

3-1-2021

## Applying the Health Justice Framework to Address Health and Health Care Inequities Experienced by People with Disabilities During and After COVID-19

Robyn M. Powell

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### Recommended Citation

Robyn M. Powell, Applying the Health Justice Framework to Address Health and Health Care Inequities Experienced by People with Disabilities During and After COVID-19, 96 Wash. L. Rev. 93 (2021).

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# **APPLYING THE HEALTH JUSTICE FRAMEWORK TO ADDRESS HEALTH AND HEALTH CARE INEQUITIES EXPERIENCED BY PEOPLE WITH DISABILITIES DURING AND AFTER COVID-19**

Robyn M. Powell, PhD, JD\*

*Abstract:* The COVID-19 pandemic has been especially devastating for people with disabilities, as well as other socially marginalized communities. Indeed, an emerging body of scholarship has revealed that people with disabilities are experiencing striking disparities. In particular, scholars have shined a light on state and hospital triage policies that allow hospitals to ration critical health care and resources, such as ventilators, for people with disabilities if resources become limited and they cannot treat all patients during the pandemic. These injustices deserve extensive consideration from policymakers, legal professionals, and scholars.

Elucidating how the inequities that people with disabilities experience during the COVID-19 pandemic result from deeply rooted historical injustices is crucial. This Article comprehensively analyzes the inequalities that people with disabilities experience before and during the pandemic, focused on examining how law and policy affect these disparities. It builds on, incorporates, and extends the existing scholarship about COVID-19 and disabled people by positioning it within the health justice framework. It also proposes normative legal and policy solutions to address deeply entrenched inequities that will affect people with disabilities during the COVID-19 pandemic and beyond.

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## INTRODUCTION

Michael Hickson, a forty-six-year-old father of five from Texas, died in June 2020 from COVID-19 after the hospital he was being treated at decided that continuing life-saving care was futile.<sup>1</sup> Hickson went into cardiac arrest three years earlier, which resulted in quadriplegia and an acquired brain injury.<sup>2</sup> Since his cardiac arrest, he had been in and out of hospitals, nursing and rehabilitation facilities, and his home.<sup>3</sup> In May 2020, while residing in a nursing home, Hickson tested positive for COVID-19.<sup>4</sup> Weeks later, he was admitted to the hospital after experiencing difficulty breathing and a low-grade fever.<sup>5</sup> Days later, Hickson's physician informed his wife that the hospital believed it was time to halt life-saving treatment.<sup>6</sup> In an audio recording, which has since gone viral, Hickson's wife pleaded with the physician to continue care and raised concerns that decisions about his care were being made based on erroneous assumptions about the quality of his life.<sup>7</sup>

Hickson's wife failed to convince her husband's legal guardian,<sup>8</sup>

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1. This narrative is adapted from Ariana Eunjung Cha, *Quadriplegic Man's Death from Covid-19 Spotlights Questions of Disability, Race and Family*, WASH. POST (July 5, 2020, 6:40 AM), <https://www.washingtonpost.com/health/2020/07/05/coronavirus-disability-death/> [<https://perma.cc/R9DQ-AM99>]; see also Joseph Shapiro, *One Man's COVID-19 Death Raises the Worst Fears of Many People with Disabilities*, NAT'L PUB. RADIO (July 31, 2020, 3:29 PM), <https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities> [<https://perma.cc/F5Q4-5HTP>].

2. Cha, *supra* note 1.

3. *Id.*

4. *Id.*

5. *Id.*

6. *Id.*

7. *Id.*

8. The court had appointed an agency to serve as Hickson's temporary guardian, which left his wife without the legal authority to make medical decisions on her husband's behalf. *Id.*

physician, or the court to continue his treatment.<sup>9</sup> Hickson died only a few days after that shocking conversation with his physician.<sup>10</sup> Disability rights advocates quickly rallied around Hickson's wife, averring that stopping his treatment exemplifies grave presumptions about the intrinsic value of disabled peoples' lives.<sup>11</sup> Similarly, the National Council on Disability, an independent federal agency that advises the President and Congress on disability policy, issued a statement condemning the denial of life-saving treatment for Hickson, saying,

The presence of a disability does not lessen a person's value, nor should it warrant a person's abandonment by the medical facilities they rely on for care. When a medical facility makes a decision to deny medical care to a person with a disability that is based on, or influenced by, biased views about life with a disability, it runs afoul of federal civil rights laws.<sup>12</sup>

Regrettably, Hickson's tragic experiences are neither unique nor uncommon. The COVID-19 pandemic has wreaked havoc on the lives of millions of people, both in the United States and across the globe.<sup>13</sup> At the time of this writing, over twenty-six million people in the United States have been infected with COVID-19, and nearly half a million people have died from the virus.<sup>14</sup> For socially marginalized populations, including people with disabilities, the virus has been particularly devastating, exposing longstanding and pervasive health and social inequities.

Although the research is still in its infancy, emerging studies suggest that people with disabilities are disproportionately affected by COVID-19.<sup>15</sup> Specifically, compared to nondisabled people, people with disabilities experience disparities in exposure to the virus, inequities in susceptibility to contracting the virus, and barriers in accessing treatment

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9. *Id.*

10. *Id.*

11. *Id.*

12. Press Release, Nat'l Council on Disability (NCD), NCD Chairman Statement on Death of Michael Hickson (July 2, 2020), <https://ncd.gov/newsroom/2020/ncd-chairman-statement-michael-hickson-death> [<https://perma.cc/TX22-VZAR>].

13. The World Health Organization declared COVID-19 a pandemic on March 11, 2020. Press Release, World Health Org., WHO Director-General's Opening Remarks at the Media Briefing on COVID-19 (Mar. 11, 2020), <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19-11-march-2020> [<https://perma.cc/88YJ-XG4L>].

14. *United States COVID-19 Cases and Deaths by State*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html> [<https://perma.cc/KL97-PQZ8>].

15. For a discussion of health and health care inequities that people with disabilities experience throughout the COVID-19 pandemic, see *infra* section I.C.

and testing.<sup>16</sup> Moreover, a developing body of scholarship examines whether state and hospital triage policies that ration critical health care and resources for people with disabilities violate federal disability rights laws.<sup>17</sup>

Certainly, the injustices that Hickson experienced did not happen in a vacuum but, rather, are emblematic of deeply rooted inequities that have festered for too long. Comprehensively examining the disparities that people with disabilities experience and how law and policy affect such disparities is necessary. Undoubtedly, the inequalities plaguing disabled people during the pandemic extend beyond the rationing of health care and resources and adverse health outcomes and instead affect all social determinants of health. Social determinants of health are factors that influence one's wellbeing, including health and health care, neighborhood and built environment, economic stability, education, and social and community context.<sup>18</sup> For example, during the COVID-19 pandemic, people with disabilities are experiencing declining employment rates,<sup>19</sup>

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16. *Id.*

17. See, e.g., Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 YALE L.J. F. 1 (2020) (asserting that disability-based distinctions violate the Americans with Disabilities Act, Rehabilitation Act, and the Affordable Care Act because these laws prohibit health care providers from discriminating against qualified individuals with disabilities based on their disabilities); Deborah Hellman & Kate M. Nicholson, *Rationing and Disability: The Civil Rights and Wrongs of Clinical Triage Protocols* (Va. Pub. L. & Legal Theory Research Paper, Paper No. 2020-33, 2020), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3570088](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3570088) [<https://perma.cc/27AU-B537>] (asserting that several states have adopted utilitarian approaches to deciding how to ration resources, and that these approaches fail to balance equity with utility, as required by federal disability rights laws); Ari Ne'eman, *When It Comes to Rationing, Disability Rights Law Prohibits More than Prejudice*, THE HASTINGS CTR. (Apr. 10, 2020), <https://www.thehastingscenter.org/when-it-comes-to-rationing-disability-rights-law-prohibits-more-than-prejudice> [<https://perma.cc/2R2L-4KV8>] (describing how Crisis Standards of Care plans discriminate against people with disabilities); Govind Persad, *Disability Law and the Case for Evidence-Based Triage in a Pandemic*, 130 YALE L.J. F. 26 (2020) (arguing in support of the use of disability-based criteria that could lead to the denial of life-saving medical care when based on "quantity of life" but not "quality of life" determinations). For a further examination of health care rationing for people with disabilities during COVID-19, see *infra* section I.C.

18. Off. of Disease Prevention & Health Promotion, *Social Determinants of Health*, HEALTHYPEOPLE.GOV, <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health> [<https://perma.cc/FU7A-GMKQ>].

19. Press Release, Kessler Found., nTIDE April 2020 Jobs Report: COVID Recession Hits Workers with Disabilities Harder (May 8, 2020), <https://kesslerfoundation.org/press-release/ntide-april-2020-jobs-report-covid-recession-hits-workers-disabilities-harder> [<https://perma.cc/XN8Z-FDCJ>] (noting that the unemployment rate of people with disabilities decreased by 20%, compared to 14% for nondisabled people); see also Allison Norlian, *Workers with Disabilities Disproportionately Impacted by Covid-19 Pandemic*, FORBES (June 22, 2020, 9:37 AM), <https://www.forbes.com/sites/allisonnorlian/2020/06/22/workers-with-disabilities-disproportionately-impacted-by-covid-19-pandemic/#1a4f9c681ad1> [<https://perma.cc/6DVX-CE5L>] (describing employment inequities experienced by disabled people during COVID-19); Glob.

rising barriers to receiving free and appropriate public education,<sup>20</sup> growing social isolation,<sup>21</sup> and mounting risks of interpersonal violence.<sup>22</sup> While worsening due to the pandemic, disabled people have always contended with structural injustices that contribute to adverse health and social outcomes. As Jasmine Harris aptly stated, “the rationing problem is not just about devaluation of the lives of individuals with disabilities; it is a symptom of something much deeper. The pervasive and negative impacts of this devaluation will endure long after the immediate healthcare issues are tackled.”<sup>23</sup>

This Article, therefore, calls for wide-ranging and robust legal and policy responses that address people with disabilities’ immediate needs during the COVID-19 pandemic as well as the root problems that have caused pervasive and longstanding inequities. To that end, this Article draws from health justice, an emergent framework for eradicating health inequities experienced by socially marginalized populations.<sup>24</sup> Health

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Disability Inclusion, *Global Disability Inclusion Survey Reports People with Disabilities Are More Negatively Affected by the Economic Impact of COVID-19*, CISION PR NEWSWIRE (May 5, 2020, 7:44 AM), <https://www.pnnewswire.com/news-releases/global-disability-inclusion-survey-reports-people-with-disabilities-are-more-negatively-affected-by-the-economic-impact-of-covid-19-301052873.html> [<https://perma.cc/Y8BL-7TNP>] (reporting on a study that found that 51% of people with disabilities have either lost their jobs, been laid off or furloughed, or believe they will lose their job in the next ninety days compared to 28% of nondisabled people).

20. Jasmine E. Harris, *The Frailty of Disability Rights*, 169 U. PA. L. REV. ONLINE 29, 38–45 (2020) (analyzing how schools are not providing legally-mandate free and appropriate public education because of remote learning).

