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Deinstitutionalization, Disease, and the HCBS Crisis

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NOTE

DEINSTITUTIONALIZATION, DISEASE, AND THE HCBS CRISIS

Jacob Abudaram*

Primarily funded by Medicaid, home- and community-based services (HCBS) allow disabled people and seniors to receive vital health and personal services in their own homes and communities rather than in institutions like nursing homes and other congregant care facilities. The HCBS system is facing a growing crisis of care nationwide; more than 600,000 people are waitlisted for services, thousands of direct care workers are leaving the industry, and states are not committed to deinstitutionalization. The COVID-19 pandemic has highlighted and exacerbated these problems, as people in institutional settings face infection and death at far higher rates than those housed outside them.

This Note offers solutions to the HCBS crisis. In particular, it explores two strategies that could help expand access to HCBS, regardless of whether the federal government increases its funding: (1) expanding and creatively using Olmstead, a landmark disability rights case, to force states to deinstitutionalize; and (2) adding a new title to the Americans with Disabilities Act focused on emergency relief. Together, these two solutions would help get people out of institutions while creating a more resilient healthcare infrastructure for future emergencies.

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INTRODUCTION

Today, fifty-six-year-old Liz Weintraub considers herself lucky.¹ Born with cerebral palsy and an intellectual disability, Liz, without being consulted, was placed in an institution as a young adult.² This separation from her family and community robbed Liz of the independence that is a cornerstone of the disability rights and disability justice movements.³ The institution assigned her a job in a sheltered workshop—a job that she found no meaning in and had no say in obtaining.⁴ Thankfully, Liz now lives with her husband in their own home.⁵ They get the help they need through home- and community-based services (HCBS), which provide a direct-support professional to help Liz and her husband with a variety of tasks, including cleaning and shopping.⁶

1. Liz Weintraub, *The Better Care Better Jobs Act Would Allow People like Me to Thrive*, HILL (Aug. 1, 2021, 3:00 PM), <https://thehill.com/opinion/healthcare/565779-the-better-care-better-jobs-act-would-allow-people-like-me-to-thrive> [perma.cc/4M7U-59B2].

2. *Id.*

3. *Id.*; see also Jerry Alan Winter, *The Development of the Disability Rights Movement as a Social Problem Solver*, 23 DISABILITY STUD. Q. 33, 38 (2003) (“From the standpoint of the disability rights movement, the right and ability to exercise autonomy over one’s own life is the basic, defining, characteristic of what it means to be human.”). This Note uses the term “disability rights” to refer to all parts of the disability movement. There are newer parts of the movement that prefer the term “disability justice,” seeking to widen the movement’s scope with an intersectional approach. See SINS INVALID, SKIN, TOOTH, AND BONE: THE BASIS OF MOVEMENT IS OUR PEOPLE (2d ed. 2019).

4. Weintraub, *supra* note 1. Zoë Brennan-Krohn provides a fuller analysis of sheltered workshops, which are typically facility-based day programs that adults with disabilities attend to complete simple tasks for pennies on the dollar. Zoë Brennan-Krohn, *Employment for People with Disabilities: A Role for Anti-Subordination*, 51 HARV. C.R.-C.L. L. REV. 239 (2016). The types of jobs that disabled people perform include roles like packaging markers, assembling promotional bags, and assembling Post Office mailing trays. *Id.* at 240.

5. Weintraub, *supra* note 1.

6. *Id.*

Because of this support, Liz now has the career of her dreams and an autonomous life in her own community.⁷

Unfortunately, many disabled people and seniors are not so lucky.⁸ Over 600,000 people are currently on waiting lists to receive HCBS.⁹ HCBS vary across states, but generally involve types of person-centered care delivered to people in their homes and the communities in which they live. HCBS include health services like home health care (such as skilled nursing care and therapies), durable medical equipment, case management, personal care, caregiver and client training, and health promotion and disease prevention.¹⁰ HCBS also include human services like senior centers, adult daycares, congregate meal sites, transportation and access, home repairs and modifications, home safety assessments, homemaker and chore services, information and referral services, financial services, and legal services.¹¹ In 2022, more than 1.1 million people lived in nursing homes or skilled-nursing facilities, two common forms of institutionalized care.¹² While Medicaid programs guarantee care to disabled people in some institutional settings, states are not required to adopt most forms of HCBS coverage.¹³ This discretion exists despite decades of data demonstrating that both allowing people to remain in their communities leads to positive outcomes for disabled people,¹⁴ and that HCBS are less expensive

7. *Id.*

8. Reed Abelson, *Biden Promised to Fix Home Care for Seniors. Much More Help May Be Needed.*, N.Y. TIMES (Nov. 1, 2021), <https://www.nytimes.com/2021/11/01/health/home-health-aides-health-care.html> [perma.cc/W9JQ-ATEW]. This Note uses the term “disabled” and “disability” to refer inclusively to and “generally describe functional limitations that affect one or more of the major life activities, including walking, lifting, learning, and breathing.” NAT’L CTR. ON DISABILITY & JOURNALISM, *DISABILITY LANGUAGE STYLE GUIDE* (2021), <https://ncdj.org/style-guide/> [perma.cc/2H7B-4DXG]. Recent years have seen shifts in terminology, and the term “disabled people” is commonly used by leaders in the community. For more on this dynamic, see, for example, *id.*

9. Alice Burns, Molly O’Malley Watts & Meghana Ammula, *A Look at Waiting Lists for Home and Community-Based Services from 2016 to 2021*, KFF (Nov. 28, 2022), <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021> [perma.cc/6RR2-N8XM].

10. *Home- and Community-Based Services*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs> [perma.cc/EVP8-Q5NA].

11. *Id.*

12. *Total Number of Residents in Certified Nursing Facilities*, KFF (2022), <https://www.kff.org/other/state-indicator/number-of-nursing-facility-residents> [perma.cc/GGB6-XZ3N].

13. See ERICA L. REAVES & MARYBETH MUSUMECI, *KAISER COMM’N ON MEDICAID & THE UNINSURED, MEDICAID AND LONG-TERM SERVICES AND SUPPORTS* (2015). Advocates refer to this dynamic as Medicaid’s “Institutional Bias.” Leah Smith, *The Institutional Bias*, CTR. FOR DISABILITY RTS., <https://cdrnys.org/blog/disability-dialogue/the-disability-dialogue-the-institutional-bias> [perma.cc/6AC4-H9YC].

14. See Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 13 n.54 (2012) (citing to a number of studies over a few decades demonstrating the positive outcomes).

than funding long-term, institution-based services.¹⁵ Many seniors and disabled people are forced to choose between leaving their communities for institutions or remaining at home and foregoing care entirely.¹⁶ The Biden Administration attempted to increase funding for HCBS as part of a proposed legislative package in 2021—originally seeking to allocate \$400 billion over eight years, then lowering its proposal to \$150 billion.¹⁷ That money, however, did not make it into the final bill that Congress enacted.¹⁸ Further, it is unclear whether Congress will fund HCBS in the future, and if they do, whether \$150 billion would solve HCBS' current issues.¹⁹

While the deinstitutionalization movement has significantly moved the needle on increasing autonomy for disabled people, there is more work to be done.²⁰ The COVID-19 pandemic has exacerbated issues people in institutional settings face,²¹ with disproportionate concentrations of confirmed cases and deaths.²² Long-term care workers in institutions and HCBS face their own challenges. Predominantly women and disproportionately Black and Latina workers, have been at risk for the same COVID outbreaks as their patients, manage difficult working conditions, and earn low wages.²³ Custodial spaces like long-term care facilities can increase the risks of COVID transmission, including for populations who are more at risk of severe illness like older people and people with underlying conditions.²⁴

The need to address the HCBS crisis, particularly in response to the pandemic, is clear. This Note attempts to do that, arguing that legal remedies exist

15. See REAVES & MUSUMECI, *supra* note 13, at 3 (finding that in 2015, the median annual cost for nursing facility care was \$91,250 compared to \$45,800 for one year of home health aide services and \$18,000 for adult day care). Importantly, having the choice to be at home is a priority for aging populations. See Joanne Binette & Kerri Vasold, *2018 Home and Community Preferences: A National Survey of Adults Ages 18-Plus*, AARP RSCH. (2018), <https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html> [perma.cc/F6VF-BS7T] (finding that while 76% of Americans age fifty and older say they prefer to remain in their current residences, just 59% anticipate that they will be able to do so).

16. Abelson, *supra* note 8.

17. *Id.*

18. American Rescue Plan Act of 2021, Pub. L. No. 117-2, 135 Stat. 4.

19. Abelson, *supra* note 8.

20. See *supra* notes 9–10 and accompanying text. While congregant settings might be the right environment for *some* disabled people and seniors, the fact that more than 600,000 people are on waitlists should indicate that far too many do not have the choice.

21. For a discussion on the harm that institutions cause, see *infra* Part I.

22. Priya Chidambaram, *Over 200,000 Residents and Staff in Long-Term Care Facilities Have Died from COVID-19*, KFF (Feb. 3, 2022), <https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19> [perma.cc/JMK3-4WYX].

23. Sarah True et al., *COVID-19 and Workers at Risk: Examining the Long-Term Care Workforce*, KFF (Apr. 23, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-and-workers-at-risk-examining-the-long-term-care-workforce> [perma.cc/L7BU-5ZF6].

24. Sarah True et al., *COVID-19 and Workers at Risk: Examining the Long-Term Care Workforce*, KFF (Apr. 23, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-and-workers-at-risk-examining-the-long-term-care-workforce> [perma.cc/XLV4-3LM3].

to mitigate the crisis. Part I describes the history and legal frameworks of HCBS—contextualized in the deinstitutionalization movement—up to the inflection point of the COVID-19 pandemic. Part II conveys the need to address the HCBS crisis through the lens of the pandemic’s impact on disabled people in institutional and HCBS settings. It also discusses the failures of various responses to the crisis. Part III proposes and analyzes two reforms that would increase access to HCBS: expanded *Olmstead* enforcement and a new title to the Americans with Disabilities Act (ADA). As with other movements asserting positive social rights, issues related to funding and budgetary constraints abound. That is particularly true here, where HCBS have become an important and popular part of the Biden Administration’s Build Back Better plan.²⁵

I. DEINSTITUTIONALIZATION AND THE RISE OF HCBS

This Part traces the history of HCBS in the context of deinstitutionalization. Understanding the legal and social structures that shaped the dark history of institutionalization sheds valuable light on the frameworks governing HCBS. Section I.A focuses on the history of institutionalization and deinstitutionalization in the United States, while Section I.B describes the foundations of HCBS and their relationship to Medicaid.

A. Deinstitutionalization

American social attitudes and treatment toward disabled people have shifted significantly over time.²⁶ Unfortunately, those shifts have not always been positive.²⁷ In colonial America, towns often lumped disabled people, criminals, and paupers together under one physical roof in an almshouse or “poor farm” run by the municipality.²⁸ Because the prevailing view was that

25. See Abelson, *supra* note 8; Eduardo Porter, *Biden Takes on Sagging Safety Net with Plan to Fix Long-Term Care*, N.Y. TIMES (Apr. 15, 2021), <https://www.nytimes.com/2021/04/15/business/economy/home-care-biden.html> [perma.cc/DHN3-K2EH]. With 78% of Americans supporting them, long-term care investments are the most popular provision in the Build Back Better plan. Anika Dandekar & Ethan Winter, *Voters Continue to Support the Build Back Better Agenda*, DATA FOR PROGRESS (Nov. 3, 2021), <https://www.dataforprogress.org/blog/2021/11/3/voters-continue-to-support-the-build-back-better-agenda> [perma.cc/9NXM-UZAM].

26. See, e.g., Jordan A. Conrad, *On Intellectual and Developmental Disabilities in the United States: A Historical Perspective*, 24 J. INTELL. DISABILITIES 85, 86–96 (2020).

27. See *id.* at 6.

28. Perri Meldon, *Disability History: Early and Shifting Attitudes of Treatment*, NAT’L PARK SERV., <https://www.nps.gov/articles/disabilityhistoryearlytreatment.htm> [perma.cc/3W9T-PSW4] (last updated Oct. 31, 2017).

disabilities were generally incurable but not dangerous, disabled people's specific needs were "largely ignored."²⁹ After the 1848 founding of the Massachusetts Asylum for Idiotic and Feeble-Minded Youth, the first residential facility to educate intellectually disabled children, similar institutions opened up across the country.³⁰ These unregulated and unsanitary institutions filled up when families and towns were unable to privately care for their disabled relatives and citizens.³¹

The late nineteenth century saw the rise of the eugenics movement, which sought to eliminate "undesirable" genetic traits in humans through selective breeding.³² Intellectuals and policymakers alike saw eugenics as a way to rid society of its many social ills.³³ W.E. Fernald, superintendent of the Massachusetts School for the Feeble-Minded, captured this sentiment:

The social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class They cause unutterable sorrow at home and are a menace and danger to the community

. . . .

. . . Every feeble-minded person, especially the high-grade imbecile, is a potential criminal

. . . .

. . . The most important point is that feeble-mindedness is highly hereditary The normal members of a definitely tainted family may transmit defect to their own children Certain families should become extinct.³⁴

This view of disabled people, shared by medical professionals,³⁵ led thirty-two states to pass eugenics-sterilization laws during the twentieth century.³⁶ While

29. Carol Beatty, Commentary, *Implementing Olmstead by Outlawing Waiting Lists*, 49 TULSA L. REV. 713, 716 (2014) (citing *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 461 (1985) (Marshall, J., concurring in part, dissenting in part)).

