

A Return to Institutionalization Despite *Olmstead v. L.C.*?

The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home- and Community- Based Waiver Services

Sandra L. Yue*

"[B]eyond the legislative record [of the Americans with Disabilities Act], it defies common sense to suggest that the perpetrators of pervasive discrimination against people with disabilities did not include agents of the States."¹

* J.D. expected 2002, University of Minnesota Law School. B.A. 1997, *summa cum laude*, University of California at Berkeley. The author is grateful to the Minnesota Disability Law Center, and Anne Henry, Pamela Hoopes, Bud Rosenfield, and Luther Granquist in particular, for the inspiration behind this Note, their invaluable suggestions, and guidance. Many thanks to the *Journal* editorial staff for their technical assistance and to Joseph Windsor and Luke Shanahan for their stalwart friendship and insight.

1. Brief of Amici Curiae State of Minnesota et al. at 17, Bd. of Trs. of the Univ. of Ala. v. Garrett, No. 99-1240, slip op. (U.S. Feb. 21, 2001). In February 2001, the Supreme Court held in *Garrett* that Eleventh Amendment sovereign immunity barred recovery of money damages in suits by state employees against a state under the Americans with Disabilities Act (ADA). See Bd. of Trs. of the Univ. of Ala. v. Garrett, No. 99-1240, 2001 WL 173556, at *3 (U.S. Feb. 21, 2001). The plaintiffs, a nurse with breast cancer and a security officer with chronic asthma, claimed that Alabama had discriminated against them in their employment because of their disabilities. See *id.* at *3-4. The district court granted summary judgment to the defendant, claiming that the ADA exceeded Congress' authority to abrogate the State's Eleventh Amendment immunity from suit by its own citizens, but the Court of Appeals for the Eleventh Circuit reversed. See *id.* at *4. The Supreme Court reversed the judgment of the court of appeals. See *id.* at *11. Chief Justice Rehnquist, writing for a narrow five-to-four majority, reasoned that Congress, when it passed the ADA, made a general finding that individuals with disabilities suffered a long history of discrimination. See *id.* at *8. However, Congress never specifically identified a pattern of employment discrimination by the states. See *id.* Because Congress' power to impose a legislative remedy pursuant to Fourteenth Amendment must be "congruent and proportional to the targeted violation," it overstepped its authority to permit individuals to recover money damages against the state. *Id.* at *11. Title I of the ADA prohibits discrimination in employment, 42 U.S.C. §§ 12111-12117 (1994), while Title II applies to public services and programs, 42 U.S.C. §§ 12131-12165 (1994). The Court in *Garrett* ruled only on the constitutionality of Title I. See *Garrett*, 2001 WL

Introduction

In May 1992, L.C., a woman with retardation diagnosed with schizophrenia was voluntarily admitted to the psychiatric unit of the Georgia Regional Hospital for treatment.² Though her treatment team at the hospital determined by May 1993 that her needs could be appropriately met in a state-supported community-based program, L.C. remained institutionalized until February 1996 because of inadequate funding.³ While still institutionalized, she filed suit against the State in May 1995, claiming that her continued confinement violated Title II of the Americans with Disabilities Act (ADA).⁴ Title II prohibits discrimination on the basis of disability in the provision of public services.⁵ The district court, in granting partial summary judgment to the plaintiffs L.C. and E.W., held that the State's failure to place them in a community-based treatment program violated Title II.⁶ The State maintained that it had not violated the ADA because lack of funding, rather than discrimination on the basis of the plaintiffs' disabilities, was the reason for the continued institutionalization.⁷ The district court rejected this reasoning and held that inadequate funding did not justify unnecessary institutional segregation.⁸ The Eleventh Circuit Court of Appeals affirmed the district court's judgment but remanded for a reassessment of the State's cost-based defense.⁹ While the State had a duty to provide services in an integrated community setting, its obligations were not boundless.¹⁰ The lack of funding defense would fail unless the State could show that the additional expenditures for these women were so unreasonable, given its mental health budget, that it would "fundamentally alter" the nature of the State-provided services.¹¹

173556, at *3. This Note discusses Title II of the ADA.

2. See *Olmstead v. L.C.*, 527 U.S. 581, 593 (1999).

3. See *id.* at 593-94.

4. 42 U.S.C. §§ 12131-12165 (1994); see *Olmstead*, 527 U.S. at 593.

5. 42 U.S.C. § 12132 ("[N]o qualified individual with a disability shall, by reason of such a disability, be excluded from participation in or be denied benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.").

6. See *Olmstead*, 527 U.S. at 593. E.W., a woman with mental retardation diagnosed with a personality disorder, was also institutionalized at the same hospital. See *id.* She intervened in L.C.'s action, stating an identical claim. See *id.*

7. See *id.* at 594.

8. See *id.*

9. See *L.C. v. Olmstead*, 138 F.3d 893, 905 (11th Cir. 1998).

10. See *id.* at 904.

11. *Id.* at 905.

In 1999, the Supreme Court entered the fray, holding that Title II requires states to provide community-based treatment to persons with mental disabilities when "the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."¹² If these conditions are met, continued institutional confinement is unjustified and constitutes disability discrimination under the ADA.¹³ The Court supported its broad interpretation of discrimination on several grounds.¹⁴ The passage of the ADA reflected Congress' determination that society had historically segregated and isolated persons with disabilities,¹⁵ while the text of the law itself equates segregation with discrimination.¹⁶ The Court also looked to the ADA's implementing regulations,¹⁷ which contain an "integration regulation" that mandates state administration of services in "the most integrated setting appropriate to the needs of qualified individuals with disabilities."¹⁸ The Court concluded that unjustified isolation was discrimination because institutionalized persons must "relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice."¹⁹

In the wake of *Olmstead's* interpretation of Title II, significant legal activity has occurred, with a number of states questioning how to apply the decision to the deinstitutionalization

12. *Olmstead*, 527 U.S. at 607.

13. *See id.* at 597. The cost-defense issue raised in the lower courts was not ignored, however. Indeed, the Court was more generous toward the states in its reading of the fundamental alterations defense than the Circuit Court. *See id.* at 605-06; *infra* note 76 and accompanying text.

14. The majority rejected the State's narrow interpretation that "discrimination" did not include instances of different treatment between members of the same group. *See Olmstead*, 527 U.S. at 598. It also favored a more comprehensive view of discrimination than the dissent. *See id.* at 598-99 n.10. Justice Thomas maintained that discrimination as traditionally understood "requires a showing that a claimant received differential treatment vis-à-vis members of a different group on the basis of a statutorily described characteristic." *Id.* at 616 (Thomas, J., dissenting).

15. *See id.* at 588.

16. *See id.* at 589 n.1. The findings section of the ADA states that discrimination persists in "critical areas" such as institutionalization. 42 U.S.C. § 12101(a)(3) (1994).

17. *Olmstead*, 527 U.S. at 592.

18. 28 C.F.R. § 35.130(d) (2000).

19. *Olmstead*, 527 U.S. at 601.

of persons with disabilities.²⁰ States' development of *Olmstead*-compliant deinstitutionalization plans²¹ and class-action challenges to states' failure to provide community-based care to eligible, yet wait-listed, persons residing in institutions constitute the bulk of legal activity since the decision.²² For instance, lawsuits recently filed in Arizona and California challenge the states' failure to deinstitutionalize as a result of inadequate wages paid to the direct care and professional staff.²³ Plaintiffs in both

20. See *infra* notes 21-23 and accompanying text. Key recent decisions involving unreasonable delays in moving persons off waiting lists include *Lewis v. New Mexico Department of Health*, 94 F. Supp. 2d 1217 (D.N.M. 2000) (finding a two- to seven-year wait for services clearly unreasonable); *Boulet v. Cellucci*, 107 F. Supp. 2d 61 (D. Mass. 2000) (holding that a reasonably prompt movement off waiting list for Medicaid waiver services is within ninety days); *Benjamin H. v. Ohl*, Civ. Action No. 3:99-0338 (S.D. W. Va. July 15, 1999) (ordering state to develop *Olmstead*-compliant plan to eliminate waiting lists within a reasonable wait time of ninety days). Deinstitutionalization involves both moving persons out of institutions and into the community, as well as preventing institutional placement in the first place. See MINN. DEP'T OF HUMAN SERVS., HOME CARE AND HCBS WAIVERS BRIEFING BOOK 7 (2000) [hereinafter HCBS WAIVERS BRIEFING BOOK].

21. States can demonstrate ADA compliance by having a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated." *Olmstead*, 527 U.S. at 605-06. However, the Court's opinion gave no criteria by which to measure the comprehensiveness or effectiveness of the plan, nor defined what constitutes a reasonable pace.

22. The National Association of Protection and Advocacy Systems (NAPAS) reports that integration mandate suits have been filed by protection and advocacy agencies in Michigan, California, Louisiana, Ohio, and Tennessee and by the Indiana Civil Liberties Union on behalf of residents of Medicaid-funded nursing homes who have been put on waiting lists for home- and community-based services. Nat'l Ass'n of Protection & Advocacy Sys., *Case Law and Case Settlements Occurring Since the Olmstead v. L.C. Decision*, at <http://www.protectionandadvocacy.com/colmste.html> (last modified Feb. 1, 2001). In August 2000, a federal suit was filed in Colorado on behalf of three developmentally disabled adults who were eligible, but waitlisted, for residential programs under Medicaid. See Editorial, *Care for Mentally Retarded the Issue: State Is Sued for Failing to Provide Care Promptly; Our View: A Settlement Is Preferable to a Loss in Court*, DENVER ROCKY MOUNTAIN NEWS, Aug. 26, 2000, at 60A.

23. In January 2000, the Arizona Center for Disability Law and the Native American Protection & Advocacy Project filed suit in *Ball v. Biedess*, available at <http://oaksgroup.org/complaint>, on behalf of a plaintiff class of persons found eligible for home- and community-based services but who were not provided the full amount of services prescribed in their care plans, putting them at continual risk of institutionalization. See Gary A. Smith, *Litigation Concerning Medicaid Services for Persons with Developmental Disabilities: Status Report*, POL'Y RES. BRIEF (Research & Training Ctr. on Cmty. Living, Univ. of Minn., Minneapolis, MN), Jan. 2001, at 13. In May 2000, a California complaint was filed in *Sanchez v. Johnson*, available at <http://oaksgroup.org/complaint>, on behalf of a class of currently institutionalized individuals with developmental disabilities. See Smith, *supra* at 13. It too claimed the State's violation, *inter alia*, of integration and other anti-

complaints allege that they were prevented from receiving the care they needed at home because the States' provider payment rates were too low to attract a sufficient number of workers to the market.²⁴ Given that many individuals rely on Medicaid home- and community-based services to allow them to live outside institutional settings, inadequate provider wages thus pose a major obstacle to state compliance with *Olmstead's* Title II integration requirements. Furthermore, failure to increase wages implicates violations of § 504 of the Rehabilitation Act of 1973,²⁵ a precursor to the ADA that contains similar language prohibiting disability discrimination,²⁶ as well as Title XIX of the Social Security Act, which governs the administration of the Medicaid program.²⁷

Olmstead's definition of discrimination to include unjustified isolation has particular currency for persons in Minnesota receiving Medicaid services under the Home and Community Based Services (HCBS) waiver program.²⁸ The current shortage of home care workers in Minnesota poses a tremendous challenge to its ability to navigate its ADA obligations under *Olmstead* and Medicaid program requirements. This Note argues that Minnesota's failure to increase wages paid to personal care attendants (PCAs) contradicts not only specific mandates spelled out in caselaw and statutes, but also the logic behind deinstitutionalizing our disabled population. Section I, Part A gives the historical and legal background of deinstitutionalization.²⁹ Part B provides an overview of Medicaid, including its HCBS waiver program.³⁰ Part C presents the factors

discriminatory regulations in reimbursing community-based care providers at a rate lower than that offered to institutions. *See id.* at 13-14.

