

# The Cost of Doing Business: Institutional Bias and Community-Based Services and Supports

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*Institutionalization bias for people with intellectual and developmental disabilities (IDD) is woven into the fabric of U.S. history. To realize the promise of the landmark Olmstead ruling and the Americans with Disabilities Act and promote meaningful community inclusion for people with IDD and their families, we must understand how institutional bias began in the U.S. and how our economic investments over time have changed to reflect social consciousness. This Article will demonstrate trends in economic investments in institutionalization and community-living long-term services and supports since the early 1900s that parallel the nation's drive, or lack thereof, to promote access to the community.*

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## I. INTRODUCTION

Proceedings of the world's first national self-advocacy conference for people with intellectual and developmental disabilities [then labeled mental retardation], held in Malimö, Sweden in 1970, translated demands of over fifty delegates in areas of leisure time activities, vacations, living conditions, education, and work. “We wish to have an apartment of our own and not be coddled by personnel”<sup>1</sup> was

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1. WOLF P. WOLFENBERGER ET AL., THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES 190 (1972), [https://digitalcommons.unmc.edu/wolf\\_books/1](https://digitalcommons.unmc.edu/wolf_books/1).

the first demand made in their statements on living conditions. Nearly half a century later, in a position statement on the closure of institutions by the national self-advocacy group Self Advocates Becoming Empowered (SABE), we hear echoes of the past: “We believe that all institutions, both private and public should be closed. All people regardless of the severity of their disabilities should live in the community.”<sup>2</sup> Despite the progress of the deinstitutionalization movement in the United States, insidious and corrosive stereotypes of people with intellectual and developmental disabilities (IDD) remain, coupled with the failure to ensure dignity of risk<sup>3</sup> that prevents people from becoming primary causal agents in their own lives. This Article introduces the conditions that led to the mass institutionalization of people with intellectual and developmental disabilities as well as the deinstitutionalization movement and the economic investments of states that convey cultural and systemic intentions of American society.

## II. INSTITUTIONALIZATION OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND HOME AND COMMUNITY-BASED SERVICES

Institutionalization of people with intellectual and developmental disabilities in the United States began in 1848 after the adoption of the European model that relocated the *feeble-minded* into isolated and confined settings away from view of refined society. Senator Frederick F. Backus of Rochester, N.Y. proposed legislation to establish an experimental public institution for the feeble-minded in the winter of 1845–1846 in Albany, N.Y.<sup>4</sup> The legislation that passed in 1851 resulted in the New York Asylum for Idiots admitting its first “pupils” that very year.<sup>5</sup> The expectation for the pupils to remain and perish within the custody of the asylum was evidenced by the purchasing of land in the Oakwood cemetery at Syracuse for the “burial of four hundred and eight such inmates of the institution as may die while residing therein.”<sup>6</sup>

Espoused societal beliefs<sup>7</sup> that parental sins and moral deficiencies were the fundamental cause of disability, along with medical professionals persuading families that the “quiet of the country” and treatment by specially trained wards was the only way to “cure” the ailments of disability, guilted family members to commit their loved ones to institutions funded through state authorities. But in 1913, the Commission for Care of the Feeble-Minded in Pennsylvania revealed the attitude of the nation when they proclaimed people with disabilities were “unfit” for citizenship and a “menace to the peace”<sup>8</sup> and petitioned for custodial care to be provided by state government. As involuntary civic commitments of people with disabilities increased, states began purchasing land in distant rural locations for the

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2. *Position on Closing Institutions*, SELF ADVOCATES BECOMING EMPOWERED (2014), <https://www.sabeusa.org/meet-sabe/policy-statements/closing-institutions>.

3. See generally, Robert Perske, *The Dignity of Risk and the Mentally Retarded*, 10 MENTAL RETARDATION 24 (1974).

4. HENRY M. HURD ET AL., *THE INSTITUTIONAL CARE OF THE INSANE IN THE UNITED STATES AND CANADA* 248 (1916).

5. *Id.*

6. Act effective Feb. 11, 1886, ch. 16, 1 N.Y. Laws 10 (1986).

7. Walter E. Fernald, *The Burden of Feeble-Minded*, 166 BOSTON MED. & SURGICAL J. 911, 911 (1912).

8. Elisabeth Tilstra, *A Living Nightmare: The History of Pennhurst Asylum*, THE LINEUP (Oct. 4, 2016), <https://the-line-up.com/pennhurst-asylum>.

establishment of new state asylums or institutions. These geographic choices were supported by the 1854 publication *On the Construction, Organization and General Arrangements of Hospitals for the Insane* written by Dr. Thomas Kirkbride, a psychiatrist at Pennsylvania Hospital and a national authority on the design of mental asylums in which two key elements were paramount: seclusion from cities, and buildings with linear walls.<sup>9</sup> Kirkbride's linear plan was a V-shaped structure with a central building and two symmetrical flanking wings.<sup>10</sup>

Large institutions on the outskirts of towns incurred high costs with limited access to utilities.<sup>11</sup> For economic self-sufficiency, agricultural endeavors became a primary source of revenue. Institutions were transitioned into "farm colonies." The purpose of the "farm colony" was to "provide suitable homes and employment to the boys, and secondly to supply the home institution with fresh food."<sup>12</sup> Institutions also supported resident labor in local factories and mills to reduce overall costs. In the 1950s, however, overcrowding and understaffing prevented resident labor and forced people to spend their days in congested rooms subject to deplorable conditions.<sup>13</sup>

