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### OLMSTEAD V. L.C.: IMPLICATIONS FOR MEDICAID AND OTHER PUBLICLY FUNDED HEALTH SERVICES

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#### I. INTRODUCTION

OLMSTEAD V. L.C., decided by the United States Supreme Court in 1999, represents a watershed in the interpretation of the Americans With Disabilities Act (ADA or the Act) as it applies to publicly operated services. The immediate focus of the case was on whether medically unjustifiable institutionalization of persons with disabilities, who can appropriately receive treatment in the community and who desire to do so, constitutes discrimination under Title II of the ADA. But Olmstead's true importance from a health policy perspective lies in its long-term potential to secure realignment of public spending on health services for persons with disabilities.

The Olmstead decision is hardly the first time that the nation has confronted its tendency to skew public expenditures on persons with disabilities toward institutional settings and away

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

<sup>&</sup>lt;sup>2</sup> 42 U.S.C. §§ 12101-12213 (1994 & Supp. V 1999).

from full community integration.<sup>3</sup> At the same time, the case has garnered considerable attention among policy makers and program analysts, perhaps in part because of the short memory span that policy analysts can possess, but in large part because of its seemingly direct implications for Medicaid,<sup>4</sup> the nation's largest means-tested entitlement program.

Olmstead is emphatically not a Medicaid case. In the end, however, because the integration of persons with disabilities into the community depends so heavily on how States approach Medicaid financing, discussions about Olmstead quickly become discussions about Medicaid. Indeed, in implementing the decision, the United States Department of Health and Human Services assigned joint responsibility to the Office for Civil Rights and the Center for Medicare and Medicaid Services, the federal agency charged with administration of the Medicaid program.

In spite of its apparent reach, Olmstead is in fact far tougher to analyze in relation to Medicaid than would seem to be the case. The standards established under the majority decision for measuring when statutory violations under the ADA occur in the context of health services for persons with disabilities are, in fact, quite murky; furthermore, the powers granted to States to determine the scope of their own obligations, as well as the affirmative defenses they are accorded, are extensive. As a result, while Olmstead is a ringing restatement of policy for persons with disabilities—and one that grows out of a half-century of efforts to reorient U.S. social welfare in this area—its actual reach may be more limited. The critical issue becomes how the courts ultimately reconcile the discretion and defenses accorded state officials under the opinion with the Court's ulti-

<sup>&</sup>lt;sup>3</sup> See Pennhurst State Sch. and Hosp. v. Halderman, 451 U.S. 1 (1981) (holding that the Developmentally Disabled Assistance and Bill of Rights Act did not create substantive rights which would require Pennsylvania to close it state-operated school for the mentally retarded in favor of community living arrangements); Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971) (stating that '[t]he failure to provide suitable and adequate treatment to the mentally ill cannot be justified by lack of staff or facilities"), aff'd in part, rev'd in part sub nom. Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974).

<sup>&</sup>lt;sup>4</sup> See infra Part IV.

<sup>&</sup>lt;sup>5</sup> As of July 1, 2001, the Health Care Financing Administration (HCFA) is the Center for Medicare and Medicaid Services (CMS). CTR. FOR MEDICARE AND MEDICAID SERVS., U.S. DEP'T OF HEALTH AND HUMAN SERVS., INTRODUCING CMS (n.d.), at http://cms.hhs.gov/about/reorg.asp (last visited Oct. 29, 2001).

mate edict that integration occur and that it do so at a "reasonable pace." Much like other seminal civil rights decisions, the Olmstead Court sought to couple basic statements about the proper course of long-term public conduct with cautionary steps designed to protect against what it feared would be an excessively rapid pace of change that could harm the very individuals the Court sought to help. It is in this balancing of interests that the future course of publicly funded health care for persons with disabilities will be charted.

Part II of this article provides an overview of the ADA and the Olmstead decision, and an examination of the federal administrative response to the decision as of the summer of 2001. Part III presents the results of a special study designed to gauge the individual circumstances that underlie "most integrated setting" administrative complaints filed under Title II of the ADA. Part IV discusses a companion line of Medicaid cases that address the right of individuals to prompt treatment in a community setting, as well as recent legal developments related to the ability of individuals to enforce federal rights against state officials through actions for prospective injunctive relief. We conclude in Part V with observations about the profound and unanswered legal questions raised by the decision, as well as the broader meaning of Olmstead for long-term U.S. policy regarding the integration of persons with disabilities into community settings.

## II. THE ADA, THE *OLMSTEAD* DECISION, AND THE FEDERAL AGENCY RESPONSE TO *OLMSTEAD*

#### A. An Overview of the Americans With Disabilities Act

The ADA—the most significant piece of civil rights legislation since the passage of the Civil Rights Act of 1964<sup>7</sup>—was intended "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." The Act expands upon the ideas set forth in §

<sup>&</sup>lt;sup>6</sup> Olmstead, 527 U.S. at 606.

<sup>&</sup>lt;sup>7</sup> Pub. L. No. 88-352, 78 Stat. 24 (1964) (codified as amended in scattered sections of 42 U.S.C.).

<sup>8 42</sup> U.S.C. § 12101(b)(1) (1994 & Supp. V 1999).

504 of the Rehabilitation Act of 1973, which prohibits discrimination against an "otherwise qualified" individual solely on the basis of the individual's disability, in any program or activity that receives federal financial assistance. 10 The ADA broadened this proscription by clarifying the reach of the term "disability", retaining the "otherwise qualified" structure of the earlier law, and most significantly, by encompassing the conduct of not only government-sponsored programs and services, but also of employers and private entities open to the public. At the time of enactment, it was estimated that the ADA would extend these expanded protections to some forty-three million persons with disabilities. 11 Enacted as broad remedial legislation aimed at combating persistent discrimination against "individuals with disabilities . . . in such critical areas as . . . housing, public accommodations, education, transportation, communication, . . . institutionalization, health services, . . . and access to public services,"12 the ADA consists of several Titles. Title I covers employers as well as employer-sponsored benefits. 13 Title III applies to places of public accommodation. 14 Title II, the portion of the Act at issue in Olmstead, applies to publicly op-

<sup>9 29</sup> U.S.C. § 794 (1994 & Supp. V 1999).

<sup>10 7.7</sup> 

<sup>&</sup>lt;sup>11</sup> See Toyota Motor Mfg., Ky., Inc. v. Williams, 121 S. Ct. 681, 691 (2002) (discussing Congress's findings); Sutton v. United Air Lines Inc., 527 U.S. 471, 484 (1999) (same).

<sup>&</sup>lt;sup>12</sup> 42 U.S.C. § 12101(a)(3) (1994 & Supp. V 1999).

<sup>&</sup>lt;sup>13</sup> See, e.g., Carparts Distrib. Ctr, Inc. v. Automotive Wholesaler's Ass'n of New Eng., Inc., 37 F.3d 12 (1st Cir. 1994) (finding the proper issue in the case to be "not whether defendants were employers of [plaintiff] within the common sense of the word, but whether they can be considered 'employers' for purposes of Title I of the ADA and therefore subject to liability for discriminatorily denying employment benefits to [plaintiff]").

<sup>14</sup> See 42 U.S.C. § 12182(a) (1994 & Supp. V 1999) (prohibiting discrimination on the basis of disability regarding "any place of public accommodation"). Under the Act, places of public accommodation include the private offices of health care providers. See, e.g., Bragdon v. Abbott, 524 U.S. 624 (1998) (finding HIV-infected dental patient had a disability under the ADA, but remanding to determine if the patient having her cavity filled at the dentist's office, rather than the hospital, would pose a direct threat to the health and safety of others). A series of rulings have concluded, however, that the ADA does not reach the content of private health insurance. See Doe v. Mutual of Omaha Ins. Co., 179 F.3d 557 (7th Cir. 1999) (holding insurance policies that put a cap on medical care benefits for those with HIV did not violate the Act); Parker v. Metro. Life Ins. Co., 121 F.3d 1006 (6th Cir. 1997) (permitting employer to provide a disability plan which was more favorable to the physically disabled than the mentally disabled).

erated and funded programs and entities. 15 Title II provides in pertinent part: "[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."16 "The term 'qualified individual with a disability' means an individual with a disability who, with or without reasonable modifications<sup>17</sup> to rules, policies, or practices . . . meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity." "The term 'disability' means . . . physical or mental impairment that substantially limits one or more of the maior life activities of [an] individual; a record of such an impairment; or being regarded as having such an impairment."20

A public entity is "any State or local government" or "any department, agency, special purpose district, or other instrumentality of a State or States or local government."21 As such, Title II covers health care financing and service delivery programs administered by state agencies.

<sup>15</sup> See 42 U.S.C. § 12132 (1994 & Supp V 1999). Incidentally, Title IV applies to transportation. See id. § 12184. Title V includes several miscellaneous provisions. See id. § 12201.

<sup>16 42</sup> U.S.C. § 12132.

<sup>&</sup>lt;sup>17</sup> See infra Part IV (discussing reasonable modifications).

<sup>&</sup>lt;sup>18</sup> 42 U.S.C. § 12131(2).

<sup>&</sup>lt;sup>19</sup> Disability includes: "Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: Neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin, and endocrine" and "[a]ny mental or psychological disorder such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities." 28 C.F.R. §35.104 (2001). "[Included are] contagious and noncontagious diseases and conditions as orthopedic, visual, speech and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease (whether symptomatic or asymptomatic), tuberculosis, drug addiction, and alcoholism." Id. The following conditions are not included in the definition of disability: homosexuality, bisexuality, transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders, compulsive gambling, kleptomania, or pyromania, or psychoactive substance use disorders resulting from current illegal use of drugs. 42 U.S.C. § 12211.

<sup>&</sup>lt;sup>20</sup> 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).

21 42 U.S.C. § 12131(1)(A)-(B) (1994 & Supp. V 1999).

As part of their mandate not to discriminate against individuals with disabilities, public entities are required to make "reasonable modifications" to their programs, offer their services in the "most integrated setting," and permit freedom of choice when offering their services to persons with disabilities:

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.