30. See Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415, 1424, 1427 (2007).

31. Meldon, *supra* note 28.

32. Brooke Carlaw, *Early American Eugenics Movement*, FIRST WAVE FEMINISMS (Dec. 12, 2019), <https://sites.uw.edu/twomn347/2019/12/12/early-american-eugenics-movement> [perma.cc/872W-UDA6]. See EDWIN BLACK, *WAR AGAINST THE WEAK* (2012), for an excellent historical account of the eugenics movement.

33. See Andrea DenHoed, *The Forgotten Lessons of the American Eugenics Movement*, NEW YORKER (Apr. 27, 2016), <https://www.newyorker.com/books/page-turner/the-forgotten-lessons-of-the-american-eugenics-movement> [perma.cc/KUU9-RJ5T].

34. W.E. Fernald, *The Burden of Feeble-mindedness*, 17 J. PSYCHO-ASTHENICS 85, 90-91, 98 (1912).

35. PRESIDENT'S COMM'N ON MENTAL RETARDATION, *MENTAL RETARDATION PAST AND PRESENT* 11-12 (1977).

36. See DenHoed, *supra* note 33.

courts rejected some of these measures,³⁷ the Supreme Court endorsed such efforts in its landmark 1927 *Buck v. Bell* decision.³⁸ The Court upheld a Virginia statute that permitted compulsory sterilization of the “unfit.”³⁹ Writing for an 8–1 majority, Justice Oliver Wendell Holmes Jr. seemed to fully embrace the principles of the eugenics movement: “It is better for 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.”⁴⁰ The Court legitimized Carrie Buck’s sterilization, infamously writing, “Three generations of imbeciles are enough.”⁴¹ In the aftermath of this decision, facilities initially established to “train” disabled children morphed into custodial institutions that deprived disabled people of participation in the community and, for many, the ability to reproduce.⁴²

Widespread legal and social support for eugenics, coupled with then-non-existent government support for at-home care, dramatically increased the institutionalized population between 1925 and 1950.⁴³ Even though these institutions were “overcrowded, understaffed, and provided little education and training,” waiting lists were lengthy because thousands of parents had no other means of securing permanent care for their disabled children.⁴⁴ In the 1960s, due in large part to increased scrutiny by a growing disability advocacy movement, the public learned of the poor conditions at these institutions.⁴⁵ Legal battles ensued. The U.S. Court of Appeals for the D.C. Circuit ruled in

37. See, e.g., *Mallory v. Priddy* (Va. Cir. Ct. Feb. 16, 1918); see also PAUL A. LOMBARDO, *THREE GENERATIONS, NO IMBECILES* 64–77 (updated ed. 2022) (describing the circumstances of *Mallory v. Priddy* and the Virginia judge’s decision to enjoin sterilizations until state laws changed).

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

39. *Id.* at 207.

40. *Id.*

41. *Id.* Holmes cited *Jacobson v. Massachusetts*, 197 U.S. 11, 25 (1905), writing that “[t]he principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.” *Buck*, 274 U.S. at 207.

42. Beatty, *supra* note 29, at 717. The logical endpoint of eugenics was realized by the Nazi regime, resulting in the murder of millions of people deemed inferior. See generally BLACK, *supra* note 32 (discussing the history of the eugenics movement and its hideous culmination under the Nazis).

43. Beatty, *supra* note 29, at 717; see DEWAYNE L. DAVIS, WENDY FOX-GRACE & SHELLY GEHSAN, NAT’L CONF. OF STATE LEGISLATURES, *DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS 2* (2000).

44. Beatty, *supra* note 29, at 717–18.

45. See DAVIS et al., *supra* note 43, at 2. Part I of Sam Bagenstos’s *The Past and Future of Deinstitutionalization Litigation* gives a helpful summary of the politics behind the litigation in the decades following the publication of the horrid conditions of institutions in the 1960s. Bagenstos, *supra* note 14, at 7–25; see also Karen M. Tani, *The Pennhurst Doctrines and the Lost Disability History of the “New Federalism,”* 110 CALIF. L. REV. 1157 (2022); Rabia Belt & Doron Dorfman, *Disability, Law, and the Humanities: The Rise of Disability Legal Studies*, in *THE OXFORD HANDBOOK OF LAW & THE HUMANITIES* (Simon Stern, Maksymilian Del Mar & Bernadette Meyler eds., 2019).

1966 that the state should bear the burden of exploring alternatives to institutionalization, introducing the legal world to the concept of “least restrictive setting.”⁴⁶ In 1975, the Supreme Court declared that people had to be a danger to themselves or others in order for their institutionalization to be constitutional.⁴⁷ A confluence of factors in the 1960s and 70s—including studies documenting the abuse and neglect of disabled people in institutions, the civil rights movement, and political motives to save money—all spurred the deinstitutionalization movement.⁴⁸

On the legislative side, advocates hailed Section 504 of the Rehabilitation Act of 1973 as the “civil rights bill of the disabled,” but courts quickly narrowed its scope.⁴⁹ The law ensured that

[n]o otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.⁵⁰

At the same time, however, studies demonstrated the benefits of deinstitutionalization for disabled people⁵¹ and its cost savings.⁵² In the 1970s and 80s, deinstitutionalization found broad political support: “Deinstitutionalization became the ideal social reform; it permitted liberal politicians to free mental patients, and at the same time allowed conservative politicians to save millions of dollars.”⁵³ Unfortunately, Section 504 failed to realize its promise in the way that deinstitutionalization advocates had hoped. “[F]ederal courts refused to interpret [the law] as a requirement that states provide services for

46. See *Lake v. Cameron*, 364 F.2d 657 (D.C. Cir. 1966).

47. *O'Connor v. Donaldson*, 422 U.S. 563 (1975).

48. See Beatty, *supra* note 29, at 718–19; Sandra L. Yue, *A Return to Institutionalization Despite Olmstead v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home- and Community-Based Waiver Services*, 19 *LAW & INEQ.* 307, 313–14 (2001).

49. Beatty, *supra* note 29, at 719; Laura C. Scotellaro, Note, *The Mandated Move from Institutions to Community Care: Olmstead v. L.C.*, 31 *LOY. UNIV. CHI. L.J.* 737, 743 (2000).

50. 29 U.S.C. § 794(a) (2012).

51. RSCH. & TRAINING CTR. ON CMTY. LIVING, UNIV. OF MINN., *BEHAVIORAL OUTCOMES OF DEINSTITUTIONALIZATION FOR PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES: THIRD DECENNIAL REVIEW OF U.S. STUDIES, 1977–2010*, at 1–2 (2011) (“[B]etween 1977 and 1999 a substantial majority of U.S. studies of adaptive behavior (daily living skills) found relative benefits accruing with movement to community settings from institutions.”).

52. See Bagenstos, *supra* note 14, at 20 n.92.

53. Gary J. Clarke, *In Defense of Deinstitutionalization*, 57 *MILBANK MEM’L FUND Q./HEALTH & SOC’Y* 461, 468 (1979).

[disabled people] in the least restrictive environment,”⁵⁴ in part because of the law’s inadequate enforcement mechanisms.⁵⁵

Passed in 1990, after decades of deinstitutionalization and years of legislative advocacy,⁵⁶ the Americans with Disabilities Act was the crowning achievement of the disability rights movement.⁵⁷ While it didn’t exactly “signal[] the end to the unjustified segregation and exclusion of persons with disabilities from the mainstream of American life,”⁵⁸ the ADA did mark significant advancement in the rights of disabled people across the country.⁵⁹ The ADA is unique among civil rights statutes in the details it includes—it gives state and local governments specific mandates.⁶⁰ This specificity also gives civil rights litigators better tools to bring disability discrimination claims. Before the ADA’s passage, litigators had to rely on shakier due process theories, but the ADA gave them firmer statutory support.⁶¹ And after courts limited the definition of “disability,” Congress passed the ADA Amendments Act of 2008, instructing courts to more broadly interpret the meaning of the term, in line with its original intent.⁶²

The four substantive titles of the ADA were meant to create a robust system of protections for the then-forty-three million disabled Americans.⁶³ Most relevant to this Note is Title II, which provides protection for public services offered by state and local governments, including state Medicaid programs.⁶⁴ States frequently use the “fundamental alteration” provision of Title II when

54. Beatty, *supra* note 29, at 719.

55. Scotellaro, *supra* note 49, at 743. Further, the law only applies to institutions and entities that receive federal funding. See 29 U.S.C. § 794(a) (1994).

56. See Beatty, *supra* note 29, at 731–732.

57. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213. The definition of disability under the ADA covers individuals who have “a physical or mental impairment that substantially limits one or more major life activity,” those who have previously had a disability, and those who are “regarded as having a disability.” See also *What is the Definition of Disability Under the ADA?*, ADA NAT’L NETWORK, <https://adata.org/faq/what-definition-disability-under-ada> [perma.cc/663H-WER3].

58. *Transcript of Statement by the President July 26, 1990*, NAT’L ARCHIVES, <https://www.archives.gov/research/americans-with-disabilities/transcriptions/naid-6037493-statement-by-the-president-americans-with-disabilities-act-of-1990.html> [perma.cc/54Q3-VEDM] (last reviewed Aug. 15, 2016).

59. See, e.g., Daron Acemoglu & Joshua Angrist, *Consequences of Employment Protection? The Case of the Americans with Disabilities Act* (Nat’l Bureau of Econ. Rsch., Working Paper No. 6670, 1998) (indicating that employment rates of disabled people fell sharply after the ADA).

60. See Beatty, *supra* note 29, at 731–32.

61. Bagenstos, *supra* note 14, at 29.

62. Doron Dorfman, *Afterword: The ADA’s Imagined Future*, 71 SYRACUSE L. REV. 933, 949 n.90 (2021).

63. Alex C. Geisinger & Michael Ashley Stein, *Expressive Law and the Americans with Disabilities Act*, 114 MICH. L. REV. 1061, 1071 (2016) (reviewing RICHARD H. MCADAMS, *THE EXPRESSIVE POWERS OF LAW* (2015)).

64. Beatty, *supra* note 29, at 732.

defending the status quo.⁶⁵ It exempts states from modifying their programs to accommodate disabled people when those modifications “would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations involved.”⁶⁶

The most important deinstitutionalization case after the ADA’s passage was *Olmstead v. L.C.*,⁶⁷ sometimes referred to as the “*Brown v. Board of Education* of the disability rights movement.”⁶⁸ In *Olmstead*, the Supreme Court recognized the right of all individuals to live independently in their own homes and communities, placing an explicit obligation on states to provide the support and services needed to vindicate that right.⁶⁹ The case arose when Lois Curtis and Elaine Wilson, two women with intellectual and mental disabilities, wanted to receive the services they needed outside of the Georgia Regional Hospital where they were living.⁷⁰ Mental health professionals treating them agreed that they were eligible for community-based programs.⁷¹ However, even after this determination, Curtis and Wilson remained confined in the institution for several years.⁷² They sued under Title II of the ADA. Challenging their continued confinement by the state of Georgia,⁷³ Curtis and Wilson sought an injunction to receive publicly financed community placements and services⁷⁴—in other words, HCBS. Writing for the majority, Justice Ruth Bader Ginsburg affirmed that Title II of the ADA requires state actors to place people with mental disabilities in community settings rather than institutions. But it was a qualified affirmation:

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.⁷⁵

The Court’s conclusion, that the wrongful institutionalization of disabled people falls within Title II, had significant support from the executive and legislative branches and several bases in policy.⁷⁶ First, President Clinton’s

65. *Id.*

66. 42 U.S.C. § 12201(f).

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

68. Samuel R. Bagenstos, *Taking Choice Seriously in Olmstead Jurisprudence*, 40 J. LEGAL MED. 5, 5 (2020).

69. *See Olmstead*, 527 U.S. at 587.

70. *See id.* at 593.

71. *Id.*

72. *Id.*

73. *Id.* at 593–94.

74. *See id.* at 594.

75. *Id.* at 607.

76. Beatty, *supra* note 29, at 735.

Department of Justice (DOJ) had consistently advanced that view.⁷⁷ Second, the ADA was at least partially intended to end the unjustified segregation of disabled people.⁷⁸ Third, unjustified segregation perpetuates unwarranted assumptions about the capabilities of disabled people.⁷⁹ Finally, the Court acknowledged that institutionalization had negative effects on the real lives of disabled people.⁸⁰

Following Justice Ginsburg's lead, the DOJ generally requires only that states move at a reasonable pace. Because of the *Olmstead* decision, DOJ regulations now include an integration mandate that "public entit[ies] shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."⁸¹ Justice Ginsburg noted that, given the potential upheaval immediate and full deinstitutionalization could have, a state could meet the reasonable modifications standard by showing it had both a working plan for placing qualified persons in less restrictive settings and a waiting list that moved at a "reasonable pace."⁸² While the DOJ guidelines certainly helped further deinstitutionalization, they did not require a major change in Medicaid rules and failed to cure its institutional bias.⁸³ In fiscal year 2018, the Court's "reasonable pace" standard manifested as an average wait time of thirty-nine months for HCBS, with 820,000 people in the queue.⁸⁴ It's hard not to see the comparison to Chief Justice Warren's ambiguous "all deliberate speed" standard in *Brown v. Board of Education*.⁸⁵ Despite *Brown*'s monumental significance, that ambiguity helped lead to a bleak picture—ten years after *Brown*, fewer than one percent of segregated schools had been desegregated.⁸⁶

The data tells a generally successful, if unfinished, story of deinstitutionalization. After the number of developmentally disabled people in institutions peaked at just under 200,000 in 1967, states shut down hundreds of institutions and downsized many others.⁸⁷ In 2019, that number was approximately

77. See *Olmstead*, 527 U.S. at 597–98, 601.

78. *Id.* at 600.

