

# NOTES

## STRENGTHENING THE RIGHT TO MEDICAID HOME AND COMMUNITY-BASED SERVICES IN THE POST-COVID ERA

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*The COVID-19 pandemic has laid bare the severe public health danger that institutional and congregate care settings pose to people with disabilities, older adults, and the care professionals who work in those settings. While the populations residing in congregate care settings are naturally more susceptible to the virus, the COVID-19 crisis in these settings could have been far more limited if there had been broader access to home and community-based services (HCBS), which allow people to live with the supports they need in their own homes and communities and avoid many of the health risks of congregate care settings.*

*A major barrier to broadening access to HCBS is existing judicial interpretations of the reasonable modifications regulation under the Americans with Disabilities Act (ADA). This regulation requires states and other public entities to “make reasonable modifications” to avoid disability-based discrimination (which includes unjustified institutionalization) but does not require measures that would “fundamentally alter” the nature of the entity’s programs. Unfortunately, the Supreme Court’s 1999 *Olmstead v. L.C.* decision and subsequent lower court decisions interpreting *Olmstead* have created a standard for this fundamental alteration defense that fails to fully protect individuals’ ADA right to services in an integrated setting and does not account for the public health risks of institutionalization. This Note argues that in light of the new and undeniable evidence from the COVID-19 pandemic of the public health risks of institutionalization, the Department of Justice should use its broad regulatory authority under the ADA to promulgate additional regulations that clarify and strengthen the fundamental alteration framework.*

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## INTRODUCTION

The COVID-19 pandemic has laid bare the severe public health danger that institutional and congregate care settings pose to people with disabilities, older adults, and the care professionals who work in those settings. As of August 2020, over forty percent of all COVID-19 deaths in the United States were linked to nursing homes and other long-term care facilities.<sup>1</sup> By November 2020, over 100,000 residents and staff at long-term care facilities had died of the virus.<sup>2</sup> Some observers referred to such institutions during the pandemic as “death pits” and the public health crisis in institutions as a “human tragedy.”<sup>3</sup> While the known death counts in institutions serving people with disabilities and older adults are horrific enough, the full magnitude of the virus’s devastation in such settings is unknown because there is no nationwide, comprehensive dataset available on COVID-19 cases and deaths across all congregate care settings, including those that primarily serve people with disabilities.<sup>4</sup>

A tragedy of this magnitude among people with disabilities and older adults was not inevitable. Even holding constant the rampant spread of the

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1. More Than 40% of U.S. Coronavirus Deaths Are Linked to Nursing Homes, N.Y. Times (Aug. 13, 2020), <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html> (on file with the *Columbia Law Review*).

2. Priya Chidambaram, Rachel Garfield & Tricia Neuman, Kaiser Fam. Found., COVID-19 Has Claimed the Lives of 100,000 Long-Term Care Residents and Staff (2020), <https://www.kff.org/policy-watch/covid-19-has-claimed-the-lives-of-100000-long-term-care-residents-and-staff/> [<https://perma.cc/2GUG-YYQS>].

3. See ACLU, Serv. Emps. Int’l Union, Am. Ass’n of People With Disabilities, Autistic Self-Advocacy Network, Disability Rts. Educ. & Def. Fund, Nat’l Council on Indep. Living, P’ship for Inclusive Disaster Strategies & World Inst. on Disability, Petition to HHS, CMS, CCSQ, and CDC 3 (June 23, 2020), <https://www.aclu.org/petition-covid-19-response-nursing-homes-and-other-congregate-settings-where-people-disabilities> (on file with the *Columbia Law Review*); Farah Stockman, Matt Richtel, Danielle Ivory & Mitch Smith, ‘They’re Death Pits’: Virus Claims at Least 7,000 Lives in U.S. Nursing Homes, N.Y. Times (Apr. 17, 2020), <https://www.nytimes.com/2020/04/17/us/coronavirus-nursing-homes.html> (on file with the *Columbia Law Review*) (last updated Mar. 15, 2021).

4. See *infra* notes 43–48 and accompanying text.

virus in the United States as a whole, infection and death rates among people with disabilities and older adults could have been far more limited if this population had broader access to home and community-based services (HCBS). HCBS offer a cheaper and typically preferred alternative to institutionalization, allowing people with disabilities and older adults to live safely with the services they need in their own homes and communities.<sup>5</sup> In the context of the pandemic, HCBS can help individuals avoid many of the health risks of institutions, where social distancing is difficult or impossible and various protocols proved insufficient to stem the increases in COVID-19 infections before vaccines became available.<sup>6</sup>

The Americans with Disabilities Act (ADA) named isolation and segregation as forms of unlawful discrimination, and its “integration regulation” declared that individuals have a right to services in the most integrated setting appropriate to their needs.<sup>7</sup> An additional regulation, however, requires states and other public entities to “make reasonable modifications” to avoid “discrimination on the basis of disability” but does not require measures that would “fundamentally alter” the nature of the entity’s programs.<sup>8</sup> Unfortunately, existing judicial interpretations of the right to community-based services under the ADA have created a standard for the fundamental alteration defense that is too deferential to states, fails

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5. See, e.g., Joshua M. Wiener & Wayne L. Anderson, Pa. Medicaid Pol’y Ctr., Univ. of Pittsburgh, *Follow the Money: Financing Home and Community-Based Services* 3 (2009), [http://www.agnewbeck.com/pdf/statewide/AMHTA\\_LTC\\_PlanningProcess/FollowtheMoney\\_Financing\\_HCBS\\_2011.pdf](http://www.agnewbeck.com/pdf/statewide/AMHTA_LTC_PlanningProcess/FollowtheMoney_Financing_HCBS_2011.pdf) [<https://perma.cc/996A-BHZT>] (discussing evidence of the preference for HCBS over institutional services among people with disabilities); H. Stephen Kaye, Charlene Harrington & Mitchell P. LaPlante, *Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?*, 29 *Health Affs.* 11, 11, 18 (2010) (“[H]ome and community-based services . . . enable[] many people with disabilities to maintain their independence; avoid institutionalization; and participate in family, community, and economic activities.”).

6. See, e.g., Jasmine E. Harris, *The Frailty of Disability Rights*, 169 *U. Pa. L. Rev. Online* 29, 59 (2020) (“[R]eduction of the population of people with disabilities in congregate settings may be the only meaningful way to prevent public health emergencies from disproportionately affecting people with disabilities because social distancing or other prescriptive practices are not possible.”); Priya Chidambaram, *Rising Cases in Long-Term Care Facilities Are Cause for Concern*, Kaiser Fam. Found. (July 21, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/rising-cases-in-long-term-care-facilities-are-cause-for-concern/> [<https://perma.cc/43EG-MTCC>] (“Long-term care facilities have implemented the strictest protocols in the country . . . . Some of these policies include universal testing for residents and staff in long-term care facilities, strict visitor restrictions, and isolating positive-testing residents. Regardless of these measures, facilities continue to see a rise in cases.”).

7. 42 U.S.C. § 12101(a) (2018); 28 C.F.R. § 35.130(d) (2019); see also *infra* section II.A. The “most integrated setting” is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” See Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans With Disabilities Act and *Olmstead v. L.C.*, DOJ C.R. Div. (June 22, 2011), [https://www.ada.gov/olmstead/q&a\\_olmstead.htm](https://www.ada.gov/olmstead/q&a_olmstead.htm) [<https://perma.cc/YJR5-UBK8>] (last updated Feb. 25, 2020).

8. 28 C.F.R. § 35.130(b)(7)(i); see also *infra* section II.A.

to fully protect individuals' right to services in an integrated setting, and does not account for the public health risks of institutionalization.<sup>9</sup> In its 1999 *Olmstead* decision, the Supreme Court answered the question of whether people with disabilities must be provided the option of services in the community rather than in institutions with "a qualified yes."<sup>10</sup> The Court ruled that the state's responsibility is "not boundless"<sup>11</sup> and the fundamental alteration defense could apply if a state can show that it has an "effectively working plan" for deinstitutionalization and a "waiting list [for HCBS] that move[s] at a reasonable pace."<sup>12</sup>

As a result of the *Olmstead* decision, subsequent circuit and district court interpretations of *Olmstead's* fundamental alteration framework,<sup>13</sup> and interpretations of certain provisions of the Medicaid statute,<sup>14</sup> states are still allowed to limit the number of people who can receive Medicaid HCBS at a time. This is in contrast to Medicaid institutional services, which states must provide to all individuals who qualify.<sup>15</sup> Consequently, the majority of states maintain long waiting lists for HCBS—over 800,000 Americans are on Medicaid HCBS waiting lists and the average wait time for services is thirty-nine months.<sup>16</sup> Many individuals have few options other than institutionalization to access the services they need.<sup>17</sup> Over two

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9. See *infra* section II.C.

10. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999); see also *id.* at 597–600 (recognizing that unjustified institutionalization of people with disabilities is a form of discrimination under the ADA).

11. *Id.* at 603.

12. *Id.* at 605–06.

13. See *infra* sections II.B.2–3.

14. See *infra* section I.B.3.

15. See Carol Beatty, *Implementing Olmstead by Outlawing Waiting Lists*, 49 *Tulsa L. Rev.* 713, 736 (2014).

16. MaryBeth Musumeci, Molly O'Malley Watts & Priya Chidambaram, Kaiser Fam. Found., *Key State Policy Choices About Medicaid Home and Community-Based Services* app. tbl.11 (2020), <https://www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based-services-issue-brief/> [https://perma.cc/NXS2-ZDL2] [hereinafter Musumeci et al., *Key State HCBS Policy Choices*]; *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*, Kaiser Fam. Found. (2018), <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> [https://perma.cc/JC95-6S2F] [hereinafter Kaiser Fam. Found., *Waiting List Enrollment*].

17. See *infra* notes 119–122 and accompanying text. Many people in institutions are eager to and fully capable of transitioning back into home and community settings with appropriate supports and services. See, e.g., H. Stephen Kaye, Cmty. Living Pol'y Ctr., Lurie Inst. for Disability Pol'y, Brandeis Univ., *Evidence for the Impact of the Money Follows the Person Program 1* (2019), [https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/Evidence%20for%20the%20Impact%20of%20MFP\\_0.pdf](https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/Evidence%20for%20the%20Impact%20of%20MFP_0.pdf) [https://perma.cc/5M2Y-THT3] (finding that in each year between 2012 and 2017, over 10,000 people transitioned from institutions to the community under the Money Follows the Person program, which provides states with funding to transition people receiving Medicaid-funded long-term services and supports to HCBS). But for others, institutionalization may prove detrimental and even irreversible,

decades after *Olmstead*, it is clear that the right to integration has not been fully realized.

The problem of institutionalization and the slow pace of deinstitutionalization efforts under the ADA, at a broad level, is not new. Other scholars have proposed a variety of legal solutions to this problem before COVID-19.<sup>18</sup> Yet prior to the COVID-19 pandemic, arguments for deinstitutionalization largely focused on how unwanted and unjustified institutionalization harms people by preventing them from living independently, making basic decisions in their everyday lives, and fully participating in their communities.<sup>19</sup> While the public health risks of institutions have always existed, few people paid attention to these risks prior to COVID-19 despite warnings from some researchers and advocates about the frequency and severity of infectious disease outbreaks in institutions.<sup>20</sup> But because of its larger scale and publicity, the COVID-19 pandemic provides new, impossible-to-ignore evidence that unjustified institutionalization is

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demonstrating the harms of even brief periods of institutionalization while on waiting lists for HCBS. See, e.g., *M.R. v. Dreyfus*, 697 F.3d 706, 735 (9th Cir. 2012) (citing expert testimony that “[i]nstitutionalization . . . creates an unnecessary clinical risk that the individual will become so habituated to, and so reliant upon, the programmatic and treatment structures . . . found in an inpatient setting that his or her ability to function in less structured, less restrictive, environments may become severely compromised”).

18. See, e.g., Charles R. Bliss & C. Talley Wells, *Applying Lessons from the Evolution of Brown v. Board of Education to Olmstead: Moving from Gradualism to Immediate, Effective, and Comprehensive Integration*, 26 Ga. St. U. L. Rev. 705, 706 (2010) (arguing that courts should shift from requiring gradual to immediate deinstitutionalization under *Olmstead*, as courts did in the years following the *Brown v. Board of Education* decision in order to quicken the pace of desegregation over time); David Ferleger, *The Constitutional Right to Community Services*, 26 Ga. St. U. L. Rev. 763, 766 (2010) (suggesting a return to constitutional arguments against involuntary institutionalization under the Due Process and Equal Protection Clauses of the U.S. Constitution); Elliott Schwalb, *Reconsidering Makin v. Hawaii: The Right of Medicaid Beneficiaries to Home-Based Services as an Alternative to Institutionalization*, 26 Ga. St. U. L. Rev. 803, 849 (2010) (suggesting that courts have erroneously failed to apply Medicaid’s “reasonable promptness” provision to Medicaid HCBS waivers and that proper application of this provision could eliminate the practice of denying services to eligible individuals for undetermined, indefinite periods).

19. See, e.g., *About Community Living*, Admin. for Cmty. Living, <https://acl.gov/about-community-living> [<https://perma.cc/SUN2-JTMF>] (last modified Sept. 29, 2020).

20. See, e.g., Larry J. Strausbaugh, Shirin R. Sukumar & Carol L. Joseph, *Infectious Disease Outbreaks in Nursing Homes: An Unappreciated Hazard for Frail Elderly Persons*, 36 *Clinical Infectious Diseases* 870, 870 (2003); see also *Nursing Home Outbreaks Lay Bare Chronic Industry Problems*, *Mod. Healthcare* (Mar. 21, 2020), <https://www.modernhealthcare.com/providers/nursing-home-outbreaks-lay-bare-chronic-industry-problems> [<https://perma.cc/RWY9-M37R>] [hereinafter *Mod. Healthcare, Chronic Industry Problems*] (“Burgeoning coronavirus outbreaks at nursing homes . . . are laying bare the industry’s long-running problems, including a struggle to control infections and a staffing crisis that relies on poorly paid aides who can’t afford to stay home sick.”); *Serious Infections and Outbreaks Occurring in LTCFs*, CDC, <https://www.cdc.gov/longtermcare/staff/report-publications.html> [<https://perma.cc/7E93-L4ST>] (last updated May 28, 2020).

not only discriminatory but also *dangerous* to the health and lives of people with disabilities and older adults.<sup>21</sup>

This Note suggests that the COVID-19 experience offers a new basis on which to clarify and strengthen existing interpretations of the *Olmstead* fundamental alteration framework. It is the first analysis to address the inconsistency between courts' interpretations of this framework and the reality of what an "effectively working plan" or "waiting list that move[s] at a reasonable pace"<sup>22</sup> would actually look like in the context of the public health risks in institutions. In light of the new evidence that the COVID-19 pandemic provides on these risks, this Note argues that the Department of Justice (DOJ) should use its regulatory authority over the ADA to promulgate new regulations that clarify and strengthen the fundamental alteration standards in order to broaden access to Medicaid HCBS.

Part I describes the current public health crisis in institutions and other congregate care settings, which is more apparent than ever during COVID-19 but has long been a risk of institutionalization in the United States. It also provides background on why and how the Medicaid statute and regulations limit access to HCBS and leave many people with few alternatives to institutionalization. Part II explores the legal structures that failed to prevent the COVID-19 crisis in institutions. It explains the statutory and regulatory framework for the right to services in an integrated setting, describes judicial interpretations of the right to services in an integrated setting, and argues that the COVID-19 crisis exposes the *Olmstead* fundamental alteration framework's failure to account for the public health risks of institutionalization. Part III argues that a regulatory approach to strengthening the fundamental alteration framework is superior to attempting to do so through litigation because of agencies' authority, expertise, and motivation on this issue, especially in the Biden Administration. It also proposes substantive ideas for regulations that DOJ might consider for strengthening each of the fundamental alteration framework elements, such as requiring separate analyses for the "effectively working plan" and "reasonable pace" elements and devising a formula for calculating whether the pace of waiting list movement is "reasonable" in any given state or program.

#### I. COVID-19 AND THE PUBLIC HEALTH CRISIS OF INSTITUTIONALIZATION

The COVID-19 pandemic has exposed unjustified institutionalization as more than an issue of liberty and independence: Institutionalization is now undeniably a massive public health crisis in which access to HCBS is a matter of life and death for many people with disabilities and older adults.<sup>23</sup> These populations often have health conditions that make them

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21. See *infra* section I.A.

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

23. See, e.g., Chidambaram, *supra* note 6; Rachel M. Werner, Allison K. Hoffman & Norma B. Coe, Long-Term Care Policy After Covid-19—Solving the Nursing Home Crisis,

more susceptible to infection, complications, and death from COVID-19 and other infectious diseases.<sup>24</sup> But because access to HCBS is so limited, many people with disabilities and older adults have few options to access the care they need other than institutions or congregate care settings, where social distancing is difficult or impossible and where visitor restrictions, testing policies, and other safety protocols proved insufficient to stem increases in COVID-19 cases before vaccines became available.<sup>25</sup>

This section proceeds in two parts to explain the nature, scope, and causes of the current public health crisis in institutions and other congregate care settings. First, it explains the extent of the harm that COVID-19 has caused in these settings and explores the federal government's and long-term care industry's roles in exacerbating this crisis. Second, it provides background on why and how the Medicaid statute and regulations limit access to HCBS and leave many people with few alternatives to institutionalization.

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383 *New Eng. J. Med.* 903, 903 (2020) (explaining the harsh impact that COVID-19 has had on nursing homes and relating that to the problems that nursing homes have long faced due to insufficient funding and staffing).

24. See, e.g., Margaret A. Turk, Scott D. Landes, Margaret K. Formica & Katherine D. Goss, *Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis*, 13 *Disability & Health J.*, May 2020, at 1, 4 (“Results from this study confirm that people with [intellectual and developmental disabilities] have higher prevalence of comorbid risk factors (i.e. hypertension, heart disease, respiratory disease, and diabetes) often associated with poorer COVID-19 outcomes.”); COVID-19 Risks and Vaccine Information for Older Adults, CDC, <https://www.cdc.gov/aging/covid19/covid19-older-adults.html> [<https://perma.cc/VL5Z-67UW>] (last modified Aug. 2, 2021) (“Older unvaccinated adults are more likely to be hospitalized or die from COVID-19.”); Joseph Shapiro, *COVID-19 Infections and Deaths Are Higher Among Those With Intellectual Disabilities*, *Nat'l Pub. Radio* (June 9, 2020), <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disability> [<https://perma.cc/3LCD-SQ8T>]; see also Scott D. Landes, Margaret A. Turk, Margaret K. Formica, Katherine E. McDonald & J. Dalton Stevens, *COVID-19 Outcomes Among People With Intellectual and Developmental Disability Living in Residential Group Homes in New York State*, 13 *Disability & Health J.*, June 2020, at 1, 1–2 (“COVID-19 appears to present greater risk to people with [intellectual or developmental disabilities (IDD)] . . . . Results from this study clearly demonstrate that COVID-19 case rates were substantially higher for people with IDD living in residential group homes in the state of New York than for the New York State general population.”).

