of the Court should be active and visible involvement in program restructuring, even if many of the reforms are ones that could take years to implement. Rather than exposing the state to further liability if such reforms are not achieved, evidence of active engagement and slow progress toward fundamental alterations signals the type of evolutionary change that the *Olmstead* majority arguably sought to accomplish.

### Defining Reasonable Pace

In applying *Olmstead's* mandate that community integration of institutionalized disabled individuals occur within a reasonable timeframe, the key question for lower courts is whether the defendant public program has in place an "effectively working plan" of "community integration" that is moving at a "reasonable pace." If a court determines that this is in fact the case -- measuring reasonableness against the totality of circumstances, as in the *Wasserman* case above -- the plaintiff's request will likely be denied, and additional community integration reform will need to be sought out through legislative channels. At the same time, courts have demonstrated a willingness to demand far speedier movement in cases in which they concluded circumstances warranted such intervention.

Analysis of reasonable pace case law indicates that when confronted with defining "reasonable pace," courts seek guidance from three sources: the *Olmstead* decision itself and its interpretation of the ADA; federal Medicaid law; and other court decisions that have considered similar issues. Medicaid rules are often implicated in reasonable pace litigation because Medicaid is so intertwined with community service litigation under the ADA generally, but also because many of the reasonable pace cases raise a parallel Medicaid "reasonable promptness" claim; that is, a claim that benefits and services covered under a state's Medicaid plan (either as a basic state plan service or as a supplemental waiver service) were not furnished with reasonable promptness, as is required under Medicaid law. Under Medicaid, state agencies must "furnish Medicaid

promptly to recipients without any delay caused by the agency’s administrative procedures.”<sup>24</sup>

As a result, in considering the concept of reasonable pace in the context of a community services case involving Medicaid, courts have defined “reasonable pace” in part by analogizing to Medicaid’s “reasonable promptness” provision. In these cases, states have defended their administration of their community care programs under Medicaid waiver programs by presenting several arguments asserting that they have not violated the reasonable pace (or reasonable promptness) requirement.

For example, states have argued that courts are generally unable to quantifiably define “reasonable pace” and therefore cannot require specific state action within a specified time period. Courts have had little trouble rejecting this argument, generally finding that plaintiffs’ right to reasonably prompt medical assistance is not so vague that it cannot be enforced by the courts. For example, *Boulet v. Cellucci*<sup>25</sup> was a case in which the plaintiffs’ parents requested residential 24-hour-per-day services for their children. The plaintiffs, all Medicaid-eligible, were unable to care for themselves and lived with their parents while awaiting residential habilitation services, but the state Department of Mental Retardation waiting list was such that the plaintiffs had been waiting years for services. In this context, the court observed that “the reasonable promptness requirement is not too vague for judicial assessment. Certain periods of time, like the three to ten or more years plaintiffs have been waiting, are ‘far outside of the realm of reasonableness’—a conclusion which a court is perfectly capable of reaching.”<sup>26</sup>

States have also claimed that insufficient funding from the legislative branch is a justifiable defense to a plaintiff’s claim that the state failed to provide waiver services in compliance with the reasonable pace/reasonable promptness standard. Yet in most cases, courts have rejected the argument that insufficient funding was alone a proper reason for excessive waiting times to receive community services. In *Benjamin H. v Ohl*,<sup>27</sup> for example, the district court noted that “[t]he defendant cannot escape liability by a conclusory declaration that no more money will be provided to meet the State’s obligations under the Medicaid Act or the ADA. The defendant will have to show more than that the State has not appropriated enough funding.”<sup>28</sup> As a result, the court required the state to develop a compliance plan to eliminate wait lists and establish reasonable time frames for the provision of ICF-MR services to qualified individuals. The court was concerned that West Virginia could renege on its promise of community services by simply failing to appropriate sufficient funds. The court in *Boulet* echoed that sentiment, writing that “inadequate funding does not excuse failure to comply with the reasonable promptness requirement.”<sup>29</sup>

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<sup>24</sup> 42 C.F.R. § 435.930.

<sup>25</sup> 107 F. Supp. 2d 61 (2000).

<sup>26</sup> *Id.* at 72.

<sup>27</sup> Civ. No. 3:99-0338 (S.D.W.V. 1999).

<sup>28</sup> *Id.*

<sup>29</sup> *Boulet*, 107 F. Supp.2d at 80.



Furthermore, states have argued that the reasonable promptness requirement applies only to mandatory Medicaid services, but not to non-mandatory community integration initiatives. According to this argument, because states initiate and administer these non-mandatory waiver programs at their option, individuals have no legal entitlement to such services, and they may not demand that the services be furnished with reasonable promptness. Several courts have rejected this argument, concluding that when a state chooses to provide optional waiver programs, the services become part of the state's Medicaid plan and eligible individuals are entitled to both program services and the associated protections of the Medicaid Act, including the reasonable promptness requirement. *Bryson v. Shumway*,<sup>30</sup> a case in which individuals with acquired brain disorders sued the state of New Hampshire claiming that human services officials failed to expeditiously provide home and community-based care, is instructive. The plaintiff class consisted of otherwise qualified individuals who had applied for services and been deemed eligible within 90 days, but were then placed on waiting lists for years. The states asserted that the *finding of eligibility* was all that was needed to satisfy the reasonable promptness requirement, since "reasonable promptness" applies only to administrative delay surrounding the determination of eligibility, not to undue delay in the actual provision of services. Relying on the plain language of the Medicaid statute, the court in *Bryson* rejected this claim, finding that the duty of reasonable promptness applies both to the "administrative aspect" of benefit delivery and the actual delivery of services.

