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Carol Beatty

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IMPLEMENTING *OLMSTEAD* BY OUTLAWING WAITING LISTS

What would happen if everyone was placed on a decades long waiting list for water? And what if the only way to be guaranteed water for your children immediately was to put them in prison? What if every state had a separate waiting list and you went to the bottom of the list if you moved? Wouldn't there be riots in the streets?

Hundreds of thousands of people with intellectual and developmental disabilities . . . are waiting for services as vital to them as water. . . . For those who need help immediately, their only option is an institution.¹

I. INTRODUCTION

One of those waiting is Seth, a twenty-three year old who has autism.² After struggling to complete high school, Seth worked for several weeks in a mailroom, supported by a job coach.³ When his allotted twenty hours of job coaching expired, Seth lost his mailroom job.⁴ Now, Seth spends his days alone at home, watching television.⁵ Describing Seth's mood as terrible, Seth's mother feels powerless to help as his behavior continues to deteriorate, and she laments that "[i]f Seth had waiver services, everything would change."⁶ Medicaid Home and Community-Based Services ("HCBS" or "waiver services") would provide Seth with meaningful activities and something to look forward to each day.⁷ Seth's mother believes that if Seth had waiver services, he would no longer

1. *Stories*, NAT'L ORG. TO END THE WAITLISTS, <http://www.noewait.net/stories.html#new> (last visited Feb. 20, 2013) (arguing that the only option for waiting individuals who need immediate care is an institution because institutional care is an entitlement program in the United States, while states are not required to provide home and community based services).

2. THE ARC OF TENN. & VANDERBILT KENNEDY CTR. FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES, TENNESSEE KINDRED STORIES OF DISABILITY SPECIAL EDITION: WAITING LIST FOR HOME AND COMMUNITY-BASED WAIVER SERVICES 12 (2013), available at http://kc.vanderbilt.edu/kennedy_files/KindredWaitListStories2013.pdf.

3. *Id.*

4. *Id.*

5. *Id.* at 13.

6. *Id.*

7. THE ARC OF TENN. & VANDERBILT KENNEDY CTR. FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES, TENNESSEE KINDRED STORIES OF DISABILITY SPECIAL EDITION: WAITING LIST FOR HOME AND COMMUNITY-BASED WAIVER SERVICES 13 (2013), available at http://kc.vanderbilt.edu/kennedy_files/KindredWaitListStories2013.pdf.

feel miserable all the time and his behavior would improve.⁸ Seth qualifies for HCBS, but he remains trapped at home⁹—one of over 300,000 adults and children with intellectual and developmental disabilities (“I/DD”) on waiting lists for HCBS.¹⁰

Waiting lists for HCBS exist because federal statutes allow states to limit the number of people with I/DD who can receive HCBS.¹¹ Most of those waiting have to choose between two unattractive options: entering an institution to receive services, or continuing to wait an unknown amount of time to receive HCBS.¹² In Oklahoma, over 7,000 adults and children with I/DD wait for HCBS.¹³ With the exception of those facing emergencies, an Oklahoman’s waiting period for HCBS currently exceeds eight years.¹⁴ About 4.6 million Americans have an intellectual or developmental disability.¹⁵ Intellectual disability (“ID”)¹⁶ originates before age eighteen and is characterized by “significant

8. *Id.* at 13.

9. *Id.* at 13.

10. Kaiser Family Found., *Waiting Lists for Medicaid Section 1915(c) Home and Community-Based Service (HCBS) Waivers*, KFF.ORG, <http://kff.org/medicaid/state-indicator/waiting-lists-for-hcbs-waivers-2010/#notes> (last visited Mar. 8, 2014) [hereinafter KFF Waiting] (stating that 316,673 Americans with ID/DD were on waiting lists for Medicaid 1915(c) HCBS in 2011).

11. See 42 U.S.C. § 1396n(c) (2012); ROBERT M. GETTINGS, FORGING A FEDERAL-STATE PARTNERSHIP: A HISTORY OF FEDERAL DEVELOPMENTAL DISABILITIES POLICY 115 (2011) (“the budget neutrality formula contained in HCFA’s regulations governing HCB waivers is the only explicit authorization the states have to establish waiver utilization and expenditure caps”) (quoting THE NAT’L ASS’N OF STATE DIRS. OF DEVELOPMENTAL DISABILITIES SERVS., HOME AND COMMUNITY-BASED SERVICES AS A MEDICAID STATE PLAN OPTION: PRESERVING STATE FLEXIBILITY AND RESPONSIVENESS (1997)).

12. See Elliot Schwalb, *Reconsidering Makin v. Hawaii: The Right of Medicaid Beneficiaries to Home-Based Services as an Alternative to Institutionalization*, 26 GA. ST. U. L. REV. 803, 832-33, 849 (2010); see Megan Flynn, Article, *Olmstead Plans Revisited: Lessons Learned from the U.N. Convention on the Rights of Persons with Disabilities*, 28 LAW & INEQ. 407, 417 (2010); Julia Gilmore Gaughan, Comment, *Institutionalization as Discrimination: How Medicaid Waivers, the ADA, and § 1983 Fail*, 56 U. KAN. L. REV. 405, 405, 418, 437-38 (2008); Melody Kubo, Casenotes, *Implementing Olmstead v. L.C.: Defining “Effectively Working” Plans for “Reasonably Paced” Wait Lists for Medicaid Home and Community-Based Services Waiver Programs*, 23 U. HAW. L. REV. 731, 754 (2001).

13. *Developmental Disabilities Services: Waiver Request Statistics*, OKLA. DEP’T HUMAN SERVS., <http://www.okdhs.org/programsandservices/dd/docs/waiting.htm> (last visited Mar. 8, 2014) [hereinafter OKDHS] (reporting the actual waiting list count as of August 19, 2013 as 7,064).

14. *Id.* (“Working applications dated April 19, 2005 as of 8/19/13.”) When waivers become available, applications are processed on a first-come, first-served basis. See Oklahoma In-Home Supports waiver for adults, [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915\(c\)#waivers](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915(c)#waivers) (last visited Mar. 2, 2013):

In accordance with OAC 317:40-1-1, initiation of services occurs in chronological order from the waiting list based on the date of receipt of a written request for services. The individual must meet the financial and medical eligibility criteria and have critical support needs that can be met by the IHSW-A. Exceptions to the chronological requirement may be made when an emergency exists.

Thus, “[w]orking applications dated April 19, 2005 as of 8/19/13” equates to a wait time of eight years and four months.

15. *Introduction to Intellectual Disabilities*, ARC, <http://www.thearc.org/page.aspx?pid=2448> (citing S.L. Larson et al., *Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D, MR/DD DATA BRIEF* (Inst. on Cmty. Integration, Minneapolis, Minn.), Apr. 2000).

16. Disability terminology changes through the years, often because of negative stereotypes associated with disability labels. Robert L. Burgdorf Jr., *Long-Overdue Reform of D.C.’s Antediluvian Developmental Disabilities Law: From Forest Haven to the 21st Century*, 13 U. D.C. L. REV. 253 n.12 (2010) (quoting ROBERT L. BURGDORF JR., *THE LEGAL RIGHTS OF HANDICAPPED PERSONS: CASES, MATERIALS, AND TEXT* 46-47 (1980)). Throughout this paper, the term I/DD predominates; older terms including “mental retardation” and “feeble-minded” are used as necessary for accuracy or clarity, such as in quotations and historical references.

limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills.”¹⁷ Developmental disabilities (“DD”) include ID and other conditions that are primarily physical issues, such as cerebral palsy and epilepsy.¹⁸ A federal statute provides that “individuals with intellectual disabilities or persons with related conditions” may be eligible for Medicaid benefits for institutional or HCBS services.¹⁹

This article examines the history of institutional segregation of people with I/DD, discusses legal challenges to state waiting lists for Medicaid HCBS waiver²⁰ benefits, and argues that federal action must be taken to change the Medicaid HCBS waiver paradigm so that people with I/DD become fully included in the “mainstream of American life.”²¹ Part II provides background information on the evolution of deinstitutionalization, the history of Medicaid long-term supports for people with I/DD, and an overview of the Americans with Disabilities Act (“ADA”).²² Part III analyzes *Olmstead v. L.C.* and its impact on waiting lists for HCBS services and presents policy arguments in favor of eliminating HCBS waiting lists for eligible people with I/DD.²³ Part IV concludes that resolving the waiting list problem requires federal action, including changing HCBS from waiver status to a state plan requirement.²⁴

II. BACKGROUND OF THE PROBLEM: WAREHOUSED, WAIVERED, AND WAITING

A. *The Evolution of Deinstitutionalization*

Society, moved by pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which

17. *FAQ on Intellectual Disability*, AM. ASS’N ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, <http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.Uvvz-ZEzJ8E> (last visited Jan. 10, 2013).

18. *Id.*

19. 42 C.F.R. § 435.1010 (2012):

Persons with related conditions means individuals who have a severe, chronic disability that meets all of the following conditions: (a) It is attributable to-- (1) Cerebral palsy or epilepsy; or (2) Any other condition, other than mental illness, found to be closely related to Intellectual Disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of individuals with intellectual disabilities, and requires treatment or services similar to those required for these persons. (b) It is manifested before the person reaches age 22. (c) It is likely to continue indefinitely. (d) It results in substantial functional limitations in three or more of the following areas of major life activity: (1) Self-care. (2) Understanding and use of language. (3) Learning. (4) Mobility. (5) Self-direction. (6) Capacity for independent living.

20. Throughout this paper, HCBS waiver(s) refers to Medicaid 1915(c) waivers. 42 C.F.R. § 441.300 (2012) (“Section 1915(c) of the [Social Security] Act permits States to offer, under a waiver of statutory requirements, an array of home and community-based services that an individual needs to avoid institutionalization.”).

21. RUTH COLKER, *THE DISABILITY PENDULUM: THE FIRST DECADE OF THE AMERICANS WITH DISABILITIES ACT I* (2005) (quoting President George Herbert Walker Bush, Statement on Signing the Americans with Disabilities Act of 1990 (July 26, 1990)).

22. See generally GETTINGS, *supra* note 11, at 63-123.

23. See generally *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 593 (1999); GETTINGS, *supra* note 11, at 53-60; Schwalb, *supra* note 12.

24. See Gaughan, *supra* note 12, at 437.

they wished to lessen . . . [W]here there must be routine and formality, and restraint, and repression of individuality, where the chores and refining influences of the true family relation cannot be had, all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society.²⁵

Society's attitude and actions towards people with I/DD have evolved, sometimes in negative directions.²⁶ Throughout the 1800s, people with I/DD were largely ignored and left to themselves, based on the prevailing view that the condition was not dangerous or curable.²⁷ Education for children with disabilities began with a school for deaf students in 1817, and then one for blind students in 1832.²⁸ In 1848, humanitarian concerns prompted founders to establish a residential facility to educate children with I/DD, and they opened the first public institution of this type, the Massachusetts Asylum for Idiotic and Feeble-Minded Youth.²⁹ Thereafter, similar residential institutions arose and shared the goal of teaching children with I/DD functional skills to enable them to return to the community.³⁰

By the 1880s, these public institutions began serving younger children with severe disabilities and older adults, and the focus shifted to a dual purpose of training and providing custody for those with I/DD.³¹ In the early 1900s, distorted conclusions arose from several scientific developments, and society began to view people with I/DD as depraved and a threat to the public.³² In the words of Dr. Walter E. Fernald, Superintendent

25. PRESIDENT'S COMM. ON MENTAL RETARDATION, MR 76 MENTAL RETARDATION: PAST AND PRESENT 5 (Mary Z. Gray ed., 1977) [hereinafter PC 76] (quoting Dr. Samuel Gridley Howe, co-founder of the Massachusetts School for Idiotic and Feeble-minded Youth, Address at Ceremonies on laying the cornerstone of the N.Y. State Inst. for the Blind, at Batavia, New York (Sept. 6, 1866)).

26. *Id.* at 2.

We can trace the process by which the first humanitarian efforts of 1850 to educate the "poor idiot" and make him socially competent were transformed by 1915 into deliberate programs to "identify, segregate, and sterilize every feeble-minded person as a menace to social decency and racial purity: to the end that they shall not reproduce their kind."

27. *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 461 (1985) (Marshall, J., concurring in part, dissenting in part) (citing STANLEY S. HERR, RIGHTS AND ADVOCACY FOR RETARDED PEOPLE 18 (1983)).

28. Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415, 1424 (2007) (citing SCOTT B. SIGMON, RADICAL ANALYSIS OF SPECIAL EDUCATION 21, 23 (1987)).

29. *Id.*

30. Mary C. Cerreto, Olmstead: *The Brown v. Board of Education for Disability Rights: Promises, Limits, and Issues*, 3 LOY. J. PUB. INT. L. 47, 54 (2001); Joanne Karger, Note, "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, 1224 (1999) (citing SAMUEL GRIDLEY HOWE, TENTH ANNIVERSARY REPORT OF THE MASSACHUSETTS SCHOOL FOR IDIOTIC AND FEEBLE-MINDED YOUTH 11 (1857)).

31. PC 76, *supra* note 25, at 6 (citing HARVEY B. WILBUR, ANNUAL REPORT FOR 1874 (1875)); Karger, *supra* note 30, at 1225 (citing R.C. SCHEERENBERGER, A HISTORY OF MENTAL RETARDATION 123 (1983)).

