

"DON'T TREAD ON THE ADA":[†] OLMSTEAD V. L.C. EX REL. ZIMRING AND THE FUTURE OF COMMUNITY INTEGRATION FOR INDIVIDUALS WITH MENTAL DISABILITIES

Persons [with mental disabilities who are institutionalized] . . . suffer not only a dramatic loss of physical freedom with . . . severely detailed control and invasive treatment, they also cannot enjoy those mundane, daily pleasures—working, shopping, enjoying the companionship of family and friends, or simply being left alone—the loss of which we on the outside would find to be not only intolerable but a threat to our very sanity.¹

INTRODUCTION

Congress passed the Americans with Disabilities Act of 1990 ("ADA") with the clear intention of eliminating the unnecessary segregation and isolation of individuals with disabilities in institutions.² Although progress has been made, after nine years, the goal of integrating persons with disabilities³ into the community has yet to be realized.⁴ Many states currently have long waiting lists of individuals

[†] TASH, "Don't Tread On The ADA": *Integration not segregation!* (visited Feb. 16, 1999) <<http://www.tash.org/action/alerts/olmstead.html>>.

¹ Wyatt v. King, 773 F. Supp. 1508, 1512 (M.D. Ala. 1991).

² See 42 U.S.C. § 12101(a)(2) (1994) ("historically, 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"); 42 U.S.C. § 12101(a)(5) ("individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities"); 42 U.S.C. § 12101(b)(1) ("[i]t is the purpose of this chapter to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities").

³ The ADA applies to all persons with disabilities, while the Supreme Court's ruling in *Olmstead* referred specifically to individuals with mental disabilities. Compare 42 U.S.C. § 12101(a)(1)–(b)(4), with 119 S. Ct. 2176, 2181, 2185, 2190 (1999). Consequently, although this Note focuses on individuals with mental disabilities, it uses the more general terms "individuals with disabilities" or "persons with disabilities" when the context requires reference to both those with mental and those with physical disabilities.

⁴ See, e.g., Sharon Davis, *People in State Institutions Waiting for Community Placement*, in THE ARC: A STATUS REPORT TO THE NATION ON PEOPLE WITH MENTAL RETARDATION WAITING FOR COMMUNITY SERVICES app. (1997), reprinted at The ARC, *Waiting Stats* (visited Mar. 20, 1999) <<http://thearc.org/report/WaitPage.html>> [hereinafter Davis, *The ARC: A Status Report*]; see

with disabilities for whom qualified professionals have recommended community placement, but who remain confined to institutions, where they lose their independence, sense of competence and feelings of self-worth and dignity.⁵ In contrast, life at home or in a community-based group setting provides the opportunity for autonomy, privacy and freedom to associate with and form meaningful relationships with whomever one chooses.⁶

The controversy regarding the integration of individuals with disabilities into the community centers on the language of the ADA and the implementing regulations of the Department of Justice.⁷ Title II of the ADA states 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."⁸ The Department of Justice regulations that implement this anti-discrimination clause mandate that "[a] public entity shall administer services, programs, and activities *in the most integrated setting appropriate* to the needs of qualified individuals with disabilities."⁹ The "most integrated setting appropriate" for such individuals is often the home or the community as opposed to an institution.¹⁰ At the same time, the Department of Justice regulations further state that "[a] public entity shall make *reasonable modifications* in policies, practices, or procedures . . . *unless* the public entity can demonstrate that making the modifications would *fundamentally alter* the nature of the service, program, or activity."¹¹

The issue entered a new phase when, on June 22, 1999, in *Olmstead v. L.C. ex rel. Zimring* ("Olmstead"), the United States Supreme Court held that the unjustified segregation of individuals with mental

also Amici Curiae Brief of ADAPT, National Council on Independent Living, and TASH in support of Respondents at **10-11, *Olmstead v. L.C. ex rel. Zimring*, 119 S. Ct. 2176 (1999) (No. 98-536) [hereinafter Brief of ADAPT].

⁵ See, e.g., Brief for Amici Curiae American Association on Mental Retardation in Support of Respondents at *15, *Olmstead* (No. 98-536) [hereinafter Brief for Am. Assoc. on Mental Retardation]; Dana M. Bessette, Note, *Reinterpreting the ADA: Finding a Freedom from Unnecessary Segregation*, 24 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 131, 171 (1998).

⁶ See, e.g., Brief for Am. Assoc. on Mental Retardation, *supra* note 5, at **14-15.

⁷ See 42 U.S.C. § 12132 (1994); 28 C.F.R. §§ 35.130(b)(7), (d) (1998).

⁸ 42 U.S.C. § 12132.

⁹ 28 C.F.R. § 35.130(d) (emphasis added).

¹⁰ See Ira A. Burnim, The ADA's "Integration Mandate" Should Promote Community Services, Opening Remarks Before the United States Commission on Civil Rights (Nov. 13, 1988), available at The Bazelon Center for Mental Health Law, *Ira Burnim Testimony of the U.S. Commission on Civil Rights* (visited Feb. 16, 1999) <<http://www.bazelon.org/ibtest.html>>.

¹¹ 28 C.F.R. § 35.130(b)(7) (emphasis added).

disabilities¹² in institutions constitutes discrimination under the ADA.¹³ The Court also held that the ADA requires states to provide community placement given the satisfaction of the following conditions: (1) the state's treatment professionals determine that such placement is appropriate; (2) the "affected individual" does not oppose the placement; and (3) the state can reasonably accommodate the placement without fundamentally altering its program, given the state's available resources and the needs of other individuals with mental disabilities.¹⁴

The Supreme Court's decision in *Olmstead* has far-reaching implications for the right of persons with mental disabilities to receive treatment in the most integrated setting appropriate.¹⁵ Although the Court's ruling referred to individuals with mental disabilities, the ruling will have an impact on those with physical disabilities as well.¹⁶ This Note argues that it is highly significant that in the first part of its ruling, the Court made the powerful statement that the unjustified segregation of individuals with mental disabilities in institutions constitutes discrimination under the ADA.¹⁷ At the same time, however, it is disappointing that in the second part of its ruling, the Court conditioned the right of individuals with mental disabilities to live in the most integrated setting appropriate on a broader interpretation of the reasonable-modifications regulation.¹⁸ This Note urges future lower courts to follow the principle set by the Supreme Court in the first part of its ruling and to hold states to a stringent standard when evaluating a fundamental alteration defense.¹⁹ Finally, this Note also recommends that Congress should take the initiative and enact new legislation that

¹² It is important to note that the Supreme Court in its opinion in *Olmstead* used the term "individuals with mental disabilities" and did not distinguish between those with developmental disabilities and those with mental illness. See 119 S. Ct. at 2181, 2185, 2190. Because the Court did not differentiate between these two groups, this Note generally does not make such a distinction, unless specifically indicated. A full discussion of the differences between these two groups of individuals as well as the varying implications of the Court's decision for the two groups is beyond the scope of this Note.

¹³ See *id.* at 2185.

¹⁴ See *id.* at 2181, 2190.

¹⁵ See *id.* at 2181, 2185, 2190. Expressing the emotional intensity of this case, one disability rights group asked: "Will *Olmstead* be our *Brown v. Board of Education* . . . [o]r, will *Olmstead* be our *Dred Scott*?" See ADAPT, *Bulletin and Upcoming Events* (visited Feb. 16, 1999) <<http://www.adapt.org/bulletin.htm>>.

¹⁶ See *Olmstead*, 119 S. Ct. at 2181, 2185, 2190.

¹⁷ See *id.* at 2185; see also *infra* notes 258-71 and accompanying text.

¹⁸ See *Olmstead*, 119 S. Ct. at 2188-90; see also *infra* notes 319-88 and accompanying text.

¹⁹ See *Olmstead*, 119 S. Ct. at 2181, 2185, 2190; see also *infra* notes 389-93 and accompanying text.

would create a mechanism to encourage and ultimately enable states to provide services in the most integrated setting appropriate.²⁰

Part I of this Note discusses the history of the institutionalization of individuals with mental disabilities in the United States, including the gradual recognition of the importance of community integration.²¹ Part II provides a brief explanation of the Medicaid system, the mechanism by which states fund home and community-based care for their citizens with disabilities.²² Part II also explores recent attempts to transform Medicaid into a more community-based system.²³ Part III details early legislative efforts to combat discrimination against individuals with disabilities that set the stage for the ADA.²⁴ Part IV examines relevant portions of the ADA and case law regarding the issue of community integration in the years leading up to *Olmstead*.²⁵ Part V discusses the recent decision of the Supreme Court in *Olmstead*.²⁶ Part VI analyzes the opinion of the Court and provides suggestions for the future.²⁷

I. HISTORY OF THE SEGREGATION OF INDIVIDUALS WITH MENTAL DISABILITIES IN INSTITUTIONS AND THE EVOLUTION OF COMMUNITY INTEGRATION

The segregation of individuals with mental disabilities in institutions apart from the rest of society has been a critical facet of the lives of such individuals in the United States for more than a hundred years.²⁸ In 1848, Massachusetts established the first public facility for persons with mental retardation, the present-day Fernald State School in Waltham.²⁹ This facility, like other early institutions for individuals with mental disabilities resembled a school, providing short-term training for young people to enable them to return to the community.³⁰

²⁰ See *infra* notes 400–26 and accompanying text.

²¹ See *infra* notes 28–59 and accompanying text.

²² See *infra* notes 60–82 and accompanying text.

²³ See *infra* notes 83–99 and accompanying text.

²⁴ See *infra* notes 100–52 and accompanying text.

²⁵ See *infra* notes 153–229 and accompanying text.

²⁶ See *infra* notes 230–57 and accompanying text.

²⁷ See *infra* notes 258–426 and accompanying text.

²⁸ See *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 461–62 (1985) (Marshall, J., dissenting).

²⁹ See Samuel Gridley Howe, *Tenth Anniversary Report of the Massachusetts School for Idiotic and Feeble-Minded Youth* 11 (1857) (on file with the Samuel Gridley Howe Library, Fernald State School, Massachusetts).

³⁰ See *id.*

In the 1880s, however, the institutions began to change from this early model of a school to that of an asylum providing long-term custodial care.³¹ Several factors led to this development, including the admission of younger individuals with severe disabilities and the admission of older persons.³² Moreover, during these years, medical and academic professionals promoted the view that individuals with mental disabilities were likely to engage in criminal activities and sexually immoral behavior and were therefore a menace to society.³³ Because of the perceived danger these individuals posed, the professionals further argued that they should be locked up and segregated from the rest of the community.³⁴ Institutionalization thus came to be viewed as an effective solution, providing individuals with mental disabilities the paternalistic protection they needed and, at the same time, safeguarding the community at large.³⁵

Toward the end of the Nineteenth and beginning of the Twentieth Century, the United States experienced a rapid economic and social transformation from a predominantly rural to an increasingly urban and industrialized society.³⁶ Nationalist sentiment grew, and with it grew xenophobia caused by the large number of immigrants who had settled in this country.³⁷ Paralleling this fear was a distrust of anyone viewed as different, including individuals with mental disabilities.³⁸ The superintendents of the large institutions and state legislatures used harsh rhetoric to describe these individuals.³⁹ For example, in 1918, the Georgia State Legislature created a "Commission on the Feeble-Minded" to help "relieve the State of the menace of the uncared-for feeble-minded who are such a fertile source of crime, poverty, prostitution and misery"⁴⁰ Furthermore, the pseudo-scientific and popular eugenics movement, which advocated principles of selective

³¹ See R.C. SCHEERENBERGER, *A HISTORY OF MENTAL RETARDATION* 123 (1983).

³² See *id.* at 124-25.

³³ See Walter E. Fernald, *The Imbecile with Criminal Instincts*, Paper Presented at the Annual Meeting of the American Medico-Psychological Association, Cincinnati, Ohio (1908), reprinted in JAMES W. TRENT, *INVENTING THE FEEBLE MIND: A HISTORY OF MENTAL RETARDATION IN THE UNITED STATES* 160-61 (1994).

³⁴ See Martin W. Barr, *The Imperative Call of Our Present to Our Future*, 7 *PSYCHO-ASTHENICS* 5-8 (1902), reprinted in TRENT, *supra* note 33, at 142-43.

³⁵ See TRENT, *supra* note 33, at 189.

³⁶ See SCHEERENBERGER, *supra* note 31, at 137-38.

³⁷ See Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 *TEMP. L. REV.* 393, 400 (1991).

³⁸ See *id.*

³⁹ See, e.g., Brief for Respondents at *2, *Olmstead v. L.C. ex rel. Zimring*, 119 S.Ct. 2176 (1999) (No. 98-536).

⁴⁰ *Id.* (citation omitted).

breeding to purify the human species, called for the sterilization and segregation of individuals with mental disabilities to prevent them from passing on their "defective" genes to future generations.⁴¹ Although the influence of the eugenics movement slowly declined in the years following World War I, sterilization continued as a practice at institutions for many years.⁴² From 1937 to 1970, for example, Georgia allowed superintendents of institutions to recommend sterilization for residents who were "likely . . . to procreate a child."⁴³

In the late 1960s and early 1970s, disability rights advocates, who gained momentum from the civil rights movement, became an increasingly vocal group.⁴⁴ One of the major goals of these disability rights advocates was to help individuals leave the institutions in which they had long been confined.⁴⁵ Additionally, sociological studies exposed the abuse and neglect occurring in institutions and thereby contributed to the impetus for change.⁴⁶ "Deinstitutionalization"—the discharge of individuals from institutions and their subsequent care in the community—thus began as a positive response to the many years

⁴¹ See SCHEERENBERGER, *supra* note 31, at 152–56, 158; TRENT, *supra* note 33, at 213 ("[T]he modern eugenics movement which is principally led by sociologists and psychologists, many of whom have little or no insight into the pathological conditions underlying many of these defects, teaches that all, or nearly all mental defect is to be attributed to heredity or to faulty parentage . . .") (quoting Charles Bernstein, 1917); see also RANDOM HOUSE WEBSTER'S COLLEGE DICTIONARY 453 (2d ed. 1999) (defining eugenics as "a science concerned with improving a species . . . by such means as influencing or encouraging reproduction by persons presumed to have desirable genetic traits").

⁴² See TRENT, *supra* note 33, at 190.

⁴³ Brief for Respondents at *2, *Olmstead* (No-98-536) (citation omitted).

⁴⁴ See Robert L. Burgdorf, Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 427 (1991). Also in the 1970s, individuals with mental retardation began to speak out for themselves and to play an important role in organizing self-advocacy conferences. See Gunnar Dybwad, *Setting the Stage Historically*, in NEW VOICES: SELF-ADVOCACY BY PEOPLE WITH DISABILITIES 5–9 (Gunnar Dybwad & Hank Bersani, Jr., eds., 1996) [hereinafter NEW VOICES]. These groups slowly gathered support over the next two decades. *Id.* at 9. In the 1990s, self-advocacy groups have become a widely-accepted and strong voice. See Michael Wehmeyer & Richard Berkoben, *The Legacy of Self Advocacy: People with Cognitive Disabilities as Leaders in their Community*, in NEW VOICES 246. One of the major goals of self-advocates is full and active participation in all aspects of community life. See The ARC, *Self-Advocacy* (visited Apr. 4, 1999) <<http://thearc.org/posits/selfadv.html>>.

