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LONG TERM CARE AFTER OLMSTEAD V. L.C.: WILL THE POTENTIAL OF THE ADA’S INTEGRATION MANDATE BE ACHIEVED?

Loretta Williams*

INTRODUCTION

When President Bush signed the Americans with Disabilities Act (ADA) on July 26, 1990, he said, “Let the shameful walls of exclusion finally come tumbling down.”¹ The ADA promised 43,000,000 Americans with disabilities an end to discrimination in all aspects of life - employment, government services, transportation and public accommodation in privately owned businesses - and provided mechanisms to enforce that promise.² The ADA reads, “[H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”³ The ADA cites institutionalization - providing services in nursing homes, mental hospitals and other institutions - as a continuing form of discrimination against people with disabilities.⁴

Nine years after the ADA’s enactment, the Supreme Court in Olmstead v. L.C. ex rel. Zimring⁵ confirmed that unjustified isolation of a person with disabilities in an institution is discrimination based upon disability. This case was brought by L.C., a woman with mental impairments who was admitted voluntarily to a public psychiatric hospital in Georgia. Although the state’s treatment professionals deemed community care appropriate for L.C. in 1993, the state did not move her to a community program until nearly three years later. L.C. claimed that the state violated her rights under the ADA by segregating her in an institution rather than providing community services.⁶ The state argued that discrimination only

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6. See id. at 593-94.
exists where a person with disabilities is treated differently from people who do not have disabilities, and that L.C. was not denied community services based upon her disability, but because the community program lacked sufficient funding. The Supreme Court held that the state did discriminate against L.C. and remanded the case for "further consideration of the appropriate relief, given the range of facilities the State maintains for the care and treatment of persons with [disabilities]."\textsuperscript{8}

This case has profound implications for the way that people with disabilities receive long term care (LTC) services from the government.\textsuperscript{9} Traditionally, people with disabilities were removed from society and placed in state psychiatric hospitals, institutions for the mentally retarded or nursing homes.\textsuperscript{10} This institutional bias remains in publicly funded programs, despite a continuing push by disability advocates for additional services in the community, and efforts by state and federal policymakers to expand these programs. In \textit{Olmstead}, the Supreme Court told state governments, which design and administer LTC services for people with disabilities, that unnecessary institutionalization violates the ADA. Will this holding remedy the current situation where more than 75% of public LTC expenditures support institutional care?\textsuperscript{11}

This Note explores the potential impact of \textit{Olmstead} on the delivery of publicly-funded long term care in the United States. Part I presents the context in which \textit{Olmstead} was decided: it briefly describes the relevant

\textsuperscript{7} See id. at 594-95.
\textsuperscript{8} Id. at 587.
\textsuperscript{9} This Note focuses on LTC services for adults with disabilities. While there are some programs that serve both adults and children, for the most part LTC services are financed and delivered differently for children and adults.
\textsuperscript{10} See ADA Handbook – History, available at http://www.dinf.ch/ada/ada_preamble.htm (Dec. 16, 1997). The preamble briefly describes the history of care for people with disabilities in the United States. Families bore the primary responsibility for care during the colonial period, with care shifting toward custodial institutions in the early 19th century. Early in the 20th century the first rehabilitation programs began in response to the increase in the number of people with physical disabilities caused by World War I and an increase in industrial accidents. Emphasis on rehabilitation and re-entering the community increased after World War II and, in the past three decades, disability policy has moved toward integration of people with disabilities into mainstream society. See id. For a more thorough discussion of trends in services for people with disabilities, see generally Nat’l Council on Disability, Toward Independence (1986) and U.S. Comm’n on Civil Rights, Accommodating the Spectrum of Individual Abilities (1983).
\textsuperscript{11} See Barbara Coleman, AARP, Trends in Medicaid Long-Term Care Spending 2 (1999).
sections of the ADA and implementing regulations, institutional bias in
the current long term care system and legislative proposals to end bias
through changes in the Medicaid program. Next, it examines two cases,
Easley v. Snider\(^{12}\) and Helen L. v. DiDario,\(^{13}\) that provided important
precedent for Olmstead and summarizes the Olmstead decision. Part II
analyzes the decision in terms of balancing individual versus collective
rights and defining fundamental alteration. Part III argues that, while
Olmstead makes a powerful promise that all qualified people with
disabilities will be served in existing community programs, the holding's
impact is limited because it operates within a system biased toward
institutional care. This Comment recommends legislative change at the
national level to encourage states to realize Olmstead's potential for
people with disabilities.

I. BACKGROUND

A. Title II of the ADA Requires States to Provide LTC Services in
the Most Integrated Setting

The ADA provides "a clear and comprehensive national mandate for
the elimination of discrimination against individuals with disabilities."\(^{14}\)
Disability is defined broadly as a physical or mental condition that
substantially limits one or more major life activities.\(^{15}\) The ADA builds
upon earlier civil rights laws for people with disabilities, notably, the
Rehabilitation Act of 1973.\(^{16}\) The ADA adopts, and is consistent with,
key provisions of the Rehabilitation Act, yet adds more protection for
people with disabilities who use public LTC services because it specifically
names isolation and segregation as forms of discrimination.\(^{17}\) Congress

\(^{12}\) 36 F.3d 297 (3rd Cir. 1994).
\(^{13}\) 46 F.3d 325 (3rd Cir. 1995), cert. denied sub nom. Pennsylvania Sec'y of
\(^{16}\) See 29 U.S.C.A. 794 (1999). Section 504 of the Rehabilitation Act
prohibits discrimination against people with disabilities by public or private
organizations that receive federal funds. See 29 U.S.C.A. 794(a) (1999). Title II of
the ADA repeats the anti-discrimination language of Section 504 and extends it to
state governments and other public entities that do not receive federal financial
General to implement Title II through regulations that are consistent with Section
\(^{17}\) 42 U.S.C. § 12101(a)(2).
found that "discrimination against individuals with disabilities persists in such critical areas as... institutionalization [and] health services" and that people with disabilities "continually encounter various forms of discrimination, including outright intentional exclusion... [and] segregation." The ADA urges the nation to end discrimination against people with disabilities and "assure quality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals."

Title II of the ADA protects individuals from discrimination by state governments and other public entities. It says 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." A qualified individual with a disability is someone who, "with or without reasonable modification to rules, policies, or practices... meets the essential eligibility requirements for the [government program or service]." Title II does not define "reasonable modifications" or "essential eligibility requirements."

The state's duty to provide reasonable modifications to qualified people with disabilities is not unlimited. The regulations implementing Title II do not require modifications where the state "can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." The terms "reasonable modification" and "fundamental alteration" are inextricably related: a request for a change in a program policy is either a reasonable modification that must be granted or, if unreasonable, can be denied because it would fundamentally alter the program. The regulations do not offer guidance on where to draw the line between reasonable modification and fundamental alteration in the context of the provision of public services.

Other sections of the ADA suggest ways to define the boundary between reasonable modification and fundamental alteration. Under

21. 42 U.S.C. § 12132 (2000). While this provision covers all programs, services and activities offered by a wide array of public entities, the term "state" is used in this paper to focus attention on the duties of the state in providing LTC services to people with disabilities.
Title I, an employer can refuse to make accommodations for an applicant or employee with disabilities when doing so would create an "undue hardship," defined as a "significant difficulty or expense" for the employer.\footnote{25} The Rehabilitation Act regulations describe several factors used to determine whether an accommodation creates an undue hardship: the overall size of the program with respect to number of employees, number and type of facilities and budget, the type of operation including the composition and structure of the workforce, and the nature and cost of the accommodation needed.\footnote{26} Title II uses an analogous test for determining the limit of a public entity's duty to remove architectural barriers.\footnote{27} To demonstrate an undue burden or fundamental alteration, the state must consider "all resources available for use in the funding and operation" of the program in question.\footnote{28}

The Title II regulations include a provision known as the "integration mandate" which states that "public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."\footnote{29} One commentator notes: "[The] integration mandate doesn't create a right to services or treatment, but it attaches to benefit programs that are already there and that the states are already doing. Like an adverb - it tells them how they have to do this program."\footnote{30} The plaintiff's theory in \textit{Olmstead} was that failure to provide community services caused unnecessary isolation, which amounts to discrimination under the ADA.\footnote{31}

Another provision in the Title II regulations allows a public entity to provide "benefits, services, or advantages to individuals with disabilities, or to a particular class of individuals with disabilities beyond those

required by this part." It supports the notion that states may provide programs for a class of individuals with disabilities without providing the same services to other individuals with disabilities.