79. *Id.*

80. *Id.* at 601.

81. 28 C.F.R. § 35.130(d) (2010).

82. *Olmstead*, 527 U.S. at 605–06. The opinion did not give any guidance as to what constituted a "reasonable pace."

83. See *infra* notes 105–109 and accompanying text.

84. MEDICAID & CHILD HEALTH INS. PROGRAM PAYMENT & ACCESS COMM'N, STATE MANAGEMENT OF HOME- AND COMMUNITY-BASED SERVICES WAIVER WAITING LISTS 4 (2020), <https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf> [perma.cc/3S9L-FUPX].

85. *Brown v. Bd. of Ed. (Brown II)*, 349 U.S. 294, 301 (1955).

86. Clarence Page, *Essay: With All Deliberate Speed*, PBS (May 11, 2004, 12:00 AM), <https://www.pbs.org/newshour/show/essay-with-all-deliberate-speed> [perma.cc/BVH9-NGE3].

87. Bagenstos, *supra* note 14, at 7–8.

16,200, and it continues to trend downward.⁸⁸ For psychiatric disabilities, the numbers are more dramatic: just under 560,000 individuals institutionalized in 1955 became fewer than 50,000 in 2003.⁸⁹

B. Medicaid and HCBS

Medicaid is complicated: such is the nature of federal-state partnerships. This Section tracks Medicaid's history since President Lyndon B. Johnson signed it into law in 1965, while also tracing the development of HCBS.⁹⁰ Although states implement their programs unevenly, coverage has increased over time.

Congress created Medicaid as part of the Social Security Act to provide healthcare to people on welfare.⁹¹ Medicaid's status as a federal-state partnership entails joint federal and state funding.⁹² Federal statutes set out the policy broadly, while federal regulations promulgated by the Centers for Medicare & Medicaid Services (CMS) delineate specific regulations.⁹³ When states take part in Medicaid (as all states do in some capacity), they must follow Medicaid regulations and can choose to take on additional programs partially funded by the federal government.⁹⁴ Medicaid is complicated and programs vary widely across the country, in large part because states have the flexibility to make decisions on benefits, eligibility, and payment to providers within the CMS guidelines.⁹⁵

Congress has amended and expanded Medicaid's coverage several times since its passage in 1965.⁹⁶ Today, it covers disabled people, seniors, low-income families, pregnant people, and others who need long-term care.⁹⁷ In

88. ADMIN. FOR CMTY. LIVING, 30 YEARS OF COMMUNITY LIVING FOR INDIVIDUALS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES (1987–2017), at 8 (2021). That number is the sum of the average population of all public residential facilities serving sixteen or more intellectually/developmentally disabled people. The number is out of 7.39 million people in the United States who had intellectual or developmental disabilities in 2019. RESIDENTIAL INFO. SYS. PROJECT, IN-HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS 2019, at 11, 23 (2022), [https://ici-s.umn.edu/files/y_7tYy\]Dmn/risp_2019_v6](https://ici-s.umn.edu/files/y_7tYy]Dmn/risp_2019_v6) [perma.cc/F8KS-XG2W].

89. Bagenstos, *supra* note 14, at 9 (citing Ronald W. Manderscheid, Joanne E. Atay & Raquel A. Crider, *Changing Trends in State Psychiatric Hospital Use from 2002 to 2005*, 60 PSYCHIATRIC SERVS. 29 (2009)).

90. *History*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/About-CMS/Agency-Information/History> [perma.cc/989X-B7JX].

91. Beatty, *supra* note 29, at 721.

92. *Id.*

93. *Id.* at 721, 725 n.126.

94. Robin Rudowitz, Rachel Garfield & Elizabeth Hinton, *10 Things to Know About Medicaid: Setting the Facts Straight*, KFF (Mar. 6, 2019), <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicare-setting-the-facts-straight> [perma.cc/F3N2-L6KY].

95. Beatty, *supra* note 29, at 721–22.

96. CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 90.

97. *Id.*

2019, the federal government paid 64% of total Medicaid costs.⁹⁸ Every year, CMS calculates the federal government's contribution to Medicaid, i.e. the Federal Medical Assistance Percentage (FMAP), for each state based on the state's per capita income.⁹⁹ In fiscal year 2022, the FMAP average across all states and D.C. was 66.9%, with a range of 56.2% to 84.51%.¹⁰⁰ FMAP numbers have trended upward in recent years because of the Biden Administration's American Rescue Plan Act, which contains a number of Medicaid-related provisions designed to increase coverage and expand benefits.¹⁰¹ The law includes a 10% increase in federal matching funds for HCBS.¹⁰² Consequently, Medicaid now covers about 20% of Americans.¹⁰³ This 10% bump is being phased out through the end of 2023.¹⁰⁴

In the provision of long term supports and services (LTSS), Medicaid has a bias toward institutional settings.¹⁰⁵ Originally, LTSS only required participating states to cover nursing home care.¹⁰⁶ Over time, LTSS funding began slowly shifting from institutional care toward HCBS, but states are still only *required* to cover institutional care.¹⁰⁷ In 1967, just after Congress initially es-

98. Robin Rudowitz, Elizabeth Williams, Elizabeth Hinton & Rachel Garfield, *Medicaid Financing: The Basics*, KFF (May 7, 2021), <https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics> [perma.cc/KB4Z-WZRT].

99. Beatty, *supra* note 29, at 722.

100. *Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier*, KFF, <https://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier> [perma.cc/36LX-FQ8N].

101. Rudowitz et al., *supra* note 98.

102. Press Release, Ctrs. for Medicare & Medicaid Servs., CMS Issues Guidance on American Rescue Plan Funding for Medicaid Home and Community Based Services (May 13, 2021), <https://www.cms.gov/newsroom/press-releases/cms-issues-guidance-american-rescue-plan-funding-medicare-home-and-community-based-services> [perma.cc/LUR3-PU5C].

103. Rudowitz et al., *supra* note 98; CTRS. FOR MEDICARE & MEDICAID SERVS., AUGUST 2022 MEDICAID AND CHIP ENROLLMENT SNAPSHOT (2022), <https://www.medicare.gov/sites/default/files/2022-11/august-2022-medicare-chip-enrollment-trend-snapshot.pdf> [perma.cc/579B-6BZ3]; *US Population by Month*, MULTPL, <https://www.multpl.com/united-states-population/table/by-month> [perma.cc/PN47-PEFG].

104. Edwin Park et al., *Consolidated Appropriations Act, 2023: Medicaid and CHIP Provisions Explained*, GEO. UNIV. HEALTH POL'Y INST. (Jan. 5, 2023), <https://ccf.georgetown.edu/2023/01/05/consolidated-appropriations-act-2023-medicare-and-chip-provisions-explained> [perma.cc/R857-EEFK].

105. Smith, *supra* note 13. LTSS includes both institutional care and HCBS. In 2018, Medicaid made up about 52% of spending on LTSS (around \$200 billion), with the rest of the spending coming from out-of-pocket spenders (16%), private insurance (11%), and other options like state programs (20%). Megan O'Malley Watts, MaryBeth Musumeci & Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF (Feb. 4, 2020), <https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief> [perma.cc/8XDN-3Z6L].

106. Kezia Scales, *Meeting the Integration Mandate: The Implications of Olmstead for the Home Care Workforce*, 27 GEO. J. ON POVERTY L. & POL'Y 261, 267.

107. *Id.*

tablished Medicaid, it passed an amendment that created a new level of institutional care: intermediate care facilities (ICF), where beneficiaries who require long-term—but less intensive—care than those in nursing homes can be served at a lower cost.¹⁰⁸ Nursing homes and other congregant settings may be the right environment for *some* seniors and disabled adults, but the data generally support a shift toward HCBS.¹⁰⁹ Even so, Medicaid’s historical regulatory and funding structure has tipped the scales in favor of funding institutional care.

In 1981, the Omnibus Reconciliation Act established 1915(c) waivers, which enabled states to provide HCBS for some targeted groups of individuals who would otherwise require institutional care.¹¹⁰ The HCBS could include nonmedical services to prevent institutionalization.¹¹¹ The waivers also exempted states from meeting Medicaid’s “comparability” and “statewideness” requirements.¹¹² The “comparability” requirement mandates that states ensure that Medicaid services are available to all eligible individuals on an equivalent basis.¹¹³ The “statewideness” requirement forces state Medicaid plans to be effective throughout the state.¹¹⁴ With these exemptions, states can target specific groups that are at risk of institutionalization and experiment with a variety of medical and nonmedical services to help these groups.¹¹⁵

Congress hoped that 1915(c) waivers would provide states with the flexibility to test out a variety of programs focused on preventing institutionalization, cutting costs, and innovating care.¹¹⁶ In fact, to incentivize this sort of innovation, CMS initially promulgated very few regulations related to 1915(c) waivers.¹¹⁷ This lack of regulation persists. Rather than analyzing the effect of HCBS waivers and updating the rules with a federal baseline based on state successes, Congress and CMS continue to give states wide latitude.¹¹⁸

108. Secretary Beatty provides an exhaustive history of ICFs. Beatty, *supra* note 29, at 723–26.

109. See CYNTHIA SHIRK, REBALANCING LONG-TERM CARE: THE ROLE OF THE MEDICAID HCBS WAIVER PROGRAM (2006), https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1161&context=sphhs_centers_nhpf [perma.cc/4HHM-RHYR]; *supra* Section I.A (describing the myriad benefits of deinstitutionalization).

110. See Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, 95 Stat. 357, 812; Scales, *supra* note 106, at 267. The other requirement is that waiver programs must be “budget neutral” in that the average per capita cost of alternative HCBS cannot exceed the average per capita cost for institutional care. Sahar Takshi, *Home Sweet Home: The Problem with Cost Neutrality for Older Americans Seeking Home- and Community-Based Services*, 5 ADMIN. L. REV. 25 (2019).

111. Beatty, *supra* note 29, at 727.

112. *Id.*

113. *Id.*

114. *Id.*

115. *Id.*

116. *Id.* at 728.

117. *Id.*

118. *Id.* at 730.

As a result, services vary widely across states. All states serve people with intellectual or developmental disabilities, seniors, and physically disabled adults. But only some states serve the following populations with 1915(c) waivers: people with mental illnesses, HIV positive people, people with traumatic brain or spinal cord injuries, and medically fragile children.¹¹⁹ Income limits for eligibility vary significantly, as do quality measures and rules related to direct-care workers.¹²⁰ States provide different versions of supported employment services and mental health services, most commonly offering home-based services and equipment modifications, day services, nursing, therapy, and case management.¹²¹ Across the United States, 68% of 1915(c) waivers serving intellectually or developmentally disabled people allow for nursing or therapy services, while just 33% of waivers serving people with mental illnesses do.¹²² Often, because of differences in services and eligibility requirements across states, disabled people and their families end up stuck in one state, tied to their Medicaid-funded services that will not transfer to another.¹²³

When Congress first promulgated 1915(c) waivers, they were extremely popular among states.¹²⁴ The Reagan Administration, however, was less keen

119. MaryBeth Musumeci, Molly O'Malley Watts & Priya Chidambaram, *Key State Policy Choices About Medicaid Home and Community-Based Services*, KFF (Feb. 4, 2020), <https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services> [perma.cc/9XSJ-H7U4].

120. *Id.*

121. *Id.*

122. *Id.*

123. See Press Release, The Arc, Independence Can't Wait: New Bill in Congress Championed by the Arc Will Make Home and Community-Based Services Available to All (Mar. 16, 2021), <https://thearc.org/blog/independence-cant-wait-new-bill-in-congress-championed-by-the-arc-will-make-home-and-community-based-services-available-to-all> [perma.cc/CZH7-6NC8]. One can imagine the situation of a disabled person living with his parents in New York while his older sister lives in Chicago. Once the parents pass away or can no longer support him, he may want to move to Chicago to live near or with his sister. But because his HCBS waiver was granted under New York state rules and won't transfer to Illinois, he faces the difficult choice of staying in New York and maintaining his services or moving to Chicago without any guarantee that he can continue to get the services he needs.

124. Beatty writes:

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.