32. *See* PC 76, *supra* note 25, at 9 ("Four scientific developments, which became popularized in distorted form, helped to fill in the final image of the feeble-minded individual as a depraved menace to society: Darwinism, sociological research, Mendelian genetics and psychometry."); *see also* Cerreto, *supra* note 30, at 54 (explaining that after children became adults, they continued to work at the state schools to protect society from "people who would 'pollute' the genetics environment of the greater society"); Karger, *supra* note 30, at 1225 (noting that medical and academic professionals argued for segregation of people with I/DD to protect society

of the Massachusetts Asylum for Idiotic and Feeble-Minded Youth:

The social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class . . . they cause unutterable sorrow at home and are a menace and danger to the community . . . Every feeble-minded person, especially the highgrade imbecile, is a potential criminal . . . The most important point is that feeble-mindedness is highly hereditary . . . The normal members of a definitely tainted family may transmit defect to their own children. Certain families should become extinct.³³

Medical and academic professionals promoted this inaccurate view of people with I/DD and recommended protecting society by segregating and sterilizing people with I/DD.³⁴ In the 1927 decision of *Buck v. Bell*, the Supreme Court reinforced the negative stereotype of people with I/DD, stating that “[i]t 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.”³⁵ The same facilities that had been established to train young people with I/DD to participate in community life were transformed into institutions of life-long custody that deprived people with I/DD from any participation in the community.³⁶

Despite I/DD advocates’ efforts to dispel the myth that people with I/DD were threats to society, institutional segregation of people with I/DD increased at its fastest rate from 1925 to 1950.³⁷ Although advocates were promoting the value of special education and adaptations to community life, public facilities housing people with I/DD continued to grow until 1969, reaching a maximum total population of 190,000.³⁸ These record-breaking institutionalization statistics were due, in large part, to medical advancements that increased the survival and lifespan of people with I/DD.³⁹ Another factor that contributed to the growth of institutionalization was the lack of government or community supports for families caring for adult children with I/DD at home.⁴⁰ Public institutions were overcrowded, understaffed, and provided little education and training.⁴¹ Despite the institutions’ deplorable conditions and parental feelings of guilt, waiting lists were lengthy because many parents had no other means of securing some type of perma-

from the alleged criminal and sexually immoral propensities of people with I/DD).

33. PC 76, *supra* note 25, at 11 (quoting W. E. Fernald, *The Burden of Feeble-mindedness*, XVIII J. OF PSYCHASTHENICS 90-98 (1912)).

34. PC 76, *supra* note 25, at 11-12; Cerreto, *supra* note 30, at 54; Karger, *supra* note 30, at 1225-26.

35. *Buck v. Bell*, 274 U.S. 200, 207 (1927).

36. *See* PC 76, *supra* note 25, at 12.

37. *Id.* at 15.

38. *Id.*

39. *Id.*

40. *See* DEWAYNE L. DAVIS, WENDY FOX-GRAGE & SHELLY GEHSAN, NATIONAL CONFERENCE OF STATE LEGISLATURES, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS 2 (2000); PC 76, *supra* note 25, at 16.

41. PC 76, *supra* note 25, at 45.

nent care for their children with I/DD.⁴²

In the 1960s, the efforts of parents and other I/DD advocates began to expose the appalling conditions of institutional life for children and adults with I/DD.⁴³ *Christmas in Purgatory*, a 1966 photo essay, graphically revealed the horrific daily life that children and adults with I/DD endured in a typical I/DD institution:

Many dormitories for the severely and moderately retarded ambulatory residents have solitary confinement cells . . . officially referred to as “therapeutic isolation.” These cells are . . . generally tiny rooms, approximately seven feet by seven feet, shielded from the outside with a very heavy metal door having either a fine strong screen or metal bars for observation of the “prisoner.” Some cells have mattresses, others blankets, still others bare floors. None that we had seen (and we found these cells in each institution visited) had either a bed, a washstand, or a toilet. What we did find in one cell was a thirteen or fourteen year old boy, nude, in a corner of a starkly bare room, lying on his own urine and feces. The boy had been in solitary confinement for several days for committing a minor institutional infraction.⁴⁴

In addition to seeking improvements in conditions at institutions, advocates began to champion deinstitutionalization.⁴⁵ The process of deinstitutionalization involves three elements: releasing people from institutional settings, reducing or preventing admissions to institutional settings, and creating or expanding alternative services in the community.⁴⁶ Throughout the 1960s and 1970s, various factors strengthened the deinstitutionalization movement.⁴⁷ Complementing advocates’ work and sociological studies that educated legislators and the public about institutional abuse, neglect, and inhumane conditions, the civil rights movement was growing, and society began placing greater emphasis on personal rights and autonomy.⁴⁸ Professionals began to understand that

42. *Id.* at 16, 21, 42, 45 (indicating that waiting lists were up to one third of the capacity of institutions, and turnover was slow).

43. DAVIS, *supra* note 40, at 2; *see* PC 76, *supra* note 25, at 45.

44. Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 14 n.60. (citing BURTON BLATT & FRED KAPLAN, CHRISTMAS IN PURGATORY: A PHOTOGRAPHIC ESSAY ON MENTAL RETARDATION 3 (1966)).

45. DAVIS, *supra* note 40, at 2; *see* PC 76, *supra* note 25, at 2; Samantha A. DiPolito, Comment, *Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation’s Conscience?*, 58 MERCER L. REV. 1381, 1385 (2007); Karger, *supra* note 30, at 1226-27; Sandra L. Yue, Article, *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*, 19 LAW & INEQ. 307, 313 (2001).

46. Lois A. Weithorn, *Envisioning Second-Order Change in America’s Responses to Troubled and Troublesome Youth*, 33 HOFSTRA L. REV. 1305, 1446 (2005).

47. *See* PC 76, *supra* note 25, at 45; DiPolito, *supra* note 45, at 1385; Karger, *supra* note 30, at 1226; Yue, *supra* note 45, at 313.

48. PC 76, *supra* note 25, at 45; DiPolito, *supra* note 45, at 1385; Karger, *supra* note 30, at 1226; Yue, *supra* note 45, at 313.

people with I/DD could improve and benefit from living in less restrictive environments.⁴⁹ Further, legislators and public officials held economic motives, recognizing the high cost of maintaining aging institutions and the necessity of building new facilities to accommodate those on waiting lists.⁵⁰

The 1970s brought both hope and disappointment to disability advocates, as judicial interpretations squelched legislation that had great potential to promote deinstitutionalization and government support for community services.⁵¹ High hopes sprung from the enactment of the first broad federal statute to address discrimination against people with disabilities—section 504 of the Rehabilitation Act of 1973 (“Section 504”)—which was regarded as “the civil rights bill of the disabled.”⁵² Section 504 stated that “[n]o otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, 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.”⁵³ Hopes dimmed, however, when federal courts refused to interpret the preceding provision of Section 504 as a requirement that states provide services for people with I/DD in the least restrictive environment.⁵⁴

Like Section 504, the Developmentally Disabled Assistance and Bill of Rights Act of 1975 (“DDA”)⁵⁵ generated unfulfilled hopes regarding enforcement of the civil rights of people with disabilities.⁵⁶ The bill of rights provision of the DDA states that people with I/DD “have a right to appropriate treatment, services, and habilitation . . . [in] the setting that is least restrictive of . . . personal liberty.”⁵⁷ However, in 1981, the Supreme Court ruled that the DDA bill of rights did not provide those with I/DD “any substantive rights to ‘appropriate treatment’ in the ‘least restrictive’ environment.”⁵⁸

Despite the judicial setbacks, the deinstitutionalization movement continued to in-

49. Yue, *supra* note 45, at 313.

50. Nancy K. Rhoden, *The Limits of Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory*, 31 EMORY L.J. 375, 381-82 (1982) (citing ANDREW SCULL, *DECARCERATION: COMMUNITY TREATMENT AND THE DEVIANT: A RADICAL VIEW 2* (1977) (noting that Scull argued that economic factors were the primary motive for deinstitutionalization)).

51. See Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 TEMP. L. REV. 393, 393-95 (1991); Sharaya L. Cabansag, Note, *Defending Access to Community-Based Services for Individuals with Developmental Disabilities in the Wake of the “Great Recession,”* 55 HOW. L.J. 1025, 1041 (2012) (“Despite Congress’ clear intent to effect the full integration of individuals with disabilities, judicial interpretations of the ADA have incorporated a cost-based analysis to decide the extent to which the ADA will be enforced.”).

52. Cabansag, *supra* note 51, at 1030; DiPolito, *supra* note 45, at 1385-86; Laura C. Scotellaro, Note, *The Mandated Move from Institutions to Community Care: Olmstead v. L.C.*, 31 LOY. U. CHI. L.J. 737, 743-44 (2000).

53. Pub. L. No. 93-112, 87 Stat. 355 (1973) (codified as amended at 29 U.S.C. § 794 (2012)).

54. DiPolito, *supra* note 45, at 1385-86 (citing *P.C. v. McGlaughlin*, 913 F.2d 1033, 1041 (2d Cir. 1990); *Phillips v. Thompson*, 715 F.2d 365, 368 (7th Cir. 1983) (holding that the state did not have an affirmative duty under the Rehab Act to create less restrictive community residential settings for persons with disabilities)).

55. Cook, *supra* note 51, at 395 (citing Pub. L. No. 94 103, 89 Stat. 486 (42 U.S.C. § 6010 (1970 & Supp. 1975)) (current version codified in scattered sections of 42 U.S.C.)).

56. See Cook, *supra* note 51, at 395; Cabansag, *supra* note 51, at 1031.

57. Cook, *supra* note 51, at 395 (quoting Pub. L. No. 94 103, 89 Stat. 486 (42 U.S.C. § 6010 (1970 & Supp. 1975)) (current version codified in scattered sections of 42 U.S.C.)).

58. Cook, *supra* note 51, at 395 (citing *Pennhurst State Sch. & Hosp. v. Halderman*, 451 U.S. 1, 10 (1981)).

tensify as it received support from disparate sources: disability advocates, academic research, the civil rights movement, liberal legislators, and fiscal conservatives.⁵⁹ Disability advocates continued to promote development of income, housing, and community supports so that individuals with I/DD could be successfully integrated into their communities.⁶⁰ Additionally, research studies of people who had moved from institutions into the community revealed numerous beneficial outcomes such as greater competence in daily living skills and decision making and increased independence, dignity, and relationships with others.⁶¹ Cost studies also confirmed the superiority of deinstitutionalization, generating support from fiscally conservative legislators and public officials.⁶² “[Deinstitutionalization] permitted liberal politicians to free mental patients, and at the same time allowed conservative politicians to save millions of dollars.”⁶³

Statistics demonstrate the impact of the deinstitutionalization movement, as the population of people with I/DD living in large public facilities decreased by 76.7 percent from 1980 to 2010.⁶⁴ By 2012, fourteen states had closed all public institutions for I/DD.⁶⁵ Although Oklahoma currently operates two institutions for people with I/DD, the Human Services Commission (“HSC”) voted in 2012 to transition the institutional residents into community homes and close both institutions within two years.⁶⁶ Oklahoma established both institutions over a century ago, and the facilities need millions of dollars in repairs and upgrades to maintain certification by the Department of Health.⁶⁷ While

59. See Bagenstos, *supra* note 44, at 20-21 (describing the importance of deinstitutionalization advocates’ alliance with fiscal conservatives); DiPolito, *supra* note 45, at 1385-88 (describing support deinstitutionalization advocates gained from civil rights movement, academic research); Karger, *supra* note 30, at 1226 (discussing how deinstitutionalization advocates gained momentum from the civil rights movement and from sociological studies exposing institutional abuse and neglect); Rhoden, *supra* note 50, at 382 (discussing support for deinstitutionalization from liberal politicians and fiscal conservatives).

60. Yue, *supra* note 45, at 313.

61. Research and Training Ctr. on Cmty. Living, Univ. of Minn., *Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of U.S. Studies, 1977-2010*, POL. RES. BRIEF (Research and Training Ctr. on Cmty. Living, Inst. On Cmty. Integration, Coll. of Educ. & Human Dev., Univ. of Minn., Minneapolis, Minn.), Apr. 2011, at 3-8 [hereinafter Cmty. Living]; DiPolito, *supra* note 45, at 1388; Karger, *supra* note 30, at 1227.

62. See Bagenstos, *supra* note 44, at 20-21; DiPolito, *supra* note 45, at 1387-88.

63. Rhoden, *supra* note 50, at 382 (quoting Gary J. Clarke, *In Defense of Deinstitutionalization*, 57 MILBANK MEMORIAL FUND Q. 461, 468 (1979)).

64. SHERYL LARSON, AMANDA RYAN, PATRICIA SALMI, DREW SMITH, & ALLISE WUORIO, RESIDENTIAL SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2010, at iii (2012).

65. NATIONAL COUNCIL ON DISABILITY, EXPLORING NEW PARADIGMS FOR THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT: SUPPLEMENT TO THE 2011 NCD PUBLICATION RISING EXPECTATIONS: THE DEVELOPMENTAL DISABILITIES ACT REVISITED 74, 88 (2012) [hereinafter NCD 2011] (listing the states which have closed all ICF/IIDs: “District of Columbia (1991), New Hampshire (1991), Vermont (1993), Rhode Island (1994), Alaska (1997), New Mexico (1997), West Virginia (1998), Hawaii (1999), Maine (1999), Minnesota (2000), Indiana (2007), Michigan (2009), Oregon (2009), and Alabama (2012)”).

66. News Release, Okla. Dep’t of Human Servs., *Human Services Commission Votes to Approve Community Services Initiative for People with Intellectual and Developmental Disabilities* [hereinafter OKDHS HSC] (Nov. 1, 2012), <http://www.okdhs.org/library/news/rel/2012/11/comm11012012b.htm>.

67. *Id.*

Both NORCE [Northern Oklahoma Resource Center of Enid] and SORC [Southern Oklahoma Resource Center in Pauls Valley] were established more than 100 years ago when that was the only option for providing care to people with intellectual and developmental

these institutions held over two thousand residents at their peak, they currently house less than two hundred and fifty people.⁶⁸ In announcing the HSC's decision to close the institutions, the HSC Chairman explained that “[c]ommunity services offer more personalized care and a higher quality of life to individuals, making institutional care a thing of the past.”⁶⁹

Advocacy efforts have been highly successful in achieving two of the three elements of deinstitutionalization: moving people with I/DD out of large institutions and into the community and reducing or preventing admissions to institutions.⁷⁰ But the ultimate goal of deinstitutionalization, community integration of people with I/DD, requires the third element—a robust system of community supports for people with I/DD.⁷¹ Advocates still have yet to succeed in replacing institutions with consistent, widespread community support systems that will allow people with I/DD to thrive in their communities.⁷² The difficulties in establishing and maintaining essential community-based services threaten the future of deinstitutionalization.⁷³

B. Medicaid's Role in Deinstitutionalization

In 1965, Congress created Medicaid as Title XIX of the Social Security Act to provide health care services to welfare beneficiaries, including people with disabilities.⁷⁴ Medicaid, a federal-state partnership program jointly funded by the federal and state governments, assigns specific roles to federal and state agencies to design and pay for each state's program.⁷⁵ Federal statutes, regulations, and policies establish broad national guidelines.⁷⁶ Within these guidelines, the states have flexibility in deciding what benefits to provide, who will be eligible, and how much health care providers will be paid.⁷⁷ Because of the discretion given to the states, eligibility and services vary considerably from

disabilities. SORC was opened in 1907 and originally known as the “State Training School for White Boys,” and NORCE opened in 1909 as the “Oklahoma Institute for the Feeble Minded.”