**B. Medicaid Law is Biased Toward Funding Institutional Care**

Public funding for long term care is provided through the Medicaid program, which serves people with low incomes. Medicaid is financed jointly by federal and state governments and administered by the states within the bounds of federal law. The structure of the Medicaid program sustains an “institutional bias” in delivery of LTC services in that Medicaid law encourages states to finance institutional care rather than community services. Medicaid covers LTC services for three groups

32. 28 C.F.R. § 130(c). This section, too, is in conformity with the Section 504 regulations. See 45 C.F.R. § 85.21(c) (1999).

33. HARRIET L. KOMISAR AND JUDITH FEDER, THE COMMONWEALTH FUND, THE PRESIDENT'S PROPOSED LONG-TERM CARE INITIATIVE: BACKGROUND AND ISSUES 2 (1999). “Medicaid is the largest source of long term care financing, followed by private out-of-pocket spending.” Id. In 1998, Medicaid paid for 39%, individuals for 29%, and Medicare for 18% of $117.1 billion in national spending for nursing home and home care. See NATALIE Graves TUCKER, ET. AL., AARP PUBLIC POLICY INSTITUTE, LONG-TERM CARE 2 (2000). “While Medicaid provides safety net coverage for [LTC], people must first exhaust their financial resources to become eligible for the program.” Id. at 1. In 1999, Medicare spending was expected to exceed $200 billion, financing health care services for 34 million elderly and five million disabled beneficiaries. See THE HENRY J. KAISER FAMILY FOUNDATION, MEDICARE AT A GLANCE 1 (1999). But Medicare’s coverage of long term care is limited: the program only covers recuperation in a skilled nursing facility for up to 100 days following a hospital stay and home health care following a hospitalization or nursing home stay. See id. States independently fund long term care programs for people with disabilities, but these programs tend to be much smaller than the states’ Medicaid programs. A national study of programs serving older people with disabilities documented $1.2 billion in state funding for these programs. See ENID KASSNER and LORETTA WILLIAMS, AARP, TAKING CARE OF THEIR OWN: STATE-FUNDED HOME AND COMMUNITY-BASED CARE PROGRAMS FOR OLDER PERSONS 5 (1997).

34. See ENID KASSNER and NATALIE GRAVES TUCKER, AARP, MEDICAID AND LONG-TERM CARE FOR OLDER PEOPLE 1 (1998). See also BARBARA COLEMAN, AARP, NEW DIRECTIONS FOR STATE LONG-TERM CARE SYSTEMS ii (2d ed. 1998). “The country’s long-term care system is actually 50 different state and five U.S. territory systems. In the absence of a national long-term care program, states have developed their own long-term care programs and services, using federal Medicaid . . . funds and state general revenues.” Id.

35. See Memorandum from Charlene Harrington, Univ. of Cal. San Francisco, A Review of Statutes and Regulations for Personal Care and Home
of adults with disabilities: elderly and younger adults with physical disabilities, adults with mental retardation or developmental disabilities (MR/DD), and adults with mental illness. Although the services available to each group vary, in all cases there are barriers to providing community-based care through Medicaid.

1. Medicaid Favors Nursing Home Care for Adults with Physical Disabilities

Physically disabled Medicaid beneficiaries who need LTC are entitled to nursing home care, but may be denied access to community services. Under Medicaid law, states must provide nursing home care to adults with disabilities who qualify for it, but community-based LTC services are optional and may require special permission from the federal government.

In addition, Medicaid allows states to offer more generous financial eligibility to people seeking nursing home care than to those who want services in the community. In 1996, Medicaid funded nursing home care and Community Based Services: A Final Report 1 (May 21, 1998) [hereinafter Harrington].

Historically, services for people with disabilities have been structured according to a medical and custodial model, which viewed persons with disabilities as sick and vulnerable and needing to be cared for and separated from society .... Used indiscriminately, this model has resulted in excessive segregation, institutionalization and dependence .... This was further reinforced when the Medicaid program established nursing home as a mandatory benefit. Id.


37. See Harrington, supra note 35, at 1-2. See also ANDY SCHNEIDER ET. AL., THE KAISER FAMILY FOUNDATION, MEDICAID ELIGIBILITY FOR THE ELDERLY 4-5 (1999) (discussing the meaning of the terms “mandatory” and “optional” as used in reference to the Medicaid program,) “State participation in Medicaid is voluntary.” Id. at 5. If they choose to participate, states must provide basic benefits to certain populations. States may offer additional benefits or offer benefits to other groups that are defined in federal law.

38. See 42 U.S.C. §§ 1396n(c)(3), 1396a(a)(10)(C)(i)(III) (2000). Medicaid’s financial eligibility criteria differ for institutional and community-based services. Generally speaking, in 1999 an individual with a disability who lived in the community could get Medicaid if his income were no more than $500 per month (the income limit for the federal Supplemental Security Income program) while states could allow an individual to qualify for institutional LTC if his income were
for about 1.6 million people. States can adopt Medicaid's personal care option to provide LTC services to physically disabled adults who live in the community. This service includes assistance with dressing, bathing and other activities of daily living. If the state chooses to offer personal care, an entitlement is created for all individuals who meet the medical necessity criteria for the service, yet the personal care option is not equivalent to nursing home services. The financial eligibility standard for this program is lower than for nursing home services, therefore, some people are denied personal care even though they meet the financial eligibility criteria for nursing home care. In most states, the personal care benefit is less comprehensive than nursing home care and is targeted to beneficiaries who are less disabled than nursing home residents. Thirty-one states and the District of Columbia provide optional personal care services.

Home and Community Based Services (HCBS) waiver programs are quite different. Congress authorized the waiver programs in 1981 "[t]o provide an alternative to the 'institutional bias' of the Medicaid program" by providing services in the community to people who would otherwise reside in a nursing home, hospital or facility for the mentally retarded. See Medicaid Recipients by Type of Service (last visited Jan. 21, 1998) http://www.hcfa.gov/medicaid/2082-4.htm.


See Harrington, supra note 35, at 6. The Administration's FY 2001 Budget proposes to allow states to set income eligibility for personal care services at 300% of the Supplemental Security Income limit, as they can for nursing home services. See U.S. Dep't of Health & Human Services FY2001 BUDGET at 69. This option is estimated to cost $140 million over five years. Id. at 75.

See Harrington, supra note 35, at 28-34.

See Id. at 12.


States with HCBS waivers can provide an array of supportive services, such as adult day programs, assistive devices or respite care, that are necessary to allow an individual to live in the community but are otherwise unavailable through the Medicaid program. Waiver programs can use the same financial eligibility standards used for nursing home services.

Waiver programs are limited in ways that nursing home services are not. HCBS waivers are optional for the state, require special approval from the federal government, and must cost no more than institutional care. For beneficiaries, the major shortcoming of HCBS waivers is that they do not create an entitlement to services: the state sets a limit on the number of people it will serve and is not required to offer services statewide. Many waiver programs have waiting lists of individuals who are eligible for services but are not being served. All fifty states operate one or more HCBS waiver programs for older people and/or younger adults with physical disabilities. In 1997, these waivers served 326,000 people at

(visited Jan. 3, 2000).

48. See Harrington, supra note 35, at 60. HCBS waiver programs also may cover services provided in residential care settings, such as assisted living residences for older people. See 42 C.F.R. § 441.310(a)(2) (1999). While Medicaid can pay for services provided in community residential settings, beneficiaries are responsible for the cost of rent and meals. See Id.


50. See 42 U.S.C. § 1396n(c)(2)(D) (2000). The aggregate per capita cost of HCBS waiver services may not exceed the aggregate per capita cost that the state would incur in the absence of the waiver (i.e. if people were served in institutions). See id. See also Harrington, supra note 35, at 60.


53. See Harrington, supra note 35, at 63-66. Waiting lists typically develop in two ways: (1) enrollment in the waiver reaches the limit set by the state and approved by HCFA, or (2) enrollment has not reached the limit but the state has not appropriated sufficient funds to operate the waiver at full capacity. See id. at 66. States sometimes use their own funding to provide community-based care for those who are waiting for waiver services. “A majority of [state-funded programs for older persons] serve people who are on waiting lists for other Medicaid services: 33 of 54 programs serve people on waiting lists for Medicaid waiver services and 31 of 54 programs serve people on waiting lists for a nursing home bed.” Kassner and Williams, supra note 33, at 6.

