Implementing Olmstead by Outlawing Waiting Lists

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).
³. Id.
⁴. Id.
⁵. Id. at 13.
⁶. Id.
feel miserable all the time and his behavior would improve. Seth qualifies for HCBS, but he remains trapped at home—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.
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 DRS. OF DEVELOPMENTAL DISABILITIES SERVS., HOME AND COMMUNITY-BASED SERVICES AS A MEDICAID STATE PLAN OPTION: PRESERVING STATE FLEXIBILITY AND RESPONSIVENESS (1997)).

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.
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 “feebleminded” 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.” Developmental disabilities (“DD”) include ID and other conditions that are primarily physical issues, such as cerebral palsy and epilepsy. 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.

This article examines the history of institutional segregation of people with I/DD, discusses legal challenges to state waiting lists for Medicaid HCBS waiver 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.” 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”). 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. Part IV concludes that resolving the waiting list problem requires federal action, including changing HCBS from waiver status to a state plan requirement.

II. BACKGROUND OF THE PROBLEM: WAREHOUSED, WAVERED, 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

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.”).
22. See generally GETTINGS, supra note 11, at 63-123.
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 Feebleminded 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 deprived 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 Feebleminded 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 feebleminded person as a menace to social decency and racial purity: to the end that they shall not reproduce their kind.”


29. Id.


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 feebleminded 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 feeblemindedness are only too well known. The feebleminded are a parasitic, predatory class . . . they cause unutterable sorrow at home and are a menace and danger to the community . . . Every feebleminded person, especially the highgrade imbecile, is a potential criminal . . . The most important point is that feeblemindedness 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-
nent care for their children with I/DD.\textsuperscript{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.\textsuperscript{43} \textit{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.\textsuperscript{44}

In addition to seeking improvements in conditions at institutions, advocates began to champion deinstitutionalization.\textsuperscript{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.\textsuperscript{46} Throughout the 1960s and 1970s, various factors strengthened the deinstitutionalization movement.\textsuperscript{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.\textsuperscript{48} Professionals began to understand that

\begin{thebibliography}{99}
\bibitem{1} Id. at 16, 21, 42, 45 (indicating that waiting lists were up to one third of the capacity of institutions, and turnover was slow).
\bibitem{2} \textsc{Davis, supra note 40, at 2; see \textsc{PC 76, supra note 25, at 45}}.
\bibitem{3} Samuel R. Bagenstos, \textit{The Past and Future of Deinstitutionalization Litigation}, \textsc{34 Cardozo L. Rev. 1}, 14 n.60. \textit{(Citing Burton Blatt \& Fred Kaplan, \textit{Christmas in Purgatory: A Photographic Essay on Mental Retardation} 3 (1966)).}
\bibitem{4} \textsc{Davis, supra note 40, at 2; see \textsc{PC 76, supra note 25, at 2}; Samantha A. DiPolito, Comment, \textit{Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation’s Conscience?}, \textsc{58 Mercer L. Rev. 1381}, 1385 (2007); Karger, \textit{supra note 30, at 1226-27}; Sandra L. Yue, Article, \textit{A Return to Institutionalization Despite \textit{Olmstead} v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home- and Community-Based Waiver Services}, \textsc{19 Law \& Ineq. 307}, 313 (2001)}.
\bibitem{5} Loin A. Weithorn, \textit{Envisioning Second-Order Change in America’s Responses to Troubled and Troublesome Youth}, \textsc{33 Hofstra L. Rev. 1305}, 1446 (2005).  
\bibitem{6} \textit{See \textsc{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}}.
\bibitem{7} \textsc{PC 76, supra note 25, at 45; DiPolito, supra note 45, at 1385; Karger, \textit{supra note 30, at 1226; Yue, supra note 45, at 313}}.
\end{thebibliography}
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 sprang 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.
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 Individu-
als 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 interpre-
tations of the ADA have incorporated a cost-based analysis to decide the extent to which the ADA will be en-
forced.”).
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)).
56. See Cook, supra note 51, at 395; Cabansag, supra note 51, at 1031.
58. Cook, supra note 51, at 395 (citing Pennhurst State Sch. & Hosp. v. Halderman, 451 U.S. 1, 10 (1981)).
transform as it received support from disparate sources: disability advocates, academic research, the civil rights movement, liberal legislators, and fiscal conservatives. 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. 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. Cost studies also confirmed the superiority of deinstitutionalization, generating support from fiscally conservative legislators and public officials. “[Deinstitutionalization] permitted liberal politicians to free mental patients, and at the same time allowed conservative politicians to save millions of dollars.”