24. *See id.*

25. 29 U.S.C. § 794(a) (1994).

26. *See infra* Part I.A.2 for a discussion of § 504.

27. 42 U.S.C. §§ 1396-1396v (1994).

28. The Medicaid HCBS waiver program allows states to furnish personal care and other services for individuals with disabilities who, without them, would require institutional care. *See* OFFICE OF SPECIAL EDUC. & REHABILITATIVE SERVS., U.S. DEPT OF EDUC., SUMMARY OF EXISTING LEGISLATION AFFECTING PERSONS WITH DISABILITIES 50 (1988) [hereinafter DEP'T OF EDUC.]; discussion *infra* Part I.B.2. *See generally* Jane Perkins & Manju Kulkarni, Nat'l Health Law Program, *Addressing Home and Community-based Waiver Waiting Lists Through the Medicaid Program*, at http://www.healthlaw.org/pubs/20005FactSheet_hcbw.html (2000) (discussing the implications of *Olmstead* on the HCBS waiver program as a way to reduce institutional placements).

29. *See infra* notes 34-84 and accompanying text.

30. *See infra* notes 85-154 and accompanying text.

fueling the PCA labor shortage in Minnesota.³¹ Section II analyzes the results of the convergence of factors laid out in Section I. Part A examines the multiple effects of the shortage on the PCA field, waiver recipients, and recipient families. It concludes that because the shortage places these recipients at direct risk of institutionalization, the state's inaction is poised to become discrimination under the ADA, as interpreted by *Olmstead*, and violates statutory requirements under the Medicaid Act.³² Finally, Part B offers some proposed changes to address Minnesota's failure to deliver authorized PCA services.³³

I. Background

A. *The Historical and Legal Background of Deinstitutionalization of Individuals with Disabilities*

1. Historical Background

Through the first half of the twentieth century, people with mental retardation and other developmental disabilities either received services in large public institutions or relied upon their families for care, with little assistance from the government.³⁴ Early cases evidenced two major themes in the treatment of the disabled: eugenics measures to control their reproduction, and forced institutionalization.³⁵ *Buck v. Bell*³⁶ upheld a Virginia statute providing for sterilization of "mental defectives"³⁷ on the grounds that it would benefit society to "prevent those who are manifestly unfit from continuing their kind."³⁸ With similar

31. See *infra* notes 155-178 and accompanying text.

32. See *infra* notes 179-218 and accompanying text.

33. See *infra* notes 219-248 and accompanying text.

34. See DeWayne Davis et al., Nat'l Conference of State Legislatures, *Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators* (2000), <http://www.ncsl.org/programs/health/forum/pub6683.htm> (last visited Mar. 2, 2001).

35. See RUTH COLKER, *THE LAW OF DISABILITY DISCRIMINATION* 3 (1995).

36. 274 U.S. 200 (1927).

37. *Id.* at 205.

38. *Id.* at 207. The Court found that Virginia's policy of sterilizing "mental defectives," that is, those with hereditary "insanity" or "imbecility," violated neither due process nor equal protection under the Fourteenth Amendment. See *id.* at 205-08. The opinion is particularly remembered for Justice Holmes' justification of the policy as promoting general social welfare:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices,

motives, states would also frequently institutionalize people with disabilities, claiming that such measures were needed to prevent sexual relations, especially for women.³⁹ Institutionalization of males with disabilities, on the other hand, was often justified as a way to protect society from the "danger" they posed to public safety.⁴⁰

Until the late 1960s, the dual attitudes of paternalism and fear ensured a segregated, institutionalized existence for people with disabilities.⁴¹ At first, claims of poor living conditions, neglect and inhumane treatment grounded legal challenges to institutionalization.⁴² By the late 1960s and into the 1970s, the Supreme Court's *Brown v. Board of Education*⁴³ decision, which established that separation was inherently unequal, lent momentum to deinstitutionalization.⁴⁴ The burgeoning civil rights movement additionally fueled litigation efforts by disability rights advocates seeking not only to improve living conditions, but to move away from unnecessary institutionalization altogether.⁴⁵ In the areas of mental retardation and mental illness, there was a growing recognition among experts that individuals could benefit, and even thrive, in less restrictive settings.⁴⁶ This change in treatment approaches was grounded in a increased societal emphasis on individual rights and personal autonomy.⁴⁷ As such, the push for deinstitutionalization was also the push for the development of income, housing, and community-based supports, all geared toward maximizing integrated living, individual choice, and active participation in treatment planning.⁴⁸

often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.

Id. at 207.

39. See COLKER, *supra* note 35, at 4.

40. See *id.* at 4-5.

41. See LAURA F. ROTHSTEIN, *DISABILITY LAW* 6 (1995).

42. See Davis et al., *supra* note 34, at 4; ROBERT M. LEVY & LEONARD S. RUBENSTEIN, *THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES* 2-3 (1996).

43. 347 U.S. 483 (1954).

44. See *id.* at 495.

45. See Davis et al., *supra* note 34, at 4; Joanne Karger, "Don't Tread on the ADA": *Olmstead v. L.C. ex rel. Zimring and the Future of Community Integration for Individuals with Mental Disabilities*, 40 B.C. L. REV. 1221, 1226 (1999).

46. See LEVY & RUBENSTEIN, *supra* note 42, at 3.

47. See *id.* at 3-4.

48. See *id.* at 3-6; see also Davis et al., *supra* note 34, at 4-5 (explaining that

*City of Cleburne v. Cleburne Living Center*⁴⁹ represented a victory for disability rights advocates and the deinstitutionalization movement. In this case, the city denied a zoning permit to plaintiffs, who wanted to open a group home for those with retardation.⁵⁰ The Court found that denial of the permit constituted a violation of the Equal Protection Clause because the denial was not rationally related to any legitimate state purpose.⁵¹ In his concurrence, Justice Marshall noted that continued isolation of persons with disabilities perpetuated negative attitudes and irrational fears toward them, which in turn deprived them of "much of what makes for human freedom and fulfillment—the ability to form bonds and take part in the life of a community."⁵² The Court would later return to this conclusion in *Olmstead*, asserting that unnecessary institutionalization "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."⁵³

2. Legal Background: Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act

In influential class action suits challenging institutional conditions in the early 1970s, the courts consistently concluded that the civil rights of individuals with mental retardation and other developmental disabilities were being violated.⁵⁴ At this time, a number of special interest groups representing persons with specific mental and physical disabilities, such as cerebral palsy and epilepsy, vigorously lobbied for disability rights in the community.⁵⁵ The key legislative impetus behind this movement

housing and income supports may also include supervision, therapy, and twenty-four-hour medical care).

49. 473 U.S. 432 (1985).

50. See *id.* at 436.

51. See *id.* at 450.

52. *Id.* at 461 (Marshall, J., concurring in the judgment and dissenting in part). In reviewing the history of discrimination against persons with mental retardation, Justice Marshall disagreed with the majority's decision to hold the city ordinance only to a rational-basis standard rather than subject it to heightened scrutiny. See *id.* at 473.

53. *Olmstead v. L.C.*, 527 U.S. 581, 601 (1999).

54. See STEPHEN LUTZKY ET AL., DEPT' OF HEALTH & HUMAN SERVS., REVIEW OF THE MEDICAID 1915(C) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAM LITERATURE AND PROGRAM DATA 4 (2000).

55. See COMM'N ON MENTAL AND PHYSICAL DISABILITY LAW, AM. BAR ASS'N, DISABILITY LAW AND POLICY: A COLLECTIVE VISION 6 (1999).

was the Rehabilitation Act of 1973.⁵⁶ The Rehabilitation Act authorizes federal support for training and job placement for persons with physical and mental disabilities.⁵⁷ Section 504 of the Act was the first federal statute to address discrimination against persons with disabilities.⁵⁸ Also known as the "civil rights bill of the disabled[,]"⁵⁹ it prohibits excluding persons from any federal program on the basis of disability.⁶⁰ Thus, § 504's protections reach employment as well as access to institutions like public schools, public transportation, hospitals, and welfare providers.⁶¹

The Americans with Disabilities Act of 1990 (ADA),⁶² put more teeth into § 504's protections by broadening the requirement of nondiscrimination to cover employment and accommodations in the private sector.⁶³ Title II of the ADA prohibits discrimination on the basis of disability in the provision of public services.⁶⁴ Title II's implementing regulations contain an "integration regulation" modeled after those of § 504 and state that entities receiving federal funding must "administer programs and activities in the most integrated setting appropriate to the needs of qualified

56. See *id.* The Rehabilitation Act is codified at 29 U.S.C. §§ 791, 793-794 (1994). It amended older vocational rehabilitation legislation that focused on providing employment training for disabled veterans after World War I. See ROTHSTEIN, *supra* note 41, at 7.

57. See DEPT OF EDUC., *supra* note 28, at 141.

58. See Karger, *supra* note 45, at 1233.

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

60. Section 504 reads, in pertinent part:

No otherwise qualified individual with a disability . . . shall, solely by reason of his or her 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 or under any program or activity conducted by any Executive agency or by the United States Postal Service.

29 U.S.C. § 794(a) (1994).

61. See ROTHSTEIN, *supra* note 41, at 8.

62. 42 U.S.C. §§ 12101-12213 (1994). Title I of the ADA, prohibits discrimination on the basis of disability in employment. *Id.* §§ 12111-12117. Title II prohibits discrimination in access to public services, including public transportation. *Id.* §§ 12131-12165. Title III pertains to public accommodations and services operated by private entities, including architectural barriers. *Id.* §§ 12181-12189. Title IV covers telecommunications relay services for persons with hearing and speech impairments. 47 U.S.C. §§ 225, 611 (1994). Finally, Title V covers miscellaneous topics, including attorney's fees and prohibition of retaliation against those asserting of rights under the ADA. 42 U.S.C. §§ 12201-12213.