21. *How COVID-19 Impacts People with Disabilities*, AM. PSYCH. ASS’N (May 6, 2020), <https://www.apa.org/topics/covid-19/research-disabilities> [<https://perma.cc/KM9U-6WYL>] (“There are unique stressors and challenges that could worsen mental health for people with disabilities during the COVID-19 crisis. . . . Some people with disabilities report higher levels of social isolation than their nondisabled counterparts. They may experience intensified feelings of loneliness in response to physical distancing measures.” (citations omitted)).

22. Emily M. Lund, *Interpersonal Violence Against People with Disabilities: Additional Concerns and Considerations in the COVID-19 Pandemic*, 65 REHAB. PSYCH. 199, 199 (2020) (“The COVID-19 pandemic and its consequences enhance the already increased risk for abuse among people with disabilities.”).

23. Harris, *supra* note 20, at 32.

24. See, e.g., Lindsay F. Wiley, *Health Law as Social Justice*, 24 CORNELL J.L. & PUB. POL’Y 47 (2014) (building from existing justice movements and the writings of political philosophers and ethicists on health justice to propose health justice as a framework that can be used to reduce health disparities through law and policy); Emily A. Benfer, *Health Justice: A Framework (and Call to Action) for the Elimination of Health Inequity and Social Injustice*, 65 AM. U. L. REV. 275 (2015) (explaining health justice as an emerging framework for eliminating health inequity and social injustice); Lindsay F. Wiley, *From Patient Rights to Health Justice: Securing the Public’s Interest in Affordable, High-Quality Health Care*, 37 CARDOZO L. REV. 833 (2016) (recommending the health justice framework as an alternative to existing health law models for examining questions of health care quality and access); Lindsay F. Wiley, *Applying the Health Justice Framework to Diabetes as a Community-Managed Social Phenomenon*, 16 HOUS. J. HEALTH L. & POL’Y 191 (2016) (applying the

justice, as a jurisprudential and legislative framework, is aimed at achieving both health equity and social justice.<sup>25</sup> It demands that legal professionals and policymakers, in collaboration with people with disabilities,<sup>26</sup> protect and support disabled peoples' needs and rights both during and after the COVID-19 pandemic by comprehensively responding to the "economic, cultural, societal, environmental, and social conditions" that cause inequities.<sup>27</sup> In short, the health and health inequities that people with disabilities are experiencing during the COVID-19 pandemic are striking failures of justice and necessitate addressing their core institutional and structural foundations.

This Article builds on, incorporates, and extends the existing scholarship about COVID-19 and disabled people. Part I provides an overview of the health and health care experiences of people with disabilities. Specifically, this Part describes the legal framework that

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health justice framework to diabetes disparities); Lindsay F. Wiley, *Tobacco Denormalization, Anti-Healthism, and Health Justice*, 18 MARQ. BENEFITS & SOC. WELFARE L. REV. 203 (2017) (applying the health justice framework to tobacco-related disparities); ELIZABETH TOBIN-TYLER & JOEL B. TEITELBAUM, *ESSENTIALS OF HEALTH JUSTICE: A PRIMER*, at x (2019) (noting that the authors "settled on health justice [for their title] because it tends to be relatively more recognized and understood by a greater number of people [than health equity]" and "[f]urthermore, 'justice' is often linked in people's minds to the legal system," and defining health justice in terms of "laws, policies, systems, and behaviors that are evenhanded with regard to and display genuine respect for everyone's health and well-being" (emphasis omitted)); Medha D. Makhoul, *Health Justice for Immigrants*, 4 U. PA. J.L. & PUB. AFFS. 235 (2019) (applying the health justice framework to assess public commitments to health care access for immigrants); Yael Cannon, *The Kids Are Not Alright: Leveraging Existing Health Law to Attack the Opioid Crisis Upstream*, 71 FLA. L. REV. 765 (2019) (applying the health justice framework to the opioid epidemic and how it results in adverse childhood experiences); Matthew B. Lawrence, *Against the "Safety Net,"* 72 FLA. L. REV. 49 (2020) (applying the health justice framework to critique the safety net metaphor for public benefits); Angela P. Harris & Aysha Pamukcu, *The Civil Rights of Health: A New Approach to Challenging Structural Inequality*, 67 UCLA L. REV. 758, 758 (2020) ("[A]rgu[ing] that a civil rights of health initiative[,] built on a health justice framework[,] can help educate policymakers and the public about the health effects of subordination, create new legal tools for challenging subordination, and ultimately reduce or eliminate unjust health disparities."); Emily A. Benfer, Seema Mohapatra, Lindsay Wiley & Ruqaiyah Yearby, *Health Justice Strategies to Combat the Pandemic: Eliminating Discrimination, Poverty, and Health Disparities During and After COVID-19*, YALE J. HEALTH POL'Y L. & ETHICS (forthcoming 2021) (applying the health justice framework to address discrimination, poverty, and health inequities during COVID-19 and beyond).

25. Benfer, *A Framework (and Call to Action)*, *supra* note 24, at 277.

26. Harris & Pamukcu, *supra* note 24, at 807 ("In our view the health justice paradigm involves another essential component: the vigorous engagement and leadership of front-line communities, the targets of subordination."). Direct engagement with people with disabilities is also aligned with the disability community's ethos, *Nothing About Us Without Us*, which asserts that disabled people should be actively involved in developing and implementing policies that affect them. JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* 3-4 (2000).

27. Benfer, *A Framework (and Call to Action)*, *supra* note 24, at 279 ("Ultimately, an individual's health is significantly influenced by economic, cultural, societal, environmental, and social conditions.").

governs health and health care access for disabled people. It then limns the health and health care inequities that people with disabilities experience, both before and during the COVID-19 pandemic, demonstrating that the current disparities are a continuation of long-lasting and deeply entrenched problems. Thereafter, Part II presents the health justice framework and its application to people with disabilities. Finally, applying the health justice framework, Part III concludes by drawing from the social determinants of health to suggest legal and policy solutions to address people with disabilities' immediate needs as well as a path forward for dismantling the roots of longstanding health and social inequities that disabled people experience.

## I. HEALTH, HEALTH CARE, AND PEOPLE WITH DISABILITIES

People with disabilities constitute one of the largest socially marginalized groups in the United States, estimated at approximately sixty-one million people, or 26% of the population.<sup>28</sup> Although having a disability does not necessarily mean one is unhealthy or sick,<sup>29</sup> many people with disabilities have significant health care needs.<sup>30</sup> Simultaneously, longstanding research demonstrates that disabled people

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28. Catherine A. Okoro, NaTasha D. Hollis, Alissa C. Cyrus & Shannon Griffin-Blake, *Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults—United States, 2016*, 67 *CTRS. FOR DISEASE CONTROL & PREVENTION: MORBIDITY & MORTALITY WKLY. REP.* 882, 882 (2018).

29. See Ani B. Satz, *Overcoming Fragmentation in Disability and Health Law*, 60 *EMORY L.J.* 277, 300 (2010) (citing Ani B. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, 83 *WASH. L. REV.* 513, 561–67 (2008)). Satz contends that while “disability” and “illness” may overlap, they are neither mutually exclusive nor identical categories. *Id.* at 300–01 (“Individuals who are sick may not be disabled, and vice-versa. Further, access to adequate health care, in terms of both coverage and the range of medical services available, is a problem for individuals with and without disabilities. While disability may seem to raise some complicating factors—including a possible higher consumption of health care resources than most individuals, health care rationing schemes that disfavor those with medical impairments, and difficulty moving between public assistance programs that include health care and the workforce—these are problems that individuals without disabilities face as well.”); see also Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra*, at 561 (“First and foremost, disability does not equate with illness. The population of individuals who are ill or medically fragile exceeds the disability class. Illness may give rise to disability, but it does not presuppose it.”).

30. NAT'L COUNCIL ON DISABILITY, *THE CURRENT STATE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES* 9–10 (2009) (explaining that “[p]eople with disabilities comprise the largest and most important health care consumer group in the United States”); see also Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 *ALA. L. REV.* 51, 53 (2000) (noting that “because many persons with disabilities have ongoing and sometimes extensive health care needs as a result of their disabilities, legal protection against discrimination in accessing health care services can be of critical importance”).



experience numerous health and health care inequities,<sup>31</sup> despite legal protections that prohibit disability-based discrimination by health care providers. To fully appreciate and respond to the health and health care disparities that people with disabilities experience during the COVID-19 pandemic, it is crucial to have a foundational understanding of their health and health care experiences before the pandemic.

This Part begins with an overview of the legal framework intended to ensure access to health care for people with disabilities. Next, it describes the health and health care inequities that disabled people experienced before the COVID-19 pandemic began. Finally, this Part discusses the health and health care inequities that people with disabilities face during COVID-19.

### A. *Legal Framework*

Three major federal laws govern health care access for people with disabilities: the Americans with Disabilities Act of 1990 (ADA),<sup>32</sup> section 504 of the Rehabilitation Act of 1973 (section 504),<sup>33</sup> and the Patient Protection and Affordable Care Act (ACA).<sup>34</sup>

The ADA's purpose is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities[, and] to provide clear, strong, consistent, enforceable standards addressing discrimination."<sup>35</sup> The ADA comprises five distinct titles: employment (Title I), public services (Title II), places of public accommodation (Title III), telecommunications (Title IV), and miscellaneous provisions (Title V).<sup>36</sup> For purposes of health and health care, Titles II and III of the ADA are the most pertinent and cover the vast majority of health care providers.

The ADA considers a person to have a disability if they (1) have a physical or mental impairment that substantially limits a major life activity, (2) have a record of such impairment, or (3) are regarded as having such impairment.<sup>37</sup> Major life activities include, inter alia, caring

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31. E. Emerson, R. Madden, H. Graham, G. Llewellyn, C. Hatton & J. Robertson, *The Health of Disabled People and the Social Determinants of Health*, 125 PUB. HEALTH 145, 145 (2011) ("There is extensive evidence that people with disabilities experience significantly poorer health outcomes than their non-disabled peers.").

32. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–213.

33. Rehabilitation Act of 1973, 29 U.S.C. §§ 701–96.

34. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010); Health Care and Education Reconciliation Act, Pub. L. No. 111-152, 124 Stat. 1029 (2010).

35. 42 U.S.C. § 12101(b)(1)–(2).

36. *Id.* §§ 12111–12, 12131–32, 12181–82.

37. *Id.* § 12102(1).

for oneself, performing manual tasks, seeing, hearing, walking, speaking, breathing, learning, communicating, and working.<sup>38</sup> In 2008, Congress amended the ADA to clarify that (1) “[a]n impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active”<sup>39</sup> and (2) a “determination . . . whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures.”<sup>40</sup> Under the ADA and the ADA Amendments Act of 2008, courts shall construe the definition of disability in favor of broad coverage of people, to the maximum extent permitted by the law.<sup>41</sup>

Title II of the ADA prohibits discrimination against people with disabilities by public entities, including state and local public health programs, services, and activities, irrespective of receipt of federal funding.<sup>42</sup> Courts have applied Title II of the ADA to state Medicaid programs<sup>43</sup> and state and county hospitals.<sup>44</sup> Title III of the ADA, conversely, prohibits discrimination based on disability by places of public accommodation, including private health care providers’ offices and hospitals.<sup>45</sup>

The ADA extends and increases section 504’s protections, which prohibit disability-based discrimination by federally-funded programs and activities.<sup>46</sup> Section 504 requires hospitals, clinics, and other health care providers that receive Medicaid, Medicare, or any other form of federal funding, to ensure equal access to programs and services.<sup>47</sup> The ADA and section 504 are comparable in most respects, and courts have relied on cases under section 504 to assist in interpreting the ADA.<sup>48</sup>

Together, the ADA and section 504 require that health care offices and

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38. *Id.* § 12102(2)(A).