Nothing . . . shall be construed to require an individual with a disability to accept an accommodation, aid, service, opportunity, or benefit provided under the ADA . . . which such individual chooses not to accept.<sup>22</sup>

At the same time, however, the Act recognizes certain basic limitations on the obligation of public entities to modify their "policies, practices, or procedures." No modification is required if "the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity" 24

In sum, Title II of the ADA focuses on publicly administered programs and services. Its basic goal is to ensure that reasonable modifications are made in public programs that serve qualified (i.e., eligible) persons with disabilities in order to afford them an opportunity to receive services in the most integrated setting possible. At the same time, public agencies do not have to "fundamentally alter" their programs in order to achieve the goal of promoting integration. Federal law places the burden of proof on a public agency whose policies, practices, and pro-

<sup>&</sup>lt;sup>22</sup> 28 C.F.R. § 35.130(b)(7), (d)-(e)-1 (2001).

<sup>&</sup>lt;sup>23</sup> Id. § 35.130(b)(7).

<sup>&</sup>lt;sup>24</sup> *Id*.

cedures are challenged to demonstrate why a requested alteration amounts to a fundamental alteration. The term "policies, practices, and procedures" is not defined in the Act.

#### B. An Overview of the Olmstead Decision

Olmstead v. L.C. arose in Georgia and involved two women who experienced various mental disabilities and were institutionalized in a state inpatient psychiatric hospital. In the cases of both women, state medical employees had deemed community services appropriate<sup>25</sup> and both women desired to receive services in an integrated setting.<sup>26</sup> As set forth in the majority opinion, the facts also showed that as part of its State Medicaid plan, Georgia's Medicaid agency operated a "home and community-based waiver" program. <sup>27</sup> This program provided community-based health care and support services for persons deemed at risk of institutionalization. However, although the federal government had approved 2109 individual community placements under the State's program, the agency in fact had filled only 700 of those slots as a result of persistent legislative under-funding of this portion of its state plan.<sup>28</sup> (Persistent under-financing of community services is a nationwide problem in Medicaid; at the time of the decision, every State except Arizona operated at least one home and community care program for one or more classes of persons with disabilities.<sup>29</sup> In most States the number of federally approved community placement slots significantly exceeded available funding from the legislature).30 Georgia also maintained a waiting list for available community services.

<sup>&</sup>lt;sup>25</sup> Olmstead v. L.C., 527 U.S. 581, 593 (1999).

<sup>&</sup>lt;sup>26</sup> See id. at 594.

<sup>&</sup>lt;sup>27</sup> See id. at 595.

<sup>&</sup>lt;sup>28</sup> *Id.* at 601.

<sup>&</sup>lt;sup>29</sup> STEVEN LUTZKY ET AL., LEWIN GROUP, INC., REVIEW OF THE MEDICAID 1915(C) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAM LITERATURE AND PROGRAM DATA 5-6 (June 2000), available at http://www.hcfa.gov/medicaid/litfinal.pdf.

<sup>&</sup>lt;sup>30</sup> It should be noted that under-funding may not simply be an act of mean-spirited denial by a legislature but may stem from the severe shortage of personnel and resources to furnish care in communities. The causes of these shortages are numerous. See generally Jane Perkins & Randolph T. Boyle, Addressing Long Waits for Home and Community-Based Care Through Medicaid and the ADA, 45 St. Louis U. L.J. 117 (2001) (discussing the shortage of community long-term care services).

Additional background facts that also are essential to understanding the Olmstead decision and reasoning involve the Medicaid program's financing arrangements. Under federal law, in fiscal year 2000, for example, the benefits and services included in Georgia's approved state plan qualified for a federal financial assistance rate of 59.88% of total state expenditures in meeting the cost of such assistance.<sup>31</sup> In other words, for every dollar the State spent on federally approved medical assistance services (such as home and community care services), the State received nearly \$.60 in federal contributions. Conversely, inpatient psychiatric services for non-elderly adults (under age sixty-five), when furnished in an "institution for mental diseases" do not qualify for any federal medical assistance contributions under federal law because of special statutory exclusionary rules.<sup>32</sup> As a result, the cost of institutionalizing the plaintiffs in Olmstead was effectively borne entirely by the State, while the cost of their community care potentially would have been borne approximately 60% by the federal government (assuming Georgia's federal matching rate did not change drastically in the years during which the litigation was ongoing). These underlying facts made it difficult to justify the women's continued confinement from either a medical or economic viewpoint.

In sum, the facts of the case were compelling: the State apparently had chosen to spend its public funds to inappropriately and, from a medical perspective, unjustifiably institutionalize the two plaintiffs, even though the State's own employees had deemed their placement in community residence appropriate. Furthermore, the State apparently had chosen to under-fund federally approved community services eligible for high rates of federal financial contributions, while paying the full cost of in-

<sup>31</sup> 3 Medicare & Medicaid Guide (CCH) ¶ 14,905 (Mar. 16, 1999).

<sup>&</sup>lt;sup>32</sup> 42 C.F.R. § 435.1008(a)(2) (2000). The so-called IMD exclusion, included in the original Medicaid statute, was included as a means of preventing States from federalizing the cost of their mental institutions using Medicaid funds. The exclusion was an early testament to the growing body of federal policies away from institutional care and toward community services. Later amendments to the Medicaid statute expanded state options to furnish community services and permitted States to claim federal contributions for the cost of services furnished to residents of mental institutions of fewer than sixteen persons in order to encourage the development of small-group living arrangements for persons with mental illness.

stitutional care as an excluded Medicaid item or service.<sup>33</sup> This decision appeared to run counter to the State's own financial interest.

The United States Court of Appeals for the Eleventh Circuit, in finding the State's practices discriminatory, also ruled that the proper standard for determining when a violation occurred under the reasonable modification/fundamental alteration test lay in comparing the cost of the plaintiffs' institutional care against the cost of their community care. Under these facts, the lower court had concluded that the circumstances of the case required provision of community services to the plaintiffs and that a cost justification would fail "[u]nless the State can prove that requiring it to [expend additional funds in order to provide L.C. and E.W. with integrated services] would be so unreasonable given the demands of the State's mental health budget that it would fundamentally alter the service [the State] provides."<sup>34</sup>

In a fractured opinion,<sup>35</sup> a majority of the Supreme Court identified the central issue as being "whether the proscription of discrimination [as embodied in the ADA] may require placement of persons with mental disabilities in community settings rather than in institutions."<sup>36</sup> Writing for the Court, Justice Ginsburg stated that "[t]he answer... is a qualified yes."<sup>37</sup> The "qualifiers" set forth in the majority opinion arose not from questions regarding whether medically unjustifiable institutionalization constituted precisely the type of conduct the ADA sought to abolish, but rather from the Court's perceived need to

<sup>&</sup>lt;sup>33</sup> Curiously, one of the State's arguments was that Medicaid encouraged an institutional bias in the case of persons with mental illness and thus effectively created an affirmative defense to plaintiffs' claims. *See Olmstead*, 527 U.S. at 601. In fact, Medicaid bars federal financial participation in the case of institutional care for services for non-elderly adults with mental illness. This would preclude federal coverage of women such as L.C. and E.W., assuming a primary diagnosis of mental illness and institutionalization in a mental health residential inpatient facility.

<sup>&</sup>lt;sup>34</sup> L.C. ex rel Zimring v. Olmstead, 138 F.3d 893, 905 (11th Cir.1998), aff'd in part, vacated in part, 527 U.S. 581 (1999).

Justice Ginsburg announced the judgment of the Court with respect to Parts I, II, and III-A, in which Justices Stevens, O'Connor, Souter, and Breyer joined, and an opinion with respect to Part III-B, in which Justices O'Connor, Souter, and Breyer joined. Justice Stevens filed an opinion concurring in part and concurring in the judgment. Justice Kennedy filed an opinion concurring in the judgment, in which Justice Breyer joined as to Part I. Justice Thomas filed a dissenting opinion, in which Chief Justice Rehnquist and Justice Scalia joined. Olmstead, 527 U.S. at 585-86.

<sup>&</sup>lt;sup>36</sup> Id. at 587.

<sup>37</sup> Id.

balance the competing interests of individuals with disabilities against those of States, whose resources "[are] not boundless" and whose obligations extend to both persons who can live in the community and those who, in the opinion of state officials, cannot. 39

Despite protests by the dissenting Justices (Thomas, Rehnquist, and Scalia) that no "discrimination" occurred as a matter of law because all persons whose needs were at issue in the case were "members of the *same* protected class" (i.e., persons with disabilities), the majority had little problem in disposing of this assertion. The Court based its discrimination holding on two facts. First, the Court determined that institutionalizing individuals who can handle and benefit from community settings perpetuates incorrect assumptions that those institutionalized are incapable or unworthy of participating in community life. Second, the Court reasoned that unwarranted institutionalization diminishes individual's capacity for, among other things, family relations, work options, economic independence, and cultural enrichment.

In citing these two basic justifications for its holding, the Court emphasized the prevention of unnecessary institutionalization of persons with disabilities as one of the hallmarks of both the ADA and its predecessor statute, the Rehabilitation Act of 1973 (specifically, § 504). In the majority's view, discrimination occurred because one group of recipients of publicly funded health services (i.e., persons with disabilities) were furnished with public services only if they agreed to accept their care on an institutional inpatient basis. Indeed, in the Court's view (as evidenced by its restatement of the facts of the case),

<sup>38</sup> Id. at 603.

Advocates for persons with disabilities take fundamental issue with the notion that any person with a disability is not capable of community residence with proper services and supports. For example, the American Disabled for Attendant Programs Today (ADAPT), a national disability rights organization, has drafted S. 1935, the Medicaid Community Attendant Services and Supports Act (MiCASSA), which would establish a national program of community-based attendant services and supports for people with disabilities. Am. DISABLED FOR ATTENDANT PROGRAMS TODAY, A COMMUNITY-BASED ALTERNATIVE TO NURSING HOMES AND INSTITUTIONS FOR PEOPLE WITH DISABILITIES (n.d.), http://www.adapt.org/casaintr.htm (last visited Oct. 1, 2001). The bill guarantees any individual who is entitled to institutional services to choose to receive those services in the community. *Id.* 

<sup>&</sup>lt;sup>40</sup> Olmstead, 527 U.S. at 616 (Thomas, J., dissenting).

<sup>41</sup> Id. at 600.

<sup>42</sup> *Id.* at 601.

the State had gone so far as to systematically under-fund its community services in order to deny plaintiffs public services in the most integrated setting.

