Mercer Law Review

Volume 58
Number 4 *Eleventh Circuit Survey*

Article 14

7-2007

Olmstead v. L.C.-Deinstitutionalization and Community Integration: An Awakening of the Nation's Conscience?

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Comment

Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation's Conscience?

I. INTRODUCTION

Olmstead v. L.C.[1] is a landmark case that originated in Georgia and has been lauded as the *Brown v. Board of Education* for the law of disability discrimination.[2] In June 1999 the United States Supreme Court decided *Olmstead v. L.C.*,[3] holding that it is a violation of the Americans with Disabilities Act ("ADA") for states to discriminate against people with disabilities by confining them to institutions when such individuals could live more appropriately in a community-based setting.[4] Yet, nearly eight years after the *Olmstead* decision and fourteen years after the passage of the ADA, progress in implementing the *Olmstead* integration mandate remains disappointingly slow. While

1. 527 U.S. 581 (1999).
2. Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits After* Olmstead v. L.C., 24 HARV. J.L. & PUB. POL'Y 695, 698 (2001).
3. 42 U.S.C. §§ 12101-12213 (2000).
4. 527 U.S. at 607.

individuals with disabilities and advocates hailed the landmark ruling, large numbers of individuals remain unnecessarily institutionalized despite the *Olmstead* integration mandate.[5]

This Comment has five primary objectives. First, this Comment makes a case for deinstitutionalization and explains some of the benefits of community life and integration. Second, this Comment outlines the history of segregation and gives an overview of the incremental movement toward community care, culminating with the ADA and the Integration Regulation[6] in the post-1990's era. Third, this Comment analyzes the *Olmstead* decision and its importance. Fourth, this Comment discusses some of the barriers affecting the states' implementation and transition to community integration, followed by a discussion of the federal government's efforts to assist the states in complying with the *Olmstead* mandate. Fifth, this Comment explains why community integration can be more beneficial today and easier than ever in a call to genuinely awaken the nation's conscience.

II. THE CASE FOR DEINSTITUTIONALIZATION

Institutionalization is the most extreme form of segregation. Institutionalized individuals suffer a dramatic loss of physical freedom with severely invasive treatment. They cannot enjoy the simple, daily pleasures that the average American takes for granted, such as shopping, working, exercising, companionship, making their own schedules, or solitude.[7] Citizens who do enjoy these freedoms of American society would undeniably find the loss of such things "not only intolerable but a threat to [their] very sanity."[8]

Institutionalized individuals are deprived of commonplace, yet precious, liberties such as inclusion, dignity, self-direction, privacy, choice, enjoyment of the responsibilities of citizenship, and participation in and contribution to one's community. More accurately, individuals in institutions experience dependency, physical segregation, social isolation, and second-class citizenship. In the worst-case scenarios, individuals in institutions suffer physical, mental, and emotional abuse and neglect. Even for those who do not suffer egregious neglect or abuse, life in an institution nonetheless leads to a certain degree of institutional

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5. Jennifer Mathis, *Where Are We Five Years After* Olmstead?, CLEARINGHOUSE REV. J. OF POVERTY LAW & POL'Y 561, 561 (Jan.-Feb. 2005).

6. 28 C.F.R. § 35.130(d) (2006).

7. Joanne Karger, *"Don't Tread on the ADA":* Olmstead v. L.C. ex rel. Zimring *and the Future of Community Integration for Individuals with Mental Disabilities*, 40 B.C. L. REV. 1221, 1221 (1999).

8. *Id.*

dependence. This dependence manifests itself in a loss of social and intellectual competencies and atrophy of the ability to live outside the institution.[9]

Just a glimpse at the immediate aftermath of the *Olmstead* ruling proves there are individuals in institutions who need not be there and have much to offer society beyond the walls of an institution. The lives of the two *Olmstead* plaintiffs, Ms. Curtis and Ms. Wilson, illustrate the benefit and magnitude of the decision and show the positive effect the decision can have on individuals as well as society as a whole. Ms. Curtis and Ms. Wilson progressed rapidly once they were moved to community-based settings. Their rapid advancements revealed the limitations of their former institutional circumstances. Ms. Curtis takes long walks and has reconnected with her mother and sister. She visits the mall, picks out her own clothes, and has learned to plan a menu. Additionally, she speaks clearly, communicates well, and has developed meaningful friendships with others that live with her in a group home. With practical assistance and encouragement from her customized support team, Ms. Curtis has started to produce and sell note cards that illustrate her own artwork.[10]

Ms. Wilson spent a year in a group home where she decorated her own room and organized picture albums. She then transitioned into a home where she lived with a caretaker and a friend. Ms. Wilson attended a prevocational program and became increasingly independent. Interestingly, she took complete responsibility for her own medical needs, which was one domain in which institutional doctors felt she could not succeed independently. Moreover, she developed her own advocacy skills by speaking around the country about her experiences, the injustices of institutional life, and her hopes for the freedom of other individuals in institutions.[11]

Indeed, the magnitude of the societal effect of *Olmstead* is undeniable because disability is an experience that will touch most Americans to some degree in their lives. Today, over fifty-four million Americans, or one in every five, are living with a disability.[12] People with disabilities make up the nation's largest minority and the only minority that any person can join at any time.[13] Individuals with disabilities cross all

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9. Smith & Calandrillo, *supra* note 2, at 703-04.

10. Atlanta Legal Aid Society, http://www.atlantalegalaid.org/impact.htm (last visited Apr. 12, 2007).

11. *Id.*

12. United States Department of Labor Office of Disability Employment Policy, www.dol.gov/odep/pubs/ek96/diverse.htm (last visited Apr. 12, 2007).

13. *Id.*

gender, racial, religious, educational, and socioeconomic lines.[14] Some individuals are born with disabilities, some may become disabled through an accident or illness, and many will face disability through the aging process. These astonishing statistics raise the moral question of whether or not we are our brother's and sister's keeper? The answer should be a resounding "yes"!

Although the *Olmstead* decision has become known as the integration mandate, there remain many post-*Olmstead* implementation issues which need to be actively addressed. There is no question that the long-term costs of home and community-based care are less than that of institutional care. Further, community care is not merely a financially superior option, but a morally and legally superior one as well. Yet, in the aggregate, our nation has made little progress toward the goal of transitioning from institutions to community integration. Why is this situation so immutable and what is holding the states back? Or more importantly, what are the states waiting for to take substantial action?

III. HISTORY OF DEINSTITUTIONALIZATION AND THE ADA

A. The Incremental Movement Toward Community Care

The discriminatory treatment and segregation of persons with disabilities has deep historical roots. Individuals with disabilities have been segregated in institutions and isolated from mainstream society in the United States for over one hundred years.[15] For over half of the twentieth century, people with mental and developmental disabilities were typically placed in large institutions, and some relied solely on their families for care and financial aid. Little to no assistance was available from the government.[16] Indeed, the majority of early cases addressing people with disabilities evidenced eugenics measures to control their reproduction and forced institutionalization.[17]

During this time, medical professionals advanced the view that individuals with disabilities were more likely to engage in criminal and sexually immoral behavior, and thus, were a menace to society.[18] This stereotypical notion, coupled with the perceived danger that such individuals posed, furthered the idea that they should be locked up and

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14. *Id.*

15. Karger, *supra* note 7, at 1224.

16. Sandra L. Yue, *A Return of Institutionalization Despite* Olmstead v. L.C.*? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home- and Community-Based Waiver Services*, 19 LAW & INEQ. 307, 312 (2001).