25. See Chidambaram, *supra* note 6; Letter from the Disability and Aging Collaborative & Consortium for Citizens With Disabilities to U.S. House of Representatives and Senate Leadership 2 (Feb. 2, 2021), [http://www.c-c-d.org/fichiers/CCD\\_DAC\\_COVID\\_HCBS\\_Letter.pdf](http://www.c-c-d.org/fichiers/CCD_DAC_COVID_HCBS_Letter.pdf) [<https://perma.cc/Q2S5-X8K3>] (“Absent enhanced HCBS funds, people with disabilities and older adults are forced to rely on dangerous congregate settings, such as nursing facilities and other institutions, where COVID-19 infections and deaths are significantly more likely and which are frequently the center of COVID-19 outbreaks.”); Press Release, *Nat'l Health L. Program, Bill to Expand Medicaid Home and Community Based Services Introduced in Congress* (Mar. 16, 2021), <https://healthlaw.org/news/bill-to-expand-medicare-home-and-community-based-services-introduced-in-congress/> [<https://perma.cc/8Y9J-PR5V>] (noting that “older adults [are] often forced into nursing facilities because of a lack of home care”).

A. *The Public Health Crisis in Institutions and Other Congregate Care Settings During COVID-19*

One of the first major COVID outbreaks reported in the United States occurred in a Washington State nursing home in February 2020.<sup>26</sup> Over the course of the following year, the virus spread rapidly through nursing homes and a range of other types of institutional and congregate care settings throughout the United States.<sup>27</sup> The death toll among residents and workers in these settings was severe: By November 2020, an estimated 100,000 residents and workers at long-term care facilities had died from the coronavirus.<sup>28</sup> By June 2021, that number had increased to nearly 187,000 reported long-term care facility deaths.<sup>29</sup>

While these known death counts are shockingly high on their own, the lack of a nationwide, comprehensive dataset on COVID-19 cases and deaths across all congregate care settings has obscured the full scale of the virus's devastation. Nursing homes are not the only settings in which people with disabilities and older adults have faced a heightened risk of COVID-19 infection or death. Similar risk factors—such as high occupancy density resulting in social distancing challenges or close contact with staff who provide self-care assistance to numerous people each day—exist in a range of other congregate care settings.<sup>30</sup> These settings include both other institutional settings and a range of community-based congregate

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26. See, e.g., John E. Dicken, U.S. Gov't Accountability Off., GAO-20-576R, *Nursing Home Infection Control: Infection Control Deficiencies Were Widespread and Persistent in Nursing Homes Prior to COVID-19 Pandemic 1* (2020); Jon Swaine & Maria Sacchetti, *As Washington Nursing Home Assumed It Faced Influenza Outbreak, Opportunities to Control Coronavirus Exposure Passed*, Wash. Post (Mar. 16, 2020), [https://www.washingtonpost.com/investigations/nursing-home-with-the-biggest-cluster-of-covid-19-deaths-to-date-in-the-us-thought-it-was-facing-an-influenza-outbreak-a-spokesman-says/2020/03/16/c256b0ee-6460-11ea-845d-e35b0234b136\\_story.html](https://www.washingtonpost.com/investigations/nursing-home-with-the-biggest-cluster-of-covid-19-deaths-to-date-in-the-us-thought-it-was-facing-an-influenza-outbreak-a-spokesman-says/2020/03/16/c256b0ee-6460-11ea-845d-e35b0234b136_story.html) (on file with the *Columbia Law Review*).

27. See, e.g., Danny Hakim, 'It's Hit Our Front Door': Homes for the Disabled See a Surge of Covid-19, N.Y. Times (Apr. 8, 2020), <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html> (on file with the *Columbia Law Review*) (last updated Apr. 17, 2020); Jordan Howington, *Arkansas's Largest State-Run Intermediate Care Facility Confirms 92 Active COVID-19 Cases*, THV11 (June 26, 2020), <https://www.thv11.com/article/news/health/coronavirus/arkansas-largest-state-ran-intermediate-care-facility-confirms-92-active-covid-19-cases/91-5648f7c9-180d-4e3a-a573-e2156cf7237e> [<https://perma.cc/U7RL-JKAP>] (last updated June 29, 2020).

28. Chidambaram et al., *supra* note 2.

29. See *State COVID-19 Data and Policy Actions*, Kaiser Fam. Found. (Aug. 30, 2021), <https://www.kff.org/coronavirus-covid-19/issue-brief/state-covid-19-data-and-policy-actions/#longtermcare> (on file with the *Columbia Law Review*) (reporting 186,740 deaths among long-term care facility residents and staff as of June 30, 2021 based on available state-reported data).

30. See, e.g., MaryBeth Musumeci & Priya Chidambaram, Kaiser Fam. Found., *COVID-19 Vaccine Access for People With Disabilities* (2021), <https://www.kff.org/medicaid/issue-brief/covid-19-vaccine-access-for-people-with-disabilities/> [<https://perma.cc/GB8T-E7FK>] [hereinafter Musumeci & Chidambaram, *COVID-19 Vaccine Access for People With Disabilities*].

care settings, such as intermediate care facilities for individuals with intellectual disabilities (ICF-IIDs), psychiatric hospitals, assisted living facilities, group homes, personal care homes, and adult day programs.<sup>31</sup> While the limited available evidence suggests that people living in non-nursing home congregate care settings have been disproportionately impacted by the pandemic, unfortunately, there is a dearth of data on infection and death rates across these settings.<sup>32</sup> This lack of data is primarily due to the federal government's failure to mandate consistent, comprehensive reporting of cases and deaths across all congregate care settings and states.<sup>33</sup>

The COVID-19 crisis in congregate care settings is integrally connected to broader issues of discrimination and injustice in the United States. For example, there is a clear racial disparity in the effects of COVID-19 in long-term care facilities.<sup>34</sup> One analysis found that nursing homes where African Americans and Latinos made up a significant portion (defined as at least a quarter) of the residents were twice as likely to see at least one COVID case compared to those where the population is overwhelmingly white.<sup>35</sup> This phenomenon mirrors the disproportionate infection and death rates among minorities in the broader U.S. population beyond long-term care centers.<sup>36</sup>

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31. See *id.*

32. See *id.*

33. See, e.g., Letter from the Consortium for Citizens With Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar, Sec'y, HHS 3 (July 7, 2020), <http://www.c-c-d.org/fichiers/Nursing-Home-Reg-Comments-final-7-7-20.pdf> [<https://perma.cc/YME9-CC9X>]. The *New York Times* acknowledges that its data "almost certainly represent[s] an undercount of the true [death] toll" and that its analysis only includes data from facilities for older adults, not other types of institutional settings for people with disabilities (such as ICF-IIDs or psychiatric hospitals). See *More Than 40% of U.S. Coronavirus Deaths Are Linked to Nursing Homes*, *supra* note 1.

34. See, e.g., Yue Li, Xi Cen, Xueya Cai & Helena Temkin-Greener, *Racial and Ethnic Disparities in COVID-19 Infections and Deaths Across U.S. Nursing Homes*, 68 *J. Am. Geriatrics Soc'y* 2454, 2459 (2020) ("This national study reveals that nursing homes caring for disproportionately more racial/ethnic minority residents tended to have more new COVID-19 confirmed cases among their residents and staff, and more new COVID-19 related deaths among residents . . ."); Jamila Taylor, Jen Mishory & Olivia Chan, *Even in Nursing Homes, COVID-19 Racial Disparities Persist*, Century Found. (July 17, 2020), <https://tcf.org/content/commentary/even-nursing-homes-covid-19-racial-disparities-persist/?agreed=1> (on file with the *Columbia Law Review*).

35. Robert Gebeloff, Danielle Ivory, Matt Richtel, Mitch Smith, Karen Yourish, Scott Dance, Jackie Fortiér, Elly Yu & Molly Parker, *The Striking Racial Divide in How Covid-19 Has Hit Nursing Homes*, *N.Y. Times* (May 21, 2020), <https://www.nytimes.com/article/coronavirus-nursing-homes-racial-disparity.html> (on file with the *Columbia Law Review*) (last updated June 14, 2021); see also Li et al., *supra* note 34, at 2459 ("[P]redicted counts of cases and deaths per facility [were] two to four times as high in nursing homes with highest proportions of racial/ethnic minority residents as in nursing homes with low proportions.").

36. See, e.g., Samantha Artiga, Bradley Corallo & Olivia Pham, *Kaiser Fam. Found., Racial Disparities in COVID-19: Key Findings From Available Data and Analysis* (2020), <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-covid-19-key-findings-available-data-analysis/> [<https://perma.cc/KL2D-DLZL>]; Daniel Wood, *As Pandemic Deaths Add Up, Racial Disparities Persist—And in Some Cases Worsen*, *Nat'l Pub.*

The nature and coverage of the crisis in institutional and congregate care settings also reflect the persistent and widespread discrimination against people with disabilities in the United States.<sup>37</sup> The media, for example, has consistently covered the COVID-19 outbreaks in nursing homes while paying less attention to equally severe outbreaks in other types of settings that primarily serve people with disabilities of all ages (not just older adults).<sup>38</sup> Similarly, many of the regulations and other actions by the Department of Health and Human Services (HHS) that were intended to address the COVID-19 crisis in long-term care facilities targeted nursing homes alone, ignoring the similar and equally pressing crises in other facilities serving people with disabilities.<sup>39</sup>

While the populations residing in congregate care settings are naturally more susceptible to the virus, the tragic effects of COVID on this population in the United States were not inevitable. The federal government, states, and the long-term care industry each exacerbated this crisis, and the sections below consider the roles of each in turn.

1. *The Federal Government and States Failed to Keep Institutions Safe.* — The federal government bears significant responsibility for the severity and scope of the COVID-19 crisis in institutional and congregate care settings. In addition to the widely criticized leadership failures of President

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Radio (Sept. 23, 2020), <https://www.npr.org/sections/health-shots/2020/09/23/914427907/as-pandemic-deaths-add-up-racial-disparities-persist-and-in-some-cases-worsen> [<https://perma.cc/4JS3-SZ5T>].

37. See, e.g., ACLU et al., *supra* note 3, at 4 (“These practices and these deaths arise not just from the pandemic, but from longstanding, entrenched attitudes that people with disabilities and seniors simply do not count as much as others.”); Thousands Sick From COVID-19 in Homes for the Disabled, Mod. Healthcare (June 11, 2020), <https://www.modernhealthcare.com/patient-care/thousands-sick-covid-19-homes-disabled> [<https://perma.cc/HJ95-VB3Y>] [hereinafter Mod. Healthcare, Thousands Sick] (“If you have developmental disabilities, you are seen as less than human. You can see it in education, civil rights, employment. And now, you can see it by how they are being treated during the pandemic.” (quoting Christopher Rodriguez, Executive Director, Disability Rights Louisiana)).

38. See, e.g., Mod. Healthcare, Thousands Sick, *supra* note 37 (“[T]he pandemic [presents a threat] to a highly vulnerable population that is flying almost completely under the radar: The developmentally and intellectually disabled. While nursing homes have come under the spotlight, little attention has gone toward facilities nationwide that experts [estimate] house more than 275,000 people with [IDD]”).

39. See Letter from the Consortium for Citizens With Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar, *supra* note 33, at 1 (imploping the Centers for Medicare and Medicaid Services (CMS) “to include all institutional facilities that receive Medicaid funding, not just nursing homes, in its interim final rule on nursing home COVID-19 reporting requirements” because “CMS has the responsibility and authority to” do so given its regulatory role).

Trump and his closest advisors,<sup>40</sup> HHS and its agencies failed in their responsibility to protect residents and staff in institutional settings<sup>41</sup> in multiple ways that unnecessarily exacerbated the death toll among these populations.<sup>42</sup> For example, HHS failed to collect sufficient data on COVID-19 infection and death rates across facilities of all types, which hid the scope of the crisis and stymied efforts to address it. The Centers for Medicare and Medicaid Services (CMS), an agency under HHS, did not require nursing homes to report COVID-19 cases or deaths to the federal government or inform residents and their families that there were infections in their facilities until May 8, 2020.<sup>43</sup> And even then, CMS did not require reporting of deaths and infections that took place prior to May 8,

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40. See, e.g., Toluse Olorunnipa, Josh Dawsey & Yasmeen Abutaleb, With Trump Leading the Way, America's Coronavirus Failures Exposed by Record Surge in New Infections, *Wash. Post* (June 27, 2020), [https://www.washingtonpost.com/politics/with-trump-leading-the-way-americas-coronavirus-failures-exposed-by-record-surge-in-new-infections/2020/06/27/bd15aea2-b7c4-11ea-a8da-693df3d7674a\\_story.html](https://www.washingtonpost.com/politics/with-trump-leading-the-way-americas-coronavirus-failures-exposed-by-record-surge-in-new-infections/2020/06/27/bd15aea2-b7c4-11ea-a8da-693df3d7674a_story.html) (on file with the *Columbia Law Review*); German Lopez, How Trump Let Covid-19 Win, *Vox* (Sept. 22, 2020), <https://www.vox.com/future-perfect/21366624/trump-covid-coronavirus-pandemic-failure> (on file with the *Columbia Law Review*).

41. ACLU et al., *supra* note 3, at 3; see also Abigail Abrams, COVID-19 Is Still Devastating Nursing Homes. The Trump Administration Isn't Doing Much to Stop It, *TIME* (Sept. 11, 2020), <https://time.com/5887699/nursing-homes-covid-19-federal-help/> [<https://perma.cc/JY8L-NV6Y>] (“The Centers for Medicare and Medicaid Services (CMS) ramped up its requirements for how often nursing homes must test staffers and residents but has so far failed to ensure that facilities will have access to all the test kits they need.”). Agencies within HHS have a regulatory oversight role over not only nursing homes but also non-nursing home institutions like psychiatric hospitals and Intermediate Care Facilities. See, e.g., 42 C.F.R. § 482 (2020); Intermediate Care Facilities for Individuals With Intellectual Disabilities (ICFs/IID), Ctrs. for Medicare and Medicaid Servs., <https://www.cms.gov/medicare/provider-enrollment-and-certification/certificationandcompliance/ICFIID> [<https://perma.cc/74JH-HSBV>] (last modified Nov. 22, 2016); Quality, Safety & Oversight—General Information, Ctrs. for Medicare and Medicaid Servs., <https://www.cms.gov/medicare/provider-enrollment-and-certification/surveycertificationgeninfo> [<https://perma.cc/X79N-NB85>] (last modified Jan. 10, 2018).

42. See ACLU et al., *supra* note 3, at 6; see also Nina A. Kohn, Nursing Homes, COVID-19, and the Consequences of Regulatory Failure, 110 *Geo. L.J. Online* 4–10 (2021) (arguing that the COVID-19 crisis in nursing homes was largely due to federal and state government failures, including an inadequate public health response, regulatory oversight gaps, and underenforcement of existing regulations).

43. See Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency, 85 *Fed. Reg.* 27,550, 27,601–02, 27,627 (May 8, 2020) (codified at 42 C.F.R. pt. 483.80 (2021)); see also MaryBeth Musumeci & Priya Chidambaram, Kaiser Fam. Found., Key Questions About Nursing Home Regulation and Oversight in the Wake of COVID-19 (2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/key-questions-about-nursing-home-regulation-and-oversight-in-the-wake-of-covid-19> [<https://perma.cc/K8EF-FCVS>] [hereinafter Musumeci & Chidambaram, Nursing Home Regulation and Oversight] (“The lack of centralized data [prior to May 2020] contributed to difficulty in tracking disease spread and coordinating dissemination of personal protective equipment and testing supplies.”); ACLU et al., *supra* note 3, at 6 (arguing that the May 8, 2020 requirements came only after public outcry about the high death rates in nursing homes).

2020,<sup>44</sup> and it did not require reporting by any non-nursing home congregate care settings.<sup>45</sup> Consequently, during much of the pandemic, the only source tracking fifty-state data on infection and death rates across the broader range of congregate care settings was a small nonprofit, the Autistic Self Advocacy Network (ASAN).<sup>46</sup> These data are compiled largely from media reports in an attempt to fill major gaps in data reported directly by states or the federal government, and ASAN itself acknowledges that its dataset is limited.<sup>47</sup> While the Kaiser Family Foundation has published state-reported data on infections and deaths in facilities serving people with disabilities, only thirty-one states had reported this data as of February 2021, and the settings included in the reported data vary widely across states.<sup>48</sup> The same disparities in oversight and reporting requirements for nursing homes compared to other settings have continued in more recent CMS regulations on COVID-19 vaccination and treatment reporting.<sup>49</sup>

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44. Because these regulations do not require reporting of deaths and infections prior to May 8, 2020, the federal government still lacks comprehensive, cumulative data on COVID deaths and infections in nursing homes (including those that took place early in the pandemic). See Musumeci & Chidambaram, *Nursing Home Regulation and Oversight*, supra note 43; ACLU et al., supra note 3, at 6.

45. Centers for Medicare and Medicaid (CMS) COVID-19 NHSN Reporting Requirements for Nursing Homes, CDC, <https://www.cdc.gov/nhsn/pdfs/covid19/lrcf/cms-covid19-req-508.pdf> [<https://perma.cc/N24Y-VL4U>] (last visited July 20, 2021) (“CMS is only collecting nursing home (i.e., skilled nursing facility and/or nursing facility) data and *not assisted living or developmental disability facility types*.”).

46. See COVID-19 Case Tracker: Documenting the Impact of COVID-19 on People With Disabilities in Congregate Settings, Autistic Self Advocacy Network, <https://autisticadvocacy.org/covid19/#info> [<https://perma.cc/AA6Z-5GFM>] (last visited on July 20, 2021); Letter from the Consortium for Citizens With Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar, supra note 33, at 3.

47. ASAN states,

The very fact that the data available is inconsistent from state to state, that some states are not making any data publicly available at all, and the fact that the majority of states fail to disaggregate staff and resident data is extremely alarming. ASAN will continue to advocate for better-quality data that properly conveys the impact of this pandemic on people with disabilities living in congregate settings.

Autistic Self Advocacy Network, supra note 46.