At the same time, one court has found that individuals are not entitled to services obtained through an optional waiver program, and that as a result waiver service recipients could be subjected to an otherwise impermissibly long waiting list. In *Makin v. Hawaii*,<sup>31</sup> a class of over 750 mentally retarded individuals who were on a wait list for services from Hawaii's Medicaid Home and Community Based Services for the Developmentally Disabled or Mentally Retarded program brought action, challenging the state's administration of the program. According to the court, the state was permitted under the Medicaid statute to limit the number of individuals who were to receive waiver services, and therefore qualified individuals were not entitled to the waiver services unless open slots existed within the population limits.

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<sup>30</sup> 177 F. Supp. 2d 78 (2001).

<sup>31</sup> 114 F. Supp.2d 1017 (1999).

## Measuring Community Integration

One of the more striking questions is what is meant by community integration itself. For example, is living in an apartment on the campus of a state mental hospital “integrated”? What if an individual living in a group home believes that she is not “integrated” unless she has her own apartment? None of the post-*Olmstead* cases deals directly with this question. Cases from other areas of disability law suggest that as with so many questions regarding whether a legal standard is met, courts will use a balancing test to arrive at an answer. They will examine relevant evidence of integration and will use objective evidence of isolation and segregation versus integration to test assertions made either by plaintiffs or defendants that integration has -- or has not -- been achieved. Thus, courts might consider quantifiable facts as important evidence of integration (e.g., how far an apartment may be from residential communities for persons without disabilities, the reasonableness of zoning restrictions, and other indicia of segregation and isolation).

## The Role of Individual Assessments in Community Integration

A key element of the *Olmstead* decision concerns the role of state professionals in the individual assessment process of determining a disabled individual’s “eligibility for habilitation in a community based program.” In *Olmstead*, the two plaintiffs were residents of a state mental institution who had been determined by the state’s own treatment professionals to be qualified to live in the community, but nonetheless languished in an institution because the state failed to make the resources available to allow this to occur. In setting the standard for state conduct in cases involving medically unnecessary institutionalization under public programs, the Court stated as follows:

[Community integration] is in order when *the state’s treatment professionals have determined that the community placement is appropriate*, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.<sup>32</sup>

However, the Supreme Court left unclear the exact scope and application of the individual assessment process, leaving lower courts to grapple with the issue of “individual assessments” to determine individuals’ initial eligibility for community integration. In interpreting and applying the Supreme Court’s assessment language, and in the context of the *Olmstead* planning process, courts and states, respectively, must address two separate types of assessments: threshold “liberty assessments” that arise when an individual residing in an institution in which the state has control seeks community integration; and the more common “coverage” assessments that arise when an individual makes a claim for the benefits or resources necessary to support a decision to live in the community.

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<sup>32</sup> *Olmstead*, 527 U.S. at 587 [italics added].

On the one hand, liberty assessments require that the state's assessment process satisfy both the substantive considerations of the ADA in terms of measuring the appropriateness of community integration and basic due process considerations. Key constitutional due process cases<sup>33</sup> involving liberty interests of confined persons identify certain elements of a fair threshold assessment process, including a process that is accessible to the individual and that the individual can seek out (i.e., not wholly at the discretion of the state), and one that utilizes qualified professionals who have the requisite training and skills to conduct an assessment. For example, in *Youngberg v. Romeo*,<sup>34</sup> the Supreme Court held that individuals in involuntary civil confinement situations have a constitutional right to have treatment designed by health professionals and that the role of professional opinion is so great that courts must defer to professional judgment.

Furthermore, liberty assessments must use objective evidence, clinical observation, and assessment tools that are reliable and valid. In the case *Doe v. Bush*,<sup>35</sup> a group of developmentally disabled individuals brought suit against the Florida Department of Health and Rehabilitative Services, alleging that the department was allowing eligible individuals to languish on waiting lists for Intermediate Care Facilities for the Developmentally Disabled (ICF/DD) services for years in violation of Medicaid. In response, the state amended its Medicaid state plan and adopted the Florida Status Tracking Survey, a uniform assessment instrument to determine for which individuals ICF/DD placement is medically necessary. The Eleventh Circuit found permissible a state process in which the first stage of the assessment regarding appropriateness of inpatient care in a facility for developmentally disabled persons was a paper screening tool based on patient files, rather than a face-to-face individualized assessment. This holding suggests that assuming that the preliminary screening device is a valid and reliable instrument and is properly applied to a relevant group of individuals (i.e., is not applied to make decisions about persons for whom the tool was not developed in the first place), such a preliminary screen would be acceptable.