17. *Id.*; *see* Buck v. Bell, 274 U.S. 200 (1927).

18. Karger, *supra* note 7, at 1225.

segregated from the rest of the community.[19] Consequently, institutions came to be viewed as the most effective solution, whereby individuals with mental disabilities could be given the paternalistic protection they were perceived to need, and society at large could be safeguarded from their alleged vices.[20]

1. 1950s–1970s: Civil Rights Era and the Rehabilitation Act. Efforts to progress forward from institutions to community care began to surface in the 1950s and continued with somewhat more force in the 1960s and 1970s.[21] "Until the late 1960s, the dual attitudes of paternalism and fear ensured a segregated, institutionalized existence for people with disabilities."[22] A strengthening civil rights movement empowered disability rights advocates to seek improved living conditions and, more importantly, to retreat from unnecessary institutionalization altogether. Further, sociological studies exposed the abuse and neglect that was occurring in institutions and became a factor in the stimulus for change.[23]

An increased societal emphasis on personal autonomy and individual rights, coupled with a strengthened agreement among experts that many people with disabilities could benefit and thrive in less restrictive settings, supported the deinstitutionalization movement.[24] By the early 1970s, courts were faced with many class action suits challenging poor institutional conditions.[25] These courts "consistently concluded that the civil rights of individuals with mental retardation and other developmental disabilities were being violated."[26] The key legislative impetus behind this movement was the Rehabilitation Act of 1973 ("Rehab Act").[27]

Section 504 of the Rehab Act was the first broad civil rights-oriented federal statute to address discrimination against people with physical and mental disabilities.[28] The Rehab Act prohibited federal programs from excluding persons on the basis of disability and provided the framework for vocational rehabilitation and independent living

19. *See id.*
20. *Id.*
21. Smith & Calandrillo, *supra* note 2, at 707.
22. Yue, *supra* note 16, at 313.
23. Karger, *supra* note 7, at 1226-27.
24. *See* Yue, *supra* note 16, at 313.
25. *Id.* at 314.
26. *Id.*
27. 29 U.S.C. Ch. 16 (2000).
28. Yue, *supra* note 16, at 314.

programs.[29] Nevertheless, circuit courts refused to find a right to the least restrictive environment under the Rehab Act and consistently denied that the Rehab Act required states to place people with disabilities in such an environment.[30] Thus, rights for persons with disabilities were recognized during the civil rights era, but more progress was needed to reach the ideal of community integration for everyone.

2. 1980s: Increased Advocacy Based on Empirical Studies. In the 1980s, empirical studies proved that community placements provided a better quality of life and were financially superior from a long-term perspective. Despite this research, in 1981 the Supreme Court refused to find an articulated right to treatment in the least restrictive environment under the Developmental Disabilities Assistance and Bill of Rights Act ("DDA Act") in *Pennhurst State School & Hospital v. Halderman*.[31] The DDA Act established a voluntary federal-state grant program whereby the federal government provided financial assistance to participating states to help create programs to care for persons with developmental disabilities.[32] Specifically, the "Bill of Rights" provision of the DDA Act states that individuals with developmental disabilities have a right to "appropriate treatment" in "the setting that is least restrictive of . . . personal liberty."[33]

In *Pennhurst* the plaintiff was a resident of the Pennhurst State School and Hospital ("Pennhurst"). The plaintiff filed suit on behalf of herself and all other residents alleging that the conditions at Pennhurst were unsanitary, inhumane, and dangerous. Specifically, she alleged that such conditions violated the class members' due process and equal protection rights and additionally constituted cruel and unusual punishment. The complaint urged that Pennhurst be closed and that community living arrangements be established for its current residents.[34]

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29. *See* 29 U.S.C. § 701 (2000).

30. *See, e.g.*, P.C. v. McGlaughlin, 913 F.2d 1033, 1041 (2d Cir. 1990); Phillips v. Thompson, 715 F.2d 365, 368 (7th Cir. 1983) (holding that the state did not have an affirmative duty under the Rehab Act to create less restrictive community residential settings for persons with disabilities).

31. 451 U.S. 1, 18-19 (1981).

32. *See* 42 U.S.C. §§ 6000-6083 (1994 & Supp. IV 1998), *repealed by* Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402, 114 Stat. 1677 (2000) (codified as amended at 42 U.S.C. §§ 15001-15115 (2000)).

33. *See* 42 U.S.C. § 6009(2) (1994 & Supp. IV 1998), *repealed by* Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402, 114 Stat. 1677 (2000) (codified as amended at 42 U.S.C. § 15009(1)(2) (2000)).

34. *Pennhurst*, 451 U.S. at 6.

The U.S. District Court for the Eastern District of Pennsylvania made factual findings that the conditions at Pennhurst were dangerous and that residents were often physically abused by staff members. The district court also found that the conditions were inadequate for any possible habilitation of its residents because the physical, intellectual, and emotional skills of some residents had in fact deteriorated while at Pennhurst. The district court held that persons with mental disabilities have a constitutional right to be provided with minimally adequate habilitation in the least restrictive environment. Accordingly, the court ordered that Pennhurst be closed and that community living arrangements be provided for all of its current residents.[35]

The Third Circuit Court of Appeals affirmed the district court's order but rested its opinion on a construction of the DDA Act instead of the plaintiff's constitutional claims.[36] Notwithstanding, the Supreme Court reversed and held that the DDA Act did not create any substantive right to treatment in the least restrictive environment.[37] The Court reasoned that it had to look beyond the explicit language of the DDA Act and instead "'look to the provisions of the whole law, and to its object and policy.'"[38] Further, the Court reasoned that an analysis of the "Bill of Rights" provision in the context of other specific provisions reveals that it merely represents a congressional preference for community-based treatment but does not require states to provide such treatment.[39] Thus, the Court held that despite the language of the statute, individuals with disabilities did not have a right under the DDA Act to receive community-based treatment.[40] As a result, *Pennhurst* became the seminal case used by states in their arguments against deinstitutionalization.[41]

Nonetheless, the movement for community care and inclusion was gaining momentum. Community-care advocates urged that such care was superior to institutions in terms of quality, cost, and equity. Evidence of abuse, neglect, and unsanitary conditions in large institutions was well documented. Empirical studies were conducted in the 1980s to evaluate the costs of community care compared to institutional care.[42] Individuals with mental disabilities were randomly placed in

35. *Id.* at 7-8.
36. *Id.* at 8.
37. *Id.* at 18-19.
38. *Id.* at 18.
39. *Id.* at 19.
40. *Id.* at 18.
41. Karger, *supra* note 7, at 1238.
42. *See* Smith & Calandrillo, *supra* note 2, at 703-04.

either an institutional or a residential setting. The studies revealed that alternative care is generally more effective and less costly than institutional care.[43] Further evidence documented that the cost-per-patient in community care is lower than the cost-per-patient in institutional settings.[44]

Large overhead expenses contribute to the high cost of institutional care. Advocates argue that overhead costs are high because institutions must recreate the services which, in reality, are components of everyday life. In contrast, community-based programs do not have to be constructed and thus cost much less to provide. Moreover, many individuals placed in community-based settings will be able to secure employment and develop personal relationships from which they can receive support. Therefore, these individuals will be less dependent on the state for future financial support.[45]