48. See Musumeci & Chidambaram, *COVID-19 Vaccine Access for People With Disabilities*, supra note 30, at app. tbl.1.

49. Current federal regulations require that nursing homes report at least weekly on the COVID-19 vaccination status of all residents and staff as well as COVID-19 therapeutic treatment administered to residents, but it does not mandate this reporting for other institutional or congregate care settings. See Medicare and Medicaid Programs; COVID-19 Vaccine Requirements for Long-Term Care (LTC) Facilities and Intermediate Care Facilities for Individuals With Intellectual Disabilities (ICFs–IID) Residents, Clients, and Staff, 86 Fed. Reg. 26,306, 26,315–16, 26,319 (May 13, 2021) (codified at 42 C.F.R. § 483.80(g) (2021)); Priya Chidambaram & MaryBeth Musumeci, Kaiser Fam. Found., *How Do CMS’s New COVID-19 Vaccine Reporting and Education Rules Apply to Different Long-Term Care Settings?* (2021), <https://www.kff.org/medicaid/issue-brief/how-do-cms-new->

HHS also failed to adequately enforce infection control policies prior to the pandemic<sup>50</sup> and did not respond with appropriate infection control guidance even after the COVID-19 outbreak began in the United States. A report by the Government Accountability Office (GAO) found that prior to the COVID-19 pandemic, most nursing homes had infection prevention and control deficiencies—a measure that includes a range of problems such as “situations where nursing home staff did not regularly use proper hand hygiene or failed to implement preventive measures during an infectious disease outbreak, such as isolating sick residents and using masks and other personal protective equipment to control the spread of infection.”<sup>51</sup> Additionally, half of the nursing homes that had infection control problems in previous years had persistent deficiencies in multiple consecutive years.<sup>52</sup> After the onset of the pandemic, HHS’s agencies collectively “failed to issue clear, robust COVID-19 specific infection prevention and control directions for [congregate care] facilities to follow.”<sup>53</sup> In fact, HHS took some actions following the U.S. COVID outbreak that worked in the wrong direction—for example, it “significantly curtailed the inspection and enforcement program [and] waived basic patient and staff protections.”<sup>54</sup>

State oversight failures and inadequate public health responses also exacerbated the COVID-19 crisis in institutions and congregate care settings. For example, many states failed to adequately inspect facilities and enforce federal and state standards, such as those regulating staffing levels and COVID testing of residents and staff.<sup>55</sup> Around half of the states

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covid-19-vaccine-reporting-and-education-rules-apply-to-different-long-term-care-settings/ [https://perma.cc/Z5Q8-UNHK]. The regulation’s requirements to educate residents and staff about the vaccine and offer the vaccine when available apply somewhat more broadly—to both nursing homes and ICF-IIDs—but they do not apply to other types of institutional or congregate care settings. Medicare and Medicaid Programs; COVID-19 Vaccine Requirements for Long-Term Care (LTC) Facilities and Intermediate Care Facilities for Individuals With Intellectual Disabilities (ICFs–IID) Residents, Clients, and Staff, 86 Fed. Reg. at 26,307, 26,312, 26,317.

50. See, e.g., Charlene Harrington, Helen Carrillo, Rachel Garfield, MaryBeth Musumeci & Ellen Squires, Kaiser Fam. Found., *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2016* (2018), <https://www.kff.org/medicaid/report/nursing-facilities-staffing-residents-and-facility-deficiencies-2009-through-2016/> [https://perma.cc/JCW6-L4YX] [hereinafter Harrington et al., *Nursing Facilities, Staffing & Residents*] (finding that in 2016, the most common type of nursing facility deficiency was for failures in infection control; state surveyors reported deficiencies in infection control in 45.4% of nursing facilities).

51. Dicken, *supra* note 26, at 4; see also Harrington et al., *Nursing Facilities, Staffing & Residents*, *supra* note 50.

52. Dicken, *supra* note 26, at 4.

53. ACLU et al., *supra* note 3, at 3.

54. *Id.*

55. Testimony of the New York Civil Liberties Union Regarding Residential Health Care Facilities and COVID-19, at 4–7 (Aug. 10, 2020), [https://www.nyclu.org/sites/default/files/field\\_documents/2020810-testimony-c19residentialcarefacilities.pdf](https://www.nyclu.org/sites/default/files/field_documents/2020810-testimony-c19residentialcarefacilities.pdf) [https://perma.cc/KRC6-42Y4]; Scott Dance, *Health Regulators Did Not Inspect Maryland Nursing Homes for*

granted long-term care facilities immunity from civil (and in a few states, criminal) liability for negligence during the pandemic, including negligent acts resulting in death or harm to a resident.<sup>56</sup> Additionally, many states have been criticized for a lack of transparency regarding the COVID-19 crisis in institutions.<sup>57</sup>

2. *Long-Term Care Industry Practices Left Institutions Vulnerable.* — Problematic long-term care industry practices also contributed to the severity and scope of the COVID-19 crisis in institutions. Around seventy percent of nursing homes are run by for-profit companies, including investment firms.<sup>58</sup> Nursing homes and other congregate care settings largely rely on Medicaid and Medicare for revenue, and these programs pay a prospectively set amount per day of care for each covered patient.<sup>59</sup> Because of this fixed-payment system and for-profit companies' focus on improving their profit margins, these companies frequently take actions that sacrifice safety and quality of care for profits, such as cutting staff while increasing

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More Than a Month as Coronavirus Pandemic Raged, Balt. Sun (June 22, 2020), <https://www.baltimoresun.com/coronavirus/bs-md-nursing-home-covid-inspections-20200619-eb67uoextbgirkjurcldsabjq-story.html> [<https://perma.cc/X468-QXP7>]; Brad Schrade, Georgia Lags on Nursing Home Inspections During Coronavirus Crisis, Atlanta J.-Const. (July 11, 2020), <https://www.ajc.com/news/state-regional-govt-politics/georgia-lags-nursing-home-inspections-during-coronavirus-crisis/PbgA0rbRg4Y5bDa0StgqcK/> [<https://perma.cc/H6FV-3W5F>] (“Georgia’s lagging inspection rate is part of a broader problem with its oversight of nursing homes that has plagued the state for years.”).

56. See, e.g., Samuel Brooks, Robyn Grant & Michael F. Bonamarte, States Move to Shield Nursing Homes From Liability in COVID-19 Deaths, 41 *Bifocal* 277, 277 (2020); Kohn, *supra* note 42, at 9–10.

57. See, e.g., J. David Goodman & Danny Hakim, Cuomo Aides Rewrote Nursing Home Report to Hide Higher Death Toll, N.Y. Times (Mar. 4, 2021), <https://www.nytimes.com/2021/03/04/nyregion/cuomo-nursing-home-deaths.html> (on file with the *Columbia Law Review*) (last updated July 14, 2021) (describing Governor Cuomo’s efforts to conceal how many nursing home residents in New York died in the pandemic); Katie LaGrone, Florida Lawmakers Demand Governor Be More Transparent About COVID-19 in Nursing Homes, WPTV (Apr. 17, 2020), <https://www.wptv.com/news/coronavirus/fl-lawmakers-demand-governor-be-more-transparent-about-covid-19-in-nursing-homes> (on file with the *Columbia Law Review*); Gregg Larson, Eilon Caspi & Kristine Sundberg, State Health Department Must Provide More Data on COVID in Minnesota Long-Term Care Facilities, StarTribune (Sept. 14, 2020), <https://www.startribune.com/state-health-department-must-provide-more-data-on-covid-in-minnesota-long-term-care-facilities/572410922/> [<https://perma.cc/36WX-GAT4>].

58. See Harrington et al., *Nursing Facilities, Staffing & Residents*, *supra* note 50; Matthew Goldstein, Jessica Silver-Greenberg & Robert Gebeloff, Push for Profits Left Nursing Homes Struggling to Provide Care, N.Y. Times (May 7, 2020), <https://www.nytimes.com/2020/05/07/business/coronavirus-nursing-homes.html> (on file with the *Columbia Law Review*).

59. Atul Gupta, Sabrina T. Howell, Constantine Yannellis & Abhinav Gupta, Does Private Equity Investment in Healthcare Benefit Patients? Evidence From Nursing Homes 7 (Nat’l Bureau of Econ. Rsch., Working Paper No. 28,474, 2021), [https://www.nber.org/system/files/working\\_papers/w28474/w28474](https://www.nber.org/system/files/working_papers/w28474/w28474) (on file with the *Columbia Law Review*).

admissions.<sup>60</sup> Staffing shortages are severe—around seventy-five percent of nursing homes in the United States do not meet federal suggested minimum levels for staffing and many workers are inexperienced and poorly paid.<sup>61</sup> And in addition to the above-described infection control deficiencies in most nursing homes prior to the COVID-19 pandemic,<sup>62</sup> about forty-three percent of nursing facilities lacked a legally mandated emergency response plan at the beginning of the pandemic.<sup>63</sup>

The long-term care industry spent enormous amounts of time and resources on mobilizing a large and well-connected team of lobbyists to advocate for tax breaks, federal cash infusions, legal protections, and other favorable policies.<sup>64</sup> As a result, the industry, including many companies with negative safety records, received billions of dollars of emergency aid during the pandemic.<sup>65</sup> Additionally, as noted above, many states granted long-term care facilities immunity from negligence during the public health emergency.<sup>66</sup> Granting this immunity removed a powerful incentive for facilities to comply with all health and safety regulations at a time when facility oversight was even more limited than usual because, for example, residents' family members and others were barred from entering facilities and thus could not monitor and raise concerns about care quality.<sup>67</sup> Overall, this industry's practices both before and during the pandemic created the conditions in institutions that facilitated disproportionately high infection and death rates among residents and staff.

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60. *Id.* at 7–8; see also Harrington et al., *Nursing Facilities, Staffing & Residents*, *supra* note 50 (citing research showing that for-profit nursing facilities generally have lower overall quality of care and that there are higher rates of deficiencies in for-profit facilities and chains compared to nonprofit and government facilities); *Opinion, How Many of These 68,000 Deaths Could Have Been Avoided?*, *N.Y. Times* (Sept. 5, 2020), <https://www.nytimes.com/2020/09/05/opinion/sunday/coronavirus-nursing-homes-deaths.html> (on file with the *Columbia Law Review*); Bruce Allen Chernof & Cindy Mann, *Building the Long-Term Care System of the Future: Will the COVID-19 Nursing Home Tragedies Lead to Real Reform?*, *Health Affs. Blog* (July 31, 2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200729.267815/full/> [<https://perma.cc/K5K9-RTMR>] (“Regulators are often ill-equipped to ensure that revenues are devoted appropriately to direct care.”).

61. See *Mod. Healthcare, Chronic Industry Problems*, *supra* note 20.

62. Dicken, *supra* note 26, at 4.

63. Bryant Furlow, Carli Brosseau & Isaac Arnsdorf, *Nursing Homes Fought Federal Emergency Plan Requirements for Years. Now, They’re Coronavirus Hot Spots.*, *ProPublica* (May 29, 2020), <https://www.propublica.org/article/nursing-homes-fought-federal-emergency-plan-requirements-for-years-now-theyre-coronavirus-hot-spots> [<https://perma.cc/B3PT-W2DQ>].

64. Jessica Silver-Greenberg & Jesse Drucker, *Nursing Homes With Safety Problems Deploy Trump-Connected Lobbyists*, *N.Y. Times* (Aug. 16, 2020), <https://www.nytimes.com/2020/08/16/business/nursing-home-safety-trump.html> (on file with the *Columbia Law Review*). The fact that individual nursing-home companies hired lobbyists rather than just relying on trade associations reflects the ambitious nature of the industry’s mobilization. See *id.*

65. *Opinion*, *supra* note 60.

66. See *supra* note 56 and accompanying text.

67. *Id.*

B. *Why and How the Medicaid Statute Limits Access to HCBS*

The COVID-19 crisis in institutions could have been far more limited if there had been broader access to home and community-based services for people who otherwise have no option other than institutionalization.<sup>68</sup> Unfortunately, access to home and community-based services is limited in the United States, and thousands of people who qualify for these services are stuck on the long HCBS waiting lists that exist in the majority of states.<sup>69</sup> It can often take years for a person to move to the top of a waiting list.<sup>70</sup> In contrast, states are not allowed to hold waiting lists for institutional services—often the same services as those one could get through HCBS.<sup>71</sup> States are required to promptly provide nursing facility and other institutional services that they choose to cover to all individuals who qualify.<sup>72</sup>

Given that institutional services are typically more costly per person than HCBS, the broader coverage of institutional services compared to HCBS may seem counterintuitive. But as this section reveals, Medicaid's bias toward coverage of institutional services is largely a statutory relic of the program's inception at a time when institutionalization of people needing long-term care was the norm.<sup>73</sup> This section first provides back-

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68. See Harris, *supra* note 6.

69. See *infra* notes 121–125 and accompanying text.

70. See *infra* note 122 and accompanying text.

71. States cannot hold waiting lists for institutional services because most institutional services are provided as Medicaid state plan services—meaning that they are among the list of “mandatory” services that all states must cover (such as nursing facility services) or “optional” services that states may choose to cover (such as intermediate care facility services for individuals with intellectual disabilities) set out in the Medicaid statute. See Mandatory and Optional Benefits, Medicaid & CHIP Payment & Access Comm’n, <https://www.macpac.gov/subtopic/mandatory-and-optional-benefits/> [<https://perma.cc/6SHH-TUWP>] (last visited July 20, 2021). The Medicaid statute requires that state plan services be provided as an entitlement to all individuals who are eligible and for whom the service is “medically necessary.” See Robin E. Cooper, Nat’l Ass’n of State Dir. of Developmental Disability Servs., *Waiting Lists and Medicaid Home and Community-Based Services 1* (2017), [https://www.nasdds.org/uploads/documents/Waiting\\_Lists\\_and\\_Medicaid\\_Home\\_and\\_Community-Based\\_Services\\_-\\_Copy.pdf](https://www.nasdds.org/uploads/documents/Waiting_Lists_and_Medicaid_Home_and_Community-Based_Services_-_Copy.pdf) [<https://perma.cc/VQ93-QDFF>]. In addition, services must be provided with “reasonable promptness” to all eligible individuals, which is typically interpreted to mean within 45 to 90 days. 42 U.S.C. § 1396a(8) (2018); Cooper, *supra*, at 2. In contrast, the “reasonable promptness” requirement has generally not been applied to Section 1915(c) HCBS services, although there is ongoing debate over this interpretation. For a discussion of this debate, see *infra* section I.B.3.

72. See Beatty, *supra* note 15, at 736 (“The institutional bias remains because Medicaid regulations forbid states from limiting access to or having waiting lists for institutional services, but allow states to limit access to and have waiting lists for home and community-based services.”).

73. See Long-Term Care in the United States: A Timeline, Kaiser Fam. Found. (Aug. 31, 2015), <https://www.kff.org/medicaid/timeline/long-term-care-in-the-united-states-a-timeline/> [<https://perma.cc/C4XP-T663>] [hereinafter Kaiser Fam. Found., Long-Term Care Timeline] (explaining that “the nursing home era,” which largely spawned from re-

ground on Medicaid's central role in the broader U.S. long-term care system, including its role in paying for both institutional services and HCBS. It then explains the bias in the Medicaid statute toward institutional services, rather than HCBS, and explains the authorities through which states may choose to cover HCBS under Medicaid. The section concludes by explaining how the statutory framework for HCBS has permitted long waiting lists for HCBS services across most states and briefly describing ongoing debates over the legality of these waiting lists.

1. *Medicaid Plays a Key Role in the U.S. Long-Term Care System.* — Medicaid, the United States' public health insurance program for low-income individuals of all ages, is the country's primary payer for institutional and community-based long-term services and supports (LTSS).<sup>74</sup> Created alongside the Medicare program as part of the Social Security Amendments in 1965, Medicaid has expanded significantly over time and today provides health insurance coverage to one in five Americans.<sup>75</sup> Un-

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restrictions on funding available through the Social Security Act in the early and mid-twentieth century, resulted in the institutional bias in Medicaid); SeniorMarketing: The Evolution of Long-Term Care Services, Nat'l Care Plan. Council (Mar. 20, 2018), <https://www.longtermcarelink.net/articles/The-Evolution-of-Long-Term-Care-Services.htm> [<https://perma.cc/S2FT-AQQ6>] ("With the advent of Social Security in 1936, a nursing home per diem stipend was included in the Social Security retirement income and this government subsidy spurred the construction of nursing homes all across the country.").

74. Medicaid Spending in Context, Medicaid & CHIP Payment & Access Comm'n, <https://www.macpac.gov/subtopic/medicaid-spending-in-context/> [<https://perma.cc/L372-UM3Y>] (last visited July 20, 2021). Medicaid is the primary payer for LTSS because Medicare provides only limited coverage of these services, and there are few affordable LTSS coverage options in the private insurance market. Erica L. Reaves & MaryBeth Musumeci, Kaiser Fam. Found., *Medicaid and Long-Term Services and Supports: A Primer* (2015), <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/> [<https://perma.cc/5HXF-GJCG>].

75. See John K. Iglehart & Benjamin D. Sommers, *Medicaid at 50—From Welfare Program to Nation's Largest Health Insurer*, 372 *New Eng. J. Med.* 2152, 2152–54 (2015) (describing Medicaid's expansion in terms of populations covered, expenditures, and other program changes since its 1965 inception); *Health Insurance Coverage of the Total Population*, Kaiser Fam. Found. (2019), <https://www.kff.org/other/state-indicator/total-population/> [<https://perma.cc/6Y9Y-UH32>] (indicating twenty percent of the total U.S. population had Medicaid coverage as of 2019 based on analysis of data from the Census Bureau's American Community Survey).

Prior to the passage of the Affordable Care Act (ACA) in 2010, Medicaid primarily covered low-income parents of dependent children, children, pregnant women, people with disabilities, and senior citizens. Iglehart & Sommers, *supra*, at 2152. But under the ACA and a related Supreme Court ruling in *National Federation of Independent Business v. Sebelius* states now have the option, and enhanced federal funding, to expand Medicaid to all individuals with incomes up to 138% of the Federal Poverty Level. 567 U.S. 519, 585–86 (2012) (holding that while Congress may not penalize states that do not adopt the ACA Medicaid expansion by withholding all existing federal Medicaid funding, the Medicaid expansion program itself is still constitutional, and Congress may withhold new ACA Medicaid expansion funding from states that choose not to adopt the expansion). As of September 2021, thirty-eight states and the District of Columbia have adopted the Medicaid expansion. See *Status of State Medicaid Expansion Decisions: Interactive Map*, Kaiser Fam. Found.,

like Medicare, which is an exclusively federal program, Medicaid is a federal–state partnership. Federal law establishes broad requirements for the program, and states have the flexibility to design their own unique programs within the federal framework.<sup>76</sup> For example, federal statutes and regulations define which populations and services must be covered by all state Medicaid programs (known as mandatory populations/services) and which services and populations states may choose to cover (known as optional populations/services).<sup>77</sup> The costs of financing Medicaid are shared between the federal government and states based on a formula that provides higher federal reimbursement to states with lower per capita incomes relative to the national average and vice versa.<sup>78</sup>

Coverage of LTSS is a key feature of each state’s Medicaid program, given both the importance of these services to the well-being of older adults and individuals with disabilities and the fact that Medicaid is the primary payer for institutional and community-based LTSS in the United States.<sup>79</sup> LTSS includes a range of services that assist individuals with activities of daily living, such as eating, bathing, and dressing, and instrumental activities of daily living, such as preparing meals, managing medication, managing money, and housekeeping.<sup>80</sup> These services can be provided at institutions, including nursing homes, ICF-IIDs, and psychiatric hospitals, or in a range of home and community-based settings, which include both people’s own houses or apartments and congregate community-based care settings, such as group homes or adult day centers.<sup>81</sup>

2. *Medicaid’s Institutional Bias and Authorities for HCBS Coverage.* — Throughout its history, the Medicaid program has had what is known as

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<https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/> [https://perma.cc/9JEE-9CSV] (last updated Sept. 8, 2021).

76. Medicaid & CHIP Payment & Access Comm’n, Report to Congress on Medicaid and CHIP 3 (2017), <https://www.macpac.gov/wp-content/uploads/2017/06/June-2017-Report-to-Congress-on-Medicaid-and-CHIP.pdf> [https://perma.cc/BMF3-KK3U].

77. *Id.* at 4.

78. *Id.* at 3; Robin Rudowitz, Elizabeth Williams, Elizabeth Hinton & Rachel Garfield, Kaiser Fam. Found., Medicaid Financing: The Basics (2021), <https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/> [https://perma.cc/X7CG-WLDB]; Financing, Medicaid & CHIP Payment & Access Comm’n, <https://www.macpac.gov/medicaid-101/financing/> [https://perma.cc/UVR2-VZPR] (last visited July 20, 2021).