On the other hand, "coverage" or "resource and benefit" assessments involve an individualized fact-finding process regarding what resources an individual needs to live in the community, and whether the state provides or could provide the resources with reasonable modification to how it administers programs and services. Thus, for example, if the individual can live in a community if certain types of housing services are available, the state's task would be to examine its housing resources to determine if the service exists or could be developed through reasonable modifications in the housing programs it does offer.

In *Easley v. Snider*,<sup>36</sup> Pennsylvania rejected a request for additional individual personal support services designed to help persons with disabilities complete tasks that

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<sup>33</sup> *Youngberg v. Romeo*, 457 U.S. 307 (1982); *Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974); *Jackson v. Indiana*, 406 U.S. 715 (1972); *Welsch v. Likins*, 550 F.2d 1122 (8th Cir. 1977).

<sup>34</sup> 457 U.S. 307 (1982).

<sup>35</sup> 261 F.3d 1037 (11<sup>th</sup> Cir. 2001).

<sup>36</sup> 36 F.3d 297 (3d Cir. 1994).

individuals receiving home and community services would have to complete on their own in order to qualify for the waiver. The state's rationale for this coverage limitation was that the ability to complete certain tasks independent of assistance by a personal aide was a basic eligibility prerequisite for its program, the purpose of which was to enable physically disabled but mentally alert adults to live in their own homes and communities. At the time of this case, one plaintiff was a 29-year-old woman left with little mobility and no speech after a car accident. She lost her attendant care services when she moved to a different part of Philadelphia not covered by her original service provider. The second plaintiff was a 53-year-old woman suffering from multiple sclerosis and undifferentiated schizophrenia.<sup>37</sup> Incapable of living alone, she had lived with her daughter but had to enter a nursing home when she was unable to get attendant care services.<sup>38</sup>

It should be noted that a coverage assessment can permissibly take into account the overall cost of the care requested, so long as a reasonable modification standard is used to ensure that modifications with modest cost implications are not overlooked and as long as a review of the decision is possible. In *Catanzano v. Dowling*,<sup>39</sup> a federal trial court held that the State of New York could require certified home health agency to consider cost-effectiveness in deciding the appropriateness of home health care versus residential care, even though such a determination amounted to a decision by the state.

#### Olmstead's Legacy in the Policy-Making Process

Thus far, this analysis has considered community integration in a judicial context. Yet one fact that clearly emerges from an analysis of judicial intervention is that courts are attentive to the limits of their own powers and will intervene when the totality of facts suggests stagnation and lack of movement. When courts see forward motion -- even if the forward motion is slow -- they are more inclined to defer intervention. Furthermore, where courts are convinced that the issues they confront amount to program redesign rather than program administration, their deference also is apparent.

Because judicial intervention powers are carefully circumscribed both by *Olmstead* and the ADA itself, the policy development and implementation processes gain critical importance in gauging progress toward community integration. In this regard, the past 5 years have witnessed considerable interest and movement, at both the federal and state levels of government. It is in these policy making settings that the very type of fundamental changes so integral to the broad goals of the ADA but beyond the reach of the courts can take place.

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<sup>37</sup> *Id.* at 299.

<sup>38</sup> *Id.*

<sup>39</sup> 847 F. Supp. 1070 (W.D.N.Y. 1994).

Broad changes can be seen in Medicaid, and these changes have persisted even as states have struggled with serious economic circumstances.<sup>40</sup> State and federal policy makers have made efforts to design new programs, new methods of service delivery, and innovative approaches to administering existing programs in order to achieve greater levels of community integration.

### Federal Policy Statements

The positive Executive Branch response to *Olmstead* spans two administrations. During President Clinton's tenure, the Center for Medicaid and State Operations and the Office for Civil Rights issued five joint State Medicaid Directors letters providing guidance on complying with *Olmstead*. The guidance focused on requirements for states to develop "effectively working plans" for moving institutionalized disabled individuals into community placements. Specifically, the first letter, dated January 14, 2000, outlined a framework for state Medicaid directors to use to respond to the challenge of developing comprehensive, effective working plans. Six initial technical assistance recommendations were identified for states to consider as they developed their working plans:

1. Develop and Implement a comprehensive, effective working plan to serve people with disabilities in the most integrated setting appropriate.
2. Provide opportunities for individuals with disabilities and their representatives to be integral participants in the plan development.
3. Take steps to prevent and correct current or future unjustified institutionalization.
4. Ensure the availability of community integration services.
5. Afford individuals with disabilities to opportunity to make informed choices regarding how their needs can best be met in community or institutional settings.
6. Take steps to ensure quality assurance, improvement and sound management.

The second and third letters, both dated July 25, 2000, reiterate the importance for states to implement plans that address the *Olmstead* decision. Furthermore, the third letter summarizes HCFA efforts to review federal policies in order to facilitate fulfillment of the ADA in critical areas such as transitioning from nursing homes to the community; expanding the availability and quality of home- and community-based services; and ensuring that services are compatible to all. The final two letters, dated January 10, 2001, address issues relating to the allowable limits in home and community-based services waivers under §1915 of the Social Security Act, as well as tools available to state health and long-term service systems to fulfill requirements under the ADA.