In 1950, parents of children with disabilities, outraged by the living conditions and support for their children began to organize and advocate on their behalf. The National Association for Retarded Children (The Arc) was established in 1953.<sup>14</sup> Concepts of social role valorization<sup>15</sup> and the principle of normalization<sup>16</sup> with human values at their core, challenged pervasive perceptions of people with intellectual disabilities and promoted the rights of people to live as members of their communities.<sup>17</sup> In 1961, President Kennedy announced the establishment of the "President's Panel on Mental Retardation."<sup>18</sup> Soon thereafter, a series of essays and media portrayals of institutional care drove public outcry against the inhumane treatment of people with disabilities. In 1965, Senator Robert Kennedy toured the Willowbrook State School in New York and stated the residents were "being denied equal access to education and deprived of their civil liberties."<sup>19</sup> *A*

9: THOMAS S. KIRKBRIDE, *ON THE CONSTRUCTION, ORGANIZATION, AND GENERAL ARRANGEMENTS OF HOSPITALS FOR THE INSANE* (1854).

10: Carla Yanni, *The Linear Plan for Insane Asylums in the United States before 1866*, 61 *J. SOC. ARCHITECTURAL HISTORIANS* 24, 31 (2003).

11: U.S. DEP'T OF COMMERCE, *BUREAU OF THE CENSUS, FEEBLE-MINDED AND EPILEPTICS IN INSTITUTIONS 1923*, at 23–25 (1926).

12: Deborah S. Metzel & Pamela M. Walker, *The Illusion of Inclusion: Geographies of the Lives of People with Developmental Disabilities in the United States*, 21 *DISABILITY STUDIES Q.* 4, 114–28 (2001) (citing *Historical Notes on Institutions for the Mentally Defective*, *J. PSYCHO-ASTHENICS*, 1(2), 69–70 (1896)).

13: DAVID GOODE ET AL., *A HISTORY AND SOCIOLOGY OF THE WILLOWBROOK STATE SCHOOL* 65 (2013).

14: JAMES W. TRENT, *INVENTING THE FEEBLE MINDED: A HISTORY OF MENTAL RETARDATION IN THE UNITED STATES* (1994).

15: Wolf Wolfensberger, *A Brief Overview of Social Role Valorization*, 38 *MENTAL RETARDATION* 105, 105 (2000).

16: Bengt Nirje, *The Basis and Logic of the Normalization Principle*, 11 *AUSTL. & N.Z. J. DEVELOPMENTAL DISABILITIES* 65, 67 (1985).

17: JAMES W. CONROY & VALERIE J. BRADLEY, *THE PENNHURST LONGITUDINAL STUDY: COMBINED REPORT OF FIVE YEARS OF RESEARCH AND ANALYSIS* 2 (1985).

18: FRED J. KRAUSE, *PRESIDENT'S COMMITTEE ON MENTAL RETARDATION: A HISTORICAL REVIEW 1966-1985*, at 5 (1985).

19: GERALDO RIVERA, *WILLOWBROOK: A REPORT ON HOW IT IS AND WHY IT DOESN'T HAVE TO BE THAT WAY* 52–56 (1972).

*Christmas in Purgatory*, released in 1974, was a series of photographic essays on mental retardation and the abysmal conditions within institutions where they lived, and it fueled the beginning of the deinstitutionalization movement.<sup>20</sup>

Economic investments demonstrated the public outcry. As part of the movement toward alternative settings, federal reimbursement was provided for skilled nursing care in 1965.<sup>21</sup> States began to take advantage of this access to funding by placing people with IDD in nursing facilities as well as state institutions.<sup>22</sup> In 1967, Immediate Care Facilities (ICF) for the elderly and the disabled were authorized under the Social Security Act.<sup>23</sup> It was at this time that institutional census for people with intellectual and developmental disabilities reached its national peak at 194,650,<sup>24</sup> and by 1970 there were 195 institutions for people with IDD across the country.<sup>25</sup>