54. See STEVEN LUTZKY, ET. AL., THE LEWIN GROUP, REVIEW OF MEDICAID 1915(c) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAM LITERATURE AND PROGRAM DATA 6 (2000). Arizona operates an HCBS program
a cost to the states and federal government of $1.7 billion.\textsuperscript{55}

2. \textit{Medicaid for People with Mental Retardation or Developmental Disabilities: Progress Toward Community Care}

Until the 1970s, states had primary responsibility for providing services to people with mental retardation or developmental disabilities. Concern about quality of care in state institutions encouraged Congress to amend Medicaid in 1971 to allow states to fund intermediate care facilities for people with mental retardation (ICF/MR).\textsuperscript{56} An ICF/MR is an institution serving four or more residents that provides ongoing evaluation, 24-hour supervision, and rehabilitative services "to help individuals function at their greatest ability."\textsuperscript{57}

Like personal care services, ICF/MR services are optional, however, once adopted by the state, they create an individual entitlement to care in this setting. States may use the more generous financial eligibility criteria available to nursing home applicants for ICF/MR applicants.\textsuperscript{58} Nationwide, an estimated 129,000 people receive services in 7,400 ICFs/MR. More than half of these people are served in facilities with more than fifty residents.\textsuperscript{59}

States have used HCBS waivers to finance a variety of community supports, including prevocational services and supported employment for people with developmental disabilities.\textsuperscript{60} As noted earlier, HCBS waivers can offer the more generous financial institutional eligibility criteria, but may not be available statewide and may have long waiting lists for

\textsuperscript{55} See id. at 9-10.
\textsuperscript{56} See Congressional Research Serv., supra note 46, at 64.
\textsuperscript{59} See ICF/MR Program Trends (visited Aug. 2, 2000) http://www.hcfa.gov/medicaid/icfmr/icftrend.htm. The size of ICFs/MR have been declining since the 1970s. The average number of people served per ICF/MR declined from 185 in 1977 to 23 in 1992. Despite this decline, "the majority of people served by the program still reside in large public ICFs/MR (as of June 1996, 88% of facilities had 16 or fewer certified beds, but 63% of the people served lived in facilities that served 17 or more people, and 57% of all people served lived in facilities that served more than 50 people.)" Id.
services. In 1998, state and federal governments spent more than $7 billion on HCBS waiver services for an estimated 240,321 people with mental retardation or developmental disabilities.

3. Medicaid Provides Limited Services for People with Mental Illness

Historically, state governments were solely responsible for services for people with mental illness. Medicaid law perpetuates this trend by prohibiting states from using Medicaid to fund institutional mental health services for adults age twenty-two through sixty-four, a provision known as the "IMD exclusion." State Medicaid programs may provide institutional care for elders and children with mental illnesses.

In 1986, Congress amended the Medicaid HCBS waiver program to permit states to offer community-based services to people with mental illness but retained the IMD exclusion. As a result, HCBS waiver services are available to non-elderly adults only if they would otherwise

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61. The Arc, an advocacy organization for people with mental retardation, has documented the size of waiting lists for HCBS waivers and other community service programs for people with mental retardation. In 1987, The Arc reported that, nationwide, approximately 139,673 people with mental retardation were waiting to receive one or more community services. This is somewhat of an over-estimate because some people were on more than one waiting list. Ten years later the Arc found a total of 223,562 people with mental retardation waiting for community services. See Sharon Davis et al., The Arc, A Status Report to the Nation on People with Mental Retardation Waiting for Community Services 2 (1997).


64. See 42 U.S.C. § 1396a(a)(27)(B) (2000). The statute prohibits payment for services to "Institutions for Mental Disease," defined as any residential setting with more than 16 beds which primarily provides services to people with mental illness. Id.

be served in an ICF/MR, nursing home or non-psychiatric hospital. Only one state has attempted to operate such a waiver.

Two optional Medicaid services are important for providing mental health services to adults with serious mental illness. Thirty-nine states offer psychiatric rehabilitation services. Twenty-six states have opted to target case management services to adults with mental illness.

4. Medicaid Spending Reflects the Law’s Institutional Bias

In 1999, total federal and state Medicaid spending for LTC was $62.4 billion. Of this, 74% purchased institutional care ($36.4 billion for nursing home and $9.6 billion for ICF/MR care.) The 26% spent on community-based care included HCBS waiver programs ($10.6 billion), personal care ($3.5 billion) and home health care ($2.2 billion). These figures actually represent a dramatic increase in the provision of community care over the past ten years: “[H]ome care spending as a percentage of total Medicaid long term care spending more than doubled - from 10.8 percent in 1987 to 24.0 percent in 1997.”

C. Legislative Proposals for Expanding Community Services in Medicaid

Two recent proposals for reforming the Medicaid program suggest ways to expand access to community-based services for people with disabilities. These proposals attempt to place community services on equal footing with institutional care. They do not address the needs of the large population of people with disabilities who are less severely impaired and, therefore, would not qualify for institutional care.

67. See id. Colorado has an HCBS waiver for individuals with serious mental illness who would otherwise reside in a nursing facility. Id.
68. See id. at 8. See also 42 U.S.C. § 1396d(a)(13).
69. See Bazelon Center, supra note 66, at 9. See also 42 U.S.C. § 1396n(g) (2000).
71. Id. at 2.
In 1997, Senator Russell Feingold of Wisconsin introduced S. 879, proposing a community LTC program similar to the Medicaid and state-funded programs available in his home state.72 This bill would have allowed states to provide community services through their Medicaid programs without a waiver and without creating an individual entitlement to community benefits.73 A national standard would replace state discretion to determine what degree of impairment requires institutional care,74 however, states would still decide what services are provided.75 This approach would revamp current HCBS waiver authority: special federal permission and cost-neutrality would no longer be required but states would retain flexibility in designing services and the ability to limit the number of people in the program.

The Medicaid Community Attendant Services and Supports Act (MiCASSA), developed by disability advocacy groups, was introduced late in 1999 by Senators Tom Harkin of Iowa and Arlen Specter of Pennsylvania.76 This bill would require states to provide community services to people with disabilities who qualify for nursing home or ICF/MR care.77 The services provided under MiCASSA include assistance with activities of daily living and household management,

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73. See S. 879 § 101(b), § 102(b) (1999).

74. See S. 879 § 103(a). People who, because of a physical or cognitive impairment, need assistance with three or more activities of daily living and those with severe or profound mental retardation would be eligible for services. The Secretary of Health and Human Services would develop a protocol for determining disability. See id.

75. See S. 879, § 104(a) (1999).

76. See 145 Cong. Rec. S14,642 (daily ed. Nov. 16, 1999) (statement of Senator Specter). The disability groups first proposed the Medicaid Community Attendant Services Act (MiCASA), which was introduced by former Speaker of the House Newt Gingrich (R-Ga.) and Minority Leader Richard Gephardt (D-Mo.) in 1997. The groups redesigned and renamed the Medicaid Community Attendant Services and Supports Act (MiCASSA) in 1999, to clarify its intent to serve equally people with physical and cognitive disabilities. Reintroduction of MiCASSA was delayed until Olmstead was decided. See Update on MiCASSA, June 1, 1999, at www.adapt.org/casa/update.htm (visited Oct. 12, 1999).

similar to the current personal care option, but with an emphasis on the ability of the personal care attendant to accompany the individual with disabilities in the community (to school, work, etc). The bill excludes assistive devices and home modifications, services currently provided by some states through HCBS waivers. Unlike the current personal care option or HCBS waiver program, MiCASSA creates a “quasi-entitlement” to services. The bill specifically requires states to give individuals who qualify for institutional care the choice of receiving services in the community instead. Yet, this choice is only guaranteed if the aggregate federal spending on community services does not exceed what would have been spent on institutional care for those beneficiaries. If federal spending is higher, the state may limit the program by denying entry to additional beneficiaries or through other unspecified measures.

D. Challenging the LTC System Through the ADA: Precursors to Olmstead

Two Third Circuit cases set the stage for the Supreme Court’s decision in Olmstead by tackling the issue of whether the ADA’s integration mandate requires states to provide LTC services in the community. Easley v. Snider found no violation of the ADA when two cognitively impaired women living in an institution were denied placement in a community program for physically impaired people who are mentally alert. In Helen L. v. DiDario, a physically disabled and mentally alert nursing home resident sought placement in the same community program. Here, the denial of community care was a violation of the ADA.