For the majority, the cumulative facts of the case suggested that, despite the lack of medical justification, the State had deprived plaintiffs of health care in any setting other than in an institution. Furthermore, although the majority's finding of discrimination did not turn on plaintiffs' particular condition (i.e., mental illness and mental retardation), the fact that both L.C. and E.W. suffered from mental illness was probably critical to the case as well, given the history of discrimination against persons with mental illness.<sup>43</sup> Thus, in the majority's opinion, the evidence pointed to a deliberate effort on the part of the State to skew its overall public health care spending patterns by overspending in one area and under-spending in another in order to achieve segregation and isolation of persons with mental illness.

The remedial portion of the majority opinion was far more ambiguous. In effect, the Court articulated what can be thought of as an aggregate population standard for measuring when state conduct amounts to a violation of the ADA and rejected the individualized test used by the Court of Appeals. Furthermore, the majority also gave States significant power to determine the lawfulness of their own performance by empowering them to identify the very class of individuals who could legitimately claim a right to community services under the Act. Finally, the majority broadened the nature of the fundamental alteration defense available to state agencies.

At the same time, the Court tempered this unusual grant of power to the States with a strong admonition to act with reasonableness. In demanding reasonableness the majority took the highly unusual step of establishing an "outcomes test" of legal conduct that in effect creates a presumption of unlawful practices where certain results fail to flow from state practices.

#### 1. The Standard of Conduct

The Court began by setting the context for its holding: "[W]e recognize... the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental

<sup>&</sup>lt;sup>43</sup> See id. at 608-15 (Kennedy, J., concurring) (recognizing "persons with mental disabilities have been subject to historic mistreatment, indifference, and hostility").

disabilities, and the States' obligation to administer services with an even hand."44 The Court then set forth the following standard for determining when States' practices amount to a violation of the ADA:

[Release into the community] is in order when the State's treatment professionals have determined that 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.45

This standard thus assigns to States the ultimate power to decide who can be appropriately served in a community placement and to make at least the initial determination of when community placement can be reasonably accommodated, taking into account the needs of the entire group of persons with disabilities and the availability of resources.

#### 2. A Broadened Affirmative Defense

The Court also broadened the "fundamental alteration" affirmative defense available to States. Rejecting the Court of Appeal's statement of the defense, the majority held:

The State's responsibility, once it provides communitybased treatment to qualified persons with disabilities, is not boundless. The reasonable-modifications regulation speaks of "reasonable modifications" to avoid discrimination, and allows States to resist modifications that entail a "fundamenta[1] alter[ation]" of the States' services and programs. . . . Sensibly construed, the fundamentalalteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a

<sup>&</sup>lt;sup>44</sup> *Id.* at 597. <sup>45</sup> *Id.* at 587.

large and diverse population of persons with mental disabilities.46

In evaluating a State's fundamental-alteration defense, the [lower courts] must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably.<sup>47</sup>

This re-formulation of the fundamental alteration defense makes several things clear. First, it is a matter of discretion for a State whether to furnish any public service. Second, although the Court of Appeals focused its assessment of reasonableness versus fundamental alteration on the incremental cost of furnishing community services to particular plaintiffs—rather than to total state spending on health care—the majority altered this focus to effectively create a "zero sum game" defense. Under the majority's expanded "fundamental alteration" defense, a State is entitled to have the plaintiffs' request weighed not against its total expenditures for health care, but rather against its expenditures on persons in the protected class (i.e., persons with disabilities). Thus, even as the majority rejected the notion that a protected class could not be separately identified for purposes of finding discrimination, the Court also appeared to elect to measure the legality of the State's conduct against its spending on the protected class alone; in effect, the Court rejected the notion that new spending might be required in order to achieve conformity to the principles of the ADA.

#### 3. Limits on State Defenses

Even as the Court expanded States' affirmative defenses and empowered States to make critical decisions regarding the scope of their own obligations, the majority placed a potentially powerful brake on state discretion over whether, and how fast, to reorient state budgets for persons with disabilities:

 $<sup>^{46}</sup>$  *Id.* at 603-04 (alterations in original).  $^{47}$  *Id.* at 597.

If . . . the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable modifications standard would be met.<sup>48</sup>

In this limitation on a State's discretion, the majority effectively empowered plaintiffs to demonstrate that despite state assertions to the contrary, there was no reasonable movement toward community integration, as measured by the actual placement of qualified persons in less restrictive settings. This limitation on state discretion both assumes a continuing identification of persons who can live in less restrictive settings, as well as a continuing expansion of community services in relation to institutional services.

#### C. The Federal Administrative Response to Olmstead

The federal government has attempted to respond to the *Olmstead* decision with a series of clarifying guidance documents, the provision of technical assistance to States regarding approaches for developing community services, and other actions designed to encourage States to embrace the basic thrust of the decision. As will be discussed at greater length below, this approach has essentially skirted the profound legal issues generated by the case.

Despite the fact that *Olmstead* is an ADA (rather than a Medicaid) case, the overwhelming importance of Medicaid in supporting publicly funded health services for persons with disabilities has caused the federal government's response to focus on this program to the near-exclusion of all other sources of public financing. Following a letter from then-HHS Secretary Donna Shalala to the nation's governors regarding the importance of the decision,<sup>49</sup> the Department's initial major policy statement was a January, 2000 letter to State Medicaid directors which emphasized avoiding the use of Medicaid to unnecessar-

<sup>&</sup>lt;sup>48</sup> Id. at 605-06.

<sup>&</sup>lt;sup>49</sup> Health Care Fin. Admin., Secretary's Letter to Governors on *Olmstead* Decision (Jan. 14, 2000) (letter from Donna E. Shalala, HHS Secretary, to nation's governors), *available at* http://www.hcfa.gov/medicaid/smd1140b.htm (on file with Health Matrix).

ily institutionalize persons and the availability of Federal Medicaid financing to engage in expanded community services. (This emphasis on Medicaid community coverage options has been repeated throughout the past two years, as evidenced by subsequent State Medicaid directors letters on Medicaid options, as well as a detailed handbook on redesigning Medicaid programs to invest more heavily in community services. (52)

The January, 2000 letter also placed great emphasis on the notion of a "comprehensive, effectively working plan." The letter restated what the Court defined as an outcomes test for measuring the reasonableness of state performance as a process requirement to actually engage in state planning around community services:

[T]he Court suggests that a State could establish compliance with [T]itle II of the ADA if it demonstrates that it has:

- a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and
- a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.<sup>54</sup>

The Department again advised that "[w]e strongly urge States to increase access to community-based services for individuals with disabilities by developing comprehensive, effectively working plans for ensuring compliance with the ADA." 55

<sup>51</sup> HEALTH CARE FIN. ADMIN., U.S. DEP'T OF HEALTH AND HUMAN SERVS., ADA/OLMSTEAD DECISION STATE MEDICAID DIRECTOR LETTERS (n.d), *at* http://www.hcfa.gov/medicaid/olmstead/smdltrs.htm (last visited Oct. 1, 2001).

<sup>&</sup>lt;sup>50</sup> Health Care Fin. Admin., Guidance on *Olmstead* Decision and Fact Sheet (Jan. 14, 2000) (letter from Timothy M. Westmoreland, Director of Center for Medicaid and State Operations, to all State Medicaid Directors), *available at* http://www.hcfa.gov/medicaid/smd1140a.htm (on file with Health Matrix).

<sup>&</sup>lt;sup>52</sup> See Gary Smith et al., U.S. Dep't of Health and Human Servs., Understanding Medicaid Home and Community Services: A Primer (Oct. 2000) (discussing how to "encourage the use of the Medicaid program in a manner that minimizes reliance on institutions and maximizes community integration in a cost-effective manner").

<sup>&</sup>lt;sup>53</sup> Health Care Fin. Admin., supra note 49.

<sup>&</sup>lt;sup>54</sup> *Id*.

<sup>55</sup> Id. at encl.

The letter provided guidance regarding the elements of a comprehensive, effectively working state plan. The elements consist of efforts aimed at achieving an inclusive planning process and at taking "steps to prevent or correct current and future unjustified institutionalization of individuals abilities."<sup>56</sup> According to the Department, the essential components of the plan as it relates to individuals include an individual assessment process under which:

- The State has a reliable sense of how many individuals with disabilities are currently institutionalized and are eligible for services in community-based settings. The plan considers what information and data collection systems exist to enable the State to make this determination. Where appropriate, the State considers improvements to data collection systems to enable it to plan adequately to meet needs.
- The State evaluates whether existing assessment procedures are adequate to identify institutionalized individuals with disabilities who could benefit from services in a more integrated setting.
- The State also evaluates whether existing assessment procedures are adequate to identify individuals in the community who are at risk of placement in an unnecessarily restrictive setting.
- The plan ensures that the State can act in a timely and effective manner in response to the findings of any assessment process.57

The guidance also identified as an element an assessment of the availability of community resources and a measurement of whether they are sufficient in amount and scope to maintain community service integration at a reasonable pace.

The January, 2000 guidance reaffirmed the Court's view that not all persons are capable of living in communities and that States bear the responsibility and the authority for identifying those who can. At the same time, the guidance added the important clarification that the reach of the decision extends to

<sup>&</sup>lt;sup>56</sup> Id. <sup>57</sup> Id.

not only those who are institutionalized, but also to those who are at risk for unnecessary institutionalization. While the guidance focused on individual assessments and services, its main thrust was aimed at the process of planning, an issue not addressed at all by the Supreme Court. Furthermore, the guidance did not set forth the minimum elements of the assessment process in areas such as initiation of assessments, assessment timelines, the validity of assessment tools, the timing of assessments, the capability of persons conducting the assessments, or minimum due process protections for appealing the results of an adverse assessment. Finally, the guidance set forth no standards regarding how the State's allocation of resources to community services versus institutional care would be measured, nor did it indicate how "reasonable pace," "fundamental alteration," or "reasonable modification" would be measured.

Subsequent government documents have expanded the role of States in refashioning programs to emphasize community services. An Executive Order issued by the Bush Administration in July, 2001 directs all federal agencies to undertake thorough reviews to identify policies and procedures that impede integration, 58 and a notice in the Federal Register invites comments from interested persons on barriers to integration.<sup>59</sup> Both the Clinton and Bush Administration thus appear to have opted for an approach that might be termed an "enthusiastic rallying" around community care (if anything, the Bush Administration has been more active in this regard), and have shied away from the more traditional role within the Executive Branch of standard setting, compliance review, and enforcement actions, although the Executive Order issued by the Bush Administration also identifies investigation of individual complaints as a high priority.60

#### III. MOST INTEGRATED SETTING COMPLAINTS

Because of succeeding Administration's emphasis on population-wide planning and the implementation of broad community service initiatives, the George Washington University

<sup>&</sup>lt;sup>58</sup> Exec. Order No. 13,217, 66 Fed. Reg. 33,155 (June 18, 2001).