Beatty, *supra* note 29, at 728.

on increasing funding for HCBS.¹²⁵ More recently, funding priorities between states and the federal government have flipped sides.¹²⁶ The federal government has expanded HCBS offerings, including incentives for states to spend more on programs.¹²⁷ States, on the other hand, still have the significant flexibility that CMS regulations offer, and they have generally applied the fiscal brakes.¹²⁸ So while federal expenditures on HCBS have grown exponentially since 1982, expenditures on ICFs and other institutional settings have stagnated¹²⁹ and waitlists for HCBS have grown.¹³⁰

Because HCBS coverage is still mostly optional for states, while institutional services continue to be mandatory, families must endure long wait times and frequently cover the costs of these essential services themselves.¹³¹ States have wide discretion in designing HCBS programs, including the power to cap 1915(c) waiver enrollment.¹³² The HCBS waitlist number has fluctuated significantly: it was 656,000 in 2016, 820,000 in 2018, and back down to 656,000 in 2021.¹³³ The average wait time is forty-five months,¹³⁴ and during that time

125. *Id.*

126. *Id.* at 729.

127. *Id.* For example, the Real Choice Systems Change Grant Program, established in fiscal year 2001 by CMS, provided funding for states to develop regulatory, administrative, programmatic, and funding infrastructure to enable disabled people to “[l]ive in the most integrated community setting appropriate to their individual support requirements and preferences; [e]xercise meaningful choices about and control over their living environment . . . ; [and] [o]btain quality services in a manner consistent . . . with their . . . preferences.” Medicaid Program; Real Choice Systems Change Grants, 69 FED. REG. 28133 (May 18, 2004), <https://www.federalregister.gov/documents/2004/05/18/04-11241/medicaid-program-real-choice-systems-change-grants> [perma.cc/44CE-ARED]. The 2005 Deficit Reduction Act created the Money Follows the Person program (MFP), which supported participating states with an enhanced federal match to provide additional services helping people transition from institutions to their communities. Scales, *supra* note 106, at 268. The Affordable Care Act also contained a number of inducements for states to expand HCBS. *See id.* at 268–69; Beatty, *supra* note 29, at 729–30.

128. Beatty, *supra* note 29, at 729.

129. RESIDENTIAL INFO. SYS. PROJECT, INST. ON CMTY. INTEGRATION, IN-HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS 2018, at 107 (Dec. 2021), <https://icis.umn.edu/files/yFXkkmRteg/2018-risp-full-report> [perma.cc/5G2P-5EBM].

130. Scales, *supra* note 106, at 271.

131. REAVES & MUSUMECI, *supra* note 13.

132. Molly O’Malley Watts, MaryBeth Musumeci & Priya Chidambaram, *State Variation in Medicaid LTSS Policy Choices and Implications for Upcoming Policy Debates*, KFF (Feb. 26, 2021), <https://www.kff.org/report-section/state-variation-in-medicaid-ltss-policy-choices-and-implications-for-upcoming-policy-debates-issue-brief> [perma.cc/H9EP-8M6T].

133. Alice Burns, Molly O’Malley Watts & Meghana Ammula, *A Look at Waiting Lists for Home and Community-Based Services from 2016 to 2021*, KFF (Nov. 28, 2022), <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021> [perma.cc/8AB4-YK88]. The fluctuation is probably accounted for by states changing their screening processes before placing individuals on waitlists. *See id.*

134. *Id.*

the work of caring for the individual often falls onto family members, predominantly women.¹³⁵ A privileged few can afford to pay for HCBS out of pocket.¹³⁶

In 2017, Republican members of Congress nearly passed the Better Care Reconciliation Act, which would have repealed and replaced the Affordable Care Act.¹³⁷ Among other provisions, the bill phased out Medicaid expansion, provided smaller subsidies for health insurance plans, and allocated less funding to government healthcare.¹³⁸ With this decrease in federal funding, states would have been forced to foot the bill for services that the federal government previously covered. Because Medicaid's funding structure gives states discretion over HCBS offerings, at least some states likely would have made major cuts to their already underfunded HCBS.¹³⁹ The disability community played a large role in stopping the passage of the bill.¹⁴⁰ Their advocacy efforts—which reached a broad audience—highlighted the importance of HCBS, leading to the inclusion of HCBS in Medicare for All proposals.¹⁴¹ Despite this recent success, seniors and disabled people still face a crisis of care caused by the institutional bias of Medicaid, the bootstrapped nature of HCBS, and the unmet legislative and regulatory need for modernization (at both the federal and state levels).

135. See, e.g., Rebecca Tan, *She's Desperate to Get Home Care for Her Mom. In Maryland, 21,000 Are on the Wait List.*, WASH. POST (Oct. 9, 2021, 6:47 PM), https://www.washingtonpost.com/local/maryland-covid-medicaid-waitlist/2021/10/07/37dfc41e-2214-11ec-b3d6-8cdebe60d3e2_story.html [perma.cc/M737-PCDS] (“Rather than admit their loved ones into an institution, some families empty their savings to pay for a professional caregiver or have a relative, often a woman, cut down on work to provide care herself.”).

136. These costs can be quite high, generally \$4,000–5,000 per month. *PACE Programs as an Alternative to Nursing Homes for Medicaid Beneficiaries*, AM. COUNCIL ON AGING (Feb. 27, 2023), <https://www.medicaidplanningassistance.org/medicare-pace-programs> [perma.cc/44WN-LBTW].

137. Better Care Reconciliation Act of 2017, H.R. 1628, 115th Cong. (2017); Leigh Ann Caldwell, *McConnell Pulls Plug on GOP Health Care Bill, Will Seek Obamacare Repeal*, NBC NEWS (July 18, 2017, 11:31 PM), <https://www.nbcnews.com/politics/congress/two-more-health-care-defections-dooms-current-gop-bill-n783926> [perma.cc/DF5S-Q66H].

138. See Sarah Kliff, *The Better Care Reconciliation Act: The Senate Bill to Repeal and Replace Obamacare, Explained*, VOX (June 26, 2017, 1:36 PM), <https://www.vox.com/policy-and-politics/2017/6/22/15846728/senate-plan-better-care-reconciliation-act> [perma.cc/26TV-4DFP].

139. See Christopher & Dana Reeve Foundation, *Home and Community Based Services HCBS What Are They and Why They Are Important? June 2021*, YOUTUBE, at 11:35 (June 9, 2021), <https://www.youtube.com/watch?v=BOClAeGCNck> [perma.cc/W9JR-PVG8] (discussing the detrimental impact that the Better Care Reconciliation Act could have had and the organizing work the disabled community did to stop its passage).

140. See Jeff Stein, “No Cuts to Medicaid!”: Protestors in Wheelchairs Arrested After Release of Health Care Bill, VOX (June 22, 2017, 2:40 PM), <https://www.vox.com/policy-and-politics/2017/6/22/15855424/disability-protest-medicaid-mcconnell> [perma.cc/S5GD-KVL8].

141. See Christopher and Dana Reeve Foundation, *supra* note 139, at 14:30.

II. COVID-19 AND HCBS TODAY

The COVID-19 pandemic intensified the unmet need for improved HCBS for seniors and disabled people across the country. Section II.A details this dynamic, while Section II.B describes some current solutions to the HCBS crisis and their shortcomings.

A. *The Pandemic Response, Congregant Care Facilities, and HCBS*

The pandemic illuminated the long-standing inadequacy of emergency response systems for disabled people. These include the provision of emergency plans, backup technology and energy systems, and other support around direct service and care workers,¹⁴² education,¹⁴³ unemployment,¹⁴⁴ housing,¹⁴⁵ and communication.¹⁴⁶ By failing to have accessible emergency plans in place that accounted for the needs of seniors and disabled people, institutions and governments heightened the risk of these more susceptible populations contracting and dying from COVID-19.¹⁴⁷ Healthcare facilities in particular adopted blanket policies during the pandemic without exceptions for disabled people.¹⁴⁸ For example, Hartford Hospital in Connecticut refused to provide a reasonable modification to the facility's no-visitor policy for a mostly nonverbal seventy-three-year-old patient with aphasia and severe short-term memory loss.¹⁴⁹ The patient typically had a support person or persons to help her communicate with others, but Hartford Hospital still denied the exception request.¹⁵⁰ While the United States Department of Health and Human Services (HHS) partially resolved the problem by having the state issue an executive order ensuring that disabled people have reasonable access to support personnel in hospital settings in a manner consistent with relevant

142. See, e.g., NAT'L COUNCIL ON DISABILITY, THE IMPACT OF COVID-19 ON PEOPLE WITH DISABILITIES 40–41 (2021) [hereinafter NCD COVID REPORT], https://ncd.gov/sites/default/files/NCD_COVID-19_Progress_Report_508.pdf [perma.cc/P75B-YLB2]. When personal care assistants, staff at nursing facilities, and others in the ecosystem of care got sick or had to care for sick family members, older and disabled people were directly at risk of infection or of not receiving the care they need. *Id.*

143. See *id.* at 19–20.

144. See *id.* at 21.

145. See *id.* at 102–07.

146. See *id.* at 169.

147. See generally *id.*

148. *Id.* at 60.

149. See Press Release, U.S. Dep't of Health & Hum. Servs., OCR Resolves Complaints After State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19 (June 9, 2020), <https://www.hhs.gov/guidance/document/ocr-resolves-complaints-after-state-connecticut-and-private-hospital-safeguard-rights> [perma.cc/85R6-JEUP].

150. *Id.*

civil rights laws,¹⁵¹ discrimination against disabled people has remained in healthcare settings throughout the pandemic.¹⁵²

COVID-19 and the American response to it is exacting a steep toll on certain populations of disabled people. COVID-19 “exposed extreme disability bias, failures in modifying policies to accommodate the needs of people with disabilities, and gaps in disability data collection and antidiscrimination laws.”¹⁵³ The onset of the pandemic, which manifested in surges of COVID infections that threatened hospital resources,¹⁵⁴ drew attention to the discriminatory manner in which hospitals applied their crisis standards of care and triage procedures, revealing that hospitals were more likely to deny COVID-19 treatment to intellectually or developmentally disabled people, medically fragile, and technology-dependent individuals.¹⁵⁵ Furthermore,

[t]he growing shortage of direct care workers in existence prior to the pandemic became worse during the pandemic. Many such workers, who are women of color earning less than a living wage and lacking health benefits, left their positions for fear of contracting and spreading the virus, leaving people with disabilities and their caregivers without aid and some at risk of losing their independence or being institutionalized.¹⁵⁶

And as schools sought to preserve educational opportunity, disabled students were deprioritized and cut off from in-person special education services.¹⁵⁷ In testing and vaccination, physical, communicative, and procedural barriers gave rise to disparities between disabled and nondisabled populations.¹⁵⁸ People with mental health disabilities that predated the pandemic

151. *Id.*

152. See, e.g., *Unlawful Disability Discrimination Regarding MedStar Health’s COVID-19 Visitation Policy*, DISABILITY RTS. D.C. (Sept. 16, 2020), <https://www.centerforpublicrep.org/wp-content/uploads/DC-OCR-Complaint-against-MedStar-Health-9.16.20.pdf> [perma.cc/3NVY-R3G2]; *Complaints of Disability Discrimination - California Hospital Visitation Policies*, DISABILITY RTS. EDUC. & DEF. FUND (Aug. 27, 2020), <https://dredf.org/2020/08/27/complaints-of-disability-discrimination-california-hospital-visitation-policies/> [perma.cc/J3KM-B26T].

153. NCD COVID REPORT, *supra* note 142, at 1.

154. See, e.g., Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 YALE L.J.F. 1, 2 (“[C]risis standards of care adopted by hospitals and state agencies often employ explicit disability-based distinctions.”). Many states and the National Academies of Science, Engineering, and Medicine did not include vulnerable populations, including disabled people and people with chronic conditions, in state and federal vaccine priority lists because of long-existing failures to collect detailed healthcare data on disabled people. NCD COVID REPORT, *supra* note 142, at 14, 65–67.

155. NCD COVID REPORT, *supra* note 142, at 1–2.

156. *Id.* at 2.

157. *Id.*

158. *Id.*

have experienced significant mental health deterioration over its course, exacerbated by a preexisting shortage of treatment options.¹⁵⁹

Residents of congregant-care facilities—including nursing and assisted living homes, psychiatric facilities, and board and care homes—have faced higher infection and death rates than nonresidents during the pandemic.¹⁶⁰ This is due in part to the need to share direct care workers and amenities, combined with close contact with others, an already higher susceptibility to infection, and a lack of personal protective equipment.¹⁶¹ And although institutional settings present a higher risk of transmission and death, states have deprioritized and limited opportunities to transition individuals out of them and into communities with HCBS.¹⁶²

Nursing homes and other congregant settings were particularly hard-hit by each wave of the pandemic.¹⁶³ As of June 30, 2021, staff and residents at long-term care facilities accounted for 31% of all COVID deaths in the United States.¹⁶⁴ That number may even be an underestimate because federal data requirements do not apply to the skilled nursing facilities where hundreds of thousands of disabled people live.¹⁶⁵ Several states contributed directly to the scale of infection and death in nursing homes by requiring these homes to readmit COVID-positive residents from hospitals at the height of the pandemic, instead of providing safer alternatives like HCBS.¹⁶⁶

When the pandemic started, all states applied for changes to their Medicaid 1915(c) waivers pursuant to Appendix K,¹⁶⁷ which allows for amending waivers during emergencies.¹⁶⁸ Some of these changes were positive, such as

159. *Id.* It should be noted that there are gaps in the data related to COVID's impact on disabled people, largely due to issues with data collection around disability, and particularly as to how disability intersects with other marginalized identities. *See id.* at 72–75.

160. *Id.* at 2.