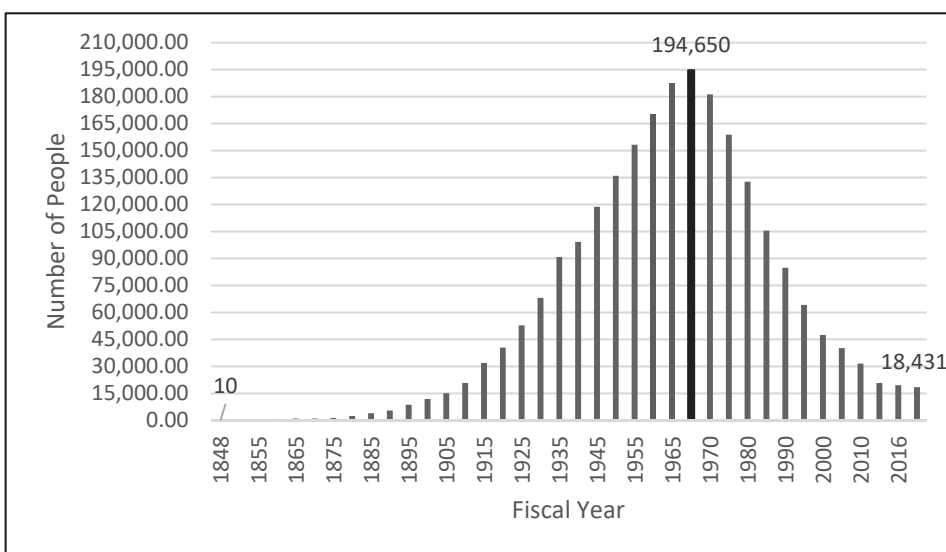


FIGURE 1: NUMBER OF PEOPLE LIVING WITH IDD INSTITUTIONS IN THE U.S. BY YEAR (FYs 1848-2017)<sup>26</sup>

20. BURTON BLATT & FRED KAPLAN, *CHRISTMAS IN PURGATORY: A PHOTOGRAPHIC ESSAY ON MENTAL RETARDATION* (1974).

21. *To Amend the Older Americans Act of 1965: Hearings on H.R. 12017 and Related Bills Before the Select Subcommittee on Education of the Committee on Education and Labor, 92nd Cong. 722* (1972) (analysis of selected provisions).

22. Scott D. Landes & Nikita Lilaney, *Trend Change in the Intellectual Disability Nursing Home Census From 1977-2004*, 124 AM. J. ON INTELL. & DEV. DISABILITIES 427, 427 (2019).

23. Social Security Act of 1935, H.R. 7260, 74th Cong. §§ 301-1305 (1935).

24. *See* Figure 1.

25. *See* Figure 2.

26. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

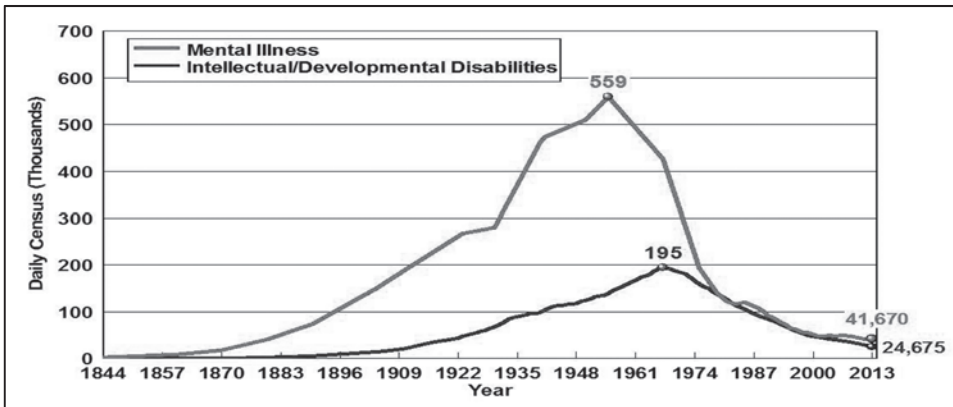


FIGURE 2: NUMBER OF INSTITUTIONS FOR MENTAL ILLNESS AND INTELLECTUAL AND DEVELOPMENTAL DISABILITIES ACROSS THE UNITED STATES<sup>27</sup>

Based upon political, budgetary, and advocacy efforts, public institutions for people with intellectual and developmental disabilities began to close their doors in 1969.<sup>28</sup> Between 1977 and 1984, nineteen public institutions for people with intellectual disabilities closed or were scheduled for closure in the United States.<sup>29</sup> The trend has continued and by 2017, fourteen states no longer operated public institutions for people with intellectual and developmental disabilities.<sup>30</sup> Based upon institutional resident census data, Arizona, Delaware, Idaho, Maryland, Montana, Nevada, and North Dakota will be the next states to close their doors to institutions in the United States.

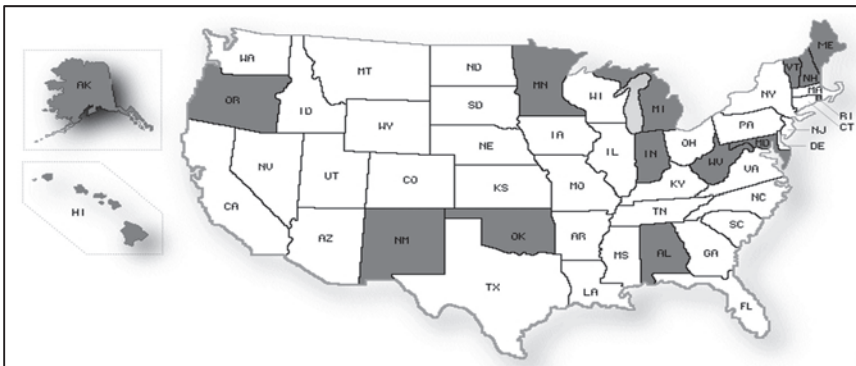


FIGURE 3: STATES NO LONGER FUNDING PUBLIC INSTITUTIONS FOR IDD<sup>31</sup>

27. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

28. DAVID BRADDOCK ET AL., *THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: EMERGENCY FROM THE GREAT RECESSION* 31 (10th ed. 2015).