<sup>&</sup>lt;sup>59</sup> Announcement of National Listening Session on Community-Based Alternatives for Individuals With Disabilities, 66 Fed. Reg. 42,864, 42,864 (Aug. 15, 2001).

<sup>60</sup> Exec. Order No. 13,217, 66 Fed. Reg. at 33,156.

School of Public Health and Health Services, with private foundation support<sup>61</sup> and with the assistance of the Office for Civil Rights (ORC) within HHS, undertook a yearlong review of "most integrated setting" administrative complaints filed with OCR under Title II of the ADA.<sup>62</sup> While the complaints span the 1996-2000 time period, the great majority of complaints were filed post-*Olmstead*; as of the summer of 2001, nearly 400 such complaints had been filed.

The purpose of the review was to aid the planning process through the provision of statistical, aggregated descriptive information regarding the characteristics of individuals who allege ongoing ADA violations as a result of inappropriate failure to receive services in the most integrated setting. The study was conducted by the authors of this article using a written review instrument that was specifically designed to extract and record relevant information. The categories of information that were extracted were identified in consultation with OCR officials, advocates, state officials, and other persons with expertise and/or interest in the issues. The review categories focused on geographic location, age, residential status, and living arrangement of the complainant, nature of the claims, disability status of the claimant, and services sought.

The analysis took place in three cycles over a twelve-month time period, with approximately 100 complaints reviewed during each cycle. A testament to the consistency of the data was that as the database increased with the completion of each cycle of reviews, the distribution of responses did not change significantly. As of May, 2001, the authors have analyzed a total of 334 complaints.

<sup>&</sup>lt;sup>61</sup> The Center for Health Care Strategies, Inc., in Lawrenceville, NJ, provided a grant to the Center for Health Services Research and Policy of The George Washington University School of Public Health and Health Services to conduct research on issues surrounding the *Olmstead* decision.

<sup>&</sup>lt;sup>62</sup> 28 C.F.R. § 35.190(b)(3) (2000) authorizes the Office for Civil Rights of the U.S. Department of Health and Human Services to oversee compliance with the ADA of publicly administered health and human services programs. OCR must investigate all complaints and attempt to reach resolution. See id. § 35.172. If resolution is not possible, OCR will issue a Letter of Findings. See id. The filing of a complaint does not preclude the complainant from filing a private action at any time. Id. § 35.172(b).

#### A. Principal Findings

1. Complaints by Region of the Country and by State<sup>63</sup>

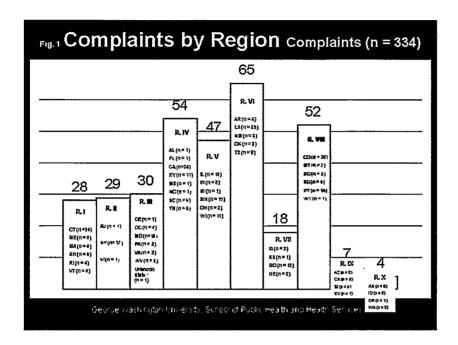
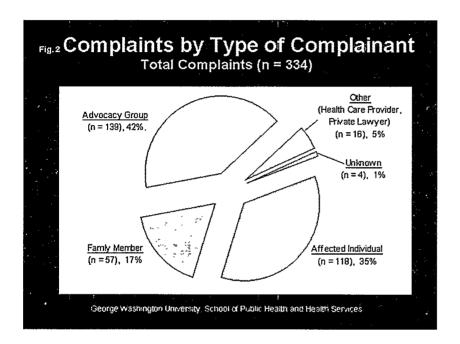


Figure 1 shows that complaints come from all HHS regions, as well as from virtually all states. This finding is consistent with the universal nature of the problem and probably also is a reflection of the widespread nature of advocacy on behalf of persons with disabilities (both by organizations and family members).

 $<sup>^{63}</sup>$  Region I consists of CT (n = 24), ME (n = 0), MA (n = 0), NH (n = 0), RI (n = 4), and VT (n = 0). Region II consists of NJ (n = 1), NY (n = 27) and VI (n = 1). Region III consists of DE (n = 1), DC (n = 0), MD (n = 18), PA (n = 2) VA (n = 2), WV (n = 6) and an unknown state (n = 1). Region IV consists of AL (n = 1), FL (n = 1), GA (n = 34), KY (n = 11), MS (n = 1), NC (n = 1), SC (n = 0) and TN (n = 5). Region V consists of IL (n=16), IN (n = 8), MI (n = 1), MN (n = 10), OH (n = 2), and WI (n = 10). Region VI consists of AR (n = 4), LA (n = 39), NM (n = 6), OK (n = 8) and TX (n = 8). Region VII consists of IA (n = 3), KS (n = 1), MO (n = 12) and NE (n = 2). Region VIII consists of CO (n = 32), MT (n = 3), ND (n = 2), SD (n = 0), UT (n = 14) and WY (n = 1). Region IX consists of AZ (n = 0), CA (n = 6), HI (n = 0) and NV (n = 1). Region X consists of AK (n = 0), ID (n = 0), OR (n = 1) and WA (n = 3).

The states located in HHS Regions Four, Five, Six, and Nine account for 217 complaints, or 65% of the total complaints reviewed. We theorize that the heavy concentration of complaints from these regions is less a reflection of greater problems in these regions and more a reflection of specific events triggering a greater level of local advocacy (such as the decision on the part of a state protection and advocacy agency to spur the planning process through the systematic filing of complaints). <sup>64</sup>

#### 2. Type of Complainant

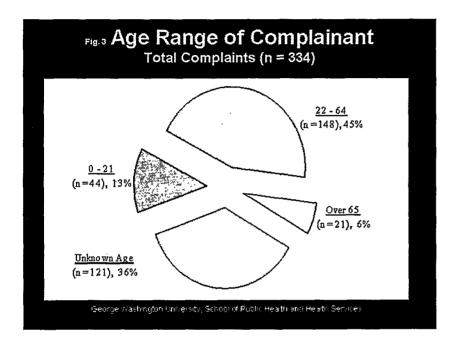


Supporting our assumption that the heavy concentration of complaints from certain regions is a reflection of a greater level of local advocate activity in the community is the fact that advocacy groups file the majority of complaints on behalf of a named individual, as indicated by Figure 2. While touring a nursing home, for example, a representative of an advocacy group may identify an individual who may be inappropriately residing in the facility. After informing the individual of the *Olmstead* decision, the advocate could encourage the filing of

<sup>&</sup>lt;sup>64</sup> This assumption is bolstered by discussions the authors have had with advocates and state officials.

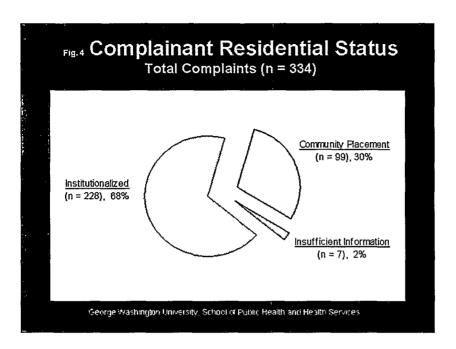
an administrative complaint and prepare such a complaint if assistance is requested. In their complaints, the complainants frequently state that they were spurred to action as a result of just having learned about the integration mandate and the right to receive, or even the existence of, community services.

#### 3. Age Range of Complainant



It is not always possible to ascertain the age of the complainant, but among the complaints where age can be discerned, the evidence suggests that unnecessary institutionalization (or its risk) affects persons of all ages. The most prevalent agerange in the data base is 22-64, accounting for nearly one-half, or 148, of the complaints. At the same time, one-in-seven complainants whose age is known is a child or adolescent.

#### 4. Residential Status



While the majority of complainants were institutionalized when they filed their complaints, a significant proportion (30%) were residing in the community but at risk for what they considered medically unjustified institutionalization.

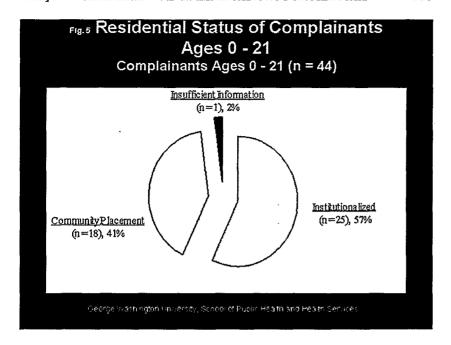


Figure 5 shows that an even higher proportion (41%) of child and adolescent complainants reside in a community setting but are at risk for what they perceive as medically unjustifiable institutionalization.

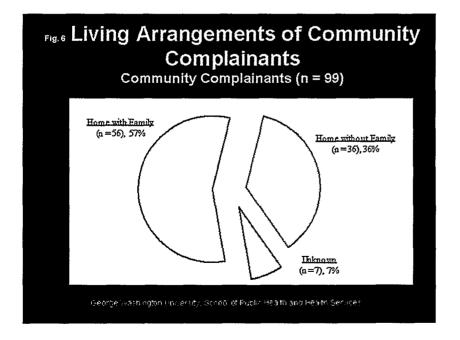


Figure 6 underscores the variable nature of the problems faced by community residents, in terms of current living arrangements. Well over half (57%) were living with families but considered themselves to be in danger of medically unjustified institutionalization in the absence of such assistance. Another 36% were living on their own (either alone or in another form of arrangement) at the time they filed their complaints. This graph indicates that living with a family member or members fails to provide a buffer against medically unjustifiable institutionalization, given the complex and extended supports that may be required to successfully maintain an individual in his or her home.