Community-care advocates contend that cost concerns are merely a facade and the true underlying issue behind the inertia to provide community-based living is unwillingness and ignorance on the part of institution administrators. Activists assert that administrators and officials are hesitant to move patients out of institutions because of their desire to maintain a high occupancy rate and their reluctance to terminate large numbers of institution employees.[46]

Significantly more relevant than the issue of costs is the contention that community care allows for greater social equality and better overall quality of life for individuals with disabilities. Confined living often leads to great institutional dependence, which manifests in a loss of social, vocational, and relational competencies.[47] Strong evidence confirms that individuals with disabilities living in community-based settings "spend more time with friends and social groups, have a higher level of self-esteem, show fewer symptoms, and comply more consistently with medication and treatment plans."[48]

B. The ADA and the Post-1990s Era

In 1990 Congress enacted the Americans with Disabilities Act ("ADA"),[49] which was by far the most comprehensive legislation geared toward the prohibition of discrimination based on disability. When

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43. *Id.*
44. *Id.* at 704.
45. *Id.* at 704-06.
46. *Id.* at 705.
47. *Id.*
48. *Id.* at 704.
49. 42 U.S.C. §§ 12101-12213 (2000).

enacting the ADA, Congress noted "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals."[50] The ADA built upon the foundations laid by the Rehab Act to further bolster support for the disability rights movement. In signing the ADA into law, President George H. W. Bush gave his praises to the effort by stating: "The Americans with Disabilities Act presents us all with an historic opportunity. It signals the end to the unjustified segregation and exclusion of persons with disabilities from the mainstream of American life."[51] Moreover, former Attorney General Dick Thornburgh lauded the ADA as "a great leap forward in the civil rights movement."[52]

Significantly, the ADA is the first statute to explicitly identify "institutionalization" as a serious issue of discrimination against individuals with disabilities. In the general provisions of the ADA, Congress expressly found the following:

> [H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem; . . .
>
> [d]iscrimination against individuals with disabilities persists in such critical areas as . . . housing, public accommodations, education, . . . [and] institutionalization . . .; . . . .
>
> [i]ndividuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . overprotective rules and policies, . . . [and] segregation . . . .[53]

Specific to the institution context and the purpose of this article, Title II of the ADA prohibits discrimination on the basis of disability in the provision of public services.[54]

Title II specifies that "no 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."[55] Title II of the ADA omits the term "otherwise" preceding the phrase "qualified

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50. *Id.* § 12101(a)(8).

51. Statement on Signing the Americans with Disabilities Act of 1990, 2 PUB. PAPERS 1070, 1071 (July 26, 1990).

52. Dick Thornburgh, *The Americans with Disabilities Act: What it Means to All Americans*, 64 TEMP. L. REV. 375, 375 (1991).

53. 42 U.S.C. § 12101(a)(2), (3), (5).

54. *See generally id.* §§ 12131-12165 (2000).

55. *Id.* § 12132.

individual with a disability;" the term was problematic in section 504 of the Rehab Act because it required plaintiffs to establish the prima facie element that they were "otherwise qualified."[56] This omission makes the language of the ADA broader and less restrictive than that of section 504 of the Rehab Act.[57] Congress instructed the Attorney General to issue regulations implementing Title II's prohibition of discrimination.[58] In so doing, the Department of Justice ("DOJ") regulations require a public entity to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability . . . ."[59] However, a public entity can avoid making changes to its programs if it can show the modifications "would fundamentally alter the nature of the service, program, or activity."[60]

The DOJ's "integration regulation" requires a public entity to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[61] Notably, the preamble to the regulations clarifies that "the most integrated setting appropriate" is "a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible."[62] "Clearly, in using this specific language concerning nondisabled persons with whom people with disabilities should be able to interact, the Attorney General did not have in mind limiting the interaction to" orderlies or nurses in an institution.[63] Thus, it appears that in enacting the ADA and its regulations, Congress and the DOJ were aware of and considered the precise issues of institutionalization and integration.

Yet, "[e]ven early efforts under the ADA and the Integration Regulation met checkered results."[64] In 1993 the Supreme Judicial Court of Massachusetts refused to hold that the ADA required states to provide specific levels of community care, and thus denied relief to a class of patients with mental disabilities.[65] Also in 1993 two federal district

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56. Karger, *supra* note 7, at 1239.

57. *Id.*

58. *See* 42 U.S.C. § 12134(a).

59. 28 C.F.R. § 35.130(b)(7) (2006).

60. *Id.*

61. 28 C.F.R. § 35.130(d) (2006).

62. 28 C.F.R. pt. 35, app. A, subpart B, § 35.130 (2006).

63. Andrew I. Batavia, *A Right to Personal Assistance Services: "Most Integrated Setting Appropriate" Requirements and the Independent Living Model of Long-Term Care*, 27 AM. J.L. & MED. 17, 31 (2001).

64. Smith & Calandrillo, *supra* note 2, at 708.

65. *See* Williams v. Sec'y of Executive Office of Human Servs., 609 N.E.2d 447, 452-53 (Mass. 1993).

courts split on the issue of whether the ADA required unnecessarily institutionalized individuals to be placed in the least restrictive environment.[66]

In addition to a lack of clarity as to what the Integration Regulation required, there was much uncertainty as to what constituted a fundamental alteration as opposed to a reasonable accommodation. This uncertainty has persisted, to some extent, even after the *Olmstead* decision. In practice, these provisions have led some courts to consider the costs to states in determining whether a community-based setting is required for an individual with a disability.[67] *Helen L. v. DiDario*,[68] a key case decided by the Third Circuit prior to *Olmstead*, addressed this issue of costs and somewhat solidified the applicability of the Integration Regulation.[69]

In *Helen L.*, the plaintiff was a forty-three year old woman who contracted meningitis, which left her paralyzed from the waist down and confined to a wheelchair. As a result, she became a patient of the Philadelphia Nursing Home. Although the plaintiff was able to dress herself, cook, and tend to most of her personal hygiene needs, she did need assistance with certain activities including laundry, shopping, house cleaning, and getting in and out of bed. The health professionals determined that the plaintiff was eligible for home-based care. However, due to a lack of funding, she was placed on a waiting list for the attendant care program and continued to live in the nursing home where she had no contact with nondisabled persons other than the nursing home staff.[70]

The plaintiff filed suit, alleging that the Department of Public Welfare had violated Title II of the ADA by providing her services in a nursing home rather than in the "'most integrated setting appropriate'" to her needs.[71] The lower court granted summary judgment for the Department of Public Welfare, holding that it had not discriminated against her on the basis of disability because it wait-listed her due to lack of funding.[72] However, the Third Circuit rejected this reasoning and rejected the State's "fundamental alteration" defense.[73] The court held that a denial of services in the most integrated setting appropriate

66. *See* Conner v. Branstad, 839 F. Supp. 1346, 1357 (S.D. Iowa 1993); Martin v. Voinovich, 840 F. Supp. 1175, 1192 (S.D. Ohio 1993).

67. Batavia, *supra* note 63, at 32.

68. 46 F.3d 325 (3d Cir. 1995).

69. *See id.* at 327.

70. *Id.* at 328-29.

71. *Id.* at 328.