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<sup>40</sup> Smith V., et. al., *States Respond to Fiscal Pressure: A 50-State Update of State Medicaid Spending Growth and Cost-Containment Strategies* (Kaiser Commission on Medicaid and the Uninsured, Washington, DC 2004).

## Federal Community Integration Initiatives

Soon after taking office, the Bush Administration, in response to the *Olmstead* decision, launched the New Freedom Initiative, a comprehensive plan aimed at ensuring that all Americans have the opportunity to participate fully in community life. The initiative's goals include expanding educational opportunities; promoting homeownership; integration into the workforce; and expansion of transportation options. The initiative also included Executive Order 13217, requiring the Departments of Health and Human Services, Justice, Education, Labor, Housing and Urban Development, and the Social Security Administration, to coordinate use of existing resources and modify policies to incentivize community integration. What follows are examples of implementation activities since the inception of the New Freedom Initiative.

### Department of Justice

- 1) In regards to *Olmstead* criteria, evaluating residential placements under the federal Civil Rights of Institutionalized Persons Act.
- 2) Devoting substantial resources to investigations and enforcement actions against developers, builders, architects, and site engineers who design and/or construct multi-family housing that does not comply with the requirements of the Fair Housing Act (FHA), and against rental offices and other places of public accommodation within housing complexes that do not comply with the ADA.
- 3) Encouraging advocacy groups and private counsel representing persons with disabilities to alert DOJ to private lawsuits where amicus participation by DOJ would assist the court in interpreting and applying the provisions of the FHA and § 504 of the Rehabilitation Act.

### Department of Labor

Office of Disability Employment Policy awarded \$500,000 to eight recipients to provide home modifications for persons with disabilities.

Congress has also taken steps to provide opportunities for disabled individuals beyond what could be achieved through the court system alone. For example, in 2000 Congress created a federal grant program called the Real Choice Systems Change Grants for Community Life to create infrastructure and service options necessary for long-term community integration. Since 2001 the Center for Medicare and Medicaid Services has awarded nearly \$160 million in Real Choice grants to states and other eligible entities.

## State Community Integration Initiatives and Plans

In response to both the Supreme Court's suggestion that an effective community integration plan that moved at a reasonable pace would go a long way toward satisfying *Olmstead*'s mandate, and the Administrations' letters and other guidance, 29 states have issued *Olmstead*-related plans or reports. Many of these plans rely on Medicaid community service options, in combination with resources from other programs, to achieve the types of community programs that make it possible for persons with serious disabilities to live and work in their own communities.

A review of the planning documents reveals a series of key community integration measures on behalf of the states:

### Key Community Integration Measures

(A) Outcome-based measures

- transitioning institutional residents to community care;
- elimination of waiting lists; and
- institutional diversion of persons at risk in the community.

(B) Intermediate measures

- building system and provider capacity;
- investment of resources to reach goals, with identification of housing, health care, and other community supports; and
- developing the appropriate tools to reach individuals eligible for community placements.

As a way of underscoring the state response to *Olmstead*, and to bring to life these integration measures, we provide below information on five illustrative state plans.<sup>41</sup>

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<sup>41</sup> In portraying this state plan information, we borrow heavily from two sources: the National Council on Disability's "*Olmstead: Reclaiming Institutionalized Lives*," available at <http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm>, and Fox-Grage W., Coleman B., and Folkemer D., "The States' Response to the *Olmstead* Decision: A 2003 Update," available at [www.ncsl.org/programs/health/forum/olmstead/2003/olms2003report.htm](http://www.ncsl.org/programs/health/forum/olmstead/2003/olms2003report.htm).

### Mississippi

Mississippi has a heavy “institutional” bias, and ranks 47th in the nation for community fiscal effort and 50th in the use of Health Care Budget Waivers for developmental disabilities. Stakeholders in this state find the lack of transportation for people with disabilities, not housing, to be the major barrier to community living. The Division of Medicaid leads *Olmstead* planning for the state. In March 2001 there was a legislative mandate for a plan, which was written and released in September 2001. It is an exemplar plan because of a unique feature: the cost of implementing each planning goal is figured out over a 10-year period so the plan can be incorporated into budgets and legislative appropriations. There are also numerical targets in the plan for increasing the number of individuals served in the community. The plan also shows a promising strategy for housing (e.g., train case managers in housing facilitation and expand services to include modification and repair of homes). The following issues are addressed in the plan: consumer education, database development, housing, simplification and standardization, transition from institution to community, transition from children to adult service, population identification, and transportation. There are no requirements in the plan for people who could handle or benefit from community care to be identified. One drawback is that the state still lacks consensus on how to ensure that waiting lists move at a reasonable pace. Because of shortfalls in the state Medicaid budget, the plan was not implemented as of March of 2003. The state’s progress report, “Implementation Report #1,” dated May 2003, argues progress has been made, though it has been slow due to budget shortfalls.