#### 5. Institutional Placement

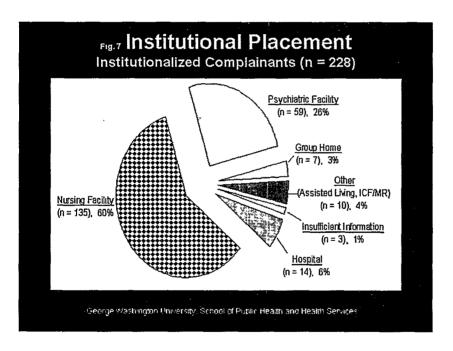
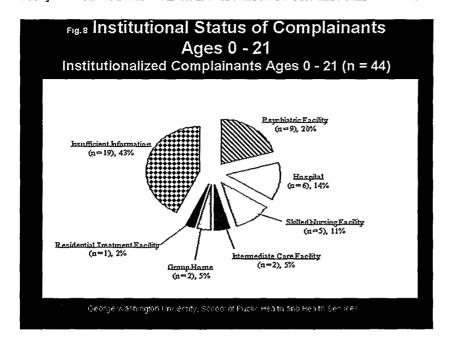
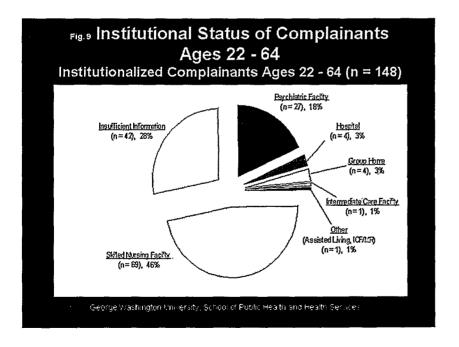


Figure 7 shows that nursing homes were the single most common institutional setting among complainants, accounting for 60% of all complaints filed by institutionalized persons. Another 30% arose in psychiatric facilities, a situation similar to the facts of the *Olmstead* case itself.



In the case of children and adolescents, Figure 8 shows that hospitals, skilled nursing facilities, and psychiatric facilities comprised the largest number of settings for the complaints among institutionalized persons.



In the case on non-elderly adults, nursing home residents accounted for nearly half of the institutionalized complainants, as Figure 9 shows.

#### 6. Nature of Complainant's Disability

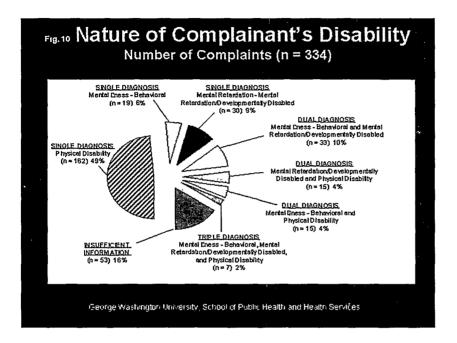
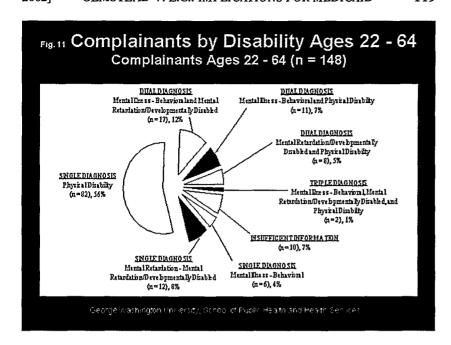


Figure 10 underscores the wide range of conditions that can lead to medically unjustified institutionalization or the threat thereof. The most dominant condition faced by the complainants by far was physical disability: Nearly half of all complainants reported a single diagnosis attached to a physical disability, while another nearly 10% reported the presence of a physical disability along with one or more mental disabilities.



Among non-elderly adults, Figure 11 indicates that the dominance of physical disabilities was even more pronounced, present either alone or in combination with a mental disability of some type in 70% of all cases.

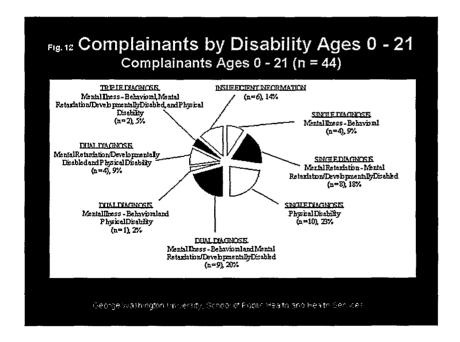
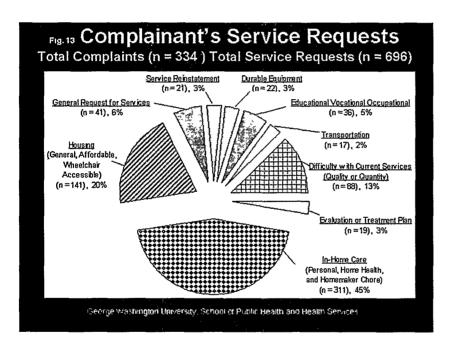


Figure 12 indicates that in the case of children and adolescents, physical disabilities either alone or in combination with mental disabilities were present in more than one-third of all complaints. Compared to adults, the picture for children suggests a greater prevalence of multiple, layered conditions. Among adults, according to Figure 11, two-thirds report a single diagnosis, while only approximately 40% of children experience a single diagnosis. Conversely, among children, over one-third experience either dual or triple diagnoses; among non-elderly adults, Figure 12 indicates that only one-quarter experience dual or triple diagnoses.

#### 7. Service Requests



The 334 complainants made a total of 696 requests for services, as indicated by Figure 13, while the average complainant requested two different services. Regardless of age, complainants reported similar service needs. The following analysis examines the data surrounding some of the more frequently requested types of services.

#### a. In-Home Care

In-home care comprised 45% of the total requests for services that the complainants considered imperative for their successful placement in the community. For purposes of our analysis, in-home care included personal care services, in-home health care, and homemaker chores.

#### b. Housing

Requests for housing services comprised 20% of total service requests. For purposes of our review, we grouped general complaints and complaints concerning affordability, accessibility, and size into one category.

#### c. Difficulty with Current Services (Quality or Quantity)

Thirteen percent of the service requests involved difficulties with existing services. In these cases, complainants indicated that they were receiving some level of services, but were experiencing sufficient difficulty with those services to prompt a complaint. Often, these individuals had an assessment from their physician indicating the need for a greater number of hours than their home health provider was willing to provide. In other situations, the complaints centered around the poor quality of available staff.

#### d. General Request for Services

Six percent of all requests for services indicated only a need for "general services." This category included those instances where complainants made a request for services, but failed to indicate their specific needs. The complaints often indicated that the disabled person could live in the community with "appropriate supports."

#### e. Educational/Vocational/Occupational Services

Five percent, or 36, of the requests for services included a request for education, vocational training, or occupational services. The requests made under this category usually came from a complainant under age twenty-one.

#### f. Durable Equipment

Our review uncovered twenty-two requests (3%) for durable equipment. The type of equipment requested included mechanical lifts, power wheelchairs, environmental control units, and home modifications.

#### g. Service Reinstatement

Three percent of service requests involved a request for resumption of one or more terminated services. In a number of cases, this request was made by individuals who had been receiving adequate services, but who found their services reduced or eliminated when, for example, they entered a hospital for a short-term stay, or upon a review of their needs by a home health provider.

#### h. Evaluation or Treatment Plan

Mindful of the fact that an evaluation by a State's treatment professional is the first prong of the Court's three-part test to gain release from an institution, nineteen complainants requested either an evaluation to determine their ability to live in the community or a treatment plan.

It is important to highlight that the majority of complainants did not request an individual evaluation and treatment plan, which may indicate that such an assessment had already been performed. However, where complainants did actually indicate that an assessment had taken place, they further indicated that the assessment merely consisted of a single sentence authorizing community living rather than an extensive assessment of needs and a description of the resources to be made available.

#### i. Transportation

Two percent of all requests for services focused on transportation needs. While this number may seem low, we believe that it reflects the complainant's focus on simply being in a community, rather than on realizing transportation within one.

#### B. Policy and Planning Implications

The individuals whose complaints were the subject of this analysis cannot be said to be representative of the population of persons with disabilities who could live in the community with appropriate support. The very low number of elderly persons alone suggests an under-representation of certain individuals. At the same time, this analysis contributes important information to the *Olmstead* planning process, because it sheds light on the needs of individuals who (or whose representatives) sense their situations acutely enough to take action. As a group, the complainants are concentrated in certain regions of the nation and tend to be adults with physical disabilities, either standing alone or in combination with one or more mental disabilities. In view of the underlying conditions that dominate the complaints, it is not surprising that adapted housing and in-home health care dominate the service requests.

While the overall number of children represented in the data base is low, the presence of any children in the complaint group is particularly disturbing, given the general belief regarding the benefits of community services for children with disabilities. Children are more likely than their adult counterparts to reside in communities but their complaints reflect the tenuous nature of this community residence, with concerns raised over the potential for institutionalization because of inadequate care. Also, among children mental disabilities are more dominant.

For both *Olmstead* planning and more general state health policy purposes, the implications of the diversity among those claiming inappropriate institutionalization (or risk thereof), and their residential status, are considerable. To highlight the point, consider the fact that the majority of non-institutionalized complainants reside at home with a family member. Seemingly, even this relatively secure community setting does little to satisfy some disabled individuals that their risk of institutionalization is low.

But beyond simply signaling the breadth of the complainants seeking relief under *Olmstead*, the data are instructive in more concrete ways applicable to policymaking. As more and more States move on to the task of devising *Olmstead* plans, the data indicate that States might want to pay particularly close attention to the need for increased in-home health care services, as well as the fact that a significant number of individuals were not as interested in gaining access to additional services as they were in experiencing an upgrade in the quality of their *existing* services. Furthermore, our review of the complaints suggests that planning for adults—who represent the great majority of complainants in our analysis—would appear to necessitate the

creation of additional community housing and increased supports for persons with physical, as opposed to mental, disabilities.

#### IV. RELATED MEDICAID LITIGATION

Despite States' arguments that the Medicaid program specifically encouraged the institutionalization of persons with mental illness and thus created a defense to claims of an ADA violation, *Olmstead* did not directly concern Medicaid at all; instead, it focused on the lawfulness of state administration of publicly funded health programs generally. At the same time, Medicaid represents the largest source of public health care financing for low-income persons with disabilities. As a result, Medicaid figures broadly in States' efforts to reorder public financing to fund community services. Furthermore, to the extent that the Medicaid program vests its beneficiaries with separate and enforceable federal legal rights related to community-based health benefits and services, it offers covered individuals separate legal claims related to the provision of community care.