68. *Id.* (“At the height of institutional care in Oklahoma, both facilities housed more than 1,000 residents . . . Today, SORC has 123 residents and NORCE has 108.”).

69. *Id.*

“We realize this is an emotional decision involving change for the residents and their families as well as the employees of the facilities,” said Wes Lane, Chairman of the Human Services Commission. “We determined after studying this issue in depth for the better part of a year that this is the right decision at the right time. DDS has spent the past 20 years developing a comprehensive community service system that provides care and support to the vast majority of people receiving services who have all levels of disabilities,” said Lane. “Community services offer more personalized care and a higher quality of life to individuals, making institutional care a thing of the past.”

70. See Bagenstos, *supra* note 44, at 6-8; Weithorn, *supra* note 46, at 1446 (defining deinstitutionalization).

71. See Bagenstos, *supra* note 44, at 6, 12-13.

72. See *id.*

73. See *id.*

74. U.S. SOC. SECURITY ADMIN., ANNUAL STATISTICAL SUPPLEMENT TO THE SOCIAL SECURITY BULLETIN, 2012, at 57 (2013) [hereinafter SSA BULLETIN].

75. *Id.*

76. *Id.*

77. *Id.*

state to state.⁷⁸ Further, state legislatures may revise Medicaid eligibility, services, or reimbursement at any time.⁷⁹

The federal government contributes at least half of each state's Medicaid expenditures.⁸⁰ Every year, the Centers for Medicare and Medicaid Services ("CMS") calculates the Federal Medical Assistance Percentage ("FMAP") for each state based upon its relative wealth; states with lower per capita income receive higher FMAPs.⁸¹ While FMAPs can range from 50 percent to 83 percent, the overall average for all states was 58.8 percent for fiscal year 2012.⁸² For the past five fiscal years, Oklahoma's FMAP ranged from a high of 67.1 percent for 2008 to a low of 63.88 percent for 2012.⁸³

An essential part of the U.S. health care system, Medicaid provides coverage for about one-fifth of the American population.⁸⁴ In 2009, nearly 800,000 Oklahomans were among the nation's 62.7 million Medicaid enrollees.⁸⁵ That same year, total Medicaid expenditures exceeded \$4 billion for Oklahomans, and nearly \$400 billion for the entire country.⁸⁶ People with disabilities represented about 14 percent of Oklahoma's Medicaid enrollees and about 15 percent of U.S. enrollees.⁸⁷ Reflecting the higher medical and health-related service needs of those with disabilities, these enrollees generated about 42 percent of Medicaid costs.⁸⁸

Medicaid plays a critical role in the provision of long-term services and supports for people with I/DD, paying over three-fourths the costs for long-term services.⁸⁹ In addition, Medicaid regulations strongly affect states' decisions regarding available supports and delivery of services.⁹⁰ Sadly, the institutional bias of the Medicaid program,⁹¹ as dis-

78. *Id.*

79. *Id.* at 57.

80. *Id.* at 61.

81. *Id.*

82. *Id.*

83. Federal Matching Shares for Medicaid for fiscal year 2008, for the Department of Health and Human Services, 71 Fed. Reg. 69,209, 69,210 (Nov. 30, 2006); Federal Matching Shares for Medicaid for fiscal year 2009, for the Department of Health and Human Services, 72 Fed. Reg. 67,304-67,306 (Nov. 28, 2007); Federal Matching Shares for Medicaid for fiscal year 2010, for the Department of Health and Human Services, 73 Fed. Reg. 72,051-72,052 (Nov. 26, 2008); Federal Matching Shares for Medicaid for fiscal year 2011, for the Department of Health and Human Services, 74 Fed. Reg. 62,315-62,316 (Nov. 27, 2010); Federal Matching Shares for Medicaid for fiscal year 2012, for the Department of Health and Human Services, 75 Fed. Reg. 69,082-69,083 (Nov. 10, 2010).

84. See Vernon K. Smith et al., *Medicaid Today; Preparing for Tomorrow: A Look at State Medicaid Program Spending, Enrollment and Policy Trends—Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2012 and 2013* (Oct. 1, 2012), available at <http://www.kff.org/medicaid/upload/8380.pdf> (62 million Americans are enrolled in Medicaid); *U.S. Population Clock*, CENSUS.GOV (Mar. 5, 2013, 2:32 PM), <http://www.census.gov/main/www/popclock.html> (U.S. population is 315,439,607; 62 million of 312 million Americans are enrolled in Medicaid, or about one-fifth of all Americans).

85. Kaiser Family Found., *Medicaid & CHIP Facts At-A-Glance*, STATEHEALTHFACTS.ORG, <http://www.statehealthfacts.org/comparecat.jsp?cat=4&rgn=38&rgn=1&print=1> (last visited Jan. 9, 2013).

86. *Id.*

87. *Id.*

88. *Id.*

89. GETTINGS, *supra* note 11, at 63.

90. See *id.*; *Intermediate Care Facilities for Individuals with Mental Retardation (ICF/IID)*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Intermediate-Care-Facilities-for-Individuals-with-Mental-Retardation-ICFMR.html>

cussed in Part III, continues to limit availability of community services and supports that would allow people with disabilities to avoid institutionalization and live as integral members of their communities.⁹² Two elements of Medicaid significantly interwoven with the deinstitutionalization movement are Medicaid's regulations regarding intermediate care facilities and home and community-based services.⁹³

1. Intermediate Care Facilities

Congress enacted Medicaid in July of 1965, and funds became available to the states on January 1, 1966.⁹⁴ States could choose whether to participate in Medicaid and could also implement the program in phases.⁹⁵ Only six states implemented Medicaid in 1966, yet the cost that year exceeded the amount estimated to be sufficient to cover full participation by every state.⁹⁶ In an attempt to control the rapid rise in costs, Congress amended the program in 1967.⁹⁷ These amendments included the creation of a new level of institutional care—an intermediate care facility (“ICF”) for Medicaid beneficiaries who required less intensive care than that of Medicaid-certified skilled nursing homes.⁹⁸ The legislature believed that payment for ICF services would reduce overall costs by avoiding the use of more expensive skilled nursing homes when a reduced level of care would suffice.⁹⁹ In addition, the ICFs would provide a benefit to Medicaid beneficiaries who did not qualify for skilled nursing home care but required care in a sheltered setting.¹⁰⁰

Unintended consequences soon resulted from this ICF legislation, as states found various ways to take advantage of it by reclassifying facilities to obtain more federal Medicaid funding for state programs.¹⁰¹ Up to this point, federal matching funds had been unavailable to share the cost of states' public institutions for people with I/DD, but several states sought to classify these I/DD institutions as ICFs to gain federal money.¹⁰² Congress worked on legislative remedies to prevent states from using the ICF provision

[hereinafter ICF/IID MEDICAID] (last visited Feb. 13, 2013).

91. See *infra* notes 244-45 and accompanying text.

92. Samuel R. Bagenstos, *The Future of Disability Law*, 2004 YALE L.J. 1, 61-62; Cabansag, *supra* note 51, at 1047; Loretta Williams, Note, *Long Term Care after Olmstead v. L.C.: Will the Potential of the ADA's Integration Mandate be Achieved?*, 17 J. CONTEMP. HEALTH L. & POL'Y 205, 210-16 (2000).

93. See generally DAVIS, *supra* note 40, at 2-15; GETTINGS, *supra* note 11; PC 76, *supra* note 25, at 164 (Mary Z. Gray, ed., 1977).

94. *Tracing the History of CMS Programs: From President Theodore Roosevelt to President George W. Bush*, Ctrs. for Medicare & Medicaid Servs., <http://www.cms.gov/About-CMS/Agency-Information/History/downloads/presidentcmsmilestones.pdf> (last visited Jan. 10, 2013).

95. See GETTINGS, *supra* note 11, at 64-65.

96. *Id.*

97. *Id.* at 65.

98. *Id.* at 65-66.

99. *Id.*

100. *Id.* at 66.

101. *Id.* (describing state tactics such as reclassifying skilled nursing facilities (SNFs) as ICFs to avoid the stricter certification requirements for SNFs, reimbursing ICFs at higher rates than SNFs even though ICFs provided a lower level of care and should have been more cost-effective, and classifying ineligible facilities as ICFs in order to receive federal funding).

102. *Id.*

in unanticipated ways that increased Medicaid spending.¹⁰³ In 1970, legislators proposed several bills to revise the Medicaid ICF provision, but after heated debate, they were unable to reach agreement.¹⁰⁴ As the congressional session neared an end in 1971, the Senate Finance Committee chose several provisions of a proposed bill for expedited action.¹⁰⁵ Then, Oklahoma's senators Henry Bellmon and Fred Harris attached language authorizing a new Medicaid option, intermediate care facilities for individuals with I/DD ("ICF/IID"), to an unrelated bill.¹⁰⁶ The Senate passed the bill without debate or congressional hearings, and the House of Representatives accepted the bill.¹⁰⁷ On December 28, 1971, President Nixon signed the bill that included the ICF/IID provision, and the law went into effect on January 1, 1972.¹⁰⁸

The passage of the ICF/IID provision resulted from two combined forces: I/DD advocates who wanted substantial improvements to the institutions' physical facilities as well as the programs and care provided within the facilities, and state governments that sought a reliable source of federal funding for these public I/DD institutions.¹⁰⁹ The ICF/IID amendment provided federal funds with the stipulation that states agree not to reduce state expenditures for patients in the institutions, reflecting congressional intent to assist the states in upgrading the infamously poor quality of care in public I/DD institutions.¹¹⁰ Prior to the amendment's passage, a number of states, including Oklahoma, had been submitting Medicaid claims for their I/DD institutions.¹¹¹ Because the federal government questioned the legitimacy of these claims, the states risked losing future federal contributions to institutional funding and risked having to repay millions of dollars in back claims for institutional funds they received from the federal government.¹¹² Lloyd Rader, director of the Oklahoma Department of Social and Rehabilitative Services from 1951 to 1982, worked with federal officials and a national I/DD advocacy group to construct the ICF/IID legislation and successfully lobby legislators for its passage.¹¹³

The ICF/IID amendment stated that "the primary purpose of [an ICF/IID] is to provide health or rehabilitative services for mentally retarded individuals [that] meet such standards as may be prescribed by the Secretary."¹¹⁴ The inclusion of "rehabilitative services" was significant for two reasons: it was the first time that Congress authorized

103. *Id.* at 66-67.

104. *Id.*

105. *Id.* at 67.

106. *Id.* Originally referred to as Intermediate Care Facilities for Persons with Mental Retardation (ICF/MRs), these facilities are now referred to as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs). See C.F.R. T. 42, ch. IV, subch. G, pt. 483, subpt. I.

107. *Id.*

108. See K. Charlie Lakin, Bradley Hill & Robert Bruininks, *An Analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program*, CTR. FOR RESIDENTIAL AND CMTY. SERVS., UNIV. OF MINN., 1-1 (1985) [hereinafter RESIDENTIAL].

109. GETTINGS, *supra* note 11, at 67.

110. RESIDENTIAL, *supra* note 108, at 1-25, 1-26.

111. GETTINGS, *supra* note 11, at 68-69.

112. *Id.* at 69.

113. *Id.* at 70.

114. RESIDENTIAL, *supra* note 108, at 1-24 (quoting Pub. L. No. 92-223) (emphasis added).

federal Medicaid funds for institutional care that was not primarily medical or “health related,” and it emphasized congressional intent that institutions focus on training and habilitation as opposed to “custodial” care.¹¹⁵ In 1974, the Social and Rehabilitation Service (“SRS”) of the Federal Department of Health, Education, and Welfare (“HEW”) issued regulations clarifying this provision.¹¹⁶ The regulations defined the requirement for ICF/IIDs to provide “active treatment” so that each person participates regularly in therapies, activities, or experiences based on an individualized professionally developed plan of care designed to assist the person in achieving his or her potential in physical, intellectual, social, and vocational functioning.¹¹⁷

The enactment of the ICF/IID provision led to a number of rulings and regulations by the SRS establishing requirements that state I/DD institutions would have to satisfy to be eligible for Federal Medicaid funding.¹¹⁸ From 1972 to 1988, the SRS issued a series of regulations prescribing minimum facility standards to ensure safety and sanitation as well as rules regarding required services.¹¹⁹ Initially, states had until 1977 to comply with the standards; however, later compromises between state and HEW officials led to revised standards and extended the compliance deadline until 1978, then 1982, and finally 1987.¹²⁰

The ICF/IID standards exceeded the requirements for general ICFs.¹²¹ Consequently, compliance necessitated costly physical renovations to state institutions, generating battles between the HEW and a number of states, including Oklahoma.¹²² After unsuccessful negotiations with HEW officials, Lloyd Rader responded by having Oklahoma’s three public I/DD institutions reclassified as general ICFs to avoid compliance with the stricter ICF/IID requirements.¹²³

By the 1970s, following decades of growth, increased demand for community-based services combined with the cost of compliance with ICF/IID regulations led some states to reduce the population of their public I/DD facilities.¹²⁴ The total number of people living in large public I/DD institutions declined over 40 percent between 1974 and 1986.¹²⁵ Originally, the CMS¹²⁶ proposed ICF/IID regulations suitable for the operation of large institutions, raising concerns among advocacy groups that this institutional em-

115. *Id.* at 1-26, 1-27.

116. *See* GETTINGS, *supra* note 11, at 72-73; RESIDENTIAL, *supra* note 108, at 1-28, 1-29.