63. See COLKER, *supra* note 35, at 19.

64. See 42 U.S.C. § 12132. This provision reads, in relevant part: "no qualified individual with a disability shall, by reason of such a disability, be excluded from participation in or be denied benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." *Id.*

handicapped persons.”⁶⁵ In passing the ADA, “Congress for the first time expressly referred to ‘segregation’ of persons with disabilities as a ‘form of discrimination,’” and recognized that it “persists in the area of ‘institutionalization.’”⁶⁶

In *Helen L. v. DiDario*,⁶⁷ the Third Circuit affirmed the integration mandate of the ADA.⁶⁸ Pennsylvania’s health professionals found the plaintiff eligible for home-based services after she became disabled.⁶⁹ However, because of lack of funding, the State placed her on a waiting list for the attendant care she needed to live outside a nursing home.⁷⁰ The lower court granted summary judgment for the Department of Welfare, holding that it wait-listed her due to lack of funding, and therefore, it had not discriminated against her on the basis of her disability.⁷¹ The Third Circuit Court of Appeals rejected this reasoning, finding that a denial of services in the most integrated setting appropriate violates the ADA despite lack of funding.⁷² While the State raised a “fundamental alterations” defense,⁷³ the court responded by stating that fiscal or administrative convenience was not a valid justification in providing services in a segregated manner.⁷⁴

In *Olmstead*, the Supreme Court further outlined the limits of Title II.⁷⁵ While its broad interpretation of the “fundamental alterations” defense would make it easier for states to raise this objection,⁷⁶ *Olmstead* is nonetheless vital for the integration

65. 28 C.F.R. § 41.51(d) (1999). The language of the corresponding regulation for the ADA is almost identical, extending coverage of the integration mandate to “services” in addition to programs and activities for qualified individuals with disabilities. *Id.* § 35.130(d).

66. *Olmstead v. L.C.*, 527 U.S. 581, 589 n.1 (1999).

67. 46 F.3d 325 (3d Cir. 1995). Plaintiff in this case was placed in a nursing home after she became paralyzed from the waist down due to meningitis. *See id.* at 328.

68. *See id.* at 339.

69. *See id.* at 329.

70. *See id.*

71. *See id.*

72. *See id.*

73. The implementing regulations of the ADA offer states an affirmative defense: “[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 entity.” 28 C.F.R. § 35.130(b)(7) (1999).

74. *See Helen L.*, 46 F.3d at 338.

75. *See supra* notes 2-19 and accompanying text (discussing the facts and the Court’s holding and reasoning in *Olmstead*).

76. *See Olmstead v. L.C.*, 527 U.S. 581, 603-06 (1999). Karger argues that the Supreme Court, in allowing states to look at fixed costs that still must be incurred at institutions when a patient moves into community-based services rather than

principles it asserted by defining discrimination more comprehensively.⁷⁷ The Court recognized that unnecessary institutionalization “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life”⁷⁸ and highlighted the detrimental effects associated with institutional confinement.⁷⁹ It drew a clear picture of discriminatory treatment that exists in these instances: persons without disabilities are not required to give up participation in community life to get medical services they need, while plaintiffs—even *after* being found by the state to be eligible for community-based services—must make this sacrifice.⁸⁰

The Court recognized, however, that “[t]he State’s responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless.”⁸¹ Yet it provided only limited guidance for state compliance. The Court did not define any specific criteria by which to determine the comprehensiveness or effectiveness of a state’s plan for placing qualified individuals into integrated community settings.⁸² Furthermore, it “contemplated only those situations involving institutionalization; the decision did not address the extent to

using the circuit court’s simple cost comparison model, has “given the states greater opportunity to legitimize their reluctance to provide community placement.” Karger, *supra* note 45, at 1260. In the latter model, the comparison is between the cost of providing services for the individual in the community versus the cost of caring for that same individual in an institution. *See id.* at 1257. As part of a fundamental alteration defense, the majority held that a state can also argue that diversion of funds from institutional programs to home- and community-based programs would alter the range of services a state can offer and thus constitute a fundamental alteration. *See id.* at 1259-60. This, however, escapes the question of whether an expansion of existing services, not the creation of new programs, is a fundamental alteration. *See id.* at 1260. In short, Karger argues that these interpretations by the majority, among other points, pushes states too little to change their existing manner of service delivery. *See id.* at 1263.

77. *See supra* notes 13-19 and accompanying text (explaining the Court’s basis for adopting a broader definition of disability).

78. *Olmstead*, 527 U.S. at 600.

79. These include barriers to personal development, economic and educational advancement, and social and cultural exposure. *See id.* at 600-01.

80. *See id.* at 601.

81. *Id.* at 603; *see also* Karger, *supra* note 45.

82. *See supra* note 21. In January 2000, the U.S. Department of Health and Human Services sent a letter to all state Medicaid directors spelling out key principles and practices states should consider in developing their plans. *See* NAT’L ASS’N OF PROTECTION & ADVOCACY SYS., *OLMSTEAD PROGRESS REPORT: DISABILITY ADVOCATES ASSESS STATE IMPLEMENTATION AFTER ONE YEAR 4 (2000)* [hereinafter *OLMSTEAD PROGRESS REPORT*]. As of July 2000, no state developed a full *Olmstead* plan that conforms to these principles. *See id.* Most states, however, at least took initial steps to either develop a plan, review existing plans for compliance, or determine the methods by which they can comply. *See id.*

which a state's limitations of services to certain relatively restrictive but community-based home settings could still be discriminatory."⁸³ Given these interpretative gaps in *Olmstead*, commentators predict that disputes will arise regarding how much cost a state should bear as they develop their *Olmstead* integration plans, and that it is too early to know how courts will treat this question.⁸⁴

B. *Medicaid and the Role of HCBS Waivers in Deinstitutionalization*

While *Olmstead* and the ADA assert important and far-reaching disability rights principles, they are of limited force in translating these principles into necessary budgetary action.⁸⁵ Justice Kennedy's concurring opinion in *Olmstead* noted that budget questions are political decisions not within the reach of the ADA.⁸⁶ Indeed, state budget allocations are more properly addressed by the Medicaid statute, which was enacted pursuant to Congress' spending power, rather than the ADA, which was enacted as civil rights legislation.⁸⁷ The statutes and regulations that implement the Medicaid program offer more specific directives in regard to state financial obligations.⁸⁸ While *Olmstead* was not a Medicaid case per se, it still has significant implications for the administration of Medicaid home- and community-based waiver programs, whose aim in large measure is the deinstitutionalization of persons with disabilities.⁸⁹

1. Medicaid

Title XIX of the Social Security Act (SSA)⁹⁰ governs Medicaid, a jointly-funded cooperative program between the federal and state governments designed to provide medical assistance for low-income persons and persons with disabilities.⁹¹

83. BUD ROSENFELD, MINN. DISABILITY LAW CTR., THE INTEGRATION MANDATE, *OLMSTEAD* AND BEYOND: AN OUTLINE FOR ADVOCATING UNDER THE ADA IN THE RECEIPT OF PUBLIC SERVICES 2-3 (Mar. 2000).

84. See Perkins & Kulkarni, *supra* note 28.

85. See *supra* notes 21, 82 and accompanying text.

86. See *Olmstead*, 527 U.S. at 612-13 (Kennedy, J., concurring in the judgment).

87. See Perkins & Kulkarni, *supra* note 28.

88. See *id.*

89. See MANJU KULKARNI, NAT'L HEALTH LAW PROGRAM, FACT SHEET: ACCESSING MEDICAID HOME AND COMMUNITY-BASED SERVICES 1-2 (2000).

90. 42 U.S.C. §§ 1396-1396v (1994).

91. See HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 4. The federal rate of reimbursement varies by state; at present it ranges from 50% to 76.82% of state

With oversight from the federal Health Care Financing Administration, Medicaid makes federal matching funds available to the states for the costs they incur in providing covered services.⁹² The Medicaid program covers more Americans than any other health insurer and is the nation's largest single purchaser of long-term care.⁹³ In Minnesota, 58% of Medicaid expenditures go toward long-term care of both the disabled and non-disabled.⁹⁴ By enrollee population, persons with disabilities comprise 13% of this state's participants in the program and utilize 40% of total expenditures.⁹⁵

State participation in Medicaid is optional; however, if a state chooses to participate, it is subject to federal requirements outlined in Title XIX.⁹⁶ Nonetheless, states have broad discretion within federal guidelines to establish eligible beneficiary groups, types of and ranges of services covered, payment levels for services, and administrative and operating procedures.⁹⁷ To be eligible for matching funds, the state must provide coverage to the "categorically needy,"⁹⁸ which include those who receive federally-assisted income maintenance payments and persons with disabilities who fall below certain income standards.⁹⁹ In addition, states have the option of extending eligibility to the "medically needy," that is, persons whose income and/or resources exceed state eligibility levels but who can "spend down" the excess on medical expenses in order to meet them.¹⁰⁰

expenditures. 65 Fed. Reg. 8979-80 (Feb. 23, 2000). The federal government currently reimburses Minnesota for 51.11% of its expenditures; thus, the state carries 48.89% of the cost. *Id.*

92. See THE KAISER COMM'N ON MEDICAID & THE UNINSURED, MEDICAID: A PRIMER 1 (1999) [hereinafter KAISER COMM'N].

93. *Id.* at 2.

94. *Id.* at 9 tbl.3.

95. *Id.* at 7 tbls.1 & 8.

96. See Ark. Med. Soc'y v. Reynolds, 6 F.3d 519, 521-22 (8th Cir. 1993).

97. 42 C.F.R. § 430.0 (1999).

98. See Health Care Fin. Admin., *Medicaid: A Brief Summary*, at <http://www.hcfa.gov/pubforms/actuary/ormedmed/default4.htm> (last visited Feb. 19, 2001). Some categorically needy persons are individuals eligible for Aid to Families with Dependent Children, children under age 6 whose family income is at or below 133% of the Federal Poverty Level (FPL), Supplemental Security Income (SSI) recipients, and pregnant women whose family income is below 133% of the FPL. *Id.*

99. See DEP'T OF EDUC., *supra* note 28, at 45. In Minnesota, income limits vary by applicant category, such as adults with children or pregnant women. See Minn. Dep't of Human Servs., *Minnesota's Medical Assistance (MA) (Medicaid) Program*, at <http://www.dhs.state.mn.us/hlthcare/asstprog/mmmap.htm> (last visited Feb. 18, 2001). In 2000, for example, the yearly income limit for a family of two was \$6996, while for a family of four, it was \$9936. *Id.* at 4.