39. *Id.* § 12102(4)(D).

40. *Id.* § 12102(4)(E)(i).

41. *Id.* § 12102(4)(A).

42. *See id.* § 12131(1).

43. Elizabeth Pendo, *Disability, Equipment Barriers, and Women’s Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y 15, 30–36 (2008) (reviewing cases applying Title II of the ADA to state Medicaid programs).

44. *See Gray v. Cnty. of Kern*, 704 F. App’x 649, 650 (9th Cir. 2017); *Judice v. Hosp. Serv. Dist. No. 1*, 919 F. Supp. 978, 980 (E.D. La. 1996).

45. *See* 42 U.S.C. § 12181(7)(F); *id.* § 12182(a); 28 C.F.R. § 36.104 (2020).

46. 29 U.S.C. § 701(b).

47. *Id.* §§ 701(a)(1), 794(b)(3)(A)(ii). Several courts have held that receipt of Medicare or Medicaid funds constitutes federal financial assistance within the meaning of the Rehabilitation Act. *See, e.g., Henrietta D. v. Bloomberg*, 331 F.3d 261, 272 (2d Cir. 2003) (noting the lack of dispute on point under section 504 of the Rehabilitation Act and the ADA).

48. *See, e.g., Davis v. Shah*, 821 F.3d 231, 259–60 (2d Cir. 2016) (citing *Henrietta D.*, 331 F.3d at 272); *Helen L. v. DiDario*, 46 F.3d 325, 330 n.7 (3d Cir. 1995).

facilities be accessible to people with disabilities. Although there are some distinctions between the specific requirements of Titles II and III of the ADA, generally, accessibility in health care settings includes physical access to health care services and facilities, including accessible spaces and the removal of barriers;<sup>49</sup> effective communication (including auxiliary aids and services, e.g., sign language interpreters or materials in alternative formats);<sup>50</sup> and reasonable modification of policies, practices, and procedures when necessary to accommodate individual needs.<sup>51</sup>

Adding to the ADA and section 504's protections, the ACA "may [also] be understood as a disability rights law."<sup>52</sup> According to Jessica Roberts, "[a]lthough not yet widely recognized as such, the ACA constitutes one of the most significant civil rights victories for the disability community in recent history."<sup>53</sup> For example, section 1557 of the ACA (section 1557) prohibits disability-based discrimination by health care providers that receive federal financial assistance.<sup>54</sup> Paralleling the ADA and section 504, section 1557 requires health care providers to provide effective communication (e.g., sign language interpreters or materials in alternative formats),<sup>55</sup> comply with accessibility standards,<sup>56</sup> ensure information and communications technology is accessible for people with disabilities,<sup>57</sup> and grant reasonable modifications to policies, practices, and procedures when necessary to accommodate individual needs.<sup>58</sup>

Furthermore, section 4203 of the ACA amended the Rehabilitation Act by adding section 510.<sup>59</sup> Specifically, section 510 requires the U.S. Access Board, an independent federal agency whose work focuses on accessibility for people with disabilities, in consultation with the Food and Drug Administration (FDA), to develop accessibility standards for medical diagnostic equipment.<sup>60</sup> The Access Board published its final

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49. 28 C.F.R. § 35.150(a); 28 C.F.R. § 36.304.

50. 28 C.F.R. § 35.160; 28 C.F.R. § 36.303(a)–(c).

51. 28 C.F.R. § 35.130(b)(7); 28 C.F.R. § 36.302(a).

52. Jessica L. Roberts, *Health Law as Disability Rights Law*, 97 MINN. L. REV. 1963, 1964 (2013).

53. *Id.*

54. 42 U.S.C. § 18116(a); 45 C.F.R. §§ 92.102–05 (2019).

55. 45 C.F.R. § 92.102.

56. *Id.* § 92.103.

57. *Id.* § 92.104.

58. *Id.* § 92.105.

59. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 4203, 124 Stat. 119, 570 (2010) (codified as amended at 29 U.S.C. § 794f).

60. *Id.*

standards on January 9, 2017, effective February 8, 2017.<sup>61</sup> While useful, the Access Board's standards are not compulsory.<sup>62</sup> Also in 2017, the U.S. Department of Justice (DOJ) withdrew four Advance Notices of Proposed Rulemaking relating to Titles II and III of the ADA, including one that would have established requirements for accessible medical diagnostic equipment.<sup>63</sup>

Other provisions of the ACA are also relevant to people with disabilities. For example, people with disabilities have benefited from the law's expansion of Medicaid, the elimination of preexisting condition exclusions and limitations on health status-based rating, and its recognition of disabled people as a health disparities group.<sup>64</sup> The statute also requires the federal government to gather and report data on people with disabilities and health care utilization and outcomes, as well as funds efforts to improve disability competency training for health care providers.<sup>65</sup>

The federal government and private lawsuits enforce the ADA, section 504, and section 1557. For example, people with disabilities may bring private lawsuits for ADA or section 504 violations.<sup>66</sup> People with disabilities can also file ADA or section 504 complaints with the DOJ, through its Disability Rights Section.<sup>67</sup> The U.S. Department of Health and Human Services' Office for Civil Rights (OCR) also has enforcement responsibilities under Title II of the ADA and section 504.<sup>68</sup> Enforcement of section 1557 is similar to section 504.<sup>69</sup>

Notwithstanding the aforementioned statutes and the legal protections that they afford to disabled people, access to health care remains a persistent issue for people with disabilities. Unfortunately, despite their

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61. Standards for Accessible Medical Diagnostic Equipment, 82 Fed. Reg. 2810 (Jan. 9, 2017) (codified at 36 C.F.R. pt. 1195 (2020)).

62. *About the Accessibility Standards for Medical Diagnostic Equipment*, U.S. ACCESS BD. (Jan. 9, 2017), <https://www.access-board.gov/mde/> [<https://perma.cc/79B5-N4GN>] (“As issued by the Board, the standards are not mandatory on health care providers and equipment manufacturers. The Department of Justice may adopt them as mandatory requirements under the Americans with Disabilities Act (ADA). Other federal agencies may implement them as well under the Rehabilitation Act which requires access to federally funded programs and services.”).

63. Nondiscrimination on the Basis of Disability; Notice of Withdrawal of Four Previously Announced Rulemaking Actions, 82 Fed. Reg. 60,932 (announced Dec. 26, 2017).

64. Roberts, *supra* note 52, at 1965.

65. *Id.* at 2027.

66. 42 U.S.C. § 12188; 45 C.F.R. § 84.61 (2019).

67. 28 C.F.R. § 35.170 (2020); *id.* § 36.502; *see also Disability Rights Section Responsibilities*, U.S. DEP'T OF JUST., <https://www.justice.gov/crt/disability-rights-section-responsibilities> [<https://perma.cc/W4P3-9EFB>].

68. 28 C.F.R. § 35.190(b)(3); *id.* § 42.530; 45 C.F.R. § 84.61.

69. 45 C.F.R. § 92.5.

broad mandates, the ADA and section 504 have “been largely ineffective at targeting health care disparities[,] while enforcement mechanisms have been inadequate to meet the requirement for health care access for people with disabilities.”<sup>70</sup> Meanwhile, the ACA is still in its infancy, making it unclear whether the statute can adequately address health disparities that disabled people experience. Moreover, the ACA’s future is uncertain at the time of this writing because the United States Supreme Court is currently considering the law’s constitutionality.<sup>71</sup>

### B. *Health and Health Care Inequities Before COVID-19*

Even in the best of times—i.e., before the COVID-19 pandemic—people with disabilities experienced a range of health and health care inequities.<sup>72</sup> Specifically, people with disabilities encounter attitudinal, communication, physical, policy, programmatic, social, and transportation barriers, which affect their ability to access appropriate and affordable health care services and information.<sup>73</sup> Such barriers, in turn, contribute to deleterious outcomes.<sup>74</sup> Indeed, “[a]s a group, people with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators and social determinants of health.”<sup>75</sup>

Although disabled people access health care at higher rates than nondisabled people, people with disabilities report lower overall health

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70. Anne Ordway, Chris Garbaccio, Michael Richardson, Kathe Matrone & Kurt L. Johnson, *Health Care Access and the Americans with Disabilities Act: A Mixed Methods Study*, DISABILITY & HEALTH J., Jan. 2021, at 1, 1 (footnote omitted). Agencies, organizations, researchers, and others have documented that the ADA and Rehabilitation Act are underenforced, including with respect to health care access. See NAT’L COUNCIL ON DISABILITY, *supra* note 30, at 14; NAT’L COUNCIL ON DISABILITY, *MONITORING AND ENFORCING THE AFFORDABLE CARE ACT: A ROADMAP FOR PEOPLE WITH DISABILITIES* 58 (2016); SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 131 (2009); Samuel R. Bagenstos, *The Perversity of Limited Civil Rights Remedies: The Case of “Abusive” ADA Litigation*, 54 UCLA L. REV. 1, 1–2 (2006).

71. *Texas v. United States*, 945 F.3d 355 (5th Cir. 2019), *cert. granted sub nom. Texas v. California*, No. 19-1019, 2020 WL 981805 (Mar. 2, 2020) (mem.).

72. Gloria L. Krahn, Deborah Klein Walker & Rosaly Correa-De-Araujo, *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH S198, S201 (2015). Research consistently shows that people with disabilities experience barriers to accessing health care and have adverse health outcomes. *Id.* (reviewing studies).

73. *Common Barriers to Participation Experienced by People with Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION (Sept. 16, 2020), <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html> [<https://perma.cc/C9AZ-QWZP>].

74. *Id.*

75. Richard Besser, *Disability Inclusion: Shedding Light on an Urgent Health Equity Issue*, ROBERT WOOD JOHNSON FOUND.: CULTURE OF HEALTH BLOG (Dec. 2, 2019, 11:00 AM), <https://www.rwjf.org/en/blog/2019/12/disability-inclusion-shedding-light-on-an-urgent-health-equity-issue.html> [<https://perma.cc/VDU8-9SZ5>].

levels,<sup>76</sup> including higher rates of co-occurring conditions.<sup>77</sup> People with disabilities are often un- or under-insured.<sup>78</sup> Compared to people without disabilities, those with disabilities are less likely to receive preventative health care services or information.<sup>79</sup> Studies indicate that disabled people are less likely than nondisabled people to receive dental care, mammograms, and certain vaccinations.<sup>80</sup> Women with disabilities are also less likely than nondisabled women to receive adequate prenatal care during pregnancies and more likely to have adverse birth outcomes, such as preterm labor and low-birth-weight infants.<sup>81</sup> People of color with disabilities and LGBTQ people with disabilities experience even worse health care outcomes and barriers to care, presumably due to the multiplicative effect of ableism combined with racism, homophobia, or transphobia.<sup>82</sup>

Public health researchers and scholars are increasingly noting that most disabled persons' health disparities result from social determinants of health barriers rather than specific conditions.<sup>83</sup> For example, compared

76. NAT'L COUNCIL ON DISABILITY, *supra* note 30, at 23; *see also id.* at 34–35 (“About half of people with complex limitations and one-third of people with basic actions difficulties assessed their health status as fair or poor, compared with the three-fourths of adults who did not have a disability who assessed their health as excellent or very good.”).