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. By 2012, fourteen states had closed all public institutions for I/DD. 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. 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. 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.


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 WIURO, RESIDENTIAL SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2010, at iii (2012).


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.\textsuperscript{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.”\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{72} The difficulties in establishing and maintaining essential community-based services threaten the future of deinstitutionalization.\textsuperscript{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.\textsuperscript{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.\textsuperscript{75} Federal statutes, regulations, and policies establish broad national guidelines.\textsuperscript{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.\textsuperscript{77} Because of the discretion given to the states, eligibility and services vary considerably from

\textsuperscript{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.”).
\textsuperscript{69}. Id.
\textsuperscript{70}. See Bagenstos, supra note 44, at 6-8; Weithorn, supra note 46, at 1446 (defining deinstitutionalization).
\textsuperscript{71}. See Bagenstos, supra note 44, at 6, 12-13.
\textsuperscript{72}. See id.
\textsuperscript{73}. See id.
\textsuperscript{74}. U.S. SOC. SECURITY ADMIN., ANNUAL STATISTICAL SUPPLEMENT TO THE SOCIAL SECURITY BULLETIN, 2012, at 57 (2013) [hereinafter SSA BULLETIN].
\textsuperscript{75}. Id.
\textsuperscript{76}. Id.
\textsuperscript{77}. Id.
state to state.\textsuperscript{78} Further, state legislatures may revise Medicaid eligibility, services, or reimbursement at any time.\textsuperscript{79}

The federal government contributes at least half of each state’s Medicaid expenditures.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{83}

An essential part of the U.S. health care system, Medicaid provides coverage for about one-fifth of the American population.\textsuperscript{84} In 2009, nearly 800,000 Oklahomans were among the nation’s 62.7 million Medicaid enrollees.\textsuperscript{85} That same year, total Medicaid expenditures exceeded $4 billion for Oklahomans, and nearly $400 billion for the entire country.\textsuperscript{86} People with disabilities represented about 14 percent of Oklahoma’s Medicaid enrollees and about 15 percent of U.S. enrollees.\textsuperscript{87} Reflecting the higher medical and health-related service needs of those with disabilities, these enrollees generated about 42 percent of Medicaid costs.\textsuperscript{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.\textsuperscript{89} In addition, Medicaid regulations strongly affect states’ decisions regarding available supports and delivery of services.\textsuperscript{90} Sadly, the institutional bias of the Medicaid program,\textsuperscript{91} as dis-

\textsuperscript{78} Id.
\textsuperscript{79} Id. at 57.
\textsuperscript{80} Id. at 61.
\textsuperscript{81} Id.
\textsuperscript{82} Id.
\textsuperscript{86} Id.
\textsuperscript{87} Id.
\textsuperscript{88} Id.
\textsuperscript{89} GETTINGS, supra note 11, at 63.
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. Two elements of Medicaid significantly interwoven with the deinstitutionalization movement are Medicaid’s regulations regarding intermediate care facilities and home and community-based services.

1. Intermediate Care Facilities

Congress enacted Medicaid in July of 1965, and funds became available to the states on January 1, 1966. States could choose whether to participate in Medicaid and could also implement the program in phases. 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. In an attempt to control the rapid rise in costs, Congress amended the program in 1967. 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. 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. 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.