100. See DEP'T OF EDUC., *supra* note 28, at 45. By taking into account the high

2. Home- and Community-Based Services Waiver Program

From its inception in 1965 through the early 1980s, Medicaid provided long-term care in institutional settings only.¹⁰¹ While states could provide some home care services at their option, the only comprehensive long-term care available in Minnesota was in an institutional setting until Title XIX was amended in 1981.¹⁰² Pursuant to the Omnibus Budget Reconciliation Act of 1981, Congress added section 1915(c) to the SSA¹⁰³, allowing for the waiver of certain federal statutory requirements to enable states to provide personal care and other services to individuals who, but for these services, would be institutionalized.¹⁰⁴ The original motivation behind the Home- and Community-Based Services waiver program rested on the belief that long-term care costs would be contained if services were provided to some individuals in a less expensive setting rather than in an institution.¹⁰⁵ To receive federal funding, states must demonstrate that the proposed program is "cost neutral," meaning that average costs under the waiver must be equal to or less than cost of services without the waiver.¹⁰⁶

Pursuant to the HCBS waiver program, states can "waive" some of the federal requirements normally attached to the provision of Medicaid services in order to develop community-

medical expenses they incur, medically needy participants can reduce their income to a level at or below their respective state's income eligibility level and thereby establish eligibility for the program. See HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 5.

101. See DEP'T OF EDUC., *supra* note 28, at 49; see also LUTZKY ET AL., *supra* note 54, at 1.

102. See HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 7.

103. This section reads in relevant part:

The Secretary may by waiver provide that a State [Medicaid] plan approved under this subchapter may include as "medical assistance" under such plan payment for part or all of the cost of home or community-based services . . . with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in a hospital or nursing facility or intermediate care facility for the mentally retarded

42 U.S.C. § 1396n(c) (1994).

104. See DEP'T OF EDUC., *supra* note 28, at 50.

105. See LUTZKY ET AL., *supra* note 54, at 2. Various studies of the HCBS waiver program show mixed results in measuring its cost-effectiveness against institutional care. See *id.* at 31-32. Existing studies tend to focus on the home- and community-based services in general, rather than on particular programs offered under the waiver, and can vary widely depending on the assumptions relied upon by the researching body. See *id.* at 32. Available evidence does suggest, however, that the program "can result in cost savings if services are targeted in a manner that maximizes the diversion from institutions." *Id.* at 33.

106. See *id.* at 2.

based treatment alternatives.¹⁰⁷ With a waiver, states have the flexibility to design the mix of services they will offer, identify target populations to receive them, and limit services to certain geographic regions, in order to best meet its population's needs.¹⁰⁸ Federal regulations specifically list seven services that may be provided under the waiver,¹⁰⁹ and other services may be provided in a state's Medicaid plan, subject to approval by the Health Care Financing Administration (HCFA).¹¹⁰ HCFA approval for a state waiver program is initially granted for three years and must be renewed every five years.¹¹¹

The HCBS waiver program has grown to become instrumental to the deinstitutionalization movement. Post-*Olmstead*, the waiver program is the most common means states use to increase community supports, and spending under the program is the primary funding stream for deinstitutionalization.¹¹² The HCFA "recognizes that many individuals at risk of being placed in these facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care" through this program.¹¹³ Minnesota's Department of Human Services (DHS) characterizes the waiver as an "alternative care package" that allows people to live in the community instead of going into an institution.¹¹⁴ Currently there are 240 HCBS waiver programs operating throughout the country, with every state participating.¹¹⁵

107. Section 1915(c)(3) allows for the waiver of requirements of statewideness (§ 1902(a)(1) of the SSA), comparability (§ 1902(a)(10)(B)), and income and resource rules applicable in the community (§ 1902(a)(10)(C)(i)(III)). See 42 U.S.C. § 1396n(c)(3) (1994).

108. See § 1396n(c)(3).

109. These services are case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care. See 42 C.F.R. § 440.180 (1999).

110. Other services needed to help participants avoid being placed in an institution that a state may request include non-medical transportation, in-home support services, minor home modifications, adult day care, and special community services. See Health Care Fin. Admin., *Home and Community-Based Services 1915(c) Waivers*, at <http://www.hcfa.gov/medicaid/hpg4.htm> (last visited Sept. 30, 2000) [hereinafter *1915(C) Waivers*]. Individuals with chronic mental illness may also receive day treatment, psychosocial rehabilitation services, and clinic services. See *id.*

111. See *id.* at 2.

112. See *OLMSTEAD PROGRESS REPORT*, *supra* note 82, at 5; see also LUTZKY ET AL., *supra* note 54, at 7.

113. *1915(C) Waivers*, *supra* note 110, at 1.

114. See *HCBS WAIVERS BRIEFING BOOK*, *supra* note 20, at 7.

115. See *1915(c) Waivers*, *supra* note 110, at 2. Arizona runs an equivalent

Spending on the waiver program has increased rapidly, with total waiver expenditures jumping from \$290 million to \$10.4 billion between 1985 and 1999.¹¹⁶ Services provided under waivers accounted for almost two-thirds of total Medicaid home- and community-based spending in 1999, while in 1992, it only composed two-fifths of this total.¹¹⁷ Spending for waivers for the developmentally disabled increased at about thirty percent per annum between 1992 and 1997, outpacing spending for aged and disabled waivers.¹¹⁸

In Minnesota, the DHS administers Medicaid and the HCBS waiver program.¹¹⁹ In addition to services not offered in the state's Medicaid plan, the waiver program offers state plan extensions necessary to avoid institutionalization.¹²⁰ The state currently operates five waivers: Elderly Waiver (EW), Mental Retardation or Related Conditions (MR/RC), Community Alternatives for Disabled Individuals (CADI), Community Alternatives for Chronically Ill Individuals (CAC), and Traumatic Brain Injury (TBI).¹²¹ Individuals receiving services under the HCBS waiver program have access to all the services already offered under the Minnesota state plan, including home health care, personal care, private duty nursing, and adult day care.¹²² Five additional services are only available to waiver recipients: non-institutional residential services, structured day program services, case management, respite care, and certain specialist services.¹²³

While the waiver program affords flexibility by allowing states to bypass three federal requirements found in § 1902 of the SSA,¹²⁴ two key provisions cannot be waived: equal access and reasonable promptness.¹²⁵ The equal access provision requires

program to the HCBS waiver program under § 1115 of the SSA, which permits states to run demonstration waivers. *See id.*

116. *See* LUTZKY ET AL., *supra* note 54, at 8.

117. *See id.* at 7.

118. *See id.*

119. The HCBS waiver program is governed by MINN. STAT. § 256B.49 (2000).

120. *See* HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 8. "Extended services allow more than the state plan in terms of type, amount, duration and scope . . ." *Id.*

121. *See id.* The CADI waiver provides services for individuals with disabilities at risk of nursing home placement, while the CAC waiver provides services for chronically ill individuals at risk of being admitted to the hospital. *See id.*

122. *See id.* at 9.

123. *See id.*

124. *See supra* note 107.

125. *See* JANE PERKINS, NAT'L HEALTH LAW PROGRAM, ASSURING HIGH QUALITY HOME AND COMMUNITY-BASED CARE THROUGH MEDICAID REIMBURSEMENT PROVISIONS 2 (Sept. 29, 2000) (on file with author).

Medicaid agencies to set reimbursement rates high enough such that recipients can have access to care providers at a level at least equal to that of their non-Medicaid counterparts.¹²⁶ This provision is enforceable against the states under 42 U.S.C. § 1983,¹²⁷ which allows both Medicaid service providers and recipients to bring an action for deprivation of their civil rights.¹²⁸ Equal access challenges to inadequate reimbursement rates typically argue that budgetary concerns impermissibly drive a state's rate-setting decision, rather than consideration of the "relevant factors" listed in the statute (efficiency, economy, quality of care, and equal access).¹²⁹ The circuit courts are split on whether the equal access clause gives rise to procedural or substantive rights.¹³⁰

126. This provision states, in pertinent part, that a state Medicaid plan must: provide such methods and procedures relating to the utilization of, and the payment for, care and services available under the plan . . . to assure that payments are consistent with efficiency, economy, quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area.

42 U.S.C. § 1396a(a)(30)(A) (2000).

127. The statute provides that:

Every person who, under color of any statute, ordinance, regulation, custom, or usage, of any State or Territory of the District of Columbia, subjects, or causes to be subjected, any citizen of the United States or other person within the jurisdiction thereof to the deprivation of any rights, privileges, or immunities secured by the Constitution and laws, shall be liable to the party injured in an action at law, suit in equity, or other proper proceeding for redress

42 U.S.C. § 1983 (1994).

128. See *Ark. Med. Soc'y v. Reynolds*, 6 F.3d 519, 527 (8th Cir. 1993). The court found that a claim under the equal access clause involved a violation of a federal right, not just federal law, and that Congress had not foreclosed a § 1983 remedy. See *id.* at 528. In finding a violation of federal rights, the court determined that the statutory provision was intended to benefit plaintiffs, created a binding obligation on the states rather than merely expressed a congressional preference, and contained language that was not too vague or amorphous for the judiciary to enforce. See *id.*

129. See *id.* at 530-31 (citing an extensive list of precedent supporting the proposition that budgetary considerations are not a conclusive factor in setting rates); *Visiting Nurse Ass'n v. Bullen*, 866 F. Supp. 1444, 1446 (D. Mass. 1994) (asserting that budget may be considered, especially in tight economic times, but not at the price of statutory compliance).

130. Challenges to provider rates will thus require different facts to demonstrate violation of the equal access clause, depending on how the clause is interpreted. The Eighth Circuit follows a procedural rights model, wherein equal access requires states to consider the "relevant factors" during the rate-setting process. See *Ark. Med. Soc'y*, 6 F.3d at 530 (finding that budgetary concerns impermissibly drove the State's decision rather than consideration of the relevant factors in setting its rates); cf. *Minn. Homecare Ass'n v. Gomez*, 108 F.3d 917, 918 (8th Cir. 1997) ("The Medicaid Act mandates consideration of the equal access factors . . . in the process of setting or changing payment rates," though it does not mandate any particular methodology for doing so); see also *Pa. Pharmacists Ass'n v. Houston*,

Under either interpretation, however, if the provider reimbursement rate ultimately set does not enlist enough providers to ensure equality of access to medical services, the state fails to perform its statutory duty. The provision's primary thrust is encouraging provider participation by setting rates at a level that will attract providers to the market.¹³¹ For example, in *Clark v. Kizer*,¹³² plaintiff-recipients challenged the State's Medicaid reimbursement rates as being too low to attract dentists in numbers that would ensure equal access to its Denti-Cal program.¹³³ The Ninth Circuit Court of Appeals identified provider participation and reimbursement as the two main criteria to gauge access to providers and found in this case that California had violated the equal access provision.¹³⁴ The court found that a forty percent provider participation rate clearly fell below the two-thirds benchmark utilized by the Department of Health and Human Services.¹³⁵ Likewise, the court found that Denti-Cal participants could not even meet their overhead expenses, much less derive some marginal profit when they were reimbursed at a forty percent rate for their services.¹³⁶ When rates are too low to

No. 99-491, 2000 WL 730344, at *3 (E.D. Pa. 2000) (holding that, in formulating payments, the State must consider the relevant factors, though it need not consider every factor to the same degree). In contrast, circuits that follow a substantive rights interpretation hold that the outcome of the rate-setting process, not the consideration of factors, is what matters. See, e.g., *Visiting Nurse Ass'n*, 93 F.3d at 1007 (deferring to the state agency's rate-setting decision and shifting the focus of the inquiry to whether the results of the decision-making met the relevant factors); *Methodist Hosps., Inc. v. Sullivan*, 91 F.3d 1026, 1030 (7th Cir. 1996) (asserting that equal access clause requires State to produce results, not employ any particular methodology for getting there). One district court put the mandate in even starker terms: the equal access clause "does not require the State to 'consider' anything; it requires the State to achieve a result . . . [S]o far as [equal access] is concerned, the State ordinarily can be as deliberative or as nonchalant as it chooses, so long as it selects a payment structure and rates that *in fact* are [consistent with the relevant factors]." *Fla. Pharmacy Ass'n v. Cook*, 17 F. Supp. 2d 1293, 1298 (N.D. Fla. 1998).