77. *Id.* at 23.

78. *Id.* at 1 (finding that “[p]eople with disabilities frequently lack either health insurance or coverage for necessary services, such as specialty care, long-term services, prescription medications, durable medical equipment, and assistive technologies”); *id.* at 11–12 (noting that “[t]he health care system in the United States is complex, highly fragmented, and sometimes overly restrictive in terms of program eligibility . . . leav[ing] some people with disabilities with no health care coverage and others with cost-sharing obligations and limits on benefits that prevent them from obtaining health-preserving prescription medications, medical equipment, specialty care, dental and vision care, long-term care, and care coordination”).

79. Thilo Kroll, Gwyn C. Jones, Matthew Kehn & Melinda T. Neri, *Barriers and Strategies Affecting the Utilisation of Primary Preventive Services for People with Physical Disabilities: A Qualitative Inquiry*, 14 HEALTH & SOC. CARE CMTY. 284, 285 (2006).

80. Heather F. de Vries McClintock, Frances K. Barg, Sam P. Katz, Margaret G. Stineman, Alice Krueger, Patrice M. Colletti, Tom Boellstorff & Hillary R. Bogner, *Health Care Experiences and Perceptions Among People with and Without Disabilities*, 9 DISABILITY & HEALTH J. 74, 74 (2016) (reviewing studies).

81. Norma I. Gavin, M. Beth Benedict & E. Kathleen Adams, *Health Service Use and Outcomes Among Disabled Medicaid Pregnant Women*, 16 WOMEN'S HEALTH ISSUES 313, 317–19 (2006).

82. Monika Mitra, Linda Long-Bellil & Robyn Powell, *Persons with Disabilities and Public Health Ethics*, in THE OXFORD HANDBOOK OF PUBLIC HEALTH ETHICS 219, 226 (Anna C. Mastroianni et al. eds., 2019) (citing studies).

83. Krahn et al., *supra* note 72, at S202–03. The authors argue that

[t]he available evidence documents that people with disabilities meet all the criteria for a disparity population. They experienced a history of social, economic, and environmental disadvantages in which children and adults with disabilities were institutionalized and marginalized. They experience documented differences in health outcomes at the population level that relate to higher rates of unmet health care needs, unhealthy lifestyle behaviors, mental

to nondisabled people, people with disabilities have lower education levels<sup>84</sup> and lower employment rates.<sup>85</sup> They also experience higher poverty rates<sup>86</sup> and food insecurity.<sup>87</sup> People with disabilities contend with barriers to securing accessible and affordable housing.<sup>88</sup> Disabled people are also more likely than nondisabled people to be survivors of crime or intimate partner violence.<sup>89</sup> People with disabilities often lack access to affordable and accessible transportation, limiting their access to health care.<sup>90</sup>

In addition to barriers relating to the social determinants of health, people with disabilities experience a range of other obstacles that result in deleterious health and health care outcomes. For example, discrimination against people with disabilities undoubtedly plays a central role in the adverse health outcomes that some disabled people experience.<sup>91</sup> Research has consistently found that healthcare providers' attitudes

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health and chronic diseases, and social determinants of poor health. Finally, many of these differences are recognized as avoidable and disproportionately affect this population.

*Id.*

84. Jennifer Karas Montez, Anna Zajacova & Mark D. Hayward, *Disparities in Disability by Educational Attainment Across US States*, 107 AM. J. PUB. HEALTH 1101, 1101 (2017).

85. Debra L. Brucker, Nicholas G. Rollins & Andrew J. Houtenville, *Striving to Work*, 139 SOC. INDICATORS RSCH. 541, 541 (2018).

86. Debra L. Brucker, Sophie Mitra, Navena Chaitoo & Joseph Mauro, *More Likely to Be Poor Whatever the Measure: Working-Age Persons with Disabilities in the United States*, 96 SOC. SCI. Q. 273, 273 (2014).

87. Debra L. Brucker & Alisha Coleman-Jensen, *Food Insecurity Across the Adult Life Span for Persons with Disabilities*, 28 J. DISABILITY POL'Y STUD. 109, 109 (2017).

88. GINA SCHAAK, LISA SLOANE, FRANCINE ARIENTI & ANDREW ZOVISTOSKI, PRICED OUT: THE HOUSING CRISIS FOR PEOPLE WITH DISABILITIES 8 (2017), <https://www.tacinc.org/wp-content/uploads/2020/04/priced-out-in-2016.pdf> [<https://perma.cc/74B5-G63B>] (describing the lack of accessible and affordable housing for people with disabilities as a "worsening crisis").

89. OFF. FOR VICTIMS OF CRIME, U.S. DEP'T OF JUST., CRIMES AGAINST PEOPLE WITH DISABILITIES (2018), [https://ovc.ojp.gov/sites/g/files/xyckuh226/files/ncvrvw2018/info\\_flyers/fact\\_sheets/2018NCVrw\\_VictimsWithDisabilities\\_508\\_QC.pdf](https://ovc.ojp.gov/sites/g/files/xyckuh226/files/ncvrvw2018/info_flyers/fact_sheets/2018NCVrw_VictimsWithDisabilities_508_QC.pdf) [<https://perma.cc/WMR8-MM2N>] ("Between 2009 and 2015, individuals with disabilities were at least twice as likely to be victims of violent victimization as people without disabilities.").

90. Mitra et al., *supra* note 82, at 226 ("Limited transportation options also create significant barriers to accessible and appropriate health care providers.").

91. See Tara Lagu, Christine Griffin & Peter K. Lindenauer, *Ensuring Access to Health Care for Patients with Disabilities*, 175 JAMA INTERNAL MED. 157, 157 (2015) ("Patients with disabilities face barriers when they attempt to access health care. These barriers include physical barriers to entering health care establishments, lack of accessible equipment, lack of a safe method for transferring the patient to an examination table, and the lack of policies that facilitate access."); Silvia Yee, Mary Lou Breslin, Tawara D. Goode, Susan M. Havercamp, Willi Horner-Johnson, Lisa I. Iezzoni & Gloria Krahn, *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity* 39 (2017) (unpublished manuscript), <https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf> [<https://perma.cc/MD2R-FTZ8>] ("Negative attitudes toward and assumptions about disabilities have an adverse effect on the health and quality of health care for people with disabilities.").

toward people with disabilities are as negative, if not more negative, than the general public.<sup>92</sup> For example, a survey of 153 emergency care providers found that only 18% of physicians, nurses, and technicians assumed they would be glad to be alive with a severe spinal cord injury; conversely, 92% of a comparison group of 128 persons with high-level spinal cord injuries reported being happy to be alive.<sup>93</sup> Furthermore, health care providers often lack training about how to work with people with disabilities. For example, information about people with disabilities has traditionally not been part of the medical school curriculum.<sup>94</sup> Given the lack of disability competence, it is not surprising that disabled people report health care providers' ignorance as one of the biggest impediments to accessing health care.<sup>95</sup>

People with disabilities also contend with physical and communication barriers that hinder their access to health care. For example, inaccessible medical diagnostic equipment contributes to health disparities among people with disabilities.<sup>96</sup> Indeed, the inability to access basic preventive health care screenings because of inaccessible examination tables and screening equipment can lead to delayed detection of serious health conditions (e.g., breast or prostate cancer).<sup>97</sup> Additionally, people who are Deaf or hard of hearing encounter communication barriers, such as health care providers not providing sign language interpreters, which can cause health disparities.<sup>98</sup>

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92. Pendo, *supra* note 43, at 43 (citing studies).

93. Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia*, 6 PSYCH. PUB. POL'Y & L. 526, 530 (2000).

94. NAT'L COUNCIL ON DISABILITY, *supra* note 30, at 13 ("Disability competency is not a core curriculum requirement for (1) accreditation or receipt of Federal funding for most medical and dental schools and other professional health care training institutions; or (2) for hospitals to participate in federally funded medical student internship and residency programs. In addition, applicants who seek either a medical or other professional health care license are generally not required to demonstrate disability competency.").

95. *Id.*; *see also id.* at 49 (explaining that "health care providers hold incorrect assumptions and stereotypes about people with disabilities, which can affect every aspect of care and can result in inadequate and inappropriate care").

96. Pendo, *supra* note 43, at 17; Elizabeth Pendo, *Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment*, 4 UTAH L. REV. 1057, 1057 (2010).

97. Pendo, *Reducing Disparities Through Health Care Reform*, *supra* note 96, at 1060–65 (describing the effect of inaccessible examination tables, examination chairs, weight scales, and x-ray and other imaging equipment on access to preventative services and screenings for people with disabilities); *see also* NAT'L COUNCIL ON DISABILITY, *supra* note 30, at 49 (explaining that health care providers "frequently conduct examinations or diagnostic tests while patients are seated in their wheelchairs, which can generate inaccurate test results or conceal physician evidence required for appropriate diagnosis and treatment").

98. Lisa I. Iezzoni, Bonnie L. O'Day, Mary Killeen & Heather Harker, *Communicating About*



C. *Health and Health Care Inequities During COVID-19*

Given the pervasive health and health care inequities that people with disabilities experienced before the COVID-19 pandemic, it is unsurprising that these injustices have only increased with the pandemic. In other words, like other socially marginalized populations, people with disabilities are facing many adverse outcomes during the COVID-19 pandemic, compounding longstanding health and health care inequities. People with disabilities experience disparities in exposure to the virus, inequities in susceptibility to contracting the virus, and barriers to accessing treatment and testing.

While disability alone may not inherently make someone more vulnerable to getting COVID-19 or more susceptible to worse outcomes from the virus, some people with disabilities are at an increased risk of infection or severe illness because of underlying medical conditions.<sup>99</sup> According to the Centers for Disease Control and Prevention,

All people seem to be at higher risk of severe illness from COVID-19 if they have serious underlying chronic medical conditions like chronic lung disease, a serious heart condition, or a weakened immune system. Adults with disabilities are three times more likely than adults without disabilities to have heart disease, stroke, diabetes, or cancer than adults without disabilities.<sup>100</sup>

A recent study found higher mortality rates due to COVID-19 among younger people with intellectual or developmental disabilities.<sup>101</sup> That same study also found that people with intellectual or developmental disabilities experience a higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes.<sup>102</sup> Strikingly, an estimated 83% of people under the age of sixty-five who have died from COVID-19 had an underlying medical condition that may meet the definition of disability, including heart disease, kidney disease, diabetes, and lung

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*Health Care: Observations from Persons Who Are Deaf or Hard of Hearing*, 140 ANNALS INTERNAL MED. 356, 356 (2004) (citing studies). See generally Alexa Kuenburg, Paul Fellingner & Johannes Fellingner, *Health Care Access Among Deaf People*, 21 J. DEAF STUD. & DEAF EDUC. 1 (2016) (reviewing fifteen years of research concern health care access among Deaf people).

99. *People with Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html> [<https://perma.cc/Q649-F2VD>].

100. *Id.*

101. 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., July 2020, at 1.

102. *Id.*

disease.<sup>103</sup> Hence, a population within the disability community is more vulnerable simply because of their conditions.