Easley v. Snider Plaintiff Tracey Easley suffered a head injury in a car accident which left her with little mobility and no ability to speak. She could communicate with her family through facial expressions and blinking, but could not communicate sufficiently to manage a personal care worker by herself. A second plaintiff, Florence Howard, had multiple sclerosis and undifferentiated schizophrenia. She needed

79. See id.
83. See 46 F.3d at 336.
84. See Easley, 36 F.3d at 299.
attendant services to help with physical tasks and a surrogate to help manage the attendant.\textsuperscript{85} Ms. Easley and Ms. Howard were denied admission to Pennsylvania's state-funded Attendant Care Program because it only serves mentally alert adults who can direct their own services.\textsuperscript{86} The plaintiffs challenged the program requirement that beneficiaries must be mentally alert and able to manage their attendant services independently, but did not contest the state's assertion that they required surrogates to direct their attendant services.\textsuperscript{87} In fact, Ms. Easley received attendant care services funded by the state program for several years, because the agency that served her allowed her mother to act as a surrogate.\textsuperscript{88}

Idell S., the plaintiff in Helen L. and the mother of two children, was paralyzed from the waist down from infection with meningitis.\textsuperscript{89} She needed assistance with bathing, getting in and out of bed, and some household chores, but could perform most of her dressing/grooming tasks and could cook independently.\textsuperscript{90} Idell S. was eligible for the Attendant Care Program, but was placed on a waiting list for services because the program lacked sufficient funding to serve all applicants.\textsuperscript{91}

The common question in Easley and Helen L. is whether the plaintiffs are qualified individuals with disabilities. The Attendant Care Program requires participants to self-direct their own services, i.e. the participant hires, trains, and discharges his or her personal care attendant.\textsuperscript{92} Helen L. Plaintiff Idell S. met the criteria for participation in the program, thus was clearly a qualified individual with a disability.\textsuperscript{93} Ms. Easley and Ms. Howard did not meet the program's stated criteria of mental alertness.

\textsuperscript{85} See id.
\textsuperscript{86} See id. at 299-300.
\textsuperscript{87} See id.
\textsuperscript{88} See id. In 1991, Ms. Easley moved to an area served by a different agency that did not allow her to use a surrogate. Id.
\textsuperscript{89} See Helen L. v. DiDario, 46 F.3d 325, 328 (3d Cir. 1995), cert. denied sub nom. Pennsylvania Sec'y of Pub. Welfare v. Idell S., 516 U.S. 813 (1995). (Helen L., the initial plaintiff, was discharged from the nursing home and subsequently dropped her ADA claim. The case was continued by Beverly D. and Ilene F. who joined as plaintiffs with Helen L. in 1992. They, too, left the nursing home and dismissed their claims. Idell S., who intervened in the lawsuit in 1994, was still in the nursing home when the case was decided by the Third Circuit early in 1995.) See id. at 327-28.
\textsuperscript{90} See id. at 328.
\textsuperscript{91} See id. at 329.
\textsuperscript{92} See Easley, 36 F.3d at 299.
\textsuperscript{93} See Helen L., 46 F.3d at 329.
Easley illustrates how the state’s fundamental alteration defense can be evaluated when the plaintiff needs reasonable accommodation to meet the state program’s eligibility criteria. The Easley court had to determine whether use of a surrogate was a reasonable accommodation that would allow the plaintiffs to obtain the program’s benefits or was a fundamental alteration of the program. If the mental alertness requirement goes to the “essential nature of the program,” the use of a surrogate would be a fundamental alteration of the program and would not be required. 94 If mental alertness is not essential to obtaining the benefits of the program, the modification requested by the plaintiffs is reasonable and the state must allow use of the surrogate. 95

To determine whether the requirement was essential to the purpose of the program, the court evaluated both the stated purposes and benefits of the program and the actual services it offered. 96 The Third Circuit was convinced that the benefit of the program went beyond simply receiving personal care from an attendant and that an individual’s control over the provision of personal care was an essential benefit unattainable by someone acting through a surrogate. 97 Thus, “[a]llowing a decision by a surrogate is at complete odds with the program objectives” and would fundamentally alter the program. 98

Oddly, the Third Circuit did not consider a key fact about Tracey Easley - she had participated in the Attendant Care Program for four years. The court excluded Ms. Easley’s experience as a program participant from its evaluation of the actual services provided by the attendant care program. Because she was able to communicate her preferences to her mother, who could then inform the attendant, Ms. Easley did exercise individual control over the provision of personal care through use of a surrogate. 99

94. Easley, 36 F.3d at 302.
95. See id.
96. See id. at 300-304.
97. See id. at 303.
98. Id. at 304.
99. A related issue in Easley was whether the mental alertness requirement discriminated against the class of people who are both physically and cognitively impaired. The ADA requires compliance with its non-discrimination provisions, but allows states to offer additional benefits or advantages to specific classes of people with disabilities. See 28 CFR § 35.130(c) (1999). The court used its analysis of the essential nature of the program to determine whether the mental alertness requirement discriminated against individuals with mental disabilities or was used to provide additional benefits to the class of individuals with physical disabilities. Because mental alertness was deemed essential to attaining the
Helen L. directly considers whether the ADA’s integration mandate requires states to provide community-based services to qualified individuals with disabilities. Idell S. claimed that the state violated the ADA’s requirement to provide services in the most integrated setting appropriate to her needs. The court examined the history and language of the ADA, observing that Congress required its regulations to adhere to the principles of the Sec. 504. This reaffirmed the validity of the integration mandate in the context of the ADA, a much broader civil rights law than the Rehabilitation Act. In enacting the ADA Congress clearly defined unnecessary segregation as impermissible discrimination against people with disabilities. The court concluded that the state had an obligation to serve Idell S. in the community unless doing so would require a fundamental alteration to the community program.

In Helen L., the Third Circuit court rejected a fundamental alteration defense based upon the state’s system of financing services for people with disabilities. The state argued that it could not provide a community placement for Idell S. because the administering agency lacked sufficient funding in the community program to admit her. Under the state constitution, the head of the agency could not transfer funds appropriated by the legislature for nursing home services into the budget for community services. The court was unconvinced by this argument.

The court noted that the stated purpose of the Attendant Care Program, increasing the availability of community services for people with disabilities, is similar to the goal of the ADA’s integration mandate. Providing Idell S. services in her own home placed no undue burden on the state, but “merely requires [the state] to fulfill its own obligations under state law.” The court rejected the state’s claim of inadequate funds, observing that providing services to Idell S. in her home would save

program’s benefits, the Third Circuit held that the attendant care program offered an additional benefit to physically disabled people who are capable of self-direction without discriminating against those who have both physical and cognitive impairments. See Easley at 302-06.

100. See Helen L., 46 F.3d at 332.
101. See id.
102. See id. at 330-33.
103. See id. at 336.
104. See id. at 320. The cost of nursing home care was $45,000 per year, of which the state paid $19,800 (the rest was paid by the federal government through the Medicaid program). The average cost per person in the community program was $10,500 per year. See id.
105. See id. at 337-38.
106. Id.
the state an average of $34,500 per year.\textsuperscript{107} The court added that the Pennsylvania legislature falls within the purview of the ADA and has a duty to properly finance its nursing home and community programs.\textsuperscript{108} Because the state offered community services for which the plaintiff was qualified, and failed to show that providing such services constituted a fundamental alteration of the program or undue burden on the state, the court held that it must serve Idell S. in the community.\textsuperscript{109}

Although the Supreme Court denied certiorari in \textit{Helen L.},\textsuperscript{110} the case attracted national attention and set the stage for the Court's decision in \textit{Olmstead}. The federal government made its first pronouncement on how the courts should interpret the integration mandate in an \textit{amicus} brief submitted on behalf of the plaintiff in \textit{Helen L.}\textsuperscript{111} When \textit{Olmstead} arose from the Eleventh Circuit seeking guidance on the same part of the law, twenty-two states signed an \textit{amicus} brief urging the Supreme Court to hear the case.\textsuperscript{112} The Court granted \textit{certiorari} because of the importance of the issue to individuals and states.\textsuperscript{113} In the \textit{Olmstead} opinion, the Court accepts, in large part, the federal government's interpretation of the integration mandate as articulated in its \textit{amicus} brief for the plaintiff in \textit{Helen L.}

\textbf{E. Summary of Olmstead}

Lois Curtis, now known nationally as "L.C.,” is a thirty-one year old Georgia citizen with mild mental retardation and schizophrenia. First hospitalized for psychiatric care at age fourteen when her disabilities caused behavior that her mother could not manage, she moved in and out of the state mental hospital eighteen times in fourteen years. While the state provided L.C.'s inpatient care, if offered no community services for either mental illness or mental retardation when she lived with her mother or in a personal care home.\textsuperscript{114} In 1995, when she filed suit against

\begin{footnotesize}
\begin{enumerate}
\item See id. at 338.
\item See id.
\item See id.
\item See \textit{Olmstead v. L.C.}, 527 U.S. at 596, n.8. Only seven states joined an \textit{amicus} brief in support of Georgia when the case was heard. See id.
\item See id.
\end{enumerate}
\end{footnotesize}
the state for violating the ADA by failing to provide services in the most integrated setting, L.C. was confined in a locked, acute care psychiatric hospital although she had been approved for community placement three years earlier. She moved to a three-person group home in 1996 and was living there in 1999 when the Supreme Court ruled on her case.