131. See *Ark. Med. Soc'y*, 6 F.3d at 530; see also *Visiting Nurse Ass'n*, 866 F. Supp. at 1454, *rev'd and vacated in part by* *Visiting Nurse Ass'n v. Bullen*, 93 F.3d 997 (1st Cir. 1996).

132. 758 F. Supp. 572 (E.D. Cal. 1990), *aff'd in part by* *Clark v. Coye*, 8 F.3d 26 (9th Cir. 1993) (affirming lower court injunction increasing the State's reimbursement rate).

133. See *id.* at 575.

134. See *id.* at 576. The district court noted other criteria by which to gauge compliance with equal access, including evidence of a steady stream of recipients reporting difficulty in obtaining services, significant numbers of providers opting out of the program, and admission of inadequate rates by the administering State agency itself. See *id.* at 578.

135. See *id.*

136. See *id.* at 577.

ensure access at least equal to that of the general population, many courts have held that states are obligated to upwardly revise rates until they achieve statutory compliance.¹³⁷

The reasonable promptness provision is likewise unwaivable under section 1915(c).¹³⁸ States must ensure that "all individuals wishing to make application for medical assistance under the plan shall have opportunity to do so," and that "such assistance shall be furnished with reasonable promptness to all eligible individuals."¹³⁹ Its implementing regulation requires state agencies to "furnish Medicaid promptly to recipients without any delay caused by the agency's administrative procedures" and "continue to furnish Medicaid regularly to all eligible individuals until they are found to be ineligible."¹⁴⁰ Individuals found eligible for home- and community-based services, but wait-listed for unreasonably long periods of time, have invoked the reasonable promptness provision in challenging the state's failure to provide services.¹⁴¹

In *Boulet v. Celluci*,¹⁴² for instance, the court issued an injunction ordering Massachusetts to furnish waived residential habilitation services to eligible plaintiffs within ninety days of their placement on a waiting list.¹⁴³ All of the plaintiffs had been on the list for at least three years, with some waiting for over ten.¹⁴⁴ As in the equal access cases, the court found the reasonable promptness provision enforceable under § 1983,¹⁴⁵ and identified

137. In *DeGregorio v. O'Bannon*, 500 F. Supp. 541, 543 (E.D. Pa. 1980), recipients eligible for care in skilled nursing facilities were routinely rejected by facilities favoring private-pay and Medicare clients. The court interpreted the equal access clause to require that the reimbursement rate be set at a level that will engage sufficient numbers of providers to make the program meaningful in all respects. See *id.* at 550. The clause requires that states attempt to rectify deficiencies in patient access to medical services via rate-setting, even if those deficiencies are the product of an undersupply of available facilities. See *id.* If providers are not induced to offer their services readily, the state is obligated to set rates "with a view toward enlarging the base of provider participation." *Id.* at 551; see also *Cal. Ass'n of Bioanalysts v. Rank*, 577 F. Supp. 1342, 1359 (C.D. Cal. 1983) ("recipients or providers may bring an action to enjoin utilization of the rate structure until it is upwardly revised"); *supra* notes 67-74 and accompanying text, for rejection of the cost defense in the *Helen L.* case.

138. See 42 U.S.C. § 1396a(a)(8) (1994).

139. See *id.*

140. 42 C.F.R. §§ 435.930a-.930b (2000).

141. See, e.g., *Boulet v. Celluci*, 107 F. Supp. 2d 61 (D. Mass. 2000); *Lewis v. New Mexico Dep't of Health*, 94 F. Supp. 2d (D.N.M. 2000).

142. 107 F. Supp. 2d 61.

143. See *id.* at 82.

144. See *id.* at 67.

145. See *id.* at 71-73.

the nexus between reasonably prompt delivery of services and reimbursement rates, commenting that:

[t]he availability of settings depends ultimately upon demand[,] and demand in this context undoubtedly turns to some considerable degree on the likelihood of reimbursement for the services necessary to function in such settings. The rulings in this case . . . are intended to encourage vendors to be willing to provide both the settings and the services to meet the promise of the Massachusetts waiver plan by assuring reimbursement up to the waiver cap.¹⁴⁶

In *Lewis v. New Mexico Department of Health*¹⁴⁷ a class of persons with physical and developmental disabilities claimed that their continued institutionalization and placement on a waiting list for less restrictive waiver services violated the reasonable promptness provision.¹⁴⁸ The district court denied the State's motion to dismiss,¹⁴⁹ finding that the delays were clearly unreasonable when plaintiffs had been waiting for two to seven years.¹⁵⁰ Even though the Medicaid Act mandates a 200-person minimum for receipt of waiver services, the court held that the scope of New Mexico's obligations was greater than this numerical floor.¹⁵¹ It maintained that just because "the State applies for a waiver for a certain number of individuals[, this] does not prevent the State from applying for a waiver to serve enough persons such that it can provide waiver services to all eligible applicants with 'reasonable promptness.'"¹⁵²

The court in *Benjamin H. v. Ohl*¹⁵³ summarized the simple rationale behind prohibiting states from raising budgetary defenses to justify their failure to provide waived services with equal access or reasonable promptness:

States could easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds. Medicaid is an optional program. States are not required to participate. Once they do elect to participate, however, they must comply with federal requirements. That requires

146. *Id.* at 67.

147. 94 F. Supp. 2d 1217 (D.N.M. 2000).

148. *See id.* at 1221-22.

149. *See id.* at 1240.

150. *See id.* at 1235.

151. *See id.* at 1234.

152. *Id.* Interestingly, the court also refused to dismiss the § 1983 claim against the governor. *See id.* at 1240. It found that his vetoing of funds for waiver programs—despite knowledge that several hundred people were on waiting lists—and submission of a budget that contained half of the requested funds amounted to a denial of HCBS to plaintiffs. *See id.*

153. Civ. Action No. 3:99-0338 (S.D. W. Va. July 15, 1999).

funding a sufficient budget to meet the needs of the program.¹⁵⁴

In order to promote the deinstitutionalization of persons with disabilities, realize the undeniable benefits of their integration into the community, achieve the cost savings of a community-based treatment approach, and fulfill its obligations under the law, Minnesota must maintain the mechanisms that support the program's existence.

C. The Personal Care Attendant (PCA) Workforce Shortage Crisis

1. PCA Services

PCA services are one of the services offered under the HCBS waiver program in Minnesota.¹⁵⁵ These services are provided to individuals who are not residents of a hospital, nursing facility, intermediate care facility for those with retardation, or institution for mental disease.¹⁵⁶ They enable individuals to accomplish tasks they would normally perform themselves if they did not have a disability.¹⁵⁷ Depending on the specific disability involved, PCAs assist their clients with a wide range of tasks, including toileting, skin care, range of motion exercises, respiratory assistance, transfers, bathing and grooming, dressing, turning and positioning, furnishing medication ordinarily self-administered, application of prosthetics, cleaning equipment, food preparation and feeding, and accompanying them for medical diagnosis and/or treatment sessions.¹⁵⁸ Minnesota's DHS requires that a PCA must be at least sixteen years old, possess competency acquired through training and/or experience to perform required tasks, have the ability to provide services according to the client's care plan, respond appropriately to the client's needs, be able to report change in the client's condition to a qualified professional responsible for his or her care, as well as pass a criminal background check.¹⁵⁹

154. *Id.* at 26.

155. See HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 9.

156. See Health Care Fin. Admin., *Personal Care Services*, at <http://www.hcfa.gov/medicaid/ltc4.htm> (last updated Mar. 11, 1999).

157. See *id.*

158. See MINN. R. 9505.0335 (1999).

159. MINN. DEPT OF HUMAN SERVS., DHS BULL. #00-56-26, "PCA CHOICE": A NEW OPTION FOR PCA SERVICES, Attachment B (Oct. 16, 2000) [hereinafter DHS BULL. #00-56-26].

Because of the home-based care that they provide, PCAs play a vital role in allowing persons with disabilities to live outside institutional settings and stay in their own communities. DHS anticipates that total state Medicaid spending on home health care services will increase at annual rate of fourteen percent between 1999 and 2003.¹⁶⁰ Personal care assistants and private duty nurses will constitute eighty-five percent of these expenditures.¹⁶¹ The state's population of persons with disabilities is steadily increasing, and each year, DHS increases the number of persons eligible to receive waiver services.¹⁶² Taken together, these factors will undoubtedly impact the demand for PCA services.¹⁶³

2. Minnesota's Labor Shortage and Its Impact on PCA Availability

Minnesota's labor market continues to be one of the strongest in the country, with a higher percentage of its labor force employed than any other state,¹⁶⁴ and an unemployment rate below three percent for the last thirty-four of thirty-five months.¹⁶⁵ Governor Jesse Ventura observed that "[o]ur continuing low unemployment rates reflect an unprecedented level of opportunity for all Minnesota workers."¹⁶⁶ The flipside to this success, however, is a shortage of labor in certain occupational sectors. The workforce is growing more slowly than the economy, and a larger number of workers have skills that are mismatched for the job requirements of both low- and high-skilled positions.¹⁶⁷ Growth in the service sector is expected to add more than half of the new jobs in the state between 1996 and 2006.¹⁶⁸ Within the service sector, health services employment is expected to increase by 21%, with the largest gains expected in practitioners' offices, nursing and

160. See HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 10.

161. See *id.*

162. See *id.* at 9, 12.

163. See *id.* at 12.

164. The state has a 75.1% labor force participation rate as of June 2000. News Release, Minn. Dep't of Econ. Sec., Minnesota Solidly at the Top in National Rankings (June 28, 2000), <http://www.mnworkforcecenter.org/news/nr2000/mbc00028.htm> (last visited Oct. 2, 2000).

165. See News Release, Minn. Dep't of Econ. Sec., Minnesota Unemployment Rate Up But Continues Under Three Percent (Sept. 12, 2000), <http://www.mnworkforcecenter.org/news/nr2000/dph00005.htm> (last visited Oct. 2, 2000).