117. GETTINGS, *supra* note 11, at 72-73; RESIDENTIAL, *supra* note 108, at 1-28, 1-29.

118. GETTINGS, *supra* note 11, at 71-73.

119. *See id.* at 71-78.

120. *See id.*

121. *Id.* at 73-74.

122. *Id.*

123. *Id.* at 74.

124. *Id.* at 76.

125. *Id.* at 76 (citing Kathryn Coucouvanis et al., *Current Populations and Longitudinal Trends of State Residential Settings (1950-2006)*, in RESIDENTIAL SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2006 (R. W. Prouty et al. eds., 2007)).

126. Throughout this article, “CMS” refers to the agency responsible for operating the Medicaid program, although CMS was formerly the Health Care Financing Administration.

phasis would detract from the development of community residential alternatives.¹²⁷ The CMS modified the ICF/IID requirements slightly in response to these concerns, but most states were initially reluctant to seek ICF/IID certification for small community-based residences serving people with I/DD.¹²⁸

In the late 1970s and early 1980s, the CMS issued guidelines that encouraged states to expand the number of smaller community-based ICF/IIDs.¹²⁹ As a result of growing consumer demand and the federal guidelines, the proportion of ICF/IID residents living in community facilities, rather than large public institutions, rose from just 6 percent in 1982 to over 34 percent in 1997.¹³⁰ Thus, the ICF/IID policy, originally enacted to improve physical conditions and programming in massive public I/DD institutions, became an instrument of deinstitutionalization; large public facilities downsized or closed, and more people with I/DD lived in smaller community residences operated by private nonprofit organizations.¹³¹ From 1982 to 2010, the number of people with I/DD living in large state ICF/IIDs shrank from 107,081 to 30,481.¹³²

2. Home and Community-Based Services

Until 1981, individuals with I/DD could only receive Medicaid coverage for long-term supports if they lived in institutions.¹³³ The enactment of Medicaid HCBS waiver authority, buried in legislation designed to slash federal spending on social programs, brought profound and lasting impact to the delivery of services to people with I/DD.¹³⁴ The HCBS waiver authority allows states to use federal Medicaid matching funds to support individuals in their communities rather than in institutions.¹³⁵ The increase in number of people with I/DD receiving HCBS waivers—from fewer than 50,000 in 1990 to more than a half million beneficiaries in 2010—reflects the shift from institutional care to community care.¹³⁶

Like the ICF/IID legislation, the HCBS waiver authority resulted from an unlikely alliance between I/DD advocates and fiscal conservatives.¹³⁷ While the HCBS waivers advanced I/DD advocates' goals of incentivizing states to expand community services and move people out of institutions,¹³⁸ the waiver's primary rationale was the cost effectiveness of replacing expensive institutional care with economical services provided in homes and in the community.¹³⁹

127. GETTINGS, *supra* note 11, at 79.

128. *Id.* at 80.

129. *Id.* at 80-81.

130. *Id.* at 81.

131. *Id.* at 82; RESIDENTIAL, *supra* note 108, at 1-31.

132. LARSON, *supra* note 64, at 99.

133. Karger, *supra* note 30, at 1229.

134. *See* GETTINGS, *supra* note 11, at 85, 92.

135. Karger, *supra* note 30, at 1229.

136. LARSON, *supra* note 64, at 109.

137. GETTINGS, *supra* note 11, at 67, 92; *see* Bagenstos, *supra* note 44, at 20.

138. *See* Bagenstos, *supra* note 44, at 6.

139. *E.g.*, GETTINGS, *supra* note 11, at 92.

Following months of negotiations and debate between President Reagan and both houses of Congress regarding the budget, deficit reduction, and social policies, the House and Senate ratified the Omnibus Budget Reconciliation Act of 1981 (“OBRA-81”) in July of that year.¹⁴⁰ OBRA-81 includes the HCBS waiver authority—language authorizing the head of the CMS to approve state waiver applications so that states can receive federal matching funds to pay for nonmedical services required to prevent institutionalization.¹⁴¹ Services covered under an HCBS waiver may include “case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, and ‘such other services requested by the state as the Secretary of Health and Human Services (HHS) may approve.’”¹⁴²

In addition to waiving the general requirement that federal Medicaid funds are limited to services provided for “medical assistance,”¹⁴³ the HCBS waiver authority permits the CMS to waive two other Medicaid provisions, the “comparability” and “statewide-ness” requirements.¹⁴⁴ The comparability requirement requires states to make Medicaid services available to all eligible individuals on an equivalent basis.¹⁴⁵ The statewide-ness provision requires the state Medicaid plan to be effective throughout the state.¹⁴⁶ Waiving these two provisions allows states to target specific groups at risk of institutionalization and to experiment with various services and delivery methods.¹⁴⁷

The bill permits the secretary to waive the current definition of covered Medicaid services to include certain nonmedical support services, other than room and board, which are provided pursuant to a plan of care to an individual otherwise at risk of being institutionalized and who would, in the absence of such services be institutionalized. . . . The committee expects that states [that] have been granted a waiver will examine innovative and cost-efficient means of rendering services to this population group.¹⁴⁸

140. *Id.* at 90.

141. Janet O’Keeffe et al., *Understanding Medicaid Home and Community Services: A Primer*, OFFICE OF THE ASSISTANT SEC’Y FOR PLANNING & EVALUATION, U.S. DEP’T OF HEALTH & HUMAN SERVS., 28 (2010) [hereinafter PRIMER]; GETTINGS, *supra* note 11, at 90.

142. PRIMER, *supra* note 141, at 28.

143. See 42 U.S.C. § 1396n(c) (2012).

144. PRIMER, *supra* note 141, at 72.

145. *Id.* at 91, 72

[S]ervices covered under a state’s Medicaid plan . . . must be available on a comparable basis to all state Medicaid beneficiaries (in an eligibility group) who need the service. States must use the same eligibility criteria for all applicants and any limits on service amount, scope, and duration must be equally applied to both individuals currently receiving services and those applying for services.

146. *Id.* at 72, 91 (“The Statewide-ness Requirement [:] States cannot restrict the availability of State Plan services to particular geographic regions.”).

147. GETTINGS, *supra* note 11, at 91.

148. Schwalb, *supra* note 12, at 808 (quoting H. R. Rep. No. 97-208, at 481-82 (1981), reprinted in 1981 U.S.C.C.A.N. 396, 747-48).

Consistent with the legislative intent to encourage state innovation in providing noninstitutional services, the CMS issued minimal regulations so that states would have substantial flexibility to design and operate their waiver programs, explaining “we will measure the states’ proposals against the statutory requirements rather than against a detailed additional set of Federal guidelines or criteria.”¹⁴⁹ In addition to promoting innovative community service programs, legislators were concerned with cost savings.¹⁵⁰ Thus, two elements that states must satisfy to qualify for HCBS waivers reflect fiscal concerns.¹⁵¹ First, states must limit eligibility to individuals who would, absent HCBS services, require institutional care.¹⁵² Second, the waiver programs must be “budget neutral” i.e., the average per capita cost of the alternative HCBS services cannot exceed the average per capita cost for institutional care.¹⁵³

The CMS approved the first HCBS waiver in December 1981, followed by approval of more than twenty waivers in 1982, with an additional twenty-one requests pending action.¹⁵⁴ Four factors explained the immediate popularity of the programs.¹⁵⁵ First, the increasing acceptance of deinstitutionalization policies stimulated community-based supports.¹⁵⁶ Second, federal ICF/IID standards required states to downsize institutions.¹⁵⁷ Third, class action lawsuits resulting in settlement agreements and court orders also forced the downsizing and closure of large state facilities.¹⁵⁸ Finally, because most states were already using public funds to develop community supports, they welcomed the opportunity to capitalize on their investments by capturing federal funds with HCBS waivers.¹⁵⁹

The federal government lacked the states’ enthusiasm for federal funding of waiver services.¹⁶⁰ Under pressure from the White House Office of Management and Budget (“OMB”), the CMS tightened its scrutiny of waiver requests and implemented an unwritten “cold bed” rule requiring states to show that institutional capacity would be reduced equivalent to the number of estimated waiver beneficiaries.¹⁶¹ From 1982 through 1985, the CMS and the OMB toughened and lengthened the waiver approval process.¹⁶² The

149. GETTINGS, *supra* note 11, at 93 (quoting 46 Fed. Reg. 48,533 (Oct. 1, 1981)).

150. *See id.* at 91.

151. *Id.*

152. *Id.*

153. *Id.*

154. *Id.* at 94-95.

155. *See id.*

156. *Id.* at 94.

157. *Id.*

158. *Id.*

159. *Id.* at 95.

160. *See id.*

161. Steven Lutzky et al., *Review of the Medicaid 1915(c) Home and Community Based Services Waiver Program Literature and Program Data2* (2000), available at http://www.lewin.com/~media/Lewin/Site_Sections/Publications/582.pdf (“Shortly after the start of the program, to meet the cost neutrality requirement, states had to demonstrate that a bed in a Medicaid-certified institution was available or would be available if a certificate of need (CON) request were filed for each waiver participant (the so-called “cold bed” requirement).”).

162. GETTINGS, *supra* note 11, at 95-97.

CMS officials announced they would withhold waiver approval unless states demonstrated that the waiver program would reduce total Medicaid expenditures by twenty or twenty-five percent, a baseless requirement that contradicted statutory intent.¹⁶³ According to one congressman, the administration was “strangling the Medicaid waiver program with Byzantine regulations.”¹⁶⁴ In 1986, Congress passed legislation that provided some relief from the CMS/OMB’s restrictive approval procedures.¹⁶⁵ However, the cold bed rule remained in effect until 1994, when the CMS simplified the cost neutrality formula and reporting requirements.¹⁶⁶ Under the revised formula, the CMS evaluates the cost neutrality of a state’s waiver request based on average per capita costs with and without waiver services regardless of the number of waiver recipients, although states must still specify the maximum number of waiver enrollees.¹⁶⁷

The retirement of the cold bed rule accompanied a second significant deinstitutionalization milestone in 1994—annual spending for Medicaid HCBS exceeded spending for ICF/IIDs for the first time.¹⁶⁸ This trend toward community supports and away from institutions has continued.¹⁶⁹ The waiver program that began with eight waivers in six states in 1982 expanded to 214 waivers in twenty-nine states by 1999.¹⁷⁰ By 2008, forty-eight states and the District of Columbia were managing 314 HCBS waiver programs.¹⁷¹ That same year, state spending for HCBS was nearly double that of ICF/IID spending, and more than five times as many people with I/DD received HCBS than resided in ICF/IIDs.¹⁷²

In a complete reversal from the first decade of HCBS waivers, the federal government now provides incentives for states to expand HCBS offerings, while many states have applied the fiscal brakes.¹⁷³ The Patient Protection and Affordable Care Act

163. *Id.* at 96

164. *Id.* at 97.

165. *Id.* at 98.

166. *Id.* at 100 (“[t]he cost-effectiveness of a waiver request was to be assessed solely on the basis of average per capita costs with and without the proposed waiver services.”); LUTZKY, *supra* note 161, at 3.

167. GETTINGS, *supra* note 11, at 100.

168. *See id.* at 122.

169. *See id.*

170. Charlene Harrington et al., *Home & Community Based Services: Public Policies to Improve Access, Costs, and Quality* 2 (2009), available at http://www.pascenter.org/documents/PASCenter_HCBS_policy_brief.pdf.

171. PRIMER, *supra* note 141, at 29:

During Federal fiscal year (FFY) 2008, 48 states and the District of Columbia operated 314 HCBS waiver programs. This number includes waivers that CMS had approved but that had not yet been implemented as of September 30, 2008. The two states that did not have HCBS waivers—Arizona and Vermont—provided similar services as part of Research and Demonstration waivers authorized by §1115 of the Social Security Act. Expenditures for waiver services totaled \$30 billion in 2008 and roughly three-fourths was used to purchase services and supports for persons with developmental disabilities, including persons with autism spectrum disorders or intellectual disabilities. Almost all other waiver expenditures in the same year were for older adults and younger adults with physical disabilities; a few smaller population groups accounted for the remaining waiver expenditures.

172. GETTINGS, *supra* note 11, at 122.

173. *See id.* at 117-122; Schwalb, *supra* note 12, at 808.

(“PPACA”) contains a number of inducements for states to expand community services as an alternative to institutionalization and to provide community supports through programs that do not limit the number of beneficiaries.¹⁷⁴ While Medicaid law requires states to provide institutional services to all eligible individuals as a mandatory benefit, provision of HCBS is optional, and states may limit eligibility for HCBS.¹⁷⁵ Despite increasing demand for HCBS, states’ fiscal crises have prevailed over federal incentives such that few states are willing to provide community services on a full open-ended entitlement basis.¹⁷⁶

When approving HCBS waivers, the CMS gives states wide discretion regarding choice of community service offerings and beneficiaries.¹⁷⁷ Thus, available services, per capita expenditures, and HCBS participation vary widely from state to state.¹⁷⁸ For example, states with the highest per capita expenditure spend nearly seven times as much for each HCBS recipient as those with the lowest per capita spending.¹⁷⁹ In at least ten states, people with I/DD are able to receive HCBS waivers promptly.¹⁸⁰ However, a lack of waiting lists is the exception, as most states have failed to accommodate the growth in demand for HCBS.¹⁸¹ As a result, more people with I/DD are waiting, and are waiting longer periods, to receive HCBS.¹⁸²

In 2009, an estimated 564,836 people with I/DD received HCBS waivers, while 221,898 people with I/DD remained on waiting lists for HCBS.¹⁸³ Texas had the largest waiting lists, with over 129,500 people waiting for waivers in 2009.¹⁸⁴ Oklahoma had the longest wait time, an average of over five years.¹⁸⁵ By 2011, HCBS waiting lists had grown to include more than 300,000 Americans with I/DD.¹⁸⁶ Oklahoma continues to have the longest wait time, and Oklahomans with I/DD now wait an average of over eight years for HCBS waivers.¹⁸⁷ HCBS provides the principal means of care for many

174. GETTINGS, *supra* note 11, at 117-18.

175. ICF/IID MEDICAID, *supra* note 90; Harrington et al., *supra* note 170, at 1.

176. GETTINGS, *supra* note 11, at 120; Harrington et al., *supra* note 170, at viii.

177. See Harrington et al., *supra* note 170, at iv, 4-6.

178. See *id.*

179. *State Options That Expand Access to Medicaid Home and Community-Based Services*, Kaiser Comm’n on Medicaid & the Uninsured, KAISER FAMILY FOUND., 4 (2011), available at <http://kff.org/medicaid/report/state-options-that-expand-access-to-medicaid/>.