29. David Lawrence Braddock, *The Transformation of Public Spending Patterns*, ECHO 666, at 4–5 (1985).

30. See Figure 3.

31. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-

Forecasts based upon historical trends predict that all publicly operated institutions will be closed by the year 2027.<sup>32</sup>

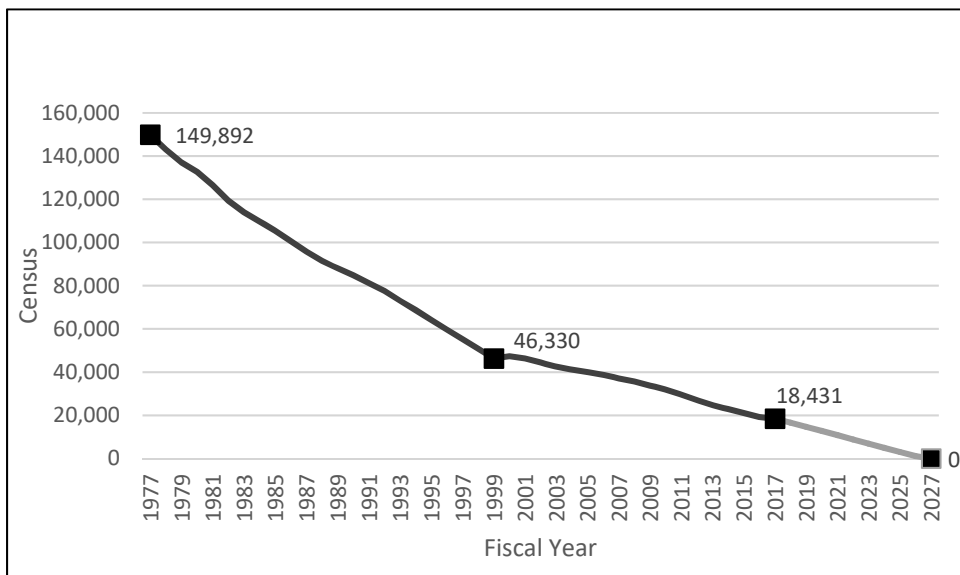


FIGURE 4: PROJECTED CENSUS FOR PUBLIC INSTITUTIONS FOR PEOPLE WITH IDD<sup>33</sup>

### III. STATE AND U.S. PRIORITIES UNVEILED: INVESTMENTS IN COMMUNITY-BASED SERVICES AND SUPPORTS FOR PEOPLE WITH IDD

To understand the convictions and mood of a political society, one need only follow economic trends of public expenditures. Total spending for IDD services and supports for people with IDD increased steadily since 1977, dropping only in 2011 (as a result of the Great Recession) and in 2014.<sup>34</sup> Total expenditures reached \$71.6 billion in FY 2017 with 72% of spending by states authorized through federal, state, and local Medicaid dollars.<sup>35</sup>

01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

32. See Figure 4.

33. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

34. See Figure 5.

35. EMILY SHEA TANIS ET AL., THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (11th ed. 2017) (in press) (page numbers for the 11th edition are not available at this time).

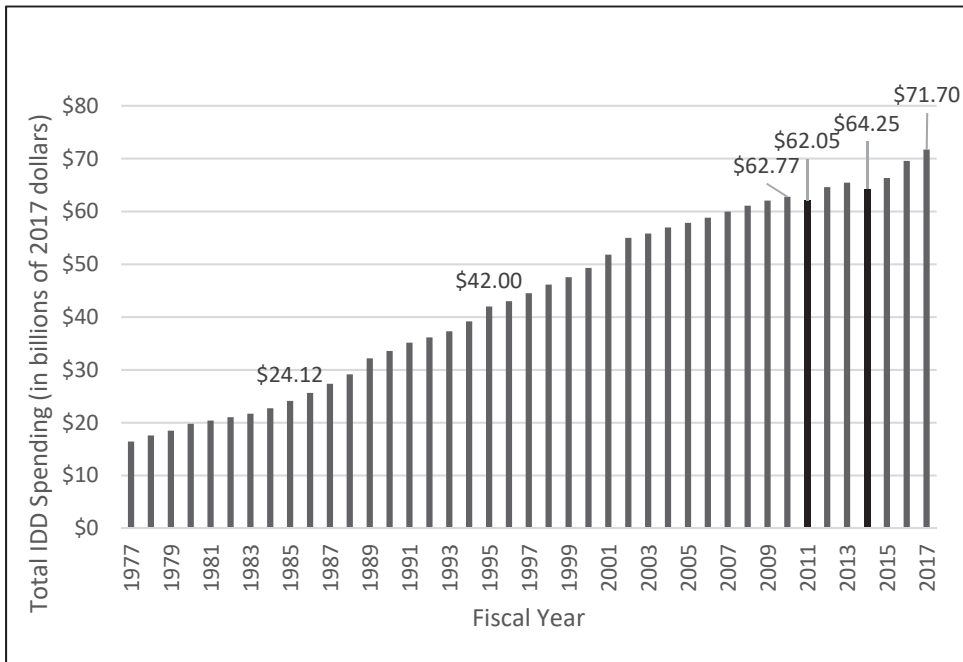


FIGURE 5: TOTAL IDD SPENDING IN THE U.S. FYS 1977-2017<sup>36</sup>

However, a truer measure of state commitment to people with IDD and their care is the evaluation of fiscal effort. Fiscal effort is a measure of how much a state spends on IDD long-term supports and services (LTSS) per \$1000 of statewide personal income. In other words, it is a measure of how much the state spends after controlling for state wealth. In FY 2017, the U.S. average fiscal effort was (\$4.41 per \$1000 of personal income).<sup>37</sup> The leading state in fiscal effort was Maine (\$11.65) and the state with the smallest fiscal effort was Nevada (\$1.62).