### Oregon

Oregon has a six-year plan that has as its goal the elimination of the waiting lists for community-based services for people with developmental disabilities. The state has succeeded in that there are no waiting lists for services for people with physical disabilities or the elderly. The current efforts related to expansion of community-based care focus on people with developmental disabilities. The “*Olmstead* Decision and Adults in Oregon’s State Hospitals” plan is a model plan because it identifies with specificity those people who should be recommended for community care, and also specifies the services these people will need after their transition to community-based care. The plan also considers the sufficiency of services, the changes in services necessary for consumer needs to be met, and the costs associated with transitioning people from institutions to community-based care. The state sold a psychiatric facility and put the funds from that sale into a housing trust fund to help towards the access and affordability of housing, and it signed the first-ever labor contract for home care workers, which will lead to \$.40/ hour wage increase and health care coverage for those in the community-care workforce. The Oregon plan is focused on the quality and availability of services and on consumer-directed service and support.



### Georgia

Georgia's plan is remarkably faithful to *Olmstead*, and it is meant to be a continuing process, confronted on an annual basis. The Department of Human Resources is the lead agency, and the Office of Planning and Budget oversees the state's efforts to address *Olmstead*. The planning goals are the following: 1) transition those in institutions to community care; 2) divert people at risk in the community from institutions; 3) build system and provider capacity; and 4) gain commitment from the state to provide resources for the plan to go forward. The state focuses on getting people out of institutions, not just on making community-care better. It provides allowances for housing and other necessary funding when transitioning individuals from institutions to the community. In the area of mental health, the state has tried to enhance the quality of the mental health services by using a general assessment tool to evaluate a person's ability to move into community care if they desire to move. The focus areas of the plan include: housing, identification and assessment, education and outreach, workforce development, transportation, assistive technology, and transition planning.

### Massachusetts

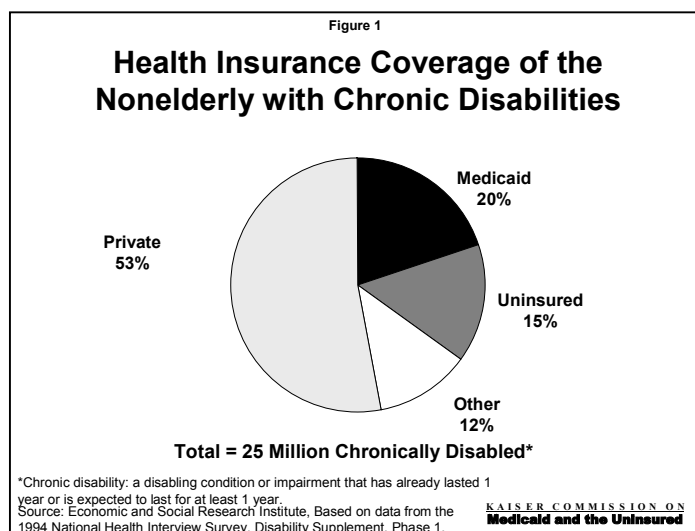
The "Enhancing Community Based Services: Phase One of Massachusetts Plan" was prepared by an *Olmstead* Advisory Group, which made recommendations to the Real Choice Consumer Task Force. Phase One, delivered in July of 2002, is basically a plan to plan, but it outlines logical steps consistent with HHS guidelines (e.g., completing an inventory of people in institutions and those at risk, and identifying how many want to leave and how many could leave if they had support and funds necessary). The next phase will be a budget proposal for the next fiscal year. The focus areas of the plan are education and outreach, identifying and assessing individuals, planning for transition, service coordination, matching service delivery system to the identified needs (consumer-directed care, including employment, assistive technology, and transportation), and housing. With respect to housing, the plan is thoughtful and solid. The state makes sure the state housing agencies are all at the table when making plans. The state is aiming for a universal design in new units, and units developed where public transportation is accessible, or within walking distance of employment and other activities for living. The state also conducts research to figure out if underused housing developments can be reconfigured to be usable and desirable for people with disabilities needing housing. The plan focuses on strong consumer-directed care, and offers transition allowances for moving from institutions to community-based care. The plan proposes the establishment of a baseline of expenditure and utilization rates for facility-based services which would be updated annually, and a developing process and timeline to compile lists of those waiting for long-term care services and to analyze current client populations at risk of facility placement.

## Texas

Texas is a heavily institutionalized state with low levels of Medicaid use. In 2000, Texas ranked 48<sup>th</sup> in the nation in regards to how many persons with developmental disabilities were living in community settings. Its *Olmstead* plan, “Promoting Independence,” seeks to examine state funding mechanisms and to figure out how they can be modified to encourage community placement. The Texas Department of Human Services established the plan. It contains two unique initiatives: 1) Rider 37 (Rider 28 for '04-'05 funds), which allows Nursing Facility funds to follow the person to community services, and 2) Rider 7, under which the state establishes procedures to control the number of Medicaid beds and for de-certification of unused Medicaid beds. The plan is also unique in that it includes children in foster care because Texas believes the most integrated setting for children is a permanent placement with a family. The state focuses on moving people from institutions to community settings, not just improving community care. The focus areas of the plan are funding and capacity (assist transitions with funding for the individual), housing (enhancing the stock and removing the barriers to accessible housing), workforce (develop recruitment and retention incentives for all providers of long-term care services), children’s issues (waiver slots for children, permanency planning), and access (consumer assessment, training and information, and technology). The state is trying to determine how best to use a Medicaid waiver for community-based treatment alternatives for children with severe emotional disturbances.