⁴⁵ See John W. Parry, *Mental and Physical Disability Rights: The Formative Years and Future Prospects*, 20 MENTAL & PHYSICAL DISABILITY L. REP. 627, 627 (1996). During this time some disability rights advocates began to promote the philosophy of independent living, which rejected "the authoritarian medical model" in favor of "a paradigm of individual empowerment and responsibility for defining and meeting one's own needs." See Gina McDonald & Mike Oxford, *History of Independent Living* (visited Jul. 6, 1999) <<http://www.acils.com/acil/ilhistory.html>>.

⁴⁶ See Nancy K. Rhoden, *The Limits of Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory*, 31 EMORY L.J. 375, 380–81 (1982).

of segregation and isolation in institutions.⁴⁷ In recent years, however, deinstitutionalization has developed a negative connotation, referring to the release of large numbers of vulnerable individuals into the streets without adequate planning and support programming.⁴⁸ One commentator has noted that "deinstitutionalization has become a convenient scapegoat for our society's current neglect of the less fortunate and most vulnerable, whether they reside in large institutions, boarding homes, or on the streets."⁴⁹ In response to this negative public perception, disability advocates are urging the integration of individuals with disabilities into the community through the provision of appropriate services and support programs.⁵⁰

Additionally, over the past two decades, many studies have documented the benefits associated with community integration.⁵¹ For example, individuals residing at home or in the community attain a greater degree of independence as well as dignity and self-worth.⁵² Similarly, such individuals can actively participate in and make decisions that affect their lives.⁵³ Moreover, they feel a part of the community and develop meaningful relationships with individuals who do not have disabilities, including both family members and friends.⁵⁴ Persons with disabilities living at home or in the community also engage in simple activities that characterize the everyday lives of others living in mainstream society, such as attending movies, participating in religious activities, eating in restaurants and attending sporting events.⁵⁵

Research has demonstrated other advantages to community integration as well. For example, persons with disabilities who live at home or in the community are more likely to develop greater competence and better adaptive skills than individuals who live in institutional settings.⁵⁶ Integrated educational programs enable individuals with disabilities to acquire a more advanced level of skills and to obtain post-

⁴⁷ See Parry, *supra* note 45, at 627.

⁴⁸ See *id.*; see also Rhoden, *supra* note 46, at 375 ("Deinstitutionalization, once hailed as an ideal social reform, is now decried as a near disaster.").

⁴⁹ Parry, *supra* note 45, at 627.

⁵⁰ See, e.g., *Community-Based Care for the Disabled: Hearing on H.R. 2020 Before the Subcomm. on Health and the Environment*, 105th Cong. (1998) (statement of Michael Auberger, on behalf of American Disabled for Attendant Programs Today (ADAPT)) [hereinafter Auberger Statement]; Bessette, *supra* note 5, at 143.

⁵¹ See, e.g., Brief for Am. Assoc. on Mental Retardation, *supra* note 5, at **14-15; Cook, *supra* note 37, at 455.

⁵² See Brief for Am. Assoc. on Mental Retardation, *supra* note 5, at *14.

⁵³ See Cook, *supra* note 37, at 455.

⁵⁴ See Brief for Am. Assoc. on Mental Retardation, *supra* note 5, at *14.

⁵⁵ See *id.*

⁵⁶ See *id.* at **14-15.

education work in integrated settings, where they receive higher wages.⁵⁷ Finally, the integration of individuals with disabilities reduces stereotyping and enhances the perspective of individuals who do not have disabilities.⁵⁸ Long-term contact between persons with disabilities and those without disabilities improves tolerance for diversity on the part of siblings, parents and educators, as well as other members of the general population.⁵⁹

II. FUNDING OF SERVICES FOR INDIVIDUALS WITH MENTAL DISABILITIES THROUGH THE MEDICAID SYSTEM

A. *Brief Description of Medicaid*

While community integration has clearly documented benefits, individuals with disabilities remain confined and isolated in institutions largely due to financial concerns of the states.⁶⁰ The issue of cost, consequently, is intricately entwined with the issue of community integration.⁶¹ In 1965, with the passage of Title XIX of the Social Security Act, Congress established Medicaid, a system of matching federal and state funds, to provide "medical assistance on behalf of families with dependent children and of the aged, blind, or disabled individuals whose income and resources are insufficient to meet the costs of necessary medical services."⁶² Although a state's participation in the Medicaid system is optional, if a state chooses to participate it must comply with all federal requirements.⁶³ For example, one of the federal requirements is that "[medical] assistance . . . be furnished with reasonable promptness to all eligible individuals."⁶⁴ States are able to determine the various parameters of their own programs, including eligibility requirements, amount of payments to facilities and administrative procedures.⁶⁵

⁵⁷ See Cook, *supra* note 37, at 454.

⁵⁸ See *id.* at 448-49.

⁵⁹ See *id.*

⁶⁰ See Lucille D. Wood, *Costs and the Right to Community-Based Treatment*, 16 YALE L. & POL'Y REV. 501, 501 (1998).

⁶¹ See *id.*

⁶² See 42 U.S.C. § 1396(1) (1994 & Supp. II 1996); see also RASHI FEIN, MEDICAL CARE, MEDICAL COSTS: THE SEARCH FOR A HEALTH INSURANCE POLICY 108-13 (1986); HCFA, *Medicaid: A Brief Summary* (visited Nov. 12, 1998) <<http://www.hcfa.gov/medicare/ormedicaid.htm#Medicaid>>.

⁶³ See *Himes v. Shalala*, 999 F.2d 684, 686 (2d Cir. 1993); *Hunter v. Chiles*, 944 F. Supp. 914, 918-19 (S.D. Fla. 1996) (quoting *Harris v. McRae*, 448 U.S. 297, 301 (1980)).

⁶⁴ 42 U.S.C. § 1396a(a)(8).

⁶⁵ See 42 U.S.C. § 1396a.

Although states have a certain degree of latitude in determining eligibility, they must include specific groups of individuals—for example, individuals with disabilities who receive Supplemental Security Income (“SSI”) from the federal government.⁶⁶ In addition to the mandatory groups, states can provide coverage for other individuals as well.⁶⁷ The optional groups include: (1) institutionalized individuals eligible according to a specific income level set by the state; (2) individuals who would be eligible if institutionalized, but who are receiving care under home and community-based service waivers; (3) elderly adults or adults with disabilities who have incomes above those requiring mandatory coverage but below the Federal Poverty Level (“FPL”); and (4) working individuals and persons with disabilities who have family income less than 250% of FPL who would qualify for SSI if they did not work.⁶⁸

Before 1981, Medicaid provided assistance for long-term care only if the individual resided in an institution.⁶⁹ That year, Congress attempted to change the “institutional bias” of Medicaid by passing § 1915(c) of Title XIX of the Social Security Act, which created the Home and Community Based Services (“HCBS”) Waiver Program for the treatment of individuals with mental retardation in the community.⁷⁰ In 1986, Congress also extended the waiver program to provide community-based services for individuals with chronic mental illness.⁷¹ The term “waiver” derives from the fact that the Secretary of the Department of Health and Human Services (“HHS”) can choose to waive certain requirements of Title XIX.⁷² The state is then able to utilize a portion of its Medicaid funds, which otherwise would have been designated for institutional use, to provide home or community-based services.⁷³ To obtain waivers, a state applies for a certain number of waiver slots and guarantees that the cost of the home or commu-

⁶⁶ See 42 U.S.C. § 1396a(a)(10)(A)(i)(II).

⁶⁷ See 42 U.S.C. § 1396a(a)(10)(A)(ii)(I)–(XIV).

⁶⁸ See 42 U.S.C. § 1396a(a)(10)(A)(ii)(IV), (VI), (X), (XIII).

⁶⁹ See Sally K. Richardson, Dir., *Foreword* to HEALTH CARE FINANCING ADMINISTRATION, MEDICAID BUREAU, APPROACHES TO QUALITY UNDER HOME AND COMMUNITY-BASED SERVICES WAIVERS, at iii (1993).

⁷⁰ See *id.*

⁷¹ See Pub. L. No. 99-509, § 9411, 100 Stat. 1874, 2061–62 (1986). Medicaid does not cover institutional care for individuals with mental illness except those over 65 or under 21. See 42 U.S.C. § 1396d(a)(xi)(14), (16), (27)(B).

⁷² See 42 U.S.C. § 1396n(c)(1)–(10); see also Brief For Respondents at *3 n.1, *Ohnstead v. L.C. ex rel. Zimring*, 119 S. Ct. 2176 (1999) (No. 98-536); MASS. DMR, THE HCBS: YOUR GUIDE TO THE HOME & COMMUNITY BASED SERVICES WAIVER 2 (1997).

⁷³ See 42 U.S.C. § 1396n(c)(1); 42 C.F.R. § 441.300 (1998).

nity-based services will not exceed that of institutional care.⁷⁴ The state must also inform all eligible individuals of the possible alternatives and provide these individuals with the opportunity to make a choice.⁷⁵

Under the HCBS Waiver Program, states have the flexibility to select the particular services that are most appropriate for their target population.⁷⁶ The waiver program allows states to choose from the following services: "case management services, homemaker/home health aid services and personal care services, adult day health services, habilitation services, [and] respite care."⁷⁷ Because the waiver program is optional and dependent on the discretion of each state, there is currently a wide disparity among the states with respect to the amount of funds used for home and community-based programming.⁷⁸ Moreover, some states do not utilize all the waiver slots for which they have applied.⁷⁹ For example, of the 2,106 waivers allotted to Georgia by the Secretary of HHS in 1996, the State only used 700.⁸⁰ Consequently, states such as Georgia that provide limited home and community-based services have long lists of individuals waiting to receive services in the community.⁸¹ Thus, the HCBS Waiver Program has not succeeded in eradicating the institutional bias of the Medicaid system.⁸²

B. Recent Congressional Efforts to Reform the Institutional Bias of Medicaid

As a result of the failure of the waiver program to provide a sufficient number of community placements, disability advocates have recently looked to Congress to enact additional legislation that would encourage states to provide more home and community-based services.⁸³ In 1997, the 105th Congress saw the introduction of a bill in the Senate and another in the House of Representatives to help change

⁷⁴ See 42 U.S.C. § 1396n(c)(2)(D); 42 C.F.R. § 441.302(e).

⁷⁵ See 42 U.S.C. § 1396n(c)(2)(C); 42 C.F.R. § 441.302(d).

⁷⁶ See 42 U.S.C. § 1396n(c)(4)(B); 42 C.F.R. § 440.180.

⁷⁷ See 42 U.S.C. § 1396n(c)(4)(B).

⁷⁸ See, e.g., Scott S. Greenberger, *Groups fight state for Medicaid home care: Advocates for disabled say Texas violates federal law by paying only for care in nursing homes*, THE AUSTIN AMERICAN-STATESMAN (Sept. 11, 1998), reprinted at The Austin American-Statesman (visited Sept. 12, 1998) <<http://www.austin360.com/news/002state/09sept/11/11ada.htm>>.

⁷⁹ See, e.g., Brief for the United States as Amicus Curiae Supporting Respondents at **20-21, *Olmstead* (No. 98-536) [hereinafter Brief for the United States].

⁸⁰ See *id.* at *21.

⁸¹ See Davis, *The ARC: A Status Report*, *supra* note 4.

⁸² See, e.g., Auberger Statement, *supra* note 50.

⁸³ See Long-Term Care and Deficit Reduction Act of 1997, S. 879, 105th Cong. (1997); Medicaid Community Attendant Services Act of 1997, H.R. 2020, 105th Cong. (1997).

the institutional bias of Medicaid and increase the proportion of individuals receiving home and community-based services.⁸⁴ Senator Feingold (D-Wis.) introduced Senate Bill 879 ("S. 879") on June 11, 1997, known as the "Long-Term Care Reform and Deficit Reduction Act of 1997."⁸⁵ Former House Speaker Newt Gingrich (R-Ga.) introduced House Bill 2020 ("H.R. 2020"), known as the "Medicaid Community Attendant Services Act of 1997" ("MiCASA"), on June 24, 1997, as an amendment to Title XIX of the Social Security Act.⁸⁶

Although the two bills differed in certain respects, each provided for some form of financial assistance to the states to help them make the transition to increased home and community-based services.⁸⁷ MiCASA, actively promoted by American Disabled for Attendant Programs Today ("ADAPT"), a national grassroots disability rights organization, had over seventy co-sponsors, many more than S. 879, and also received considerably more publicity.⁸⁸ For example, Christopher Reeve gave his support to MiCASA, stating, "I think the home environment is much more psychologically conducive to health than a nursing home environment so I would certainly support [H.R. 2020]."⁸⁹ At the end of the 105th Congress, S. 879 remained stalled in the Senate Finance Committee, and H.R. 2020 similarly had not moved out of the House Subcommittee on Health and the Environment of the House Commerce Committee.⁹⁰

Because these earlier bills met with only limited success, members of ADAPT are currently urging support for the "Medicaid Community Attendant Services and Supports Act of 1999" ("MiCASSA"), which is still in the early stages of development.⁹¹ The drafters of this prospec-

⁸⁴ See S. 879; H.R. 2020.

⁸⁵ See S. 879.

⁸⁶ See H.R. 2020.

⁸⁷ See S. 879, tit. I, §§ 108-109; H.R. 2020 § 2(b)(1)(B).

⁸⁸ See, e.g., Liberty Resources, *Medicaid Community Attendant Services Act: There's no place like home!* (visited Oct. 18, 1998) <<http://www.libertyresources.org/mc/ca-index.html>> (providing summary of and background for MiCASA, noting "ADAPT are the foot soldiers of the MiCASA Movement").

⁸⁹ See Liberty Resources, *Christopher Reeve Connects with Disabled on Radio: Supports Key "MiCASA" Legislation: Improving Disabled Image in Movies* (visited Oct. 18, 1998) <<http://on-airoradio.com/CRelease.html>>.

⁹⁰ See THOMAS, Legislative Information on the Internet, *Bill Summary & Status for the 105th Congress: S. 879* (visited July 3, 1999) <<http://thomas.loc.gov/cgi-bin/bdquery/z?d105:SN00879:@@C>>; THOMAS, Legislative Information on the Internet, *Bill Summary & Status for the 105th Congress: H.R. 2020* (visited July 3, 1999) <<http://thomas.loc.gov/cgi-bin/bdquery/z?d105:HR02020:@@C>>.