79. See Reaves & Musumeci, *supra* note 74; Molly O’Malley Watts, MaryBeth Musumeci & Priya Chidambaram, Kaiser Fam. Found., Medicaid Home and Community-Based Services Enrollment and Spending (2020), <https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/> [https://perma.cc/828Z-NBVZ] (showing that Medicaid accounted for 52% of all LTSS spending in 2018); Medicaid Spending in Context, *supra* note 74.

80. HHS, An Overview of Long-Term Services and Supports and Medicaid: Final Report 1 (2018), <https://aspe.hhs.gov/system/files/pdf/259521/LTSSMedicaid.pdf> [https://perma.cc/SU6G-GPTS]; Reaves & Musumeci, *supra* note 74.

81. Reaves & Musumeci, *supra* note 74. HCBS are often provided on an informal, unpaid basis by an individual’s family members or friends. *Id.* This Note, however, focuses on the more formal, paid forms of LTSS.

an “institutional bias” built into its statute: State Medicaid programs are required to cover nursing facility services but may choose to exclude or place strict limits on most HCBS.<sup>82</sup> This bias persists despite the fact that HCBS are typically preferred over institutional services by people with disabilities and older adults and are also usually more cost effective.<sup>83</sup>

The history of the development of the American long-term care system in the early- and mid-twentieth century explains how and why Medicaid’s institutional bias came to exist. The original passage of the Social Security Act (SSA) in 1936 included a per diem stipend in the Social Security retirement income. Though intended to provide support for seniors to secure care in their homes, this government subsidy unexpectedly spurred the advent of the private nursing home industry and the construction of nursing homes across the country.<sup>84</sup> A series of amendments to the SSA in 1950, 1956, and 1960 then boosted cooperative federal–state funding for nursing homes by expanding eligibility and authorizing states to make vendor payments to nursing homes.<sup>85</sup> By the time Medicaid was enacted by Congress in 1965, the United States already had a “large nursing home industry ready, willing and eager to accept the new Medicaid funding.”<sup>86</sup> The nursing home industry fought to get and keep Medicaid funding and lobbied Congress to create new, lower levels of nursing home care eligible for Medicaid reimbursement—intermediate care facilities (ICFs) and intermediate care facilities for individuals with intellectual

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82. Reaves & Musumeci, *supra* note 74.

83. Even the conservative Trump-appointed administrator of the Centers for Medicare and Medicaid Services (CMS), Seema Verma, acknowledged the preference for and cost effectiveness of HCBS over institutional services. See Press Release, Ctrs. for Medicare & Medicaid Servs., CMS Announces New Federal Funding for 33 States to Support Transitioning Individuals From Nursing Homes to the Community (Sept. 23, 2020), <https://www.cms.gov/newsroom/press-releases/cms-announces-new-federal-funding-33-states-support-transitioning-individuals-nursing-homes> [https://perma.cc/TB4Q-JUQP] (“Home and community-based care is not only frequently more cost effective, but is preferred by seniors and adults with disabilities seeking to maintain the dignity of independent living.” (internal quotation marks omitted) (quoting Seema Verma, Administrator, Ctrs. for Medicare & Medicaid Servs.)).

84. Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid’s History*, 26 *Ga. St. U. L. Rev.* 937, 939 (2010) (“[T]he Social Security Act, with its emphasis on cash pensions and public assistance, was intended to move care from institutions—the old almshouses for the poor—into the community, but instead spurred a new private nursing home industry.”); see also Kaiser Fam. Found., *Long-Term Care Timeline*, *supra* note 73; SeniorMarketing: *The Evolution of Long-Term Care Services*, *supra* note 73.

85. Watson, *supra* note 84, at 945.

86. *Id.* at 968.

disabilities (ICF-IIDs)<sup>87</sup>—thereby creating new kinds of institutions for people with disabilities.<sup>88</sup>

Medicaid's broad coverage of institutional services is also a result of both the populations eligible for the program and the limitations of Medicare and private insurance. Medicaid eligibility was initially linked to receipt of cash assistance from the former Aid to Families with Dependent Children (AFDC) program.<sup>89</sup> Beginning in 1972 it was also linked to receipt of Supplemental Security Income (SSI) benefits,<sup>90</sup> ensuring the program's coverage of a large population of seniors and people with disabilities in need of long-term care services. Additionally, Medicare does not cover most LTSS, private long-term care insurance has never been common,<sup>91</sup> and the costs of LTSS are extremely high,<sup>92</sup> making LTSS difficult to afford without insurance. Medicaid thus became the program that fills in the LTSS gaps in Medicare and private insurance, serving as a safety net for the many people who become impoverished as a result of their LTSS needs.<sup>93</sup>

The Medicaid statute has included a bias toward institutional services since its inception: It has always required states to cover nursing facility services while making coverage of most community-based services a state

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87. ICF-IIDs were originally known as intermediate care facilities for the mentally retarded (ICF/MRs). Congress first provided for Medicaid coverage of ICF and ICF-IID care in 1971. See Watson, *supra* note 84, at 958–59.

88. Watson, *supra* note 84, at 968.

89. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 replaced the AFDC program with the Temporary Assistance for Needy Families (TANF) program. See Off. of the Assistant Sec'y for Plan. and Evaluation, Aid to Families With Dependent Children (AFDC) and Temporary Assistance for Needy Families (TANF) – Overview, <https://aspe.hhs.gov/aid-families-dependent-children-afdc-and-temporary-assistance-needy-families-tanf-overview-0z> [<https://perma.cc/6JZ7-MAV5>] (last visited July 20, 2021).

90. See, e.g., Gary Smith, Cille Kennedy, Sarah Knipper & John O'Brien, Using Medicaid to Support Working Age Adults With Serious Mental Illnesses in the Community: A Handbook 34 (2005), <https://aspe.hhs.gov/system/files/pdf/74111/handbook.pdf> [<https://perma.cc/2QCC-TFT7>]; Christie Provost & Paul Hughes, Medicaid: 35 Years of Service, 22 *Health Care Financing Rev.* 141, 142 (2000).

91. See Boon or Bane? Examining the Value of Long-Term Care Insurance: Hearing Before the S. Special Comm. on Aging, 111th Cong. 5 (2009) [hereinafter *Hearing on Long-Term Care Insurance*] (statement of Diane Rowland, Executive Vice President, Henry J. Kaiser Family Foundation) (“Few people have private health insurance to help pay for their nursing home stays . . . Unlike insurance for healthcare services, private insurance for long-term care is still a very limited option for financing care.”).

92. See Cost of Care Trends & Insights, Genworth Fin., Inc. (Feb. 12, 2021), <https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights.html> [<https://perma.cc/G5MT-RSWN>] (explaining that in 2020 the yearly median cost of a private room in a nursing home is \$105,850, and that of a private room in an assisted living facility is \$51,600).

93. *Hearing on Long-Term Care Insurance*, *supra* note 91, at 10–11 (2009) (statement of Diane Rowland, Executive Vice President, Henry J. Kaiser Family Foundation).

option.<sup>94</sup> Partly as a result of this bias in the statute, which created powerful financial incentives for families and states to institutionalize seniors and people with disabilities, the advent of Medicaid rapidly accelerated the growth in the utilization of and spending on nursing home care across the United States.<sup>95</sup>

Almost immediately after creating Medicaid, Congress recognized the need to rebalance the program's institutional bias to bring the program closer to its stated purpose of providing "rehabilitation and other services to help . . . families and individuals attain or retain capability for independence or self-care."<sup>96</sup> Congress thus took multiple steps to expand the authorities through which states can cover HCBS, including creating the Section 1915(c) HCBS waiver option in 1981.<sup>97</sup> This provision allows the Secretary of HHS to grant states waivers of certain Medicaid program rules governing long-term care services in order to expand Medicaid financial eligibility and offer HCBS to seniors and people with disabilities who would otherwise qualify for an institutional level of care.<sup>98</sup> Section 1915(c) waivers remain the primary authority through which HCBS are provided, both in terms of number of individuals served and percentage of total HCBS spending.<sup>99</sup> States may use 1915(c) waivers to target specific services to particular population groups and limit the number of people served, and many states have more than one 1915(c) waiver.<sup>100</sup> A minority of states

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94. The one exception to community-based services for adults being optional for states is home health care services, a specific category of HCBS defined in 42 C.F.R. § 440.70 (2020), which were first made mandatory for adult public assistance recipients and for medically needy recipients for whom states cover nursing home care under a 1968 amendment to the Medicaid statute. Watson, *supra* note 84, at 956, 960–61.

95. See Watson, *supra* note 84, at 957–60. Spending on nursing home care in the United States grew by approximately 1,400% between 1960 and 1974. Catherine Hawes & Charles D. Phillips, The Changing Structure of the Nursing Home Industry and the Impact of Ownership on Quality, Cost, and Access, *in* For-Profit Enterprise in Health Care 492, 498 (Bradford H. Gray ed., 1986) (citing Staff of S. Subcomm. on Long-Term Care, 94th Cong., Nursing Home Care in the United States: Failure in Public Policy XII (Comm. Print 1975)).

96. See 42 U.S.C. § 1396–1 (2018); Watson, *supra* note 84, at 960–64.

97. See Watson, *supra* note 84, at 961, 963.

98. Nancy A. Miller, Sarah Ramsland & Charlene Harrington, Trends and Issues in the Medicaid 1915(c) Waiver Program, 20 Health Care Fin. Rev. 139, 140 (1999).

99. O'Malley Watts et al., *supra* note 79. Congress added Section 1915(c) to the Social Security Act in 1981. 42 U.S.C. § 1396n(c); Miller et al., *supra* note 98, at 140; see also Jennifer Ryan & Barbara Edwards, Health Policy Brief: Rebalancing Medicaid Long-Term Services and Supports 1–2 (2015), [https://www.healthaffairs.org/doi/10.1377/hpb20150917.439553/full/healthpolicybrief\\_144.pdf](https://www.healthaffairs.org/doi/10.1377/hpb20150917.439553/full/healthpolicybrief_144.pdf) (on file with the *Columbia Law Review*) (“[W]aiver programs today . . . continue to represent more than half of HCBS spending, even as new state plan and waiver options have become available.”).

100. Musumeci et al., Key State HCBS Policy Choices, *supra* note 16. As of FY 2018, forty-seven states and the District of Columbia had a total of 265 1915(c) waivers. *Id.* at app. tbl.5. For detailed data on the populations each state targets under 1915(c) waiver(s), see *id.*

(twelve as of FY 2018) use Section 1115 research and demonstration waivers to cover HCBS.<sup>101</sup> States also have multiple options to provide HCBS benefits through their state Medicaid plans.<sup>102</sup>

During a public emergency, such as the COVID-19 pandemic, states have additional flexibility to temporarily modify or expand HCBS coverage under Section 1915(c) Appendix K.<sup>103</sup> For example, states can seek CMS approval under Appendix K to “modify or expand HCBS eligibility or services, modify or suspend service planning and delivery requirements, and

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101. Similar to 1915(c) waivers, Section 1115 waivers allow states flexibility to offer HCBS to people with an institutional level of care, target services to particular population groups, and limit the size of the population served. Musumeci et al., *Key State HCBS Policy Choices*, supra note 16.

102. State Medicaid plans are agreements between the federal government and each state that describe how the state administers its Medicaid program, including specifying which populations and services are covered. HHS, *Understanding Medicaid Home and Community Services: A Primer* (2010), <https://aspe.hhs.gov/system/files/pdf/76201/primer10.pdf> [<https://perma.cc/YK4Z-CRZ8>] [hereinafter HHS, *Understanding Medicaid HCBS*]; O’Malley Watts et al., supra note 79; Ctrs. for Medicare and Medicaid Servs., *Medicaid State Plan Amendments*, <https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html> [<https://perma.cc/7F3E-N3BG>] (last visited July 20, 2021) (explaining what a state plan is and must include). The major state plan HCBS include home health (which is the only category of HCBS that all states are required to cover); personal care; Section 1915(i) (which authorizes HCBS targeted to a particular population with functional needs that are less than an institutional level of care); and Community First Choice attendant services and supports (also known as the Section 1915(k) state plan option). See O’Malley Watts et al., supra note 79 (describing each of the state plan authorities and providing state-level data on enrollment and spending within each authority). States can and do use multiple authorities to provide coverage for a range of services to various populations. See Musumeci et al., *Key State HCBS Policy Choices*, supra note 16, at app. tbl.1.

These state choices about the authorities through which they provide HCBS are more than behind-the-scenes administrative decisions—they have significant implications for beneficiary eligibility, access, and benefits. For example, some state plan authorities, unlike the waiver authorities, allow states to offer HCBS to individuals with functional needs that are less than what a state requires to qualify for an institutional level of care. See Musumeci et al., *Key State HCBS Policy Choices*, supra note 16; Ctrs. for Medicare and Medicaid Servs., *Roadmap for Medicaid Reform 3*, <https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/Rvltcneeds.pdf> [<https://perma.cc/FA99-N8U8>] (last visited July 20, 2021).

103. See MaryBeth Musumeci, Kaiser Fam. Found., *How Are States Supporting Medicaid Home and Community-Based Services During the COVID-19 Crisis?* (2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/how-are-states-supporting-medicaid-home-and-community-based-services-during-the-covid-19-crisis/> [<https://perma.cc/XUP8-QESJ>]; 1915(c) HCBS Waiver Appendix K Modifications, Medicaid & CHIP Payment & Access Comm’n, <https://www.macpac.gov/subtopic/1915c-hcbs-waiver-appendix-k-modifications/> [<https://perma.cc/2XDD-G59W>] (last visited July 20, 2021); Emergency Preparedness and Response for Home and Community Based (HCBS) 1915(c) Waivers, Ctrs. for Medicare & Medicaid Servs., <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html> [<https://perma.cc/3LVK-HTNM>] (last visited July 20, 2021).

adopt policies to support providers.”<sup>104</sup> During the COVID-19 pandemic, CMS has also offered multiple other Medicaid emergency authorities through which states could make temporary changes to their LTSS programs.<sup>105</sup> While all states have used Appendix K authority to change their HCBS programs during the COVID-19 pandemic, and many states took HCBS-related actions under other emergency authorities, Appendix K and many other emergency authorities are only temporary, and only two states have used Appendix K to serve additional people in their HCBS waivers during the pandemic.<sup>106</sup> Consequently, the Appendix K authority and other Medicaid emergency authorities are not sufficient to address the institutionalization crisis during the current pandemic or beyond.

Reliance on Congress to appropriate additional funding for HCBS during public health crises is also an insufficient strategy. Despite widespread advocacy for the inclusion of dedicated HCBS funding in COVID-19 relief legislation,<sup>107</sup> Congress did not include new dedicated funding for HCBS in any of the COVID-19 relief packages until the American Rescue Plan Act of 2021, signed by President Biden on March 11, 2021.<sup>108</sup> And although that was a welcome step toward expanding access to HCBS during the pandemic, the funding is only temporary (from April 1, 2021 to March 31, 2022)<sup>109</sup> and came too late to help broaden access to HCBS during the height of the pandemic.

Federal, state, and local governments have engaged in a concerted effort over the last three decades to shift long-term care utilization and spending in Medicaid toward community-based, rather than institutional, LTSS.<sup>110</sup> The partial success of these ongoing “rebalancing” efforts is

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104. Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19, Kaiser Fam. Found., <https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/> [https://perma.cc/GWB6-8EST] (last updated July 1, 2021).

105. See MaryBeth Musumeci, Rachel Dolan & Madeline Guth, Kaiser Fam. Found., State Actions to Sustain Medicaid Long-Term Services and Supports During COVID-19 (2020), <https://www.kff.org/medicaid/issue-brief/state-actions-to-sustain-medicaid-long-term-services-and-supports-during-covid-19/> [https://perma.cc/C9KS-2S73].

106. See Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19, *supra* note 104.

107. See, e.g., Letter from Disability & Aging Collaborative & Consortium for Citizens With Disabilities to Mitch McConnell, Majority Leader, U.S. Senate & Charles Schumer, Minority Leader, U.S. Senate (June 15, 2020), <http://www.c-c-d.org/fichiers/National-and-State-Sign-on-COVID-19-Senate-Letter.pdf> [https://perma.cc/Z9NJ-FTWG].

108. American Rescue Plan Act of 2021, Pub. L. No. 117-2, § 9817(a), 135 Stat. 4, 216; see also American Rescue Plan Act Funding Breakdown, Nat'l Ass'n of Cntys. (Apr. 12, 2021), <https://www.naco.org/resources/featured/american-rescue-plan-act-funding-breakdown> [https://perma.cc/D4ER-7MLX].

109. See American Rescue Plan Act of 2021 § 9817(a).

110. Ryan & Edwards, *supra* note 99, at 1 (“Since enactment of the ADA on July 26, 1990, there has been a concerted effort at the state, federal, and community levels to transform one of the Medicaid program’s primary roles as an institutional care-focused financing mechanism into a comprehensive and flexible community-based long-term services and

shown by the increase in the proportion of Medicaid LTSS spending on HCBS over time.<sup>111</sup> Spending on HCBS surpassed spending on institutional care for the first time in 2013 and comprised fifty-seven percent of total Medicaid LTSS spending as of 2016.<sup>112</sup>

Despite this progress, overcoming Medicaid's institutional bias has proven to be an extremely difficult and slow process. Although HCBS are generally cheaper per person compared to institutional services,<sup>113</sup> many argue that broadening access to HCBS to all individuals who qualify for Medicaid LTSS would increase costs overall because many more people would seek HCBS services who are currently eligible for, but choose not to use, institutional services.<sup>114</sup> Additional challenges to "rebalancing" efforts

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supports program."). This process is known as Medicaid "rebalancing." See *id.* Medicaid's Money Follows the Person (MFP) program, which provides enhanced federal matching funds to states to help transition seniors and people with disabilities from institutions to the community, has played a large role in Medicaid rebalancing efforts. See MaryBeth Musumeci, Priya Chidambaram & Molly O'Malley Watts, Kaiser Fam. Found., Medicaid's Money Follows the Person Program: State Progress and Uncertainty Pending Federal Funding Reauthorization (2019), <https://www.kff.org/medicaid/issue-brief/medicaids-money-follows-the-person-program-state-progress-and-uncertainty-pending-federal-funding-reauthorization/> [<https://perma.cc/4LH6-QTBJ>] ("The program is credited with helping many states establish formal institution to community transition programs that did not previously exist by enabling them to develop the necessary service and provider infrastructure."). Between 2007 and June 2018, the program helped over 90,000 people transition from institutions to the community. *Id.* The program has historically been time-limited and has relied on periodic congressional funding extensions to continue operating, which has created uncertainty at times about the program's continuation. See *id.* The Consolidated Appropriations Act of 2021 extended MFP funding through 2023 and President Biden's American Jobs Plan proposes further extending the program. See Consolidated Appropriations Act, 2021, Pub. L. No. 116-260, § 204(a), 134 Stat. 1182, 2979 (2020); Fact Sheet: The American Jobs Plan, White House (Mar. 31, 2021), <https://www.whitehouse.gov/briefing-room/statements-releases/2021/03/31/fact-sheet-the-american-jobs-plan/> [<https://perma.cc/6GAP-5NVN>].