Moreover, research indicates that people with disabilities are at greater risk of infection because of where they live and who supports them.<sup>104</sup> In particular, numerous studies have shown that people living in congregate or institutional settings, such as nursing homes, group homes, psychiatric hospitals, jails, and prisons, have significantly higher rates of COVID-19 compared to the general population.<sup>105</sup> People with disabilities who live in the community and rely on in-home supports are also vulnerable because most caregivers do not have access to personal protective equipment.<sup>106</sup>

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103. Jonathan M. Wortham et al., *Characteristics of People Who Died with COVID-19—United States, February 12–May 18, 2020*, 69 *CTRS. FOR DISEASE CONTROL & PREVENTION: MORBIDITY & MORTALITY WKLY. REP.* 923, 924 (2020), <https://www.cdc.gov/mmwr/volumes/69/wr/mm6928e1.htm> [<https://perma.cc/2RB3-9HTV>].

104. 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/5PHT-GWG2>] (describing how COVID-19 has disproportionately affected people with disabilities and older adults who live in nursing homes and other congregate living situations).

105. *See, e.g.*, 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.*, Oct. 2020, at 1 (analyzing data from a coalition of organizations providing over half of the residential services for the state of New York and from the New York State Department of Health and finding deleterious outcomes); *More than 100,000 U.S. Coronavirus Deaths Are Linked to Nursing Homes*, *N.Y. TIMES* (Dec. 4, 2020), <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html> [<https://perma.cc/6HJB-VLSE>] (finding that 40% of COVID-19 deaths are linked to nursing homes); 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> [<https://perma.cc/LF7Y-RZJA>] (“As of Monday, 1,100 of the 140,000 developmentally disabled people monitored by the state had tested positive for the virus, state officials said. One hundred five had died — a rate, far higher than in the general population, that echoes the toll in some nursing homes. Separately, a study by a large consortium of private service providers found that residents of group homes and similar facilities in New York City and surrounding areas were 5.34 times more likely than the general population to develop Covid-19 and 4.86 times more likely to die from it. What’s more, nearly 10 percent of the homes’ residents were displaying Covid-like symptoms but had not yet been tested, according to the consortium, New York Disability Advocates.”); *COVID-19 Case Tracker*, *AUTISTIC SELF ADVOC. NETWORK*, <https://autisticadvocacy.org/covid19/> (last visited Feb. 8, 2021) (finding that as of February 8, 2021, 1,028,728 people with disabilities living in congregate settings have been diagnosed with COVID-19, and 154,314 have died); Letter from Robert P. Casey, U.S. Sen., et al., to Mitch McConnell, U.S. Sen., U.S. Senate Majority Leader (July 29, 2020), <https://www.casey.senate.gov/download/hcbs-letter-casey-warren> (last visited Feb. 7, 2020) (citing studies indicating that nearly 60,000 COVID-19 deaths have residents and workers in nursing homes and other long-term care settings).

106. C.E. DRUM, A. OBERG, K. COOPER & R. CARLIN, *AM. ASS’N ON HEALTH & DISABILITY, COVID-19 & ADULTS WITH DISABILITIES: HEALTH AND HEALTH CARE ACCESS: ONLINE SURVEY SUMMARY REPORT 8* (2020), <https://www.aahd.us/wp-content/uploads/2020/05/COVID->

As Hickson’s heartbreaking story at the beginning of this Article illustrates,<sup>107</sup> people with disabilities have experienced inadequate access to health care during the COVID-19. The rationing of life-saving treatment has been especially alarming for disabled people. Specifically, when the COVID-19 pandemic intensified, several states implemented ventilator and ICU-bed rationing plans that either prioritized nondisabled people for treatment, or categorically excluded certain people with disabilities from receiving life-saving treatment if resources become limited. For example, Alabama’s rationing plan listed “severe or profound mental retardation,” dementia, and brain injury as among potential reasons to be denied a ventilator during the COVID-19 pandemic.<sup>108</sup> Other states’ plans included similarly discriminatory language.<sup>109</sup> After steadfast advocacy by disability rights activists, attorneys, and scholars, the OCR affirmed that health care providers that receive federal funding must comply with federal civil rights laws, including the ADA.<sup>110</sup> Specifically, the OCR said that states and health care providers cannot adopt rationing policies based on “stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or

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19\_Summary\_Report.pdf [https://perma.cc/B4ZD-MWSW]; Kristi L. Kirschner, Lisa I. Iezzoni & Tanya Shah, *The Invisible COVID Workforce: Direct Care Workers for Those with Disabilities*, COMMONWEALTH FUND: TO THE POINT (May 21, 2020), https://www.commonwealthfund.org/blog/2020/invisible-covid-workforce-direct-care-workers-those-disabilities [https://perma.cc/8SQH-WEFM] (describing examples of caregivers of people with disabilities unable to secure personal protective equipment).

107. See *supra* Introduction.

108. See RESPONSE DIV., ALA. EMERGENCY MGMT. AGENCY, ANNEX TO ESF 8 OF THE STATE OF ALABAMA EMERGENCY OPERATIONS PLAN: CRITERIA FOR MECHANICAL VENTILATOR TRIAGE FOLLOWING PROCLAMATION OF MASS-CASUALTY RESPIRATORY EMERGENCY 8 (2010), https://adap.ua.edu/uploads/5/7/8/9/57892141/alabamas\_ventilator\_rationing\_plan.pdf [https://perma.cc/A3SJ-VGQV] (“[P]ersons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support.”).

109. See, e.g., ESF-8 HEALTH & MED. SECTION, LA. DEP’T OF HEALTH, STATE HOSPITAL CRISIS STANDARD OF CARE GUIDELINES IN DISASTERS 35 (2018), https://int.nyt.com/data/documenthelper/6856-louisiana-triage-guidelines/d95555bb486d68f7007c/optimized/full.pdf#page=1 [https://perma.cc/DHQ5-TW2X] (including among “exclusion criteria” for triage “[k]nown severe dementia”); TENN. ALTERED STANDARDS OF CARE WORKGROUP, GUIDANCE FOR THE ETHICAL ALLOCATION OF SCARCE RESOURCES DURING A COMMUNITY-WIDE PUBLIC HEALTH EMERGENCY AS DECLARED BY THE GOVERNOR OF TENNESSEE 8 (2016), https://int.nyt.com/data/documenthelper/6851-tennessee-triage-guidelines/02cb4c58460e57ea9f05/optimized/full.pdf#page=1 [https://perma.cc/KUH7-MW6X] (“[T]here are certain medical conditions or situations where maximally aggressive care will not be able to be provided to every individual. . . . [Including t]hose who require such a large amount of resources that it is not feasible to accommodate their hospitalization in a prolonged mass-casualty situation.”).

110. OFF. FOR C.R. IN ACTION, U.S. DEP’T OF HEALTH & HUM. SERVS., BULLETIN: CIVIL RIGHTS, HIPAA, AND THE CORONAVIRUS DISEASE 2019 (COVID-19), at 1 (2020), https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf [https://perma.cc/2D7W-5V5C].

absence of disabilities or age.”<sup>111</sup> The OCR’s guidance, combined with numerous complaints filed by disability rights advocates, pushed several states to rescind or clarify facially discriminatory ventilator rationing policies that previously discriminated based on certain disabilities and age.<sup>112</sup>

People with disabilities face other challenges relating to accessing adequate health care services and information during the COVID-19 pandemic. For example, people who are Deaf or hard of hearing people and are hospitalized because of COVID-19 encounter barriers to communicating with health care providers, such as face masks that hinder lipreading and a lack of sign language interpreters.<sup>113</sup> Hospital policies that prohibit visitors are also problematic for disabled people who rely on others’ assistance for activities of daily living.<sup>114</sup> Notably, the OCR reached a resolution with the State of Connecticut, which agreed to change

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111. *Id.*

112. *See, e.g.*, Press Release, Off. for C.R., U.S. Dep’t of Health & Hum. Servs., OCR Reaches Early Case Resolution with Alabama After It Removes Discriminatory Ventilator Triage Guidelines (Apr. 8, 2020), <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html> [<https://perma.cc/W6ZA-AF8X>] (announcing completion of compliance review of the State of Alabama after Alabama removed ventilator rationing guidelines in response to formal complaints filed alleging discrimination on the basis of disability or age); Press Release, Off. for C.R., U.S. Dep’t of Health & Hum. Servs., OCR Resolves Civil Rights Complaint Against Pennsylvania After It Revises Its Pandemic Health Care Triage Policies to Protect Against Disability Discrimination (Apr. 16, 2020), <https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html> [<https://perma.cc/M43S-RRX4>] (resolving compliance review after the Pennsylvania Department of Health revised existing triage guidelines, including those that “used ‘preexisting conditions that are disabilities’ to determine a priority score”); Press Release, Off. for C.R., U.S. Dep’t of Health & Hum. Servs., OCR Resolves Complaint with Tennessee After It Revises Its Triage Plans to Protect Against Disability Discrimination (June 26, 2020), <https://www.hhs.gov/about/news/2020/06/26/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against-disability.html> [<https://perma.cc/AR6E-KJU3>] (resolving compliance review after Tennessee revised its crisis standards of care protocols to ensure that such guidelines do not discriminate against people on the basis of age or disability); Press Release, Off. for C.R., U.S. Dep’t of Health & Hum. Servs., OCR Resolves Complaint with Utah After It Revised Crisis Standards of Care to Protect Against Age and Disability Discrimination (Aug. 20, 2020), <https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html> [<https://perma.cc/AG2B-NEHJ>] (announcing that the agency reached a resolution with the state of Utah after it revised its crisis standards of care guidelines to ensure that such criteria do not discriminate against people on the basis of age or disability).

113. Leila Miller, *Coronavirus Poses Added Challenges for Hospital Patients Who Are Deaf or Hard of Hearing*, L.A. TIMES (Apr. 16, 2020, 2:48 PM), <https://www.latimes.com/california/story/2020-04-16/coronavirus-deaf-hearing-hospitals-interpreters> (last visited Feb. 4, 2021).

114. Coleen A. Boyle, Michael H. Fox, Susan M. Havercamp & Jennifer Zubler, *The Public Health Response to the COVID-19 Pandemic for People with Disabilities*, DISABILITY & HEALTH J., July 2020, at 1, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7246015/> [<https://perma.cc/2BHE-H49B>].

its policies so that caregivers and other supports can visit disabled people during hospitalizations throughout the COVID-19 pandemic.<sup>115</sup>

Even COVID-19 testing is inaccessible to some people with disabilities. For example, communities across the country are utilizing drive-through testing sites, where people must drive to a place and then often wait numerous hours to be tested for COVID-19.<sup>116</sup> People with disabilities, especially those who cannot drive themselves or sit in a car for several hours, are facing difficulty accessing COVID-19 testing.<sup>117</sup> In Nebraska, disability rights advocates filed a complaint with the OCR, asserting that the state's testing program, which requires people to register online and then drive to a testing site, is inaccessible to people with disabilities who cannot use the internet or drive.<sup>118</sup>

People with disabilities also face difficulty accessing information about the virus. People who are Deaf or hard of hearing, for example, contend with public officials providing information in an inaccessible manner. The National Association of the Deaf successfully sued the White House for failing to provide sign language interpreters during press briefings regarding the pandemic.<sup>119</sup> Disability rights organizations also sued governors, including Andrew Cuomo of New York and Ron DeSantis of Florida, for not providing sign language interpreters during televised press

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115. Press Release, Off. for C.R., U.S. Dep't of Health & Hum. Servs., OCR Resolves Complaints After State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19 (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html> [<https://perma.cc/K9HL-AL2C>] (resolving complaints with the state and a private hospital, and Connecticut issuing an executive order "to ensure that people with disabilities have reasonable access to support personnel in hospital settings in a manner that is consistent with disability rights laws and the health and safety of patients, health care providers, and support persons").