In 1977, the average daily expenditure per resident in public institutions for people with intellectual disability was \$44.77.<sup>38</sup> By 1984, the daily cost per resident reached \$106.27 (adjusted for inflation).<sup>39</sup> One of the first cost-comparison studies completed was by James et al.,<sup>40</sup> which was inspired by the court-ordered closure of the Pennhurst State School and Hospital in *Halderman v. Pennhurst State School and Hospital*.<sup>41</sup> The study concluded, “analyses indicate that community-based programs now serving the people who formerly lived at Pennhurst are less costly on average than those at the institution in terms of most

36. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

37. TANIS ET AL., *supra* note 35.

38. *Id.*

39. *Id.*

40. CONROY & BRADLEY, *supra* note 17, at 8.

41. *Halderman v. Pennhurst State Sch. & Hosp.*, 612 F.2d 84 (3d Cir. 1979), *rev'd* 451 U.S. 1 (1981).

cost measures.”<sup>42</sup> In 2017, the average annual cost per person demonstrated a nearly threefold increase for people living in large (over sixteen people) public institutions (ICF-IDs) when compared to community-based living funded through the home and community-based waiver system. There have been several studies that have supported the conclusion that community-based settings are more cost effective than institutional settings, however, with differences in staff wages, individualized supports, redistributed costs, and cost variation, it is valuable to perform cost-comparison evaluations at the individual level to capture more accurate representations.<sup>43</sup>

In 1983, the availability of federal funds to provide home and community-based services (HCBS) to people with disabilities transformed the long-term supports services system.<sup>44</sup> Section 1915(c) of the Social Security Act authorizing HCBS waivers was part of the Omnibus Reconciliation Act of 1981.<sup>45</sup> It provided states the opportunity to receive a waiver for Medicaid requirements and apply the waiver to Medicaid nursing or other facilities, thereby making Medicaid funding available to those living in home-like and family settings.<sup>46</sup> In 2017, there were nearly 300 HCBS waivers nationwide.<sup>47</sup> States have broad discretion to establish eligibility criteria, limit the number of recipients, cap the amount of money spent, limit geographical areas and determine services within their written waivers.<sup>48</sup> Over the past few decades, with added federal incentives, states have moved toward rebalancing their long-term services and supports (LTSS) by committing larger portions of Medicaid funding to home and community-based settings than to institutional care facilities (ICF-IDs).<sup>49</sup> In 1989, funding for community-based services (\$16.52 billion) surpassed institutional spending (\$15.68 billion) in the United States,<sup>50</sup> demonstrating the nation’s consciousness, but was the movement in geographical locale enough to transform the treatment of people with IDD?<sup>51</sup>

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42: CONROY & BRADLEY., *supra* note 17, at 172.

43: Kevin K. Walsh et al., *Cost Comparison of Community and Institutional Residential Settings: Historical Review of Selected Research*, 41 MENTAL RETARDATION 103, 117 (2003).

44: BRADDOCK ET AL., *supra* note 28, at 48.

45: Omnibus Budget Reconciliation Act of 1981: Titles III, VI, IX, XI, XXVI, H.R. 3982, 97th Cong. § 1915(c) (1981).

46: *Id.*

47: TANIS ET AL., *supra* note 35.

48: Mary C. Rizzolo et al., *Home and Community Based Services (HCBS) Waivers: A Nationwide Study of the States*, 51 INTELL. & DEV. DISABILITIES, no. 1, Feb. 2013, at 3.

49: BRADDOCK ET AL., *supra* note 28, at 16.

50: *See* Figure 6.

51: *See* Figure 7.