166. *Id.*

167. See CITIZENS LEAGUE, HELP WANTED MORE OPPORTUNITIES THAN PEOPLE 1 (1998).

168. See MINN. DEP'T OF ECON. SEC., MINNESOTA EMPLOYMENT OUTLOOK TO 2006, at 3 (1999).

personal care facilities, and home healthcare service firms.¹⁶⁹ Within the healthcare industry itself, home health services were the fastest growing component during the 1990s.¹⁷⁰ Because of this, employers expect great difficulty filling 54% of current healthcare support openings.¹⁷¹

Employers in Minnesota appear to be experiencing particular difficulty in recruiting and retaining PCAs.¹⁷² PCAs are one of the five groups within the larger healthcare support occupations that have an above-average turnover rate,¹⁷³ with 65% of employers reporting that they are “always hiring” for these jobs due to vacancy.¹⁷⁴ PCA jobs are typically entry-level,¹⁷⁵ offer few benefits, and pay a state average hourly wage of \$7.71.¹⁷⁶ During its Health Professions Workforce Forum in January 2000, the Minnesota Department of Health identified the need to step up recruitment and retention efforts in the healthcare field.¹⁷⁷ It focused on the need to increase reimbursement rates and benefits, as well as to establish improved incentive structures, such as training, rewards for experience, and opportunities for advancement.¹⁷⁸

169. David Senf, *Where Is Job Growth Headed in Minnesota?*, MINN. ECON. TRENDS, Mar. 1999, at <http://www.mnworkforcecenter.org/lmi/trends/mar99/growth.htm> (last visited Aug. 8, 2000).

170. See MINN. STATE COLLS. AND UNIVS. & MINN. DEPT OF ECON. SEC., OCCUPATIONS IN DEMAND: FINDINGS FROM VACANCY SURVEYS OF SELECTED INDUSTRIES, FOURTH QUARTER OF 1999, at 9 (2000) [hereinafter OCCUPATIONS IN DEMAND].

171. See *id.* at 20-21.

172. See *id.* at 20.

173. See *id.* at 22.

174. *Id.* at 66.

175. See *id.* at 22-23. Healthcare support jobs, including those as PCAs, typically lack “well defined training pathways into an occupation . . .” *Id.* at 23.

176. Of employers surveyed, only 39% offered vacation, 16% offered sick leave, and 23% offered health benefits. *Id.* at 68. For comparison, the respective figures for medical assistants are 100%, 90%, 100%; for dental assistants, 92%, 59%, 52%; for nursing assistants, 74%, 71%, 58%; and the average for all healthcare support, 74%, 66%, 58%. *Id.* at 66.

177. Minn. Dep’t of Health, *Minnesota Health Professions Workforce Forum Executive Summary* (2000), <http://www.health.state.mn.us/divs/chs/orhworkfrc.htm> (last updated May 23, 2000).

178. See *id.*

II. Analysis¹⁷⁹

A. *Effects of the PCA Shortage*

The collision of the PCA shortage and continued low Medicaid provider reimbursement rates threatens the deinstitutionalization effort in Minnesota, particularly with regard to the operation of the HCBS waiver program. A primary barrier to deinstitutionalization is the high staff turnover rate due to inadequate wages and benefits for support personnel like PCAs in community-based settings.¹⁸⁰ More than just failing to attract adequate numbers of PCAs to the market, low reimbursement rates are directly tied to the competency of the workers that ultimately do fill these positions, and the resulting decline in the quality of services provided.¹⁸¹ Furthermore, Minnesota's failure to deliver needed medical services because of low wages implicates wider systemic issues, such as the role of provider agencies, the effects on families now forced to provide the care themselves, and the imminent threat of institutionalization resulting from such a precarious status quo.¹⁸² Inaction will seriously compromise Minnesota's ability to adhere to the integration mandates

179. A bulk of the data upon which this analysis is built derives from telephone interviews conducted by the author, working for the Minnesota Disability Law Center, of recipients and parents of recipients of PCA and Private Duty Nursing services under Medicaid and the HCBS Waivers program throughout Minnesota. All names and identifying personal information have been omitted to protect confidentiality. Hard copies of interview data are on file with the author.

180. See *infra* Part II.A.1. Commentators have identified a host of other barriers to deinstitutionalization across the country, including resistance from communities who regard the placement of small group homes in their neighborhoods as a blight, inadequacy of formal training for medical providers serving disabled populations, closure or movement of supporting institutions like treatment centers when large institutions shut down, resistance by private for-profit institutional facilities, federal funding bias toward uniform care and easier monitoring associated with institutions, and occasional opposition from clients and families who see institutions as a safe, secure form of public assistance. See Davis et al., *supra* note 34, at 15. Moreover, by maintaining dual systems of care, whereby states sustain both large institutions and community living programs, funds for community living will shrink as the per capita costs of keeping large facilities open increase. See *id.* at 14. One study, conducted for the American Association on Mental Retardation, identifies three main factors contributing to low wages in direct care occupations: historical pay differences between men and women (direct care workers tend to be women), a general wage bias against care-giving occupations, and a history of limited funding to community organizations that got "locked in" when state agencies entered the picture to provide reimbursement. See DAVID BRADDOCK & DALE MITCHELL, *RESIDENTIAL SERVICES AND DEVELOPMENTAL DISABILITIES IN THE UNITED STATES* 5-8 (Michael J. Begab ed. 1992).

181. See *infra* notes 183-193 and accompanying text.

182. See *infra* notes 194-210 and accompanying text.

embodied in *Olmstead*, the ADA, and § 504, rendering the state itself an agent of discrimination. Unless Minnesota actively remedies the inadequacy of PCA wages, its inaction will violate the equal access and reasonable promptness provisions of the Medicaid Act.

1. The Central Problem: Inadequate Reimbursement

Provider agencies, which employ and train the PCAs that directly work with clients, are reimbursed by the state and take a share of the funds for administrative overhead expenses before passing the remainder in wages to the PCA.¹⁸³ Inadequate state reimbursement manifests itself not only in the low wages direct care workers receive, but frequently in the lack of employee benefits and reimbursement for transportation to clients' homes.¹⁸⁴ As such, the PCA worker must absorb the cost of mileage, gasoline, and time on the road, creating a major disincentive to pursue this job.¹⁸⁵ Also, after taking into account the physical and emotional demands that can accompany providing personal care services, an average hourly wage of \$7.71 is especially low when compared with those for other service occupations in Minnesota.¹⁸⁶ Given this situation, provider agencies' difficulties in finding and retaining PCAs to continually fill vacant positions is not surprising.

183. See DHS BULL. #00-56-26, *supra* note 159, at 2. Besides hiring and training, the agency assigns PCAs to clients, supervises the PCA, and handles payroll and billing. See *id.* Many waiver participants express frustration at agencies and feel they are unnecessary middlemen. See, e.g., Telephone Interview 8 (Sept. 22, 2000) (reporting that PCA gets six to eight dollars and fifty cents of thirteen to fourteen dollars paid to agencies); Telephone Interview 27 (Nov. 3, 2000) (reporting that PCA gets seven of twelve dollars); Telephone Interview 29 (Nov. 3, 2000) (reporting that her PCA of eleven years started at seven dollars per hour and is now only up to nine dollars per hour; she does not understand why she even needs an agency); Telephone Interview 30 (Nov. 6, 2000) (reporting that PCA gets seven of the fourteen dollars paid to the agency).

184. See, e.g., Telephone Interview 15 (Oct. 6, 2000) (reporting that PCA's agency did not reimburse for travel).

185. One mother recalls that "years ago" a local home health agency would even pay for taxi fare in order to get PCAs out to clients' homes. Telephone Interview 29 (Oct. 3, 2000).

186. By way of comparison, the 1998 average hourly wage in Minnesota for amusement and recreation attendants was \$7.03, janitors \$8.85, cashiers \$7.31, retail salespersons \$8.89, taxi drivers \$7.48, and vehicle washers \$8.35. MINN. DEPT. OF ECON. SEC., 1998 WAGE AND EMPLOYMENT BY OCCUPATION, <http://www.mnworkforcecenter.org/lmi/sal94/mnalphabet.htm> (last visited Jan. 13, 2001).

2. Effects on PCA Workers and the Occupation

Lack of available staff and high turnover rates are immediate effects of the low rate of reimbursement from the state. Without adequate numbers of employees, providers are unable to supply backup when PCAs call in sick, go on vacation, or otherwise do not show up.¹⁸⁷ Clients frequently report that PCAs will show up for only a brief period, sometimes just a few visits, before they quit.¹⁸⁸ Besides its effect on PCA availability, low reimbursement rates impact the quality and competency of the workers attracted to the job. Agencies will often provide their PCAs with some preliminary training, such as on sterile technique or how to move clients, but PCAs do not require any licensure, specific experience, or formal program completion.¹⁸⁹ As such, employment as a PCA is typically viewed as an entry-level, low-skill, low-paying, high-turnover job.¹⁹⁰ In addition, it lacks opportunity for advancement and offers few incentives for acquiring increased skills, striving for above average performance, or providing support in dealing with more difficult cases.¹⁹¹ High school or college students tend to fill a number of PCA positions in a part-time capacity and often quit upon returning to school or graduating.¹⁹² Moreover, work in other settings, such as retail, can prove to be a more attractive choice with higher or comparable compensation and more regular hours.¹⁹³

187. See, e.g., Telephone Interview 19 (Oct. 16, 2000) (reporting that agency has no backup to send when PCAs call in sick or take vacation); Telephone Interview 20 (Oct. 16, 2000) (reporting that there is rarely backup when PCAs call in sick or go on vacation, and even if there is, the worker sent does not necessarily know what to do because they have never been at her home); Telephone Interview 23 (Oct. 20, 2000) (reporting that no-shows and PCAs calling in sick at the last minute are common occurrences).

188. See, e.g., Telephone Interview 16 (Oct. 9, 2000) (reporting that PCAs sent do not stay for long because they are mostly students and have other activities going on); Telephone Interview 29 (Nov. 3, 2000) (reporting that a PCA showed up for one day and quit).

189. See, e.g., Telephone Interview 18 (Oct. 9, 2000) (reporting by a mother of paralyzed child that PCAs have no training in catheterization or giving enemas, so she has to train each new worker herself).

190. See TASK FORCE ON DIRECT SUPPORT WORKFORCE DEV., WORKFORCE ISSUES SUPPORTING PERSONS WITH DISABILITIES 7-8 (2000) [hereinafter TASK FORCE].

191. See *id.* at 8.

192. See, e.g., Telephone Interview 24 (Oct. 23, 2000) (reporting that current PCA is a high school student and previous PCA over summer was a college student who stopped working to go back to school); Telephone Interview 28 (Nov. 3, 2000) (reporting that child with autism has only had one PCA so far, a college student who stayed a year but who stopped working to go back to school); Telephone Interview 29 (Nov. 3, 2000) (reporting that students have typically been the PCAs during the summers for child with brain damage).