161. *Id.*

162. *See id.*; Molly O'Malley Watts, MaryBeth Musumeci & Meghana Ammula, *State Medicaid Home & Community-Based Services (HCBS) Programs Respond to COVID-19: Early Findings from a 50-State Survey*, KFF (Aug. 10, 2021), <https://www.kff.org/coronavirus-covid-19/issue-brief/state-medicare-home-community-based-services-hcbs-programs-respond-to-covid-19-early-findings-from-a-50-state-survey> [perma.cc/22LX-FNSQ].

163. Priya Chidambaram & Rachel Garfield, *Nursing Homes Experienced Steeper Increase in COVID-19 Cases and Deaths in August 2021 than the Rest of the Country*, KFF (Oct. 1, 2021), <https://www.kff.org/coronavirus-covid-19/issue-brief/nursing-homes-experienced-steeper-increase-in-covid-19-cases-and-deaths-in-august-2021-than-the-rest-of-the-country> [perma.cc/BC4A-PEZ5].

164. *Id.*

165. NCD COVID REPORT, *supra* note 142, at 39.

166. *Id.* at 41; *see also id.* at 91 (“HCBS provides people with an opportunity to live full lives in the communities where they and their support systems are located, and, as we learned during COVID-19, serving people at home rather than in a [congregant-care facility] . . . helps to control the spread of the virus.”).

167. *Id.* at 102.

168. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., 1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER INSTRUCTIONS AND TECHNICAL GUIDANCE APPENDIX K: EMERGENCY

expanded coverage for testing services and waiver of enrollment fees and service limits, but there were also negative outcomes, such as allowances to contract existing benefits and lower provider qualifications.¹⁶⁹ The American Rescue Plan Act also included a one-year 10% FMAP bump for states, giving them more money to fund Medicaid.¹⁷⁰ In 2022, CMS gave states an additional year to use the funding from that bump with the goal of expanding HCBS access.¹⁷¹

As with other emergencies,¹⁷² disabled people have been at higher risk of institutionalization during the pandemic than they were before it.¹⁷³ Reliance on institutional settings increases when housing expenses are also rising, as they have been during the pandemic.¹⁷⁴ The 4.8 million disabled people who rely on Supplemental Security Income earn an average of only \$9,156 per year, which prices them out of every housing rental market in the country.¹⁷⁵

Even for individuals with access to HCBS, or those who were scheduled to transition into it, the pandemic hit hard.¹⁷⁶ The wellbeing of the direct care workforce itself heavily impacted the welfare of seniors and disabled people in both institutional and HCBS settings during the pandemic.¹⁷⁷ Even before COVID-19, the direct care workforce had been subject to high turnover and worker shortages as the overall U.S. population ages.¹⁷⁸ In 2019, one out of

PREPAREDNESS AND RESPONSE, <https://www.medicaid.gov/medicaid/home-community-based-services/downloads/1915c-appendix-k-instructions.pdf> [perma.cc/5X67-7F6U].

169. *Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19*, KFF (July 1, 2021), <https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19> [perma.cc/7VP4-T635].

170. See *supra* notes 101–104 and accompanying text.

171. Press Release, Ctrs. for Medicare & Medicaid Servs., HHS Extends American Rescue Plan Spending Deadline for States to Expand and Enhance Home- and Community-Based Services for People with Medicaid (June 3, 2022), <https://www.cms.gov/newsroom/press-releases/hhs-extends-american-rescue-plan-spending-deadline-states-expand-and-enhance-home-and-community> [perma.cc/M5AN-2SMM].

172. See generally NAT'L COUNCIL ON DISABILITY, PRESERVING OUR FREEDOM: ENDING INSTITUTIONALIZATION OF PEOPLE WITH DISABILITIES DURING AND AFTER DISASTERS (2019), https://ncd.gov/sites/default/files/NCD_Preserving_Our_Freedom_508.pdf [perma.cc/8TKZ-AJPB].

173. See NCD COVID REPORT, *supra* note 142, at 91–94.

174. Katelyn Li, *A Crisis Decades in the Making: Disability Housing Policy and COVID-19*, HARV. POL. REV. (Oct. 11, 2020), <https://harvardpolitics.com/congregate-care-covid> [perma.cc/5G5W-CDNR].

175. *Id.*

176. See, e.g., NCD COVID REPORT, *supra* note 142, at 92 (where a community provider asked to delay transitions out of institutions in part as a response to the pandemic); *id.* at 113 (where direct care workers lacked access to critical training and personal protective equipment to facilitate the best continued HCBS).

177. See *id.* at 113–34; MaryBeth Musumeci, Meghana Ammula & Robin Rudowitz, *Voices of Paid and Family Caregivers for Medicaid Enrollees Receiving HCBS*, KFF (Oct. 8, 2021), <https://www.kff.org/medicaid/issue-brief/voices-of-paid-and-family-caregivers-for-medicicaid-enrollees-receiving-hcbs> [perma.cc/J63A-NMBN].

178. NCD COVID REPORT, *supra* note 142, at 31.

every six direct care workers lived below the federal poverty level.¹⁷⁹ In 2020, their median hourly wage was \$13.56.¹⁸⁰ As the pandemic spread across the country, direct care workers bore the responsibility of providing essential care to seniors and disabled people. Nonetheless, they typically received little training on the risks of COVID and were not provided with adequate testing or personal protective equipment.¹⁸¹ These low-wage workers, who play an essential role in both institutional and HCBS settings, also often lack comprehensive employee benefits, adequate unemployment benefits, and hazard pay.¹⁸² It's not difficult to see how the pandemic pushed workers out of these undercompensated, high-risk jobs.¹⁸³ As of early 2022, 99% of nursing homes and 96% of assisted living facilities were experiencing staffing shortages—and those shortages have continued.¹⁸⁴

The pandemic has brought to light and intensified existing disparities. It has also demonstrated the weaknesses and interconnected issues of the healthcare infrastructure meant to protect the rights of seniors and disabled people.

B. *Why Most Current Responses Are Inadequate*

Federal and state governments have proposed and attempted to implement a number of solutions to the HCBS crisis, particularly in light of COVID-19, with mixed results. The American Rescue Plan Act's twelve-month 10% FMAP bump was intended to be a stopgap measure to continue state funding

179. *Id.*

180. PHI NAT'L, DIRECT CARE WORKERS IN THE UNITED STATES 1 (2021), <https://phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2> [perma.cc/4SAR-2VFH].

181. NCD COVID REPORT, *supra* note 142, at 113.

182. *Id.*

183. A direct care worker might leave her job for fear of contracting the virus, to care for her child who had transitioned to remote learning, because she is exhausted, because she found a more highly compensated job, etc. In just the first three months of the pandemic, 232,000 home care workers left their jobs. STEPHEN CAMPBELL, ANGELINA DEL RIO DRAKE, ROBERT ESPINOZA & KEZIA SCALES, CARING FOR THE FUTURE: THE POWER AND POTENTIAL OF AMERICA'S DIRECT CARE WORKFORCE 77 (2021), <http://phinational.org/wp-content/uploads/2021/01/Caring-for-the-Future-2021-PHI.pdf> [perma.cc/RQ28-URMT].

184. Kevin Gibas, Opinion, *Investing in Our Direct-Care Workers Could Help Put an End to the Worker Shortages*, TENNESSEAN (Jan. 21, 2022, 8:00 AM), <https://www.tennessean.com/story/opinion/2022/01/21/direct-care-workers-could-help-end-worker-shortages/6583483001> [perma.cc/6A85-6GS7]; Press Release, Am. Health Care Assoc., *Historic Staffing Shortages Continue To Force Nursing Homes To Limit New Admissions, Creating Bottlenecks at Hospitals and Reducing Access To Care For Seniors* (July 14, 2022), <https://www.ahcancal.org/News-and-Communications/Press-Releases/Pages/Historic-Staffing-Shortages-Continue-To-Force-Nursing-Homes-To-Limit-New-Admissions,-Creating-Bottlenecks-at-Hospitals-and-.aspx> [perma.cc/WV6T-6DCS]. This direct care worker shortage is an impending problem, as population projections estimate that, from 2016 to 2060, the population of adults aged sixty-five and older in the United States will nearly double. See PHI NAT'L, *supra* note 180, at 3.

of HCBS through the pandemic.¹⁸⁵ According to the Congressional Budget Office, this could result in up to \$12.7 billion flowing to states for HCBS, including home healthcare, personal care, habilitation services, supported employment, and rehabilitative services.¹⁸⁶ To get this funding, states must meet criteria related to keeping HCBS eligibility and services accessible without affecting funding levels.¹⁸⁷ States must also use FMAP funding to strengthen and enhance HCBS.¹⁸⁸ States have responded by submitting plans that include several HCBS supports, such as increased provider rates, expanded training and behavioral health capacity, and increased access to telehealth.¹⁸⁹ Some promising data show that the FMAP bump has improved states' abilities to maintain HCBS for senior and disabled populations.¹⁹⁰ Despite its short-term success, the one-year injection of funds is entirely insufficient to sustain long-term improvements that have been necessary since well before the pandemic.¹⁹¹

President Biden's original Build Back Better agenda included the most public solutions to the HCBS crisis thus far, but it's unlikely that the proposed changes, even if the agenda is achieved, will be sufficient.¹⁹² An influx of \$400 billion dollars into the HCBS system would provide states with more funds to shift resources from institutions to homes and communities.¹⁹³ While distribution plans for the money have yet to be fully explored, support for the direct care workforce, investment in more consistent and higher quality services, and a reduction in waitlist numbers would help address many of HCBS's structural issues. Even the post-compromise \$150 billion investment (the Better Care Better Jobs Act) would have a similar, albeit smaller, effect.¹⁹⁴ But none of these bills or proposals have passed. And even if they did, it's not clear that \$150

185. See JENNIFER SULLIVAN, CTR. FOR BUDGET & POL'Y PRIORITIES, STATES ARE USING ONE-TIME FUNDS TO IMPROVE MEDICAID HOME- AND COMMUNITY-BASED SERVICES, BUT LONGER-TERM INVESTMENTS ARE NEEDED 3 (2021), <https://www.cbpp.org/sites/default/files/9-24-21health.pdf> [perma.cc/5BUG-KA4Z].

186. *Id.*

187. *Id.* Some of the requirements are that states cannot impose stricter HCBS eligibility levels and methodologies than were in place as of April 2021, must maintain HCBS provider payment rates at least as high as they were in April 2021, and must maintain the amount, duration, and scope of HCBS benefits that they already provide as of April 2021. See Letter from Ctrs. for Medicare & Medicaid Servs. to State Medicaid Dirs. (May 13, 2021), <https://www.medicare.gov/federal-policy-guidance/downloads/smd21003.pdf> [perma.cc/9BQN-EYQR].

188. Letter from Ctrs. for Medicare & Medicaid Servs., *supra* note 187.

189. See SULLIVAN, *supra* note 185.

190. See Watts et al., *supra* note 132; SULLIVAN, *supra* note 185.

191. See SULLIVAN, *supra* note 185, at 4.

192. See Abelson, *supra* note 8.

193. See *id.*

194. *Id.* The plan included important incentives and new funding streams for states to move away from institutional care and toward HCBS and self-directed care. See BETTER CARE BETTER JOBS ACT: A Historic Investment in the Care Economy, U.S. SENATE SPECIAL COMM. ON AGING (June 2021), <https://www.aging.senate.gov/imo/media/doc/Better%20Care%20Better%20Jobs%20Act%20One%20Pager%20SBS%20072821.pdf> [perma.cc/ST44-XDQ9].

billion would be enough.¹⁹⁵ Only the 10% FMAP increase from the American Rescue Plan has actually circulated to states.¹⁹⁶ While the larger federal funding initiatives would be highly impactful—particularly to help stimulate a workforce boost across the country¹⁹⁷—other, more permanent solutions are necessary to build a HCBS system that is long-lasting and resilient. Further, the solutions explored in Part III ought to be pursued regardless of whether more federal funding (beyond what states can currently receive) comes in for HCBS.

At the state level, results from HCBS interventions have varied, particularly during the pandemic. There is substantial variation in HCBS eligibility, spending, and benefits across states.¹⁹⁸ As of August 2021, two thirds of states reported permanent closures of HCBS providers, despite state and federal interventions.¹⁹⁹ States most often attributed closures to workforce shortages and social distancing measures.²⁰⁰ While some, over time, have made improvements, the opportunity to build on the American Rescue Plan’s stopgap measure may be slipping away. If states continue to push away direct care workers and allow providers to close, they may, once again, resort to favoring institutional care, an outcome that would undo decades of HCBS progress.

195. Abelson writes:

“You have to be very realistic about the amount of need you have in the system right now,” said David Grabowski, a professor of health care policy at Harvard Medical School. The \$150 billion does represent a significant influx of funds, but there are limits, he said: “Once you start to do the math, the dollars don’t go as far as you’d like.”

See Abelson, *supra* note 8.

196. Priya Chidambaram & MaryBeth Musumeci, *Potential Impact of Additional Federal Funds for Medicaid HCBS for Seniors and People with Disabilities*, KFF (May 28, 2021), <https://www.kff.org/medicaid/issue-brief/potential-impact-of-additional-federal-funds-for-medicaid-hcbs-for-seniors-and-people-with-disabilities> [perma.cc/7GLJ-CXXC]; see, e.g., Press Release, Ctrs. for Medicare & Medicaid Servs., HHS Extends American Rescue Plan Spending Deadline for States to Expand and Enhance Home- and Community-Based Services for People with Medicaid (June 03, 2022), <https://www.cms.gov/newsroom/press-releases/hhs-extends-american-rescue-plan-spending-deadline-states-expand-and-enhance-home-and-community> [perma.cc/HJ4A-YH69]. This \$12.7 billion, while helpful, lasts only for one year and seems largely designed to be a stopgap measure during the pandemic.