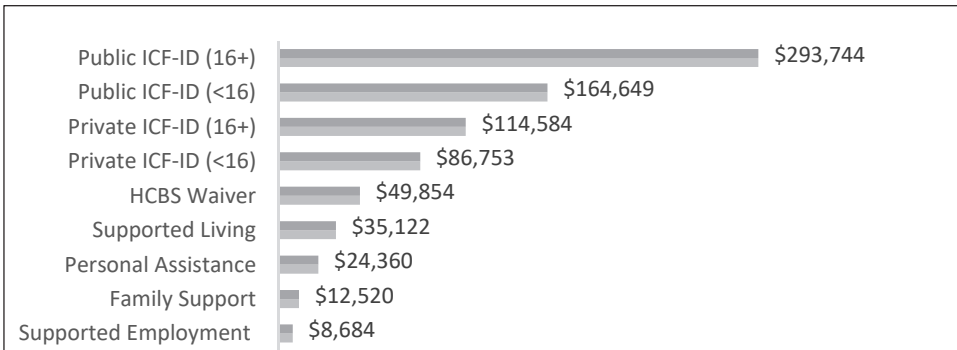


FIGURE 6: AVERAGE ANNUAL PER PERSON COST BY SETTING FY 2017<sup>52</sup>

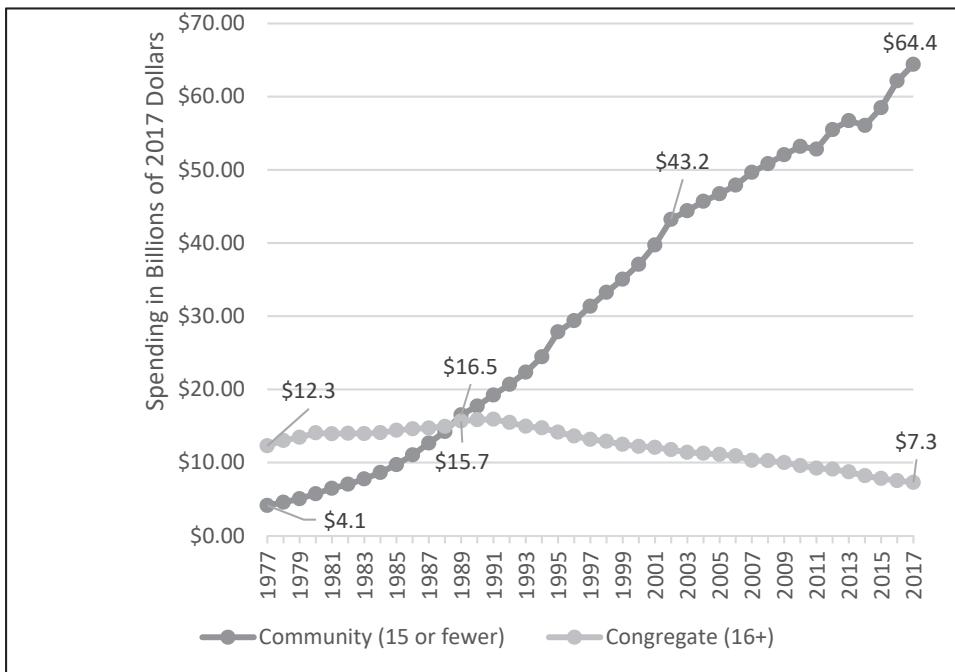


FIGURE 7: U.S. INSTITUTION AND COMMUNITY SPENDING FY 2017<sup>53</sup>

52. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

53. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

IV. *OLMSTEAD* AND DEFINING “COMMUNITY”

Signed into law in 1990, the Americans with Disabilities Act (ADA)<sup>54</sup> addressed the shortcomings of Section 504 of the 1973 Rehabilitation Act.<sup>55</sup> Although a cornerstone of the disability rights movement, Section 504 failed to address social segregation of people with disabilities and only covered federally-funded entities.<sup>56</sup> The Americans with Disabilities Act sought to prohibit the discrimination of people with disabilities in employment, public services, public accommodations, telecommunications and other areas where one may coerce, threaten, or retaliate against people with disabilities. The law was a statement that sought to eliminate discrimination of people with disabilities in public and private sectors. The law also put forth four national goals of equal opportunity, full participation, economic self-sufficiency, and independent living for people with disabilities.<sup>57</sup>

In *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court affirmed an Eleventh Circuit decision that ruled the Title II of the ADA entitled plaintiffs—two residents, L.C and E.W., of the Georgia State Hospital—to services and supports in an “integrated community setting” and prohibited a state from unjustly segregating people with disabilities.<sup>58</sup> Justice Ruth Bader Ginsburg delivered the landmark decision on June 22, 1999. Placing persons with disabilities in community settings over institutions was required when (1) treatment professionals deem community placement as appropriate; (2) the individual does not oppose services in the community; and (3) placement is a “reasonable accommodation when balanced with the needs of others with mental disabilities.”<sup>59</sup> The *Olmstead* decision while profound, did “not require the immediate, state-wide deinstitutionalization of all eligible developmentally disabled persons.”<sup>60</sup> The case did however establish the requirement that each state develop an *Olmstead* plan to support the deinstitutionalization movement. The “*Olmstead* plan,” submitted by the state was to be, “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and waiting lists that moves at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated.”<sup>61</sup> Smaller settings and community living have been found to contribute to better outcomes for quality of life including improved self-determination, social inclusion, material well-being, physical well-being, and interpersonal relationships.<sup>62</sup> Based on research and policy, the demand for smaller community-living options has increased steadily over the years. In FY 2017, 84% of

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54: Americans with Disabilities Act of 1990, Pub. L. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. § 12101, *et seq.*).

55: Rehabilitation Act of 1973, H.R. 8070, 93rd Cong. (1973).

56: Laura C. Scotellaro, *The Mandated Move from Institutions to Community Care: Olmstead v. L.C.*, 31 LOY. U. CHI. L.J. 737, 743 (2000).

57: Americans with Disabilities Act of 1990, 104 Stat. at 328.

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

59: *Id.* at 582.

60: *See Sanchez v. Johnson*, 416 F.3d 1051, 1068 (9th Cir. 2005).

61: *Id.* at 584.