⁹¹ See Memorandum from ADAPT to MiCASSA Supporters, at i (Feb. 1, 1999) (providing text of prospective MiCASSA bill) (on file with author) [hereinafter MiCASSA].

tive bill changed the name to MiCASSA in order to add the word "Supports," signifying the inclusion of cognitive assistance.⁹² MiCASSA describes in greater detail the kinds of services states should provide and adds a section on findings and purposes.⁹³ For example, the prospective bill states in its findings that "[t]here is a growing recognition that disability is a natural part of the human experience that in no way diminishes a person's right to: live independently; enjoy self-determination; make choices; contribute to society; and enjoy full inclusion and integration in the mainstream of American society."⁹⁴ The major purpose of MiCASSA is to provide federal funding to encourage states to make systemic changes in their provision of services to individuals with disabilities.⁹⁵ Under MiCASSA, states can utilize the federal financial assistance in a variety of ways—for example, to conduct a needs assessment of individuals with disabilities within their state, implement strategies to change the institutional bias of their services, help with institutional overhead costs or provide training for professionals or para-professionals.⁹⁶ MiCASSA also aims to enable individuals with disabilities to make an informed choice with respect to high-quality services in the most integrated setting appropriate.⁹⁷ Furthermore, the prospective bill encourages the development of quality-assurance state plans and suggests methods to monitor state compliance with such plans.⁹⁸ Members of ADAPT are currently promoting MiCASSA and are hoping to obtain a sponsor in the 106th Congress.⁹⁹

III. LEGISLATION PRIOR TO THE ADA

The role that disability advocates would like Congress to play at the present time in passing MiCASSA parallels congressional efforts that began twenty-five years ago to combat discrimination against individuals with disabilities.¹⁰⁰ This early civil rights legislation includes the Rehabilitation Act of 1973 and the Developmental Disabled Assistance and Bill of Rights Act of 1975 ("DDA Act").¹⁰¹ These statutes helped to inspire the overall vision of the ADA as well as its specific provisions

⁹² See *id.*

⁹³ See *id.* § 2 (a), (b).

⁹⁴ *Id.* § 2(a)(3).

⁹⁵ See *id.* § 2(b)(2).

⁹⁶ See MiCASSA, *supra* note 91, at § 4(c)(1)–(11).

⁹⁷ See *id.* § 2(a)(5), (c)(1).

⁹⁸ See *id.* § 3(b)(1)(B).

⁹⁹ See *id.* at i.

¹⁰⁰ See Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (1994).

¹⁰¹ See *id.*; 42 U.S.C. §§ 6000–6083 (1994, Supp. II 1996 & Supp. III 1997).

with respect to community integration.¹⁰² In order to understand fully the impact of the ADA on the issue of community integration, it is first necessary to examine this prior legislation.¹⁰³

A. Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 ("§ 504") was the first federal statute to deal with discrimination against individuals with disabilities and is often referred to as "the civil rights bill of the disabled."¹⁰⁴ The purpose of § 504 was to rectify "the country's 'shameful oversights,' which caused the handicapped to live among society 'shunted aside, hidden, and ignored.'"¹⁰⁵ The relevant portion of § 504 reads, "[n]o otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance"¹⁰⁶ The coordinating regulations of the Department of Justice state that entities that receive federal funding must "administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons."¹⁰⁷ Congress later incorporated these anti-discrimination principles into Title II of the ADA.¹⁰⁸

Although § 504 was an attempt to combat discrimination against individuals with disabilities, it fell short of its ultimate goal for several reasons, including limited applicability and choice of language.¹⁰⁹ Section 504 focuses only on discriminatory actions taken by federally-funded programs and excludes programs managed by private employers or state and local activities that do not receive federal assistance.¹¹⁰ In addition to its limited applicability, § 504 has problematic language, centering on the use of the words "otherwise" and "solely."¹¹¹ Section 504 uses the language "[n]o *otherwise* qualified handicapped individ-

¹⁰² See Burgdorf, *supra* note 44, at 414.

¹⁰³ See *infra* notes 153-225 and accompanying text for a discussion of the role of the ADA in relation to the issue of community integration.

¹⁰⁴ See *ADAPT v. Skinner*, 881 F.2d 1184, 1187 (3d Cir. 1989).

¹⁰⁵ See *Alexander v. Choate*, 469 U.S. 287, 296 (1985) (quoting Representative Vanik, who originally introduced § 504 as an amendment to Title VI, 117 CONG. REC. 45974 (1971)).

¹⁰⁶ 29 U.S.C. § 794(a).

¹⁰⁷ 28 C.F.R. § 41.51(d) (1998).

¹⁰⁸ See *Easley v. Snider*, 36 F.3d 297, 300-01 (3d Cir. 1994).

¹⁰⁹ See John J. Coleman III & Marcel L. Debruge, *A Practitioner's Introduction to ADA Title II*, 45 ALA. L. REV. 55, 57 (1993); Burgdorf, *supra* note 44, at 430-31.

¹¹⁰ See Coleman & Debruge, *supra* note 109, at 57.

¹¹¹ See Burgdorf, *supra* note 44, at 522 n.93.

ual."¹¹² Consequently, plaintiffs attempting to bring claims under § 504 have the difficult burden of establishing the prima facie element that they are "otherwise qualified."¹¹³ The phrase "solely by reason of . . . disability" is likewise problematic, implying that only discrimination motivated solely by an individual's disability is actionable.¹¹⁴ Such an interpretation leaves open the question of discrimination based on other motivations.¹¹⁵

The coordinating regulations of § 504 include a provision that has ultimately provided a loophole, allowing defendants in discrimination cases to offer an affirmative defense for practices that appear to violate the statute.¹¹⁶ The "undue hardship regulation" states that "[a] recipient shall make reasonable accommodation to the known physical or mental limitations of an otherwise qualified handicapped applicant or employee unless the recipient can demonstrate that the accommodation would impose an undue hardship on the operation of its program."¹¹⁷ Although there is no bright-line test to determine what constitutes an undue hardship, the regulations list several guiding factors: "(1) The overall size of the recipient's program . . . ; (2) [t]he type of the recipient's operation, including the composition and structure of the recipient's workforce; and (3) [t]he nature and cost of the accommodation needed."¹¹⁸ The undue hardship regulation allows defendants to claim that compliance with the plaintiff's demands would be too expensive and would place an excessive cost burden on the plaintiff.¹¹⁹

The United States Supreme Court twice attempted to define the scope of § 504.¹²⁰ First, in 1979, in *Southeastern Community College v. Davis*, the Court held that § 504 does not compel educational institutions to take affirmative action to make significant modifications in

¹¹² See Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794(a) (emphasis added).

¹¹³ See Burgdorf, *supra* note 44, at 522 n.93. Burgdorf further explains, "[a]rguably, the notion of otherwise qualified should be subsumed in the question of discrimination on the basis of disability: if an individual is denied an opportunity because of a failure to meet qualifications standards, then that individual is not being disadvantaged on the basis of disability, but rather because of a failure to meet applicable job standards." *Id.* at 442. An added problem is that the term "otherwise" is somewhat offensive and demeaning toward an individual with a disability, characterizing the disability as a negative attribute. See *id.*

¹¹⁴ See 29 U.S.C. § 794(a) (emphasis added); Burgdorf, *supra* note 44, at 522 n.93.

¹¹⁵ See *id.*

¹¹⁶ See Wood, *supra* note 60, at 505.

¹¹⁷ 28 C.F.R. § 41.53 (emphasis added).

¹¹⁸ See 28 C.F.R. § 42.51(c); 45 C.F.R. § 84.12(c) (same).

¹¹⁹ See Wood, *supra* note 60, at 505.

¹²⁰ See *Choate*, 469 U.S. at 309; *Southeastern Community College v. Davis*, 442 U.S. 397, 414 (1979).

their programs to accommodate individuals with disabilities when such modifications would create a fundamental alteration in the nature of the program.¹²¹ In *Davis*, a woman who suffered from a severe hearing disability brought a claim against Southeastern Community College, a state institution that received federal funding, alleging, *inter alia*, that the college's denial of her admission to the nursing program violated § 504.¹²² The Court stated that in certain circumstances it may be unreasonable and discriminatory for a program to refuse to take affirmative action and make modifications to meet the needs of "qualified handicapped persons."¹²³ The Court defined an "otherwise qualified person" as one who could meet the requirements of the program in spite of the individual's disability.¹²⁴ The Court explained, however, that in this case it seemed unlikely that the plaintiff could participate in and benefit from the program even with substantial modifications.¹²⁵ Therefore, the Court held that Southeastern Community College did not violate § 504 because the statute does not compel entities to take affirmative action to make substantial modifications that would fundamentally alter the nature of the program.¹²⁶ The Court further held that such substantial modifications "would constitute an unauthorized extension of the obligations imposed by [§ 504]."¹²⁷ Following *Davis*, several federal court decisions applied the narrow holding of the case to the provision of home and community-based services and held that § 504 did not create a statutory right to receive treatment in the community.¹²⁸

The Supreme Court continued the analysis begun in *Davis* concerning the scope of § 504 in its 1985 decision in *Alexander v. Choate*.¹²⁹ In *Choate*, the Court held that disparate-impact discrimination does not necessarily constitute a *prima facie* case of discrimination under § 504.¹³⁰ Medicaid recipients brought a class-action claim against the State of Tennessee for reducing from 20 to 14 the number of inpatient hospital days for which the State would pay each year under Medi-

¹²¹ See 442 U.S. at 411, 414.

¹²² See *id.* at 400-02.

¹²³ See *id.* at 412-13.

¹²⁴ *Id.* at 406.

¹²⁵ See *id.* at 409.

¹²⁶ See *Davis*, 442 U.S. at 411.

¹²⁷ See *id.* at 410.

¹²⁸ See, e.g., *Kentucky Ass'n for Retarded Citizens, Inc. v. Connecticut*, 674 F.2d 582, 585 (6th Cir. 1982); *Sabo v. O'Bannon*, 586 F. Supp. 1132, 1137 (E.D. Pa. 1984); *Garrity v. Gallen*, 522 F. Supp. 171, 213 (D.N.H. 1981).

¹²⁹ See 469 U.S. at 299.

¹³⁰ See *id.* at 309.

caid.¹³¹ The plaintiffs alleged that such a reduction violated § 504 because it would have a disproportionate effect on individuals with disabilities and was therefore discriminatory.¹³² The Court disagreed, holding that not all instances of disparate impact constitute discrimination under § 504.¹³³ Following the line of reasoning in *Davis*, the Court further stated that the reduction in the number of inpatient days did not deny the plaintiffs "meaningful access to the benefit" of receiving Medicaid services.¹³⁴ The Court stated that modifications to a program may be necessary when weighing the rights of individuals with disabilities to be integrated into society against the interests of the state to maintain the integrity of its program.¹³⁵ The Court reasoned that the "administrative costs of [plaintiffs'] requests" would be well beyond the accommodations that are required under *Davis*.¹³⁶ Therefore, the Court held that in this instance, disparate impact discrimination did not violate § 504.¹³⁷

B. *The Developmental Disabled Assistance and Bill of Rights Act of 1975*

Following the passage of the Rehabilitation Act of 1973 but prior to the passage of the ADA, Congress enacted the Developmental Disabled Assistance and Bill of Rights Act in 1975, which established a system of federal-state grants.¹³⁸ Under the DDA Act, the federal government gives money to states to help them create programs for the care and treatment of individuals with developmental disabilities.¹³⁹ Although states utilizing federal funding to run their programs must meet minimum standards, participation is voluntary.¹⁴⁰ 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."¹⁴¹ The phrase

¹³¹ See *id.* at 289.

¹³² See *id.* at 290. The United States District Court for the Middle District of Tennessee dismissed the complaint, holding that the reduction in the number of inpatient days was not the type of discrimination that § 504 prohibited. See *id.* at 292 n.6. The United States Court of Appeals for the Sixth Circuit disagreed, holding that the plaintiffs had established a *prima facie* case of discrimination under § 504 because the reduction would disproportionately affect individuals with disabilities. See *id.* at 291-92.

¹³³ See *id.* at 309.

¹³⁴ See *Choate*, 469 U.S. at 301-02.

¹³⁵ See *id.* at 300.

¹³⁶ See *id.* at 308.

¹³⁷ See *id.* at 309.

¹³⁸ See 42 U.S.C. §§ 6000-6083.

¹³⁹ See *id.* § 6000(b)(1).

¹⁴⁰ See *id.* § 6000(c).

¹⁴¹ See *id.* § 6009(2).

"least restrictive" has played a major role in disability litigation during the past twenty-five years.¹⁴²

The United States Supreme Court addressed the issue of the right to treatment in the least restrictive environment under the DDA Act in *Pennhurst State School & Hospital v. Halderman*.¹⁴³ In *Pennhurst*, a 1981 decision, the Court held that under the "Bill of Rights" provision of the DDA Act, individuals with disabilities do not have a substantive right to receive treatment in the least restrictive environment.¹⁴⁴ In *Pennhurst*, an individual with mental retardation who was a resident at the Pennhurst State School and Hospital ("Pennhurst") brought a claim on behalf of herself and the other residents at Pennhurst, alleging that the unsanitary, inhumane and dangerous conditions at the institution violated the residents' rights under the DDA Act.¹⁴⁵ The plaintiff argued that the Court should require the Commonwealth of Pennsylvania to close Pennhurst and create alternative community-based living arrangements.¹⁴⁶ The Court stated 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 . . ."¹⁴⁷ The Court reasoned that an analysis of the "Bill of Rights" provision in the context of other specific provisions of the DDA Act reveals that it merely represents a preference on the part of Congress for community-based treatment and does not require states to provide such treatment.¹⁴⁸ The Court further observed that there is nothing in the "Bill of Rights" provision to suggest that a particular kind of treatment is a condition for receiving federal funding under the DDA Act, and that the funding sections of the DDA Act are separate from the "Bill of Rights" provision and merely encourage states to participate.¹⁴⁹ Therefore, the Court held that in spite of the language of the statute, individuals with disabilities do not have a substantive right under the DDA Act to receive community-based treatment.¹⁵⁰ Additionally, the Court held that the DDA Act does not compel the Commonwealth of Pennsylvania to close Pennhurst and create alternative community

¹⁴² See Parry, *supra* note 45, at 628.

¹⁴³ See 451 U.S. 1, 18 (1981).

¹⁴⁴ See *id.* at 18-19.

¹⁴⁵ See *id.* at 6.

¹⁴⁶ See *id.*

¹⁴⁷ *Id.* at 18 (quoting *Philbrook v. Glodgett*, 421 U.S. 707, 713 (1975)).

¹⁴⁸ See *Pennhurst*, 451 U.S. at 19.

¹⁴⁹ See *id.* at 23-24.