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. 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. Congress worked on legislative remedies to prevent states from using the ICF provision...
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/IID s). See C.F.R. T. 42, ch. IV, subch. G, pt. 483, subpt. I.
107. Id.
109. GETTINGS, supra note 11, at 67.
111. GETTINGS, supra note 11, at 68-69.
112. Id. at 69.
113. Id. at 70.
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. In 1974, the Social and Rehabilitation Ser-
vice (“SRS”) of the Federal Department of Health, Education, and Welfare (“HEW”) is-
sued regulations clarifying this provision. The regulations defined the requirement for
ICF/IIDs to provide “active treatment” so that each person participates regularly in ther-
apies, 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, intellec-
tual, social, and vocational functioning.

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. 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. 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 fina-

The ICF/IID standards exceeded the requirements for general ICFs. Consequently,
compliance necessitated costly physical renovations to state institutions, generating
battles between the HEW and a number of states, including Oklahoma. After unsuc-
cessful 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.

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. The total number of peo-
ple living in large public I/DD institutions declined over 40 percent between 1974 and
1986. Originally, the CMS 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. Id. 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 Res-
idential 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{134} The HCBS waiver authority allows states to use federal Medicaid matching funds to support individuals in their communities rather than in institutions.\textsuperscript{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.\textsuperscript{136}

Like the ICF/IID legislation, the HCBS waiver authority resulted from an unlikely alliance between I/DD advocates and fiscal conservatives.\textsuperscript{137} While the HCBS waivers advanced I/DD advocates’ goals of incentivizing states to expand community services and move people out of institutions,\textsuperscript{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.\textsuperscript{139}

\begin{itemize}
\item \textsuperscript{127} \textit{Gettings}, supra note 11, at 79.
\item \textsuperscript{128} \textit{Id.} at 80.
\item \textsuperscript{129} \textit{Id.} at 80-81.
\item \textsuperscript{130} \textit{Id.} at 81.
\item \textsuperscript{131} \textit{Id.} at 82; \textit{Residential}, supra note 108, at 1-31.
\item \textsuperscript{132} \textit{Larson}, supra note 64, at 99.
\item \textsuperscript{133} Karger, supra note 30, at 1229.
\item \textsuperscript{134} \textit{See Getting}, supra note 11, at 85, 92
\item \textsuperscript{135} Karger, supra note 30, at 1229.
\item \textsuperscript{136} \textit{Larson}, supra note 64, at 109.
\item \textsuperscript{137} \textit{Gettings}, supra note 11, at 67, 92; \textit{see Bagenstos}, supra note 44, at 20.
\item \textsuperscript{138} \textit{See Bagenstos}, supra note 44, at 6.
\item \textsuperscript{139} \textit{E.g., Getting}, supra note 11, at 92.
\end{itemize}
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. 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. 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.’”

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

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.

140. Id. 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
146. Id. at 72, 91 (“The Statewideness Requirement [:] States cannot restrict the availability of State Plan services to particular geographic regions.”).
147. GETTINGS, supra note 11, at 91.
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.” In addition to promoting innovative community service programs, legislators were concerned with cost savings. Thus, two elements that states must satisfy to qualify for HCBS waivers reflect fiscal concerns. First, states must limit eligibility to individuals who would, absent HCBS services, require institutional care. 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.

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. Four factors explained the immediate popularity of the programs. First, the increasing acceptance of deinstitutionalization policies stimulated community-based supports. Second, federal ICF/IID standards required states to downsize institutions. Third, class action lawsuits resulting in settlement agreements and court orders also forced the downsizing and closure of large state facilities. 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.

The federal government lacked the states’ enthusiasm for federal funding of waiver services. 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. From 1982 through 1985, the CMS and the OMB toughened and lengthened the waiver approval process. 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.

According to one congressman, the administration was “strangling the Medicaid waiver program with Byzantine regulations.”

In 1986, Congress passed legislation that provided some relief from the CMS/OMB’s restrictive approval procedures. However, the cold bed rule remained in effect until 1994, when the CMS simplified the cost neutrality formula and reporting requirements. 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.

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. This trend toward community supports and away from institutions has continued. The waiver program that began with eight waivers in six states in 1982 expanded to 214 waivers in twenty-nine states by 1999. By 2008, forty-eight states and the District of Columbia were managing 314 HCBS waiver programs. 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.

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.