#### A. Background and Overview of Medicaid

To understand the nature of the Medicaid litigation that has arisen concurrently with ADA claims over the past several years, it is necessary to review the basic structure of the program. A seminal component of the modern U.S. health care financing system, <sup>66</sup> Medicaid is also one of the most complex pieces of social welfare legislation ever enacted. In 1998 Medicaid insured approximately forty million persons, most of whom

<sup>&</sup>lt;sup>65</sup> In 1995, for example, state and local government expenditures on Medicaid represented the single largest state and local health expenditure. That year, state and local governments spent \$55.6 billion on Medicaid, compared to \$47.1 billion on premium contributions to employer-sponsored plans and \$54.3 billion on other expenditures. NAT'L CTR. FOR HEALTH STATISTICS, U.S. DEP'T OF HEALTH AND HUMAN SERVS. HEALTH, UNITED STATES 338 tbl.120 (2001), http://www.cdc.gov/nchs/data/hus/hus01.pdf.

<sup>&</sup>lt;sup>66</sup> See Sara Rosenbaum & David Rousseau, *Medicaid at Thirty-Five*, 45 St. Louis U. L.J. 7, 8-10 (2001) (reviewing the history of Medicaid as a major contributor to U.S. health care over the past thirty-five years).

would otherwise have no access to health insurance because of age, disability, or lack of attachment to the workforce.<sup>67</sup>

Medicaid is a federal grant-in-aid program that entitles eligible persons to coverage for a defined set of medical services and benefits (known collectively as "medical assistance"). States that participate in Medicaid and administer approved state plans are entitled to federal financial assistance for the medical assistance and administrative costs they incur in administering their programs. The federal contribution level for administrative costs averages 50%; <sup>69</sup> in the case of medical assistance benefits and services, the federal financial assistance rate for fiscal year 2002 ranges from 50% to over 83%. <sup>70</sup>

A legal entitlement,<sup>71</sup> Medicaid provides participating States with open-ended federal financing to support the costs of their state programs. Although participating States must comply with certain federal requirements, state agencies have broad discretion in the design of their program eligibility, benefit and coverage structures, and the overall administration of their state plans (e.g., establishing provider qualification standards and compensation rates, conducting eligibility determinations and re-determinations, and so forth).<sup>72</sup>

Medicaid functions as a health insurance program and thus also entitles participating providers to payments for covered services furnished to eligible persons. In rare cases, federal law establishes substantive payment standards for providers; in gen-

 $<sup>^{67}</sup>$  Kaiser Comm'n on Medicaid and the Uninsured, Henry J. Kaiser Family Found., The Medicaid Program at a Glance (Jan. 2001), http://www.kff.org/content/2001/2004b/2004b.pdf.

<sup>68 42</sup> U.S.C.A. §§ 1396a(a)(10), 1396d(a) (West Supp. 2001).

<sup>&</sup>lt;sup>69</sup> See 42 U.S.C.A § 1396b(a)(2)(B) (providing calculations for amounts expended for nursing aide training and competency evaluation programs). Federal contributions are higher for certain administrative costs, such as the services of skilled medical professionals or the cost of establishing and operating computerized management information systems. *Id.* § 1396b(a)(2)(A),(C).

<sup>&</sup>lt;sup>70</sup> See 3 Medicare & Medicaid Guide (CCH) ¶ 14,905 (Mar. 6, 2001).

<sup>&</sup>lt;sup>71</sup> See Cong. Budget Office, The Budget and Economic Outlook: Fiscal Years 2002-2001 ch.4 (Jan. 2001), http://www.cbo.gov/showdoc/cfm?index=2727& sequence=5 (discussing means-tested entitlement spending).

<sup>&</sup>lt;sup>72</sup> See Rosenbaum & Rousseau, supra note 66, at 17 (discussing requirements that States administer their programs through a 'single state agency', that eligibility requirements be made by the state welfare agency, and that outstationing be performed).

eral, however, payment rates and rules on provider participation are left to state discretion.<sup>73</sup>

In order to participate in Medicaid, States must submit "State plans" to the U.S. Department of Health and Human Services, which is authorized under federal law to administer the program. 74 Once approved, the plan qualifies for federal payments. States typically amend their plans frequently; federal standards are ambiguous regarding when a state administrative decision can be effectuated as a matter of state discretion and without formal federal approval of a "plan amendment." As a basic matter, however, altering eligibility categories or adding or removing entire classes of benefits would be considered to be plan amendments. 75

Federal Medicaid law establishes certain conditions with which state plans must comply in order to receive federal financial assistance. In the context of this article, the most important conditions relate to eligibility and coverage.

At a minimum, States must extend coverage to certain persons known as "mandatory categorically needy" individuals. States also may cover certain "optional categorically needy" persons and may also extend coverage to the medically needy, a group of individuals that falls into a categorically needy class but whose income and resources exceed categorically needy financial eligibility thresholds. 8

One of the mandatory categorically needy coverage groups consists of all persons who meet the eligibility standards for Supplemental Security Income (SSI),<sup>79</sup> a means-tested federal cash entitlement program under the Social Security Act that extends subsistence-level benefits to low-income persons whose disability is severe enough to preclude substantial gainful employment.<sup>80</sup> This test of disability—the virtual inability to work—is significantly more narrow than the functional test of

<sup>&</sup>lt;sup>73</sup> Id. at 23.

<sup>&</sup>lt;sup>74</sup> 42 U.S.C.A. § 1396 (West 1995).

<sup>&</sup>lt;sup>75</sup> See 42 C.F.R. § 430.12(c)(1)(ii) (2000) (stating "material changes" will cause a plan to be amended).

<sup>&</sup>lt;sup>76</sup> See id. §§ 435.100-.170; see generally Rosenbaum & Rousseau, supra note 66, at 17-20 (discussing eligibility).

<sup>&</sup>lt;sup>77</sup> See 42 C.F.R. §§ 435.200-.236.

<sup>&</sup>lt;sup>78</sup> See id. §§ 435.300-.350.

<sup>&</sup>lt;sup>79</sup> See 42 U.S.C.A. § 1396a(a)(10)(A)(i)(II) (West Supp. 2001).

<sup>&</sup>lt;sup>80</sup> See id. § 1382(a) (listing eligibility requirements).

disability that applies under the ADA and that, in its application to employment, is predicated on the assumption of work.<sup>81</sup>

At their option, States can elect to adopt a more liberal definition of disability (e.g., one that utilizes the ADA functional test rather than the more narrow "inability to work" test). States also may at their option adopt more liberalized financial eligibility standards for persons with disabilities. Most have elected not to do so, however, presumably because of the cost related to the program, as well as States' discomfort with the expansion of a legal entitlement that obligates them to furnish comprehensive coverage to all eligible individuals who satisfy the state plan conditions of eligibility. Despite the generosity of federal financial contribution levels, the strain on state budgets of an open-ended legal entitlement to medical care services is significant.

Regardless of whether a State defines eligibility broadly or narrowly, federal law specifies that "medical assistance... be furnished with reasonable promptness to all eligible individuals." It is in fact this "reasonable promptness" standard, coupled with the entitlement nature of the program and program coverage standards, that has served as a springboard to much of the related Medicaid litigation discussed below.

State Medicaid programs must cover certain "required" services for categorically needy beneficiaries. <sup>86</sup> At their option, they also may cover numerous additional categories of services, known as "optional" services. <sup>87</sup> However, whether required or optional, all federally enumerated benefits found within the definition of medical assistance are mandatory for individuals

<sup>&</sup>lt;sup>81</sup> For the ADA's definition of disability, see *supra* Part II.A.

<sup>82</sup> See 42 U.S.C.A. § 1396a(e)(3)(A)-(B) (West Supp. 2001).

<sup>83</sup> See id. § 1396a(r)(2)(A).

<sup>&</sup>lt;sup>84</sup> In its analysis of Medicaid, the Congressional Budget Office (CBO) estimates that Medicaid spending will reach some \$295 billion by 2011, with annual average rates of cost increases significantly above general inflation (8.6%). Cong. Budget Office, *supra* note 71. The CBO specifically notes legal challenges under the ADA as a factor in this rapid cost increase, as litigation causes States to expand Medicaid spending on persons with disabilities. *Id*.

<sup>85 42</sup> U.S.C.A. § 1396a(a)(8).

<sup>&</sup>lt;sup>86</sup> See id. §§ 1396a(a)(10)(A), 1396d(a)(1)-(27).

<sup>&</sup>lt;sup>87</sup> See 42 C.F.R. § 440.225 (2000). For an overview of Medicaid mandatory and optional benefits, see Kaiser Comm'n on Medicaid and the Uninsured, Henry J. Kaiser Family Found., Summary of Medicaid "Mandatory" and "Optional" Eligibility and Benefits (Aug. 2001), http://www.kff.org/content/2001/4002/4002.pdf.

under age twenty-one under Medicaid's special pediatric component, known as Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). 88 Furthermore, in the case of both required and optional services, Medicaid's "comparability" provisions require that all categorically needy persons be covered for the same classes of benefits. 89

The most important required services for purposes of this article are nursing facilities<sup>90</sup> and home health care services.<sup>91</sup> Benefits commonly utilized by persons with serious chronic illness and disability and that qualify for federal assistance as optional benefits include intermediate care facility services for persons with mental retardation and related developmental disabilities,<sup>92</sup> personal care services,<sup>93</sup> physical, speech, and occupational therapy and other rehabilitation services,<sup>94</sup> private duty nursing care,<sup>95</sup> and prescribed drugs.<sup>96</sup> The federal statute and regulations specify definitions for most covered benefits.<sup>97</sup> These definitions would control state coverage design decisions. As noted previously, federal financial participation is prohibited in the case of services furnished by institutions for mental disease.

As a general matter, both required and optional forms of medical assistance benefits are subject to certain statutory and regulatory tests of reasonableness.<sup>98</sup> Under these tests medical necessity utilization management criteria may be employed,<sup>99</sup> but a State may not set fixed limits on the number of individuals who may receive a particular class of service. States also must

<sup>&</sup>lt;sup>88</sup> Rosenbaum & Rousseau, *supra* note 66, at 22; SARA ROSENBAUM ET AL., GEORGE WASHINGTON UNIV. MED. CTR., NEGOTIATING THE NEW HEALTH SYSTEM: A NATIONWIDE STUDY OF MEDICAID MANAGED CARE CONTRACTS vol. 1 (Ctr. for Health Servs. Research and Pol'y, 2000), *available at* http://www.gwu.edu/~chsrp/; *see also* 42 U.S.C.A §§ 1396a(a)(10)(A)(III), 1396d(a)(4)(B), 1396d(r).

<sup>89</sup> See 42 U.S.C.A. § 1396a(a)(10)(B).