¹⁵⁰ See *id.* at 18.

placements.¹⁵¹ *Pennhurst* has subsequently become the seminal case used by states in their arguments against deinstitutionalization.¹⁵²

IV. THE ADA AND CASE LAW LEADING UP TO *OLMSTEAD*

In response to the limitations of earlier legislation such as § 504 of the Rehabilitation Act of 1973 and the DDA Act of 1975, Congress enacted the ADA in 1990 with the clear objective of ending discrimination for individuals with disabilities.¹⁵³ One commentator has stated, "The ADA constitutes a second-generation civil rights statute that goes beyond the 'naked framework' of earlier statutes and adds much flesh and refinement to traditional nondiscrimination law."¹⁵⁴ The ADA passed by a large majority in both houses and with bipartisan support.¹⁵⁵ When enacting the ADA, Congress noted that "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[.]"¹⁵⁶ Similarly, upon signing the ADA into law, President Bush made the following statement: "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."¹⁵⁷ At the time, Congress estimated that there were approximately 43,000,000 Americans with mental or physical disabilities.¹⁵⁸

The legislative history of the ADA reveals considerable discussion about the importance of integrating individuals with disabilities into the community.¹⁵⁹ For example, the House Report stated that "[t]he ADA is a comprehensive piece of civil rights legislation which promises a new future: a future of *inclusion* and *integration*, and the end of exclusion and segregation."¹⁶⁰ Similarly, the House Report compared the institutional segregation of individuals with disabilities to the segregation that African-Americans experienced, stating that "segregation

¹⁵¹ See *id.*

¹⁵² See Bessette, *supra* note 5, at 143.

¹⁵³ See Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(b)(1) (1994).

¹⁵⁴ Burgdorf, *supra* note 44, at 415.

¹⁵⁵ See *id.* at 433-34 (noting that the House passed the ADA bill on July 12, 1990 by a vote of 377 to 28 and the Senate passed the bill on July 13, 1990 by a vote of 91 to 6).

¹⁵⁶ 42 U.S.C. § 12101(a)(8).

¹⁵⁷ President George Bush, Pub. L. No. 101-336, Americans with Disabilities Act of 1990, reprinted in 1990 U.S.C.C.A.N. 601 (statement upon signing S. 933) (1990).

¹⁵⁸ See 42 U.S.C. § 12101(a)(1).

¹⁵⁹ See, e.g., H.R. REP. NO. 101-485(III) at 26 (1990), reprinted in 1990 U.S.C.C.A.N. 267, 448-49.

¹⁶⁰ *Id.*, reprinted in 1990 U.S.C.C.A.N. 267, 449 (emphasis added).

for persons with disabilities 'may affect their hearts and minds in a way unlikely ever to be undone.'"¹⁶¹

Section 12132 of Title II of the ADA, the relevant portion of the legislation to this Note, states 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."¹⁶² The ADA omits the word "otherwise" preceding the phrase "qualified individual with a disability," which proved problematic in § 504 because it required plaintiffs to establish the *prima facie* element that they were "otherwise qualified."¹⁶³ Moreover, the ADA, in contrast to § 504, also excludes the term "solely" preceding the phrase "by reason of such disability."¹⁶⁴ The word "solely" implied that only discrimination motivated by an individual's disability was actionable and left open the question of discrimination based on other motivations.¹⁶⁵ With the omission of these two words, the language of the ADA is broader and less limiting than that of § 504.¹⁶⁶

The ADA specifies that the Department of Justice has the authority to establish implementing regulations with regard to public entities.¹⁶⁷ The ADA further indicates that these regulations must be consistent with the coordinating regulations of § 504.¹⁶⁸ The implementing regulations of the Department of Justice for the ADA state that "a public entity shall administer services, programs, and activities *in the most integrated setting appropriate* to the needs of qualified individuals with disabilities."¹⁶⁹ This provision parallels the similar provision in the coordinating regulations of § 504.¹⁷⁰ The interpretation of the phrase "in the most integrated setting appropriate" is at the center of the current debate concerning the provision of home and community-based services.¹⁷¹

In addition to the words "in the most integrated setting appropriate," the phrases "reasonable modifications" and "fundamentally alter"

¹⁶¹ *Id.*, reprinted in 1990 U.S.C.C.A.N. 267, 448-49 (quoting *Brown v. Board of Educ.*, 347 U.S. 483, 494 (1954)).

¹⁶² See 42 U.S.C. § 12132.

¹⁶³ See Burgdorf, *supra* note 44, at 522 n.93.

¹⁶⁴ See *id.*

¹⁶⁵ See *id.*

¹⁶⁶ See *id.* at 442-44.

¹⁶⁷ See 42 U.S.C. § 12134(a).

¹⁶⁸ See 42 U.S.C. § 12134(b).

¹⁶⁹ 28 C.F.R. § 35.130(d) (1998) (emphasis added).

¹⁷⁰ See 28 C.F.R. § 41.51(d).

¹⁷¹ See, e.g., Brief of ADAPT, *supra* note 4, at **14-15.

in the implementing regulations are also significant in relation to the provision of home and community-based services.¹⁷² The relevant provision states: "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, *unless* the public entity can demonstrate that making the modifications would *fundamentally alter* the service, program, or activity."¹⁷³ This provision enables states to offer an affirmative defense for an alleged violation of the statute.¹⁷⁴ At the same time, Title II of the ADA does not mention the concept of "undue hardship" with respect to cost, which was included in § 504.¹⁷⁵ One commentator believes that Congress instructed the Department of Justice to omit the undue hardship provision with respect to cost because Congress felt that the benefits of integration greatly surpassed the hardship that would result from additional costs.¹⁷⁶

The interpretation of the phrases "in the most integrated setting appropriate" and "fundamentally alter" came to the forefront of the debate concerning the provision of home and community-based services in *Helen L. v. DiDario*.¹⁷⁷ In *Helen L.*, a 1995 decision, the United States Court of Appeals for the Third Circuit held that under the ADA individuals are entitled to receive treatment in the most integrated setting appropriate and that a public entity violates the ADA when it requires an individual to receive nursing home care against her wishes when she is qualified to receive home-based care.¹⁷⁸ In *Helen L.*, the plaintiff, a forty-three year-old mother who contracted meningitis, was paralyzed from the waist down and confined to a wheelchair.¹⁷⁹ Consequently, she had difficulty with activities such as bathing and shopping.¹⁸⁰ The Pennsylvania Department of Public Welfare ("DPW") offered two programs for individuals with physical disabilities who needed help with certain daily activities.¹⁸¹ One, funded through Medicaid, provided nursing home care; the other provided home or community-based care through an "attendant care program," as authorized

¹⁷² See, e.g., Amicus Curiae Brief of the States in Support of Petitioners at *8, *Olmstead v. L.C. ex rel. Zimring*, 119 S. Ct. 2176 (1999) (No. 98-536) [hereinafter Brief of the States].

¹⁷³ 28 C.F.R. § 35.130(b)(7) (emphasis added).

¹⁷⁴ See *id.*

¹⁷⁵ See 28 C.F.R. § 41.53.

¹⁷⁶ See Cook, *supra* note 37, at 430-31.

¹⁷⁷ See 46 F.3d 325 (3d Cir. 1995), *cert. denied*, *Pennsylvania Secretary of Public Welfare v. Idell S.*, 516 U.S. 813 (1995).

¹⁷⁸ See *id.* at 333, 337-38.

¹⁷⁹ See *id.* at 328.

¹⁸⁰ See *id.*

¹⁸¹ See *id.*

by a Pennsylvania statute.¹⁸² Professionals evaluated the plaintiff and found her eligible for attendant care services.¹⁸³ The Commonwealth of Pennsylvania, however, placed her on a waiting list to receive attendant care services, requiring her to remain in a nursing home.¹⁸⁴ The plaintiff brought a claim against the Pennsylvania DPW, alleging that the DPW had violated Title II of the ADA by forcing her to live in the segregated setting of a nursing home.¹⁸⁵

The United States District Court for the Eastern District of Pennsylvania granted summary judgment in favor of the DPW, finding that the DPW had not discriminated against her based on her disability but rather due to a lack of funds.¹⁸⁶ The United States Court of Appeals for the Third Circuit, however, reversed, holding that under the ADA individuals are entitled to receive services in the most integrated setting appropriate and that denial of such services by a public entity constitutes a violation of the ADA.¹⁸⁷ The United States Supreme Court declined to grant certiorari.¹⁸⁸

The Third Circuit reasoned that "integration is fundamental to the purposes of the Americans with Disabilities Act" and that the legislative history of the ADA reveals that unjustified segregation is the type of discrimination the drafters intended to eliminate.¹⁸⁹ The court noted that all parties agreed that the most integrated setting appropriate for the plaintiff was her home.¹⁹⁰ The DPW, however, argued that it could not provide treatment in the plaintiff's home without fundamentally altering its mental health system.¹⁹¹ Funding for both the nursing home and attendant care programs had already been set for the fiscal year, and according to Pennsylvania's Constitution, funds from one program could not be transferred to the other.¹⁹² The court responded that the explanation of the DPW concerning the need to shift funds was inadequate.¹⁹³ Moreover, the court stated that the plaintiff was not asking the DPW to make a change in either the requirements for admission to the program or in the substantive nature of the

¹⁸² See *Helen L.*, 46 F.3d at 328-29.

¹⁸³ See *id.* at 329.

¹⁸⁴ See *id.*

¹⁸⁵ See *id.*

¹⁸⁶ See *id.*

¹⁸⁷ See *Helen L.*, 46 F.3d at 329.

¹⁸⁸ See *Pennsylvania Secretary of Pub. Welfare v. Idell S.*, 516 U.S. 813, 813 (1995).

¹⁸⁹ See *Helen L.*, 46 F.3d at 332-33.

¹⁹⁰ See *id.* at 337.

¹⁹¹ See *id.*

¹⁹² See *id.*

¹⁹³ See *id.*

program, both of which would constitute a fundamental alteration.¹⁹⁴ The court concluded that providing attendant care for the plaintiff in her home would not create a fundamental alteration in Pennsylvania's attendant care or nursing home program.¹⁹⁵

The court further stated that the DPW could not justify administering its attendant care program in a discriminatory manner because of a state funding mechanism already in place and then argue that compliance with the ADA would involve a fundamental alteration of its program.¹⁹⁶ The court referred to the legislative history of the ADA, which stated that "[t]he fact that it is more convenient, either administratively or fiscally, to provide services in a segregated manner, does not constitute a valid justification for separate or different services under . . . [Title II of the ADA]."¹⁹⁷ The Third Circuit thus held that the DPW's failure to provide services in the most integrated setting appropriate for the plaintiff constituted a violation of the ADA.¹⁹⁸

Ironically, according to the statement of facts presented in the court's decision, the Commonwealth of Pennsylvania was spending, on average, \$45,000 per year to care for the plaintiff in a nursing home while the cost of appropriate home care would have been only \$10,500.¹⁹⁹ Therefore, by requiring the DPW to provide home care for the plaintiff, the court was not imposing a large expense on the Commonwealth of Pennsylvania.²⁰⁰ One commentator suggested that the Third Circuit in *Helen L.* did not adequately address the issue of cost in relation to the provision of home and community-based services because it only discussed costs with regard to this particular case—that is, the court made a simple comparison between the cost of providing care for one particular individual in her home and the corresponding cost of maintaining the same individual in an institution.²⁰¹ The court therefore failed to provide standards to help guide future courts to determine the impact of cost.²⁰²

Following *Helen L.*, there have been several district court cases concerning the issue of community placement under the ADA.²⁰³ For

¹⁹⁴ See *Helen L.*, 46 F.3d at 337.

¹⁹⁵ See *id.*

¹⁹⁶ See *id.* at 338.

¹⁹⁷ *Id.* (quoting H.R. REP. NO. 101-485(III) at 29, reprinted in 1990 U.S.C.C.A.N. 267, 473).

¹⁹⁸ See *id.* at 333, 339.

¹⁹⁹ See *Helen L.*, 46 F.3d at 338.

²⁰⁰ See *id.*

²⁰¹ See Wood, *supra* note 60, at 501, 513.

²⁰² See *id.* at 501.

²⁰³ See, e.g., Kathleen S. v. Department of Pub. Welfare, 10 F. Supp. 2d 460 (E.D. Pa. 1998);

example, in 1996, in *Williams v. Wasserman*, the United States District Court for the District of Maryland held that while the ADA does not require states to create a new program or fundamentally alter an existing community-based program, the ADA does require states to provide community placement to qualified individuals with disabilities.²⁰⁴ In *Williams*, a group of residents in state institutions brought a claim against the State of Maryland, alleging that Maryland did not follow the determination of the state's professionals, who had recommended that the residents were able to live in the community.²⁰⁵ Maryland argued that placing the plaintiffs in a community setting would necessitate a redesign of its mental health program through the creation of a large number of community placements.²⁰⁶ The plaintiffs claimed that they were not asking for fundamental changes in Maryland's mental health system but rather were requesting "admission to an existing program of treatment on behalf of plaintiffs for whom such treatment is recommended."²⁰⁷ Both sides gave a different assessment of the expected cost.²⁰⁸ The court reasoned that the Third Circuit's holding in *Helen L.* would not require a fundamental alteration in a state's program that involved the transfer of a large amount of funds from institutions to community care.²⁰⁹ The court, however, denied Maryland's motion for summary judgment, rejecting its claim that providing community placement for the plaintiffs would require a "'precipitous' transfer of funds to create 'hundreds' of community treatment slots."²¹⁰

Similarly, in 1998, another district court case relied on the Third Circuit's decision in *Helen L.*²¹¹ In *Kathleen S. v. Department of Public Welfare*, the United States District Court for the Eastern District of Pennsylvania held that the Commonwealth of Pennsylvania's DPW violated the ADA's integration mandate by its failure to provide community-based services to individuals for whom such services were appropriate and by its utilization of discriminatory methods of admini-

Williams v. Wasserman, 937 F. Supp. 524 (D. Md. 1996); *Charles Q. v. Houston*, No. CIV. A. 1:CV-95-280, 1996 WL 447549 (M.D. Pa. Apr. 22, 1996) (mem.).

²⁰⁴ See 937 F. Supp. at 530.

²⁰⁵ See *id.* at 526.

²⁰⁶ See *id.* at 528.

²⁰⁷ *Id.* (emphasis added). See *infra* notes 347-55 and accompanying text for a discussion of the difference between expansion of existing services and creation of new programs.

²⁰⁸ See *Williams*, 937 F. Supp. at 528.

²⁰⁹ See *id.* at 531.

²¹⁰ See *id.* at 528, 531.

²¹¹ See *Kathleen S.*, 10 F. Supp. 2d at 468-89.

stration in planning.²¹² In *Kathleen S.*, 255 residents at Haverford State Hospital ("HSH") brought a claim against the DPW, alleging violation of the ADA as a result of the DPW's failure to provide community placement and to develop a plan that began within a reasonable time period and moved at a reasonable pace.²¹³ The plaintiffs argued that they were not asking the DPW to create new programs but rather to expand the DPW's capacity to provide existing programs to additional individuals.²¹⁴ The plaintiffs also argued that cost was not a factor.²¹⁵ Because the DPW was closing an entire institution and because the cost of providing community placement was less than that of providing institutional care, the Commonwealth of Pennsylvania would actually realize a savings by placing the plaintiffs in community-based settings.²¹⁶ As noted by the Secretary of Public Welfare in her announcement regarding plans to close HSH, the closing of institutions reflected a nationwide trend toward community integration and "[a]n integrated system of community and residential support . . . makes good sense for the consumer, the taxpayer and the entire community."²¹⁷ Prior to this announcement, the DPW had convened a Task Force that issued a report delineating a re-structuring of the mental health system of Pennsylvania with the goal of creating a more integrated system.²¹⁸ The Task Force had recommended the consolidation of HSH and another facility by placing many of the residents in community-based settings.²¹⁹ The DPW, however, did not issue a plan regarding the consolidation until seven months had elapsed.²²⁰

²¹² See *id.* at 476.