180. *Medicaid Home and Community-Based Services Programs: 2009 Data Update*, Kaiser Comm’n on Medicaid & the Uninsured, KAISER FAMILY FOUND., 11 (Dec. 2012), available at <http://kff.org/medicaid/report/medicaid-home-and-community-based-service-programs/> [hereinafter KAISER].

181. See *id.*; Gary Smith, John Agosta & Jon Fortune, *Gauging the Use of HCBS Support Waivers for People with Intellectual and Developmental Disabilities: Final Project Report*, Office of Disability, Aging, and Long-Term Care Policy, U.S. DEP’T OF HEALTH & HUMAN SERVS., 10-11 (2007), available at <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.htm>.

182. See KAISER, *supra* note 180, at 3, 11; SMITH, *supra* note 181, at 10; Harrington et al., *supra* note 170, at 12-13.

183. Terence Ng & Charlene Harrington, *Medicaid Home- and Community-Based Service Programs: A Data Update* 6 (2011), available at <http://www.kff.org/medicaid/upload/LTC-Slides-02-07-2011.pdf>.

184. *Id.* This figure is for all HCBS waivers in Texas for people with I/DD, and other elderly and disabled.

185. *Id.*

186. KFF Waiting, *supra* note 10.

187. OKDHS, *supra* note 13 (“Working applications dated April 19, 2005 as of 8/19/13.”). When waivers become available, applications are processed on a first-come, first-served basis. See *Oklahoma In-Home Sup-*

people with I/DD, yet waiting lists force individuals to choose between institutionalization and going without assistance necessary for basic activities of everyday life.¹⁸⁸ Twenty-five states have faced legal action from citizens with I/DD on waiting lists for HCBS, resulting in a number of settlement agreements in which the states have agreed to expand HCBS availability.¹⁸⁹

C. *The Americans with Disabilities Act*

Today, I am signing S. 933, the “Americans with Disabilities Act of 1990.” In this extraordinary year, we have seen our own Declaration of Independence inspire the march of freedom throughout Eastern Europe. It is altogether fitting that the American people have once again given clear expression to our most basic ideals of freedom and equality. The Americans with Disabilities Act represents the full flowering of our democratic principles. . . . [and] presents us all with an historic opportunity. It signals the end to the unjustified segregation and exclusion of persons with disabilities from the mainstream of American life. As the Declaration of Independence has been a beacon for people all over the world seeking freedom, it is my hope that the Americans with Disabilities Act will likewise come to be a model for the choices and opportunities of future generations around the world.

—President George H.W. Bush¹⁹⁰

The Americans with Disabilities Act (“ADA”) differed from other major civil rights legislation because it was drafted in greater detail than any prior civil rights legislation, and it faced no serious opposition.¹⁹¹ The ADA began with a report from the 1986 National Council on Disability, “Toward Independence,” that proposed broad legislation to extend federal civil rights laws to include people with disabilities.¹⁹² Senator Lowell Connecticut, parent of a child with Down syndrome, introduced the first version of the ADA on April 28, 1988.¹⁹³ Congress spent several years discussing and revising the leg-

ports waiver for adults, *available at* [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915\(c\)#waivers](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915(c)#waivers) (last visited Mar. 2, 2013):

In accordance with OAC 317:40-1-1, initiation of services occurs in chronological order from the waiting list based on the date of receipt of a written request for services. The individual must meet the financial and medical eligibility criteria and have critical support needs that can be met by the IHSW-A. Exceptions to the chronological requirement may be made when an emergency exists.

Thus, “[w]orking applications dated April 19, 2005 as of 8/19/13” equates to a wait time of eight years and four months.

188. Schwab, *supra* note 12, at 809; *see* Harrington et al., *supra* note 170, at 12-13.

189. SMITH, *supra* note 181, at 11.

190. President George H.W. Bush, Statement on Signing the Americans with Disabilities Act of 1990 (July 26, 1990), *available at* http://bushlibrary.tamu.edu/features/2010-ada/StatementbythePresident_2.pdf.

191. COLKER, *supra* note 21, at 23.

192. Press Release, Office of the Press Sec’y, White House, Fact Sheet: The Americans with Disabilities Act of 1990 at 1 (July 26, 1990); *see* COLKER, *supra* note 21, at 26.

193. COLKER, *supra* note 21, at 27.

isolation, but the overall legislative intent remained crystal clear throughout this time: the broad purpose of the ADA was to assist Americans with disabilities.¹⁹⁴ The ADA addressed congressional findings that included the recognition that “society has tended to isolate and segregate individuals with disabilities” and that “such forms of discrimination . . . continue to be a serious and pervasive social problem.”¹⁹⁵ Congress specifically included “institutionalization” among the critical areas where discrimination against people with disabilities exists.¹⁹⁶

To remedy discrimination and promote integration, the ADA encompasses a wide range of subjects, from private employment in Title I to telecommunications in Title IV.¹⁹⁷ Title II covers state and local government programs and services, including state Medicaid programs.¹⁹⁸ Relevant to the choice of HCBS rather than institutional services, the statute requires that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁹⁹ One provision of the ADA that states frequently use as a defense in waiting list lawsuits is the “fundamental alteration” provision that exempts the failure to “make reasonable modifications . . . [to accommodate] individuals with disabilities” when such modifications “would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations.”²⁰⁰

III. ANALYSIS: INSTITUTIONALIZATION IS DISCRIMINATION (SOMETIMES)

A. *Olmstead v. L.C.: The Landmark Case Impacting HCBS*

In 1999, the Supreme Court decided the groundbreaking case of *Olmstead v. L.C.*, often referred to as the *Brown v. Board of Education* for disability rights.²⁰¹ Both *Olmstead* and *Brown* involved individuals subjected to pervasive discrimination and segregation, and both created huge challenges to the Court in designing effective practical remedies.²⁰² Like integration of African American children into public schools, integra-

194. The Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2(b), 104 Stat. 327:

PURPOSE.—It is the purpose of this Act—(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities; (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities; (3) to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities; and (4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

See COLKER, *supra* note 21, at 23.

195. Americans with Disabilities Act at § 2(a)(2).

196. *Id.* at § 2(a)(3).

197. See 42 U.S.C. §§ 12101 et. seq. (2012).

198. See 42 U.S.C. §§ 12131-12165 (2012).

199. 28 C.F.R. § 35.130 (d) (2011).

200. 28 C.F.R. § 35.130 (b)(7) (2011).

201. Charles R. Bliss & C. Talley Wells, *Applying Lessons from the Evolution of Brown v. Board of Education to Olmstead: Moving from Gradualism to Immediate, Effective, and Comprehensive Integration*, 26 GA. ST. U. L. REV. 705, 705 (2010).

202. *Id.* at 705-06.

tion of people with I/DD into communities necessitated massive changes to state and federal government entities, substantial monetary investment, and new thought patterns for public officials and private citizens.²⁰³ In *Olmstead*, as in *Brown*, the Court's holding left important questions unanswered, thus limiting relief for victims of discrimination.²⁰⁴

The *Olmstead* Court considered the proper construction of ADA Title II's antidiscrimination provision and attempted to answer the question, "[d]oes Title II of the ADA require placing people with mental disabilities in community settings rather than in institutions?"²⁰⁵ As the petitioners explained, "[t]his case represents an attempt by a federal agency with no historic expertise in the area of mental health care to resolve a complex social and medical debate through the general terms of the Americans with Disabilities Act (the ADA)."²⁰⁶ The Court answered the thorny question with a qualified yes, holding that:

under Title II of the ADA, States are required to provide community-based treatment for 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.²⁰⁷

The *Olmstead* legacy began when the Atlanta Legal Aid Society brought an action against the state of Georgia challenging the continued confinement of two women in an institutional setting despite community-based programs that could meet their needs.²⁰⁸ The two women, Lois Curtis and Elaine Wilson, each had a mental illness in addition to I/DD.²⁰⁹ In May of 1992, Lois voluntarily entered Georgia Regional Hospital at Atlanta ("GRH") for treatment in a psychiatric unit.²¹⁰ A year later, Lois's treatment team agreed that a state-supported community-based program could appropriately serve her needs.²¹¹ However, Lois remained institutionalized until the State placed her in community-based treatment in February 1996.²¹² Similarly, Elaine was voluntarily admitted to GRH for psychiatric treatment and continued to be confined there despite her psychiatrist's evaluation that she could be appropriately treated in the community.²¹³

203. *Id.*

204. See Cerreto, *supra* note 30, at 69-70.

205. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999).

206. Brief for Petitioners at *2, *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999) (No. 98-536), 1999 WL 54623.

207. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999).

208. Cerreto, *supra* note 30, at 49-50.

209. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 at 593 (noting that Lois Curtis was diagnosed with schizophrenia while Elaine Wilson was diagnosed with a personality disorder).

210. *Id.*

211. *Id.*

212. *Id.*

213. *Id.*

The Atlanta Legal Aid Society brought action in the United States District Court for the Northern District of Georgia and argued that the ongoing institutionalization of Lois and Elaine violated the Fourteenth Amendment and the ADA.²¹⁴ They requested an injunction providing public financed community placements and services, but did not seek any damages.²¹⁵ Refraining from ruling on the plaintiff's constitutional claim, the district court based its ruling on the ADA claim and ordered the State to immediately place Lois and Elaine in residential community settings and provide all appropriate services.²¹⁶ The district court held that "under the ADA, unnecessary institutional segregation of the disabled constitutes discrimination *per se*, which cannot be justified by a lack of funding."²¹⁷ On appeal, the Eleventh Circuit Court of Appeals affirmed the judgment that the State discriminated against the women by confining them in a segregated institution rather than in community-based programs.²¹⁸ The court of appeals emphasized that legislative history and the clear language of ADA Title II regulations showed that "Congress wanted to permit a cost defense only in the most limited of circumstances."²¹⁹ The court of appeals remanded the case to the district court "for further findings related to the State's defense that the relief sought by plaintiffs would 'fundamentally alter the nature of the service, program, or activity.'"²²⁰

The state of Georgia appealed the Eleventh Circuit's decision to the Supreme Court, which granted certiorari and heard the case on April 21, 1999.²²¹ By this time, the State had acquiesced, and Lois and Elaine were receiving services in community settings.²²² However, the case continued because the controversy was "capable of repetition, yet evading review," as indicated by Lois and Elaine's multiple institutional placements.²²³

The Supreme Court affirmed the Eleventh Circuit's decision in substantial part, holding that undue institutionalization "is properly regarded as discrimination based on disability."²²⁴ However, the Court found the court of appeals' remand instruction to be improperly restrictive, so the Court remanded the case for further consideration of the appropriate relief in view of the State's available resources, range of services for people

214. Brief for Petitioners at *11, *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999) (No. 98-536), 1999 WL 54623.

215. *Id.*

216. *Id.* at *12.

217. *L.C. ex rel. Zimring v. Olmstead* at *3, 1997 WL 148674 (N.D. Ga. Mar. 26, 1997), *aff'd and remanded sub nom. L.C. ex rel. Zimring v. Olmstead*, 138 F.3d 893 (11th Cir. 1998), *aff'd in part, vacated in part, remanded sub nom. Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

218. *L.C. ex rel. Zimring v. Olmstead*, 138 F.3d 893, 895 (11th Cir. 1998), *aff'd in part, vacated in part, remanded sub nom. Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

219. *Id.* at 902.

220. *Id.* at 895 (citing 28 C.F.R. § 35.130(b)(7)).

221. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 594-96 (1999); Atlanta Legal Aid Society, *Olmstead v. LC and EW Landmark Case*, ATLANTALEGALAID.ORG, <http://www.atlantalegalaid.org/impact.htm> (last visited Mar. 2, 2013) [hereinafter Atlanta].

222. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 594 n.6 (1999) (internal citations omitted); Atlanta, *supra* note 221.

223. *Id.*

224. *Id.* at 597.

with mental disabilities, and obligation to administer these services equitably.²²⁵ Consistent with the district court and the court of appeals, the Supreme Court limited its assessment to the statutory issue of the meaning of ADA Title II and declined to address the Fourteenth Amendment claims.²²⁶

The Supreme Court provided several bases for its holding that unjustified institutional isolation of people with disabilities fits within ADA Title II's definition of "discrimination."²²⁷ First, the Court noted that the Department of Justice ("DOJ"), the agency responsible for issuing regulations to implement Title II, has consistently advanced that view.²²⁸ Also, the Supreme Court emphasized that Congress expressly stated in the ADA that unjustified "segregation" of people with disabilities is a "form of discrimination."²²⁹ In addition, the Court explained that unjustified institutional segregation of people with disabilities "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."²³⁰ Finally, the Supreme Court described the impact of institutionalization as "severely diminish[ing] the everyday life activities . . . including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."²³¹

Because ADA Title II recognizes unjustified institutionalization of people with disabilities as discrimination, Title II regulations include an "integration mandate" that states, "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."²³² However, the "reasonable modifications regulation" of Title II allows states to continue to segregate people with disabilities, as the Supreme Court noted:²³³

A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.²³⁴

The Supreme Court criticized the court of appeals construction of the reasonable modifications regulation as unacceptable because "it would leave the State virtually defenseless once it is shown that the plaintiff is qualified for the service or program she

225. *Id.*

226. *Id.* at 588.

227. *See Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597-602 (1999).

228. *Id.* at 597.

229. *Id.* at 600 (citing 42 U.S.C. § 12101(a)(2), (a)(5)).

230. *Id.* at 600.

231. *Id.* at 601.

232. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 592 (1999) (quoting 28 C.F.R. § 35.130(d)(1998)).

233. *See id.* at 592.