### Specific Developments in Medicaid

The past five years have brought ever-growing attention to Medicaid’s special role for persons with disabilities. For millions of persons with disabilities, Medicaid coverage is integral to the achievement of ADA, because of several specific features. One is Medicaid’s accessibility regardless of health status. Medicaid serves 8 million persons with disabilities under age 65<sup>42</sup> and millions of elderly persons with serious activity limitations. Among the estimated 25 million persons under age 65 with chronic disabilities, Medicaid serves one in five persons (Figure 1). Furthermore,



<sup>42</sup> Jeffrey Crowley and Risa Elias, *Medicaid’s Role for People with Disabilities* (Kaiser Commission on the Medicaid and the Uninsured, Washington, DC 2004).

Medicaid uses no pre-existing condition exclusions or waiting periods<sup>43</sup> and is specifically designed to extend coverage to people of any age with the most severe disabilities (e.g., children, working-age and elderly adults who receive or who are linked to the Supplemental Security Income Program, children in foster care who experience high rates of disability,<sup>44</sup> children and adults eligible for special Medicaid waiver programs which are designed to extend coverage in community settings to otherwise ineligible persons at risk for institutionalization, and medically needy persons).<sup>45</sup> Additionally, Medicaid has for many years provided options for states to extend coverage for workers with disabilities. The 1999 Ticket to Work and Work Incentives Improvement Act, enacted in the wake of *Olmstead*, expands these options further by permitting coverage to be extended to workers with incomes as high as 450% of the federal poverty level. It also allows coverage to continue despite improvements in functioning of the type that normally would disqualify a person with an activity limitation from being considered “disabled” within the meaning of Medicaid.<sup>46</sup>

In short, the crucial role that Medicaid plays in financing health care is perhaps at its most visible in the case of persons with severe disabilities, because of its ability to cover persons who do not work by reason of disability or have no connection to employer-sponsored coverage through a relative (e.g., minor children with disabilities) or to commercial coverage.

Another equally distinguishing aspect of Medicaid, which makes it pivotal to persons with disabilities, is the breadth of its coverage and its protections against high out-of-pocket expenditures. Medicaid offers coverage that extends far beyond the furthest reaches of conventional health insurance. This special coverage design includes not only services considered long-term care in nature, such as nursing facility and home health care, but a broad range of services in the community that both finance medical care and enable the receipt of care. Examples of such services include clinic benefits offering integrated and therapeutic services for children and adults with physical and mental disabilities, comprehensive prescription drug benefits,<sup>47</sup> medical transportation, case management, and special home and community care services that enhance state plan benefits and can be furnished via special waivers.<sup>48</sup> Medicaid thus supports a broad range of expenditures in community settings and makes integrated services possible

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<sup>43</sup> Sara Rosenbaum, “Health Policy 2002: Medicaid,” *NEJM* 346:8 (Feb. 21, 2002) pp. 635-640; Andy Schneider et al., *Medicaid Source Book* (Kaiser Commission on Medicaid and the Uninsured, Washington DC 2003).

<sup>44</sup> An estimated 30-70 percent of children in foster care have serious emotional conditions. J. McCarthy, “Meeting the Health Care Needs of Children in the Foster Care System: Summary of State and Community Efforts, Key Findings” (Georgetown University Child Development Center, Washington, DC 2002).

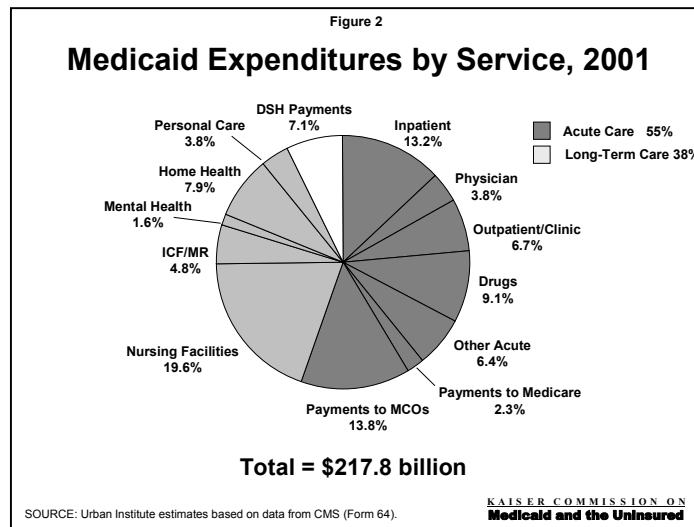
<sup>45</sup> Crowley and Elias, *supra* note 44.

<sup>46</sup> *Id.*

<sup>47</sup> The Medicare Prescription Drug, Improvement and Modernization Act of 2003 ends prescription drug coverage under Medicaid for Medicaid beneficiaries with disabilities who also receive Medicare. It is as yet unclear whether the new Medicare drug benefit will offer the same breadth of coverage available in Medicaid.