111. O'Malley Watts et al., *supra* note 79, at fig.2.

112. O'Malley Watts et al., *supra* note 79. This is a significant improvement from 1988, when only ten percent of Medicaid long-term care spending went toward community-based services. See Watson, *supra* note 84, at 965.

113. See, e.g., Charlene Harrington, Terence Ng & Martin Kitchener, Do Medicaid Home and Community Based Service Waivers Save Money?, 30 *Home Health Care Servs. Q.* 198, 206 fig.2, 209 tbl.1 (2011); Charlene Harrington, Terence Ng, H. Stephen Kaye & Robert J. Newcomer, Medicaid Home and Community Based Services: Proposed Policies to Improve Access, Costs, and Quality, 19 *Pub. Pol'y & Aging Rep.* 13, 15 (2009) (finding waiver services expenditures were \$44,000 per person lower than Medicaid institutional spending in 2002); Martin Kitchener, Terence Ng, Nancy Miller & Charlene Harrington, Institutional and Community-Based Long-Term Care: A Comparative Estimate of Public Costs, 22 *J. Health & Soc. Pol'y* 31, 33 (2006).

114. See, e.g., *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003) (arguing that plaintiffs' assertion "that it is cheaper [per capita] to provide long-term care services to individuals in a community-based setting rather than a nursing home" fails to consider costs of serving additional persons who were previously eligible but did not seek care offered only in an institutional environment); see also Sharaya L. Cabansag, Note, Defending Access to Community-Based Services for Individuals With Developmental Disabilities in the Wake of the "Great Recession," 55 *How. L.J.* 1025, 1047 (2012).

include: shortages of affordable and accessible community-based housing; the prohibition on use of Medicaid funds to pay for room and board (except in institutions);<sup>115</sup> HCBS workforce shortages;<sup>116</sup> and insufficient state political support and funding for HCBS.<sup>117</sup> Partly due to these factors, the process of expanding access to Medicaid HCBS to all individuals who need and qualify for these services is far from complete, as demonstrated by the hundreds of thousands of people stuck on waiting lists for Medicaid HCBS across the United States.<sup>118</sup>

3. *HCBS Waiting Lists and Debates Over Their Legality.* — The optional waiver authorities that states use to provide most HCBS, Sections 1915(c) and 1115, have long been interpreted to allow states to cap the number of people who can receive HCBS at a time in the state.<sup>119</sup> These caps often result in long waiting lists for services when the number of people seeking HCBS exceeds the number of waiver “slots.”<sup>120</sup> As of 2018, nearly 820,000 people were on waiting lists for Section 1915(c) and 1115 HCBS services across the United States, and this number is growing significantly over time.<sup>121</sup> The waiting period for services averaged thirty-nine months across all waivers with waiting lists in 2018 and varied by population group, with the highest average waiting period by population being seventy-one months for people with intellectual and developmental disabilities across states.<sup>122</sup>

Waiting list size and wait time alone are incomplete measures of state capacity and demand for HCBS because of variation in the populations states choose to cover, how they define those populations, whether they

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115. See 42 C.F.R. § 441.360(b) (2011); HHS, Understanding Medicaid HCBS, *supra* note 102, at 92.

116. See, e.g., Medicaid & CHIP Payment & Access Comm’n, State Management of Home- and Community-Based Services Waiver Waiting Lists 10 (2020), <https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf> [<https://perma.cc/2HE2-SDV3>] [hereinafter Medicaid & CHIP Payment & Access Comm’n, State Management of HCBS Waiting Lists].

117. See *id.* at 11; Watson, *supra* note 84, at 965, 969.

118. See *infra* section I.B.3.

119. See, e.g., MaryBeth Musumeci, Priya Chidambaram & Molly O’Malley Watts, Kaiser Fam. Found., Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists (2019), <https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/> [<https://perma.cc/6JJJ-WSH8>] [hereinafter Musumeci et al., Key Questions About HCBS Waiting Lists] (showing increases in Medicaid HCBS waiver waiting list enrollment in every year since 2010).

120. *Id.*

121. Kaiser Fam. Found., Waiting List Enrollment, *supra* note 16 (showing the distribution of waiting list enrollment for Medicaid section 1915(c) HCBS by state and population group); Musumeci et al., Key Questions About HCBS Waiting Lists, *supra* note 119, fig.1 (showing increases in total national HCBS waiver waiting list enrollment in every year since 2010); Musumeci et al., Key State HCBS Policy Choices, *supra* note 16, at app. tbl.10 (showing the percent change in Medicaid HCBS waiver waiting list enrollment from 2017 to 2018, both in individual states and in the United States overall).

122. Musumeci et al., Key State HCBS Policy Choices, *supra* note 16, at app. tbl.11.

screen individuals for waiver eligibility before placing them on a waiting list, and other factors.<sup>123</sup> The size of HCBS waiting lists across the country does, however, demonstrate a degree of unmet need for HCBS.<sup>124</sup> And some research suggests that there are racial and ethnic disparities in access to high-quality HCBS.<sup>125</sup> While many people on waiting lists receive community-based services from (typically unpaid) family caregivers or from the limited HCBS benefits available outside of the waivers, others may have little choice other than institutionalization to receive the LTSS they need while waiting for an HCBS waiver slot.<sup>126</sup>

Although states have been permitted to cap HCBS waiver slots and maintain long waiting lists for decades, some attorneys and scholars argue that long waiting periods for HCBS are illegal under the Medicaid statute.<sup>127</sup> This argument is perhaps most often asserted under Medicaid's "reasonable promptness" provision, which requires that medical assistance "be furnished with reasonable promptness to all eligible individuals."<sup>128</sup> Courts frequently interpret "reasonable promptness" to mean within ninety days.<sup>129</sup> Thus, if the provision applies to HCBS waiver services, states could be violating "reasonable promptness" by maintaining waiting lists with waiting periods longer than ninety days.<sup>130</sup>

The counterargument here, as argued successfully before the first district court that took up this question,<sup>131</sup> is that the Medicaid statute, and

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123. See *id.*; Medicaid & CHIP Payment & Access Comm'n, State Management of HCBS Waiting Lists, *supra* note 116, at 7.

124. Medicaid & CHIP Payment & Access Comm'n, State Management of HCBS Waiting Lists, *supra* note 116, at 10–11.

125. See, e.g., Rebecca J. Gorges, Prachi Sanghavi & R. Tamara Konetzka, A National Examination of Long-Term Care Setting, Outcomes, and Disparities Among Elderly Dual Eligibles, 38 *Health Affs.* 1110, 1110 (2019).

126. Medicaid & CHIP Payment & Access Comm'n, State Management of HCBS Waiting Lists, *supra* note 116, at 8.

127. See, e.g., Schwalb, *supra* note 18, at 832–33.

128. 42 U.S.C. § 1396a(a)(8) (2018); see also Jane Perkins, Pin the Tail on the Donkey: Beneficiary Enforcement of the Medicaid Act Over Time, 9 *St. Louis U. J. Health L. & Pol'y* 207, 223–24, 226 (2016) (explaining that one reason that the reasonable promptness provision, instead of other Medicaid provisions, is used to argue against HCBS waiting lists is that courts have consistently interpreted it as privately enforceable (i.e., as allowing a private right of action under 42 U.S.C. § 1983)).

129. See *Doe v. Chiles*, 136 F.3d 709, 721 (11th Cir. 1998); see also *Boulet v. Cellucci*, 107 F. Supp. 2d 61, 72–73 (D. Mass. 2000) (stating that the ninety-day standard established in a regulation governing Medicaid eligibility determinations provides guidance in the context of Medicaid's reasonable promptness provision).

130. See Musumeci et al., Key State HCBS Policy Choices, *supra* note 16, at app. tbl.11 (showing that the average waiting period for HCBS across the thirty states that reported such data was thirty-nine months).

131. *Makin ex rel. Russell v. Hawaii*, 114 F. Supp. 2d 1017 (D. Haw. 1999); see also Schwalb, *supra* note 127, at 809 ("The key case authorizing states to limit growth and availability of community based services was *Makin v. Hawaii*, the first case to address directly and decisively how, and whether, the waiver programs must follow Medicaid's general requirement that services be provided to beneficiaries with 'reasonable promptness.'").

especially its regulations, expressly allow for population caps on HCBS waiver services and implicitly exempt HCBS waivers from the reasonable promptness provision.<sup>132</sup> Yet a thorough look at this argument, including an analysis of whether deference to the CMS regulations is warranted under *Chevron U.S.A. Inc. v. Natural Resources Defense Council, Inc.*,<sup>133</sup> may suggest that the *Makin v. Hawaii* court and the subsequent courts that followed its reasoning got this wrong. A full *Chevron* analysis, according to one scholar, suggests that deference to the CMS regulations is not warranted because: (1) the statute is ambiguous about whether Congress intended to allow strict population limits in waiver programs;<sup>134</sup> (2) Congress did not explicitly or implicitly delegate rulemaking authority to CMS to set limits on the waiver program; and (3) a more natural reading of the statutory and regulatory HCBS waiver framework would view references to waiver limits as part of a procedure to demonstrate a waiver's cost-neutrality rather than to place a limit on population growth in the waiver.<sup>135</sup> This analysis also asserts that the plain language of the Medicaid statute does not exclude the HCBS waiver program from the "reasonable promptness" provision.<sup>136</sup>

As these arguments illustrate, the legal basis for population caps on HCBS services and long waiting lists may not be as solid as many assume it is. There appears to be room to challenge previous courts' failures to apply the reasonable promptness provision to HCBS. Yet this Note instead focuses on challenging the length of waiting lists and unjustified institutionalization more broadly under the ADA because the ADA's fundamental alteration framework appears more directly affected by the new evidence of the public health risks of institutionalization that COVID-19 provides.

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132. *Makin*, 114 F. Supp. 2d at 1027–28, 1030–31. The court in *Makin* found that the state did not violate reasonable promptness because CMS regulations, and to a lesser extent the Medicaid statute, allow population limits. *Id.* at 1027–28. The court found that the state is only required to provide available medical assistance with reasonable promptness, and since HCBS services are not "available" when the population limits are full, keeping people on waiting lists that take longer than a typical period of "reasonable promptness" is not a violation of the reasonable promptness provision. *Id.* at 1030–31.

133. 467 U.S. 837, 842–44 (1984) (laying out the standard by which courts should evaluate and decide whether to defer to an agency's construction of a statute which it administers).

134. Although the Medicaid Section 1915(c) waiver statutory provisions include two vague references to limits on the size of a state's waiver program, the *Makin* court itself acknowledged that these provisions are "ambiguous" about whether Congress intended to allow strict population limits in waiver programs. See Schwalb, *supra* note 127, at 811–13.

135. Schwalb, *supra* note 127, at 817–23. Cost-neutrality in the Section 1915(c) waiver context means that the estimated per capita costs of HCBS and other Medicaid services under the waiver do not exceed the per capita costs without the waiver. A state must demonstrate cost-neutrality of a waiver proposal in order for CMS to approve its waiver request. 42 U.S.C. § 1396n(c)(2)(D) (2018); 42 C.F.R. § 441.303(f)(1) (2020); Sahar Takshi, Note, Home Sweet Home: The Problem With Cost-Neutrality for Older Americans Seeking Home- and Community-Based Services, 5 *Admin. L. Rev. Accord* 25, 31 (2019).

136. See Schwalb, *supra* note 127, at 823–25.

## II. THE LEGAL FRAMEWORK THAT FAILED TO PREVENT THE CRISIS IN INSTITUTIONS

Two of the most pivotal events in the history of disability rights in the United States were the passage of the Rehabilitation Act (specifically, Section 504) in 1973 and the passage of the Americans with Disabilities Act in 1990. Among other civil rights victories, these statutes and their implementing regulations established the right of people with disabilities to receive services in an integrated setting.<sup>137</sup> Yet over two decades later, when waiting lists for Medicaid HCBS services have grown to over 800,000 people,<sup>138</sup> it is clear that the right to integrated services has not been fully realized.<sup>139</sup>

This Part explores the legal structures that contributed to the current public health crisis in institutions. Section II.A explains the statutory and regulatory framework for the right to services in an integrated setting. Section II.B describes judicial interpretations of the right to services in an integrated setting, including the 1999 *Olmstead* Supreme Court decision and later cases that interpreted the standards set out in *Olmstead*. Section II.C then argues that the *Olmstead* fundamental alteration framework fails to account for the public health risks of institutionalization and, thus, that the COVID-19 pandemic challenges continued application of the current legal framework for deinstitutionalization.

### A. *The Statutory and Regulatory Framework for the Right to Services in an Integrated Setting*

Section 504 of the Rehabilitation Act, the ADA, and the integration and reasonable modification regulations make up the statutory and regulatory framework governing the right to receive services in an integrated setting in the United States—the framework that the Supreme Court later interpreted in *Olmstead*. Section 504, the first federal statute addressing discrimination against and the civil rights of people with disabilities in the United States,<sup>140</sup> made it illegal for any program or activity receiving federal financial assistance to exclude from participation, deny benefits to, or discriminate against “otherwise qualified individual[s] with a disability in the United States.”<sup>141</sup> Section 504’s implementing regulations further require that recipients of federal financial assistance “administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”<sup>142</sup> Although progressive for its time,

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137. See 42 U.S.C. § 12101(a); 28 C.F.R. § 35.130(d) (2020).

138. Kaiser Fam. Found., *Waiting List Enrollment*, supra note 16.

139. See Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans With Disabilities Act and *Olmstead v. L.C.*, supra note 7.

140. Cabansag, supra note 114, at 1030.

141. 29 U.S.C. § 794(a) (2018).

142. 28 C.F.R. § 41.51(d).

Section 504 was limited in numerous ways<sup>143</sup> and ultimately had little impact on deinstitutionalization.<sup>144</sup>

In 1990, Congress enacted the ADA to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”<sup>145</sup> The ADA identified and targeted discrimination in a wide range of areas<sup>146</sup> and, unlike Section 504, explicitly recognized that persons with disabilities experience discrimination in “institutional[]” settings and that “segregation” itself is a form of discrimination.<sup>147</sup> Title II of the ADA, the provision that prohibits discrimination on the basis of disability and is most relevant to the institutionalization issue, declares, “[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”<sup>148</sup> It also specifically instructed the Attorney General to issue regulations implementing provisions of Title II, including its discrimination proscription.<sup>149</sup>

The two Attorney General regulations that are arguably the most important to the deinstitutionalization issue are the integration mandate and reasonable modifications regulation. The integration mandate requires public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>150</sup> The “most integrated setting” was defined as the “setting

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143. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 n.11 (1999) (“Unlike the ADA, § 504 of the Rehabilitation Act contains no express recognition that isolation or segregation of persons with disabilities is a form of discrimination. Section 504’s discrimination proscription, a single sentence attached to vocational rehabilitation legislation, has yielded divergent court interpretations.”); Bonnie P. Tucker, *Section 504 of the Rehabilitation Act After Ten Years of Enforcement: The Past and the Future*, 1989 U. Ill. L. Rev. 845, 915 (1989) (“There are three primary reasons that [Section 504] has not been as effective as Congress intended: inadequate enforcement of the law; conflicting interpretations with respect to the requirement that ‘reasonable accommodation’ be made for ‘otherwise qualified’ handicapped persons; and the limited scope of the law itself.”).

144. See Ferleger, *supra* note 18, at 768. A number of courts held that the denial of community-based habilitation services to mentally disabled individuals does not constitute a viable cause of action under Section 504. See, e.g., *Ky. Ass’n for Retarded Citizens, Inc. v. Conn.*, 674 F.2d 582, 585 (6th Cir. 1982); *Conner v. Branstad*, 839 F. Supp. 1346, 1356 (S.D. Iowa 1993); *Sabo v. O’Bannon*, 586 F. Supp. 1132, 1137 (E.D. Pa. 1984); *Manecke v. Sch. Bd.*, 553 F. Supp. 787, 790 n.4 (M.D. Fla. 1982), *aff’d in part and rev’d in part*, 762 F.2d 912 (11th Cir. 1985); *Garrity v. Gallen*, 522 F. Supp. 171, 213 (D.N.H. 1981).

145. 42 U.S.C. § 12101(b)(1) (2018).

146. *Id.* § 12101(a).

147. *Id.* § 12101(a)(3), (5).

148. *Id.* § 12132.

149. *Id.* § 12134(a). The ADA specifically directed that the regulations be consistent with the regulations applicable to recipients of federal financial assistance under Section 504. *Id.* § 12134(b).

150. 28 C.F.R. § 35.130(d) (2020); see also *The Americans With Disabilities Act of 1990 and Revised ADA Regulations Implementing Title II and Title III*, ADA.gov, [https://www.ada.gov/2010\\_regs.htm](https://www.ada.gov/2010_regs.htm) [<https://perma.cc/5VFW-PNP7>] (last visited July 20,

that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.”<sup>151</sup> The reasonable modifications regulation requires a public entity to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate conclusively that making the modifications would fundamentally alter the nature of the service, program, or activity.”<sup>152</sup>

While certainly a stronger and clearer framework for protecting the civil rights of people with disabilities than Section 504, the ADA left open the question of whether people with disabilities have a right to community-based services. This question made its way to the Supreme Court less than a decade after the ADA’s passage in the historic *Olmstead* case.

B. *Judicial Interpretations of the Right to Services in a Community-Based Setting*

*Olmstead v. L.C. ex rel. Zimring* is a landmark desegregation decision in which the Court ruled that unjustified institutionalization of people with disabilities is unlawful discrimination under the ADA and that people with disabilities have a qualified right to community-based services.<sup>153</sup> This right is “qualified” because the Court ruled that the state’s responsibility is “not boundless”<sup>154</sup> and the fundamental alteration defense<sup>155</sup> can apply if a state can show that it has an “effectively working plan” for deinstitutionalization and a “waiting list [for HCBS] that move[s] at a reasonable pace.”<sup>156</sup> Although *Olmstead* was progressive for its time in articulating a limited right to community-based services, over two decades after the 1999 *Olmstead* decision, hundreds of thousands of Americans remain stuck on waiting lists for Medicaid HCBS.<sup>157</sup> After first explaining key elements of

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2021) (noting the original publication of the Attorney General’s regulations in 1991 and describing later revisions to them). The ADA’s integration regulation was modeled after a § 504 regulation, requiring recipients of federal funds to “administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.” 28 C.F.R. § 41.51(d).

151. 28 C.F.R. pt. 35 app. B. In 2011, DOJ issued a statement on enforcement of the integration mandate, which reiterates the definition of “most integrated setting” as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible” and provides additional clarifications on the differences between integrated and segregated settings. See Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans With Disabilities Act and *Olmstead v. L.C.*, supra note 7.

152. 28 C.F.R. § 35.130(b)(7)(i).

153. 527 U.S. 581, 587 (1999).

154. *Id.* at 603.

155. For context on the fundamental alteration defense under the ADA’s reasonable modifications regulation, see supra text accompanying note 152.

156. *Olmstead*, 527 U.S. at 605–06.

157. See supra note 16 and accompanying text.

the *Olmstead* decision itself, this section shows how subsequent court interpretations of the elements of the *Olmstead* fundamental alteration analysis have rendered the standard overly lenient, deferential to states, and vague.