62: *See generally* Agnes Kozma et al., *Outcomes in Differential Residential Settings for People with Intellectual Disability: A Systematic Review*, 114 AM. J. ON INTELL. & DEV. DISABILITIES 193 (2009).

the 707,931 individuals supported by public funds were living in settings of six or fewer.<sup>63</sup>

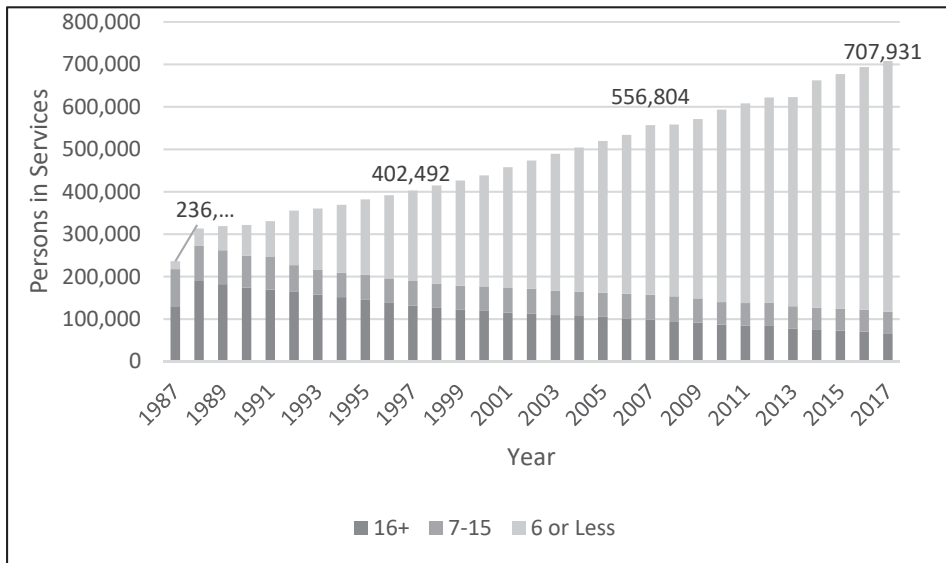


FIGURE 8: INCREASED DEMAND FOR SMALLER SETTINGS<sup>64</sup>

To date there have been eighty-two *Olmstead* cases addressing violations, seventeen of which targeted institutions for persons with IDD.<sup>65</sup> In 2020, the Department of Justice had seventeen reported cases in eleven states and Puerto Rico.<sup>66</sup> Over time, *Olmstead*'s mandate to place individuals in the most "integrated setting" has expanded beyond institutions and been applied to segregation in education and employment settings.

At the height of the deinstitutionalization movement, the term "community" referred to a geographical location, a place where people with disabilities can engage in activities with their peers without disabilities. However, defining "community" as simply a geographical location is insufficient in today's society and requires further consideration in the law. The "community" concerns people connected through social relations, which may or may not be associated with a place and may occur where people do not meet in person such as online.<sup>67</sup> In 2014, the Centers for Medicare and Medicaid Service (CMS) outlined qualities of setting that were eligible for federal financial reimbursement provided under Social

63. See Figure 8.

64. Figure contributed by the State of the States Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance funded by the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disability (Grant No. 90-DNPA0003-01-00). Established in 1982 to investigate the determinants of public spending for intellectual and developmental disabilities services in the U.S.

65. *Olmstead Enforcement – Cases by Issue*, ADA.GOV, [https://www.ada.gov/olmstead/olmstead\\_cases\\_by\\_issue.htm#institutions](https://www.ada.gov/olmstead/olmstead_cases_by_issue.htm#institutions) (last visited Mar. 5, 2020).

66. *Id.* (select "Institutions for Individuals with Intellectual and Developmental Disabilities" for list of cases).

67. Anatolij Gruz & Carolyn Haythornwaite, *Enabling Community Through Social Media*, 15 J. MED. INTERNET RES. no.10, at 2 (2013).

Security Act sections 1915(c), 1915(i), and 1915(k) of the Medicaid statute.<sup>68</sup> This was titled the Home and Community-Based Services Settings Final Rule (CMS 22249-F/2296-F).<sup>69</sup> The Final Settings Rule provided states guidance on the institutional qualities and community based programs under which state-funded settings could be evaluated for. In the Final Settings Rule, CMS noted the movement away from geographical location as the defining feature of community and instead “. . . defining them by the nature and quality of individuals’ experiences.”<sup>70</sup>

#### V. AS THE PENDULUM SWINGS: THE SLOW RETURN OF DISABILITY SPECIFIC COMMUNITIES

Investment in community-based settings that began with 3073 individuals with IDD receiving services from the Home and Community Based Services waiver in 1983, grew to serve 808,333 people across the U.S. in FY 2017.<sup>71</sup> There was a 33% increase in people served between 2010 and 2017.<sup>72</sup> The HCBS waiver represented 72.9% of the \$55.3 billion in total federal-state Medicaid expenditures in FY 2017.<sup>73</sup> However, on March 22, 2019 CMS issued guidance that would change the criteria for settings under “heightened scrutiny” within the HCBS final settings rule.<sup>74</sup> The guidance by CMS noted greater “flexibility to streamline regulation,” resulting in settings otherwise determined “institution-like” to receive federal funds.<sup>75</sup> Removing the language that would include “disability specific complexes” as institutional settings and a rebuttable presumption that would allow public input to apply the rule of heightened scrutiny to a setting, challenged the progress made over several decades toward full and inclusive community settings.