<sup>90</sup> See id. § 1396d(a)(4)(A).

<sup>&</sup>lt;sup>91</sup> See id. § 1396d(a)(7).

<sup>92</sup> See id. § 1396d(a)(15).

<sup>93</sup> See id. § 1396d(a)(24).

<sup>94</sup> See id. § 1396d(a)(11), (13).

<sup>95</sup> See id. § 1396d(a)(27).

<sup>&</sup>lt;sup>96</sup> See id. § 1396d(a)(12).

<sup>&</sup>lt;sup>97</sup> See 42 C.F.R. §§ 440.1-.185 (2000) (definitions).

<sup>&</sup>lt;sup>98</sup> See 42 U.S.C.A. § 1396a(a)(17) (requiring a plan to include "reasonable standards" for determining eligibility); 42 C.F.R. § 440.230 (2000) (requiring each service reasonably achieve its purpose).

<sup>99 42</sup> C.F.R. § 440.230(d).

ensure that utilization and coverage criteria result in services that are "sufficient in amount, duration, and scope to reasonably achieve [their] purpose" and may not discriminate in the provision of required benefits on the basis of an individual's diagnosis or condition. 100 Medicaid's rules of coverage, as well as the individuals who receive benefits, set the program radically apart from conventional insurance. 101 Unlike private insurance, which, in the absence of state law regulating the content of coverage, permits arbitrary service limits tied to certain conditions, 102 Medicaid functions under the rule of reasonableness in recognition of the special health needs of so many of its beneficiaries.

However, an exception to Medicaid's "amount, duration and scope" rules and comparability of services requirements is found in the Medicaid home and community-based care waiver program. 103 This program permits States to furnish expanded coverage for care and services presumably not otherwise found in a state plan<sup>104</sup> to certain designated sub-groups of elderly and disabled beneficiaries.<sup>105</sup> Home and community-based care waiver services and benefits are designed to assist individuals who, in the absence of home care, would require institutional level services and benefits. 106

As of 2000, virtually all States operated at least one Medicaid home and community care waiver program for at least one

101 See generally Rosenbaum & Rousseau, supra note 66, at 16-25 (presenting

a legal overview of Medicaid).

103 See 3 Medicare & Medicaid Guide (CCH) ¶ 14,625 (presenting broad

discussion of requirements and limitations under the waiver program).

<sup>5</sup> See id. (listing federal requirements that can be waived, as well as exam-

ples of waivers in individual States' waivers).

106 Id. ¶ 14,625.31.

<sup>&</sup>lt;sup>100</sup> Id. § 440.230(b)-(c).

<sup>102</sup> See generally Doe v. Mutual of Omaha Ins. Co., 179 F.3d 557 (7th Cir. 1999) (holding insurance policies that put a cap on medical care benefits for those with HIV did not violate the ADA); McGann v. H & H Music Co., 946 F.2d 401 (5th Cir. 1991) (holding employer did not violate ERISA when it reduced the maximum benefits payable to AIDS-infected employees). For a discussion of the limits of private insurance coverage, particularly in cases of persons with chronic illness and disability, see RAND E. ROSENBLATT, SYLVIA A. LAW, & SARA ROSENBAUM, LAW AND THE AMERICAN HEALTH CARE SYSTEM (1997 & Supp 2001-2001).

<sup>104</sup> There is no requirement that services listed as part of the State's waiver program be limited exclusively to persons receiving waiver services. However, the statute identifies certain services that may be furnished pursuant to a home and community care waiver (e.g., case management, homemaker services, home health aide services, personal care, habilitation, and respite care). Id.

category of elderly or disabled beneficiaries. 107 In operating home and community care waiver programs, States may vary the benefits they offer by beneficiary sub-category (that is, they may restrict aid to certain types of disabilities or to certain age groups of beneficiaries). 108 States may also, with the permission of the Secretary of HHS, establish fixed upper limits on the number of individuals within any group of beneficiaries eligible for the services who may receive "waiver" care. 109 This means that there may be waiting lists of persons who qualify for waiver services (i.e., who in the absence of these services require institutional care), but who exceed the number of approved slots or, alternatively, who, as in Olmstead, exceed the number of approved and funded slots.

Once approved, home and community care waiver services become part of a State's approved State Medicaid plan and all "non-waivable" conditions of federal participation (such as the promptness of medical assistance requirements) apply.

Medicaid contains no statutory individual right of action; however, settled jurisprudence permits litigants to bring claims against state officials for violation of statutory legal rights established under § 1983. Similarly, courts have consistently held that under the doctrine of Ex parte Young 111 beneficiaries and providers affected by the conduct of state officials can seek prospective injunctive relief. 112 Over the decades since Medicaid's enactment in 1965, countless lawsuits have been brought

 $<sup>^{107}</sup>$  See id.  $\P$  14,625.35, 14,625.55 (state summaries).  $^{108}$  See id.  $\P$  14,625 (discussing how States may waive federal requirement for comparability and "statewideness").

<sup>&</sup>lt;sup>110</sup> See, e.g., Wilder v. Va. Hosp. Ass'n, 496 U.S. 498 (1990) (holding health care providers could bring an action for declaratory and injunctive relief to insure State compliance with the Boren Amendment). For a review of the role of § 1983 in litigation to enforce Federal Medicaid rights, see Rand E. Rosenblatt, The Courts, Health Care Reform, and the Reconstruction of American Social Legislation, 18 J. HEALTH POLS. POL'Y & L. 439, 457, 460, 467-68 (1993).
111 209 U.S. 123 (1908).

<sup>112</sup> See Idaho v. Couer d'Alene Tribe of Idaho, 521 U.S. 261 (1997) (reaffirming and discussing the Ex parte Young doctrine, but finding it inapplicable in this particular case); Pennhurst State Sch. and Hosp. v. Halderman, 465 U.S. 89 (1984) (recognizing the validity of permitting prospective relief pursuant to Ex parte Young, but holding the need to vindicate the supreme authority of federal law is not present when the claim is that the state official violated state, rather than federal, law); Hutto v. Finney, 437 U.S. 678 (1978) (holding a lower court's prospective relief power includes the issuing orders to enforce a prospective injunction).

under § 1983 to compel state compliance with the terms of the Federal Medicaid statute and with federally secured rights.

Finally, the financial consequences of Medicaid to a State must be emphasized. Because Medicaid is a legal entitlement, once a State settles on its state plan, it must furnish medical assistance up to the full limits of the plan. Unlike a discretionary program, a State cannot refuse to fund a portion of its plan (i.e., fund only certain plan services or cover only certain plan eligibles). A State may of course submit amendments to the Secretary of HHS reducing the categories of eligible persons served or eliminating or reducing benefits, but as long as the state plan is in effect, beneficiaries have a legal right to its coverage in accordance with federal requirements.

#### B. The Medicaid Community Care Cases

The Medicaid community care cases lie at the intersection of state plans for medical assistance (including institutional and non-institutional care services, mandatory and optional state plan services, and waiver services) and the federal prompt assistance statute. These cases focus on the right of Medicaid beneficiaries to receive home and community care services, as well as other types of services related to the long-term care of persons with disabilities covered under their States' Medicaid plan, with reasonable promptness. 113 These cases consistently have found an enforceable right in the structure of the Medicaid statute's coverage and reasonable promptness requirements; furthermore, they have rejected, as neither permissible under Medicaid nor a colorable fundamental alteration claim under the ADA, a defense related to the cost of complying with plaintiffs' request for timely medical assistance services that are covered under the plan. 114 While the Medicaid prompt assistance cases

<sup>113</sup> See Doe v. Chiles, 136 F. 3d 709 (11th Cir. 1998); Boudreau v. Ryan, No. 00 C 5392, 2001 WL 840583 (N.D. Ill May 2, 2001); Makin ex rel Russell v. Hawaii, 114 F. Supp. 2d 1017 (D. Haw. 2000); Lewis v New Mexico Dep't of Health, 94 F. Supp. 2d 1217 (D.N.M. 2000), aff'd, 261 F.3d 970 (10th Cir. 2001); Boulet v Cellucci, 107 F. Supp. 2d 61 (D. Mass. 1999); Benjamin H. v. Ohl, No. 3:99-0338, 1999 U.S. Dist. LEXIS 22469 (S.D. W. Va. July 15, 1999); Cramer v. Chiles, 33 F. Supp. 2d 1342 (S.D. Fla. 1999); see generally, Jennifer Mathis, Community Integration of Individuals with Disabilities: An Update on Olmstead Litigation, 25 MENTAL & PHYSICAL DISABILITY L. REP. 158 (2001) (reviewing case law interpreting Olmstead).

<sup>114</sup> See Doe, 136 F.3d at 716-718; Cramer, 33 F.2d at 1354. Cases rejecting the cost defense as impermissible in the case of services covered under the State Medicaid plan all emanate from Alabama Nursing Home Ass'n v. Harris, 617 F. 2d

are remarkably unified in their analysis, there are indications that the very ability of Medicaid beneficiaries to bring individual actions to enforce federal rights may be under increasing judicial scrutiny as part of the "federalism jurisprudence" that has taken decisive hold over the past decade. 115 For example. the availability to plaintiffs of § 1983 in Medicaid litigation was recently called into question by a federal district court in Michigan in the case of Westside Mothers v Haveman. 116 The Westside Mothers court found that § 1983 does not form the basis of actions to enforce Medicaid state plan requirements, because the statute is simply a contract between sovereign governments and its requirements are thus enforceable against a State only through actions brought by the Secretary of HHS. In the court's view, Medicaid beneficiaries are no more than "third-party beneficiaries" to a public contract, a status that is not recognized under §1983. The court further ruled that the Ex Parte Young doctrine does not cover actions for prospective iniunctive relief against State Medicaid officials because such actions are in reality suits against States proscribed by the Eleventh Amendment. 118

In light of the Supreme Court's established jurisprudence regarding the relationship between federally secured rights under the Social Security Act (and other spending clause statutes) and individual enforcement actions under § 1983, it is difficult to imagine that the Westside Mothers defense will achieve broad judicial acceptance. Indeed, the Olmstead case itself involved an individual challenge brought under Title II of the ADA, which like § 504 of the Rehabilitation Act is based on Congress's Spending Clause power. At the same time, the recent trend toward diminished federal legal powers and expanded state sovereignty has been striking, and the court's decision in Westside Mothers may in fact command an appreciable following.