72. *Id.*

73. *Id.* at 335-39.

violated the ADA, despite a lack of funding.[74] The United States Supreme Court declined to grant certiorari.[75]

The court reasoned that fiscal or administrative convenience was not a valid justification for providing services in a segregated manner.[76] Furthermore, the court determined that placing the plaintiff in attendant care would actually save the state an average of $34,500 per year.[77] Thus, by requiring the Department of Public Welfare to provide home care for the plaintiff, the court was in no way imposing a large expense on the State of Pennsylvania.[78] In making this decision, the court relied heavily on Congress's statement that "'[t]he Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, [] independent living,'" and economic self-sufficiency for such individuals.[79] Also, the court referred to the DOJ's statement that "'[i]ntegration is fundamental to the purposes of the Americans with Disabilities Act.'"[80]

Therefore, prior to *Olmstead*, the Third Circuit affirmed that the ADA mandated the maximum possible integration into the community.[81] This opinion has been interpreted to disallow cost considerations when analyzing whether an individual should be placed in a community setting.[82] Notably, the Eleventh Circuit Court of Appeals decision in *Olmstead* relied on the reasoning of *Helen L.*[83] However, by 1999 the United States Supreme Court granted certiorari and was ready to consider the issue in *Olmstead*.

IV. THE *OLMSTEAD* DECISION

In 1999, in *Olmstead v. L.C.*,[84] the United States Supreme Court held that the unjustified segregation of individuals with mental disabilities in institutions constitutes discrimination under the ADA.[85] Additionally, the Court held that the ADA requires states to provide placement for individuals with mental disabilities in community settings rather than in institutions when: (1) the state's treatment professionals determine

74. *Id.* at 338.
75. *Id.*
76. *Id.*
77. *Id.*
78. *See id.*
79. *Id.* (quoting 42 U.S.C. § 12101(a)(8)).
80. *Id.* at 332 (quoting 28 C.F.R. Part 35, App. A § 35.130 (2006)).
81. *See id.* at 327.
82. Batavia, *supra* note 63, at 32.
83. 46 F.3d 325 (3d Cir. 1995).
84. 527 U.S. 581 (1999).
85. *Id.* at 607; 42 U.S.C. §§ 12101-12213 (2000).

that such placement is appropriate; (2) the affected individual does not oppose the placement; and (3) the state can reasonably accommodate the placement without creating a fundamental alteration, given the state's available resources and the needs of other individuals with mental disabilities.[86]

A. *Factual Background*

The plaintiffs, Lois Curtis and Elaine Wilson, were Georgia residents who had cognitive disabilities. In addition, Ms. Curtis suffered from schizophrenia, and Ms. Wilson was diagnosed with a personality disorder. Previously, both women had been treated in institutional settings and were Medicaid beneficiaries. In May 1992 Ms. Curtis was voluntarily admitted to the psychiatric unit of Georgia Regional Hospital ("GRH") where her condition was stabilized by May 1993. Accordingly, her treatment team determined her needs could be sufficiently met in a state supported community-based program. Despite this evaluation, Ms. Curtis remained institutionalized for nearly three more years. Ms. Wilson was also voluntarily admitted to the psychiatric unit of GRH in February 1995. By 1996 Ms. Wilson's psychiatrist determined that she could be treated appropriately in a community-based setting, but she remained institutionalized until late 1997.[87]

In May 1995 Ms. Curtis filed suit against the Georgia Department of Human Resources (then led by Commissioner Tommy Olmstead) in the United States District Court for the Northern District of Georgia. Ms. Curtis challenged her continued institutional confinement and alleged that the State's failure to transfer her to a community-based setting, after her doctors found such placement to be appropriate, violated Title II of the ADA. She sought placement in a community residential program and treatment that would integrate her into mainstream society. Ms. Wilson intervened in the action.[88]

B. *Lower Court Decisions*

The district court granted partial summary judgment for the plaintiffs and ordered their placement in a community-based treatment program. The State unsuccessfully argued that inadequate funding, rather than discrimination, was the reason the plaintiffs remained at GRH. The court rejected this argument and concluded that unnecessary institution-

86. *Olmstead*, 527 U.S. at 607.
87. *Id.* at 593.
88. *Id.* at 593-94.

al segregation constitutes per se discrimination under Title II and could not be justified by a lack of funding.[89]

The Eleventh Circuit affirmed the district court's judgment, but did not conclusively order community care for the plaintiffs. Instead, the court remanded for a reassessment of the State's cost-based defense. The Eleventh Circuit interpreted the statute and regulations to allow for such a defense in very limited circumstances. Thus, the court of appeals remanded with instructions for the district court to determine whether the additional treatment costs of the women in community-based settings would be unreasonable in light of the demands on the State's mental health budget and would fundamentally alter the State's mental health program.[90] The United States Supreme Court granted certiorari because "of the importance of the question presented to the States and affected individuals," and affirmed the Eleventh Circuit's decision in substantial part.[91]

C. Supreme Court's Rationale

In a 6-3 decision, the Supreme Court held that unjustified segregation constitutes "discrimination based on disability."[92] Justice Ginsburg, writing for the majority, phrased the issue before the Court as "whether the proscription of discrimination [in Title II] may require placement of persons with mental disabilities in community settings rather than in institutions."[93] The Court held the answer to be a "qualified yes."[94] Initially, the Court pointed out the "legislative and regulatory prescriptions on which the case turn[ed]."[95] In so doing, the Court emphasized the Title II regulation, known as the "Integration Regulation," which reads as follows: "'A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.'"[96] Further, the Court noted the preamble to the Attorney General's Title II regulations which defines "'the most integrated setting appropriate to the needs of qualified individuals with disabilities'" to be "'a setting that enables individuals

89. *Id.* at 594.
90. *Id.* at 595-96.
91. *Id.* at 596-97.
92. *Id.* at 597.
93. *Id.* at 587.
94. *Id.*
95. *Id.* at 588.
96. *Id.* at 592 (quoting 28 C.F.R. § 35.130(d) (2006)).

with disabilities to interact with non-disabled persons to the fullest extent possible.'"[97]

Relying on these provisions, the Court held that unjustified placement or retention of persons in institutions is discrimination based on disability.[98] The Court reasoned that the ADA extended the scope and strengthened earlier attempts, such as the Rehab Act[99] and the DDA Act,[100] to secure opportunities for people with disabilities to enjoy the benefits of community living.[101] Through the ADA, Congress secured these opportunities not only by prohibiting discrimination by all public entities, but additionally by specifically identifying unjustified segregation of persons with disabilities as a type of discrimination.[102]

The Court noted two important premises that supported the contention that unjustified isolation is a form of discrimination. First, institutional placement of persons who can thrive in and "benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in" the community.[103] Second, institutional isolation "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[104] Accordingly, dissimilar treatment exists for such individuals because "[i]n order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice."[105]

However, the Court cautioned that its ruling does not mean that people who are unable to cope with or benefit from community living should be removed from the institutions, nor does it mean that community-based treatment may be imposed on those who do not desire it.[106] Thus, the state may rely on the reasonable assessments of its own professionals to determine whether an individual meets the eligibility requirements for removal to a community-based setting.[107]