²¹³ See *id.* at 462; see also Plaintiffs' Post-Trial Memorandum at 9-10, 32 *Kathleen S.*, 10 F. Supp. 2d at 382-84 [hereinafter *Kathleen S.* Post-Trial Mem.]. See *infra* notes 382-88 and accompanying text for a discussion of state plans moving at a reasonable pace.

²¹⁴ See *Kathleen S.* Post-Trial Mem., *supra* note 213, at 24-26. See *infra* notes 347-55 and accompanying text for a discussion of the difference between expansion of existing services and creation of new programs.

²¹⁵ See *Kathleen S.* Post-Trial Mem., *supra* note 213, at 21-23.

²¹⁶ See *id.* at 23.

²¹⁷ *Kathleen S.*, 10 F. Supp. 2d at 463.

²¹⁸ *Id.* at 463-64.

²¹⁹ See *id.* at 463. The DPW had not recommended community placement for all of the plaintiffs. See *id.* at 465. Under the provisions of its plan for closing HSH, the DPW had agreed to fund an independent assessment for any resident who requested one. See *Kathleen S.* Post-Trial Mem., *supra* note 213, at 33. The plaintiffs alleged that the DPW had not followed through with the provisions of its plan and that it had failed to conduct a comprehensive assessment of all of the residents of HSH. See *id.* at 33, 39. The plaintiffs' independent expert identified several residents, for whom the DPW had not recommended community placement, as capable of living in the community. See *id.* at 11. See also *infra* notes 277-98 and accompanying text for a discussion of assessments made by state and independent professionals.

²²⁰ See *Kathleen S.*, 10 F. Supp. 2d at 465.

The court held that in enacting the ADA, Congress intended to strengthen the mandate instituted in § 504 and its coordinating regulations that individuals with disabilities should be integrated into the community.²²¹ Relying on the Third Circuit's reasoning in *Helen L.*, the district court found that unnecessary segregation constitutes a form of discrimination under the ADA.²²² The court rejected the DPW's argument that the plaintiffs were seeking deinstitutionalization and that the "planning and preparation of community services and facilities" for the plaintiffs would create a fundamental alteration in the mental health program of the Commonwealth of Pennsylvania.²²³ Therefore, the district court held that the DPW's failure to provide community placement for individuals for whom its own professionals had determined that such placement was appropriate violated the integration regulation of the ADA.²²⁴ Similarly, the court held that the DPW used discriminatory methods of administration by failing to plan adequately for the placement of individuals in the community and by failing to provide a reasonable rate of placement.²²⁵

Thus, the Third Circuit's decision in *Helen L.* became the standard on which subsequent courts have relied.²²⁶ The decision of the United States Court of Appeals for the Eleventh Circuit in *Olmstead v. L.C. ex rel. Zimring* similarly relied on *Helen L.*²²⁷ It is interesting that in the case of *Helen L.*, the United States Supreme Court refused to grant certiorari, while in the case of *Olmstead*, the Court agreed to do so.²²⁸ As will be discussed in the next two sections, the Supreme Court's ruling in *Olmstead* represents a departure, in certain respects, from the decision of the Third Circuit in *Helen L.*²²⁹

²²¹ See *id.* at 468.

²²² See *id.*

²²³ See *id.* at 470-71.

²²⁴ See *id.* at 472, 476.

²²⁵ See *Kathleen S.*, 10 F. Supp. 2d at 472, 476.

²²⁶ See *supra* notes 203-25 and accompanying text.

²²⁷ See *L.C. ex rel. Zimring v. Olmstead*, 138 F.3d 893, 899, 901, *aff'd in part, vacated in part*, remanded, 119 S. Ct. 2176 (1999) (No. 98-536).

²²⁸ Compare *Olmstead v. L.C. ex rel. Zimring*, 119 S. Ct. 617, 617 (1998), with *Pennsylvania Secretary of Pub. Welfare v. Idell S.*, 516 U.S. 813, 813 (1995). Perhaps the Supreme Court decided to grant certiorari in *Olmstead* because twenty-two states and the Territory of Guam filed a brief urging the Court to do so. See *Olmstead*, 119 S. Ct. at 2185 n.8.

²²⁹ See *infra* notes 230-426 and accompanying text.

V. *OLMSTEAD V. L.C. EX REL. ZIMRING*:
THE DECISION OF THE SUPREME COURT

In 1999, in *Olmstead v. L.C. ex rel. Zimring*, the United States Supreme Court held that the unjustified segregation of individuals with mental disabilities in institutions constitutes discrimination under the ADA.²³⁰ The Court also 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 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.²³¹

In *Olmstead*, L.C., a woman with mild mental retardation and schizophrenia, brought a claim against the State of Georgia.²³² L.C. alleged that because Georgia's professionals had recommended that her needs could be more appropriately met in a community-based setting, her continued confinement in a state psychiatric hospital constituted a violation of Title II of the ADA, the Title II implementing regulations of the Department of Justice and the Due Process Clause of the Fourteenth Amendment.²³³ E.W., a woman with mild mental retardation and a personality disorder, intervened and stated an identical claim.²³⁴ Georgia argued that it had not provided community placement for L.C. and E.W. because of a lack of funds and that such placement would fundamentally alter its mental health system.²³⁵ Georgia further argued, *inter alia*, that its failure to provide community placement for L.C. and E.W. did not constitute discrimination "by reason of" their disabilities under Title II.²³⁶

²³⁰ See *Olmstead v. L.C. ex rel. Zimring*, 119 S. Ct. 2176, 2185 (1999).

²³¹ See *id.* at 2181, 2190.

²³² See Brief for Respondents at **5-6, *Olmstead* (No. 98-536).

²³³ See *Olmstead*, 138 F.3d at 895.

²³⁴ See *id.* Both L.C. and E.W. are currently living and thriving in the community. See The Bazelon Centre for Mental Health Law, *Who Are L.C. and E.W.?* <<http://www.bazelon.org/lean-dew.html>> (last visited July 6, 1999). L.C. is living in a group home for three persons, receiving assistance but continually acquiring new skills and adjusting to a very different kind of life from that she had known for most of her years in an institution. See *id.* E.W. is living in her own apartment and receiving support services. See *id.* Both traveled to Washington, D.C. to be present during the Oral Arguments of the *Olmstead* case. See *id.*

²³⁵ See *Olmstead*, 119 S. Ct. at 2184.

²³⁶ See *id.*

The United States District Court for the Northern District of Georgia granted partial summary judgment in favor of L.C. and E.W., holding that Georgia's actions violated Title II of the ADA and its implementing regulations.²³⁷ The United States Court of Appeals for the Eleventh Circuit affirmed this decision, but also remanded the case to the district court to determine whether the additional expense to Georgia as a result of the community placement was unreasonable and would fundamentally alter the State's mental health program.²³⁸ On remand, the district court found that the cost of providing placement in the community for the two women would not be excessive in comparison to the State's entire mental health budget.²³⁹

The Supreme Court affirmed the decision of the Eleventh Circuit "in substantial part."²⁴⁰ In a 6-3 decision authored by Justice Ginsburg, the Court held that unjustified segregation constitutes "discrimination based on disability."²⁴¹ The Court rejected the arguments presented by the State of Georgia, and supported by Justice Thomas in his dissent, that L.C. and E.W. did not experience discrimination "by reason of" their disabilities and that the segregation of individuals with disabilities is not actionable discrimination under the ADA because discrimination necessarily requires a comparison class of similarly situated individuals.²⁴² The Court explained, "[w]e are satisfied that Congress had a more comprehensive view of the concept of discrimination advanced in the ADA" and cited three non-disability discrimination cases to support its conclusion.²⁴³ The Court also found that Congress had intended the ADA to extend the scope of previous disability rights

²³⁷ See *Olmstead*, 138 F.3d at 895. The district court did not address the plaintiffs' constitutional claims. See *id.* at 895 n.3.

²³⁸ See *id.* Because the district court did not address the constitutional claims, the Eleventh Circuit also declined to do so. See *id.*

²³⁹ See *Olmstead*, 119 S. Ct. at 2185 n.7.

²⁴⁰ See *id.* at 2181.

²⁴¹ See *id.* at 2185. Justices Stevens and Kennedy issued separate concurring opinions. See *id.* at 2190 (Stevens, J., concurring); *id.* at 2191-94 (Kennedy, J., concurring). Justice Stevens stated that he would have preferred to affirm the opinion of the Eleventh Circuit. See *Olmstead*, 119 S. Ct. at 2190 (Stevens, J., concurring). In his concurring opinion, Justice Kennedy indicated that he saw the need to apply a great deal of deference to the medical recommendations of treating physicians; expressed concern about the repercussions of deinstitutionalization; and concluded that the case should be remanded to the lower courts to determine whether discrimination occurred as a result of dissimilar treatment of those with and those without mental disabilities. See *id.* at 2191-94 (Kennedy J., concurring). Justice Thomas wrote the sole dissenting opinion, objecting to the Court's definition of discrimination and stating that discrimination requires "differential treatment vis-à-vis members of a different group on the basis of a statutorily described characteristic." See *id.* at 2194-99 (Thomas, J., dissenting).

²⁴² See *id.* at 2186.

²⁴³ See *id.* at 2186 & n.10.

legislation, such as § 504 and the DDA Act, and that Congress had explicitly identified unjustified segregation as a form of discrimination in the congressional findings of the ADA.²⁴⁴ Moreover, the Court noted that unnecessary segregation perpetuates the stereotypic assumption that individuals with disabilities are unable to be part of the community and seriously curtails the opportunities available to individuals with disabilities to experience aspects of everyday living such as educational activities and employment and to form relationships with friends and family.²⁴⁵ Thus, the Supreme Court held that the unjustified isolation of individuals with mental disabilities in institutions constitutes discrimination under the ADA.²⁴⁶

At the same time, however, the Court noted that the responsibility of the states to provide community placement is not "boundless."²⁴⁷ Recognizing that states have a need to provide a range of services to a large population of individuals with diverse mental disabilities and an obligation to administer services in an equitable manner, the Court interpreted fundamental alteration as encompassing more than a simple comparison of cost between placement in the community for a particular individual and placement in an institution for that same individual.²⁴⁸ Rather, the Court found that future courts must consider additional factors in light of a state's available resources—namely, overall costs, the range of services a state provides to other individuals with mental disabilities and the responsibility of a state to provide services in an equitable manner.²⁴⁹ The Court reasoned that states need sufficient "leeway" to manage their mental health systems.²⁵⁰ Accordingly, the Court held that a state could meet its burden by showing that "it had a comprehensive, effectively working plan . . . and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated"²⁵¹ The Court also noted that individuals could not receive community placement ahead of others on the waiting list merely by filing a lawsuit.²⁵²

In keeping with its explanation of the fundamental alteration defense, the Supreme Court rejected the interpretation of the Eleventh

²⁴⁴ See *Olmstead*, 119 S. Ct. at 2186–87.

²⁴⁵ See *id.* at 2187.

²⁴⁶ See *id.* at 2185.

²⁴⁷ See *id.* at 2188.

²⁴⁸ See *id.* at 2185.

²⁴⁹ See *Olmstead*, 119 S. Ct. at 2185.

²⁵⁰ See *id.* at 2189.

²⁵¹ *Id.*

²⁵² See *id.* at 2190.

Circuit, stating that the lower court erroneously focused on a simple cost comparison.²⁵³ The Supreme Court found the latter to be unduly restrictive and virtually unworkable for the states.²⁵⁴ Additionally, the Court pointed out that the interpretation of the term "fundamental alteration" used in the implementing regulations of the Department of Justice must be consistent with the Department's regulations for § 504, which included a provision pertaining to "undue hardship."²⁵⁵ The Court noted that the regulations for § 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 size and type of the program.²⁵⁶ Therefore, the Court affirmed the Eleventh Circuit's opinion in part, vacated it in part and remanded the case to the district court for an examination of a variety of factors beyond a simple cost comparison to determine if the community placement represented a fundamental alteration of Georgia's program.²⁵⁷

VI. DISCUSSION OF THE SUPREME COURT'S OPINION AND RECOMMENDATIONS FOR THE FUTURE

A. *Unjustified Segregation Constitutes Discrimination Under the ADA*

The United States Supreme Court's ruling in *Olmstead* represents a critical first step toward achieving the goal of community integration for individuals with disabilities, a goal envisioned by the drafters of the ADA nine years ago.²⁵⁸ For persons with disabilities who are currently living in institutions and waiting to receive placement in the community, the first part of the Supreme Court's ruling in *Olmstead* offers great promise.²⁵⁹ In a powerful statement, the Court declared that the unjustified segregation of individuals with mental disabilities in institutions constitutes discrimination under the ADA.²⁶⁰ Such recognition on the part of the Supreme Court is particularly noteworthy in light of the nation's unfortunate history of segregating individuals with mental disabilities in institutions and echoes the intent of Congress in

²⁵³ See *id.* at 2188-89.

²⁵⁴ See *Olmstead*, 119 S. Ct. at 2188-89.

²⁵⁵ See *id.* at 2190 n.16.

²⁵⁶ See *id.*

²⁵⁷ See *id.* at 2190.

²⁵⁸ See *Olmstead v. L.C. ex rel. Zimring*, 119 S. Ct. 2176, 2185 (1999); Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(a)(2), (a)(5), (b)(1) (1994).

²⁵⁹ See 119 S. Ct. at 2185.

²⁶⁰ See *id.*

enacting the ADA.²⁶¹ Moreover, the Court's ruling accepts the documented benefits of community integration and acknowledges the negative impact of institutionalization—for example, the perpetuation of stereotypic images of individuals with disabilities and the lack of opportunity for those individuals in institutions to engage in ordinary life experiences.²⁶² Ideally, the positive tone of the Court's ruling in *Olmstead* will not only create optimism among individuals with disabilities, but will also impact future decisions of lower courts and serve as a harbinger of change to the states, leading them to emulate the standard set by the Court.²⁶³ In this respect, the Court's ruling in *Olmstead* represents an important beginning of the realization of community integration.²⁶⁴

It is likewise significant that the Court clearly rejected the argument presented by the State of Georgia and supported by Justice Thomas in his dissent that Georgia's failure to provide community placement for L.C. and E.W. did not constitute discrimination by reason of such disability.²⁶⁵ Thomas stated that the Court "has never endorsed an interpretation of the term 'discrimination' that encompassed disparate treatment among members of the same protected class."²⁶⁶ The Court responded decisively that the dissent's view was incorrect on the basis of both "precedent and logic."²⁶⁷ According to the Court, in enacting the ADA, Congress intended a more expansive definition of discrimination.²⁶⁸ Consequently, following the Court's ruling in *Olmstead*, states will no longer be able to argue, as they have in the past, that their failure to provide community placement does not constitute discrimination by reason of such disability.²⁶⁹

²⁶¹ See *supra* notes 28–43, 156–61 and accompanying text.