The recent increase in HCBS participants and waiver caps has led to 193,828 people across the country being placed on the states’ waitlist for services.<sup>76</sup> It is critical to note, that of all individuals receiving state developmental disability services supports, 71% live at home with family caregivers, 59% of which are 41 years of age or older.<sup>77</sup> Sadly, only 17% of families receive family supports through the state IDD agency.<sup>78</sup> This is because the majority of support funding is directed for the sole beneficiary (individual with the disability), ignoring the impact of disability supports on family members. Federally funded family supports

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68. *See generally* CTRS. FOR MEDICARE AND MEDICAID SERVS., FACT SHEET: SUMMARY OF KEY PROVISIONS OF THE HOME AND COMMUNITY-BASED SERVICES (HCBS) SETTINGS FINAL RULE (2014), <https://www.medicare.gov/sites/default/files/2019-12/hcbs-setting-fact-sheet.pdf>.

69: *Id.*

70: *Id.*

71. TANIS ET AL., *supra* note 35.

72: *Id.*

73: *Id.*

74: *See generally* CTRS. FOR MEDICARE AND MEDICAID SERVS., SDM # 19-001 RE: HOME AND COMMUNITY-BASED SETTINGS REGULATION – HEIGHTENED SCRUTINY (2019), <https://www.medicare.gov/federal-policy-guidance/downloads/smd19001.pdf>.

75: *Id.* at 1.

76. SHERYL LARSON ET AL., IN HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2016, at 10 (2018).

77: TANIS ET AL., *supra* note 35.

78: *Id.*

that are provided may include cash subsidies, community-based training, respite services, counseling, and some home modifications.

With extensive needs and limited resources, old models of care are reemerging across the United States. Over fifty new disability specific settings have been built over the past ten years, predominantly funded through private donations.<sup>79</sup> Environmentally sustainable agricultural communities are on the rise where people with disabilities such as autism spectrum disorders are provided specialized treatment in rural communities. In 2015, the Autistic Self Advocacy Network (ASAN) wrote a letter to the Arizona Medicaid agency disputing the classification of segregated “farmsteads” as community-based settings.<sup>80</sup> The letter stated, “We believe that settings that cluster people with disabilities together in a setting where they both live and work, isolated from the broader community, bear little resemblance to traditional community farms and therefore cannot pass heightened scrutiny. . . .”<sup>81</sup> The creation of disability specific settings is not due to malicious intent, but rather the hopes of families looking for solutions to support their loved ones as they exit the protection of the special education system and face demoralizing evaluations proclaiming deficits to qualify for services that often take several years to procure.

Based upon these emerging trends and the watering-down of policies (e.g. shift in guidance provided by CMS under settings of heightened scrutiny, allowing federal funding to “institution-like” settings), there should be a deep sense of concern and caution so as not to replicate the horrors of the past. It may simply be that we have not sufficiently eradicated the noxious ableism of the past and are just experiencing new manifestations of the social opinion. The first step toward institutionalization in the early 19<sup>th</sup> century was the segregation and social isolation of people with intellectual and developmental disabilities and now we see the tenants of isolation on the horizon. Without education, evidence toward valued outcomes, and robust policies we may head down the path of our ancestors and build a society in which people with intellectual and developmental disabilities no longer have the opportunities act as causal agents in their own lives.

Education must begin with young family members and self-advocates about the history of the disability rights movement and deinstitutionalization. Supporting state-wide leadership and advocacy programs like Partners in Policymaking<sup>82</sup> and national and local self-advocacy groups like Self Advocates Becoming Empowered (SABE) and the Autistic Self Advocacy Network help to preserve the past and direct progressive future policies and programs. Partners in Policymaking is a state-funded program initially designed for families of young children with disabilities and self-advocates. The program provides information and training in disability history, civic engagement and service delivery. The training program developed by the Minnesota Governor’s Council on Developmental Disabilities

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79. TANIS ET AL., *supra* note 35.

80. Letter from Samantha Crane, Director of Pub. Pol’y, Autistic Self Advocacy Network, to Monica Coury, Off. of Intergovernmental Rel. (Dec. 14, 2015), <http://autisticadvocacy.org/wp-content/uploads/2015/12/2015-12-14-ASAN-Comments-on-AHCCCS-HCBS-Transition-Plan.pdf>.

81. *Id.* at 1.

82. Robin Cunconan-Lahr & Mary Jane Brotherson, *Advocacy in Disability Policy: Parents and consumers as advocates*, 34 MENTAL RETARDATION 352, 352–58 (1998).

has been replicated nationally and internationally graduating more than 27,000 people by 2017.<sup>83</sup>

Peer-to-peer advocacy training and the organizing of self-advocacy groups to advance social change have made tremendous strides in the U.S. However, perpetuating prejudices of our society demonstrated through economic investments of antiquated service programs frustrate and even prevent progress toward community-living, civic engagement, and economic self-sufficiency for people with for people with intellectual and developmental disabilities. It is up to civil society to break from history and promote the dignity and respect that can only be achieved through education, progressive policies, and firm economic investments toward meaningful community inclusion upholding the promise of *Olmstead*.

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83: *Partners in Policymaking 30<sup>th</sup> Anniversary 1987-2017*, MINN. DEP'T ADMIN. COUNCIL ON DEVELOPMENTAL DISABILITIES (May 22, 2017), <http://mn.gov/mnddc/news/newsitems/partners-30th-anniversary.html>.