197. Nearly all states reported that workforce shortages were the number-one impact of the pandemic on HCBS services. See Robin Rudowitz et al., *Medicaid: What to Watch in 2023*, KFF (Jan. 24, 2023), <https://www.kff.org/medicaid/issue-brief/medicaid-what-to-watch-in-2023> [perma.cc/TUK8-X3QN].

198. Molly O’Malley Watts, MaryBeth Musumeci & Meghana Ammula, *Medicaid Home & Community-Based Services: People Served and Spending During COVID-19*, KFF (Mar. 4, 2022), <https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-appendix> [perma.cc/2SK4-DQWX].

199. Andrew Donlan, *Two-Thirds of States Have Reported Permanent Closures of HCBS Providers During the Pandemic*, HOME HEALTH CARE NEWS (Aug. 15, 2021), <https://homehealthcarenews.com/2021/08/two-thirds-of-states-have-reported-permanent-closures-of-hcbs-providers-during-the-pandemic> [perma.cc/H5PA-FQCM].

200. *Id.*

Some have proposed outlawing waitlists or putting states on mandated plans to eliminate waitlists within some time frame.²⁰¹ As now-Secretary of the Maryland Department of Disabilities Carol Beatty argued in 2014, the grace period Justice Ginsburg granted states to deinstitutionalize without upending their Medicaid programs after *Olmstead* has expired.²⁰² Since *Olmstead*, states have taken advantage of the Supreme Court's loose language around waitlists to satisfy its "reasonable modifications" standard.²⁰³ At this point, almost ten years after Beatty made her observation, and more than twenty years post-*Olmstead*, states have had the time to experiment. Beatty argues that the federal government should pick some best-in-class examples of HCBS, set those as the standard, and mandate that states eliminate their waitlists and follow the model programs.²⁰⁴ This idea, however, only seems likely to work if several conditions are met: (1) states are given a definite timeline for emptying their waitlists,²⁰⁵ (2) Medicaid's institutional bias is legislated away,²⁰⁶ and (3) states are provided with adequate funding to work through their waitlists.²⁰⁷

III. LEGAL REMEDIES TO THE HCBS CRISIS

This Part explores two solutions to the HCBS crisis. Section III.A focuses on ramping up an innovative usage of *Olmstead* litigation that would force states to pull funding and resources from institutional care and direct them toward HCBS. This solution is easily implemented and would empower dis-

201. See Beatty, *supra* note 29.

202. *Id.*

203. Beatty quotes *Olmstead*:

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.

Id. at 736 (quoting *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605–06 (1999)); see also MEDICAID & CHILD HEALTH INS. PROGRAM PAYMENT & ACCESS COMM'N, *supra* note 84.

204. Beatty, *supra* note 29, at 740.

205. Even with funding, it would take time for states to build infrastructure for adequate HCBS, including a direct care workforce, housing for those who don't have it, and other general needs for the major ramp-up in services that will be required. See *infra* notes 213–215 and accompanying text. This point also runs up against the same implementation problems faced by *Brown v. Bd. of Educ. (Brown II)*, 349 U.S. 294 (1955). See *supra* notes 85–86 and accompanying text.

206. Federal legislation (which is always difficult to pass) would have to amend Medicaid to require states to provide adequate HCBS rather than just institutional care.

207. While HCBS is more cost-efficient than institutional care, not all individuals on waitlists are currently in institutional care, and the financial cost of this huge shift will leave many behind if the prohibition against waitlists is not accompanied by sufficient funding. 3 *Major Benefits of Community-Based Services vs. Institutional Care*, INTEGRITY INC. (Sep. 30, 2015), <https://www.integrityinc.org/3-major-benefits-of-community-based-services-vs-institutional-care> [perma.cc/2QKK-48EL].

bled plaintiffs. Section III.B proposes a new title of the ADA focused on emergency relief. This broader, longer-term solution would require HCBS systems across the country to become more resilient in the face of future emergencies, whether pandemics or otherwise.

A. *Ramping Up Olmstead Litigation*

1. *Olmstead* Cases and Federal Action After *Olmstead*

Disabled people, disability advocates, and the federal government can use *Olmstead* as a way to push states to deinstitutionalize and move resources toward HCBS. In 2020, the Disability Rights Section of the Civil Rights Division of the DOJ reaffirmed both “its commitment to vindicate the right of individuals with disabilities to live integrated lives under the ADA and *Olmstead*” and its interpretation of the case as reading an integration mandate into Title II of the ADA.²⁰⁸ For disabled individuals and their advocates, these *Olmstead* suits can result in impactful settlements for individuals and groups of disabled people.²⁰⁹ When the federal government (through the DOJ’s Civil Rights Division) brings these suits, settlements have resulted in critical, systemic, and deinstitutionalizing changes.

After the *Olmstead* decision, the Clinton and second Bush Administrations implemented smaller initiatives geared toward deinstitutionalization.²¹⁰ The Clinton Administration asked states to develop “*Olmstead* Plans,”²¹¹ such that, in line with Justice Ginsburg’s holding, a state could meet “the reasonable-modifications standard” if it “demonstrate[d] that it had a comprehensive,

208. U.S. DEP’T OF JUST., STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND *OLMSTEAD V. L.C.* (Feb. 25, 2020), https://www.ada.gov/olmstead/q&a_olmstead.htm [perma.cc/XCE3-AJUH].

209. See, e.g., *Lane v. Brown*, 166 F. Supp. 3d 1180, 1187 (D. Or. 2016). On August 12, 2022, the U.S. District Court for the District of Oregon found that “the State of Oregon ha[d] fulfilled the terms of a settlement agreement with the Justice Department and people with disabilities in a landmark case challenging the state’s provision of employment services for people with disabilities in segregated settings.” The Department of Justice described the settlement:

The agreement required Oregon to provide supported employment services and related employment services so that 1,115 sheltered workshop workers would newly receive jobs in the community at competitive wages over the agreement’s term. The agreement also required at least 7,000 people—including more than 4,900 youth exiting school—to receive supported employment services aimed at enabling them to secure and maintain integrated, competitive employment opportunities.

United States v. Oregon / Lane v. Brown, U.S. DEP’T OF JUST., <https://www.justice.gov/crt/case/united-states-v-oregon-lane-v-brown> [perma.cc/Q6R2-FCRG] (last updated August 19, 2022).

210. See Laura Sloan & Chinmoy Gulrajani, Editorial, *Where We Are on the Twentieth Anniversary of Olmstead v. L.C.*, 47 J. AM. ACAD. PSYCHIATRY & L. 408, 409 (2019).

211. *The Olmstead Decision*, MINN. GOVERNOR’S COUNCIL ON DEV. DISABILITIES, <https://mn.gov/mnddc/ada-legacy/ada-legacy-moment18.html> [https://perma.cc/QU27-F3HY].

effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace.”²¹² The Bush Administration launched the New Freedom Initiative in 2001 as an attempt to remove barriers to community living for disabled people and to implement *Olmstead*.²¹³ While even today not every state has an *Olmstead* Plan,²¹⁴ states palpably felt the federal government’s push to deinstitutionalize—“By 2003, 42 states had created a legislative *Olmstead* committee or task force.”²¹⁵ These initiatives helped push Medicaid funding away from institutions and toward HCBS,²¹⁶ although there is still much ground to be gained.

Since *Olmstead*, courts have taken inconsistent approaches to the issue of waitlists. For instance, in *Makin v. Hawaii*, a district court held that, if the population limit for a specific waiver had been reached, it was permissible for Hawai‘i to have individuals on waitlists (although some had been waiting more than two years), so long as other appropriate treatment was available through Medicaid.²¹⁷ In *Shepardson v. Stephen*, another district court held that the average waiting time in New Hampshire, approximately one year, was reasonable.²¹⁸ Other courts have mandated that states be able to show that their *Olmstead* plans are working and waitlists are moving at a reasonable pace for individual plaintiffs, rather than for disabled and senior populations at large.²¹⁹

More recently, *Olmstead* enforcement suits have “shift[ed] toward further social integration, not just physical integration.”²²⁰ In 2012’s *Lane v. Brown*, eight developmentally disabled people filed a class action lawsuit against Oregon, alleging that the state unnecessarily segregated disabled individuals in sheltered workshops instead of helping them find integrated jobs in their communities.²²¹ Oregon settled with the DOJ in 2015, committing to provide part-

212. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605–06 (1999).

213. *The 2004 Progress Report: The President’s New Freedom Initiative for People with Disabilities (Executive Summary)*, THE WHITE HOUSE ARCHIVES, <http://georgewbush-whitehouse.archives.gov/infocus/newfreedom/summary-2004.html> [perma.cc/FS6U-BZTJ]. The initiative, among other things, funded research for universally designed assistive technology. *Id.*

214. Sloan & Gulrajani, *supra* note 210, at 409. A number of states only created their *Olmstead* plans in response to lawsuits from the federal government or other litigants. *Id.*

215. *Id.*

216. *See supra* note 127 and accompanying text.

217. *Makin v. Hawaii*, 114 F. Supp. 2d 1017, 1023, 1028 (D. Haw. 1999).

218. *Shepardson v. Stephen*, No. 99-CV-558-SM, 2006 U.S. Dist. LEXIS 71775, at *24 (D.N.H. Sept. 29, 2006).

219. *See, e.g., Disability Advocs., Inc. v. Paterson*, 598 F. Supp. 2d 289, 335 (E.D.N.Y. 2009); *G. v. Hawaii*, 676 F. Supp. 2d 1046, 1061 (D. Haw. 2009).

220. *See Sloan & Gulrajani, supra* note 210, at 412.

221. *Lane v. Brown*, 166 F. Supp. 3d 1180, 1184–85 (D. Or. 2016). The case was originally filed in 2012. The DOJ intervened in 2013. *Id.* at 1185.

or full-time competitive-wage employment for about 7,000 individuals—“including more than 4,900 youth exiting school”—over seven years at facilities where the disabled employees interact with nondisabled people.²²² The DOJ reached a similar consent decree settlement agreement with Rhode Island and the city of Providence following an investigation that revealed the state and city were unnecessarily segregating disabled people in a sheltered workshop.²²³

In 2018, however, the DOJ’s important *Olmstead* work was stunted by then-Attorney General Jeff Sessions’s memo on consent decrees with state and local governmental entities.²²⁴ Among other things, the new guidance required that consent decrees be approved by top political appointees rather than by the career DOJ lawyers who had previously held this authority.²²⁵ Casting consent decrees as inflexible and potentially overly burdensome for defendants, the memo required DOJ attorneys to engage in cost-benefit analysis for the decree and include sunset dates for all consent decrees.²²⁶ The guidance led to a steep decline in DOJ involvement in *Olmstead* cases until April 2021, when it was rescinded by Attorney General Merrick Garland.²²⁷ The rescission gave civil litigating bodies like the Disability Rights Section of the Civil Rights Division more agency in seeking consent decrees.²²⁸

Under the Biden Administration, the DOJ seems to be reinvesting in *Olmstead* enforcement. In June 2021, the DOJ entered into a settlement agreement with the Maine Department of Health and Human Services on behalf of an individual complainant who was left without necessary services in the “most integrated setting appropriate to their needs.”²²⁹ The DOJ required Maine to provide the complainant with access to all necessary in-home services and \$100,000 in damages.²³⁰ In a later case in March 2022, the DOJ sent a Letter of Findings to Colorado, alleging that the state violated the integration

222. United States v Oregon / Lane v Brown, *supra* note 209.

223. *Department of Justice Reaches Landmark Americans with Disabilities Act Settlement Agreement with Rhode Island*, U.S. DEP’T OF JUST., <https://www.justice.gov/opa/pr/department-justice-reaches-landmark-americans-disabilities-act-settlement-agreement-rhode> [perma.cc/X7GD-8CCF] (last updated Aug. 5, 2015).

224. Memorandum from the Att’y Gen., U.S. Dep’t of Just., to Heads of Civ. Litig. Components & U.S. Att’y’s (Nov. 7, 2018), <https://www.justice.gov/opa/press-release/file/1109621/download> [perma.cc/7H9W-7S9G].

225. *Id.*

226. *Id.*

227. Memorandum from the Att’y Gen., U.S. Dep’t of Just., to Heads of Civ. Litig. Components & U.S. Att’y’s (Apr. 16, 2021), <https://int.nyt.com/data/documenttools/justice-dept/21d2019efd4541a7/full.pdf> [perma.cc/4VPS-HL8W].

228. *Id.*

229. See *Settlement Agreement DJ# 204-34-72*, ARCHIVE ADA (June 2021), https://www.ada.gov/maine_hhs_sa.html [perma.cc/9S85-GQJ3].