193. See, e.g., Telephone Interview 23 (Oct. 20, 2000) (reporting that new Wal-

3. Effects on Clients

Worker shortage, incompetency, and high turnover rates present a host of negative effects on persons with disabilities who rely on PCAs to provide supportive services that would allow them to live at home rather than in an institution. The inability to find PCAs, either through an agency or through their own efforts, is a prevalent problem for waived and non-waived home care recipients alike.¹⁹⁴ Of all clients surveyed, none were receiving all the hours for which they were authorized, and in more than a few instances, they were receiving no PCA services at all.¹⁹⁵ While a few clients and their parents reported dissatisfaction only with the number of hours filled, many indicated that the workers sent by agencies were of questionable competency.¹⁹⁶ Children with mental and behavioral health problems often end up with merely a babysitter—assuming they can even find a PCA to fill a portion of their authorized hours—rather than a qualified health care worker who can assist with their actual medical needs, such as development of social, learning, and coping skills.¹⁹⁷

Mart being built in Rochester is more appealing; it offers better wages and benefits); Telephone Interview 8 (Sept. 22, 2000) (reporting that PCAs are leaving to work in hospitals, schools, and retail instead of providing care in homes); Telephone Interview 30 (Nov. 6, 2000) (reporting by a father of a child with emotional behavioral disorder that he has never heard of a PCA who left one agency to work for another but rather, they leave the field entirely).

194. *See, e.g.*, Telephone Interview 21 (Oct. 16, 2000) (reporting by a mother that, of the 100 agencies she called, she could not find a single agency that had staff to send); Telephone Interview 27 (Nov. 3, 2000) (reporting that she contacted fifty agencies with none willing to take her case due to staff shortage).

195. *See, e.g.*, Telephone Interview 26 (Oct. 30, 2000) (reporting seven and a half hours per day authorized and zero hours delivered); Telephone Interview 27 (Nov. 3, 2000) (reporting four hours per day authorized and zero hours delivered); Telephone Interview 28 (reporting fifteen and three-quarters hours per week authorized and zero hours delivered).

196. *See, e.g.*, Telephone Interview 15 (Oct. 6, 2000) (reporting by a client with depression that her friend overheard PCA discussing client's case with a neighbor); Telephone Interview 24 (Oct. 23, 2000) (reporting that PCA would fall asleep on the job); Telephone Interview 25 (Oct. 30, 2000) (reporting that PCAs she worked with had little experience or training dealing with people with mental illness; one PCA kept borrowing money and another suggested that if she went to church, she would not be mentally ill).

197. *See, e.g.*, Telephone Interview 20 (Oct. 16, 2000) (reporting that high turnover rate difficult for child with quadriplegia, mental retardation and blindness; instead of regularity and structure, she must adapt and re-adapt to each new worker); Telephone Interview 30 (Nov. 6, 2000) (reporting that children with emotional behavioral disorder need PCA who knows how to deal with their specific disabilities, not just clean up after them); Telephone Interview 21 (Oct. 16, 2000) (reporting by a mother of child with mild retardation and schizo-affective disorder that she needs PCA to help with child's development, not to babysit her).

Especially for clients with more severe disabilities requiring constant care and clients with mental illness, the worker shortage has far deeper ramifications than just doing without services. Without a PCA, a client may not be able to take a bath, care for wounds, go to school, go to work, or even breathe.¹⁹⁸ In some cases, going without the PCA services for which an individual is entitled leads to hospitalization or institutionalization, either due to an emergency arising from a lack of regular, necessary medical support in the home, or because it becomes the only means to access this support.¹⁹⁹ For example, one Elderly Waiver recipient had to be hospitalized after she developed an infection at her amputation site that went untreated.²⁰⁰ Had a PCA been available to change her prosthetic leg regularly or clean her wounds early, she would not have had to go to the hospital.²⁰¹ Nonetheless, she stated that the best part about being in the hospital was being able to bathe for the first time in three months.²⁰²

4. Effects on Families of Clients

In many instances, recipients of HCBS waivers live with their families in the community. However, because of the PCA shortage, many family members find themselves having to provide the care the state failed to deliver. Faced with lack of staff from provider agencies, many families have placed their own advertisements in newspapers or local schools and churches, hoping to recruit workers directly.²⁰³ Indeed, some agencies will not even take on a case unless clients find their own PCAs.²⁰⁴ For

198. *See, e.g.*, Telephone Interview 18 (Oct. 9, 2000) (reporting that client paralyzed from chest down cannot ever be left alone or might choke); Telephone Interview 19 (Oct. 16, 2000) (reporting that developmentally disabled waiver client only able to take night classes due to PCA unavailability during day, jeopardizing ability to have college career).

199. *See, e.g.*, Telephone Interview 11 (Sept. 25, 2000) (reporting that son institutionalized in psychiatric ward due to lack of PCA); Telephone Interview 16 (Oct. 9, 2000) (reporting by a mother that if son with depression and ADHD had enough PCA supports, he would not have been placed in a residential mental facility); Telephone Interview 23 (Oct. 20, 2000) (reporting by a quadriplegic client that she was hospitalized three times in two years when no PCA came to help her when she was ill with the flu and diarrhea).

200. *See* Telephone Interview 6 (Sept. 18, 2000).

201. *See id.*

202. *See id.*

203. *See, e.g.*, Telephone Interview 28 (Nov. 3, 2000) (reporting by a mother of child with autism that agency had no PCAs to send, but that she could find people on her own); Telephone Interview 27 (Nov. 3, 2000) (reporting that agencies would take on her case only if she found the PCA herself).

204. *See, e.g.*, Telephone Interview 23 (Oct. 10, 2000) (reporting that child with

those families that can afford it, some pay PCAs extra money directly out of their own pockets, in order to provide the PCAs incentives to stay.²⁰⁵ Out-of-pocket payments are not the only economic effect: in many cases, the caregiving family member must quit or work fewer hours, assuming he or she can pursue work at all.²⁰⁶

The intangible effects on families are likewise great. There is tremendous personal stress and physical exhaustion associated with constantly having to care for, or arranging the care for, a child or spouse with a disability.²⁰⁷ For instance, a mother of a child with cerebral palsy reported that she even considered putting her son into foster care because she simply "couldn't provide the help he needed anymore" herself.²⁰⁸ Frustration runs high at not being able to pursue one's own appointments and work plans. In addition, the strain on other family relationships besides the one between the caregiver and the recipient can be overwhelming.²⁰⁹

quadriplegia being dropped by current agency due to lack of staff, while other agencies mother is seeking as replacement are telling her that they cannot take on her case unless she finds her own workers).

205. *See, e.g.*, Telephone Interview 15 (Oct. 6, 2000) (reporting by a client with depression that she pays PCA out of her own pocket to "make it worth her while" to stay); Telephone Interview 22 (Oct. 20, 2000) (reporting by a mother of child with cerebral palsy that she has not had a major problem with high turnover because her family can afford to pay extra to retain a PCA).

206. *See, e.g.*, Telephone Interview 8 (Sept. 22, 2000) (reporting by a mother that she had to quit her job to care for son with cerebral palsy); Telephone Interview 11 (Sept. 25, 2000) (reporting by a mother that she has never worked because she has to stay home to care for her three children with disabilities); Telephone Interview 12 (Sept. 25, 2000) (reporting by a mother that she used to have a "good paying job" but had to quit and is now on public assistance); Telephone Interview 14 (Oct. 3, 2000) (reporting by a mother that she has never held a job since daughter with disability was born); Telephone Interview 27 (Nov. 3, 2000) (reporting by a mother that "working is out of the question"); Telephone Interview 29 (Nov. 3, 2000) (reporting by a mother that she cannot hold even a part-time job because she has to care for daughter with brain damage); Telephone Interview 30 (Nov. 6, 2000) (reporting by a mother of sons with emotional behavioral disorder that she has no time to work at all).

207. *See, e.g.*, Telephone Interview 13 (Sept. 29, 2000) (reporting by a grandmother of traumatic brain injury waiver client that she has spent thirty-two hours straight caring for him; grandmother herself is over seventy years old, has arthritis, and has had to postpone her own surgeries to care for him).

208. Telephone Interview 10 (Sept. 25, 2000).

209. *See, e.g.*, Telephone Interview 18 (Oct. 9, 2000) (reporting that family must be split up in order to have an outing, because someone must stay at home to care for daughter with paralysis); Telephone Interview 21 (Oct. 16, 2000) (reporting by a mother that she has no free time to spend with her spouse and that child with disability fights with siblings unless PCA is present to help with behavioral problems); Telephone Interview 22 (Oct. 20, 2000) (reporting by a mother that she feels guilty for not being able to spend more time with her other son, who does not have disability); Telephone Interview 30 (Nov. 6, 2000) (reporting marital strain).

Moreover, many family caregivers feel intense resentment at having to assume those responsibilities the state failed to fulfill.²¹⁰

5. How the PCA Labor Shortage Implicates Minnesota's Statutory Obligations

A primary goal of the HCBS waiver program is promoting the benefits of living in the community rather than in an institution.²¹¹ Yet, for the Medicaid recipients in Minnesota who rely on waived PCA services, the unavailability of PCAs severely compromises their—and their families'—ability to pursue independent and fulfilling lives. If medical needs go unmet because of a scarcity of workers to provide home care, Minnesotans with disabilities are put at direct risk of institutionalization.

The current PCA workforce crisis is, at least in significant measure, the result of inadequate wages paid under Medicaid.²¹² Should low wages continue unaddressed, Minnesota will have effectively shirked its statutory duties under the equal access and reasonable promptness provisions of the Medicaid Act. Current wage rates fail to attract sufficient numbers of providers to ensure access that is equal to that enjoyed by individuals who can afford to pay more.²¹³ Simultaneously, the limits of reasonable promptness are undoubtedly surpassed if authorized PCA hours are never even furnished.²¹⁴ Furthermore, the state violates *Olmstead's* ADA Title II community integration mandate when its failure to deliver authorized PCA services results in institutionalization.²¹⁵ Given Minnesota's budget surplus,²¹⁶ its ability to raise a "fundamental alterations" defense²¹⁷ should only

210. See, e.g., Telephone Interview 28 (Nov. 3, 2000) (reporting by a mother of child with autism that caring for her son is her full time job, calling herself a "PCA with no pay").

211. See discussion *supra* Parts I.A., I.B.2 (describing deinstitutionalization and the role of the HCBS program in this movement).

212. See discussion *supra* Parts I.C.2, II.A.1 (detailing PCAs' low wages).

213. See *supra* note 205 and accompanying text. While an analysis of provider reimbursement rates under other payment schemes like Medicare or private insurance is beyond the scope of this Note, the fact that recipients who can afford to pay PCAs extra out of their own pockets are willing to do so indicates that low wages are a major barrier to equal access to services. It stands to reason that an individual who can afford to pay more, from whatever source, will be more attractive to a PCA, at least from the standpoint of financial incentives.