116. Rachel Weiner, *As Cases Surge, Lines for Coronavirus Tests Sometimes Stretch Miles in the Summer Heat*, WASH. POST (July 1, 2020, 12:30 PM), [https://www.washingtonpost.com/health/as-cases-surge-lines-for-covid-19-tests-sometimes-stretch-miles-in-the-summer-heat/2020/07/01/f0951586-ba4b-11ea-80b9-40ece9a701dc\\_story.html](https://www.washingtonpost.com/health/as-cases-surge-lines-for-covid-19-tests-sometimes-stretch-miles-in-the-summer-heat/2020/07/01/f0951586-ba4b-11ea-80b9-40ece9a701dc_story.html) [<https://perma.cc/KJ6T-P28M>] (describing people waiting in "lines stretching miles in the summer heat" to be tested for COVID-19).

117. Joseph J. Fins & Samuel Bagenstos, *The Americans with Disabilities Act at 30: A Cause for Celebration During COVID-19?*, THE CONVERSATION (July 26, 2020), <https://theconversation.com/the-americans-with-disabilities-act-at-30-a-cause-for-celebration-during-covid-19-143399> [<https://perma.cc/LU3C-AHTV>] (describing instances where people with disabilities were unable to be tested because they could not independently get to a testing site).

118. *CPR and Partners File Complaint Regarding Inaccessibility of COVID-19 TestNebraska Program*, CTR. FOR PUB. REPRESENTATION (June 17, 2020) [hereinafter CTR. FOR PUB. REPRESENTATION], <https://www.centerforpublicrep.org/news/cpr-and-partners-file-complaint-regarding-inaccessibility-of-covid-19-testnebraska-program/> [<https://perma.cc/3NVL-F5L8>].

119. Nat'l Ass'n of the Deaf v. Trump, No. 20-2107, 2020 WL 5411171, at \*1 (D.D.C. Sept. 9, 2020).

conferences and briefings.<sup>120</sup> People with intellectual disabilities or low literacy also face difficulties accessing information because the government has largely not provided information about COVID-19 in a plain language format.<sup>121</sup>

Additionally, people with disabilities experience other barriers during the COVID-19 pandemic that may have adverse health effects. For example, students with disabilities face barriers to receiving a free and appropriate public education, as mandated by federal law, due to remote learning.<sup>122</sup> Higher education students and faculty with disabilities similarly experience accessibility barriers as colleges and universities transition to distant learning.<sup>123</sup> In addition, the disability employment gap has grown since the COVID-19 pandemic began, with significantly fewer people with disabilities working than nondisabled people.<sup>124</sup> People with disabilities face difficulties getting hired because some employers are concerned that people with disabilities will become ill with COVID-19.<sup>125</sup> Similarly, some employers deny disabled employees at heightened risk of

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120. Morgan Gstalter, *DeSantis Sued for Not Having ASL Interpreter at Coronavirus Briefings*, THE HILL (July 14, 2020), <https://thehill.com/homenews/state-watch/507252-desantis-sued-for-not-having-asl-interpreter-at-coronavirus-briefings> [<https://perma.cc/DJ9P-B3UW>].

121. Robyn Powell, *The Coronavirus Pandemic Has Brought Out Society's Alarming Disregard for People with Disabilities*, THE APPEAL (Mar. 25, 2020), <https://theappeal.org/coronavirus-disabilities/> [<https://perma.cc/2EUC-E2ES>] (explaining that “[d]isability organizations have begun developing information about the illness in plain language so that people with intellectual disabilities or low literacy levels are informed—something the government has also failed to do”).

122. Harris, *supra* note 20, at 38–45 (describing ongoing barriers to providing students with disabilities free and appropriate public education). Empirical data collected from a national survey of school leaders revealed that approximately three out of four school districts determined that the most onerous “service to provide during COVID-19 was equitable education and related services for students with disabilities.” NAT’L SCH. BDS. ASS’N, SCH. SUPERINTENDENTS ASS’N, & ASS’N OF EDUC. SERV. AGENCIES, *SCHOOL LEADER VOICES: CONCERNS AND CHALLENGES TO PROVIDING MEANINGFUL IDEA-RELATED SERVICES DURING COVID-19*, at 9 (2020), <https://nsba.org/-/media/Files/nsba-aasa-aesa-IDEA-white-paper-july-14-20.pdf> [<https://perma.cc/4NUU-AVTK>].

123. Carla D. Chugani & Amy Houtrow, Editorial, *Effect of the COVID-19 Pandemic on College Students with Disabilities*, 110 AM. J. PUB. HEALTH 1722, 1723 (2020) (“It is imperative that future pandemic planning in higher education is responsive to the needs of students with disabilities and that clear guidance on protecting their rights, access, and equitable educational experiences is available.”); *see also* Greta Anderson, *Accessibility Suffers During Pandemic*, INSIDE HIGHER ED (Apr. 6, 2020), <https://www.insidehighered.com/news/2020/04/06/remote-learning-shift-leaves-students-disabilities-behind> [<https://perma.cc/4DWK-U5EQ>] (“In the quick shift by colleges from in-person to online instruction in response to the coronavirus pandemic, the needs of students with disabilities can sometimes be overlooked.”).

124. Press Release, Kessler Found., *supra* note 19 (reporting employment data); *see also* Norlian, *supra* note 19 (describing employment inequities experienced by disabled people during COVID-19).

125. Monica Torres, *Job Security Was Already Precarious for Individuals with Disabilities. Then COVID Hit*, HUFFPOST (July 28, 2020, 5:45 AM), [https://www.huffpost.com/entry/job-security-individuals-disabilities-coronavirus\\_1\\_5f060ae4c5b6480493ca63d9](https://www.huffpost.com/entry/job-security-individuals-disabilities-coronavirus_1_5f060ae4c5b6480493ca63d9) [<https://perma.cc/FA4B-R5BA>] (describing challenges disabled people faced when applying to jobs during the COVID-19 pandemic).

COVID-19 the opportunity to work from home as a reasonable accommodation.<sup>126</sup> Job accessibility is also more challenging for disabled people during the COVID-19 pandemic. For example, Deaf or hard of hearing employees face communication access barriers at work because of face masks that impede lipreading.<sup>127</sup>

In sum, despite the legal protections afforded to people with disabilities by the ADA, section 504, and the ACA, disabled people experience substantial health and health care inequities. People with disabilities have poorer health outcomes compared to nondisabled people. They also encounter a range of barriers to accessing health care. Regrettably, the COVID-19 pandemic has exacerbated these injustices.

## II. HEALTH JUSTICE AND PEOPLE WITH DISABILITIES

People with disabilities experience substantial health injustices, which are worsening during the pandemic.<sup>128</sup> Although biological factors account for some health disparities, many inequities are linked to the social determinants of health. The health justice framework, which recognizes that health is shaped by the conditions in which we live and work, not just our access to health care, is premised on the understanding that law and policy must respond to the social determinants of health.<sup>129</sup> The health justice framework, therefore, provides the ideal foundation for tackling people with disabilities' immediate needs during the COVID-19 pandemic, and addressing the root problems that have caused longstanding inequities.

Scholars drew from the health justice framework to propose legal and policy solutions to address inequities that people of color and low-income populations experience during the COVID-19 pandemic and beyond, noting the critical need to eradicate structural inequalities to address people's immediate and long-term needs.<sup>130</sup> This Article applies similar principles to respond to the disparities that disabled people experience. To that end, this Part first describes the health justice framework, including

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126. Alex Ellerbeck, *Looming Fight: Millions of Disabled Workers Could Ask for COVID-19 Protections Under ADA*, CTR. FOR PUB. INTEGRITY (Aug. 28, 2020), <https://publicintegrity.org/health/coronavirus-and-inequality/disabled-workers-covid-protections-ada/> [https://perma.cc/Z4J8-PCX3] (saying that “[t]he cases are likely to multiply” as employees with underlying medical conditions are increasingly expected to return to work).

127. Torres, *supra* note 125.

128. *See supra* Part I.

129. Benfer et al., *Health Justice Strategies to Combat the Pandemic*, *supra* note 24, at 138 (“Intermediary determinants include the material and environmental circumstances in which people live and work and their access to and treatment within the health system.”).

130. *Id.*

ways in which scholars have applied it to other socially marginalized communities. Thereafter, it makes a case for using the health justice framework to dismantle the deeply rooted inequities experienced by people with disabilities through law and policy.

A. *Overview of the Health Justice Framework*

The health justice framework is a developing framework aimed at dismantling structural inequities that result in adverse health outcomes and experiences through law and policy.<sup>131</sup> It supplements existing understandings of health law and policy by demonstrating the need to focus not only on access to quality health care but also on the social, economic, and environmental factors that affect socially marginalized communities' health and wellbeing.<sup>132</sup> Moreover, the health justice framework diverges from extant models of health law and policy by shifting the focus from "legal duties rooted in concern for particular individuals" to the broad concerns of people as interdependent members of communities.<sup>133</sup>

The health justice framework draws on the experiences of other contemporary social justice movements, such as the reproductive justice, environmental justice, and food justice movements, as well as on the scholarship of political philosophers and ethicists on health justice.<sup>134</sup> The health justice framework is rooted in a communitarian conception of social justice.<sup>135</sup> Moreover, it stresses the importance of "listening to, engaging, and developing affected communities" as a crucial component of health justice.<sup>136</sup>

The health justice framework emphasizes the need for in-depth inquiry into the effects of systems of oppression on the design and implementation of policies and programs to reduce health and social inequities.<sup>137</sup> It also urges policymakers and health care providers to prioritize social-ecological interventions over individually-targeted

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131. See *supra* note 24 for examples of ways in which scholars have applied the health justice to a variety of communities and issues.

132. Wiley, *From Patient Rights to Health Justice*, *supra* note 24, at 881–82.

133. William M. Sage, *Relational Duties, Regulatory Duties, and the Widening Gap Between Individual Health Law and Collective Health Policy*, 96 GEO. L.J. 497, 500 (2008); Wiley, *Health Law as Social Justice*, *supra* note 24, at 55 (contrasting the social justice model's focus on collective responsibility with the progressivist focus on individual rights).

134. Wiley, *Health Law as Social Justice*, *supra* note 24, at 53–63.

135. *Id.* at 52.

136. Benfer, *Health Justice: A Framework (and Call to Action)*, *supra* note 24, at 338.

137. Wiley, *Health Law as Social Justice*, *supra* note 24, at 95–101.



interventions.<sup>138</sup> Ultimately, the health justice framework advances that the social determinants of health are just as imperative to an individual's health as the health care that they receive.<sup>139</sup> Therefore, to improve health and health care outcomes, laws and policies must address the social determinants of health.