230. *Id.*

mandate in its provision of LTSS to disabled Coloradans, unnecessarily isolating them in nursing facilities.²³¹ The DOJ has also written a number of statements of interest in cases brought by disabled individuals and advocacy organizations, seeking to clarify standing issues and the nature of discrimination on the basis of disability in *Olmstead* cases,²³² effectively signaling the federal government's support for deinstitutionalization.²³³

Disabled individuals seeking to obtain HCBS, advocates seeking to deinstitutionalize, and a federal government seeking to enforce civil rights will find common ground through *Olmstead*. Circuits have split on a wide variety of issues in *Olmstead* litigation,²³⁴ but the unprecedented harms that COVID has wrought against disabled and senior communities living in institutionalized settings present a unique opportunity to advance *Olmstead* litigation.

In litigation that involves the DOJ or larger class actions, settlement discussions with the state can also push toward larger-scale deinstitutionalization, as seen in the past. In late 2020, the DOJ entered into a comprehensive settlement with North Dakota to resolve complaints that the state discriminated against physically disabled individuals by unnecessarily institutionalizing them in nursing facilities rather than providing them HCBS.²³⁵ The agreement requires North Dakota to transform its long-term care system so that over 2,500 physically disabled people can access HCBS.²³⁶ There are also political incentives for state governments to make big deinstitutionalizing changes. State administrations were heavily criticized for their failure to care

231. See Letter from U.S. Dep't of Just., C.R. Div., to Jared Polis, Gov. of Colo. (Mar. 3, 2022), https://archive.ada.gov/olmstead/documents/colorado_lof.pdf [perma.cc/JR8R-ST9N].

232. E.g., Statement of Interest of the United States of America, *A.A. v. Bimestefer*, No. 1:21-cv-2381 (D. Colo. Jan. 14, 2022), https://www.ada.gov/bimestefer_soi.pdf [perma.cc/5KTN-UJJ9]; Statement of Interest of the United States of America, *Z.S. v. Durham County*, No. 1:21-cv-663 (M.D. N.C. Oct. 25, 2021), <https://www.justice.gov/crt/page/file/1446341/download> [perma.cc/D62Z-R6Q4].

233. Victor Zapana, Note, *The Statement of Interest as a Tool in Federal Civil Rights Enforcement*, 52 HARV. C.R.-C.L. L. REV. 227, 252 (2017) (“[P]ublishing a general statement sends a signal that the civil right at issue is a priority for the federal government.”).

234. See SANDRA J. STAUB & STEVEN J. SCHWARTZ, FACT SHEET: *OLMSTEAD PLANS AND FUNDAMENTAL ALTERATION: LITIGATION STRATEGIES FOR THESE CONNECTED DEFENSES 2-3* (2019), <http://materials.ndrn.org/virtual20/session33/Olmstead%20Litigation%20in%20Nursing%20Facilities/Fundamental%20Alteration%20and%20Olmstead%20Plan.Fact%20Sheet.2019.pdf> [perma.cc/72HD-N3P4].

235. *Settlement Agreement Between the United States and the State of North Dakota*, ARCHIVE ADA (Dec. 2020), https://www.ada.gov/nd_sa.html [perma.cc/W8KT-SGF7].

236. See *id.*

for patients in nursing homes during the pandemic,²³⁷ and many political activists are focused on HCBS.²³⁸ Governors across the country seem more incentivized to push funding toward HCBS and away from institutions, reducing waitlists and making political amends for grave mistakes made during COVID.

2. Bringing *Olmstead* Cases

To bring an *Olmstead* case, plaintiffs must make a prima facie case and later prove that the State or other public entity has failed to provide sufficient and appropriate services in integrated settings; the plaintiff must also propose reasonable modifications to the government defendant's system that would remedy the purported failure.²³⁹ In defending against *Olmstead* cases, the State can rely on two affirmative defenses: fundamental alteration and an *Olmstead* plan.²⁴⁰ Given today's circumstances, plaintiffs can make strong arguments to rebut each of these available affirmative defenses and advance their own claims.

After alleging that the State or public entity has failed to provide sufficient and appropriate services, plaintiffs must propose reasonable modifications. In proposing those reasonable modifications, plaintiffs meet their burden by showing there is some plausible accommodation that the State entity could, but does not, offer.²⁴¹ For plaintiffs, these sorts of accommodations include things like having the entity make small methodological changes (to the way

237. See, e.g., Luis Ferré-Sadurní, *Health Agency Under Cuomo 'Misled the Public' on Nursing Home Deaths*, N.Y. TIMES (Mar. 15, 2022), <https://www.nytimes.com/2022/03/15/nyregion/nursing-home-deaths-cuomo-covid.html> [perma.cc/B6LZ-HWP2]; Emily Hoeven, *Newsom Admin Ripped for Nursing Home Policies*, CALMATTERS (Oct. 6, 2021), <https://calmatters.org/newsletters/whatmatters/2021/10/newsom-admin-ripped-for-nursing-home-policies> [perma.cc/J5JV-7FW3].

238. See, e.g., Ady Barkan & Debbie Dingell, *Opinion, Strengthen and Expand Home- and Community-Based Health Care*, N.Y. DAILY NEWS (Oct. 26, 2021, 10:00 AM), <https://www.nydailynews.com/opinion/ny-oped-strengthen-and-expand-home-and-community-based-health-care-20211026-yg73valtzbz5ouaj4szbmo2me-story.html> [perma.cc/9WDL-XKUN].

239. See STAUB & SCHWARTZ, *supra* note 234, at 1–2.

240. As Justice Ginsburg stated in *Olmstead*:

To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow. If, for example, the State were to demonstrate 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, the reasonable-modifications standard would be met.

See *Olmstead v. L.C. ex. rel. Zimring*, 527 U.S. 581, 605–06 (1999) (Ginsburg, J., concurring).

241. STAUB & SCHWARTZ, *supra* note 234, at 3.

that the entity allocates funding)²⁴² or having the entity provide individuals with certain services or items (e.g. a water walker for water aquatics).²⁴³ In the COVID and post-COVID world, judges may find that the bounds of reasonableness have shifted. In a pre-COVID example, a judge found that *Olmstead* did not require a state to increase its established maximum number of individuals with access to HCBS through 1915(c) waivers.²⁴⁴ But now, an increase in or even the elimination of these state-imposed limits might be within reach. The argument would sound something like: given *Olmstead*'s status as an integrationist opinion,²⁴⁵ the length of time it has been since the integration mandate became clear, the additional funds available to states through various federal programs,²⁴⁶ and the significant health risk that institutionalization imposes on seniors and disabled people,²⁴⁷ it is reasonable for the State to modify its Medicaid services by doing X.²⁴⁸ States and judges may even consider these accommodations more reasonable in the context of class actions or actions brought by the federal government, where States and judges might consider the combined interests even weightier.

Once a plaintiff has met the prima facie burden of describing the reasonable modifications to a State's service system, a State can put forward the affirmative defense that the requested change would result in a "fundamental alteration" to the State's service system.²⁴⁹ Under this defense, the State can: (1) assert that the proposed change amounts to a fundamental alteration in terms of the benefits, services, or programs that the system provides,²⁵⁰ or (2) assert that the cost of the proposed accommodation would fundamentally

242. See *Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 435 (6th Cir. 2020).

243. See *Stogsdill v. S.C. Dep't of Health & Hum. Servs.*, No. 3:12-CV-0007-JFA, 2021 WL 4551143, at *16–17 (D.S.C. Oct. 5, 2021).

244. See *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615 (9th Cir. 2005).

245. Bagenstos, *supra* note 68, at 7 (“[*Olmstead*] refers to the choice of the ‘affected individual,’ but only in a sense that is subordinate to the opinion’s primary focus on integration.”).

246. See *supra* note 127 and accompanying text.

247. See *supra* Part II.

248. X might include signing up for the Money Follows the Person program (a federal grant for states to transition people from institutional care to HCBS), the Medicaid Balancing Incentive Program (a federal grant and enhanced FMAP for LTSS structural reforms), or other federal incentives for improved access to HCBS. See Scales, *supra* note 106, at 268; MOLLY O'MALLEY WATTS, ERICA L. REAVES & MARYBETH MUSUMECI, MEDICAID BALANCING INCENTIVE PROGRAM (2015), <https://files.kff.org/attachment/report-medicaid-balancing-incentive-program-a-survey-of-participating-states> [perma.cc/V865-XPCH]. Of course, in the shorter term, while COVID waves continue to occur, reasonable accommodations might look like more personal protective equipment, new vaccine distribution prioritization schemes, and other pandemic-related changes. See generally NCD COVID REPORT, *supra* note 142.

249. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 603–06 (1999); *Henrietta D. v. Bloomberg*, 331 F.3d 261, 280–81 (2d Cir. 2003).

250. See *Disability Advocs., Inc. v. Paterson*, 598 F. Supp. 2d 289, 335–36 (E.D.N.Y. 2009).

harm the State's ability to provide other health services.²⁵¹ Distinguishing between reasonable modifications and fundamental alterations can be tricky, and there is a fair amount of variance in how courts think about this.²⁵² Successful plaintiffs fighting this defense in the COVID and post-COVID world can argue that, in light of the health dangers and other drawbacks of institutional settings,²⁵³ courts should extend the bounds of the reasonable expectations of deinstitutionalization. Specifically, the current risks that individuals face in institutions warrant swift moves to deinstitutionalize, including a hefty diversion of resources and financial support.

In a hypothetical case, take State Institution A, which houses 100 people. A plaintiff may argue that diverting \$100,000 per year from Institution A's budget would allow the State to move between three and thirteen people out of Institution A.²⁵⁴ But the State will argue that Institution A will still need to be able to house the rest of the people. Thus, the \$100,000 deduction in its funding will lead to reduced services for the people still left in Institution A. The plaintiff could counter that the reasonable modification to the State's system ought to be shutting down Institution A, moving all of its inhabitants who meet the *Olmstead* standard into their homes and communities,²⁵⁵ and transferring the small number of inhabitants who still need some sort of institutional care into Institution B. This sort of argument, in light of mass deaths in congregant care facilities during COVID, helps reframe the bounds of reasonableness while taking into account states' long-term interest in deinstitutionalizing, yet conserving resources.²⁵⁶

A State's second affirmative defense against an *Olmstead* suit can be thought of as an "*Olmstead* plan defense." It can put forward this defense by showing that it has a "comprehensive, effectively working plan for placing qualified persons with . . . disabilities in less restrictive settings . . ." ²⁵⁷ The State's commitment must be more than "[g]eneral assurances and good-faith intentions [which] . . . are simply insufficient guarantors in light of the hardship daily inflicted upon [disabled people] through unnecessary and indefinite institutionalization."²⁵⁸ At the bare minimum, a State must prove that it developed and is implementing an *Olmstead* plan that demonstrates a specific and

251. See *id.* at 349–54.

252. See STAUB & SCHWARTZ, *supra* note 234, at 12–13.

253. See *supra* Section IIA.

254. National per enrollee spending on HCBS ranges from \$8,000 to nearly \$30,000 per year, so \$100,000 covers about three-to-thirteen people. See Watts et al., *supra* note 105.

255. Per *Olmstead*, the person would need: (1) a determination from treatment professionals that home/community placement is appropriate and (2) a desire to live at home or in their community. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 583–84 (1999).

256. It should be reiterated here that institutional care can cost states up to *double* the amount per person that HCBS does. See *supra* note 15 and accompanying text.

257. *Frederick L. v. Dep't of Pub. Welfare*, 422 F.3d 151, 157 (3d Cir. 2005) (quoting *Olmstead*, 527 U.S. at 605–06).

258. *Id.* at 158.

measurable commitment to action for which the entity can be held accountable.²⁵⁹ Here, plaintiffs can defeat those defenses by pointing to the slower rates of deinstitutionalization across states.²⁶⁰ Discovery may also reveal segments of institutionalized persons that have been under-deinstitutionalized, which can be the basis for finding an *Olmstead* plan inadequate.²⁶¹ Of course, States could plausibly argue that their plans would be back on track after the pandemic, which affected all services and drove the current shortage of direct care workers. However, given the American Rescue Plan's increased funding and the present risks of remaining in institutions for older and disabled people, courts would have all the more reason to find that the pandemic necessitates a faster pace of deinstitutionalization. And in responding to the direct care worker argument: pay them more, and they will come!²⁶²

259. *Id.*

260. See, e.g., NCD COVID REPORT, *supra* note 142, at 92 (“[T]he pandemic’s impact in slowing down discharges and diversions from [Congregant Care Facilities] and hampering the community service system meant that people with disabilities had little chance of achieving their right to community integration and were stuck in CCFs that in many cases had become dangerous.”).