234. *Id.* (quoting 28 C.F.R. § 35.130(b)(7) (1998) and explaining that "[w]e recite these regulations with the caveat that we do not here determine their validity.").

seeks.”²³⁵ The Court held that the fundamental alteration doctrine allows a state to show that allocating its available resources to provide immediate relief for plaintiffs would be inequitable because of the state’s responsibility to provide care and treatment for a large diverse class of people with mental disabilities.²³⁶ The Court stated that for some individuals “no placement outside the institution may ever be appropriate” and expressed concern that phasing out state institutions would place some patients at risk.²³⁷

Emphasizing that the ADA does not require states to phase out their institutions, the Court provided an example of how a state could meet the reasonable modifications standard.²³⁸ By showing that “it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated,” a state would satisfy the reasonable modifications standard.²³⁹ Since *Olmstead*, more than half the states have used this example to develop “*Olmstead* plans.”²⁴⁰ After developing *Olmstead* plans, a number of states have used their plans as a defense in lawsuits brought by people on waiting lists for HCBS.²⁴¹

The *Olmstead* decision elated many disability advocates as they anticipated a rapid expansion of Medicaid HCBS,²⁴² while others expressed skepticism and lamented the shortcomings of the Court’s holdings.²⁴³ Dr. Paul Applebaum opined that “the decision in *Olmstead v. L.C.* is unlikely to precipitate the widespread creation of community-based services for persons with mental disabilities.”²⁴⁴ Although the Court decided that requiring individuals to receive services in segregated institutions qualifies as illegal discrimination under the ADA, it did not order an end to institutional isolation or require a change in Medicaid’s institutional bias.²⁴⁵ The institutional bias remains because Medicaid regulations forbid states from limiting access to or having waiting lists for institutional services, but allow states to limit access to and have waiting lists for home and community-based services.²⁴⁶ Further, although states’ implementation of robust *Olmstead* plans expand access to HCBS, numerous disability advocates and commenta-

235. *Id.* at 603.

236. *Id.* at 604.

237. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604-05 (1999).

238. *Id.* at 605-06.

239. *Id.*

240. See Terence Ng, Alice Wong & Charlene Harrington, *Olmstead Plans and Related State Activity*, UCSF Nat’l Ctr. for Pers. Assistance Servs., <http://www.pascenter.org/olmstead/olmsteadplans.php> (last updated Dec. 2012).

241. See e.g., *Benjamin v. Dep’t of Pub. Welfare of Penn.*, 768 F. Supp. 2d 747, 754 (M.D. Pa. 2011) (“Defendants assert that there is no violation of Title II and Section 504 because DPW now has an *Olmstead* plan.”).

242. *Olmstead v. L.C.: The Interaction of the Americans with Disabilities Act and Medicaid*, Kaiser Comm’n on Medicaid & the Uninsured, KAISER FAMILY FOUND., 3 (2004), available at <http://www.kff.org/medicaid/7096a.cfm> [hereinafter KFF OLMSTEAD].

243. See e.g., Michael L. Perlin, “*What’s Good Is Bad, What’s Bad Is Good, You’ll Find Out When You Reach The Top, You’re On The Bottom*”: Are the Americans With Disabilities Act (and *Olmstead v. L.C.*) Anything More Than “*Idiot Wind*?””, 35 U. MICH. J.L. REF. 235, 257-58 (2002).

244. *Id.* at 258, (quoting Paul S. Appelbaum, *Least Restrictive Alternative Revisited: Olmstead’s Uncertain Mandate for Community-Based Care*, 50 PSYCHIATRIC SERV. 1271, 1272 (1999)).

245. KFF OLMSTEAD, *supra* note 242, at 3.

246. ICF/IID MEDICAID, *supra* note 90.

tors cite courts' deference to state plans, and even the plans themselves, as "roadblocks to integration."²⁴⁷

Olmstead parallels *Brown* with regard to the slow pace of reversing discrimination.²⁴⁸ Ten years after *Brown*, despite the Court's "all deliberate speed" requirement, many southern school districts remained segregated.²⁴⁹ Similarly, more than ten years after *Olmstead*, and despite the Court's requirement that waiting lists move at a "reasonable pace," thousands of people with I/DD wait years for HCBS so that they can be integrated into life in their communities.²⁵⁰

B. Implementing Olmstead

Because the issue in *Olmstead* involved two women who remained institutionalized without justification, the Court did not address the applicability of ADA's integration mandate to individuals living outside of institutions.²⁵¹ Subsequent courts in various jurisdictions have extended the scope of the integration mandate to include people living at home or in the community who are in imminent need of services in order to avoid institutionalization.²⁵² In *Fisher v. Oklahoma Health Care Authority*, the Tenth Circuit explained the rationale, stating, "[the integration mandate] would be meaningless if plaintiffs were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation."²⁵³

Although the *Olmstead* Court held that the fundamental alteration doctrine limits the state's responsibility to provide community services to qualified individuals with disabilities,²⁵⁴ this defense requires more than a mere budget constraint.²⁵⁵ In *Benjamin H. v. Ohl*, which involved individuals with I/DD on waiting lists for HCBS, the district court explained that if courts permitted budget constraints alone to constitute a defense, "[s]tates could easily renege on their part of the Medicaid bargain by simply failing to

247. Eric Carlson & Gene Coffey, *10-Plus Years after the Olmstead Ruling: Progress, Problems, and Opportunities*, NAT'L SENIOR CITIZENS LAW CTR. 26 (Sept. 2010), available at <http://www.nslc.org/wp-content/uploads/2011/07/NSCLC-Olmstead-Report.pdf>.

248. Bliss, *supra* note 201, at 718-19.

249. *Id.* at 712.

250. Bliss, *supra* note 201, at 718-19; Terence Ng, *HCBS Waiver Wait Lists: National Estimates 2012*, at 3 (2013), available at http://nasuad.org/documentation/HCBS_2013/Presentations/9.11%2010.00-11.15%20Roosevelt.pdf (last visited Mar. 14, 2014).

251. *See generally* *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

252. David Ferleger, *The Constitutional Right to Community Services*, 26 GA. ST. U.L. REV. 763, 795-96 (2010); *see Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.*, Civil Rights Div., U. S. DEP'T OF JUSTICE 3 (2011), available at http://www.ada.gov/olmstead/q&a_olmstead.htm; Training and Advocacy Support Center, Docket of Cases Related to Enforcement of the ADA Title II "Integration Regulation" 5 (2012), available at http://www.ndrn.org/images/Documents/Issues/Community_integration/Resources/Docket_of_Olmstead_Litigation_updated_September_2012.pdf.

253. *Id.* at 796 (citing *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1180 (10th Cir. 2003)).

254. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 603 (1999).

255. Kubo, *supra* note 12, at 756-57.

appropriate sufficient funds.”²⁵⁶

The Civil Rights Division of the DOJ provides guidance on compliance with the integration mandate of the ADA.²⁵⁷ Consistent with the *Benjamin H.* holding, the DOJ instructs that “budget cuts can violate the ADA and *Olmstead* when significant funding cuts to community services create a risk of institutionalization or segregation.”²⁵⁸ Further, the DOJ explains that “[a] state’s obligations under the ADA are independent from the requirements of the Medicaid program For example, the fact that a state is permitted to ‘cap’ the number of individuals it serves in a particular waiver program under the Medicaid Act does not exempt the state from serving additional people in the community to comply with the ADA or other laws.”²⁵⁹

In 2009, the DOJ initiated efforts to enforce the *Olmstead* decision.²⁶⁰ The DOJ works with state and federal officials to ensure that people with disabilities receive services in the most integrated setting appropriate to their needs.²⁶¹ In addition, the DOJ investigates complaints of violations of *Olmstead*, including complaints from people with I/DD on waiting lists for HCBS.²⁶² Recent DOJ investigations in Georgia and Virginia have resulted in settlement agreements in which the States have agreed to substantial increases in the number of HCBS waivers available to people with I/DD.²⁶³ To date, the DOJ has been involved in federal courts in efforts to enforce *Olmstead* in nineteen states.²⁶⁴

C. Policy Considerations Compel an End to Waiting Lists

In law as in science, a paradigm shift occurs when pressure builds up to the point of no return.²⁶⁵ Then an abrupt change occurs.²⁶⁶ When society evolves and established

256. Jane Perkins & Randolph T. Boyle, *Addressing Long Waits for Home and Community-Based Care through Medicaid and the ADA*, 45 ST. LOUIS U. L.J. 117, 142-43 (2001) (quoting *Benjamin H. v. Ohl*, Civ. No. 3:99-0338, slip op. at 25-26 (S.D. W. Va. July 15, 1999)).

257. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, Civil Rights Div., U.S. DEP’T OF JUSTICE, 3 (2011), available at http://www.ada.gov/olmstead/q&a_olmstead.htm.

258. *Id.*

259. *Id.*

260. *Olmstead: Community Integration for Everyone*, DEP’T OF JUSTICE, <http://www.ada.gov/olmstead/> (last visited Mar. 8, 2013).

261. *Id.*

262. See *Olmstead Cases by Circuit Court of Appeals*, DEP’T OF JUSTICE, http://www.ada.gov/olmstead/olmstead_enforcement.htm (last visited Mar. 8, 2013).

263. U. S. DEP’T OF JUSTICE, *United States v. Georgia*, Civil No. 1:10-CV-249-CAP, Settlement Agreement fact sheet 1 (2010), available at http://www.ada.gov/olmstead/documents/georgia_fact_sheet.pdf (last visited Mar. 2, 2013) (“Georgia will create 1150 home and community based waivers for individuals with developmental disabilities by July 1, 2015”); U. S. DEP’T OF JUSTICE, *Virginia ADA Settlement Fact Sheet 1* (2012), available at http://www.ada.gov/olmstead/documents/virginia_fact_sheet.pdf (last visited Mar. 2, 2013) (“A total of approximately 4,200 home and community based waivers to help individuals with intellectual and developmental disabilities leave institutional settings, including Training Centers, and to prevent the unnecessary institutionalization of individuals who are currently on long waitlists for services in the community.”).

264. See Ng et al., *supra* note 240. The DOJ participated in *Olmstead* and *Olmstead*-related lawsuits in Alabama, Arkansas, California, Connecticut, Delaware, Florida, Georgia, Illinois, Louisiana, Mississippi, Missouri, New Jersey, New York, North Carolina, Pennsylvania, Tennessee, Texas, Virginia, and Washington.

265. Rex. J. Zedalis, Professor of Law at The University of Tulsa College of Law, Lecture to Property Law

precedents produce results in direct conflict with society's goals, the rules must change.²⁶⁷ *Brown v. Board of Education*²⁶⁸ illustrates this, as the Supreme Court finally rejected its dysfunctional "separate but equal" doctrine.²⁶⁹ With *Olmstead*, as with *Brown*, the Supreme Court's decision signaled a paradigm shift, but many states reacted slowly and discrimination continued.²⁷⁰ Criticizing state and local governments' resistance to compliance with *Brown*, Justice Black emphasized that "[t]here has been entirely too much deliberation and not enough speed. . . ."²⁷¹ Similarly, a number of states continue to violate the *Olmstead* requirement²⁷² that a waiting list for HCBS must "[move] at a reasonable pace."²⁷³ As Congress noted in the PPACA:

Despite the . . . *Olmstead* decision, the long-term care provided to our Nation's elderly and disabled has not improved. In fact, for many, it has gotten far worse. . . . Although every State has chosen to provide certain services under home and community-based waivers, these services are unevenly available within and across States, and reach a small percentage of eligible individuals.²⁷⁴

What would happen if people had to add their names to a list and wait, sometimes years, before there was an opening allowing them to vote, or go to public schools, or use public transportation?²⁷⁵ Congress passed the ADA "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."²⁷⁶ The legislators specifically noted that people with disabilities faced discrimination that includes "institutionalization"²⁷⁷ and the Supreme Court concurred in that respect.²⁷⁸ Inexplicably contradicting themselves, the legislature and courts perpetuate a federal and state Medicaid system that discriminates against thousands of individuals with I/DD by offering them a "choice" between unnecessary segregation in an institution

Class at The University of Tulsa College of Law (Jan. 29, 2013) (lecture notes on file with author) (citing THOMAS S. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* 92 (3d ed. 1996)).

266. *Id.*

267. *Id.*

268. *Brown v. Bd. of Ed. of Topeka*, 347 U.S. 483, 495 (1954).

269. *Plessy v. Ferguson*, 163 U.S. 537, 549 (1896).

270. Bliss, *supra* note 201, at 718-19.

271. *Id.* at 713 (citing *Griffin v. Cnty Sch. Bd. of Prince Edward Cnty.*, 377 U.S. 218, 229 (1964)).

272. See Bliss, *supra* note 200, at 718; Kaiser Family Found., *Waiting Lists for Medicaid 1915(c) Home and Community-Based (HCBS) Waivers, 2010*, STATEHEALTHFACTS.ORG, <http://www.statehealthfacts.org/comparatable.jsp?ind=246&cat=4&sub=62&yr=138&typ=1> (last visited Mar. 17, 2014) (showing the number of Americans with ID/DD on waiting lists in each state for Medicaid 1915(c) HCBS in 2010).

273. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 606 (1999).

274. *Carlson & Coffey*, *supra* note 247, at 3 (quoting the PPACA, Pub. L. No. 111-148, § 2406).

275. Gaughan, *supra* note 12, at 418.

276. 42 U.S.C. § 12101(b)(1) (2012).

277. 42 U.S.C. § 12101(a)(3) (2012).

278. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999) ("Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments . . .").

or a lengthy wait for services.²⁷⁹

1. States Have Had Ample Time to Experiment with HCBS Waiver Programs

States have been participating in Medicaid's HCBS waiver program since Congress enacted it in 1981.²⁸⁰ By authorizing CMS to waive several Medicaid provisions when approving state HCBS programs, the legislature hoped to encourage states to experiment and thus develop innovative ways of providing community services.²⁸¹ The statutory language for demonstration projects fails to adequately address the scope of HCBS required today.²⁸² After three decades of experience with waivers, at least two commentators believe that "[i]f Medicaid waivers have taught us anything, it is that state experimentation in this program teaches us very little."²⁸³ There are vast disparities in access to HCBS programs, as people with I/DD receive services without delay in some states while residents of other states wait years to receive HCBS.²⁸⁴ The time has come for improved federal oversight so that the best practices are adopted nationwide.²⁸⁵

Enacting HCBS as an optional and experimental program made sense as a starting point for deinstitutionalization at a time when large state institutions provided long-term care for people with I/DD.²⁸⁶ When Congress created the HCBS waiver authority, numerous policy experts expected HCBS to later become a part of regular Medicaid state plan coverage.²⁸⁷ Although Congress granted states authority to include HCBS under Medicaid state plans in 2007, the statute allowed states to disregard several Medicaid requirements.²⁸⁸ The PPACA went even further, eliminating a state's authority to cap enrollment if the state chooses to offer coverage of HCBS in its state plan under Section 1915(i) authority.²⁸⁹ But, because states have the option to choose whether to include HCBS in their state Medicaid plans, the majority of states continue to use Section 1915(c) waiver authority for HCBS for people with I/DD so that the states can limit en-

279. See Gaughan, *supra* note 12, at 437.

280. See GETTINGS, *supra* note 11, at 94; discussion *supra* Part II.

281. See GETTINGS, *supra* note 11, at 90-91; discussion *supra* Part II.

282. See Williams, *supra* note 92, at 236.

283. Abigail R. Moncrieff & Eric Lee, *The Positive Case for Centralization in Health Care Regulation: The Federalism Failures of the ACA*, 20 KAN. J.L. & PUB. POL'Y 266, 283 (2011) (citing Frank J. Thompson & Courtney Burke, *Executive Federalism and Medicaid Demonstration Waivers: Implications for Policy and Democratic Process*, 32 J. HEALTH POL., POL'Y & L. 971 (2007)).

284. Ng & Harrington, *supra* note 183, at 6-7 (2011), available at <http://www.kff.org/medicaid/upload/LTC-Slides-02-07-2011.pdf> (last visited Mar. 2, 2013); see Harrington et al., *supra* note 170, at 3-6.

285. See Harrington et al., *supra* note 170, at iv.

286. See Bagenstos, *supra* note 44, at 6-8, 42 (citing statistics on deinstitutionalization and noting the shift from institutional care to community services: "[T]he official position of the professional leadership of most states' developmental disability and mental health agencies is that the overwhelming majority of people with those disabilities do not need to live in institutions. . . . deinstitutionalization advocates shifted their goals from rights to services . . .").

287. GETTINGS, *supra* note 11, at 114.

288. *Id.* at 116 (explaining that section 1915(i) allows states to disregard the statewideness and income/resources provisions of the act, and section 1915(j) allows states to disregard the comparability, statewideness, and income/resources provisions of the act).

289. *Id.* at 117-18.

rollment.²⁹⁰

2. States Offer Unconvincing Arguments against HCBS Expansion

Despite recent federal encouragement for states to expand HCBS,²⁹¹ state programs have not kept up with demand.²⁹² Blaming the recession, states limit HCBS coverage and access, leaving many people with I/DD underserved or without any services.²⁹³ In reality, limiting access to HCBS represents a political choice, not an economic imperative.²⁹⁴ HCBS waiver programs are a prime target for state budget cuts for two reasons.²⁹⁵ First, unlike institutional care, federal Medicaid law does not mandate HCBS coverage.²⁹⁶ Second, citizens with I/DD have historically lacked political power,²⁹⁷ and many have been deprived of their right to vote.²⁹⁸ About thirty states ban voting by individuals after court

290. See Smith et al., *supra* note 84, at 48 (stating that nine states had the HCBS state plan option in place during FY 2012, and four more plan to implement it by FY 2014).

291. *Id.* (discussing PPACA options that provide incentives for states to expand HCBS).

292. KAISER, *supra* note 180, at 3.

293. Cabansag, *supra* note 51, at 1046.

294. For example, Oklahomans with I/DD wait over eight years for HCBS, yet state leaders want to cut the state income tax rate, which would decrease revenue available to fund state services such as HCBS. OKDHS, *supra* note 13 (“Working applications dated April 19, 2005 as of 8/19/13.”). When waivers become available, applications are processed on a first-come, first-served basis. See Oklahoma In-Home Supports waiver for adults, available at [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915\(c\)#waivers](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915(c)#waivers) (last visited Mar. 2, 2013):

In accordance with OAC 317:40-1-1, initiation of services occurs in chronological order from the waiting list based on the date of receipt of a written request for services. The individual must meet the financial and medical eligibility criteria and have critical support needs that can be met by the IHSW-A. Exceptions to the chronological requirement may be made when an emergency exists.

Thus, “[w]orking applications dated April 19, 2005 as of 8/19/13” equates to a wait time of eight years and four months; Governor Mary Fallin’s 2014 State of the State Address at 11 (Feb. 3, 2014) (“this legislative session I have included in my budget an additional quarter-point income tax reduction that will return over \$100 million to the state economy once fully realized.”); Randy Ellis, *Oklahoma House Approves Tax Cut Bill*, OKLAHOMAN, Mar. 6, 2014:

Following passionate debate, the Oklahoma House of Representatives approved a bill Thursday to cut the state’s top individual income tax rate by 0.25 percent and the corporate income tax rate by 1 percent. . . . The state Senate previously passed its own income tax cut bill, so negotiators from the two chambers will now meet to see if they can agree on a version that can pass both houses and be presented to the governor for final approval.

See *Budget and Taxes*, Okla. Policy Inst., OKPOLICY.ORG, <http://okpolicy.org/issues/responsible-budget-taxes> (last visited Mar. 8, 2014); Tim Westmoreland, *Standard Errors: How Budget Rules Distort Lawmaking*, 95 GEO. L.J. 1555, 1598 (2007):

So there is institutionalization by the budget. The legislation to require Medicaid to pay for home and community-care has been introduced for a decade and never moved past hearings and scoring. Legislators can feel confident that they can camouflage their decision to oppose or simply fail to support such legislation as simply “the budget,” without confronting the values implicit in that calculation.

295. See *Still Waiting . . . The Unfulfilled Promise of Olmstead*, Bazelon Ctr. for Mental Health Law, 8 (2009), available at <https://www.bazelon.org/LinkClick.aspx?fileticket=S5nUuNhJSOM%3d&tabid=104> (citing Nat’l Council on Disability, National Disability Policy: A Progress Report 30 (2009)).

296. Harrington et al., *supra* note 170, at 2.

297. *Cleburne Living Ctr. Inc. v. Cleburne*, 726 F.2d 191, 197-98 (1984).

298. ALLISON C. CAREY, ON THE MARGINS OF CITIZENSHIP: INTELLECTUAL DISABILITY AND CIVIL RIGHTS IN TWENTIETH-CENTURY AMERICA 2, 9-10 (2010); Jennifer A. Bindel, *Equal Protection Jurisprudence and the*

proceedings in which the individuals have been determined to be “mentally incompetent” or “mentally incapacitated.”²⁹⁹ While these court determinations assess an individual’s ability to meet basic needs of food, clothing, and shelter, the assessment rarely involves voter competence.³⁰⁰ In addition to legally sanctioned obstacles to voting, election officials, poll workers, and residential care workers sometimes improperly prevent people with intellectual disabilities from exercising their lawful rights to vote.³⁰¹

Even in good economic times, legislation to provide HCBS for all eligible individuals has met resistance because of conjecture that providing services in community settings brings people who need services “out of the woodwork.”³⁰² To be eligible for HCBS, an individual must meet the criteria for an institutional level of care.³⁰³ Informal caregivers, such as family and friends, allow many HCBS-qualified people to avoid institutionalization; decision makers fear that these people would use HCBS if it was available, adding to the cost of the programs.³⁰⁴ There is dispute over the accuracy of the woodwork effect, and a study of state spending on long-term care services from 1995 to 2005 showed that expanding HCBS resulted in cost savings in the long run, despite an initial short-term spending increase.³⁰⁵ Further, policymakers explain that state expansion of HCBS represents a stimulus to a state’s economy.³⁰⁶ The federal government contributes at least one dollar for every dollar the state spends on HCBS, and those monies buy services that create jobs and stimulate the state’s economy.³⁰⁷ Also, a state’s economy benefits when expanded access to HCBS relieves the demands on family members and friends who serve as informal caregivers for people with I/DD.³⁰⁸ Without HCBS, many of these informal caregivers cut back on household spending, postpone personal medical care, and limit their work hours, leading to losses in business productivity and economic activity that ultimately hurt state revenue.³⁰⁹ Congress also recognized the economic as

Voting Rights of Persons with Diminished Mental Capacities, 65 N.Y.U. ANN. SURV. AM. L. 87, 87 (2009); Cabansag, *supra* note 51, at 1046; Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 105-06.

299. Kimberly Leonard, *Keeping the “Mentally Incompetent” from Voting*, ATLANTIC, Oct. 17, 2012, available at <http://www.theatlantic.com/health/archive/2012/10/keeping-the-mentally-incompetent-from-voting/263748/> (citing Election Protection, *State Laws Affecting the Voting Rights of People with Mental Disabilities*, 866OURVOTE.ORG, <http://www.866ourvote.org/newsroom/publications/body/0049.pdf>).

300. *Id.* at 5.

301. *Id.* at 6-7.

302. Mark C. Weber, *Home and Community Based Services, Olmstead and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269, 288 (2004); See Gaughan, *supra* note 12, at 415; Perkins & Boyle, *supra* note 256, at 119.

303. 42 C.F.R. § 441.302 (2012).

304. Harrington et al., *supra* note 170, at 19.

305. *Id.* at 19-20 (2009) (citing H. Stephen Kaye, Mitchell P. LaPlante, & Charlene Harrington, *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?*, 28(1) HEALTH AFFS. 262 (2009)).

306. 2010 Policy Directors Annual Meeting CSI Briefing Book, Ctr. for State Innovation 64 (2010), available at <http://www.stateinnovation.org/Events/Event-Listing/PDAM-09/Briefing-Book/Complete-Briefing-Book-with-Cover--PDAM-2010-FOR-W.aspx> [hereinafter Innovation]; Jim Nicholson, Director of Developmental Disabilities Services Division of Oklahoma Department of Human Services (“OKDHS/DDSD”), Remarks at the OKDHS/DDSD Waiting List Meeting (Dec. 18, 2012) (meeting notes on file with author).

307. Innovation, *supra* note 306, at 64; Nicholson, *supra* note 306.

308. Innovation, *supra* note 306, at 65; Nicholson, *supra* note 306.

309. Innovation, *supra* note 306, at 65.

well as moral benefits of fully integrating people with I/DD into society, finding when it enacted the ADA that:

the [continuing] existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.³¹⁰

3. Individuals and Society Benefit when People with I/DD are Fully Integrated

Ending discrimination against people with disabilities should prevail regardless of whether HCBS helps or hurts state economies.³¹¹ Justin Dart, Jr., recognized as the “father of the ADA,”³¹² testified before a Senate Committee with these convicting words:

Is ADA affordable? Equality affordable in America? Would this question be asked about black, Hispanic or Jewish people? The very question reveals an unconscious assumption of inequality. The very question demonstrates most dramatically the absolute necessity for a national mandate of equality. Not since the abolition of slavery has the principle of equality been negotiable for money in the United States of America.³¹³

Hostility, prejudice, and fear flourish when people with I/DD remain segregated and out of sight.³¹⁴ Government endorsement of the segregation reinforces the stereotype of inferiority and the acceptability of discrimination.³¹⁵ While reshaping attitudes takes time, interactions between people with and without disabilities break down barriers and reduce prejudice.³¹⁶

Although some controversy remains regarding the wisdom of abolishing institutions and providing community services regardless of impairments,³¹⁷ studies show that even individuals with severe disabilities can thrive in community settings.³¹⁸ Institutional

310. Cook, *supra* note 51, at 457-58 (1991) (quoting 42 U.S.C.A. § 12101(a)(8)).

311. See DiPolito, *supra* note 45 at 1388.

312. *In Memoriam: Justin Dart, Jr.*, Office of Special Educ. & Rehabilitative Servs., U.S. DEP'T OF EDUC., <http://www2.ed.gov/about/offices/list/osers/dart.html> (last visited Mar. 9, 2013).

313. Cook, *supra* note 51, at 459 (quoting *Americans with Disabilities Act: Hearing Before the Senate Comm. on Labor and Human Resources and the Subcomm. on the Handicapped*, 101st Cong., 1st Sess. 66 (1989) (statement of Mr. Dart)).

314. Weber, *supra* note 302, at 274-75.

315. *Id.* at 274.

316. See Cook, *supra* note 51, at 397-98; Weber, *supra* note 302, at 274-75.

317. Colker, *supra* note 28, at 1420, 1423.

318. Bagenstos, *supra* note 44, at 12-13.

resources can be replicated in the community, allowing medically fragile individuals and individuals with severe behavioral and cognitive challenges to successfully live in the community with the provision of necessary supports.³¹⁹ Oklahoma transitioned over four hundred children and adults with I/DD into community homes when the Hissom Memorial Center was closed in 1994 after parents filed a class action lawsuit demanding community service options.³²⁰ Studies tracking the transitioned residents show success in all cases, as moving into the community resulted in healthier, more active lives.³²¹ In addition, a number of the former Hissom residents who had the most severe impairments showed the greatest progress.³²²

Numerous studies provide evidence of benefits for people with I/DD who move from institutions into small community homes with appropriate supports.³²³ These benefits include more interaction and better relationships with family, friends, and social groups;³²⁴ greater dignity and self-esteem;³²⁵ gains in adaptive behavior and daily living skills such as self-care and domestic skills;³²⁶ and better compliance with medication and treatment plans.³²⁷ Also, community living for people with I/DD results in increased independence and sense of competence, improved decision making, and better perceived quality of life.³²⁸

Moreover, society as a whole benefits when people with I/DD participate in community life.³²⁹ Ongoing interactions among people with and without I/DD promote the development of relationships, break down stereotypes, and promote understanding and tolerance.³³⁰ Research shows that peers without I/DD have more positive attitudes about individuals with I/DD when those individuals interact with them in community settings.³³¹ Neighbors, teachers, employers, and even parents have better outlooks and higher expectations for individuals with I/DD who are fully included in integrated settings.³³²

4. Piecemeal Litigation Has Failed to Solve the Problem

The federal government has made efforts to encourage states to implement *Olmstead* but has yet to establish a national plan for community integration of people

319. Cook, *supra* note 51, at 444.

320. OKDHS HSC, *supra* note 66; see *Homeward Bound, Inc. v. Hissom Mem'l Ctr.*, 85-C-437-E, 1987 WL 27104 (N.D. Okla. July 24, 1987).