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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. Getting, supra note 11, at 100.
168. See id. at 122.
169. See id.
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. Getting, 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{176}

When approving HCBS waivers, the CMS gives states wide discretion regarding choice of community service offerings and beneficiaries.\textsuperscript{177} Thus, available services, per capita expenditures, and HCBS participation vary widely from state to state.\textsuperscript{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.\textsuperscript{179} In at least ten states, people with I/DD are able to receive HCBS waivers promptly.\textsuperscript{180} However, a lack of waiting lists is the exception, as most states have failed to accommodate the growth in demand for HCBS.\textsuperscript{181} As a result, more people with I/DD are waiting, and are waiting longer periods, to receive HCBS.\textsuperscript{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.\textsuperscript{183} Texas had the largest waiting lists, with over 129,500 people waiting for waivers in 2009.\textsuperscript{184} Oklahoma had the longest wait time, an average of over five years.\textsuperscript{185} By 2011, HCBS waiting lists had grown to include more than 300,000 Americans with I/DD.\textsuperscript{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.\textsuperscript{187} HCBS provides the principal means of care for many

\begin{itemize}
\item \textsuperscript{174} GETTINGS, supra note 11, at 117-18.
\item \textsuperscript{175} ICF/IID MEDICAID, supra note 90; Harrington et al., supra note 170, at 1.
\item \textsuperscript{176} GETTINGS, supra note 11, at 120, Harrington et al., supra note 170, at viii.
\item \textsuperscript{177} See Harrington et al., supra note 170, at iv, 4-6.
\item \textsuperscript{178} See id.
\item \textsuperscript{182} See KAISER, supra note 180, at 3, 11; SMITH, supra note 181, at 10; Harrington et al., supra note 170, at 12-13.
\item \textsuperscript{184} Id. This figure is for all HCBS waivers in Texas for people with I/DD, and other elderly and disabled.
\item \textsuperscript{185} Id.
\item \textsuperscript{186} KFF Waiting, supra note 10.
\item \textsuperscript{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.\textsuperscript{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.\textsuperscript{189}

C. \textit{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. Bush\textsuperscript{190}

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.\textsuperscript{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.\textsuperscript{192} Senator Lowell Connecticut, parent of a child with Down syndrome, introduced the first version of the ADA on April 28, 1988.\textsuperscript{193} Congress spent several years discussing and revising the leg-
islation, but the overall legislative intent remained crystal clear throughout this time: the broad purpose of the ADA was to assist Americans with disabilities. 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.” Congress specifically included “institutionalization” among the critical areas where discrimination against people with disabilities exists.

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. Title II covers state and local government programs and services, including state Medicaid programs. 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.” 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.”

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. 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. Like integration of African American children into public schools, integra-
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.\textsuperscript{203} In Olmstead, as in Brown, the Court’s holding left important questions unanswered, thus limiting relief for victims of discrimination.\textsuperscript{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?”\textsuperscript{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).”\textsuperscript{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.\textsuperscript{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.\textsuperscript{208} The two women, Lois Curtis and Elaine Wilson, each had a mental illness in addition to I/DD.\textsuperscript{209} In May of 1992, Lois voluntarily entered Georgia Regional Hospital at Atlanta (“GRH”) for treatment in a psychiatric unit.\textsuperscript{210} A year later, Lois’s treatment team agreed that a state-supported community-based program could appropriately serve her needs.\textsuperscript{211} However, Lois remained institutionalized until the State placed her in community-based treatment in February 1996.\textsuperscript{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.\textsuperscript{213}

\begin{itemize}
\item[203.] \textit{Id.}
\item[204.] \textit{See} Cerreto, supra note 30, at 69-70.
\item[208.] Cerreto, supra note 30, at 49-50.
\item[209.] Olmstead v. L.C. \textit{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).
\item[210.] \textit{Id.}
\item[211.] \textit{Id.}
\item[212.] \textit{Id.}
\item[213.] \textit{Id.}
\end{itemize}
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. They requested an injunction providing public financed community placements and services, but did not seek any damages. 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. 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.” 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. 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.” 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.’”