²⁶² See 119 S. Ct. at 2187; see also *supra* notes 51–59 and accompanying text.

²⁶³ See Bill Rankin, *Ruling Extends Rights of Mentally Disabled: Georgians Win Partial Victory in Picking Home*, ATLANTA J. & ATLANTA CONST., June 23, 1999, at F4 ("The state now knows it can no longer keep people in an institution when they don't need to be there. Period.") (quoting Susan Jamieson, attorney for Atlanta Legal Aid, who represented respondents).

²⁶⁴ See 119 S. Ct. at 2185.

²⁶⁵ See *id.* at 2186. Justice Kennedy pointed out that the Court's statement about the dissimilar treatment of those with mental disabilities and those without mental disabilities suggests a theory under which the respondents may have been able to prove discrimination

based on their mental disabilities. See *id.* at 2192 (Kennedy, J., concurring).

²⁶⁶ *Id.* at 2194 (Thomas, J., dissenting).

²⁶⁷ *Id.* at 2186 n.10.

²⁶⁸ *Id.* at 2186.

²⁶⁹ See, e.g., Brief for Petitioners at **20–21, *Olmstead* (No. 98–536).

Furthermore, the Court's ruling concerning discrimination by reason of such disability may have additional implications in the future. The question of whether actionable discrimination under the ADA may occur among classes of individuals with disabilities or whether it must necessarily occur between individuals with disabilities and those without disabilities has troubled courts for years.²⁷⁰ Therefore, the Court's ruling in *Olmstead* may provide support in future disability rights discrimination cases that do not involve community placement but nonetheless pertain to the issue of discrimination among classes of individuals with disabilities—for example, discrimination based on the differential treatment of persons with severe and mild mental retardation or those with mental and physical disabilities.²⁷¹

B. *The ADA Requires States to Provide Community Placement Upon Fulfillment of Three Conditions*

While the first part of the Court's ruling in *Olmstead* represents an important achievement for individuals with mental disabilities, the second part has very different implications.²⁷² In the latter, the Court held that the ADA does not require states to provide placement in the community in all situations, but rather imposes such an obligation upon the fulfillment of three specified conditions.²⁷³ Although the Court presented the three conditions as a unit, the first two differ from the third in that they pertain to the meaning of the term "appropriate" in the integration regulation, while the third relates to a clarification of the reasonable-modifications regulation.²⁷⁴ Each of these conditions may make it more difficult for an individual to receive community placement in the future.²⁷⁵ It is the third, however, that creates the greatest obstacle to the goal of community integration.²⁷⁶

²⁷⁰ Compare, e.g., *Flight v. Gloeckler*, 68 F.3d 61, 63 (2d Cir. 1995) (finding that failure to make modifications based on severity of disability was not discrimination because the Rehabilitation Act "[d]oes not clearly establish an obligation to meet [a disabled person's] particular needs vis-à-vis the needs of other handicapped individuals, but mandates only that services provided non-handicapped individuals not be denied [to a disabled person] because he is handicapped.") (citing *P.C. v. McLaughlin*, 913 F.2d 1033, 1041 (2d Cir. 1990)), with *Jackson ex rel. Jackson v. Fort Stanton Hosp. & Training Sch.*, 757 F. Supp. 1243, 1299 (D.N.M. 1990), *rev'd in part on other grounds*, 964 F.2d 980 (10th Cir. 1992) (finding that severity of disability is itself a disability under § 504 and that severity of disability cannot be the sole reason for denying access to community programs).

²⁷¹ See, e.g., *Flight*, 68 F.3d at 63; *Jackson*, 757 F. Supp. at 1299.

²⁷² See 119 S. Ct. at 2181, 2185, 2190.

²⁷³ See *id.* at 2181, 2190.

²⁷⁴ See *id.* at 2183, 2188–90.

²⁷⁵ See *infra* notes 277–399 and accompanying text.

²⁷⁶ See *infra* notes 319–88 and accompanying text.

1. Determination by the State's Treatment Professionals

The first condition specified by the Court is that the state's treatment professionals must determine that community placement is appropriate.²⁷⁷ At the oral arguments, there was considerable discussion by the Justices concerning which professionals should be allowed to make a recommendation for community placement.²⁷⁸ The Justices expressed concern that a "battle of the experts" might unfold, with the state's professionals arguing that community placement is not appropriate for a particular individual and a second group of professionals, testifying on behalf of the individual, arguing the opposite.²⁷⁹ In *Kathleen S.*, for example, an independent expert recommended that community placement was appropriate for certain individuals for whom the state's professionals had determined that such placement was inappropriate.²⁸⁰ Therefore, it is likely that the Court specified that the professionals should be those of the state because it wanted to avoid a situation involving contradictory professionals.²⁸¹ Moreover, it is also quite possible that with respect to professional judgment, the Court wanted to give the states sufficient leeway to manage their own programs, as it had done in other parts of its opinion.²⁸²

Unfortunately, however, the Court in *Olmstead* did not address the question of impartiality in a judgment made by the state's professionals.²⁸³ A conflict of interest arises when a state employee—that is, the professional—must make a decision that adversely affects the financial situation of his or her employer—that is, the state.²⁸⁴ There is the possibility that the state's professionals will place the interests of the state above those of the individual for whom they are recommending some form of care.²⁸⁵ According to one commentator, the terms "pro-

²⁷⁷ See 119 S. Ct. at 2181, 2190.

²⁷⁸ See Oral Argument Before the United States Supreme Court, *Olmstead v. L.C. ex rel. Zimring*, 119 S. Ct. 2176 (1999) (No. 98-536) (Apr. 21, 1999) (transcript available in *Olmstead*, No. 98-536, 1999 WL 252681, at **37-43) [hereinafter Oral Arg.].

²⁷⁹ See *id.* at *38.

²⁸⁰ See *Kathleen S.* Post-Trial Mem., *supra* note 213, at 11.

²⁸¹ See 119 S. Ct. at 2181, 2188, 2190.

²⁸² See *id.*; see also *infra* notes 319-93 and accompanying text.

²⁸³ See Susan Stefan, *Leaving Civil Rights to the "Experts": From Deference to Abdication Under the Professional Judgment Standard*, 102 YALE L.J. 639, 655-61 (1992) (arguing that the Supreme Court's paradigm of the neutral mental health professional does not reflect reality).

²⁸⁴ See *id.* at 655.

²⁸⁵ See, e.g., *Jackson ex rel. Jackson v. Fort Stanton Hosp. & Training Sch.*, 964 F.2d 980, 992 (10th Cir. 1992) (holding that professionals must make their recommendations for community placement based on cost considerations); see also Stefan, *supra* note 283, at 655.

professionals" and "professional judgment" automatically connote a false sense of neutrality and objectivity.²⁸⁶ In reality, professionals do not make decisions in a vacuum; personal and ideological biases inherently influence their decisions.²⁸⁷ Therefore, the Court in *Olmstead* should have specified, at a minimum, that the determinations regarding community placement made by the state's professionals cannot be based on criteria such as administrative and cost concerns.²⁸⁸

While the Court explicitly indicated that it is the state's professionals who are to make the recommendations for community placement, the Court was less clear regarding the degree of deference courts in the future should give to the decisions of the state's professionals.²⁸⁹ In reference to reliance on determinations made by the state's professionals, the Court used the rather vague expression that "the State *generally may* rely on the *reasonable assessments* of its own professionals in determining whether an individual 'meets the essential eligibility requirements' for habilitation in a community-based program."²⁹⁰ The terms "generally may" and "reasonable assessments" used by the Court hopefully leave open the possibility that an individual in the future might contest the recommendation of the state's professionals.²⁹¹ In such a case, the burden will be on the individual to prove that the state's professionals either were not qualified to make such an assessment or that the state's professionals did not make a reasonable assessment.²⁹²

Following the Court's decision in *Olmstead*, individuals with disabilities arguing for community placement and their attorneys may find themselves in an awkward position. It is important to remember that in many cases, it was the state's professionals who had recommended community placement.²⁹³ For L.C. and E.W., for example, the

²⁸⁶ See Stefan, *supra* note 283, at 648, 655.

²⁸⁷ See *id.*

²⁸⁸ See, e.g., Clark v. Cohen, 613 F. Supp. 684, 704 (E.D. Pa. 1985), *aff'd* 794 F.2d 79 (3d Cir. 1986) (stating that professional judgment should "be based on medical or psychological criteria and not on exigency, administrative convenience, or other non-medical criteria."); Brief for the United States, *supra* note 79, at *19 (stating that professional judgment should not be "affected by extraneous considerations such as administrative convenience and costs").

²⁸⁹ See 119 S. Ct. at 2188. The Supreme Court had previously addressed the issue of deference to state professionals in a 1982 case concerning a substantive due process right to "minimally adequate training." See *Youngberg v. Romeo*, 457 U.S. 307, 318, 322-23 (1982) (holding that determinations of treatment professionals deserve a great deal of deference and are to be treated as "presumptively valid"); see also *School Bd. of Nassau County v. Arline*, 480 U.S. 273, 288 (1987) ("In making [findings of fact], courts normally should defer to the reasonable medical judgments of public health officials.").

²⁹⁰ See *Olmstead*, 119 S. Ct. at 2188 (emphasis added).

²⁹¹ See *id.*; see also Kathleen S. Post-Trial Mem., *supra* note 213, at 11, 33, 39.

²⁹² See Oral Arg., *supra* note 278, at **42-43.

²⁹³ See, e.g., 119 S. Ct. at 2188 ("The State's own professionals determined that community-

state's professionals determined that community placement was appropriate for the two women prior to their discharge from the state psychiatric hospital.²⁹⁴ Therefore, individuals with disabilities may benefit if courts defer to the opinions of the state's professionals because such deference implies that the state would have to provide community placement for the individuals.²⁹⁵ At the same time, however, individuals with disabilities and their attorneys may find themselves asking whether they want the courts to invest so much deference and power in the decisions of professionals paid by the state.²⁹⁶ Hopefully, the state's professionals will exercise objectivity and fairness to the fullest extent possible in keeping with their role as "professionals."²⁹⁷ Depending on the facts of the case, however, an individual may want to contest the recommendation of the state's professionals and present a second opinion from an independent professional.²⁹⁸

2. Affected Individual Does Not Oppose Community Placement

The second condition included as part of the Court's holding is that the affected individual must not oppose the community placement.²⁹⁹ This condition, although it does not contain the word "appropriate," also speaks to the issue of appropriateness in the integration regulation.³⁰⁰ The Court seemed to be concerned with the impact of the decision regarding community placement on the individual, and to a certain extent this requirement does protect the person.³⁰¹ The specific language used by the Court—namely, the "affected individual" and "not oppose"—warrants attention.³⁰²

based treatment would be appropriate for L.C. and E.W. . . ."); *Helen L. v. DiDario*, 46 F.3d 325, 329 (3d Cir. 1995), *cert. denied*, *Pennsylvania Secretary of Pub. Welfare v. Idell S.*, 516 U.S. 813 (1995) ("DPW agrees that 'the most integrated setting appropriate to [the plaintiff]' is her home"); *Kathleen S. v. Department of Pub. Welfare*, 10 F. Supp. 2d 460, 465 (E.D. Pa. 1998) ("[There are] approximately 95 class members who have been identified by DPW as appropriate for treatment in the community but . . . for whom facilities and services are not presently available for their treatment in the community.").

²⁹⁴ See 119 S. Ct. at 2188.

²⁹⁵ See, e.g., Brief for Respondents at *5, *Olmstead* (No. 98-536) (noting that Georgia professionals had identified 523 individuals in institutions who could be served more appropriately in the community, but who remained institutionalized).

²⁹⁶ See *supra* notes 283-88 and accompanying text.

²⁹⁷ Cf. Oral Arg., *supra* note 278, at *41.

²⁹⁸ See, e.g., *Kathleen S.* Post-Trial Mem., *supra* note 213, at 11, 33, 39.

²⁹⁹ See 119 S. Ct. at 2181, 2190.

³⁰⁰ See *id.* at 2188 (finding that both the requirement that the state's professionals recommend that community placement is appropriate and the requirement that the individual not oppose the placement determine whether the individual is "qualified" for community placement).

³⁰¹ See *id.*

³⁰² See *id.* at 2181, 2190.

The Court did not elaborate on the meaning of the term "affected individual."³⁰³ Since a parent or guardian is often involved in situations pertaining to individuals with mental disabilities, the requirement as articulated raises a question regarding the respective roles of the individual and the parent or guardian.³⁰⁴ There is the possibility that an individual may clearly express a desire to be placed in the community, while the individual's parent or guardian opposes such placement.³⁰⁵ The State of Connecticut, for example, provides parents and guardians with the right to notice and a hearing prior to the transfer of their children or wards to the community.³⁰⁶ Hopefully, because the Court used the words "affected individual," future courts will interpret this phrase to mean the *individual*, and not a third party guardian, in cases in which there is a difference of opinion.³⁰⁷

The Court used the words "not oppose," apparently following the language of the implementing regulations of the ADA.³⁰⁸ The Court noted that there is no federal requirement that community placement be *imposed* on an individual who does not want such placement.³⁰⁹ The Court cited the implementing regulations of the ADA, which state that an individual should not be required to accept an unwanted placement and that an individual must have the option of declining a particular placement.³¹⁰ The requirement of "not oppose" is an easier condition to fulfill than "consent to," which would necessitate some indicia of consent on the part of the individual.³¹¹

³⁰³ See *id.*

³⁰⁴ See, e.g., Stanley S. Herr, *Representation of Clients with Disabilities: Issues of Ethics and Control*, 17 N.Y.U. REV. L. & SOC. CHANGE 609, 614 (1989/1990) ("guardians . . . may have interests that conflict or at least diverge in some respects from those of the person with mental disabilities.").

³⁰⁵ See, e.g., David H. Neely, *Handicapped Advocacy: Inherent Barriers and Partial Solutions in the Representation of Disabled Children*, 33 HASTINGS L.J. 1359, 1399 (1982) (arguing that the law is unclear for lawyers of clients with mental disabilities "regarding how the client's expressed desires are to be represented if they conflict with those of the guardian.").

³⁰⁶ See *Messier v. Southbury Training Sch.*, 183 F.R.D. 350, 359 (D. Conn. 1998) (citation omitted).

³⁰⁷ See 119 S. Ct. at 2181, 2190.

³⁰⁸ See *id.* at 2188.

³⁰⁹ See *id.* The requirement that the individual not oppose the placement is somewhat analogous to the requirement in the federal Medicaid statute which mandates that states participating in the HCBS Waiver Program must inform eligible individuals of the possible alternatives and provide such individuals with a choice of services. See *supra* note 75 and accompanying text.