In the context of the COVID-19 pandemic, Emily Benfer and colleagues called for use of the health justice framework to develop and implement laws and policies that “prevent and eliminate health disparities during and after the COVID-19 pandemic.”<sup>140</sup> To that end, Benfer and colleagues put forth three interrelated principles for addressing inequities during the pandemic and beyond<sup>141</sup>: First, laws and policies must address the social determinants of health.<sup>142</sup> Second, interventions that mandate behaviors or conduct must be supplemented by legal protections and supports that facilitate compliance with mandates without furthering social and economic inequities.<sup>143</sup> Third, socially marginalized communities must be actively engaged throughout the development and implementation of interventions to address health justice.<sup>144</sup>

#### *B. The Importance of Health Justice for People with Disabilities*

Whereas the health justice framework has been utilized to shed light on the numerous inequities that socially marginalized communities experience and how these injustices lead to significant health disparities, scholars have not yet extended the framework to people with disabilities.<sup>145</sup> This omission from an otherwise burgeoning body of scholarship, therefore, provides an ideal opportunity to extend the framework to an often overlooked disparity population: people with disabilities.<sup>146</sup>

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138. Lindsay F. Wiley, *Shame, Blame, and the Emerging Law of Obesity Control*, 47 U.C. DAVIS L. REV. 121, 184 (2013).

139. Benfer, *A Framework (and Call to Action)*, *supra* note 24, at 278–79 (“The social determinants of health often lead to inequities.”); *see id.* at 279–306 (describing ways in which social determinants of health cause health inequities).

140. Benfer et al., *Health Justice Strategies to Combat the Pandemic*, *supra* note 24, at 137.

141. *Id.* at 137.

142. *Id.* at 137–38.

143. *Id.* at 138.

144. *Id.* at 138–39.

145. Notably, in developing the health justice framework, Emily Benfer and colleagues briefly described child welfare cases involving disabled parents as an example of how court systems' failure to use an individualized approach leads to inequities against socially marginalized communities. *See* Benfer, *Health Justice: A Framework (and Call to Action)*, *supra* note 24, at 320–24.

146. Krahn et al., *supra* note 72, at S202–03 (arguing that “[t]he available evidence documents that

Like other socially marginalized communities, people with disabilities experience a range of pervasive and persistent health and health care inequities. While some of these disparities may be associated with biological factors (i.e., related to individuals' disabilities), scholars increasingly recognize that many injustices are linked to the social determinants of health.<sup>147</sup> The COVID-19 pandemic has undoubtedly increased these inequalities.<sup>148</sup> Hence, the health justice framework is crucial to responding to the health inequities that people with disabilities experience during and after the pandemic by developing and implementing laws and policies that address disability-related needs and the social determinants of health.

In many ways, the health justice framework complements the social model of disability, which understands disability as “a relationship between people with impairments and a discriminatory society.”<sup>149</sup> Traditionally, disability has been treated as a medical tragedy needing to be cured or managed by health care providers.<sup>150</sup> As a rebuke to the medical model, disability rights activists and scholars developed the social model of disability, which perceives disability as a limitation imposed by the interaction between a person's impairment and their physical and social environment rather than a functional limitation.<sup>151</sup> Thus, disability

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people with disabilities meet all the criteria for a disparity population”). Traditionally, there has been a disconnect between public health and people with disabilities, resulting in disabled people being largely overlooked in most health disparities research. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 30, at 12 (analyzing the “dissonance” between “the longstanding public health goal of eliminating disability and disease and the emerging view . . . defin[ing] disability as a demographic characteristic”); *see also* Mitra et al., *supra* note 82, at 224 (“With respect to disability, the principles requiring a focus on population health and prevention have historically been interpreted as requiring a focus on primary prevention, with disability viewed primarily as an outcome that public health initiatives should endeavor to minimize in the general population.”).

147. Krahn et al., *supra* note 72, at S202 (“Although differences in health outcomes between people with and without disabilities are substantial, they are often dismissed with the argument that they do not represent true disparities. The arguments frequently fall into 1 of 2 categories: (1) these differences are caused by the condition that led to the disability— ‘they're disabled, of course their health is poor’—or (2) that the poor health was present first and subsequently led to the functional limitation—‘how do you know what came first?’ The health differences observed in disability populations are more complexly determined than implied by these arguments. Some portion of observed differences likely are attributable to the condition (causal circularity); the critical concern is that a closer look is needed to identify those differences that are preventable and unjust within this population.”).

148. *See supra* section I.C.

149. Tom Shakespeare, *Disability, Identity and Difference*, in *EXPLORING THE DIVIDE* 94, 97 (Colin Barnes & Geof Mercer eds., 1996).

150. *See* Arlene S. Kanter, *The Law: What's Disability Studies Got to Do with It or an Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403 (2011).

151. Michael Ashley Stein, *Disability Human Rights*, 95 CALIF. L. REV. 75, 85 (2007) (“The social

is viewed as a social construct, which shifts the focus from the individual body of the disabled person to the structural failings of the society at large.<sup>152</sup> Such an approach is consistent with the health justice framework, which calls for attention to laws and policies to address the social determinants of health. The health justice framework promotes “collective action grounded in community engagement and participatory parity.”<sup>153</sup> Similarly, the social model of disability champions people with disabilities as the legitimate experts about themselves and their own experience.<sup>154</sup> Hence, both the health justice framework and the social model of disability value the importance of incorporating the lived experiences of socially marginalized populations to develop and implement laws and policies that directly affect these communities.

Accordingly, the health justice framework is uniquely suited to address people with disabilities’ immediate needs that are arising during the COVID-19 pandemic as well as respond to the structural inequalities that have caused pervasive and persistent injustices. Like the health justice framework, the social model of disability necessitates a comprehensive understanding of, and response to, the inequities that people with disabilities experience, focused on how social and environmental factors cause disparities. Moreover, both the health justice framework and the social model of disability recognize the importance of directly engaging socially marginalized communities to inform the development of interventions aimed at assisting and protecting them.

### III. APPLYING THE HEALTH JUSTICE FRAMEWORK TO ADDRESS HEALTH AND HEALTH CARE INEQUITIES DURING AND AFTER COVID-19

The health and health care inequities that people with disabilities have experienced for too long—and which have been further exacerbated during the COVID-19 pandemic—require a multifaceted legal and policy

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model of disability asserts that contingent social conditions rather than inherent biological limitations constrain individuals’ abilities and create a disability category.”); *see also* Tom Shakespeare, *The Social Model of Disability*, in *THE DISABILITY STUDIES READER* 197, 226–72 (Lennard J. Davis ed., 2d ed. 2006) (explaining the application of the social model of disability in the United Kingdom).

152. Shakespeare, *supra* note 151, at 198 (“Impairment is distinguished from disability. The former is individual and private, the latter is structural and public.”).

153. Wiley, *Health Law as Social Justice*, *supra* note 24, at 47.

154. Tania Burchardt, *Capabilities and Disability: The Capabilities Framework and the Social Model of Disability*, 19 *DISABILITY & SOC’Y* 735, 737 (2004) (“[S]ince collective action is likely to be required to change society, social model theorists emphasise the need for disabled people’s organisations, that is, democratic organisations of disabled people. People who live with impairments are the experts on the impact of disability, not doctors, therapists, social workers, care assistants or researchers.”).

response that addresses both disabled people's immediate needs during the pandemic and the deeply rooted structures that have caused such inequalities. Specifically, laws and policies must consider and address how disability intersects with the social determinants of health. "As this pandemic challenges both the strength and elasticity of every social system involved in health and wellness, it is important to examine the underpinnings of existing health disparities and the values and beliefs of existing systems that created inequities for individuals with disabilities."<sup>155</sup> Accordingly, a systems change approach is crucial to eliminating health and health care disparities.

Applying the health justice framework, this Part proposes normative legal and policy solutions to eliminate health and health care inequities that disabled people are experiencing during the COVID-19 pandemic and beyond. To demonstrate the application of the health justice framework and its principles, this Part describes how law and policy should respond to the health and health care injustices that disabled people experienced throughout the COVID-19 pandemic and beyond. First, this Part briefly explains the importance of engaging people with disabilities as leaders in developing law and policy interventions and attaining health justice. Thereafter, this Part proposes legal and policy considerations relating to each of the social determinants of health that must be addressed to achieve health equity. Although a complete agenda is beyond this Article's scope, this Part describes general principles that legal professionals, policymakers, and scholars must recognize and offers several critical solutions that are worthy of consideration.

#### A. *Disabled People Should Serve as Leaders*

As previously mentioned, a vital component of the health justice framework is "listening to, engaging, and developing affected communities."<sup>156</sup> This commitment is consistent with the disability community's ethos, *Nothing About Us Without Us*, which asserts that disabled people should be actively involved in developing and implementing policies that affect them.<sup>157</sup> Notwithstanding the disability rights movement's many achievements, the disability community is still

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155. Erin E. Andrews, Kara B. Ayers, Kathleen S. Brown, Dana S. Dunn & Carrie R. Pilarski, *No Body Is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic*, AM. PSYCH. (forthcoming 2021) (manuscript at 5).

156. Benfer, *Health Justice: A Framework (and Call to Action)*, *supra* note 24, at 338.

157. CHARLTON, *supra* note 26, at 3–4.

not fully engaged in the political process.<sup>158</sup> Thus, there is an urgent need to engage people with disabilities in policymaking and activism.

Active engagement requires a deliberate understanding of and respect for people with disabilities sharing their lived experiences. It also necessitates elevating people with disabilities to leadership positions, rather than tokenizing their participation.<sup>159</sup> Collaboration leads to legal and policy responses that are disability-competent and address the actual needs of people with disabilities. Indeed, “[t]o disrupt the cycle of social, health, and economic disparities that people with disabilities experience, sustained representation and participation of people with disabilities is necessary.”<sup>160</sup>

Importantly, all local, state, and federal law and policy responses relating to the COVID-19 pandemic and beyond must involve the ongoing and purposeful engagement of people with disabilities. Disabled people should participate in developing and implementing all law and policy interventions, both those specific to disabled people and those relating to the general public. Including people with disabilities on advisory boards can be a starting point. For example, bioethics scholars have called for an increase in disabled bioethicists as well as the inclusion of disabled people to participate on committees responsible for triage decision-making.<sup>161</sup> Likewise, the legal profession should commit to increasing the number of attorneys who have disabilities.<sup>162</sup> Disabled attorneys can help develop and implement law and policy solutions that are informed by their

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158. See Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2, 104 Stat. 328 (amended 2008) (acknowledging that people with disabilities have been “relegated to a position of political powerlessness in our society”).

159. See generally Ruthie-Marie Beckwith, Mark G. Friedman & James W. Conroy, *Beyond Tokenism: People with Complex Needs in Leadership Roles: A Review of the Literature*, 4 INCLUSION 137 (2016) (reviewing the literature on how people with disabilities are engaged in leadership development, public policy advocacy, and community activities).

160. SANDY HO, SUSAN EATON & MONIKA MITRA, LURIE INST. FOR DISABILITY POL’Y, FORD FOUND., CIVIC ENGAGEMENT AND PEOPLE WITH DISABILITIES: A WAY FORWARD THROUGH CROSS-MOVEMENT BUILDING 5 (2020), <https://heller.brandeis.edu/sillerman/pdfs/reports/civic-engagement-and-people-with-disabilities-report.pdf> [<https://perma.cc/NN76-LA5Y>].