Elaine Wilson, who intervened in the case as “E.W.,” has mild mental retardation and brain damage resulting from meningitis. She had been homeless for twenty years after being discharged from a mental retardation facility, was repeatedly admitted and discharged from the psychiatric hospital, and had been placed in personal care homes in the community that lacked services for mental disabilities. E.W. was eventually discharged to the same group home as L.C., and was receiving supportive services in her own apartment at the time the Supreme Court heard Olmstead.

Plaintiffs L.C. and E.W. argued that the state, having committed itself to offering both institutional and community mental health services, was required to serve L.C. and E.W. in the most integrated setting appropriate to their needs. Because the hospital’s treating psychiatrist concluded that L.C. and E.W. could be served in the community, the state discriminated against them by failing to move them to a community program. The state countered on two points. First, the state argued that L.C. and E.W. had failed to state a claim for discrimination because they had not shown that Georgia treated them differently from a comparable group of non-disabled individuals. Second, the state contended that treating the women in the community would fundamentally alter its community program because the state lacked funding for those services.

The United States District Court for the Northern District of Georgia granted partial summary judgment for the plaintiffs, holding that unnecessary segregation of the women in the hospital constituted discrimination by reason of disability and violated Title II of the ADA. The district court rejected the state’s fundamental alteration defense, noting that (1) the services the state’s existing program provides in the

117. See id. at 2.
118. See Olmstead, 527 U.S. at 594.
119. See id. at 593-94.
120. See id. at 594.
121. See id.
community are the type of services for which L.C. and E.W. qualify, and (2) the cost of caring for L.C. and E.W. in the community would be considerably less than the cost of their care in the institution.\footnote{122}

The Eleventh Circuit Court of Appeals upheld the finding of discrimination but remanded for reconsideration of the state's fundamental alteration defense.\footnote{123} The appellate court concluded that the state's cost-based defense should get a more thorough review, but suggested that the ADA may require Georgia to incur additional costs to serve L.C. and E.W. in the community unless the state could prove that the incremental costs would "be so unreasonable given the demands of the State's mental health budget that it would fundamentally alter the service."\footnote{124} On remand, the district court held that the additional cost to the state was not unreasonable in comparison to its total mental health budget.\footnote{125}

The Supreme Court affirmed that unjustified segregation of individuals with disabilities is discrimination prohibited by the ADA.\footnote{126} The Court cited both the ADA's findings that identify segregation and isolation as forms of discrimination and the regulatory mandate to provide services in the most integrated setting.\footnote{127} The Court understood the ADA as responding to two harms caused by segregation that are tantamount to discrimination: (1) depriving individuals with disabilities of the benefits of everyday life in the community, such as social interaction, cultural pursuits, education and employment, and (2) stigmatizing people with disabilities by perpetuating an unwarranted belief that they are unable or unworthy of living in the community.\footnote{128}

The Court rejected the notion that discrimination against people with disabilities could only exist in relation to treatment of non-disabled individuals, commenting that Congress had a broader concept of discrimination in mind when enacting the ADA.\footnote{129} Nonetheless, the

\begin{itemize}
  \item \footnote{122}{See id. at 594-595.}
  \item \footnote{123}{See id. at 595.}
  \item \footnote{124}{L.C. ex. rel. Zimring v. Olmstead, 138 F.3d. 893, 905 (11th Cir. 1998).
  \item \footnote{125}{See Olmstead v. L.C., 527 U.S. at 596 n.7. The state's appeal of the district court's decision on remand was pending in the Eleventh Circuit at the time the Supreme Court made its decision. This appeal was subsequently remanded to the district court in December 1999. See L.C. v. Olmstead, 198 F.3d 1259 (11th Cir. 1999).
  \item \footnote{126}{See Olmstead v. L.C., 527 U.S. at 597.}
  \item \footnote{127}{See id. at 600.}
  \item \footnote{128}{See id. at 600-01.}
  \item \footnote{129}{See id. at 598.}
\end{itemize}
Court commented that L.C. and E.W. were treated differently from non-disabled individuals in obtaining medical care. Because of their mental disabilities, L.C. and E.W. had to "relinquish participation in community life" to obtain medical care in an institution while people who do not have mental disabilities could receive medical services in the community.\textsuperscript{130}

The \textit{Olmstead} opinion set parameters on its finding that unnecessary segregation is discrimination. The opinion is careful to assure that the ADA does not require large scale deinstitutionalization of people with mental illness.\textsuperscript{131} The state's professionals may determine whether an individual is capable of living in the community and meets the essential eligibility requirements of a community program.\textsuperscript{132} The ADA does not require states to offer certain benefits to people with disabilities; it only requires that services already offered be provided in a non-discriminatory manner.\textsuperscript{133}

The constitutionality of the ADA was not at issue in the \textit{Olmstead} case.\textsuperscript{134} The decision construed the statute and its regulations, without commenting on their validity.\textsuperscript{135} This limitation on the holding is significant because some states have claimed that Title II of the ADA violates their Eleventh Amendment right to sovereign immunity. This issue is on the Court's docket for the 2000-2001 term: \textit{certiorari} has been granted in \textit{University of Alabama Board of Trustees v. Garrett}, an employment case from the Eleventh Circuit.\textsuperscript{136}

\textsuperscript{130} \textit{Id.} at 601.
\textsuperscript{131} \textit{See id.}
\textsuperscript{132} \textit{See id.} at 602.
\textsuperscript{133} \textit{See id.} at 603 n.14.
\textsuperscript{134} \textit{See id.} at 589.
\textsuperscript{135} \textit{See id.} at 592.
\textsuperscript{136} 193 F. 3d 1214 (11th Cir. 1999), \textit{(cert granted}) 120 S.Ct. 1669. Congress clearly intended the ADA to abrogate the states' Eleventh Amendment immunity from suits in federal court. \textit{See} 42 U.S.C. § 12202 (2000). The findings of the ADA highlight continuing discrimination against people with disabilities in many areas typically regulated or administered by states, such as housing, education, transportation, recreation, institutionalization, health services, voting and public services. \textit{See} 42 U.S.C. § 12101 (2000). From this, one can infer that Congress abrogated state immunity in response to state discrimination against people with disabilities. In \textit{Alsbrook v. City of Maumelle}, 184 F.3d 999 (8th Cir. 1999), the Eighth Circuit found the ADA language inadequate to abrogate state immunity because it failed to document widespread state discrimination against people with disabilities. While the ADA clearly states an intent to abrogate state immunity, and was enacted pursuant to Section 5 of the Fourteenth Amendment, the Eighth Circuit found it lacked "congruence and proportionality" to the extent of the
Olmstead holds that where a state's treatment professionals determine that an individual can be served in a community program and the person would prefer community treatment, the state is obligated to serve that person in the community unless doing so would cause a fundamental alteration to the community program. The opinion describes the parameters of fundamental alteration in Section III-B, in which Justice Ginsburg was joined by Justices O'Connor, Souter and Breyer. While this section is dicta, it is influencing the way that advocates, states and the federal government are responding to this decision. Section III-B would allow the state to defend against an alleged violation of Title II of the ADA by contending that "in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities." The Court rejected the Eleventh Circuit's interpretation of the fundamental alteration defense as too limited. The appeals court would allow the state to compare the costs of serving L.C. and E.W. to its entire mental health budget. This construction effectively excludes costs from the fundamental alteration defense because a state is unlikely to encounter a situation where the costs of serving a few more people would appear large compared to its overall program budget. The Court cited the state's responsibility to make institutional care available to those who need it and to equitably serve a diverse group of people with disabilities. To meet these obligations, states need more leeway in demonstrating the problem of discrimination by state governments against the people with disabilities. See Alsbrook, 184 F.3d at 1005-09. The Eleventh Circuit in Dickson v. Florida Department of Corrections held to the contrary. Dickson held that the ADA includes a clear statement of Congressional intent to abrogate immunity, identifies people with disabilities and a "discrete and insular minority" in need of Fourteenth Amendment protection, and is a proper exercise of congressional power under the Fourteenth Amendment. See Dickson v. Fa. Dept. of Corr., 139 F.3d 1426, 1433 (11th Cir. 1998). The Supreme Court granted certiorari to hear Alsbrook and Dickson during the Spring 2000 term; however, both cases settled and certiorari was dismissed. See ABA Commission on Mental & Physical Disability Law, Supreme Court Watches as Parties Play Musical Chairs with ADA Sovereign Immunity Question, at http://www.abanet.org/disability/reporter/alert.html (visited Mar. 2, 2000).