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97. *Id.* (quoting 28 C.F.R. pt. 35, app. A, subpart B, § 35.130 (2006)).
98. *Id.* at 597.
99. 9 U.S.C. ch. 16 (2000).
100. 42 U.S.C. §§ 15001-15115 (2000).
101. *Olmstead*, 527 U.S. at 599.
102. *Id.* at 600 (citing 42 U.S.C. §§ 12101(a)(2), 12101(a)(5)).
103. *Id.*
104. *Id.* at 601.
105. *Id.*
106. *Id.* at 602.
107. *Id.*

Nonetheless, the Court cautioned that once the State provides community-based treatment to qualified persons, its responsibilities are not "boundless."[108] The State must make reasonable modifications, but the State is not required to make modifications that would create a fundamental alteration of the States' services and programs.[109] The Eleventh Circuit interpreted this regulation to permit a cost-based defense in limited circumstances.[110] However, the Supreme Court rejected this simple cost comparison as inappropriate because "it would leave the State virtually defenseless once it is shown that the plaintiff is qualified for the service or program she seeks."[111] Additionally, the Court pointed out that the DOJ regulation's interpretation of the term "fundamental alteration" must be consistent with the DOJ regulations for § 504 of the Rehab Act, which included a similar defense pertaining to "undue hardship."[112] The Court noted the regulations for section 504 define "undue hardship" to mean more than mere cost; rather, the concept involves a case-by-case analysis of additional factors such as the overall type and size of the program.[113]

Under the proper construction of the fundamental alteration defense, the State must show that immediate relief for the plaintiffs would be inequitable in light of available resources and the State's responsibility to care for a large and diverse population of other persons with disabilities as well as the State's responsibility to provide services in an equitable manner.[114] The Court found that future courts must consider these additional factors in light of a state's available resources.[115] Thus, in order for the State to maintain its mental health facilities and render services effectively, it needed more leeway than the Eleventh Circuit found the fundamental alteration defense to allow.[116]

The Court gave direction to the states on implementation of this mandate by way of example. For illustration, the reasonable modifications standard would be met if the State could show it had a comprehensive and effective plan for placing qualified persons in less restrictive settings, and "a waiting list that moved at a reasonable pace" that was not controlled by the State's efforts to keep its institutions at full

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108. *Id.* at 603.
109. *Id.*
110. *Id.*
111. *Id.*
112. *Id.* at 606 n.16.
113. *Id.*
114. *Id.* at 604.
115. *See id.* at 604-05.
116. *Id.* at 605.

capacity.[117] Moreover, individuals could not receive community placement ahead of others on the waiting list merely by filing a lawsuit.[118]

For these reasons, the Court held that states are required to provide community-based treatment for persons with mental disabilities when: (1) treatment professionals find that such placement is appropriate; (2) the person with disabilities does not oppose community-based treatment; and (3) the placement can be reasonably accommodated in light of the state's available resources and the needs of others with mental disabilities.[119] Thus, the Court affirmed the Eleventh Circuit in part, vacated in part, and remanded the case for an examination of many factors beyond a simple cost comparison to determine if the community placement represented a fundamental alteration of Georgia's program.[120]

V. WHY THE SUPREME COURT INTERVENED

The Supreme Court's ruling in *Olmstead*[121]—that the ADA[122] and the Integration Regulation[123] prohibit discrimination against unnecessarily institutionalized individuals—illustrated the Court's concern for, and recognition of, the need for federal intervention in the institutional arena. Thus, the Court recognized the need for federal involvement in an area where state legislatures were not well-suited to correct the problem. Additionally, individuals with mental disabilities, as a group, are less capable of representing their interests in monolithic power centers.[124] These individuals "vote less frequently, donate less money, and lobby less loudly."[125] Moreover, evidence indicated that state institutions often were not providing adequate care, and the states continued to allow this substandard existence despite the data proving community care was less expensive and more effective.[126] "This reality provides a measure of empirical evidence that states were not sufficiently equipped, or perhaps not sufficiently motivated, to resolve the problems facing the unnecessarily institutionalized . . . population."[127]

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117. *Id.* at 605-06.
118. *Id.* at 606.
119. *Id.* at 607.
120. *Id.*
121. 527 U.S. 581 (1999).
122. 42 U.S.C. §§ 12101-12213 (2000).
123. 28 C.F.R. § 35.130(d) (2006).
124. Smith & Calandrillo, *supra* note 2, at 715.
125. *Id.*
126. *Id.*
127. *Id.*

Therefore, the need for federal intervention was an additional concern that weighed in favor of the Court's conclusion in *Olmstead*.

VI. THE IMPORTANCE OF THE *OLMSTEAD* DECISION

The *Olmstead*[128] decision places an important obligation on states as they seek to comply with Title II of the ADA.[129] The *Olmstead* decision did not merely hold that unjustified institutionalization amounts to discrimination under the ADA. More importantly, *Olmstead* established that states have a legal obligation to affirmatively remedy such discriminatory practices through reasonable modifications to their programs and services. This obligation is often referred to as the "integration mandate."[130] Title II of the ADA applies to public entities and to the use of public funds.[131] Thus, the *Olmstead* decision has grave implications for publicly funded Medicaid services which treat and care for people with disabilities. The decision confirmed that states must ensure that Medicaid-eligible persons do not experience discrimination by being institutionalized when they could be better served in an integrated community setting.[132]

However, courts, commentators, and practitioners find the *Olmstead* decision both "profound and ambiguous."[133] While the decision did establish broad safeguards for individuals with disabilities, it also raised many questions regarding how the integration mandate should be implemented.[134] The Court made limited recommendations as to the nature of state compliance with the ADA in light of *Olmstead*. The Court illustrated that states may comply by creating a comprehensive and effectively-working plan to reduce institutionalization and by ensuring that the waiting lists for services move at a reasonable pace.[135]

Federal officials, state officials, and advocates seized upon this language as the heart of the remedial portion of the opinion.[136] An "'effectively working state plan'" for community placement and waiting

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128. 527 U.S. 581 (1999).

129. 42 U.S.C. §§ 12101-12213 (2000).

130. Center for Personal Assistance Services, *Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans* (Oct. 2006), http://pascenter.org/-olmstead/.

131. *See* 42 U.S.C. § 12132.

132. Center for Personal Assistance Services, *supra* note 130.

133. Sara Rosenbaum & Joel Teitelbaum, Kaiser Commission on Medicaid and the Uninsured, Olmstead *at Five: Assessing the Impact* 1 (June 2004), www.kff.org.

134. *See id.*

135. *Id.* at 6.

136. *Id.*

lists that move at a "'reasonable pace'" became "fundamental jumping-off points for implementation."[137] Yet, the decision did not offer clarity on such matters as when changes in Medicaid and other programs cross the line from reasonable modification to fundamental alteration, when a waiting list is moving at a reasonable pace, or what constitutes an effectively working plan.[138] Further, measuring the progress of *Olmstead* implementation is problematic because "there are no clearly stated objectives, budgets, or timetables."[139] In fact, an emerging theme from post-*Olmstead* cases is judicial encouragement of policy change, but minimal desire to actually enforce the change process.[140] Lower courts have generally decided that evidence of states' active commitment, yet slow progress towards community integration, satisfies the ADA.[141] Commentators criticize these decisions as "[r]ewarding rather than sanctioning states that move slowly toward change."[142]

The current issue for most states today, including Georgia, is how to implement and complete the transition from institutions to a system of home- and community-based services.[143] Institutionalization of individuals with disabilities has been generally declining since the 1960s. Since 1991 eight states and the District of Columbia have closed all of their institutions, and most states have closed at least one institution.[144] Unfortunately, this slow but positive trend has decreased in recent years. Surprisingly, the lowest rate of deinstitutionalization in thirty years occurred in the period between 2001 and 2003, which was *after* the Supreme Court issued the *Olmstead* mandate.[145]

A study conducted by the National Conference of State Legislatures in January 2003 revealed that twenty-one states had issued *Olmstead* plans or reports, and at least twelve other states planned to issue them during 2003.[146] In 2006 a study revealed that thirty states had issued

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137. *Id.*

138. *Id.*

139. Randy Desonia, National Health Policy Forum, *Is Community Care a Civil Right? The Unfolding Saga of the* Olmstead *Decision* 17 (Mar. 12, 2003), http://www.nhpf.org (search "unfolding saga").