214. See *supra* note 195 and accompanying text (reporting accounts of authorized time not delivered by PCAs).

215. See *Olmstead v. L.C.*, 527 U.S. 581, 607 (1999).

216. See discussion *infra* Part II.B.2 (suggesting injunctive relief).

217. See *supra* note 73 and accompanying text (explaining the "fundamental alterations" defense).

be granted limited force. Moreover, under the caselaw of Medicaid, equal access, and reasonable promptness, any budgetary defense should be granted even less.²¹⁸

B. Proposed Solutions

Minnesota's DHS recognizes "the need to redesign the current system to prepare for and meet future demands of growing numbers of people . . . with disabilities."²¹⁹ Proposed solutions would target legislative efforts to inject greater flexibility and consumer direction in the operation of the HCBS Waiver program by expanding several existing home care options offered by DHS.²²⁰ This effort should be coupled with the filing of class action suits, such as those filed in California and Arizona, as a means to place more immediate and direct pressure on the state to make clearly-needed changes to the current program.²²¹ Meanwhile, the PCA worker shortage calls for a number of changes in state policy that would both induce more and better-qualified workers to enter the labor market.²²² Only with increased PCA availability and competency will consumer direction of services be a worthwhile option in keeping with the waiver program's goal of allowing persons with disabilities to receive the care they need at home or in their own communities.

1. Greater Consumer-Directed Control in the Delivery of Services

Consumer direction "encompasses decision-making, personal choice, self-advocacy, self-determination, and self-expression" in the selection of services and service providers.²²³ In order for consumer direction to be effective, it must be sensitive to the limitations specific to different disabilities.²²⁴ For example, children, families, and elderly people with fewer cognitive impairments might prefer a greater degree of autonomy, while

218. See *supra* notes 124-154 and accompanying text (explaining the limits to budgetary defenses under Medicaid Act in the face of inadequate provider reimbursement rates).

219. HCBS WAIVERS BRIEFING BOOK, *supra* note 20, at 11.

220. See *infra* Part II.B.1 (discussing consumer direction).

221. See *infra* Part II.B.2 (discussing injunctive relief).

222. See *id.* (discussing policy solutions).

223. LUTZKY ET AL., *supra* note 54, at 23. States developing *Olmstead* plans are actively incorporating language to reflect a commitment to promoting consumer direction and choice, as well as including people with disabilities in plan development and eliminating unnecessary institutionalization. See *OLMSTEAD PROGRESS REPORT*, *supra* note 82, at 7-10.

224. See LUTZKY ET AL., *supra* note 54, at 23.

persons living alone or having greater cognitive impairments might want less consumer direction but retain the option of hiring a family or friend to be a care provider.²²⁵

In Minnesota, the Consumer Support Grants (CSG) program²²⁶ assists individuals with functional limitations and their families in purchasing those supports, including PCA services that the individual needs to "live independently and productively in the community."²²⁷ The program allows these consumers to receive a cash grant equivalent to the non-federal portion of services.²²⁸ In effect, they trade their Medicaid home care services in exchange for only the state share of funds.²²⁹ In so doing, the consumer can purchase needed services and supports in a more flexible manner, because the administrative restraints that normally are attached to the federal share do not come into play.²³⁰ As such, CSG participants can purchase PCA services from family members, friends, or others without them having to be employed by home care agencies first.²³¹ The recipient and the participating county develop an agreement specifying amounts of payment and the services to be purchased with it, while the recipient must be able to arrange for and purchase services on her own.²³²

Because the CSG allows family caregivers to be paid as PCAs and permits a greater degree of individual choice in purchasing services, the program is useful in addressing some of the effects of the PCA shortage.²³³ Given the worker shortage, getting only the state share of Medicaid funds—and purchasing services under its more flexible rules—can be more attractive than receiving federally-matched, but more restrictive, funds. While extending the terms of the CSG program to reach the federal share of

225. *See id.*

226. MINN. STAT. § 256.476 (1998) governs this program.

227. MINN. DEP'T OF HUMAN SERVS., DHS BULL. #00-56-8, DHS REQUESTS INFORMATION ON ESTIMATED PARTICIPATION IN THE CONSUMER SUPPORT PROGRAM, Attachment A (May 26, 2000).

228. *See id.* at 2.

229. *See* ANNE L. HENRY, MINN. DISABILITY LAW CTR., DHS BUDGET LIMITS CONSUMER SUPPORT PROGRAM, TAKES \$15 MILLION SAVINGS 1-3 (2001).

230. *See* MINN. DEP'T OF FIN., STATE OF MINNESOTA 2002-03 BIENNIAL BUDGET C-197 (2001), <http://morefinance.state.mn.us/budget/operating/20022003/recommendedrequests/125388.pdf> (last visited Feb. 23, 2001) [hereinafter BIENNIAL BUDGET].

231. *See id.*

232. Minn. Dep't of Human Servs., *Consumer Support Grants: "An Opportunity to Manage Your Home Care"*, <http://www.dhs.state.mn.us/agingint/Services/csprog.htm> (last visited Nov. 11, 2000). Other services CSG participants can purchase are chore, homemaker, and home health aide services. *See id.*

233. *See supra* Parts II.A.1-4 (discussing the effects of the PCA shortage).

Medicaid would, of course, represent the greatest degree of consumer control for Minnesotans in the program, approval of such an extension is up to the federal government.²³⁴ Despite the obvious necessity for the CSG program in the meantime, however, Governor Jesse Ventura recently proposed to cap participation in the program at 200, in order to realize a savings of approximately \$15 million over fiscal years 2002-2003²³⁵ with no plans to reinvest this money into disability services.²³⁶ Given the fact that inadequate wages paid to PCAs creates the very need for a program like the CSG to prevent institutionalization, the proposed participation cap amounts to another state failure to meet its federal statutory obligations.

In October 2000, DHS announced a new service option available to PCA recipients called "PCA Choice," whereby they bypass the use of provider agencies in selecting their personal service care provider.²³⁷ The recipient teams up with a qualified professional, who assists with development of a care plan and supervision, and a "PCA Choice Provider," who conducts billing and payroll functions only.²³⁸ Meanwhile, the recipient can hire and fire the PCA directly, as well as provide training specific to her own needs.²³⁹ By teaming up responsibilities, DHS anticipates that PCAs will be paid higher wages as a result of reducing administrative overhead otherwise incurred by agencies.²⁴⁰ While this program is still very new, its design seems to address at least several key problems PCA recipients and their families found with the prior system. These included complaints that agencies took too large a cut of the state reimbursement before paying its PCAs, and that due to inadequate training, families would have to retrain PCAs once they arrived to their home.²⁴¹ However, a major drawback of this program is that PCAs cannot be a parent or spouse of the person with the disability, unlike in the CSG program.²⁴² Given that the central problem facing persons receiving PCA services under the HCBS waiver is a sheer lack of available workers in the market, the PCA Choice program appears to be of limited utility for the present time.

234. See BIENNIAL BUDGET, *supra* note 230.

235. See *id.*

236. See HENRY, *supra* note 229, at 1-3.

237. See DHS BULL. #00-56-26, *supra* note 159, at 2.

238. See *id.*

239. See *id.*

240. See *id.*

241. See *supra* note 189 (reporting mothers having to "train" PCAs).

242. See DHS BULL. #00-56-26, *supra* note 159, at Attachment B.

2. Injunctive Relief: Mandating Funding for Higher Wages and Establishing Other Incentives

While consumer-directed programs are promising, they are only partial solutions because of limitations on their scope of application or their novelty. The use of legal injunctive pressure to the state is still necessary to ameliorate such a widespread problem. In November 2000, the Minnesota Department of Finance projected a \$924 million budget surplus for the fiscal year 2000-2001.²⁴³ The Department forecasts "continuing, very strong economic growth" and expects a \$2.086 billion budget surplus for the 2002-2003 biennium.²⁴⁴ Yet this budget surplus includes those very funds Minnesota has saved by not fulfilling its HCBS waiver program obligations completely.²⁴⁵ In light of this surplus, Minnesota should not be allowed a viable lack-of-funds defense under the ADA and the *Olmstead* decision if its failure to deinstitutionalize is challenged in court. The state's failure to set wages high enough to enlist PCAs in numbers that would ensure equal access to services or reasonable promptness in their delivery raises potential challenges under the Medicaid Act, wherein caselaw has well established that budgetary considerations cannot be the dispositive factor in setting reimbursement rates.²⁴⁶

Increasing wages and benefits would have effects greater than simply attracting more PCAs to the market. Requiring more competitive wages would likely draw more qualified and experienced workers.²⁴⁷ Moreover, it may also bring back PCAs

243. See MINN. DEPT OF FIN., NOVEMBER FORECAST 1 (2000)

244. *Id.*

245. See *supra* note 195 and accompanying text (reporting non-fulfillment of authorized hours).

246. See *supra* notes 67-74, 124-154 and accompanying text (discussing limits to a lack of funds defense). Though a full analysis of the lack of funds defense is beyond the scope of this Note, an additional economic consideration in favor of injunctive pressure against the state is the fact that many family members, usually mothers of PCA service recipients, are forced to stay at home because the state has not provided all the hours necessary to keep recipients out of institutional care. See *supra* note 206 (reporting by mothers that they have lost their jobs or cannot work). One mother reported that a PCA who had worked for her family for eleven years reduced her weekly hours from twenty-five to seven and a half. See Telephone Interview 29 (Oct. 3, 2000). This PCA now works full time as a medical records clerk in order to retain health insurance benefits for herself and her spouse, since the provider agency did not offer them. See *id.* If PCAs are quitting in search of full time jobs for medical benefits coverage, it stands to reason that mothers—especially single mothers—who cannot even pursue work because they have to stay at home to be caregivers—are likewise jeopardizing their own medical insurance coverage. Removing these women from the workforce would presumably have spillover effects in the areas of income tax revenue and consumer spending.

247. See OCCUPATIONS IN DEMAND, *supra* note 170, at 24.

who enjoyed the work, but who quit solely because of low wages. Simultaneously, the state should consider establishing certification programs to train students in skills specific to providing PCA services to people with physical and mental disabilities. These programs could stand alone or be added onto larger academic programs in health care occupations or social work, in the manner of an externship. In so doing, certified workers would be better positioned to demand higher wages. Moreover, the existence of a recognized, structured training route would lend more legitimacy, respect, and appeal to an occupation too often characterized as low-skill, high-turnover, and lacking in opportunities for career advancement.²⁴⁸ Consumer choice will only be meaningful to the extent that the choices themselves are.

Conclusion

The Supreme Court's assertion in *Olmstead* that unjustified institutionalization constituted disability discrimination defined a principle with far-reaching implications for Minnesota's efforts to deinstitutionalize. Through the use of the Home- and Community-Based Services Waiver under the Medicaid program, the state is equipped with a potentially powerful means by which to advance this effort. However, in light of the current PCA labor shortage crisis, the state has fallen short of its various statutory obligations, only to pass off these duties to the families of persons with disabilities. In so doing, the state violates the very logic behind the existence of the HCBS waiver program. Without effective measures to increase reimbursement to PCA workers that will ensure equal access to and reasonably prompt provision of services, Minnesota is setting the stage for a return to the institutionalization of its residents with disabilities.

248. See TASK FORCE, *supra* note 190, at 7-8.