<sup>388 (5</sup>th Cir. 1980), the first case to reject insufficiency of funds as a defense to a state plan enforcement action.

<sup>&</sup>lt;sup>115</sup> See Roderick M. Hills, Jr., The Eleventh Amendment as Curb on Bureaucratic Power, 53 STAN. L. REV. 1225 (2001) (discussing how in forbidding damages, the doctrine of sovereign immunity prevents state agencies from using federal mandates to enlarge their own budgets).

<sup>116 133</sup> F. Supp. 2d 549 (E.D. Mich. 2001).

<sup>117</sup> Id at 557

See id. at 560-574 (providing four reasons why Ex parte Young is inapplicable).

#### V. CONCLUSION

The Olmstead decision is one of the important landmarks in the movement toward achieving the goals of enlightened disability policy in the United States. The ADA is as much a national policy statement about the full social integration of persons with disabilities as it is a body of legally enforceable operating rules that bind the public and private sectors. To be sure, recent judicial decisions under the ADA in the area of public and private employment suggest greater constraints on enforceability than envisioned at the time of enactment. But these decisions should not be allowed to cause policy makers to lose sight of the fundamental thrust of the ADA or its embodiment of strong popular sentiment regarding how the world should relate to persons with disabilities.

At the same time, applying the ADA to the complexity of public health care spending raises tremendous conceptual and legal difficulties. Because the federal government has elected to pursue an "enthusiastic" support role for voluntary state reforms rather than pure enforcement strategies, it seems that relatively definitive answers will come only through further litigation. This is unfortunate, perhaps, depending on one's point of view, because it encourages a high level of litigation and much regional uncertainty and inconsistency.

One obviously key area lies at the intersection of the ADA and the Medicaid statute. In the case of both Medicaid and private health insurance, it now appears to be settled law that demands for alteration in the design of coverage itself qualify for a "fundamental alteration" defense. Once a court determines that what plaintiffs seek is a restructuring of the *design* of an insurance program, whether public or private, the fundamental alteration defense appears to be available. However, because the concept of insurance design is potentially so broad (applying to every conceivable aspect of insurance, from eligibility to coverage, cost-sharing, provider compensation, and administration), the consequence of its use to trigger the fundamental al-

<sup>119</sup> See Rodriguez v. City of New York, 197 F.3d 611 (2d Cir. 1999) (holding that a State is not obligated to provide benefits to a particular group when it does not provide the benefits to any group); Doe v. Mutual of Omaha Ins. Co., 179 F.3d 557, 560 (7th Cir. 1999) (discussing how a cap on medical benefits for HIV-infected beneficiaries is only refusing to make a service as valuable to a disabled person as to a nondisabled person, and not violative of the ADA).

teration defense is that virtually every claim for modification of insurance practices would be swallowed by the defense. This liberal use of the concept of "design" relegates the ADA's distinction between reasonable modifications and fundamental alterations meaningless.

One case in particular illustrates the propensity of courts to allow the concept of design to claim all aspects of insurance modifications as a fundamental alteration. In Rodriguez v City of New York, 120 Medicaid beneficiaries with mental illness challenged the refusal on the part of the city and State to pay for cueing services furnished by personal attendants in the home unless they were furnished as an incident to other services related to the treatment of a physical disability. Plaintiffs alleged that without payment for cueing services on a stand-alone basis. they risked the very lack of in-home support that could result in their institutionalization.

With virtually no analysis, the United States Court of Appeals for the Second Circuit accepted the defendants' assertion that the plaintiffs challenged a coverage limitation and thus sought a remedy that involved a matter of insurance design, thereby triggering a fundamental alteration defense. 121 However. the court could have just as easily accepted the notion that the challenge did not involve coverage design (particularly since personal care services were undeniably covered under the New York State Medicaid plan) and instead focused on how the State was administering its approved coverage design. The heart of the case concerned the State's failure to pay for a covered service on a stand-alone basis, not its failure to cover the service at all. The decision whether to pay for a covered procedure on a stand-alone basis or merely as an incident to another procedure would appear to be precisely the type of administration question that Title II of the ADA aims to reach.

Thus, the "design" approach is an unsatisfactory means of distinguishing between requests for insurance practices that involve fundamental alterations and those that are merely reasonable modifications. Particularly in the case of Medicaid, whose funding availability is so dispositive of the opportunity to receive community-based health care, there needs to be a more satisfactory framework.

<sup>&</sup>lt;sup>120</sup> 197 F.3d 611 (2d Cir. 1999). <sup>121</sup> See id. at 618-19.

One possible starting point might be to consider as potentially a "fundamental alteration" any change in Medicaid policies, practices, and procedures that under federal rules require approval under the Federal Medicaid state plan amendment process before they can qualify for federal financial participation. Alterations that trigger an obligation to file a state plan amendment might at least raise a presumption of a fundamental alteration that rises above day-to-day administration.

Federal regulations pertaining to the state plan amendment process specify that plans must be amended "whenever necessary to reflect—[c]hanges in Federal law, regulations, policy interpretations, or court decisions; or [m]aterial changes in state law, organization, or policy, or in the State's operation of the Medicaid program." The question thus becomes what is a "material" change that at least potentially triggers a fundamental alteration defense under the ADA.

In PGA Tour, Inc. v Martin, 123 which involved the obligation under the ADA of the Professional Golf Association to permit a golfer with a disability to use a cart, the Supreme Court ruled that a fundamental alteration for purposes of the ADA is one that changes the essential character of a program or activity (in this case, the game of golf). Assuming that this definition of "fundamental alteration" would be equally relevant under Title II, then for purposes of the ADA, Medicaid state plan revisions that alter a basic characteristic of the State's Medicaid program (e.g., adding an eligibility or benefit category, recognizing a new class of qualified providers, or changing cost-sharing rules) might be considered the types of material changes that amount to a fundamental alteration in the nature of the State's program. Other changes, such as permitting beneficiaries to receive greater levels of an already-covered service under revised utilization management criteria, fully funding a service that is already identified as covered under the state plan, or expanding the circumstances and settings in which a covered benefit can be obtained (e.g., permitting a covered service to be furnished in additional locations such as schools or homes in order to accommodate the needs of persons with disabilities), would not amount to the types of material changes that trigger a fundamental alteration defense. Even were the change one that trig-

123 121 S. Ct. 1879 (2001).

<sup>&</sup>lt;sup>122</sup> 42 C.F.R. § 430.12(c)(1)(i)-(ii) (emphasis added).

gered the need to file a plan amendment, it would not change the basic character of the State's program.

This approach to fundamental alteration jurisprudence is obviously factually intensive and involves weighing the nature of the proposed change against the overall structure and operation of a State's Medicaid plan. It also involves a determination of whether the change is considered "material" by the U.S. Department of Health and Human Services for federal financial participation purposes under Medicaid; such a determination would be relevant but not necessarily dispositive of the question for ADA purposes, since what may be material in the context of Federal Medicaid financing may not "fundamentally alter" the character of a State's program in a way that triggers the fundamental alteration defense.

Another major area of focus concerns the power of States to establish the process of individual assessment and treatment planning. The *Olmstead* decision vests States with the authority to decide for whom community living is appropriate and the range and level of services that are necessary to make the community arrangement appropriate. Although the federal guidance essentially encourages States to address this issue as part of their planning process, it offers no minimum due process standards for the assessment procedure itself. The guidance is silent on matters ranging from the duty to initiate or respond to assessments, the timing of the assessment, the nature of the process, evidentiary standards governing the assessment and any assessment instruments that are used, and questions of burdens of proof. Similarly, no procedural standards exist for the development of treatment plans, nor are there standards governing the content of plans.

As with the issue of fundamental alteration, there surely are models that can serve as a basis for designing standards for individualized assessments and treatment planning. Examples can be found in the Individuals with Disabilities Education Act, 125 which entitles children with disabilities to a free and appropriate education and requires assessments and the development and oversight of treatment plans, as well as the provision of long-

<sup>&</sup>lt;sup>124</sup> Since the State of Georgia at one point discharged one of the plaintiffs in *Olmstead* to a homeless shelter, this allocation of powers seems a bit jarring. On the other hand, since the issue at stake is eligibility for publicly funded benefits, vesting the State with this authority appears inevitable.

<sup>125 20</sup> U.S.C. §§ 1400-1491o (1994 & Supp. V 1999).

term institutional care services in Medicaid, which since 1987 has obligated States to utilize pre-admission screening and treatment planning procedures.

Finally, there is the question of "reasonable pace." As noted, some courts have begun to address this issue, but as of yet, there are no general standards for measuring what constitutes a "reasonable pace" for purposes of *Olmstead*-related planning, nor is there an explanation regarding how the reasonable pace standard might vary depending on the nature of the condition or service need at issue. For example, the review of the most integrated setting complaints identified housing for persons with serious physical disabilities as an enormous unmet need. The permissible "reasonable pace" standard in developing this type of housing might be much slower than the standard that should be tolerated in the case of persons with physical disabilities who can return to a family home with relatively simple adaptations and in-home health support.

Because so many important issues remain unresolved, it is difficult to know how far Olmstead will take this latest generation of efforts to achieve full community integration for persons with disabilities. Certainly the case underscores the primacy of integration as the national goal. Furthermore, the decision represents a potentially major advance in disability case law in its establishment of a measurable outcome standard as a legal benchmark. But how to operationalize this outcome is very difficult. To achieve integration at a reasonable pace eventually requires the restructuring of Medicaid, as well as the augmentation of existing federal funding and options to States through financial incentives that encourage investment in restructuring. Examples of such incentives are raising the federal contribution rate in the case of services furnished to persons with disabilities in homes and community settings, 126 providing incentives for States to expand the definition of disability to approximate that used in the ADA itself, and removing barriers to the use of Medicaid to pay room and board costs in the case of persons whose physical disabilities make adapted residences essential (under current law, Medicaid can pay for room and board costs essentially only when an individual is a resident of a licensed

<sup>126</sup> Cf. 42 U.S.C. § 1397aa-1397jj (1994 & Supp. V 1999) (governing the State Children's Health Insurance Program which provides funds to States to provide health coverage to low-income children); 42 U.S.C.A §1396a(aa) (West Supp. 2001) (expanding funding for certain breast and cervical cancer patients).

medical facility). Making these service changes and federal financial enhancements is costly, but if the nation is serious about actively pursuing the statement of national policy that is embodied in the ADA, these changes would appear to be basic.