140. Rosenbaum & Teitelbaum, *supra* note 133, at 9.

141. Center for Personal Assistance Services, *supra* note 130.

142. *See* Rosenbaum & Teitelbaum, *supra* note 133, at 9.

143. *See* Georgia's Developmental Disabilities Council, *Understanding the Challenges and Options of Transitioning People with Developmental Disabilities from Institutions to Community Living* 1, http://www.gcdd.org/publicpolicy/index.htm (follow "Deinstitutionalization-Challenges and Options").

144. *Id.*

145. *See id.*

146. Wendy Fox-George, Donna Folkemer & Jordan Lewis, *The States' Response to the* Olmstead *Decision: How are States Complying?*, National Conference of State Legislatures,

Olmstead plans, fourteen states had developed alternative responses to *Olmstead*, and eight states have neither an *Olmstead* plan nor an alternative response to the *Olmstead* mandate.[147] Thus, incremental change has altered the landscape since the *Olmstead* decision in important, yet subtle, ways.

VII. BARRIERS TO IMPLEMENTATION

In the eight years since the *Olmstead*[148] mandate, states' responses have fallen short of advocates' expectations. On the five-year anniversary of *Olmstead*, the director of the Bazelon Center for Mental Health Law criticized that "'[m]ost states are enacting . . . reforms at a snail's pace, defying the spirit of the ruling and preventing Americans with mental illnesses from participating in their communities.'"[149] The director stated that "'[r]hetoric has far outstripped action to promote community services for people with mental illnesses. States are quick to trumpet their limited efforts to implement Olmstead, but these have produced little actual movement of people . . . into integrated community settings.'"[150] Furthermore, advocates contend that any real progress that has occurred is largely because states have been sued.[151] Advocates opine it is "'past time for Olmstead implementation to move out of the courtroom and into America's communities.'"[152]

A major problem is that numerous barriers exist in implementing aggressive *Olmstead* plans, including: financial constraints on Medicaid and state budget cuts; lack of affordable and accessible housing; labor shortage and disincentive of home care workers; inertia; and political pressure of institutional care facilities.[153] Thus, the overhaul and transition to community-based services is undoubtedly a considerable undertaking. Nevertheless, these barriers and challenges will continue to inhibit the transition to community care if the states fail to embrace the opportunity *Olmstead* provided for positive change.

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http://www.ncsl.org/programs/health/forum/olmsreport.htm. (follow "Findings").

147. Center for Personal Assistance Services, *supra* note 130.

148. 527 U.S. 581 (1999).

149. Bazelon Center for Mental Health Law, *Legal Advocate Cites Ongoing Segregation on Eve of Olmstead Anniversary* (June 2004), http://www.bazelon.org/newsroom/archive/2004/6-21-04olmstead.htm.

150. *Id.*

151. *Id.*

152. *Id.*

153. *See* Center for Personal Assistance Services, *supra* note 130.

A. *Shortage of Qualified Community-Care Workers*

The quality of care individuals with disabilities receive is closely related to crucial aspects of job enrichment for the workers providing the care.[154] Often, the front-line workers earn low wages and receive few benefits. These inadequacies and disincentives result in high rates of turnover, job dissatisfaction, and difficulty with recruiting qualified workers in community-based programs.[155] These issues directly affect the deinstitutionalization effort and the continuity of care for those being served. Private providers of services are better able to adjust wages to attract employees. Public providers who are funded by public dollars are not as readily able to address the issue.[156] Public providers of direct support services for people with disabilities are paid by the state according to fixed reimbursement rates that may lag behind current wage conditions in other sectors.[157]

Furthermore, benefits are also less than adequate in the direct support profession. Nationally, one in four of these direct care workers do not have health insurance, which is fifty percent higher than in the general population under age sixty-five.[158] Consequently, despite the necessity of their work, direct support workers do not receive adequate salaries to support their families and receive fewer benefits than other comparable professions. This creates a transition barrier to community-based care because as institutions close, former residents need competent, well-trained support staff to serve them in the community.[159] Unfortunately, states currently provide little incentive for anyone to work in this vital capacity. Therefore, there is an overall shortage of qualified and experienced staff.

B. *Financial Barriers*

It is well known and acknowledged that serving individuals in the community is more cost-effective than serving the same individuals in an institution.[160] Paradoxically, financing is one of the biggest barriers to implementation of *Olmstead* plans. Funding for state initiatives is meager largely due to on going state budget woes.[161] In addition, the

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154. Georgia's Developmental Disabilities Council, *supra* note 143, at 2.
155. *Id.*
156. *See id.*
157. *Id.*
158. *Id.* at 3.
159. *Id.*
160. *Id.* at 3-4.
161. Mathis, *supra* note 5, at 562.

financial arrangements that govern Medicaid payments remain institutionally biased. Until 1981 Medicaid provided assistance for long-term care only if the individual lived in an institution.[162] In 1981 Congress attempted to change the "institutional bias" of Medicaid by creating the Home and Community Based Services ("HCBS") Waiver Program[163] for the treatment of individuals with disabilities in the community.[164] This "waiver" allows the state to utilize a portion of its Medicaid funds, which would have been for institutional use, to provide community-based services instead.[165]

In order to obtain waivers, states apply for a limited number of waiver slots and guarantee that the cost of the community-based services will not exceed that of institutional care. The waiver program is optional and up to the state's discretion as to the number of individuals with disabilities that will receive home- and community-based services.[166] There is currently a wide disparity among the states with respect to the amount of funds used for community-based services and programming. In addition, some states, including Georgia, have not used all of the waiver slots for which they applied. Those states that provide only limited community-based services have long lists of individuals waiting to receive services in the community.[167] Nationally, Medicaid program growth shows that institutions are still the primary vehicle for delivering long-term care.[168] Consequently, the HCBS Waiver Program has not succeeded in eradicating the institutional bias of the Medicaid system.

Moreover, when individuals with developmental disabilities move from an institution into the community, federal law allows them to take with them the dollars used for their care in the institution. Thus, the "money follows the person" through the transition.[169] In contrast, individuals who have been institutionalized for mental health reasons cannot bring the funds with them when an institution closes. Additionally, state budget procedures often do not sustain the concept of ensuring that the money follows the person into the community.[170]

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162. Karger, *supra* note 7, at 1229.

163. Social Security Act tit. XIX, § 1915(c), 42 U.S.C. § 1396 (2000).

164. Karger, *supra* note 7, at 1229.

165. *Id.*

166. *See id.* at 1229-30.