³¹⁰ See *Olmstead*, 119 S. Ct. at 2188 (citing 28 C.F.R. § 35.130(c)(1) (1998) and 28 C.F.R. pt. 35, app. A, 450 (1998)).

³¹¹ See, e.g., Dennis P. Saccuzzo, *Legal Regulation of Behavior Modification for Developmentally Disabled and Other Handicapped Persons*, 25 OHIO N.U. L. REV. 27, 37-38 (1999).

It is noteworthy that the holding of the Court concerning the appropriateness of the placement vis-à-vis the role of the decision of the state's professionals and the role of the affected individual reflects the Court's strong opposition to deinstitutionalization.³¹² The Court pointed out that the ADA does not mandate community placement for all individuals with disabilities—that is, the state's professionals must recommend that the community is the appropriate setting for the particular individual, and the affected individual must not oppose such placement.³¹³ At the oral arguments, the justices expressed concern regarding the repercussions of a massive emptying of the institutions.³¹⁴ Justice Kennedy articulated this apprehension in his concurring opinion.³¹⁵ This fear reflects the negative connotations associated with the term deinstitutionalization.³¹⁶ Although deinstitutionalization began as a positive step in response to the pervasive institutionalization of persons with disabilities, its meaning has changed over the years, and deinstitutionalization has come to symbolize the release of large numbers of individuals onto the street without adequate support programming.³¹⁷ Disability advocates have agreed that the ADA does not mandate deinstitutionalization and that community placement is not the appropriate option for all individuals with disabilities.³¹⁸

3. Reasonable Modifications/Fundamental Alteration

In addition to the two conditions pertaining to the concept of appropriateness, the Court also held that the reasonable-modifications regulation limits the obligation of states to provide community placement.³¹⁹ According to the regulation: "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, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."³²⁰ In *Olmstead*, the Supreme Court tried to clarify

³¹² See *Olmstead*, 119 S. Ct. at 2189 ("the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk.").

³¹³ See *id.* at 2187 ("We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.").

³¹⁴ See Oral Arg., *supra* note 278, at **47–48.

³¹⁵ See *Olmstead*, 119 S. Ct. at 2191–92 (Kennedy, J., concurring).

³¹⁶ See *supra* notes 48–49 and accompanying text.

³¹⁷ See *supra* notes 45–49 and accompanying text.

³¹⁸ See *supra* note 52 and accompanying text.

³¹⁹ See *Olmstead*, 119 S. Ct. at 2188–90.

³²⁰ 28 C.F.R. § 35.130(b)(7) (1998) (emphasis added).

the concept of fundamental alteration by stating that future courts should consider the following: (1) the overall cost to the state; (2) the range of existing services the state provides to other individuals with disabilities; and (3) the state's obligation to provide these services in an equitable manner.³²¹ Prior to *Olmstead*, courts had struggled with the scope of the fundamental alteration defense.³²² The Third Circuit in *Helen L.* referred to a change in the nature of a program or a change in the requirements for admission to a program as fundamental alterations, but was reluctant to find a fundamental alteration due to a lack of funds.³²³ The problem with the concept of fundamental alteration, as with that of undue hardship in § 504, is that there is no bright-line test to determine what constitutes a reasonable modification and what constitutes a fundamental alteration.³²⁴ Rather, as the Supreme Court in *Alexander v. Choate* suggested, an evaluation of a fundamental alteration involves balancing the right of the individual to be integrated into society against the right of the state to maintain the integrity of its mental health system.³²⁵

In discussing the issue of cost, the Supreme Court in *Olmstead* was clear that courts in the future should consider overall expenses to the state rather than a simple cost comparison.³²⁶ The latter involves a comparison between the cost of providing services in the community for a particular individual and the corresponding cost of providing services for that same individual in an institution.³²⁷ In a simple comparison, care in the community is less expensive.³²⁸ The Court noted, however, that as the number of residents in an institution decreases, states still incur certain fixed overhead expenses, leading to a higher per capita cost, unless the facility is closed.³²⁹ According to the Court, these fixed costs must be considered in determining the overall cost

³²¹ See 119 S. Ct. at 2185. The factors recommended by the Court for future courts to consider when evaluating a fundamental alteration defense are similar to and appear to be as extensive as the factors included by the Department of Justice to describe "undue hardship" in the coordinating regulations of § 504. See *supra* note 118 and accompanying text. In rejecting a simple cost comparison, the Court in *Olmstead* specifically mentioned the "undue hardship" factors in a footnote. See 119 S. Ct. at 2190 n.16.

³²² See, e.g., *Williams v. Wasserman*, 937 F. Supp. 524, 531 (D. Md. 1996) (attempting to limit the Third Circuit's holding in *Helen L.* regarding fundamental alteration).

³²³ See 46 F.3d at 337.

³²⁴ See, e.g., *Borkowski v. Valley Cent. Sch. Dist.*, 63 F.3d 131, 137 (2d Cir. 1995) (noting that undue hardship is a "relational term" that warrants a cost/benefit analysis).

³²⁵ See 469 U.S. 287, 300 (1985).

³²⁶ See *Olmstead*, 119 S. Ct. at 2188-89.

³²⁷ See *id.*

³²⁸ See *id.*

³²⁹ See *id.* at 2189 n.15.

to the state of providing community placement.³³⁰ The Court noted that states will be unable to close every institution because there will always be individuals who must live in such facilities, and further, that the ADA does not require "states to phase out institutions."³³¹ Again, as with the Court's requirements that the state's professionals approve the placement and the individual not oppose it, this statement reflects the Court's concern about and disapproval of deinstitutionalization.³³² The Court further emphasized that some individuals living in the community may need to return to an institution from time to time to receive acute psychiatric care, as was the case with L.C. and E.W.³³³ As a result of the Court's rejection of the simple cost comparison in favor of overall expenses to the state, individuals with disabilities seeking placement in the community in the future will no longer be able to argue a simple cost comparison.³³⁴ By focusing on the overall cost to states, the Court has made it easier for states to prove a fundamental alteration defense by showing that they will incur excessive expenses that will fundamentally alter the nature of their mental health system.³³⁵

Moreover, in its efforts to emphasize the impact of the overall cost on the capacity of states to provide community-based services, the Court failed to point out that fixed overhead expenses do not automatically result in a fundamental alteration of a state's program.³³⁶ Studies indicate that in the face of reduced institutional populations, states can deal with fixed costs by implementing measures such as staff sharing and/or institution consolidation.³³⁷ The Court should have specified that it is not sufficient for states merely to point to the existence of certain fixed costs.³³⁸ Rather, states should be required to demonstrate that they are considering alternative approaches to the issue of costs and that they are also actively seeking more funding.³³⁹ Furthermore, the Court should have noted that certain policies will be cost-effective in the long-term and that the benefits of community

³³⁰ See *id.* at 2189.

³³¹ *Olmstead*, 119 S. Ct. at 2189.

³³² See *id.*

³³³ See *id.*

³³⁴ See, e.g., *Helen L.*, 46 F.3d at 329.

³³⁵ See *Olmstead*, 119 S. Ct. at 2188-89.

³³⁶ See, e.g., Brief Amici Curiae for American Psychiatric Association and the National Alliance for the Mentally Ill Supporting Respondents at **28-29, *Olmstead* (No. 98-536) [hereinafter Brief for Am. Psychiatric Assoc.].

³³⁷ See *id.* at *29; Brief for United States, *supra* note 79, at *22.

³³⁸ See *id.* at *20 ("Unsubstantiated claims of . . . costs . . . are no substitute for proof.")

³³⁹ See, e.g., Brief for Am. Psychiatric Assoc., *supra* note 336, at *29.

integration may in some instances outweigh the additional costs required.³⁴⁰ A stronger message from the Court would have given a sense of urgency and a need for acceleration in keeping with the earlier part of its opinion hailing community integration.³⁴¹

Also in its attempt to highlight the role of overall cost, the Supreme Court hastily rejected the Eleventh Circuit's construction of the reasonable-modifications regulation as overly narrow and restrictive.³⁴² The Supreme Court itself recognized that the Eleventh Circuit had found that a determination of a fundamental alteration should consist of an examination of "other things" in addition to cost.³⁴³ In fact, some of the "other things" mentioned by the Eleventh Circuit were quite extensive.³⁴⁴ The Eleventh Circuit remanded the case to the district court to determine, *inter alia*, "(1) whether the additional expenditures necessary to treat L.C. and E.W. in community-based care would be unreasonable given the demands of the State's mental health budget; (2) whether it would be unreasonable to require the State to use additional available Medicaid waiver slots . . . ; and (3) whether any difference in the cost of providing institutional or community-based care will [sic] lessen the State's financial burden."³⁴⁵ As Justice Stevens stated in his concurrence, the Supreme Court should have affirmed the decision of the Eleventh Circuit, noting that if the district court chose to adopt a purely cost-based analysis, such a decision should have been appealed as an arguable error on the part of the district court.³⁴⁶

The second factor noted by the Supreme Court for consideration in an evaluation of a fundamental alteration defense is the range of services provided by the state.³⁴⁷ The Department of Justice has determined that the ADA does not require states to create new programs because to do so would require a fundamental alteration.³⁴⁸ A further question, however, pertains to the expansion of already existing programs.³⁴⁹ Does the ADA require states to expand their current programs to provide treatment in the most integrated setting appropri-

³⁴⁰ See *id.* at **27-28; Brief for Respondents at *49, *Olmstead* (No. 98-536).

³⁴¹ See *Olmstead*, 119 S. Ct. at 2185.

³⁴² See *id.* at 2188.

³⁴³ See *id.*

³⁴⁴ See *L.C. ex rel. Zimring v. Olmstead*, 138 F.3d 893, 905, *aff'd in part, vacated in part, remanded*, 119 S. Ct. 2176 (1999).

³⁴⁵ *Id.*

³⁴⁶ See *Olmstead*, 119 S. Ct. at 2190 (Stevens, J., concurring).

³⁴⁷ See *id.* at 2185.

³⁴⁸ See Brief for the United States, *supra* note 79, at *20 n.3.

³⁴⁹ See, e.g., Kathleen S. Post-Trial Mem., *supra* note 213, at 24-26.

ate?³⁵⁰ The Department of Justice has stated that although the creation of new programs would constitute a fundamental alteration, the expansion of existing programs would not.³⁵¹ Lower courts similarly have held that the ADA requires states to expand existing programs to provide services in the most integrated setting appropriate.³⁵² For example, in *Kathleen S.*, the plaintiffs argued that "[i]f a public entity could avoid its obligations under the integration mandate simply by contending that additional capacity in existing programs must be developed, it would nullify the meaning of the mandate."³⁵³ The Court in *Olmstead* did not specifically answer this question.³⁵⁴ It appears, however, that its answer would be that the ADA requires states to expand their existing programs, unless doing so would necessitate a fundamental alteration.³⁵⁵

By including range of services as one of the bases of a fundamental alteration defense, the Court has again, as with overall cost, given the states greater opportunity to legitimize their reluctance to provide community placement.³⁵⁶ It will be relatively easy for a state to hide behind a defense that the requested community placement will fundamentally alter the state's range of services by diverting resources from where they are needed.³⁵⁷ For example, a state could henceforth argue that because it has the enormous responsibility of administering a wide array of services, it cannot redirect resources of time, persons, funds, etc. to expand a program to meet the needs of a small group of individuals.³⁵⁸ The state could therefore argue that such an expansion would create a fundamental alteration in its overall system.³⁵⁹

The third factor mentioned by the Court as basic to a fundamental alteration defense is the equitable distribution of a state's resources.³⁶⁰

³⁵⁰ See *id.*

³⁵¹ See Brief for the United States, *supra* note 79, at *20 n.3.

³⁵² See, e.g., *Williams*, 937 F. Supp. at 530.

³⁵³ *Kathleen S.* Post-Trial Mem., *supra* note 213, at 25.

³⁵⁴ See 119 S. Ct. 2176-90.

³⁵⁵ See *id.* at 2189.

³⁵⁶ See *id.* It is interesting that approximately 75% of Medicaid funding goes to institutional care while only 25% goes to community-based care. See MICASSA, *supra* note 91, § 2(a)(1). One could ask: does such a proportion really constitute a meaningful "range" of services?

³⁵⁷ See Brief of the National Conference of State Legislatures, as Amici Curiae Supporting Petitioners at **9-10, *Olmstead* (No. 98-536) (arguing that it should not be a fundamental alteration for a state to continue to keep an individual confined to an institution when immediate placement of that individual would disrupt the state's allocation of resources) [hereinafter Brief of State Legislatures].

³⁵⁸ See *id.*

³⁵⁹ See *Olmstead*, 119 S. Ct. at 2189.

³⁶⁰ See *id.* at 2185.

The Court articulated this concept in several different forms throughout the opinion without explaining its precise meaning at any time.³⁶¹ The Court recognized that states have an obligation "to administer services with an even hand" and "to mete out those services equitably."³⁶² Similarly, the Court held that the states could prove the fundamental alteration defense by demonstrating that "immediate relief for the plaintiffs would be inequitable"³⁶³ The Court further noted that the placement of individuals with mental disabilities in community settings must take into account the needs of other individuals with disabilities.³⁶⁴

By including the equitable distribution of resources, the Court clearly had in mind a desire for some degree of fairness.³⁶⁵ Yet, because this third factor is so vague, it is open to varying interpretations.³⁶⁶ The Court expressed concern about the impact that the immediate release of individuals who file lawsuits may have on the services that a state provides to a diverse population of individuals with mental disabilities.³⁶⁷ Moreover, the Court explained that individuals who file lawsuits to receive community placement cannot jump ahead of others on the waiting list to receive that placement.³⁶⁸ Because of its concern for the equitable distribution of resources, the Court apparently did not want states to put the needs of those awaiting community placement ahead of the needs of those requiring institutional care.³⁶⁹ The same argument, however, holds true in the reverse—where is the equity for individuals who have been waiting for community placement for five, ten or even fifteen years?

An additional question concerns individuals currently living at home, who are on waiting lists to receive community placement or additional community-based services.³⁷⁰ It is unclear how these individuals fit into the equity equation.³⁷¹ Although the Court phrased the

³⁶¹ See *id.* at 2185, 2189.

³⁶² *Id.* at 2185.

³⁶³ *Id.* at 2189.

³⁶⁴ See *Olmstead*, 119 S. Ct. at 2181, 2190.

³⁶⁵ See *id.*; see also RANDOM HOUSE WEBSTER'S COLLEGE DICTIONARY 445 (2d ed. 1999) (defining "equitable" as "fair").

³⁶⁶ See *Olmstead*, 119 S. Ct. at 2185.

³⁶⁷ See *id.* at 2189.

³⁶⁸ See *id.* at 2190.

³⁶⁹ See *id.*

³⁷⁰ Cf. Davis, *The ARC: A Status Report*, *supra* note 4.