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. By this time, the State had acquiesced, and Lois and Elaine were receiving services in community settings. However, the case continued because the controversy was “capable of repetition, yet evading review,” as indicated by Lois and Elaine’s multiple institutional placements.

The Supreme Court affirmed the Eleventh Circuit’s decision in substantial part, holding that undue institutionalization “is properly regarded as discrimination based on disability.” 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

215. Id. at *12.
218. Id. at 902.
219. Id. at 895 (citing 28 C.F.R. § 35.130(b)(7)).
221. Id.
222. Id. at 597.
with mental disabilities, and obligation to administer these services equitably.\textsuperscript{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.\textsuperscript{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.”\textsuperscript{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.\textsuperscript{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.”\textsuperscript{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.”\textsuperscript{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.”\textsuperscript{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.”\textsuperscript{232} However, the “reasonable modifications regulation” of Title II allows states to continue to segregate people with disabilities, as the Supreme Court noted:\textsuperscript{233}

\begin{quote}
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.\textsuperscript{234}
\end{quote}

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

\textsuperscript{225} Id.
\textsuperscript{226} Id. at 588.
\textsuperscript{228} Id. at 597.
\textsuperscript{229} Id. at 600 (citing 42 U.S.C. §12101(a)(2), (a)(5)).
\textsuperscript{230} Id. at 600.
\textsuperscript{231} Id. at 601.
\textsuperscript{233} See id. at 592.
\textsuperscript{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.

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. 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.

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. 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. Since Olmstead, more than half the states have used this example to develop “Olmstead plans.” 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.

The Olmstead decision elated many disability advocates as they anticipated a rapid expansion of Medicaid HCBS, while others expressed skepticism and lamented the shortcomings of the Court’s holdings. 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.” 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. 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. Further, although states’ implementation of robust Olmstead plans expand access to HCBS, numerous disability advocates and comment
tors cite courts’ deference to state plans, and even the plans themselves, as “roadblocks to integration.”

Olmstead parallels Brown with regard to the slow pace of reversing discrimination. Ten years after Brown, despite the Court’s “all deliberate speed” requirement, many southern school districts remained segregated. 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.

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. 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.

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.”

Although the Olmstead Court held that the fundamental alteration doctrine limits the state’s responsibility to provide community services to qualified individuals with disabilities, this defense requires more than a mere budget constraint. 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

249. Id. at 712.
253. Id. at 796 (citing Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1180 (10th Cir. 2003)).
The Civil Rights Division of the DOJ provides guidance on compliance with the integration mandate of the ADA.\textsuperscript{257} Consistent with the Benjamin\textsuperscript{H.} holding, the DOJ instructs that “budget cuts can violate the ADA and \textit{Olmstead} when significant funding cuts to community services create a risk of institutionalization or segregation.”\textsuperscript{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.”\textsuperscript{259}

In 2009, the DOJ initiated efforts to enforce the \textit{Olmstead} decision.\textsuperscript{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.\textsuperscript{261} In addition, the DOJ investigates complaints of violations of \textit{Olmstead}, including complaints from people with I/DD on waiting lists for HCBS.\textsuperscript{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.\textsuperscript{263} To date, the DOJ has been involved in federal courts in efforts to enforce \textit{Olmstead} in nineteen states.\textsuperscript{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.\textsuperscript{265} Then an abrupt change occurs.\textsuperscript{266} When society evolves and established


\textsuperscript{259} Id.


\textsuperscript{261} Id.


\textsuperscript{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. Brown v. Board of Education illustrates this, as the Supreme Court finally rejected its dysfunctional “separate but equal” doctrine. With Olmstead, as with Brown, the Supreme Court’s decision signaled a paradigm shift, but many states reacted slowly and discrimination continued. 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.” Similarly, a number of states continue to violate the Olmstead requirement that a waiting list for HCBS must “[m]ove at a reasonable pace.” 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.

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? Congress passed the ADA “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” The legislators specifically noted that people with disabilities faced discrimination that includes “institutionalization” and the Supreme Court concurred in that respect. 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
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-
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 (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.
   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.
296. Harrington et al., supra note 170, at 2.
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 right 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
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

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


\(^{321}\) 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.