1. *Olmstead's Qualified Right to Community-Based Services.* — The central question at issue in *Olmstead* was “whether the [ADA’s] proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions.”<sup>158</sup> Writing for a plurality of four, Justice Ginsburg expressed the Court’s answer as “a qualified yes.”<sup>159</sup> While the Court held that “unjustified isolation . . . is properly regarded as discrimination based on disability,” it simultaneously recognized the states’ competing need, given resource limitations, “to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand.”<sup>160</sup> Balancing these competing pressures, the Court ruled that a state must provide community-based treatment when: (1) treatment professionals determine that such placement is appropriate, (2) the individual does not oppose such treatment, and (3) the placement is a reasonable modification, taking into account the resources available to the State and the needs of others with mental disabilities.<sup>161</sup> While the first two prongs are typically low hurdles, the third prong of the *Olmstead* test has been a major focus of post-*Olmstead* litigation.<sup>162</sup>

Under the third prong above, the Court affirmed the ability of a state to resist making modifications to its programs or policies if it can demonstrate that those modifications entail a “fundamental alteration” of existing programs or policies.<sup>163</sup> It held that a state would meet the standard for successfully applying the fundamental alteration defense if, for example, it 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.<sup>164</sup> But the Court failed to elaborate on what constitutes an “effectively working plan” or a “waiting list that move[s] at a reasonable pace,”<sup>165</sup>

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158. *Olmstead*, 527 U.S. at 587.

159. *Id.*

160. *Id.* at 597.

161. *Id.* at 607.

162. Bliss & Wells, *supra* note 18, at 721–22.

163. The Court’s broad interpretation of the fundamental alteration defense “allow[s] the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.” *Olmstead*, 527 U.S. at 604.

164. *Id.* at 605–06.

165. See *Olmstead*, 527 U.S. at 605–06; Melody M. Kubo, Implementing *Olmstead v. L.C.*: Defining “Effectively Working” Plans for “Reasonably Paced” Wait Lists for Medicaid Home and Community-Based Services Waiver Programs, 23 U. Haw. L. Rev. 731, 734 (2001). In

and beyond these vague examples it did not provide much guidance on what constitutes a fundamental alteration.<sup>166</sup> Consequently, it created “murky” standards that granted states extensive power “to determine the scope of their own obligations, as well as the affirmative defenses they are accorded,”<sup>167</sup> and allowed courts to “embark[] on a path of judicial interpretation that threatens to render the ‘working plan’ provision in *Olmstead* a ‘get out of jail free’ card for states otherwise in violation of the decision’s integration mandate.”<sup>168</sup>

2. *Post-Olmstead Interpretations of “Effectively Working Plan”*. — The *Olmstead* decision left open the question of what constitutes an “effectively working plan” for deinstitutionalization under the fundamental alteration standard.<sup>169</sup> The two circuits that have thoroughly considered and addressed this question have adopted divergent standards that both grant a great degree of deference to states. The Ninth Circuit adopted a lenient, backward-looking “effectively working plan” standard that does not require states to produce written *Olmstead* plans with measurable outcomes and target deadlines.<sup>170</sup> As one author summarized,

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addition to failing to define the meaning of these standards, *Olmstead* left lower courts confused about whether an effectively working plan and reasonably paced waiting list are necessary to the fundamental alteration defense or merely examples of one (but not the only) way states could show that the defense is warranted. Compare *Frederick L. v. Dep’t of Public Welfare of Pa.*, 422 F.3d 151, 157 (3d Cir. 2005) (“We interpret the Supreme Court’s opinion to mean that a comprehensive working plan is a necessary component of a successful ‘fundamental alteration’ defense in these proceedings.”), with *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 339 (E.D.N.Y. 2009) (“[T]he court concludes that *Olmstead* does not require a plan to comply with the integration mandate as a prerequisite to considering the other elements of a fundamental alteration defense.”), and *Martin v. Taft*, 222 F. Supp. 2d 940, 985–86 (S.D. Ohio 2002) (“[T]he State has no plan or waiting lists that move at a reasonable pace. Although this is not a good thing for defendants, it does not necessarily mean that defendants cannot prevail.”).

166. See, e.g., Jefferson D.E. Smith & Steve P. Calandrillo, Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits After *Olmstead v. L.C.*, 24 Harv. J.L. & Pub. Pol’y 695, 702 (2001).

167. Ferleger, *supra* note 144, at 775; see also *supra* sections II.B.2–3.

168. John F. Muller, Comment, *Olmstead v. L.C.* and the Voluntary Cessation Doctrine: Toward a More Holistic Analysis of the “Effectively Working Plan”, 118 Yale L.J. 1013, 1014 (2009).

169. Amy Tidwell, Note, Deinstitutionalization: Georgia’s Progress in Developing and Implementing an “Effectively Working Plan” as Required by *Olmstead v. L.C. Ex Rel.*, 25 Ga. St. U. L. Rev. 699, 707 (2009).

170. See *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 621–22 (9th Cir. 2005) (finding that Washington had an effectively working plan under *Olmstead* based on past progress toward deinstitutionalization, including an increase in the cap on HCBS slots in the previous two decades and significant reductions in the size of the state’s institutionalized population in past years); *Sanchez v. Johnson*, 416 F.3d 1051, 1068 (9th Cir. 2005) (explaining that California demonstrated an effectively working plan because it “ha[d] a successful record of personalized evaluations leading to a reasonable rate of deinstitutionalization” and had “undertaken to continue and to increase its efforts to place current residents of Developmental Centers into the community when such placement is feasible”).

A state may demonstrate that it has an effectively working plan [in the Ninth Circuit] if it has made significant [past] progress in (1) moving people out of institutions, (2) increasing its budget for community services in spite of fiscal constraints, and (3) increasing the size of its [HCBS] waiver program over time.<sup>171</sup>

By contrast, the Third Circuit adopted a somewhat stricter standard for the fundamental alteration defense that requires states to show more than a past commitment to deinstitutionalization.<sup>172</sup> While it does not find evidence of past progress irrelevant, the Third Circuit has held that courts should not allow the fundamental alteration defense absent a plan that includes a commitment to future progress toward community placement “in a manner for which it can be held accountable by the courts.”<sup>173</sup> The court subsequently further clarified that at a minimum, an “effectively working plan” should

specify the time-frame or target date for patient discharge, the approximate number of patients to be discharged each time period, the eligibility for discharge, and a general description of the collaboration required between the local authorities and the housing, transportation, care, and education agencies to effectuate integration into the community.<sup>174</sup>

Thus, the central difference between the Ninth and Third Circuit standards for what constitutes an “effectively working plan” sufficient to apply the fundamental alteration defense is that the Ninth Circuit requires only evidence of past progress toward deinstitutionalization, whereas the Third Circuit demands that states have plans with specific and measurable goals for which they may be held accountable.<sup>175</sup> The only other circuit court to have partially clarified the effectively working plan question is the D.C. Circuit, which ruled in 2019 that plaintiffs need not identify a “concrete systemic deficiency” in the defendants’ transition services in order to overcome a fundamental alteration defense.<sup>176</sup> But the circuit court did

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171. Tidwell, *supra* note 169, at 708 (footnote omitted).

172. *Frederick L. v. Dep’t of Pub. Welfare*, 422 F.3d 151, 154 (3d Cir. 2005); *Frederick L. v. Dep’t of Pub. Welfare*, 364 F.3d 487 (3d Cir. 2004); Tidwell, *supra* note 169, at 712 (“The court was looking for verifiable benchmarks or timelines.”).

173. *Frederick L.*, 364 F.3d at 500; see also *Pa. Prot. & Advoc., Inc. v. Pa. Dep’t of Pub. Welfare*, 402 F.3d 374, 383 (3d Cir. 2005) (holding that the district court erred by failing to require the defendant to “demonstrate a reviewable commitment to action” in order to apply the fundamental alteration defense). Some district courts in other circuits have followed the Third Circuit’s standard here. See, e.g., *Jensen v. Minn. Dep’t of Hum. Servs.*, 138 F. Supp. 3d 1068, 1072 (D. Minn. 2015) (approving a state’s revised *Olmstead* plan based on “(1) the addition of concrete baseline data and specific timelines to establish measurable goals; (2) improvements to each goal that make the *Olmstead* Plan . . . measurable [and] strategically tailored . . . and (3) added commitments to make the *Olmstead* Plan . . . continue to respond to the changing needs of individuals . . . over time”).

174. *Frederick L.*, 422 F.3d at 160.

175. See Tidwell, *supra* note 169, at 708–13; see also Muller, *supra* note 168, at 1016–17.

176. *Brown v. District of Columbia*, 928 F.3d 1070, 1087 (D.C. Cir. 2019).

not provide much clarity on its “effectively working plan” standard beyond that before remanding the case.<sup>177</sup>

3. *Post-Olmstead Cases Have Not Fully Clarified the “Reasonable Pace” Standard.* — Case law interpreting *Olmstead*’s requirement for the fundamental alteration defense that states have a “waiting list that move[s] at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated”<sup>178</sup> is sparse. Courts frequently focus their fundamental alteration analysis on the “effectively working plan” element without conducting an analysis of whether the pace of waiting list movement is “reasonable.”<sup>179</sup>

Among courts that have considered whether the pace of waiting list movement in the case is “reasonable,” many only include vague references to the pace of waiting list movement and do not specify why the waiting list pace was or wasn’t reasonable or what the court’s standard is for a reasonable pace of waiting list movement.<sup>180</sup> Some courts are inclined to defer to states that show policy changes, even if the pace of actual change in deinstitutionalization and waiting list movement is slow.<sup>181</sup> Other courts analyze the waiting list pace within the “effectively working plan” analysis and may accept commitment in an *Olmstead* plan to increasing the pace of waiting list movement in the future as sufficient to meet the “reasonable pace” standard.<sup>182</sup>

The lack of a clear standard on what constitutes a “reasonable pace” for waiting list movement is problematic. It leaves judges broad discretion to apply the “reasonable pace” requirement as they see fit, raising questions about consistency or fairness in the application of the standard across

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177. *Id.* at 1086–87.

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

179. See, e.g., *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 621–22 (9th Cir. 2005) (allowing the fundamental alteration defense without an analysis of the pace of the state’s waiting list, noting only that “all Medicaid-eligible disabled persons will have an opportunity to participate in the program once space becomes available”).

180. See, e.g., *Makin ex rel. Russell v. Hawaii*, 114 F. Supp. 2d 1017, 1035 (D. Haw. 1999) (denying the state’s summary judgment motion in part because “[t]he only evidence of any effort to decrease the wait list is the increase in ‘slots’ over the next few years [but] [t]hat single piece of evidence . . . does not show that the State is complying with the ADA”).

181. *Williams v. Wasserman*, 164 F. Supp. 2d 591 (D. Md. 2001); see also Sara Rosenbaum & Joel Teitelbaum, Kaiser Comm’n on Medicaid & the Uninsured, *Olmstead at Five: Assessing the Impact 9–10* (2004) <https://www.kff.org/wp-content/uploads/2013/01/olmstead-at-five-assessing-the-impact.pdf> [<https://perma.cc/YL3E-PH7S>].

182. *Jensen v. Minn. Dep’t of Hum. Servs.*, 138 F. Supp. 3d 1068, 1074 (D. Minn. 2015) (“[T]he State’s measurable goals related to the waiver waiting lists are reasonable. Under these goals going forward, the waiting lists will either be eliminated or move at a reasonable pace within a reasonable timeframe. The State has committed to implementing initiatives to increase the pace of the waiting lists . . . .” (footnote omitted) (citation omitted)).

jurisdictions and individual judges.<sup>183</sup> The lack of a clear standard for “reasonable pace” also threatens to render this component of *Olmstead* meaningless when a state can show barriers to integration—even if addressing those barriers is within the state’s power.<sup>184</sup>

4. *Budgetary Constraints Alone Cannot Support a Fundamental Alteration Defense but Are Considered in the Fundamental Alteration Analysis.* — Courts have consistently ruled that state budgetary constraints alone are insufficient to establish a fundamental alteration defense.<sup>185</sup> Yet *Olmstead* does suggest that the fundamental alteration analysis should take costs into account in a holistic assessment of whether “in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.”<sup>186</sup> Thus, lower courts post-*Olmstead* typically consider the costs of the requested relief in the context of the range of services the state provides to others with disabilities, assessing whether the provision of the community-based services requested would harm other state residents with disabilities.<sup>187</sup> Some courts require the state to show that the funds would necessarily come from the *Medicaid* budget and could not come instead from cuts to other portions of the state’s budget.<sup>188</sup>

183. See Brandon L. Garrett, *Constitutional Reasonableness*, 102 Minn. L. Rev. 61, 124–25 (2017) (“If it is judges . . . calling conduct reasonable post hoc, without setting any standards of care, then reasonableness turns into a form of blanket deference that does not inform officials or give the public clear guidance on what their rights actually are.”).

184. The D.C. Circuit’s *Brown v. District of Columbia* decision demonstrates this risk in the majority’s statement:

We are especially troubled by the concurrence’s suggestion that we propose “to measure success of the ADA claims based primarily on the number of completed or pending placements of disabled individuals in outside housing.” . . . [T]he district court could find, consistent with our opinion, that, in light of the lack of available public housing, the placement of only one individual in a given year *could* be a “reasonable pace” of movement from the District’s waiting list.

*Brown v. District of Columbia*, 928 F.3d 1070, 1086 (D.C. Cir. 2019).

185. See, e.g., *Pa. Prot. & Advoc., Inc. v. Pa. Dep’t of Pub. Welfare*, 402 F.3d 374, 380–81 (3d Cir. 2005); *Frederick L. v. Dep’t of Pub. Welfare*, 364 F.3d 487, 495 (3d Cir. 2004); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1182–83 (10th Cir. 2003) (“If every alteration in a program or service that required the outlay of funds were tantamount to a fundamental alteration, the ADA’s integration mandate would be hollow indeed.”); *Makin*, 114 F. Supp. 2d at 1034 (“These [cost-based] arguments fail to show how the modification would fundamentally alter the program, since it merely argues that the State would potentially have a problem funding it.”).

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

187. See, e.g., *M.R. v. Dreyfus*, 697 F.3d 706, 736–37 (9th Cir. 2012); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 613–15 (7th Cir. 2004).

188. *Dreyfus*, 697 F.3d at 737; *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2004) (“[E]ven if extension of community-based long term care services to the medically needy were to generate greater expenses for the state’s Medicaid program, it is unclear whether

C. *The COVID-19 Crisis in Institutions Exposes the Olmstead Fundamental Alteration Framework's Flaws, Including Failure to Account for the Public Health Risks of Institutionalization*

With over 800,000 people on Medicaid HCBS waiting lists as of 2018 and trend data showing consistent increases in this figure every year,<sup>189</sup> the *Olmstead* framework has clearly failed to achieve the ADA's stated goal of eliminating discrimination, which includes segregation and undue institutionalization, against people with disabilities.<sup>190</sup> The consequences of this failure and the flaws in the *Olmstead* framework have taken on a new dimension in the context of the COVID-19 tragedy in institutions. The pandemic has exposed how access to Medicaid-covered HCBS is a matter of life and death for many people with disabilities and older adults.<sup>191</sup> Given the gravity of the right to services in an integrated setting for this population, courts' current interpretations of *Olmstead's* effectively working plan requirement are untenable.<sup>192</sup> States must not be permitted to avoid their obligation to provide services in an integrated setting by merely showing a plan that promises gradual progress toward deinstitutionalization in the future, or by showing some degree of past progress without any clear plan for future progress. It is also hard to conceive of the current pace of HCBS waiting list movement in most states as "reasonable" given the shockingly long waiting periods for HCBS and the essential nature of these services, especially during a pandemic.<sup>193</sup> In sum, the *Olmstead* framework in its current state is simply not up to the task of addressing the current public health crisis in institutions, or the future public health events that are sure to occur.

One silver lining to the current public health crisis is that it could offer an opportunity for a breakthrough in the fight for deinstitutionalization. The crisis not only provides new evidence of the urgency of the institutionalization issue but also challenges continued application of the current legal framework for deinstitutionalization because the framework

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these extra costs would, in fact, compel cutbacks in services to other *Medicaid* recipients." (emphasis added)).

189. See supra note 121 and accompanying text.

190. See 42 U.S.C. § 12101 (2018); *Olmstead*, 527 U.S. at 597–98 (deferring to DOJ's position that "undue institutionalization qualifies as discrimination" under the ADA); see also Eric Carlson & Gene Coffey, Nat'l Senior Citizens L. Ctr., 10-Plus Years After the *Olmstead* Ruling: Progress, Problems, and Opportunities 8 (2010), [http://www.aucd.org/docs/policy/community\\_living\\_supports/Protecting%20the%20Rights%20of%20Low-Income%20Older%20Adults%2010-Plus%20Years%20After%20the%20Olmstead%20Ruling.pdf](http://www.aucd.org/docs/policy/community_living_supports/Protecting%20the%20Rights%20of%20Low-Income%20Older%20Adults%2010-Plus%20Years%20After%20the%20Olmstead%20Ruling.pdf) [<https://perma.cc/XE82-TM9E>] ("[U]nnecessary institutionalization is still a routine problem for too many older adults and people with disabilities, especially those with lower incomes."). Some evidence suggests that transitions out of institutions slowed in the years following the *Olmstead* decision. See Ferleger, supra note 144, at 771–72.

191. See supra section I.A.

192. See supra section II.B.2 (describing the Ninth and Third Circuit frameworks for assessing an "effectively working plan").

193. See supra note 122 and accompanying text.

was formulated without taking the public health risk element of this issue into account. The three sections below demonstrate the *Olmstead* Court's failure to account for the public health risks of institutionalization, highlight the same oversight by the lower courts that subsequently interpreted *Olmstead's* fundamental alteration framework, and argue that the current fundamental alteration framework is overly burdensome on the legal system and costly to parties because it encourages protracted litigation.

1. *Olmstead Does Not Account for the Public Health Risks of Institutionalization.* — The *Olmstead* Court did not demonstrate awareness or consideration of the public health risks of institutionalization. It explained that its holding reflected “two evident judgements”: first, that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life” and second, that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”<sup>194</sup>

While still true, these findings miss an important aspect of the problem: Institutionalization puts individuals at greater risk of harm during public health crises and reduces their freedom to protect their own health through precautions like social distancing and quarantining.<sup>195</sup> Given how COVID-19 has put this aspect of the problem in the spotlight, it would almost certainly be included in the Court's findings if *Olmstead* were decided today. This suggests that the public health risks of institutionalization should be factored into courts' fundamental alteration analyses that balance individuals' right to integrated services—which are based on and supported by the Court's findings above—and states' need to “maintain a range of facilities and to administer services with an even hand.”<sup>196</sup> Taking the health risks into account, the fundamental alteration analysis should weigh more heavily toward protecting people's right to integration.<sup>197</sup>

2. *Lower Courts Interpreting Olmstead's Fundamental Alteration Elements Also Fail to Account for the Public Health Risks of Institutionalization.* — The new evidence of the public health risks of institutionalization also suggests a need to strengthen each of the major fundamental alteration framework

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194. *Olmstead*, 527 U.S. at 600–01.

195. See, e.g., Werner, Hoffman & Coe, *supra* note 23.

196. *Olmstead*, 527 U.S. at 605.