261. See STAUB & SCHWARTZ, *supra* note 234, at 10.

262. See, e.g., *How Michigan Permanently Increased Wages for Direct Care Workers*, PHI NAT’L (Nov. 29, 2022), <https://www.phinational.org/news/how-michigan-permanently-increased-wages-for-direct-care-workers> [perma.cc/54H2-726S] (“Across the board, agencies that hire direct care workers and direct care workers themselves would agree that [Michigan’s] wage increase [for direct care workers] definitely helped with recruitment and retention.”). In addition to potential *Olmstead* claims, plaintiffs may also do well to bring auxiliary substantive due process claims under *Youngberg v. Romeo*, 456 U.S. 307 (1982). The case involved Nicholas Romeo, a developmentally disabled man who was committed to the Pennhurst State School and Hospital in 1974. *Id.* at 310. Pennhurst is a stain on American history, a place where medical experimentation and physical and psychological abuse were rampant. See PENNHURST AND THE STRUGGLE FOR DISABILITY RIGHTS (Dennis B. Downey & James W. Conroy eds., 2020). Disabled people were, among other things, subjected to forced segregation and sterilization. *Id.* Romeo’s mother sued under the Eighth and Fourteenth Amendments in 1976 after becoming concerned about the numerous injuries he had incurred while living at Pennhurst. *Romeo*, 456 U.S. at 310. The Supreme Court ultimately held for Romeo and recognized that people subject to commitment proceedings have a protected interest in safe conditions and minimally adequate habilitation while confined. *Id.* at 315–16. Those rights are balanced against those of the State. *Id.* at 321. Deinstitutionalization cases during the pandemic can be analogized to *Romeo*: in both situations, a State institution denied the plaintiff access to safe conditions and the court should rectify the circumstances. Unfortunately, it’s not hard to see this argument losing, considering how a State could characterize its interest quite broadly as stopping the COVID-19 pandemic and the hundreds of thousands of deaths that occurred in and out of institutional settings. If a judge accepts that characterization, any interest asserted by plaintiffs seems likely to fail. That being said, balancing tests are hard to administer, so there may be more room than we think. See Don Herzog, *The Kerr Principle, State Action, and Legal Rights*, 105 MICH. L. REV. 1, 2 (2007) (discussing the “indefensible project of balancing”).

B. *An Emergency Relief Title for the ADA*

In a 2022 piece in the *Syracuse Law Review*, Professor Doron Dorfman imagines a fifth title of the ADA—one that would adequately account for disabled people during emergencies.²⁶³ This Section argues that Congress ought to add that title through the lens of its impact on HCBS. The particularities of this new provision are fit for another Note, but this Section will justify the title as a method to address the HCBS crisis, outline some of the title’s general contours, and address various considerations associated with a law like this.

Emergencies have always exacerbated preexisting disparities that disabled people face.²⁶⁴ This includes all sorts of emergencies, from “natural” disasters like hurricanes²⁶⁵ and wildfires,²⁶⁶ to school shootings that have plagued the country.²⁶⁷ Many state and local governments have developed emergency preparedness plans to ensure the safety of their citizens, but these plans frequently ignore the rights of disabled people.²⁶⁸ Although Title II of the ADA prohibits discrimination on the basis of disability in government services,²⁶⁹ the ADA itself never explicitly confers an obligation on these government entities to account for disabled people in planning.²⁷⁰ There are some related federal regulations that mention emergencies but without much clarity.²⁷¹ Some federal

263. Dorfman, *supra* note 62, at 942.

264. See Jacob Abudaram, Exploring How Disabled People Are Treated During Crises and Charting a Path Forward for a Justice-Based, Person-Centered Approach to Crisis Response (July 1, 2020) (unpublished manuscript), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4072363 [perma.cc/Z7GX-MJRB].

265. For example, when Hurricane Katrina hit New Orleans in 2005, the American Red Cross, which was providing shelter for people, turned away people with obvious disabilities. NAT’L COUNCIL ON DISABILITY, THE IMPACT OF HURRICANES KATRINA AND RITA ON PEOPLE WITH DISABILITIES (2006), <https://ncd.gov/publications/2006/aug072006> [perma.cc/T2HZ-WMLF]. The tragedy of Ethel Freeman, a ninety-one-year-old Black woman, made national headlines: she was a wheelchair user who died while waiting for an accessible bus that never arrived after being given erroneous directions by police officers. *Katrina Victim Who Dies in Wheelchair Honored*, NBC NEWS (Sept. 1, 2006, 6:09 PM), <https://www.nbcnews.com/id/wbna14627601> [perma.cc/JY2R-XBKJ]. Dorfman, *supra* note 62, at 935–38. Note that “natural” is in quotation marks given the growing consensus that many of these natural hazards are only made to be disasters because of how poorly humans have planned for them. See, e.g., Kendra Pierre-Louis, *There’s Actually No Such Thing as a Natural Disaster*, POPULAR SCI. (Oct. 2, 2017, 3:30 PM), <https://www.popsoci.com/no-such-thing-as-natural-disaster> [perma.cc/7SES-AHJM].

266. Dorfman, *supra* note 62, at 938–39.

267. See Barry Taylor, *The Development of Emergency Planning for People with Disabilities Through ADA Litigation*, 51 JOHN MARSHALL L. REV. 819, 832–34 (2018); Abudaram, *supra* note 264, at 19–21.

268. See, e.g., NAT’L COUNCIL ON DISABILITY, *supra* note 265.

269. 42 U.S.C. § 12132 (1994).

270. Taylor, *supra* note 267.

271. See, e.g., 25 C.F.R. § 35.160(c)(2)(i) (2023) (“A public entity shall not rely on an adult accompanying an individual with a disability to interpret or facilitate communication except — [i]n an emergency involving an imminent threat to the safety or welfare of an individual or the public where there is no interpreter available . . .”).

agencies have developed guidance and resources to help government stakeholders incorporate disability issues into emergency planning.²⁷² But experience shows that when push comes to shove, disabled people have been thrown to the wayside during disasters, including COVID-19. State and local governments *need* more incentives to include disabled people in their emergency planning going forward.

A new title of the ADA focused on emergency planning will strengthen the distribution and safety of HCBS. It may also increase access to them. Because government entities would be required to account for the needs of disabled people during emergencies, they would, in turn, be incentivized to find cost-effective methods to keep people safe in the first place. Of course, institutional and congregant care facilities proved to be some of the most dangerous places during the pandemic.²⁷³ And during other emergencies like Hurricane Sandy, “[t]housands of people with disabilities and older adults were left stranded in apartment buildings or nursing homes without working elevators, medical assistance, running water, and electricity and with very little food for nearly two weeks.”²⁷⁴ During the COVID-19 pandemic, an accessible LTSS system would have seen more seniors and disabled people in their homes, likely with some sort of coordinated podding system that would have allowed for services like home health aides to still provide for their clients. Likewise, during Hurricane Sandy, this would have meant more funding of homecare administrative systems that could have helped meet people’s needs.²⁷⁵ Bottom line: if more people had been in their homes and communities with access to the care they needed, fewer would have died.

Professor Dorfman’s proposal is modeled after the United Nations Convention on the Rights of People with Disabilities (CRPD).²⁷⁶ Article 11 of the CRPD requires parties to “take . . . all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including . . . humanitarian emergencies and the occurrence of natural disasters.”²⁷⁷ Such language would be helpful, as it adds an affirmative duty, but it also falls out

272. Taylor, *supra* note 267, at 836.

273. See *supra* Part II.

274. Dorfman, *supra* note 62, at 937–38.

275. In *Brooklyn Center for Independence of the Disabled v. Bloomberg*, 980 F. Supp 2d 588 (S.D.N.Y. 2013), the District Court for the Southern District of New York found that the city had violated its obligations under the ADA and Section 504. Had the city had better emergency and healthcare infrastructure in place, this may never have been an issue.

276. Dorfman, *supra* note 62, at 942. As an aside, the United States has not ratified the CRPD despite myriad calls for it to do so. See Rochelle Jones, *U.S. Failure to Ratify the Convention on the Rights of Persons with Disabilities*, AWID (Apr. 19, 2013), <https://www.awid.org/news-and-analysis/us-failure-ratify-convention-rights-persons-disabilities> [perma.cc/UQ4Z-8RL3].

277. U.N. Convention on the Rights of Persons with Disabilities art. 11, Dec. 13, 2006, 2515 U.N.T.S. 3.

of accord with the structure of the other ADA titles.²⁷⁸ So, even stronger language might be something like: “It shall be considered discrimination for a local or state government to fail to make emergency plans, including but not limited to disasters and pandemics, not readily accessible to and inclusive of individuals with disabilities, as prescribed by the DOJ in regulations issued under this title.”

Professor Dorfman’s proposal also seems more promising as a way to ensure that disabled lives are saved *ex ante*.²⁷⁹ A perpetual problem in disability rights litigation (and civil rights litigation more broadly) is the *ex post* nature of the work—suits have to be brought after harm has been done. Of course, the federal government uses carrots and sticks across its interactions with states. An effective scheme to increase accountability could tie broader Medicaid funding to compliance with this new title and deinstitutionalization—a scheme that may be warranted given the fatal consequences of emergencies like natural disasters and contagious disease.

A more affirmative emergency relief title like the one Professor Dorfman has proposed, accompanied by the promulgation of rules by federal agencies like the DOJ, FEMA, and HHS, would instruct state and local governments on where funding, resources, and planning ought to go.²⁸⁰ Those regulations should accord with a number of important principles outlined by Adrien Weibgen, including: (1) “detailed plans that anticipate the needs of [people with disabilities] and outline clear strategies for meeting those needs”; (2) effective, detailed, and accessible communication with disabled people before, during, and after emergencies; (3) enlistment of outside experts with experience in accessible emergency planning; and (4) involvement from actually disabled people in emergency planning processes, which can be achieved through centers for independent living (community-based entities that exist by statute in every state).²⁸¹

The federal guidance should include clear instructions and sample budgets to steer states to deinstitutionalize and fund HCBS. If, for example, the Michigan Department of Health & Human Services (HHS) needs to ensure that it is protecting disabled people in emergencies, it wouldn’t make much sense to have those people living in congregant settings where disease could easily spread. Rather, Michigan HHS should be incentivized to create a resilient LTSS system, with lower chances of disease spread, that prioritizes everyone’s safety. With this incentive, more funding would go toward HCBS more

278. The other titles use strong language like “it shall be considered discrimination for . . .” 42 U.S.C. §§ 12101–12213.

279. See Dorfman, *supra* note 62, at 935.

280. *Id.* at 942. These regulations could provide clear guidance on procedures to ensure equitable vaccine distribution, accessible communication plans, and others. *Id.* at 942–43 (arguing for creating and managing healthcare distribution systems during emergencies).

281. Adrien A. Weibgen, Note, *The Right to Be Rescued: Disability Justice in an Age of Disaster*, 124 YALE L.J. 2406, 2466–68 (2015).

broadly and to reducing HCBS waitlists. Offering additional contingent Medicaid funding would further incentivize Michigan HHS to deinstitutionalize before the next emergency.

The political feasibility of amending landmark civil rights legislation like the ADA is a serious concern. Today, civil rights are politically polarized, with congressional Democrats supporting civil rights and Republicans opposing them.²⁸² The ADA and the ADA Amendments Act, however, were both passed with Republican congressional support and signed into law by Republican presidents.²⁸³ Most Americans at the time viewed disability through the lens of pity and charity.²⁸⁴ Legislators seemed to approach disability in the same way, adding a cost-benefit lens.²⁸⁵ Of course, disability advocates have sought to move away from the pity lens and more towards a civil rights lens.²⁸⁶ In this light, it is hard to see a political path towards further ADA amendments.

CONCLUSION

Home- and community-based services play an important role in fulfilling the ADA's promise of ensuring that disabled people have equal opportunities to fully participate in all aspects of life. While the HCBS crisis existed long before the COVID-19 pandemic, the pandemic has highlighted and exacerbated many of the existing cracks in the system. Patching up HCBS and its crumbling infrastructure will require billions of dollars, dollars that both the federal and state governments have continually failed to pony up. Further, improving HCBS requires not viewing HCBS as a healthcare silo, but rather embracing "cross-sector" efforts to address housing and other social determinants of health.²⁸⁷ In the meantime, legal remedies, including expanding the use of *Olmstead* and adding a new title to the ADA, can play important roles in (1) getting people out of often-dangerous institutional settings in the

282. See Ronald Brownstein, *The Republican Axis Reversing the Rights Revolution*, ATLANTIC (Dec. 24, 2021), <https://www.theatlantic.com/politics/archive/2021/12/republican-states-rights-restrictions/621101> [perma.cc/WGY3-5LTR].

283. See Allen Smith, *President Bush's Support Helped Make Americans with Disabilities Act a Reality*, SOC'Y FOR HUM. RES. MGMT. (Dec. 4, 2018), <https://www.shrm.org/resourcesandtools/legal-and-compliance/employment-law/pages/bush-secured-bipartisan-support-for-ada.aspx> [perma.cc/L9V6-VB3Z]; Paul Buchanan, *Bipartisan Consensus on Our Human Frailty: The ADA Amendments Act 10 Years Later*, HILL (Sept. 9, 2018, 4:00 PM), <https://thehill.com/opinion/civil-rights/405655-bipartisan-consensus-on-our-human-frailty-the-ada-amendments-act-10> [perma.cc/MXV8-B8BE].

284. Samuel R Bagenstos, *Disability Rights and the Discourse of Justice*, 73 SMU L. REV. F. 26, 32 (2020) (citing JOSEPH R. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 328 (1993)).

285. Bagenstos, *supra* note 284.

286. See, e.g., JOSEPH R. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1993).

287. Similar to HCBS, there are years-long waitlists for housing vouchers throughout much of the country. See SULLIVAN, *supra* note 185, at 6. Only one in four families eligible for federal rental assistance receives it. *Id.* How can someone receive HCBS without adequate housing?

short term, while (2) ensuring that state and local governments build resilient support infrastructures in the long term. With these proposed strategies, disabled people, advocates, and policymakers can create an America that fulfills its promise as an inclusive country that helps everyone build an independent life.