321. Letter from Cody Inman, Senior Public Affairs Officer, State of Oklahoma Office of the Governor, to Susan Witte, Oklahoma resident who has I/DD and has been on the waiting list for HCBS since 2007 (Jan. 9, 2013) (on file with author); OKDHS HSC, *supra* note 66.

322. Inman, *supra* note 321.

323. *E.g.*, Cmty. Living, *supra* note 61, at 3-8.

324. DiPolito, *supra* note 45 at 1388; see Cook, *supra* note 51, at 450-51.

325. DiPolito, *supra* note 45 at 1388; Karger, *supra* note 30, at 1227.

326. Cmty. Living, *supra* note 61, at 8.

327. DiPolito, *supra* note 45 at 1388.

328. See Brief for United States as Amici Curiae, *Olmstead v. L.C., E.W.*, 527 U.S. 581 (1999) (No. 98-536), 1999 WL 143937, at *12-*15.

329. See DiPolito, *supra* note 45 at 1404, 1409.

330. See Cook, *supra* note 51, at 448-49.

331. *Id.*

332. *Id.*

with I/DD.³³³ Further, most states have failed to commit to providing HCBS for all eligible individuals with I/DD.³³⁴ These shortcomings have produced an environment in which litigation has become the primary means of expanding access to HCBS.³³⁵ In addition to DOJ-initiated actions, individuals and advocacy groups have brought over fifty federal actions since *Olmstead* seeking HCBS for people living in the community who are at risk of institutionalization.³³⁶ Although settlements and court orders have granted some relief,³³⁷ waiting lists for HCBS remain a chronic problem that litigation alone is unlikely to solve.³³⁸

Olmstead does not provide a bright line rule to decide if a state's failure to provide HCBS violates the ADA integration mandate or is excused by the fundamental alteration doctrine.³³⁹ To be sure, jurisdictions vary in their interpretations of the *Olmstead* ruling and the integration mandate, and many courts often interpret them narrowly and with deference to state defendants.³⁴⁰ Because of federalism concerns and the complexity of Medicaid statutes, federal courts hesitate to rule against states that claim fundamental alteration as a defense to an *Olmstead* lawsuit.³⁴¹ Even when courts rule against state defendants or people with I/DD achieve apparent victory through a settlement agreement, success may be short lived if a state's legislature refuses to allocate the funding needed to comply with the settlement agreement.³⁴² People with I/DD face another obstacle when trying to gain HCBS through judicial avenues: the challenge of navigating the legal system.³⁴³ As one Senator explained during ADA hearings:

[Y]ou do not find many individuals who have mental and physical disabilities that have the time or the resources to go down to the courthouse to be able to get that injunction and bring the case. For the most part, they are spending their full time just coping with the difficulties and challenges of life. What we have seen in the areas of the disability

333. See DiPolito, *supra* note 45 at 1406-07.

334. See DiPolito, *supra* note 45 at 1407 (“[F]ederal initiatives are vital and necessary steps; but, ultimately, a deep commitment by the state is required to make community living a reality for all citizens with disabilities.”); see also Smith et al., *supra* note 84, at 46 (“[M]ost states already have limits in place for their community-based services such as coverage limits, enrollment caps, and waiting lists for services . . . seven states in FY 2012 and four states in FY 2013 imposed additional restrictions directed at HCBS programs and services . . .”).

335. See DiPolito, *supra* note 45 at 1400, 1407.

336. Training & Advocacy Support Ctr., *supra* note 252, at 48-71 (2012).

337. See *id.* (describing litigation brought by people with I/DD at risk of institutionalization).

338. See KFF Waiting, *supra* note 10 (stating 316,673 Americans with ID/DD were on waiting lists for Medicaid 1915(c) HCBS waivers in 2011).

339. Ferleger, *supra* note 252, at 774-75.

340. See Cabansag, *supra* note 51, at 1048, 1050-51.

341. See Kubo, *supra* note 12, at 762-63.

342. E.g., Margaret K. Feltz, *Playing the Lottery: HCBS Lawsuits and Other Medicaid Litigation on Behalf of the Developmentally Disabled*, 12 HEALTH MATRIX 181, 236-38 (2002) (describing the *Boulet* case in which the Massachusetts legislature made drastic cuts following a settlement agreement, and disability advocates had to battle to reverse the budget cuts).

343. See Cook, *supra* note 51, at 465 n.471 (Edward M. Kennedy, Senator, 135 Cong. Rec. S10,742 (daily ed. Sept. 7, 1989)).

movement is a different pattern in terms of litigation than has been in the case of some of the other violations of the basic civil rights.³⁴⁴

Disappointed with the failure of litigation to produce widespread integration of people with disabilities, advocates contend that it is “past time for *Olmstead* implementation to move out of the courtroom and into America’s communities.”³⁴⁵

D. Recommendations for Action

Much like the judiciary’s limited impact³⁴⁶ on the HCBS waiting list problem, the federal executive branch’s efforts³⁴⁷ have also fallen short.³⁴⁸ Ultimately, the solution to the waiting list problem lies with the legislature—Congress must pass legislation that changes HCBS from waiver status to a state plan requirement.³⁴⁹ Elevating HCBS to the same status as other Medicaid programs will ensure that states no longer deny HCBS to qualified individuals with I/DD.³⁵⁰ As a result, more people with I/DD will be able to preserve their independence, maintain relationships with family and friends, and actively contribute to their communities, free from institutionalization.³⁵¹

A second step the federal government should take is assessing which HCBS programs are most effective and implementing these programs nationwide.³⁵² CMS has a deep well of experience to draw best practices from, because states have been experimenting with HCBS waivers for over thirty years,³⁵³ and there are now over two hundred and fifty different waivers in place.³⁵⁴ Waiting times for HCBS vary widely from state to

344. *Id.*

345. DiPolito, *supra* note 45, at 1400 (quoting *Legal Advocate Cites Ongoing Segregation on Eve of Olmstead Anniversary*, BAZELON CTR. FOR MENTAL HEALTH LAW, <http://www.bazelon.org/LinkClick.aspx?fileticket=brBHCvIwpf4%3D&tabid=328>. (last updated June 2004)).

346. See discussion *supra* Part III.C.4.

347. See Exec. Order No. 13, 217, 66 F.R. 33155 (2001); Bagenstos, *supra* note 44, at 5 (describing President Obama’s Community Living Initiative and DOJ involvement in *Olmstead* enforcement); Harrington et al., *supra* note 170, at 6 (“In 2001, President Bush announced the New Freedom Initiative (NFI) (using an executive order), a cross-governmental policy and funding program that aimed to remove barriers to community living for people with disabilities and provide additional momentum to efforts to comply with the *Olmstead* court ruling and the [ADA].”).

348. The number of Americans with ID/DD on waiting lists for HCBS continues to grow, from 268,220 in 2010, to 316,673 in 2011. Kaiser Family Found., *supra* note 272; KFF Waiting, *supra* note 10.

349. See Gaughan, *supra* note 12, at 437; Harrington et al., *supra* note 170, at iv, 6; *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*, NAT’L COUNCIL ON DISABILITY, 30 (2005), available at <http://www.ncd.gov/publications/2005/12152005>.

350. See Schwalb, *supra* note 12, at 849.

351. See NAT’L COUNCIL ON DISABILITY, *supra* note 349, at 88.

352. Harrington et al., *supra* note 170, at iv; see generally Ctrs. for Medicare and Medicaid Servs., *Quality of Care*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Quality-of-Care/Quality-of-Care.html> (last visited Feb. 28, 2013) (“Medicaid and the Children’s Health Insurance Program (CHIP) seek to provide safe, effective, efficient, patient-centered, high quality and equitable care to all enrollees. To achieve these goals, the Centers for Medicare and Medicaid Services (CMS) partners with states to share best practices and to provide technical assistance to improve the quality of care.”).

353. See GETTINGS, *supra* note 11, at 90-91.

354. See NAT’L COUNCIL ON DISABILITY, *supra* note 349, at 89.

state,³⁵⁵ including ten states reporting no waiting lists in 2011.³⁵⁶ Simply put, there are best practices in HCBS programming that need to be shared among the states.³⁵⁷

While eliminating HCBS waiting lists will significantly expand opportunities for individuals with I/DD to be fully included in society, other challenges remain.³⁵⁸ HCBS represents one component of long-term services and supports (“LTSS”) for people with disabilities and the elderly.³⁵⁹ The growing demand and increasing costs of LTSS have produced a system that “is fast becoming financially unsustainable.”³⁶⁰ Therefore, substantial changes to federal policies and programs will be required³⁶¹ to “assure equality of opportunity, full participation, [and] independent living” for people with I/DD.³⁶² Accordingly, the National Council on Disability and the Human Services Research Institute have proposed policies and innovative solutions, including collaboration of private and government entities and resources, that will create a robust sustainable network of LTSS.³⁶³

V. CONCLUSION

People with I/DD “have been subjected to a history of unfair and often grotesque mistreatment.”³⁶⁴ Disability advocates have convinced many states to close public institutions³⁶⁵ but have been less successful in establishing essential community supports.³⁶⁶ Although “[f]ew assaults on individual dignity and self-determination are harsher than being forced to leave one’s home and community to live in a segregated environment,”³⁶⁷ people with I/DD often face the dilemma of moving into an institution to receive services or going without.³⁶⁸ To alleviate this, CMS should determine the most effective HCBS

355. KAISER, *supra* note 180, at 3.

356. *Id.* at 11.

357. See Harrington et al., *supra* note 170, at iv; see generally Ctrs. for Medicare & Medicaid Servs., *Quality of Care*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Quality-of-Care/Quality-of-Care.html> (last visited Feb. 28, 2013) (“Medicaid and the Children’s Health Insurance Program (CHIP) seek to provide safe, effective, efficient, patient-centered, high quality and equitable care to all enrollees. To achieve these goals, the Centers for Medicare and Medicaid Services (CMS) partners with states to share best practices and to provide technical assistance to improve the quality of care.”).

358. See generally NAT’L COUNCIL ON DISABILITY, NATIONAL DISABILITY POLICY: A PROGRESS REPORT 7-9 (2009) (the report “focus[es] on the current status of the quality of life of people with disabilities, and the emerging trends that warrant changes in the Federal Government’s disability policies and programs.”).

359. See NAT’L COUNCIL ON DISABILITY, *supra* note 349, at 13, 17, 22.

360. *Id.* at 21, 47.

361. See NCD 2011, *supra* note 65 at 11, 79-80.

362. 42 U.S.C. § 12101(a)(7) (2012).

363. See NCD 2011, *supra* note 65 at 79-80; see generally HUMAN RES. RESEARCH INST., WORKING TOWARD A SUSTAINABLE FUTURE FOR DEVELOPMENTAL DISABILITY SERVICE SYSTEMS (2012).

364. *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 454 (1985) (Stevens, J., concurring) (quoting *Cleburne Living Ctr., Inc. v. Cleburne*, 726 F.2d 191, 197 (5th Cir. 1984)).

365. NCD 2011, *supra* note 65 at 74, 88 (listing the states which have closed all ICF/IIDs: “District of Columbia (1991), New Hampshire (1991), Vermont (1993), Rhode Island (1994), Alaska (1997), New Mexico (1997), West Virginia (1998), Hawaii (1999), Maine (1999), Minnesota (2000), Indiana (2007), Michigan (2009), Oregon (2009), and Alabama (2012).”).

366. See Bagenstos, *supra* note 44, at 21, 42.

367. NAT’L COUNCIL ON DISABILITY, NATIONAL DISABILITY POLICY: A PROGRESS REPORT 30 (2009).

368. See Schwalb, *supra* note 12, at 832-33, 849; Flynn, *supra* note 12, at 417; Gaughan, *supra* note 12, at

waiver programs and work with states to implement these.³⁶⁹ Ultimately, the federal government must eliminate waiver waiting lists by making HCBS a Medicaid state plan requirement³⁷⁰ so that people with I/DD will have “the opportunity to blend fully and equally into the rich mosaic of the American mainstream.”³⁷¹

In the 1960’s and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun. In the 1970s and 80s you discovered we could be taught—we could learn—and we were treated like pets. You taught us all types of tricks and we stood by your side. But now . . . Here we are. We are not plants. We are not your pets. We are people like you and we want to be treated as real people. We want the same opportunities as anybody.³⁷²

Carol Beatty

437; Kubo, *supra* note 12, at 754.

369. Harrington et al., *supra* note 170, at iv; *see generally* Ctrs. for Medicare & Medicaid Servs., *Quality of Care*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Quality-of-Care/Quality-of-Care.html> (last visited Feb. 28, 2013) (“Medicaid and the Children’s Health Insurance Program (CHIP) seek to provide safe, effective, efficient, patient-centered, high quality and equitable care to all enrollees. To achieve these goals, the Centers for Medicare and Medicaid Services (CMS) partners with states to share best practices and to provide technical assistance to improve the quality of care.”).

370. Harrington et al., *supra* note 170, at iv, 6; *see* NAT’L COUNCIL ON DISABILITY, *supra* note 349, at 30; Gaughan, *supra* note 12, at 437.

371. President George H.W. Bush, Remarks by the President during Ceremony for the Signing of the Americans with Disabilities Act of 1990, at 2 (July 26, 1990), *available at* <http://bushlibrary.tamu.edu/features/2010-ada/RemarksbythePresident.pdf>.

372. *Working Toward A Sustainable Future for Developmental Disability Service Systems*, HUMAN RES. RESEARCH INST. 11 (2012), *available at* <http://www.hsri.org/news-events/working-toward-a-sustainable-future-for-developmental-disability-service-sy/>.