<sup>48</sup> Crowley and Elias, *supra* note 44.

(Figure2).<sup>49</sup> Medicaid also fills critical coverage gaps for low-income Medicare beneficiaries. For all enrollees, Medicaid ensures that beneficiary cost-sharing obligations are kept low.



Of particular interest is increasing investment in home and community-based waiver services. All states cover at least some level of home and community-based services for persons at risk of institutional care.<sup>50</sup> Although room and board are not permissible expenditures under waivers, in the case of mental illness states have the option to extend residential coverage in small group arrangements and combine this coverage with home and community services.<sup>51</sup> Since 1992, Medicaid spending on home and community-based waiver services has increased exponentially, growing from 37% to 66% of all spending on community services between 1992 and 2001. In 1992, 15% of all long-term care spending went to home and community care waiver benefits. By 2002 that figure had risen to 30%.<sup>52</sup>

Increasingly, benefit design for persons with disabilities also includes a concept known as “cash and counseling” (the official demonstration name for cash and counseling programs is “Independence Plus,” a special demonstration program launched by the Bush Administration in 2002). When carefully designed,<sup>53</sup> these arrangements can increase the ability of persons with disabilities to control benefits and services by

<sup>49</sup> Indeed, so strong is Medicaid’s ability to support community services that the Supreme Court in *Olmstead* specifically rejected Georgia’s arguments that the program contained an “institutional bias.”

<sup>50</sup> Crowley and Elias, *supra* note 44.

<sup>51</sup> Sara Rosenbaum et al., “An Analysis of the Medicaid IMD Exclusion,” available at [http://www.gwhealthpolicy.org/downloads/behavioral\\_health/reports/IMD%20Report%201202.pdf](http://www.gwhealthpolicy.org/downloads/behavioral_health/reports/IMD%20Report%201202.pdf) (accessed June 4, 2004).

<sup>52</sup> Heidi Reester, Raad Missmar, and Anne Tumlinson, “Recent Growth in Medicaid Home and Community Based Waivers” (Kaiser Commission on Medicaid and the Uninsured, Washington, DC, 2004).

<sup>53</sup> Jeffrey Crowley, “An Overview of the Independence Plus Initiative to Promote Consumer Direction of Services in Medicaid” (Kaiser Commission on Medicaid and the Uninsured, Washington, DC 2003)

allowing greater levels of control over the mix of services, the source of services, and service settings.

Not only are benefits broad in Medicaid, but the rules of coverage are unlike those that typically are found in commercial insurance arrangements. Medicaid specifically requires that coverage limits be reasonable and mandates a particularly high level of coverage for children as an Early and Periodic Screening, Diagnosis, and Treatment benefit, including children with disabilities. Medicaid prohibits the types of arbitrary coverage limits that insurers tend to apply to disabling physical and mental conditions (e.g., flat dollar limits on coverage, such as \$5,000 for HIV/AIDS coverage, or treatment limits for mental illness). While these condition-specific limits are permissible in private coverage even in the wake of the ADA, they are prohibited under Medicaid (at the same time of course, Medicaid may use across-the-board limits as long as they are applied fairly).<sup>54</sup> Similarly, the anti-discrimination provisions of Medicaid could be expected to prohibit medical necessity criteria that limit coverage to treatments that “restore functioning” because of the tendency of such a definition to discriminate against persons whose specific conditions prevent the “restoration” of functioning (e.g., children born with developmental disabilities, adults with permanent or degenerative conditions).<sup>55</sup>

Medicaid also enables the development of integrated service delivery arrangements through managed care options that allow states and communities, working with health care providers, to couple community health services with broad social benefits for enrollees. Several states have ongoing efforts in this regard, and while many of these programs tend to be small (owing to the complexity of the service model), the innovations are critical to advancing integrated support arrangements for persons with disabilities.<sup>56</sup>