³⁷¹ See *id.* The Supreme Court in *Olmstead* did not indicate whether "others with mental disabilities" and "a large and diverse population of persons with mental disabilities" include those individuals who are living at home and waiting to receive community placement. See 119 S. Ct. at 2181, 2189, 2190.

provision of services to individuals with mental disabilities in terms of an equitable distribution of resources, the result seems to be a playing of one group against the other in the hope that none of the groups—individuals in institutions requiring institutional care, those waiting for community placement and those at home waiting for community services—is hurt to any great extent.³⁷² Such an approach does not appear to be equitable and certainly does not advance the goal of community integration.³⁷³ With equitable distribution, as with the first two factors, the Court has given the states room to maneuver in providing placement for individuals in community-based settings.³⁷⁴

Moreover, while states may argue that increased costs and/or the need to provide an equitable range of services are the reasons for their failure to provide community placement, it is important to point out that states sometimes mask inappropriate motivations under the guise of more acceptable ones.³⁷⁵ For example, states may experience bureaucratic resistance to change on the part of administrators or reluctance to phase down institutions because of a loss of jobs to administrators and other employees.³⁷⁶ There may be pressure from state politicians to preserve the status quo with respect to institutions in order to maintain jobs for their constituents.³⁷⁷ Resistance may also come from members of the community who may have a "not in my backyard" reaction to the creation of group homes for individuals with mental disabilities.³⁷⁸ These motivations have nothing to do with cost, range of services or equitable distribution.³⁷⁹ In the past, states have sometimes used the defense of excessive costs to conceal their true motivation.³⁸⁰ The Court's explication of the fundamental alteration defense in terms of range of services and equitable distribution—as well as cost—provides the states with additional ways to hide their true intentions.³⁸¹

³⁷² See *Olmstead*, 119 S. Ct. at 2181, 2189, 2190.

³⁷³ See *id.*; see also Brief for Am. Psychiatric Assoc., *supra* note 336, at **28–29 ("discrimination against one individual is hard to justify on the ground that it benefits another individual . . .")

³⁷⁴ See *supra* notes 326–59 and accompanying text.

³⁷⁵ See Brief for Respondents at *49, *Olmstead* (No. 98–536); Amicus Curiae Brief of 58 Former State Commissioners and Directors of Mental Health and Developmental Disabilities in Support of Respondents at **23–26, *Olmstead* (No. 98–536) [hereinafter Brief of Former State Commissioners].

³⁷⁶ See Brief of Former State Commissioners, *supra* note 375, at *26.

³⁷⁷ See *id.* at *25.

³⁷⁸ See *id.* at *24.

³⁷⁹ See *id.*; Brief for Respondents at **9–10, *Olmstead* (No. 98–536).

³⁸⁰ See Brief of Former State Commissioners, *supra* note 375, at *26.

³⁸¹ See *Olmstead*, 119 S. Ct. at 2185.

The Supreme Court suggested that a state could satisfy the fundamental alteration defense if, for example, it had a "comprehensive, effectively working plan" with a waiting list moving at a "reasonable pace."³⁸² While the development of a state plan would certainly be a positive step, the Court did not go far enough since it provided no guidance to the lower courts concerning the parameters of a comprehensive plan or the rate of a reasonable pace.³⁸³ If, for example, an individual had been institutionalized for ten years and a state plan required a further three-year wait to receive placement in the community, would such a time-frame constitute a reasonable pace? While such a pace may be reasonable for the state, it clearly is not reasonable for the individual.³⁸⁴ Again, the Court has left the states too much opportunity to avoid the introduction of change in the manner in which they deliver services to individuals with disabilities.³⁸⁵ The Court did not stress the importance of developing an effective plan.³⁸⁶ Nor did the Court mandate a state plan as a prerequisite for satisfying the fundamental alteration defense.³⁸⁷ The Court should have been more directive to the lower courts by noting some basic components that a comprehensive plan should encompass—for example, the substantiation of costs, the reduction of overhead costs by consolidation, full utilization of a state's allotted HCBS waivers and a system of monitoring to ensure compliance.³⁸⁸

The factors specified by the Court as important for evaluating a fundamental alteration defense are imprecise and therefore provide too much latitude for states to procrastinate and avoid making changes toward a more community-based system.³⁸⁹ Before the Court's decision in *Olmstead*, piecemeal litigation occurred among various lower courts regarding the issue of community placement.³⁹⁰ The Court's opinion, unfortunately, will not put an end to this type of litigation.³⁹¹ It is

³⁸² *Id.* at 2189.

³⁸³ *See id.* The requirement that a waiting list move at a reasonable pace is similar to the vague requirement of "reasonable promptness" in the federal Medicaid statute. *See supra* note 64 and accompanying text.

³⁸⁴ *See, e.g., Kathleen S.*, 10 F. Supp. 2d at 473 (finding a three-year state plan to transfer individuals to community-based settings to be "unreasonable").

³⁸⁵ *See Olmstead*, 119 S. Ct. at 2189.

³⁸⁶ *See id.*

³⁸⁷ *See id.* (stating that a comprehensive plan is merely an "example" of how to satisfy the reasonable-modifications regulation).

³⁸⁸ *See, e.g., MiCASSA, supra* note 91, § 4(a)(1), (c)(1)–(11); *see also infra* notes 410–26 and accompanying text.

³⁸⁹ *See supra* notes 319–88 and accompanying text.

³⁹⁰ *See* Brief of the States, *supra* note 172, at *8.

³⁹¹ *See Olmstead*, 119 S. Ct. at 2188–90.

therefore critical for future lower courts to be mindful of the principle set forth by the Supreme Court in the first part of its opinion that unnecessary segregation constitutes discrimination under the ADA, and to hold the states to a stringent standard when evaluating a fundamental alteration defense.³⁹² In this regard, lower courts can play an important role in preventing states from shirking their statutory obligation to provide services in the most integrated setting appropriate.³⁹³

In summary, in its ruling in *Olmstead*, the Court stated that the ADA requires states to provide community placement for individuals with mental disabilities when the following three conditions are met: (1) the state's treatment professionals determine 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 to its program, given the state's available resources and the needs of other individuals with mental disabilities.³⁹⁴ The first two conditions speak to the appropriateness of the placement for the individual with disabilities.³⁹⁵ The third, however, pertains to the needs of the states, and the Court has essentially conditioned the right of individuals with mental disabilities to receive services in the most integrated setting appropriate on an expanded explanation of the reasonable-modifications regulation.³⁹⁶ The Court's attempt to clarify the concept of fundamental alteration gives the states too much leeway in arguing a fundamental alteration defense.³⁹⁷ If, as the Supreme Court noted in *Choate*, the concept of fundamental alteration should be a balancing of the right of the individual to be placed in the community and the right of the state to manage its mental health program, then the expanded explication of fundamental alteration has tipped the balance in favor of the states.³⁹⁸ Hopefully, courts in the future will have the insight to hold states to a strict standard when evaluating a fundamental alteration defense.³⁹⁹

C. *The Role of Congress in the Aftermath of Olmstead*

Because the Supreme Court's opinion will likely lead to continued litigation in the lower courts with inconsistent results, it is important

³⁹² See *id.* at 2185.

³⁹³ See *id.* at 2188-90; see also *supra* notes 319-92 and accompanying text.

³⁹⁴ See *Olmstead*, 119 S. Ct. at 2181, 2190.

³⁹⁵ See *supra* notes 277-318 and accompanying text.

³⁹⁶ See *supra* notes 319-88 and accompanying text.

³⁹⁷ See *id.*

³⁹⁸ See 469 U.S. at 300.

³⁹⁹ See *supra* notes 389-93 and accompanying text.

for the United States Congress to take the initiative at this juncture.⁴⁰⁰ Congress should enact new legislation that would create a mechanism to encourage states to provide services in the most integrated setting appropriate, thereby complying with the intent of the drafters of the ADA.⁴⁰¹ MiCASSA, the proposed bill supported by ADAPT and described in Part II, has the potential to develop into such legislation.⁴⁰²

As indicated by the Court's focus on the overall cost to the states, one of the major obstacles thwarting the extension of community integration is the issue of cost.⁴⁰³ Although the placement of individuals with disabilities in the community rather than in institutions will ultimately result in savings to the states, states remain concerned about the short-term impact of providing community placement due to fixed overhead costs.⁴⁰⁴ After the Court delivered its opinion, Tommy Olmstead, the Commissioner of the Department of Human Resources in Georgia, commented that "it's a matter of financing. We either need to get more money . . . or we've got to close hospitals."⁴⁰⁵ Federal financial assistance to the states for community placement would ease the short-term financial burden on states and mitigate the effect of cost in the debate over community placement.⁴⁰⁶ MiCASSA proposes financial incentives to the states to encourage systemic changes in their programs and thus enables them to make the transition to a more community-based mental health system.⁴⁰⁷ Increased financial assistance will make it less likely that states will be able to hide behind a defense of a fundamental alteration based on excessive costs.⁴⁰⁸

Moreover, MiCASSA provides a number of suggestions as to how states might use financial incentives to bring about real change in their mental health systems.⁴⁰⁹ The proposed bill thus contains some of the specifics that are absent from the Court's discussion of state plans.⁴¹⁰ For example, MiCASSA suggests that states conduct a needs assessment

⁴⁰⁰ See *supra* notes 389-93 and accompanying text.

⁴⁰¹ See, e.g., MiCASSA, *supra* note 91, §§ 1-7.

⁴⁰² See *id.*

⁴⁰³ See *Olmstead*, 119 S. Ct. at 2188-89; Brief of State Legislatures, *supra* note 357, at *4 (arguing that the ADA does not impose a "costly mandate on state mental health programs"); Wood, *supra* note 60, at 501.

⁴⁰⁴ See, e.g., Brief for the United States, *supra* note 79, at *21.

⁴⁰⁵ Rankin, *supra* note 263, at F4 (quoting Tommy Olmstead, Commissioner of the Department of Human Resources).

⁴⁰⁶ See *supra* notes 60-61, 326-46 and accompanying text.

⁴⁰⁷ See MiCASSA, *supra* note 91, § 4.

⁴⁰⁸ See, e.g., Brief of State Legislatures, *supra* note 357, at *5.

⁴⁰⁹ See MiCASSA, *supra* note 91, §§ 4(c)(1)-(11).

⁴¹⁰ Compare MiCASSA, *supra* note 91, § 4(c)(1)-(11), with *Olmstead*, 119 S. Ct. at 2189.

to determine the number of individuals currently in institutions for whom community placement is appropriate, the availability of community-based settings to accommodate these individuals and the anticipated change in demand for home or community-based services.⁴¹¹ Such an assessment would enable a state to set up a specific timetable for the provision of community placement for individuals with disabilities.⁴¹² In addition, a state could utilize the incentives to develop and implement strategies to change current state policies and procedures that perpetuate an institutional bias in the state's mental health system.⁴¹³ Alternatively, states could use the financial assistance to initiate training for professionals or para-professionals, alleviate fixed costs as individuals move out of institutions or help with other transitional costs.⁴¹⁴ By allowing the states to decide how funding would best assist their programs, MiCASSA gives states flexibility in the management of their complex mental health programs, an issue deemed important by the Supreme Court.⁴¹⁵ At the same time, by encouraging the states to adopt some of these procedures, MiCASSA would help the states move in the direction of a more community-based mental health system.⁴¹⁶

MiCASSA additionally specifies that a state must maintain a quality assurance program, including an external system for the monitoring of services by the individuals with disabilities, their family members, disability organizations and members of the community.⁴¹⁷ The states must also establish a procedure for appealing denials of eligibility and reporting grievances, as well as a process for filing complaints about abuse and neglect.⁴¹⁸ Moreover, MiCASSA proposes that the Secretary of HHS conduct periodic reviews of the progress of the individuals that the state serves.⁴¹⁹ Given the states' flexibility and autonomy in the design and implementation of their mental health programs, it is crucial that there be a system for the independent monitoring of state compliance with their plans.⁴²⁰ There is nothing in the Court's opinion to ensure follow-through on the part of the states.⁴²¹

⁴¹¹ See MiCASSA, *supra* note 91, § 4(c)(1).

⁴¹² See *id.* § 4(a)(1).

⁴¹³ See *id.* § 4(c)(2).

⁴¹⁴ See *id.* § 4(c)(5), (7), (8).

⁴¹⁵ See *Olmstead*, 119 S. Ct. at 2189 (holding that states need sufficient leeway to maintain a range of services).

⁴¹⁶ See MiCASSA, *supra* note 91, § 2(b).

⁴¹⁷ See *id.* § 3(b)(1)(B).

⁴¹⁸ See *id.*

⁴¹⁹ See *id.*

⁴²⁰ See *id.*

⁴²¹ See 119 S. Ct. at 2189.

Furthermore, MiCASSA provides methods for involving the individual with disabilities in the decision-making process regarding placement.⁴²² Although the Supreme Court's opinion stated that an individual with disabilities must not oppose community placement, the Court failed to indicate how important it is for individuals with disabilities to receive adequate information in order to make informed decisions.⁴²³ The role of the individual in the decision-making process concerning community placement is central to MiCASSA, which specifies that the individual must have sufficient information to be able to make "real choices" concerning services that meet his or her needs in the most integrated setting appropriate.⁴²⁴ The prospective bill also states that neither federal nor state policies should impede an individual's choice.⁴²⁵ Thus, a bill such as MiCASSA will help fill in the gaps that remain after the Supreme Court's ruling in *Olmstead*.⁴²⁶

CONCLUSION

It is highly significant that in its recent ruling in *Olmstead*, the Supreme Court clearly stated that unjustified segregation in institutions constitutes discrimination under the ADA. This statement holds out great promise for the future for individuals with mental disabilities. Unfortunately, in another part of its ruling, the Court conditioned the right of individuals with mental disabilities to live in the most integrated setting appropriate on an expanded explanation of the reasonable-modifications regulation. By giving the states too much leeway and by virtually providing the states with a road-map of how to argue the fundamental alteration defense, the Court has created a potentially serious obstacle to the goal of community integration. Hopefully, courts in the future will hold states to a strict standard when evaluating a fundamental alteration defense. As a result of the increased litigation that will likely occur, Congress should enact legislation, such as MiCASSA, to enable individuals with disabilities to enjoy the benefits of life outside an institution, a life enriched by friendships and a multitude of experiences. The issue of community integration is a prime

⁴²² See, e.g., MiCASSA, *supra* note 91, § 2(b)(2) (specifying that each state should develop "a comprehensive consumer-responsive statewide system . . . that provides real consumer choice and direction . . .").

⁴²³ See *supra* notes 299-311 and accompanying text. The federal statutory requirements under the HCBS Waiver Program also emphasize the importance of individuals receiving adequate information. See *supra* note 75 and accompanying text.

⁴²⁴ See MiCASSA, *supra* note 91, § 2(c)(1).

⁴²⁵ See *id.* § 2(c)(3).

⁴²⁶ See *id.* §§ 1-7.

concern in the disability rights community. What is needed now is a rekindling and a re-energizing of interest on the part of the general population. It has been almost a decade since the passage of the ADA; it is time for Congress to act again. The Supreme Court's opinion in *Olmstead* should serve as a catalyst, providing momentum to Congress to forge ahead with new legislation for the millennium.

JOANNE KARGER