138. See id. at 587.
139. Id. at 604.
140. See id.
141. See id.
impact of costs in a fundamental alteration defense.\textsuperscript{142}

Because Title II and its regulations do not define fundamental alteration in the context of public benefits, the Court looked to the "undue hardship" defense used in employment cases. This test requires a balancing of the cost of the accommodation, size of the program's budget, and type of operation being conducted by the program. The Court found the Eleventh Circuit's standard for a fundamental alteration much stricter than this undue hardship test.\textsuperscript{143}

The plurality opinion further suggests that a state could legitimately claim that community placement would fundamentally alter its community program if: (1) the state has a comprehensive, effectively working plan for placing qualified persons with disabilities in community settings, (2) the waiting list for community services moves at a reasonable pace, and (3) the movement of the waiting list is not controlled by the state's desire to keep its institutions fully populated.\textsuperscript{144} The movement of the waiting list can be influenced by the amount of resources available to the state and the needs of other individuals with disabilities.\textsuperscript{145}

II. Analysis: Olmstead Creates a Framework to Reshape LTC Services, But Leaves a Critical Question Unanswered

Olmstead v. L.C. has the potential to reshape the way in which LTC services are provided, so that community services are favored over institutional care. The "integration mandate" prohibits discrimination against qualified individuals with disabilities,\textsuperscript{146} which the ADA defines to include both physical and mental impairments.\textsuperscript{147} Thus, while Olmstead involves services for people with mental disabilities, the principles espoused by the ADA, as interpreted by the Supreme Court, apply to LTC services for any disabled population.

Olmstead balances individual and collective rights to ensure that LTC programs meet the integration requirements of the ADA. On the one hand, the decision strengthens the individual's claim for community placement, while on the other hand it expands the state's defenses against that claim. The case does not answer the central question: What does "fundamental alteration" mean in the context of community-based service

\begin{itemize}
\item[142.] See id. at 605.
\item[143.] See id. at 606 n.16.
\item[144.] See id. at 605-06.
\item[145.] See id.
\item[146.] See 28 C.F.R. § 35.130(d) (1999).
\item[147.] See 42 U.S.C. § 12102(2) (2000).
\end{itemize}
A. Strengthening Individual Rights

Two aspects of the Olmstead decision strengthen individual rights: the declaration that unnecessary segregation equals discrimination and the requirement that states ensure that any waiting lists for services move at a reasonable pace. Equating unnecessary segregation with discrimination creates an entitlement for community treatment services (albeit with significant limitations). Requiring that waiting lists for community programs move at a reasonable pace establishes an outcome against which to measure the effectiveness of a state's efforts to end unnecessary segregation.

Olmstead is a victory for people with disabilities because it recognizes the discrimination many have faced through unnecessary segregation. A long term care system which primarily funds institutional care when community care is appropriate deliberately segregates people with disabilities. "People with severe physical disabilities have been forced to live in institutional facilities not because they needed segregated settings... [but] because historically that was the way people with disabilities were kept out of sight and away from the public." In the past, courts have minimized the loss of freedom experienced by individuals who enter institutions, considering it an inevitable consequence of disability.

By linking the ADA finding that segregation is discrimination to the integration mandate and applying the provisions in tandem to public LTC programs, Olmstead clearly demonstrates the need to provide services in the community. The Court's holding that the ADA does not require states to develop new services or programs seems contrary to these provisions. If unnecessary segregation is discrimination and services must be provided in the most integrated setting appropriate to the needs of the individual, how could a state justify offering only institutional services to people who could remain in the community with assistance?

When considered together, the anti-discrimination provision and the


150. Id. at 7-8.

151. See id.
integration mandate seem to create a limitless entitlement to community services for qualified individuals with disabilities. The Court limited this entitlement, however, by allowing the state to raise a cost-based fundamental alteration defense to the integration mandate. The plurality opinion in Section III-B of the *Olmstead* decision suggests that a state may have a defense against an ADA claim if it has a comprehensive plan to end unnecessary segregation and any waiting list for community services moves at a "reasonable pace."\(^{152}\) *Olmstead* does not address what constitutes a "reasonable pace," but lower courts have considered this question.

In *Kathleen S. v. Department of Public Welfare*, the state of Pennsylvania sought to move three people per month from a state psychiatric hospital to community programs, completing the transition in three years.\(^{153}\) The district court found this progression too slow, agreeing with the plaintiffs, who recommended moving five people per month for a transition period of eighteen months. The court based its ruling on past experience of the state in moving residents out of a different psychiatric hospital.\(^{154}\) The state appealed the judgment to the Third Circuit, which urged the parties to settle in light of the decision handed down by *Olmstead*.\(^{155}\) The settlement agreement allowed the state three additional months to place members of the plaintiff class in the community.\(^{156}\) The


\(^{154}\) See id. at 472.


\(^{156}\) See *Kathleen S.*, 10 F. Supp. 2d at 472. In a different context, the Eleventh Circuit upheld a ruling that individuals with developmental disabilities must receive services within 90 days of being determined eligible for Medicaid. In *Doe v. Chiles* the plaintiff class consisted of people with developmental disabilities who were awaiting services in an [ICF/MR]. Some of the plaintiffs had been on the waiting list for several years. See *Doe v. Chiles*, 136 F.3d 709, 711 (11th Cir. 1998). The class relied on a section of Medicaid law that requires states to provide necessary medical services with "reasonable promptness." 42 U.S.C. § 1396a(a)(8) (2000), cited in *Doe v. Chiles*, 136 F.3d at 711-12. The Eleventh Circuit agreed that this statutory requirement vested a right in the individual, and upheld an injunction ordering the state to provide services within 90 days of disabled applicants becoming eligible for Medicaid. *Id.* at 718. This case did not contain an ADA claim, nor does it require community-based services. It is important because it recognizes a private right of action to enforce Medicaid's "reasonable promptness" requirement which some people waiting for services can use in addition to an ADA claim. See *id.* at 719.
state's prior experience in deinstitutionalizing people with disabilities is one factor that can be used to determine a reasonable pace.

While the "reasonable pace" at which a waiting list should move may be defined on a case-by-case basis, Olmstead's inclusion of this standard gives disability groups a means by which to measure a state's compliance with the ADA. If there is a waiting list for state services, the pace at which the waiting list moves is the measure of whether a state's comprehensive plan is effective. Advocates can support a claim that a state has not met Title II's requirements by documenting the length of time that people with disabilities wait for community services or showing that community placements can be successfully made at a specific rate.

B. Recognizing the State's Role in Addressing Collective Needs

The Olmstead decision creates only a limited right to community LTC for people with disabilities. As Justice Ginsburg phrased the issue faced by the Court, "we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes." That "qualified yes" means that the individual's right to community care is treated like a reasonable accommodation - it will be granted when feasible, given the state's commitment to serve others with disabilities. Thus, there is a balancing of the needs of the individual and the collective needs of people with disabilities, with the state as arbiter.

The Court also recognizes a state role in meeting the collective needs of people with disabilities through publicly funded services by holding that the Eleventh Circuit offered too limited a fundamental alteration defense. "To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below [allowed]." Section III-B of Olmstead provides this leeway by allowing states to develop and implement comprehensive plans to expand community programs. This permits the state to determine how it will meet its ADA requirements through policy, rather than through litigation. In an amicus brief supporting Georgia in Olmstead, states asserted their responsibility for determining the appropriate mix of settings where services are provided to people with disabilities: the ADA does not reflect Congressional intent to "usurp the states' prerogative to make these fundamental policy decisions themselves." The states were

158. Id. at 605.
concerned that Helen L. and the Eleventh Circuit's decision in Olmstead created a possibility that "piecemeal litigation rather than planning may now determine the manner in which services will be provided to individuals with disabilities." The United States Attorney General agreed that "nothing in the ADA suggests that courts must ignore the States' legitimate administrative concerns in accomplishing the transition of eligible individuals from institutional to community-based care.... States will need to locate appropriate community placements and determine which eligible individuals should receive priority for available slots." If the state makes its decisions in accordance with a comprehensive state plan, an institutionalized individual could not use litigation against the state as a means of "jumping" to the top of the waiting list for community services.