197. Public health risks also undermine the Court's reasoning for granting states more leeway under the fundamental alteration defense. For example, the Court quotes a statement from the state's attorney in the oral argument, stating, “It is reasonable for the State to ask someone to wait until a community placement is available.” *Olmstead*, 527 U.S. at 606. But the Court may not have viewed asking an individual to “wait” as “reasonable” if the Court thought about the health implications of this decision and realized that waiting, potentially in an institution, could mean risking the individual's life during a public health crisis.

elements articulated in *Olmstead*: (1) an “effectively working plan,” (2) a “waiting list that move[s] at a reasonable pace,” (3) and the consideration of costs and state budgetary constraints.

Neither of the major circuit court interpretations of the requirements of an “effectively working plan” are strong enough to ensure real progress toward integration and deinstitutionalization: The retrospective approach “gives undue weight to past state actions” and the prospective approach “relies uncritically on state promises to take future action.”<sup>198</sup> At this point in time, over three decades after passage of the ADA and two decades after *Olmstead*, states have had ample time to develop and implement deinstitutionalization plans. Courts’ failures to mandate more out of states than these retrospective and prospective approaches require are partially to blame for people in institutions experiencing disproportionate harm during the COVID-19 pandemic.<sup>199</sup> It is difficult to comprehend how a majority of states across the country could have “effectively working” plans for deinstitutionalization in the face of the high COVID-19 death rates in institutions and the large numbers of people who still cannot access HCBS.<sup>200</sup>

The scarce interpretations of what it means for a waiting list to move at a “reasonable pace” also fail to account for the public health risks of institutionalization and are inconsistent with the ADA’s demands. Some courts, such as the D.C. Circuit in *Brown v. District of Columbia* and the District Court for the District of New Hampshire in *Bryson v. Stephen*, have found that hardly any movement each year or a waiting list that never decreases in size could meet the “reasonable pace” standard.<sup>201</sup> But it is hard to imagine that such slow or stagnant waiting list movement could ever be “reasonable” under Congress’s original intent for the ADA’s protections, especially in light of the COVID-19 experience. Congress specified that the ADA was enacted “to provide a clear and comprehensive national mandate for the *elimination* of discrimination against individuals with disabilities.”<sup>202</sup> Full *elimination* of unjustified institutionalization—one form of discrimination under the ADA<sup>203</sup>—is an even more urgent goal knowing that the consequences of unjustified institutionalization include heightened

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198. Muller, *supra* note 168, at 1014; see also *supra* section II.B.2 for more context on the retrospective (Ninth Circuit) and prospective (Third Circuit) approaches for assessing whether an *Olmstead* plan is “effectively working.”

199. See *supra* section I.A.

200. See *supra* sections I.A, I.B.3.

201. See *Brown v. District of Columbia*, 928 F.3d 1070, 1086 (D.C. Cir. 2019) (“[T]he district court could find, consistent with our opinion, that, in light of the lack of available public housing, the placement of only one individual in a given year *could be* a “reasonable pace” of movement from the District’s waiting list.”); *Bryson v. Stephen*, No. 99-CV-558-SM, 2006 WL 2805238, at \*6 (D.N.H. Sept. 29, 2006) (“The list moves at a reasonable pace given that the number of persons on the list has remained fairly stable while new slots have been added and vacant ones filled . . .”).

202. 42 U.S.C. § 12101(b)(1) (2018) (emphasis added).

203. See *supra* note 190 and accompanying text.

vulnerability to illness and death from disease. If full elimination of unjustified institutionalization is the goal, then surely the “reasonable pace” standard must be stronger than courts like the *Brown* and *Bryson* courts<sup>204</sup> understand it to be and require an actual decrease in the size of waiting lists over time so that a larger portion of the population is able to live safely in their own homes and communities. It does not seem “reasonable” to ask people to wait anywhere near the current average wait list time for HCBS.<sup>205</sup>

The evidence of the public health risks of institutionalization also impacts the costs and state budget constraints element of the fundamental alteration analysis in a way that courts have failed to account for. The costs to states and institutions of taking additional infection-control precautions, treating sick residents, and other COVID-related expenses have been “extraordinary.”<sup>206</sup> The fundamental alteration analysis should consider the long-term savings that states could accrue from expanding access to HCBS,<sup>207</sup> especially in light of research predicting more frequent pandemics and other public health crises going forward.<sup>208</sup>

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204. See *supra* note 201 and accompanying text.

205. See *supra* note 122 and accompanying text.

206. Dave Altamari, *State Will Pay Nursing Homes \$35 Million to Cover COVID-19 Costs; Plans to Reopen Closed Facility in Meriden*, Hartford Courant (Apr. 3, 2020), <https://www.courant.com/coronavirus/hc-news-coronavirus-nursing-homes-covid-costs-20200403-nubueejinvgz7ju7nniqd5zfhq-story.html> (on file with the *Columbia Law Review*) (“[Connecticut’s 213] nursing homes will receive a 10% across-the-board increase in Medicaid payments to help meet extraordinary costs from the public health emergency created by the coronavirus pandemic.”); see also *States Leverage Medicaid to Provide Nursing Homes a Lifeline Through COVID-19*, LeadingAge (April 27, 2020), <https://www.leadingage.org/regulation/states-leverage-medicaid-provide-nursing-homes-lifeline-through-covid-19> [<https://perma.cc/7Z4G-7KDD>] (last updated June 12, 2020).

207. HCBS are generally cheaper per person compared to institutional services. See *supra* note 113. There is not yet comprehensive data on pandemic-related costs for different forms of long-term care services. Nonetheless, the nature of these services suggests these costs would be lower for HCBS compared to institutional care. Although HCBS during COVID still requires additional spending on pandemic-related costs, such as personal protective equipment and testing for direct care professionals, HCBS better facilitates social distancing, isolation, and other behaviors that limit infection rates, and thus can help avoid the costs of treatment for sick residents. In addition, HCBS typically eliminates the state or facility’s need to fund additional cleaning, barriers, or other modifications necessary to improve the safety of the environment in an institution.

208. See, e.g., Jeff Tollefson, *Why Deforestation and Extinctions Make Pandemics More Likely*, 584 *Nature* 175, 175 (2020) (highlighting growing evidence that links biodiversity loss with disease outbreaks); Victoria Gill, *Coronavirus: This Is Not the Last Pandemic*, BBC (June 6, 2020), <https://www.bbc.com/news/science-environment-52775386> [<https://perma.cc/XS5Z-QRF7>] (noting that human-transformed ecosystems are likely to increase contact between humans and disease-bearing species); Leon McDougle, *Opinion, Climate Change Threatens More Than the Environment; It’s a Public Health Crisis*, Balt. Sun (June 24, 2021), <https://www.baltimoresun.com/opinion/op-ed/bs-ed-op-0625-climate-health-race-20210624-yndfkautava6ndwfs6jwde5mly-story.html> (on file with the *Columbia Law Review*).

Some may still argue that the costs of an influx of people seeking HCBS who do not currently use Medicaid institutional services will exceed the savings from transitioning other people out of institutions and reducing pandemic-related institutional expenditures. While the likelihood of this occurring is uncertain, even if it does, these state costs are necessary to achieve the explicit purposes of the ADA, which include creating a “national mandate for the elimination of discrimination against people with disabilities.”<sup>209</sup> Furthermore, Congress designed Medicaid as an entitlement program with a primary purpose of “furnish[ing] medical assistance” and a secondary purpose of providing “rehabilitation and other services to help . . . families and individuals attain or retain capability for independence or self-care.”<sup>210</sup> State budget concerns have never been a legitimate basis for denying Medicaid services to eligible individuals,<sup>211</sup> and nothing in Title II of the ADA suggests that such concerns may be prioritized over the right to be free from discrimination either.<sup>212</sup> The fundamental alteration exception to the ADA’s requirements comes from DOJ’s regulations rather than the statute, and the permission to consider costs and budget constraints within the fundamental alteration analysis comes from the *Olmstead* decision rather than either the regulations or the statute.<sup>213</sup> Therefore, in recognition of the public health risks of institutionalization, DOJ can and should use its regulatory authority to significantly limit the influence of budget constraints in the fundamental alteration analysis.

3. *The Current Fundamental Alteration Framework Requires Protracted Litigation to Enforce Rights and Overly Burdens the Legal System.* — Another reason to consider clarifying and strengthening the fundamental alteration standards is to help reduce the burden that lengthy, complicated, and inefficient *Olmstead* litigation places on the legal system. Currently, the fundamental alteration analysis requires “a complex fact-intensive inquiry” demanding review of extensive evidence and significant amounts of courts’ time.<sup>214</sup> The number of open *Olmstead* cases working their way through the courts across the country at any given time is substantial,<sup>215</sup>

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209. 42 U.S.C. § 12101(b)(1) (2018).

210. *Id.* § 1396–1; see also *Gresham v. Azar*, 950 F.3d 93, 100–02 (D.C. Cir. 2020).

211. See Medicaid 101, Medicaid & CHIP Payment & Access Comm’n, <https://www.macpac.gov/medicaid-101/> [<https://perma.cc/9HYJ-DTLQ>] (last visited July 28, 2021) (“Medicaid is an entitlement program. Eligible individuals have rights to payment for medically necessary health care services defined in statute; the federal government is obligated to fund a share of the outlays for those services.”).

212. See 42 U.S.C. § 12132 (2018).

213. See *supra* sections II.A, II.B.4.

214. *Martin v. Taft*, 222 F. Supp. 2d 940, 986 (S.D. Ohio 2002); see also *Williams v. Wasserman*, 164 F. Supp. 2d 591, 595 (D. Md. 2001) (noting that this opinion followed a 32-day bench trial that took place after denial of cross-motions for summary judgment).

215. See *Olmstead* Enforcement—Cases by Issue, ADA.gov, [https://www.ada.gov/olmstead/olmstead\\_cases\\_by\\_issue.htm](https://www.ada.gov/olmstead/olmstead_cases_by_issue.htm) [<https://perma.cc/8ER5-VKHJ>] (last visited July 21, 2021).

and courts are rarely able to dispense with these cases on summary judgment.<sup>216</sup> Courts themselves recognize that litigation is not the best approach for resolving the complicated issue of institutionalization.<sup>217</sup> And yet they are resigned to the idea that, “difficult or not,” federal courts cannot “shrink from [their] duty to apply the law and reach conclusions on these profound issues”<sup>218</sup> even though it requires them to tread through “murky waters.”<sup>219</sup> The consequence of this heavy reliance on protracted litigation is a system that has “allow[ed] states to drag their feet toward *Olmstead* compliance while people who have a legal right to live in the community must remain apart from it.”<sup>220</sup>

Clarifying and strengthening the fundamental alteration standards would help reduce the burden on courts and ultimately benefit all parties involved in the litigation. Bringing the fundamental alteration framework closer to the “clear, strong, consistent, [and] enforceable standards” that Congress called for in the ADA<sup>221</sup> would help streamline courts’ analyses, reduce the costs of *Olmstead* enforcement to both the legal system and the parties in each case,<sup>222</sup> and make enforcement of the ADA more consistent and equitable across jurisdictions and populations.<sup>223</sup> Although states oppose court intervention in their budgetary decisions and are concerned

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216. See, e.g., *Disability Advocs., Inc. v. Paterson*, 598 F. Supp. 2d 289, 335 (E.D.N.Y. 2009) (noting that courts have found the question of whether requested relief constitutes a fundamental alteration to be an inquiry “particularly inappropriate for summary judgment”).

217. See, e.g., *Taft*, 222 F. Supp. 2d at 987; *Wasserman*, 164 F. Supp. 2d at 595 (noting that this case in which plaintiffs seek relief for defendants’ failure to provide community treatment “raises complex medical, social and fiscal issues not easily addressed by litigation”).

218. *Taft*, 222 F. Supp. 2d at 987.

219. See *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 617 (9th Cir. 2005) (“We navigate once again the murky waters between two statutory bodies: Medicaid and the [ADA].”).

220. *Muller*, supra note 168, at 1021 (arguing that courts should approach *Olmstead*-related inquiries using the voluntary cessation doctrine).

221. 42 U.S.C. § 12101(b)(2) (2018).

222. Clearer standards would help the parties better predict the outcome of a potential case, thus increasing the likelihood of settlement without the need for litigation. See, e.g., William M. Landes & Richard A. Posner, *Legal Precedent: A Theoretical and Empirical Analysis*, 19 *J.L. & Econ.* 249, 271 (“[T]he ratio of lawsuits to settlements is mainly a function of the amount of uncertainty, which leads to divergent estimates by the parties of the probable outcome of litigation.”).

223. More consistent enforcement of the integration right without the need for litigation will help courts avoid advantaging individuals who commenced litigation over those who did not—a situation that the *Olmstead* Court sought to avoid. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 606 (1999) (explaining that when a state can show the requested relief constitutes a fundamental alteration, a court has “no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions”); see also *Frederick L. v. Dep’t of Pub. Welfare of Pa.*, 364 F.3d 487, 494 (3d Cir. 2004) (“*Olmstead* explains that the ADA does not compel states to provide relief where the requested relief would require the state to neglect the

about the costs of broadening access to HCBS, they generally support the goal of community integration.<sup>224</sup> A stronger fundamental alteration framework might give state Medicaid agencies leverage to advocate for more HCBS funding from their state legislatures, and that potential funding, in addition to funds conserved through a reduced need for litigation, might make it easier for them to work toward the goal of integration.

### III. LEVERAGING THE COVID-19 EXPERIENCE TO STRENGTHEN THE *OLMSTEAD* FUNDAMENTAL ALTERATION FRAMEWORK

In light of the new evidence that the COVID-19 pandemic provides on the public health risks that institutions pose, the fundamental alteration framework under *Olmstead* must be clarified and strengthened in order to broaden access to Medicaid HCBS. The COVID-19 experience, as well as the beginning of a Democratic presidential administration that is committed to tackling issues of disability, racial, and health equity,<sup>225</sup> present a unique opportunity to make real progress toward this goal. Given the political realities of the current Congress and the makeup of the federal judiciary, the most effective approach to strengthening the fundamental alteration framework is likely to be through DOJ's regulatory authority under the ADA. DOJ, potentially in collaboration with two agencies within HHS—CMS and the Office for Civil Rights (OCR)—should promulgate regulations that clarify and strengthen the fundamental alteration framework.

Section III.A argues that a regulatory approach to strengthening the fundamental alteration framework is superior to a litigation approach because of agencies' authority, expertise, and motivation on this issue. Section III.B describes several specific proposals for regulatory provisions that agencies might consider for strengthening each of the fundamental alteration framework elements.

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needs of other segments of the mentally disabled population who are not litigants before the court.”).

<sup>224</sup> As explained in *Martin v. Taft*,

No one with a conscience and any sense of fundamental fairness would argue that . . . people who are capable of living in the community should be kept in segregated institutions . . . [D]efendants are in no way opposed to providing such community-based services . . . Defendants do, however, oppose the notion that a federal court may direct them as to when and how to provide such services . . .

222 F. Supp. 2d 940, 987 (S.D. Ohio 2002).

<sup>225</sup> See Exec. Order No. 14,035, 86 Fed. Reg. 34,593 (June 25, 2021); Exec. Order No. 14,031, 86 Fed. Reg. 29,675 (May 28, 2021); Exec. Order No. 13,985, 86 Fed. Reg. 7009 (Jan. 20, 2021); Exec. Order No. 13,995, 86 Fed. Reg. 7193 (Jan. 21, 2021).

A. *Agencies, Through Rulemaking Authority, Are in a Better Position Than Courts to Clarify and Strengthen the Fundamental Alteration Standards*

In recognition of the many flaws in current interpretations of the fundamental alteration defense that section II.C describes, DOJ should clarify and strengthen the fundamental alteration framework through its rulemaking authority. Although courts could strengthen this framework themselves, agencies have greater expertise in this area,<sup>226</sup> are likely more motivated to tackle this issue, and are in a better position to set a national standard and ensure compliance with it.

1. *Agency ADA Rulemaking Authority and Expertise.* — Congress explicitly delegated rulemaking authority under a wide range of provisions of the ADA to the Attorney General (AG), who is the head of DOJ.<sup>227</sup> The AG originally promulgated ADA Title II and III regulations in 1991 and has revised these regulations on multiple occasions since.<sup>228</sup> In addition to having rulemaking authority, DOJ is well-positioned to clarify and strengthen the fundamental alteration framework because it is in charge of *Olmstead* enforcement and has substantial expertise in litigating *Olmstead* cases that turn on the fundamental alteration defense.<sup>229</sup> As a result, DOJ is well-aware of the ambiguities in the current fundamental alteration framework that have led to lengthy, inefficient litigation and disparate interpretations across jurisdictions.

DOJ can also enlist assistance in drafting new fundamental alteration regulations from agencies within HHS, including CMS and OCR. Like DOJ, OCR has extensive experience in litigating *Olmstead* cases involving unjustified institutionalization or risk of institutionalization<sup>230</sup> and may offer a unique and helpful perspective to DOJ given OCR's particular focus

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226. See Garrett, *supra* note 183, at 122 (“[A]gencies can be presumed to have expertise, as well as delegated authority, regarding statutes concerning their own regulatory authority . . .”).

227. See 42 U.S.C. § 12134(a) (2018) for the ADA Title II delegation of rulemaking authority to the Attorney General.

228. The Americans With Disabilities Act of 1990 and Revised ADA Regulations Implementing Title II and Title III, *supra* note 150 (describing revisions to DOJ's ADA regulations published in September 2010, August 2016, and December 2016).

229. *Olmstead*: Community Integration for Everyone, ADA.gov, [https://www.ada.gov/olmstead/olmstead\\_cases\\_list2.htm](https://www.ada.gov/olmstead/olmstead_cases_list2.htm) [<https://perma.cc/8LHW-PM9J>] (last visited Aug. 16, 2021).

230. See Medicaid & CHIP Payment & Access Comm'n, *Twenty Years Later: Implications of Olmstead v. L.C. on Medicaid's Role in Providing Long-Term Services and Supports 8* (2019), <https://www.macpac.gov/wp-content/uploads/2019/07/Twenty-Years-Later-Implications-of-Olmstead-on-Medicoids-Role-in-LTSS.pdf> [<https://perma.cc/SAB8-5Z9T>] (“The OCR has intervened, often with DOJ, in over 80 cases of Medicaid beneficiaries in institutional or segregated settings, as well as for persons at-risk for institutionalization or loss of community-based services.”).

on healthcare-related civil rights issues.<sup>231</sup> CMS may also be helpful in advising DOJ on the technical aspects of Medicaid HCBS waiver policy, given CMS's expertise in the operations and limitations of state Medicaid programs, including HCBS waiver programs.<sup>232</sup>

2. *Agencies Are Likely More Motivated Than Courts to Clarify and Strengthen the Fundamental Alteration Framework.* — While courts have expressed reluctance to take the steps necessary to strengthen and standardize various elements of the fundamental alteration defense, the Biden Administration's commitment to prioritizing the civil rights issues affecting people with disabilities, including institutionalization, indicates that the administration's agencies may be motivated to take action in this area. The fundamental alteration case law to date reflects courts' hesitance to set standards applicable outside of the unique facts of the case at issue. Judges seem especially reluctant to get involved in state budgetary decisions and have explicitly stated that directing those budgetary decisions is outside the role of courts.<sup>233</sup> Yet clarifying and strengthening the fundamental alteration framework will require setting a more generally applicable standard for the extent to which the ADA requires states to prioritize spending on compliance with the integration mandate. Furthermore, because courts' enforcement powers are limited, even if courts were willing to strengthen the fundamental alteration standards, they may not be able to ensure compliance with the new standards.<sup>234</sup>

Pursuing a strengthened fundamental alteration framework through the courts may also risk doing more harm than good on the institutional-

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231. See About Us, HHS Off. for C.R., <https://www.hhs.gov/ocr/about-us/index.html> [<https://perma.cc/P3JD-HCZS>] (last visited July 21, 2021).