\(^{329}\) See DiPolito, *supra* note 45 at 1404, 1409.

\(^{330}\) See Cook, *supra* note 51, at 448-49.

\(^{331}\) Id.

\(^{332}\) Id.
with I/DD. Further, most states have failed to commit to providing HCBS for all eligible individuals with I/DD. These shortcomings have produced an environment in which litigation has become the primary means of expanding access to HCBS. 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. Although settlements and court orders have granted some relief, waiting lists for HCBS remain a chronic problem that litigation alone is unlikely to solve.

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. 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. 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. 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. People with I/DD face another obstacle when trying to gain HCBS through judicial avenues: the challenge of navigating the legal system. 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.
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).
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.\textsuperscript{344}

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

D. Recommendations for Action

Much like the judiciary’s limited impact\textsuperscript{346} on the HCBS waiting list problem, the federal executive branch’s efforts\textsuperscript{347} have also fallen short.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{351}

A second step the federal government should take is assessing which HCBS programs are most effective and implementing these programs nationwide.\textsuperscript{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,\textsuperscript{353} and there are now over two hundred and fifty different waivers in place.\textsuperscript{354} Waiting times for HCBS vary widely from state to state, and there are well over one million Americans with ID/DD on waiting lists for HCBS.

344. Id.


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 \textit{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 \textit{Olmstead} court ruling and the [ADA].”).


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., \textit{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 SETTINGS, supra note 11, at 90-91.

354. See NAT’L COUNCIL ON DISABILITY, supra note 349, at 89.
state,\textsuperscript{355} including ten states reporting no waiting lists in 2011.\textsuperscript{356} Simply put, there are best practices in HCBS programming that need to be shared among the states.\textsuperscript{357}

While eliminating HCBS waiting lists will significantly expand opportunities for individuals with I/DD to be fully included in society, other challenges remain.\textsuperscript{358} HCBS represents one component of long-term services and supports (“LTSS”) for people with disabilities and the elderly.\textsuperscript{359} The growing demand and increasing costs of LTSS have produced a system that “is fast becoming financially unsustainable.”\textsuperscript{360} Therefore, substantial changes to federal policies and programs will be required\textsuperscript{361} to “assure equality of opportunity, full participation, [and] independent living” for people with I/DD.\textsuperscript{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.\textsuperscript{363}

V. CONCLUSION

People with I/DD “have been subjected to a history of unfair and often grotesque mistreatment.”\textsuperscript{364} Disability advocates have convinced many states to close public institutions\textsuperscript{365} but have been less successful in establishing essential community supports.\textsuperscript{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,”\textsuperscript{367} people with I/DD often face the dilemma of moving into an institution to receive services or going without.\textsuperscript{368} To alleviate this, CMS should determine the most effective HCBS

\begin{itemize}
  \item \textsuperscript{355} \textit{Kaiser}, supra note 180, at 3.
  \item \textsuperscript{356} Id. at 11.
  \item \textsuperscript{357} See Harrington et al., supra note 170, at iv; see generally Ctrs. for Medicare & Medicaid Servs., \textit{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.”).
  \item \textsuperscript{359} See \textit{Natl’ Council on Disability}, supra note 349, at 13, 17, 22.
  \item \textsuperscript{360} Id. at 21, 47.
  \item \textsuperscript{361} See NCD 2011, supra note 65 at 11, 79-80.
  \item \textsuperscript{362} 42 U.S.C. § 12101(a)(7) (2012).
  \item \textsuperscript{363} See NCD 2011, supra note 65 at 79-80; see generally \textit{Human Res. Research Inst., Working Toward A Sustainable Future for Developmental Disability Service Systems} (2012).
  \item \textsuperscript{365} See Bagenstos, supra note 44, at 21, 42.
  \item \textsuperscript{367} 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. Ultimately, the federal government must eliminate waiver waiting lists by making HCBS a Medicaid state plan requirement so that people with I/DD will have “the opportunity to blend fully and equally into the rich mosaic of the American mainstream.”

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.

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.