C. What is a "Fundamental Alteration?"

Prior to the Olmstead decision, the fundamental alteration defense was used in situations where the individual with disabilities was not "qualified" for the program without a reasonable modification to the program. Easley found a fundamental alteration of a program where the accommodation needed by the applicant would be at complete odds with program objectives. To determine whether the accommodation amounted to a fundamental alteration, the court closely examined the statutory and programmatic purposes and benefits of the program, giving some deference to the state's characterization of the population to be served, services provided and program goals. A fundamental alteration, therefore, would be found when admitting an individual to the program would require the state to modify policies to the point where the purposes of the program would no longer be met.

The lesson from Helen L. is that there is no fundamental alteration of a program where placement of a qualified individual in the community violates state restrictions on how money may be allocated. The inability of the administering agency to reallocate program funds was of no


160. Id. at 8.
161. Amicus Curiae Brief of the United States, supra note 111, at 22.
164. See Easley, 36 F.3d at 302-304. It is hard to distinguish this test from one where the focus is on whether or not the applicant is a "qualified" individual with a disability, i.e., do they meet the eligibility criteria that are necessary to enjoy the full benefits of the program. See id. at 302.
consequence to the Third Circuit. The community placement fit within the stated purposes of the program, if not within its budget.\textsuperscript{165}

\textit{Olmstead} allows states to apply the fundamental alteration defense when a qualified individual with a disability asserts her right to treatment in the most integrated setting. The decision adopts the Attorney General's interpretation of the integration mandate, making the individual's right to placement in the most integrated setting subject to the reasonable modification requirement when "such placement would . . . require an unreasonable change in state policy or a fundamental change in the state's treatment program[]."\textsuperscript{166} The reasonable modification language of Title II is no longer limited to the definition of "qualified individual with disabilities," but now applies to the integration mandate as well.

\textit{Olmstead} adopts this interpretation in dicta, because the plurality is concerned about the expense states will incur if they must provide both community and institutional care.\textsuperscript{167} \textit{Olmstead} suggests that a fundamental alteration of a state's program would exist if "in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the state has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities."\textsuperscript{168} The Court is sympathetic to the states' concern about the cost of providing community services, and fears that if forced to offer immediate relief, states would close institutions without providing appropriate community care.

The state \textit{amici} in \textit{Olmstead} argued that limited fiscal resources preclude states from providing community-based services for all individuals with disabilities.\textsuperscript{169} While community-based services are generally considered less costly than institutional care on a per capita basis, states may experience increased costs in the aggregate when moving people from institutions to community-based programs.\textsuperscript{170} The increased costs arise when the state moves many people into the community but is then unable to consolidate or close its institutions.\textsuperscript{171} The states were concerned that they would have to keep institutions open for those who

\textsuperscript{166} Amicus Curiae Brief of the United States, \textit{supra} note 111, at 9.
\textsuperscript{167} \textit{See Olmstead}, 527 U.S. at 604.
\textsuperscript{168} \textit{Id}.
\textsuperscript{169} \textit{See Amicus Curiae Brief of the United States, \textit{supra} note 159, at 4.}
\textsuperscript{170} Amicus Curiae Brief of the States, \textit{supra} note 111, at 21.
\textsuperscript{171} \textit{See id}.
need such care, while increasing spending on community-based care “until some unknown point at which there is a ‘fundamental alteration’ to its programs.”\textsuperscript{172} The plurality opinion in \textit{Olmstead} found it unlikely that a state could ever prevail under this construction of the fundamental alteration defense.\textsuperscript{173}

\textit{Olmstead} holds that a fundamental alteration would exist if the state had to create a new community-based program to offer services in the most integrated setting.\textsuperscript{174} As interpreted by the Second Circuit in \textit{Rodriguez v. City of New York}, \textit{Olmstead} does not require states to add a new benefit to an existing program.\textsuperscript{175} In \textit{Rodriguez}, the appellate court overturned a decision in which people with mental impairments were granted a permanent injunction against the New York Medicaid program under an ADA claim. The plaintiffs argued that New York discriminated against people with mental impairments in its personal care program because it did not provide safety monitoring as a service.\textsuperscript{176} The Second Circuit reasoned that safety monitoring was a new benefit needed to allow a new population (those with mental impairments) into an existing program for people with physical disabilities.\textsuperscript{177} In essence, the addition of a new benefit and new population would create a new program.

From the state’s perspective, the legislative parameters governing the program may be considered fundamental to the nature of the program. In

\begin{itemize}
\item \textsuperscript{172} Amicus Curiae Brief of the States, \textit{supra} note 159, at 8.
\item \textsuperscript{174} See id. at 603 n.14. See also, Amicus Curiae Brief of the United States, \textit{supra} note 111, at 20.
\item \textsuperscript{175} 197 F.3d 611, 619 (2nd Cir. 1999), \textit{(cert. denied)}, ___ S. Ct. ___, 2000 WL 869366 (U.S. Oct. 2, 2000) (No. 99-1240).
\item \textsuperscript{176} See id. at 613. The plaintiffs in \textit{Rodriguez} were people with cognitive impairments, including Alzheimer’s Disease, who could not be left safely alone at home. The service they requested, “safety monitoring,” would allow a caregiver to remain in their home to provide supervision, but without providing personal care tasks. \textit{Id.} at 614. New York’s personal care services include “some or total assistance with personal hygiene, dressing and feeding; nutritional and environmental support functions; and health-related tasks.” \textit{Id.} at 613. The plaintiffs argued that New York discriminated against people with mental disabilities by providing personal care services that were adequate to allow people with physical disabilities to live at home, but were inadequate for people with mental disabilities because they lacked the safety monitoring this group needs to live at home. \textit{Id.} at 614. The Second Circuit disagreed, commenting that the ADA does not require states to provide a certain level of benefits to people with disabilities. \textit{Olmstead}’s holding is limited to requiring non-discrimination in the services the state chooses to provide. \textit{Id.} at 619.
\item \textsuperscript{177} See \textit{id.} at 618.
\end{itemize}
the case of Medicaid HCBS waivers, for example, the state's ability to restrict the size of the program and limit the cost of services provided is very different from the rest of the Medicaid program. Are these factors fundamental to the nature of the HCBS waiver program? *Olmstead* does not reach this question, perhaps because Georgia operated its waiver program at one-third of its capacity.\(^\text{178}\) This question is likely to arise, however, as plaintiffs challenge such program characteristics as eligibility requirements related to severity of disability,\(^\text{179}\) placement or exclusion based upon dual diagnosis,\(^\text{180}\) and limits on the cost of community care relative to nursing home care.\(^\text{181}\)

### III. *Olmstead* is Necessary, But Not Sufficient, to Refocus the Public LTC System

Policymakers are taking seriously *Olmstead*'s statement that unjustified isolation in an institution is discrimination. President Clinton welcomed the decision, saying "I am pleased that the Supreme Court decision . . . upholds the purposes of the ADA by recognizing that unjustified isolation of institutionalized persons with disabilities is prohibited discrimination. This decision will increase access to home- and community-based long term care services and support of these persons."\(^\text{182}\) State policymakers have declared their intentions to comply with the integration mandate\(^\text{183}\) but have also expressed concern about the potential cost of expanding...

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\(^{178}\) See *Olmstead* v. L.C., 527 U.S. at 601.