232. See Kathryn G. Allen, Walter Ochinko, Eric Anderson, Connie Peebles Barrow & Kevin Milne, Gov't Accountability Off., GAO-03-576, Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened 8–9 (2003).

233. See *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 364 F.3d 487, 498 (3d Cir. 2004) (“[T]he judiciary is not well-suited to superintend the internal budgetary decisions of [the Department of Public Welfare] . . .”). Justice Kennedy made a similar point in his *Olmstead* concurrence, stating,

The State is entitled to wide discretion in adopting its own systems of cost analysis, and, if it chooses, to allocate health care resources based on fixed and overhead costs for whole institutions and programs. We must be cautious when we seek to infer specific rules limiting States' choices when Congress has used only general language in the controlling statute.

*Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 615 (1999) (Kennedy, J., concurring).

234. See, e.g., Sixth Annual Report Submitted by Clarence J. Sundram Independent Reviewer at 16, *United States v. New York*, No. 1:13-cv-04166-NGG-ST, (E.D.N.Y. filed Apr. 1, 2020) (explaining that following a settlement agreement in an *Olmstead* case, the state has “consistently fallen short with the one [benchmark set forth in the agreement] that is key to the success of the initiative: transitioning class members to the community”).

zation issue, especially following the appointment of large numbers of conservative federal judges in recent years.<sup>235</sup> And while a Supreme Court affirmation of the strengthened fundamental alteration framework would be necessary to ensure its application nationwide, the Court's new 6-3 conservative justice majority following Justice Amy Coney Barrett's confirmation means that Supreme Court review of a fundamental alteration case could result in further limitation of the right to services in integrated settings, rather than the desired strengthening of it.<sup>236</sup>

DOJ and CMS, especially under the current administration, are likely to be both more willing and better able to strengthen and clarify the fundamental alteration framework. The Biden Administration has shown a commitment to making full participation and equality of people with disabilities a priority.<sup>237</sup> It has already taken several steps to expand access to

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235. See, e.g., John Gramlich, How Trump Compares With Other Recent Presidents in Appointing Federal Judges, Pew Rsch. Ctr. (Jan. 13, 2021), <https://www.pewresearch.org/fact-tank/2020/07/15/how-trump-compares-with-other-recent-presidents-in-appointing-federal-judges/> [<https://perma.cc/KJV5-VPQK>]; Rebecca R. Ruiz, Robert Gebeloff, Steve Eder & Ben Protes, A Conservative Agenda Unleashed on the Federal Courts, N.Y. Times (Mar. 14, 2020), <https://www.nytimes.com/2020/03/14/us/trump-appeals-court-judges.html> (on file with the *Columbia Law Review*) (last updated Mar. 16, 2020).

236. Three conservative justices—Justices Thomas and Scalia and Chief Justice Rehnquist—dissented from the majority decision in *Olmstead*, arguing that temporary exclusion from community placement does not constitute discrimination and that the majority's decision raises federalism concerns because it directs state decisions about the delivery of public services. *Olmstead*, 527 U.S. at 616, 624 (Thomas, J., dissenting). This suggests that today's conservative justices may be inclined to limit, rather than strengthen, the rights provided to individuals in *Olmstead*.

237. In announcing new CMS guidance on American Rescue Plan funding for HCBS, HHS Secretary Xavier Becerra stated:

Millions of individuals across the country – including people with disabilities and older Americans – rely on home based care and the workforce that provides that critical care. The Biden-Harris Administration continues to support states and workers by making critically needed investments in home and community based services . . . . The American Rescue Plan helps to ensure that states can benefit from an increased federal investment in HCBS systems across the country, so that Medicaid beneficiaries receive high quality, cost-effective, person-centered services in their homes and remain a valued part of their communities.

Press Release, HHS, CMS Issues Guidance on American Rescue Plan Funding for Medicaid Home and Community Based Services (May 13, 2021), <https://www.hhs.gov/about/news/2021/05/13/cms-issues-guidance-american-rescue-plan-funding-medicaid-home-and-community-based-services.html> [<https://perma.cc/R458-69AX>].

President Biden's commitment to integration and full participation of people with disabilities began before he took office. For example, he mentioned the need for equality of opportunity for people with disabilities in his victory speech. See Ja'han Jones, Disability Advocates Express Joy After Biden Name-Checks Them With Important Word, HuffPost (Nov. 8, 2020), [https://www.huffpost.com/entry/joe-biden-disability-advocates-express-joy\\_n\\_5fa83941c5b66009569bb896](https://www.huffpost.com/entry/joe-biden-disability-advocates-express-joy_n_5fa83941c5b66009569bb896) [<https://perma.cc/DLZ2-4AYV>] (last updated Nov. 10, 2020). President Biden continued to express his commitment to disability rights issues as president-elect during his presidential transition. See, e.g., Press Release, Biden-Harris Transition, Statement by President-Elect Joe Biden on United Nations International Day of

HCBS, such as negotiating the passage of the American Rescue Plan Act of 2021, which provides temporary enhanced federal funding for states that enhance or expand HCBS,<sup>238</sup> and proposing the American Jobs Plan, which calls on Congress to put \$400 billion toward expanding access to quality, affordable HCBS.<sup>239</sup> President Biden’s campaign published extensive plans to promote inclusion and equality of people with disabilities and protect this population during the pandemic.<sup>240</sup> These plans indicate an intent to “aggressively enforce the civil rights of people with disabilities,” “ensure every agency aggressively enforces *Olmstead*’s integration mandate,” “provide greater access to home and community-based services,” and “end the institutional bias in the Medicaid program.”<sup>241</sup> The Biden Administration may be further motivated to work on this issue because of the clear racial inequality dimension of this issue,<sup>242</sup> since advancing racial equity is one of the Biden Administration’s top priorities.<sup>243</sup> CMS and OCR

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Persons With Disabilities (Dec. 3, 2020), <https://wayback.archive-it.org/15505/20201230052758/https://buildbackbetter.gov/press-releases/statement-by-president-elect-joe-biden-on-united-nations-international-day-of-persons-with-disabilities> [<https://perma.cc/QDR7-6KFP>].

238. American Rescue Plan Act of 2021, Pub. L. No. 117-2, § 9817(a), 135 Stat. 4, 216 (codified as amended in scattered titles of the U.S.C.).

239. Fact Sheet: The American Jobs Plan, White House (Mar. 31, 2021), <https://www.whitehouse.gov/briefing-room/statements-releases/2021/03/31/fact-sheet-the-american-jobs-plan/> [<https://perma.cc/6GAP-5NVN>].

240. See The Biden Plan for Full Participation and Equality for People With Disabilities, Biden Harris: Democrats, <https://joebiden.com/disabilities/> [<https://perma.cc/H38D-B2TP>] (last visited Dec. 5, 2020); Supporting People With Disabilities During the Coronavirus (COVID-19) Pandemic, Biden Harris: Democrats, <https://joebiden.com/covid19-disabilities/> [<https://perma.cc/Z8JS-THS3>] (last visited Dec. 5, 2020).

241. The Biden Plan for Full Participation and Equality for People With Disabilities, *supra* note 240. President Biden’s campaign proposals indicated his intention to take a legislative approach to change on the disability rights issues described above. Since he took office, there has been some momentum toward permanent HCBS-related legislative reforms. For example, the Better Care Better Jobs Act, proposed by Democratic lawmakers in June 2021 to implement President Biden’s American Jobs Plan, proposes offering permanent enhanced federal Medicaid matching funds for HCBS if states choose to participate and meet certain requirements. The bill would also make both Money Follows the Person and the requirement for states to apply spousal impoverishment protections to HCBS permanent. Better Care Better Jobs Act, S. 2210, 117th Cong. (2021); see also MaryBeth Musumeci, Kaiser Fam. Found., How Could \$400 Billion New Federal Dollars Change Medicaid Home and Community-Based Services? (2021), <https://www.kff.org/medicaid/issue-brief/how-could-400-billion-new-federal-dollars-change-medicaid-home-and-community-based-services/> [<https://perma.cc/TK2W-FSYN>]. However, the likelihood of passage of this bill or of even more comprehensive reform expanding HCBS to all individuals who qualify remains questionable. A regulatory approach to strengthening the fundamental alteration framework could offer quicker and easier progress toward deinstitutionalization in the short-term, without closing the door to more comprehensive legislative reform on issues like Medicaid’s institutional bias in the future.

242. See *supra* notes 34–36 and accompanying text.

243. See The Biden-Harris Administration Immediate Priorities, White House, <https://www.whitehouse.gov/priorities/> [<https://perma.cc/ZKP5-BT9V>] (last visited July 21, 2021) (“President Biden is putting equity at the center of the agenda with a whole of

are also likely to be extra motivated to work on this issue to make up for HHS's failures during the Trump Administration to effectively respond to the COVID-19 crisis in institutional settings.<sup>244</sup> A regulatory approach still entails a risk of doing more harm than good, as judicial review of the new regulations could result in further limitation of the right to services in an integrated setting compared to the status quo. However, agencies can take steps to minimize this risk<sup>245</sup> and the risk seems worth taking given the severity of the current institutionalization crisis.

B. *Potential Regulatory Changes to Strengthen the Fundamental Alteration Framework*

In promulgating revised regulations clarifying and strengthening the fundamental alteration framework, DOJ and other agencies should give special attention to strengthening the definitions of what qualifies as an “effectively working plan” and a “waiting list that move[s] at a reasonable pace” so that they constitute reasonable interpretations of the ADA in light of the new evidence of the public health risks of institutionalization. They should also clarify exactly how costs of integration and state budget constraints should be considered and weighed against individuals’ right to integration in the fundamental alteration analysis. This section does not attempt to provide an exhaustive list of proposed regulatory provisions, but instead offers some examples of changes that agencies might consider.

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government approach to embed racial justice across Federal agencies, policies, and programs. [He] will take bold action to . . . deliver criminal justice reform [and] end disparities in healthcare access and education . . . among other actions . . .”).

244. See *supra* section I.A.1.

245. Such steps may include (1) diligently following every step of the notice-and-comment rulemaking process in anticipation of potential attempts to strike the regulations down on procedural grounds, and (2) proceeding under the assumption that a reviewing court would see the new rule as a “change” in agency policy of a type that requires a more detailed justification, and accordingly providing a highly detailed “reasoned justification” in order to protect the change against even the most scrutinizing standard of judicial review. See *F.C.C. v. Fox Television Stations, Inc.*, 556 U.S. 502, 515–16 (2009); *Motor Vehicle Mfrs. Ass’n of U.S. v. State Farm Mut. Auto. Ins. Co.*, 463 U.S. 29, 43 (1983).

DOJ may have authority to promulgate an interim final rule in this case based on the urgent need to address the public health emergency in institutions. The APA authorizes agencies to finalize some rules without first publishing a proposed rule and completing the entire notice-and-comment process when there is “good cause” to suggest that notice-and-comment would be “impracticable, unnecessary, or contrary to the public interest.” 5 U.S.C. § 553(b)(3)(B) (2018). Such cases “may include emergencies where problems must be addressed immediately to avert threats to public health and safety.” Office of the Federal Register, *A Guide to the Rulemaking Process*, [https://www.federalregister.gov/uploads/2011/01/the\\_rulemaking\\_process.pdf](https://www.federalregister.gov/uploads/2011/01/the_rulemaking_process.pdf) (last visited Jan. 1, 2021). But because this approach would open another avenue for judicial challenge, it appears advisable for DOJ to wait and publish a final rule after the completion of notice-and-comment process in order to avoid this vulnerability, despite the urgency of this regulatory action.

Regulations defining what constitutes an “effectively working plan” should go further than either the Third or the Ninth Circuit interpretations of this phrase in order to prevent these plans from becoming “get out of jail free” cards that make the fundamental alteration defense much more widely available than Congress intended.<sup>246</sup> Agencies should require a showing of both past progress and a commitment to future progress, and they should be as specific as possible about exactly what degree of past progress and future commitment is necessary for the fundamental alteration defense to apply. For example, agencies should require state data reporting and improvement over time on one or more measures of unmet demand for HCBS other than HCBS waiting list size. They might also require that the plans be evaluated in terms of their effectiveness in past and potential future public health emergencies<sup>247</sup> and whether the plan successfully reduces existing and avoids future racial and ethnic disparities in access to HCBS.<sup>248</sup>

Agencies should consider requiring that states show a reasonably paced waiting list in addition to an effectively working plan in order to qualify for the fundamental alteration defense, as *Olmstead* suggests is necessary,<sup>249</sup> rather than allowing an effectively working plan alone to be sufficient.<sup>250</sup> They should also revise the “reasonable pace” standard with the goal of ensuring that this “reasonableness standard[] . . . [is] informed by objective and empirical sources, and not just whatever the reviewing judge calls reasonable.”<sup>251</sup> To that end, agencies might consider whether it is possible to devise a formula for calculating what constitutes a “reasonable pace” in a given state or program. In order to require actual progress toward *elimination* of discrimination, this formula should consider not just

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246. See *supra* note 168 and accompanying text.

247. For example, a state’s inability to respond to the COVID-19 pandemic by decreasing the size of the population in institutions or diverting new admissions might indicate a flawed deinstitutionalization plan that is not “effectively working.” Agencies could also consider requiring states to prioritize people on their waiting lists who are in institutions or at risk of institutionalization, as some states already choose to do. See Musumeci et al., Key Questions About HCBS Waiting Lists, *supra* note 119. This could be required at all times or only during public health emergencies.

248. See *supra* note 125 and accompanying text.

249. The Court’s use of “and” in the following phrase suggests that both elements are necessary: “If . . . 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.” *Olmstead v. L. C. ex rel. Zimring*, 527 U.S. 581, 605–06 (1999) (emphasis added). Agencies should also clarify that the reasonable pace requirement is independent of the requirement that the pace not be controlled by efforts to keep institutions populated.

250. Many courts grant a fundamental alteration defense based on an effectively working plan, without specifically looking at the pace of the waiting list. See *supra* note 179 and accompanying text.

251. See Garrett, *supra* note 183, at 121.

how long it takes the average person on the waiting list to receive services but also how quickly the size of the waiting list itself is decreasing.

Finally, agencies should contemplate limiting the extent to which costs and state budget constraints may be evaluated in the fundamental alteration analysis in a manner that better aligns with the Medicaid program's limitations on cost considerations.<sup>252</sup> Agencies could consider contradicting *Olmstead* and fully eliminating the consideration of costs and state budgets.<sup>253</sup> But even if they are not willing to go that far, they could still significantly constrain the role of these factors compared to their current broad role under *Olmstead*.<sup>254</sup> For example, agencies might require the fundamental alteration analysis to assess not just the costs of the requested relief in the short-term but also the longer-term savings that the expansion of HCBS to the plaintiffs and other similarly situated state residents might produce. Agencies might also require that consideration of costs and savings be on a per capita, rather than aggregate, basis. This would align the fundamental alteration analysis with the per capita cost-neutrality assessment that CMS conducts as part of the HCBS waiver approval process.<sup>255</sup>

In promulgating the new regulations, DOJ will have a choice between simply building on the *Olmstead* framework or offering a different, and potentially conflicting, interpretation. Under the Supreme Court's *Brand X* precedent, DOJ is probably not bound by *Olmstead*'s construction of the fundamental alteration framework, since "[a] court's prior judicial construction of a statute trumps an agency construction otherwise entitled to *Chevron* deference only if the prior court decision holds that its construction follows from the unambiguous terms of the statute and thus leaves no room for agency discretion."<sup>256</sup> The portion of the *Olmstead* decision at issue in this Note is the Court's interpretation of DOJ's reasonable modification/fundamental alteration regulation,<sup>257</sup> not an "unambiguous statute."<sup>258</sup> Therefore, if DOJ decides to replace the fundamental alteration framework, a reviewing court would probably be required to uphold

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252. See *supra* notes 210–212 and accompanying text.

253. See *infra* notes 256–259 and accompanying text.

254. See *supra* section II.B.4.

255. See *supra* note 135.

256. *Nat'l Cable & Telecomms. Ass'n v. Brand X Internet Servs.*, 545 U.S. 967, 982 (2005).

257. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 603–07 (1999).

258. It does not appear that *Olmstead* declared that its ruling on the fundamental alteration defense was the only permissible interpretation of the statute. Indeed, the *Olmstead* Court explicitly declined to inquire whether the ADA unambiguously compelled the reading that DOJ gave to it. See *Olmstead*, 527 U.S. at 597–98 ("Because the Department is the agency directed by Congress to issue regulations implementing Title II . . . its views warrant respect. We need not inquire whether the degree of deference described in [*Chevron*] . . . is in order."). The Court only held that the lower court's interpretation of DOJ's reasonable modification regulation was "unacceptable," not that this regulation was itself the only "[a]cceptable" interpretation of the ADA. *Id.* at 603.

the regulations as long as they are a “reasonable construction” of an ambiguous part of the ADA and otherwise meet the requirements for *Chevron* deference.<sup>259</sup> If DOJ chooses this somewhat riskier approach of replacing the *Olmstead* standard in its new regulations, it should fully explain the basis of its authority to do so in the regulation to bolster its durability in the face of a challenge on the basis of its conflict with *Olmstead*.

#### CONCLUSION

Over three decades after the ADA declared unjustified institutionalization to be unlawful discrimination, far too many people still lack access to HCBS and may have few options other than institutionalization to receive the services they need. The consequences of the slow pace of deinstitutionalization over time have never been so apparent as during the COVID-19 pandemic, which resulted in tragically high infection and death rates across a wide range of institutional and congregate care settings. Yet by providing the most clear and irrefutable evidence of the public health risks of institutionalization to date and challenging continued application of the *Olmstead* legal framework that fails to take these risks into account, the COVID-19 experience may offer an opportunity to make long-overdue reforms to this framework. In light of this opportunity, as well as the current civil rights-focused Democratic administration, DOJ, potentially in collaboration with agencies within HHS, should promulgate regulations through the notice-and-comment process that clarify and strengthen the fundamental alteration standards. Clarifying and strengthening what is currently a highly “murky”<sup>260</sup> legal framework has the potential to conserve the resources of the legal system and its stakeholders. And more importantly, it could protect the health, lives, and liberty of hundreds of thousands of people with disabilities and older adults both during the COVID-19 pandemic and beyond, when disease control and other public health concerns will continue to put people living in institutions at risk.

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259. See *Chevron, U.S.A. Inc. v. Nat. Res. Def. Council, Inc.*, 467 U.S. 837 (1984); Edwin E. Huddleson, *Chevron Under Siege*, 58 U. Louisville L. Rev. 17, 20–23 (2019).

260. See *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 617 (9th Cir. 2005).