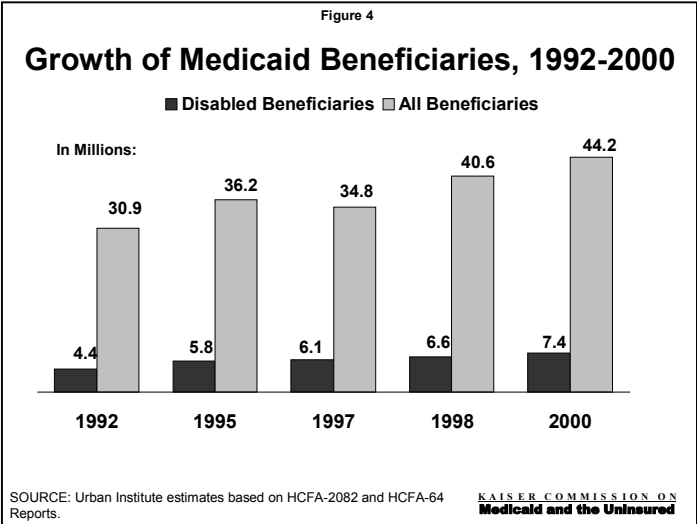
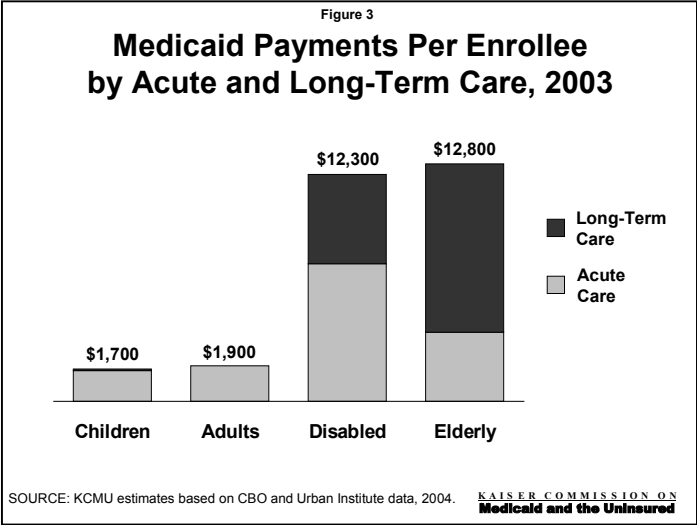
As a result of all these unique features, Medicaid represents an enormously important investment in persons with disabilities. While persons with disabilities account for 16% of all beneficiaries, their care consumes 43% of all expenditures, and average per capita expenditures are five-to-six times higher than those made for child and adult populations without disabilities (Figure 3). Furthermore, the population of Medicaid beneficiaries has steadily grown over the decade since the ADA was enacted, nearly doubling between 1992 and 2000 as a result of greater survival rates among children and adults with disabilities, a generally greater focus on community services, and new Medicaid options (Figure 4). Thus, even as the judicial response to Medicaid claims has been uneven in *Olmstead*'s wake, and the pace of change remains considerably slower than might be optimal, Medicaid has been steadily transformed since enactment of the ADA in ways that benefit potentially millions of children and adults with disabilities.

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<sup>54</sup> Rosenbaum, *supra* note 45.

<sup>55</sup> *Id.*

<sup>56</sup> Examples of such programs can be seen at the website maintained by the Center for Health Care Strategies: [http://www.chcs.org/info-url\\_nocat3961/info-url\\_show.htm?doc\\_id=206323](http://www.chcs.org/info-url_nocat3961/info-url_show.htm?doc_id=206323) (accessed June 4, 2004).



## Conclusion

Like many seminal civil rights decisions, *Olmstead* has different meanings. The decision established a broad legal standard for measuring the adequacy of publicly funded health program design for persons with disabilities. At the same time, it is evident that its lofty goals, which parallel those of the ADA itself, can be reached only through a national commitment to reforms that extend far beyond the power of courts to devise. United States courts are among the most powerful in the world in terms of their ability to intervene in broad questions of policy and to frame remedies. But in a democratic society, the center of power for transforming evolving social mores into policy and law is (most appropriately) found in the legislative process. Here the power of *Olmstead* to help generate change is equally great, although not so direct.

This review underscores the role of courts and legislative and administrative policy making in advancing the type of fundamental shift in social policy that is the hallmark of important civil rights litigation. The ADA represented a dramatic strengthening of prior U.S. policy toward persons with disabilities. *Olmstead* represents the power of courts to ensure that all public programs -- health, education, transportation, and so forth -- are administered in a manner that is consistent not only with the terms of the ADA but its most profound goals. Some of the most important changes can be linked directly to *Olmstead*, in particular state planning efforts and new investment opportunities enacted by Congress over the past five years. Other changes, such as the sea changes in Medicaid structure, which have occurred since 1990, both preceded *Olmstead* and help explain why the Supreme Court dismissed any notion that Medicaid was inherently institutional in nature and thus offered no relevant tools for community integration.

Without question, a long road lies ahead. Programs that make housing, transportation, education, jobs and other activities of daily living possible for persons with disabilities remain underdeveloped and seriously underfunded. Medicaid's evolution is still a work in progress, with much reform needed to make the program more accessible to children and adults with disabilities. Particularly important are two types of changes. The first would be aimed at further modernization of the very stringent test of disability that guides Medicaid (i.e., an inability to perform substantial gainful work) in favor of one that focuses on persons who are qualified persons under the ADA (i.e., who can live and work in communities with reasonable modifications in services and supports). The 1999 amendments which permit retention of Medicaid in the face of improvement are a start, but much more is needed.

The second change is one that would further incentivize investments in community services. This could be done by making home and community services a state Medicaid option for which no waivers are needed. It also could be promoted by establishing a preferred rate of federal financial contribution for community-based programs, especially those that integrate health, education, social, and employment-based programs and that contain strong links to housing, transportation, and family support services.

The ideal of community integration lies at the heart of the ADA. This ideal is given expression in the power of the ADA to directly and indirectly spur the strengthening and modification of public programs in order to promote community integration of persons with disabilities. Whether this change comes through courts or through legislation will depend on unique circumstances that historically have guided the interplay of the branches of government in advancing social welfare reform. The important challenge that lies ahead is to ensure that progress continues, and that the path to reforming public programs such as Medicaid and other essential community supports mirrors the ADA in both letter and spirit.



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