\(^{181}\) See Charles M. v. Gilbert (W.D. Tex. 1998) (where plaintiff was denied HCBS waiver services because the cost of his care would exceed the cost of nursing home care) cited in *Amicus Curiae* Brief of the States, *supra* note 159, at 5.


community-based services. 184

Action to end the institutional bias in the LTC system is occurring slowly. In the year following the Olmstead decision, individuals and organizations filed more than 150 complaints with the federal government alleging that state governments are not providing services to people with disabilities in the most integrated setting. 185 The federal government has responded to Olmstead by investigating these complaints and by encouraging states to develop comprehensive plans to expand the availability of community-based services. 186

Although Olmstead's suggestion that states develop comprehensive plans for ending unnecessary institutionalization appears in dicta, advocates and some states have followed the Court's recommendation. As of July 26, 2000, the tenth anniversary of the ADA and the date some advocacy groups had set for all states to develop comprehensive plans, 187 seven states had an executive order or law in place to require an Olmstead plan by a specific date. 188 States have focused their implementation efforts primarily on people with developmental disabilities, rather than concentrating on those in institutions or at risk for institutionalization regardless of the type of disability. 189 Thirty-four states increased funding for HCBS in the year following the Olmstead decision; however, advocates attribute these increases to prior commitments and other reasons unrelated to Olmstead. 190 The public proclamations of federal and state policymakers and advocacy groups indicate a change in attitude resulting from Olmstead, but the institutional bias in the LTC delivery

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184. See Medicaid: Program Spending Second Largest Expense for 2000 State Budgets, NGA Says, 8 BNA'S HEALTH CARE POLICY REPORT 84 (2000). The National Governors' Association noted that Medicaid expenditures could rise if implementing the Olmstead decision results in increasing numbers of people with disabilities receiving LTC services in the community. See id.


186. See id. at 3.


189. See id. at 4.

190. See id. at 6.
system has not been corrected.

Olmstead offers states an opportunity to implement the ADA’s integration mandate in an orderly fashion. If the Court simply rejected the possibility of the state using a cost-based fundamental alteration defense, it would have created an immediate, individual entitlement to community-based services. The Court recognizes, however, that state HCBS programs currently lack the capacity needed to serve all qualified individuals with disabilities in the community and feared states would move people to the community without providing essential services. The plurality’s moderate position creates an individual entitlement, but allows states to fulfill their duties by developing comprehensive plans and implementing them over a reasonable time period. The Court’s decision is reasonable — too reasonable to end the institutional bias in long term care. This decision alone will not ensure that people with disabilities receive LTC services in the most integrated setting.

The impact of Olmstead is limited because it operates within the context of a biased LTC system. The Court referenced the institutional bias in Medicaid in the past tense, noting the availability of HCBS waivers. Although HCBS waivers have been available for two decades, and in some states the programs are quite large, they operate under statutory language intended to create demonstration projects rather than sustain service delivery systems. State action alone will not end the institutional bias in Medicaid.

Olmstead’s promise to end unnecessary institutionalization will be fulfilled only if states dramatically expand community-based programs. There are many things states can do to expand HCBS under current Medicaid law: adopt the Medicaid personal care option; operate HCBS waivers statewide; increase the number of people served through HCBS waivers; expand rehabilitation services; provide targeted case management to people who want to leave institutions; and elect the more generous financial eligibility criteria available under current law.

192. See CONGRESSIONAL RESEARCH SERV., supra note 46, at 384.
193. For example, in 1998, California served 35,105 people in its MR/DD waiver, Indiana served 28,563 in its Elderly and Disabled waivers, Missouri served 38,946 in its Elderly waiver, New York served 31,000 in its MR/DD waiver and 18,649 in its Aged/Disabled waiver, Oregon served 29,119 in its Aged/Disabled waiver (1997 figures), and Texas served 24,045 in its Aged/Disabled waiver. See Nagy and Partridge, supra note 36, at 25.
194. See generally Harrington, supra note 35; Bazelon Center for Mental Health Law, supra note 66.
However, states have had these options for years but have not chosen to use them.

Congress should offer a stronger incentive for states to move beyond planning and into expansion of community-based programs. The best policy option would be a mandatory long-term care benefit that entitles people to services, not settings, as proposed in MiCASSA. Rather than an entitlement to nursing home, ICF/MR or community-based services, people with disabilities would be entitled to long-term care services and could choose where to live. Given the lack of congressional interest in long-term care, and high cost estimates generally associated with LTC proposals, an incremental approach is more politically feasible.

Congress should add an HCBS option to the Medicaid program: once a state chose the option it would create a state-wide entitlement to a broad array of community-based services for people with disabilities, like the package proposed in the Feingold bill. The goal of the HCBS option is to implement Olmstead by allowing states to provide community services on par with Medicaid nursing home and ICF/MR services. This proposal does not address the broader issue of reforming LTC policy to meet the needs of all people with disabilities.

Like existing HCBS waivers, the HCBS option would target people needing institutional level of care, provide a wide range of supportive services, and use the more generous institutional financial eligibility criteria. Like the existing personal care option, the HCBS option would create an entitlement to services and would be available without a waiver.

The proposed HCBS option should be offered in addition to existing HCBS waivers so that states could expand community services incrementally, if necessary. States with HCBS waivers serving small numbers of people or limited geographic areas could expand services gradually through the waiver then move to the entitlement when they have the capacity to serve all qualified individuals. Maintaining HCBS waivers also retains the demonstration nature of waivers so that states could develop new services for specific populations as the need arose.

Like the Feingold and MiCASSA bills, the HCBS option would be limited to people requiring institutional level of care. However, the

195. The Congressional Budget Office priced an earlier version of MiCASSA at $20 billion per year. See Home-Based Care Legislation Picks Up Bipartisan Support, OLDER AMERICANS REPORT, (Mar.20, 1998) at 99.

196. This Comment suggests modification of current federal law to address the institutional bias that must be overcome to implement the Olmstead decision. The broader reforms required to provide adequate LTC services to all people who need them are beyond the scope of this Comment.
HCBS option should not be limited to those who “would otherwise be served in an institution” because this current limitation precludes states from serving people with serious mental illness in community settings. Rather, the HCBS option would allow states to target services to individuals with severe physical disabilities, serious mental illness, or severe/profound mental retardation. The state could choose to provide HCBS to one or more of these groups, or people with dual diagnoses across groups.

To create a real choice between community and institutional services within the Medicaid program, the HCBS option needs to eliminate the cost-neutrality requirement of existing waivers. This creates an open-ended entitlement, such as that for nursing home or ICF/MR care, where the state must purchase services for all eligible individuals. The problem is that Congress is unlikely to enact, or many states to adopt, an option that has no cost limitations. The sentiment that costs must be considered permeates the Olmstead case. It is evident in the state’s argument that the cost of serving qualified people in the community is a fundamental alteration of its programs, in the Attorney General’s application of reasonable modification language to the integration mandate, and in the plurality’s utilization of the undue hardship balancing test when considering the fundamental alteration defense.

MiCASSA’s “quasi-entitlement” offers the best compromise on the cost issue at this point in time. When spending on community care exceeds the cost of serving the same group of people in an institution, the state chooses whether and how to limit costs. Some states would likely choose to close enrollment in the program and start a waiting list. Others might refuse community placement to people whose cost of care would be lower in an institution. A few might choose not to limit costs and to offer a real entitlement.

Borrowing from the Feingold and MiCASSA bills, the HCBS option proposes to improve equity in the Medicaid statute’s treatment of institutional and community services. The HCBS option would allow people with physical or mental disabilities who are eligible for institutional services in the state to choose community care instead.

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197. This change would add a new benefit to the Medicaid program: community mental health services for adults who would otherwise be served in a psychiatric facility. While the federal government would face increased community service costs, it would not bear the expense of institutional psychiatric care for adults with mental illness. The provision creates a strong incentive for states to expand community-based mental health services, with federal matching funds, and to reduce state-funded institutional care.
Financial eligibility criteria would be the same for institutional or HCBS option services. The option would allow states to offer a wide array of services and to target services to specific populations. The option adopts MiCASSA’s quasi-entitlement and punts the cost issue to the states.

CONCLUSION

Title II of the ADA requires states to provide services for people with disabilities in the most integrated setting. Olmstead interprets this requirement to mean that when a state offers both institutional and community-based services, an individual who is qualified for both programs and prefers community services must be provided those services unless doing so would require a fundamental alteration of the program. Fundamental alteration is not defined by Olmstead, but the decision allows states to assert a defense based on the cost of serving a diverse group of people with disabilities in addition to the plaintiffs. A plurality of the Court suggests that the test could be whether a state is effectively implementing a comprehensive plan to ensure integration. This formulation carefully balances individual rights with the state’s responsibility to provide a wide range of services for a heterogenous group of people with disabilities.

While the Court is sensitive to state concerns about costs, the extent of the Medicaid bias toward institutional care is glossed over by the decision and limits the likelihood of compliance with the ADA as construed by Olmstead. Congress should amend the Medicaid program to allow states to offer HCBS without the limitations of existing waivers. An HCBS option would allow states to create an entitlement to community services for people who meet the qualifications for institutional care. Such an entitlement would offer individuals with disabilities a real opportunity to obtain services in the most integrated setting appropriate to their needs. Only where this occurs will Olmstead’s promise to end unnecessary segregation be kept.