167. *Id.* at 1230.

168. Cynthia Shirk, National Health Policy Forum, Rebalancing Long-Term Care: The Role of Medicaid HCBS Waiver Program 11 (Mar. 3, 2006), http://www.nhpf.org (search "rebalancing long-term care").

169. Georgia's Developmental Disabilities Council, *supra* note 143, at 4.

170. Shirk, *supra* note 168, at 18.

A closer look at Georgia's current situation further illustrates this institutional bias. Georgia ranks lowest in the nation for the number of persons with disabilities living in small community residential settings per 100,000 in the population.[171] In Georgia, the state pays approximately forty percent of the waiver population costs directly from its budget. Then Georgia reports the number of individuals living in institutions to the federal government, which assists the state by giving it sixty percent of the costs of caring for them. However, the cost of institutional care, unlike that of community-based services, is not required to be a line-item budget expense. Rather, the funding of institutional care can be amortized, which amounts to a much more politically suitable financial arrangement.[172] As a result, the government's bias in favor of institutions is perpetuated.

Transitioning from institutional to home- and community-based care in Georgia presents two main financial challenges. First, Georgia must allocate funds to pay the forty percent state match of waiver costs for those individuals living in the community, while the state is not held accountable for its percentage of institutional costs.[173] Second, when an institution closes, the patients with mental illness or mental disabilities must be wholly supported by the state. This transition period requires Georgia to simultaneously finance both systems. While this transitional phase is costly, the long-term total cost to support and serve individuals with disabilities in community-based settings is less expensive. Rather than view these temporary transitional costs as an extra burden on the state's budget, lawmakers and citizens should consider the expense from a long-term perspective. Currently, Georgia still channels large amounts of money into costly institutions. Thus, despite the cost-effectiveness of community care and the demonstrated improved quality of life, the system of payment remains institutionally biased.[174] "This bias serves as a powerful disincentive to a successful transition."[175]

1. Inertia and Societal Attitude Barriers. Numerous barriers and challenges exist to slow implemention of the *Olmstead* mandate. While financial constraints and financial disincentives seem to be the biggest obstacle for most states, there is also an inevitable inertia to change, particularly a change of the magnitude *Olmstead* mandates.

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171. Georgia's Developmental Disabilities Council, *supra* note 143, at 2.
172. *Id.* at 4.
173. *Id.*
174. *Id.*
175. *Id.*

However, as more individuals with disabilities become productive members of society and societal attitudes as a whole change, hopefully so too will the speed with which *Olmstead* initiatives are put into action.

What catalysts are necessary to inspire and awaken our nation's conscience? Perhaps public awareness is the critical missing link. Disability advocates, lobbyists, and legislators must better educate the public to the fullest extent possible. A call to action from our nation's citizens will be the impetus for increased state action. As citizens become more informed of the lower costs of community care and the long-term benefits to individuals with disabilities, there will be a public outcry for change. The average American citizen is perhaps unaware of the Supreme Court's ruling that affirmatively obligated states to place individuals with disabilities in the least restrictive environment. More importantly, most citizens are ignorant of the fact that implementation of the mandate will save state funds while also benefiting society as a whole. It is important that all stakeholders, including families, advocates, educators, and the public at large, gain a broader understanding of the potential impact of *Olmstead* and the benefits that can be realized by everyone in the process of deinstitutionalization and community integration.

Clearly, there are some individuals with more challenging mental and physical needs, including multiple medical complications, who would require an intense support system to be able to live in the community. These individuals may not be capable enough to completely function in mainstream society. However, there is a greater number of individuals living in institutions or other large group settings today who could prosper, thrive, and even contribute as productive members of society with minimal support. More importantly, there are individuals who can learn and further develop their untapped potential or atrophied skills to the point of thriving in the community with minimal personal support. These citizens are the intended beneficiaries of the *Olmstead* integration mandate, and these are the citizens who need the opportunity to enjoy life in the least restrictive environment.

VIII. FEDERAL GOVERNMENT'S EFFORTS TO DELIVER ON THE *OLMSTEAD* PROMISE

In response to *Olmstead*,[176] the Bush Administration launched the New Freedom Initiative, a multiagency comprehensive plan aimed at ensuring that all Americans have the opportunity to participate fully in

176. 527 U.S. 581 (1999).

community life.[177] As part of the New Freedom Initiative, on June 18, 2001, President George W. Bush issued Executive Order 13217, "Community-Based Alternatives for Individuals with Disabilities."[178] The Order reads in part:

> [I]t is hereby ordered as follows: . . . The Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.[179]

The Order further directs six federal agencies, including the Departments of Justice, Health and Human Services, Education, Labor, Housing and Urban Development, and the Social Security Administration to "evaluate the policies, programs, statutes, and regulations . . . to determine whether any should be revised . . . to improve the availability of community-based services for qualified individuals with disabilities."[180]

The United States Department of Health and Human Services discusses the Order on the New Freedom Initiative section of its website and refers to the President's Order as "Delivering on the Promise."[181] The Order could be a milestone in the implementation of the ADA's[182] integration mandate because it recognizes the federal government has a role to play in promoting community living, and represents the first time federal agencies have been directed to act in concert to ensure compliance with Title II of the ADA.[183]

The Order is also considered remarkable because it emphasizes public input, and a federal-state partnership to achieve community living for individuals with disabilities, a "groundbreaking" achievement.[184] Thus, the Executive Order is significant because of what it requires federal agencies to accomplish and because it affirms the *Olmstead* mandate. However, the Order will be inconsequential unless the states take their own aggressive action toward community integration.

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177. Rosenbaum & Teitelbaum, *supra* note 133, at 17.

178. Exec. Order No. 13,217, 66 Fed. Reg. 33,155 (June 18, 2001).

179. *Id.* at 33, 156.

180. *Id.*

181. U.S. Department of Health & Human Services, *New Freedom Initiative Delivering on the Promise: Preliminary Report*, http://www.hhs.gov/newfreedom/prelim/intro.html.

182. 42 U.S.C. §§ 12101-12213 (2000).

183. U.S. Department of Health & Human Services, *supra* note 181.

184. *Id.*

The Executive Order further directed the Attorney General and Secretary of the Department of Health and Human services to "fully enforce Title II of the ADA" by investigating and resolving individual complaints of alleged discrimination and to work cooperatively with states to resolve these complaints whenever possible.[185] The public input combined with the agencies' self-evaluation process revealed the need for a variety of advancements to fully comply with *Olmstead*.[186] Some of these advancements include: greater federal oversight of programs that serve individuals with disabilities; stronger enforcement of laws that protect the rights of these individuals; more effective technical assistance to aid states in appropriately serving individuals in the most integrated setting appropriate to their needs; greater and more effective outreach to assist individuals with disabilities and their families in understanding the ADA and *Olmstead*'s requirements.[187]

Congress has also taken steps to provide funding for state integration initiatives. In addition to HCBS Waiver Programs, recent federal legislation has attempted to eliminate the institutional bias in funding for community-based services. In 2000 Congress created Real Choice Systems Change Grants for Community Life to help build the infrastructure and service options necessary for long-term community integration.[188] The Center for Medicare and Medicaid Services has awarded $240 million in Real Choice grants to states.[189] Beginning in January 2007, a Money Follows the Person demonstration project[190] will provide grants to seventeen approved states. The law appropriates $1.8 billion over a five-year period for states to provide community services to individuals who currently receive Medicaid in an institution.[191] The federal government will pay the total costs of the community services for one year.[192]

In sum, the federal government's commitment to the New Freedom Initiative was welcomed. However, it has also been criticized for not moving quickly or aggressively enough toward implementation of the *Olmstead* mandate. Specifically, the federal government's actions have been criticized for lack of an overall national policy framework for community integration and failure to adequately stimulate change in the

185. Exec. Order No. 13, 217, 66 Fed. Reg. at 33, 156.

186. U.S. Department of Health & Human Services, *New Freedom Initiative Delivering on the Promise: Preliminary Report*, http://www.hhs.gov/newfreedom/prelim/comply.html.

187. *Id.*

188. Rosenbaum & Teitelbaum, *supra* note 133, at 17.

189. Shirk, *supra* note 168, at 7.

190. Deficit Reduction Act of 2005, Pub. L. No. 109-171 § 6071, 120 Stat. 4, 102 (2006).

191. Shirk, *supra* note 168, at 21.

192. Georgia's Developmental Disabilities Council, *supra* note 143, at 7.

long-term care system.[193] Conversely, the federal government did not design these measures to create large-scale development of community-based services and movement of institutional residents into integrated settings.[194] Rather, these efforts were merely designed to assist states in getting their planning efforts off the ground.[195] These federal initiatives are vital and necessary steps; but, ultimately, a deep commitment by the state is required to make community living a reality for all citizens with disabilities. The limitations of state and federal *Olmstead* implementation efforts have created a landscape in which litigation has proven to be the most effective means of achieving meaningful reform and progress for many people with disabilities.[196]

The federal government has provided a substantive response to the problem by attempting to restructure Medicaid so that money truly does follow the person into the community as well as other federal grant initiatives. The federal government has also given instructions to the states regarding methods and procedures to implement the *Olmstead* integration mandate. Yet, the states' response has been consistently modest. In order for these initiatives to be effective, states must have the will to utilize the resources offered by the federal government. States must also make significant commitments to actively pursue full community integration for their citizens with disabilities.

IX. A CALL TO GENUINELY AWAKEN THE NATION'S CONSCIENCE

The arena of disability law reform and recognition of rights for persons with disabilities has strengthened significantly over the past seventeen years. In 1990 the ADA[197] accelerated and enhanced the earlier efforts of the Rehab Act.[198] Then in 1999 the Supreme Court's landmark *Olmstead* decision provided a call to state programs nationwide to develop a system that promotes integration of people with disabilities into the social mainstream with equal opportunities and independence to make their own choices.[199] The *Olmstead* decision further enhanced the power of the ADA and further defined states' obligations under the ADA.[200] A great deal remains unknown about the scope and timeline of *Olmstead* implementation, but it is evident that the decision has had

193. Center for Personal Assistance Services, *supra* note 130.
194. Mathis, *supra* note 5, at 562.
195. *Id.*
196. *Id.*
197. 42 U.S.C. § 12101-12213 (2000).
198. 29 U.S.C. Ch.16 (2000).
199. *See* 527 U.S. 581, 607 (1999).
200. *See id.*

an impact on policymakers' understanding of the ADA and its strengthened protection for individuals with disabilities.

As the ten-year anniversary of the *Olmstead* decision rapidly approaches, many question whether adequate efforts have been made to implement the Supreme Court's mandate, and progress remains unacceptably slow. No one, not even disability advocates, contended that the transition would be easy or inexpensive. However, community integration has been mandated for persons with disabilities and is the change that will vastly improve their quality of life. In addition, care in community-based settings has proven to be a more cost-effective long-term alternative to institutional care. The transition from institutionalization to community-based care is a process that requires a dedicated, collaborative effort on the part of all stakeholders including states, legislatures, institutions, providers, consumers, and families.

The *Olmstead* decision proposes a national vision of community life for virtually everyone with few exceptions, regardless of disability. The states are now obligated to achieve this result. It is time for our nation to take action and move from a focus on intense regulations towards ensuring basic human rights for all citizens, truly fulfilling the *Olmstead* promise. Individuals need to be removed from segregated institutions and large congregate living settings and placed into community-based housing to enjoy a life similar to that which is enjoyed by most Americans.

The deinstitutionalization movement has already proven that individuals with disabilities can live successfully in the community with varying degrees of support. Personal Assistance Services can be individually designed to provide that support. Across the country, there is a network of community providers, both public and private, that offer a continuum of care including supported housing, respite, and supported employment. These community-based providers must have adequate and stable funding to ensure necessary treatment offered by the highest credentialed staff.

Legislation to ensure that the money truly does follow the person into the community will enable the availability of necessary funding for individualized services. Once adequately funded, these services can focus on recovery and resiliency that will prepare the individual with disabilities to enjoy a more meaningful and productive life. Part of fulfilling the *Olmstead* mandate is advocating for quality, state-of-the-art disability services so that individuals can access affordable treatment by qualified clinicians despite their location.

Moreover, individuals with disabilities need to be active participants in their care and treatment decisions as well as active members of the interdisciplinary teams that plan and design their services. Person-

centered planning and personalized services should be the hallmark of care. Today, person-centered teams meet to identify opportunities for the individual with disabilities to develop personal relationships, participate in their communities, increase control over their own lives, and develop the skills needed to achieve these goals. Planning in isolation, without involving the person with disabilities and other key stakeholders, will not produce the most advantageous results. Gaining input from everyone involved will create a symbiotic result, optimizing all the community has to offer the individual and all the individual with disabilities has to offer the community. Successful integration into the community is the *Olmstead* goal that has yet to be fully realized.

Particularly in the field of mental health, the emerging view is that individuals should only be hospitalized for short periods during acute phases of their illness. Many community programs now offer Crisis Stabilization Programs as the first option and an alternative to more costly hospitalization in a psychiatric hospital. The Crisis Stabilization Program can also be used as an interim placement after a necessary hospitalization to reintegrate the individual back into the community. These programs and integration efforts work to further dispel the myths and stigmas surrounding mental and physical disabilities. Dispelling stigmas is crucial because it is often such stigmas and myths that are destructive to individual lives.

Many advances have been made in the medical and rehabilitation fields that also make integration easier today. New generation medications and psychosocial rehabilitation interventions are typically used in combinations that allow most mental disorders to be treated effectively without prolonged hospitalization. Great strides have been made in medical interventions as well as in treatment modalities. Now mental illnesses, like physical illnesses, are responding to these new treatments with much promise. These advancements allow community integration to be achieved more easily than ever before. *Olmstead* should serve as a continuous catalyst for change as behavioral health-care is transformed in America.

When individuals with disabilities are valued by society and are met with compassionate, caring, and competent service providers who treat them as collaborative partners, they become empowered individuals with increased self-esteem. As respected and empowered individuals, they can develop their abilities and skills to become fulfilled and productive members of society. This dream became a reality for Ms. Curtis and Ms. Wilson, but with the ten-year anniversary of the *Olmstead* decision approaching, too much time has passed with too little real progress achieved for the nation's largest minority. It was a hard-fought battle but worth every effort because the decision obligated states to make this

dream a reality for all citizens like Ms. Curtis and Ms. Wilson. Aggressive action must be taken and stable funding must be provided to ensure that every state can rapidly deliver on the *Olmstead* promise.

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