161. Marina Tsaplina & Joseph A. Stramondo, *#WeAreEssential: Why Disabled People Should Be Appointed to Hospital Triage Committees*, THE HASTINGS CTR. (May 15, 2020), <https://www.thehastingscenter.org/weareessential-why-disabled-people-should-be-appointed-to-hospital-triage-committees/> [<https://perma.cc/WF2A-UWFB>] (“Given the history of conflict, we must now do everything we can to avoid a triage decision-making process that pushes disabled people to the side. One important action is to appoint people with disabilities, and especially those of color, to hospital triage committees. To our knowledge, no hospital or state crisis standards of care protocol mandates this kind of representation.”).

162. NAT’L ASS’N FOR L. PLACEMENT, 2019 REPORT ON DIVERSITY IN U.S. LAW FIRMS 30 (2019), [https://www.nalp.org/uploads/2019\\_DiversityReport.pdf](https://www.nalp.org/uploads/2019_DiversityReport.pdf) [<https://perma.cc/P7JK-UZLQ>] (finding that 0.55% of attorneys have a disability).

lived experiences.

*B. Health and Health Care Inequities Must Be Eliminated*

Certainly, health and health care—i.e., access to health care, primary care, and health literacy—are essential social determinants of health.<sup>163</sup> Throughout the COVID-19 pandemic, people with disabilities are experiencing many barriers to adequate health and health care, which are rooted in social, legal, and policy structures. Law and policy solutions should prioritize access to adequate and affordable health care services and information for people with disabilities during the COVID-19 pandemic. Moreover, law and policy responses should dismantle the longstanding barriers to health and health care.

As described in Part I, people with disabilities contend with a range of health and health care inequities, such as discriminatory state and hospital resource allocation protocols, no-visitor policies that restrict people with disabilities who are hospitalized from having access to necessary in-person supports, and access barriers to getting testing and treatment.<sup>164</sup> It is vital, then, that local, state, and federal government responses be swift and ongoing.

For example, the OCR, and the U.S. Department of Justice (DOJ), as appropriate,<sup>165</sup> should continue to promulgate COVID-19-specific guidance about health care providers' obligations under the ADA, section 504, and section 1557. The guidance should address health care and resource allocation policies, hospital visitor policies, and other policies that affect care for people with disabilities. The OCR and DOJ should also increase their investigation and enforcement efforts to ensure that health care providers comply with their legal mandates concerning disabled people during the COVID-19 pandemic. States should also consider legislation that prevents discrimination against people with disabilities, including prohibiting rationing health care and resources during an emergency and allowing visitors. Notably, the State of Oregon recently passed legislation that prohibits rationing care and resources for people with disabilities and allows a family member or support person to accompany a disabled person in the hospital.<sup>166</sup> Other states should

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163. Off. of Disease Prevention & Health Promotion, *supra* note 18 (describing “health and health care” as a social determinant of health).

164. *See supra* section I.C.

165. The U.S. Department of Justice has enforcement authority over Titles II and III of the ADA. *See* 28 C.F.R. § 35.190 (2020); *id.* § 36.503.

166. *See* Lauren Dake, *New Oregon Law Bars Discrimination Against People with Disabilities During Pandemic*, OR. PUB. BROAD. (July 11, 2020, 6:00 AM), <https://www.opb.org/news/article/la>

follow suit.

Likewise, states and hospitals should address discriminatory policies. Governments and hospitals, for example, should immediately amend their health care and resource allocation policies to ensure that they do not exclude disabled people from receiving care based on biases about people with disabilities. Moreover, hospitals must provide reasonable modifications pursuant to the ADA, section 504, and section 1557 to permit formal (e.g., paid support staff) and informal (e.g., parents) caregivers to assist disabled people, starting during admission and continuing throughout treatment. To ensure compliance with federal disability rights laws, the OCR and DOJ should swiftly investigate, and enforce as appropriate, violations by health care providers.

Local, state, and federal governments should work together to gather data on COVID-19 and people with disabilities. While the federal government releases data on COVID-19 among other populations, it still does not issue similar statistics about people with disabilities. Congress is currently considering legislation that would require U.S. Department of Health and Human Services to use all available surveillance systems to post daily updates on the Centers for Disease Control and Prevention website showing data on testing, treatment, and fatalities, disaggregated by race, ethnicity, sex, age, socioeconomic status, *disability status*, county, and other demographic information.<sup>167</sup> Additionally, data on disability and race and ethnicity are needed to understand how specific segments of people with disabilities are being affected.<sup>168</sup> Such data is crucial. Certainly “[w]ith every emergency, addressing the needs of high-risk populations requires scientific data: to highlight who is at greatest risk so we can target intervention strategies and, subsequently, to monitor the effectiveness of interventions.”<sup>169</sup> Until there is a clear

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w-bars-disability-discrimination-covid-19/ [https://perma.cc/7B3P-KAMA] (describing the recently enacted legislation).

167. Equitable Data Collection and Disclosure on COVID-19 Act, H.R. 6858, 116th Cong. (2020) (emphasis added).

168. Jayajit Chakraborty, *Social Inequities in the Distribution of COVID-19: An Intra-Categorical Analysis of People with Disabilities in the U.S.*, DISABILITY & HEALTH J., Jan. 2021, at 1 (finding disparities in incidence of COVID-19 amongst people of color with disabilities); see also Daniel Young, *Black, Disabled and Uncounted*, NAT’L HEALTH L. PROGRAM (Aug. 7, 2020), <https://healthlaw.org/black-disabled-and-uncounted/> [https://perma.cc/4LJ3-GAXG] (“But even where COVID data has been stratified, it has been either by race *or* by disability. Almost nothing looks at both race *and* disability. The lack of actual statistics addressing this intersection makes it impossible to know the true scope of the impact COVID-19 is having on Black people with disabilities. This missing information is one more example in a long list of how the experience of Black people with disabilities remains largely invisible and ignored by the dominant identities of this country.”).

169. Boyle et al., *supra* note 114.

national picture of the rates of testing, treatment, and fatalities among people with disabilities, law and policy will be unable to respond adequately.

Local, state, and federal governments, as well as private entities involved in COVID-19 testing, must also ensure that testing is widely available and accessible to people with disabilities.<sup>170</sup> Again, entities that conduct testing may need to provide reasonable modifications to enable disabled people to receive COVID-19 testing. For example, drive-through testing sites must consider how they will serve people with disabilities who cannot drive or wait long periods to be tested. One possible reasonable modification would be to offer in-home testing.

Similarly, as antiviral therapies and vaccines become available, local, state, and federal governments, as well as private entities, need to consider how they will treat people with disabilities. Antiviral therapies and vaccines should be prioritized for people with disabilities, especially those living in congregate and institutional settings, given disabled people's higher susceptibility and exposure to the virus than nondisabled people. Moreover, disability status should not be used to deny or deprioritize people with disabilities from receiving antiviral therapies or vaccines.<sup>171</sup> In addition, entities distributing vaccines must be accessible to people with disabilities and may need to provide reasonable modifications to ensure access, including home visits.

Furthermore, a key component in safeguarding people with disabilities throughout the COVID-19 pandemic is providing accurate and accessible health information on the virus and ways to continue to protect oneself. Unfortunately, some government officials, including former President Trump,<sup>172</sup> have not included sign language interpreters during press briefings about the pandemic. Title II of the ADA and section 504 mandate that government services be accessible to people with disabilities, including providing auxiliary aids and services (e.g., sign language interpreters, Braille, and captioning).<sup>173</sup> In addition, all government-provided information should be accessible to people with low literacy levels.

While addressing COVID-19 inequities must be prioritized, laws and

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170. CTR. FOR PUB. REPRESENTATION, *supra* note 118 (complaint filed in Nebraska about inaccessible COVID-19 testing).

171. CONSORTIUM FOR CITIZENS WITH DISABILITIES, COVID-19 VACCINE ALLOCATION PRINCIPLES 1 (2020), <http://c-c-d.org/fichiers/CCD-Vaccine-Allocation-Principles-October-2020.pdf> [<https://perma.cc/ZL94-BLVT>].

172. Nat'l Ass'n of the Deaf v. Trump, No. 20-2107, 2020 WL 5411171 (D.D.C. Sept. 9, 2020).

173. Americans with Disabilities Act of 1990, 42 U.S.C. § 12132; Rehabilitation Act of 1973, 29 U.S.C. §§ 701–796.



policies must also respond to the structures that have caused these longstanding injustices. Indeed, health and health care disparities are deeply rooted in ableist structures and based on a history of mistreatment and segregation by the health care system.<sup>174</sup> Despite legal protections afforded by the ADA, section 504, and section 1557, discrimination by health care providers remains a significant barrier to accessing care.<sup>175</sup> As such, legal and policy responses should address the attitudinal, communication, physical, policy, programmatic, social, and transportation barriers that impact disabled people's ability to access health care services and information. The DOJ and the OCR should prioritize investigating and enforcing complaints of violations of federal disability rights laws by health care providers. The federal agencies should also issue updated guidance on health care providers' legal responsibilities, including ways in which the ADA, section 504, and section 1557 intersect.

To ensure physical accessibility, the federal government must finally enact regulations concerning medical diagnostic equipment (e.g., examination tables, examination chairs, weight scales, mammography equipment, x-ray machines, and other radiological equipment commonly used for diagnostic purposes). Since the ADA's passage, there have been many attempts to promulgate specific medical diagnostic equipment standards through regulation and legislation.<sup>176</sup> Nonetheless, as previously discussed, the federal government has failed to adopt regulations, leaving health care providers with no guidance on accessible medical diagnostic equipment.<sup>177</sup>

In addition, Congress should protect existing laws that mandate accessible health care for people with disabilities. Strikingly, proposed federal COVID-19 relief legislation has included threats to existing federal disability rights laws. For example, the HEALS Act contains liability protections for employers and places of public accommodations

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174. See, e.g., Brad Byrom, *A Pupil and a Patient: Hospital-Schools in Progressive America*, in *THE NEW DISABILITY HISTORY: AMERICAN PERSPECTIVES* 133, 136 (Paul K. Longmore & Lauri Umansky eds., 2001) (describing the establishment of hospital-school specifically tailored and named for the "Ruptured and Crippled"); see also PAUL A. LOMBARDO, *THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT, AND BUCK V. BELL* 45 (2008); Anita Silvers, *Formal Justice*, in *DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY* 13, 42 (1998).

175. See generally Anne Ordway et al., *supra* note 70 (reporting findings from a survey, focus group, and interviews showing ongoing barriers to health care despite federal laws).

176. Elizabeth Pendo, *The Costs of Uncertainty: The DOJ's Stalled Progress on Accessible Medical Equipment Under the Americans with Disabilities Act*, 12 *ST. LOUIS U. J. HEALTH L. & POL'Y* 351, 355–59 (2019) (reviewing regulatory and legislative attempts to issue standards for accessible medical diagnostic equipment).

177. See *supra* section I.A.

for alleged violations of federal laws, inter alia, the ADA.<sup>178</sup> Such waivers of liability would likely lead to disability-based discrimination by health care providers and others, thereby worsening disparities for disabled people. Thus, Congress must reject all attempts to undermine disability rights.

Comprehensive health insurance is also critical to improving health and health care outcomes for people with disabilities. The ACA has been incredibly valuable for people with disabilities.<sup>179</sup> In particular, people with disabilities have benefited from expanded Medicaid eligibility, greater access to long-term services and supports, and pre-existing condition protections.<sup>180</sup> Nonetheless, Congress has made several attempts to repeal the ACA, all of which people with disabilities swiftly and firmly opposed.<sup>181</sup> Now, the United States Supreme Court is considering a case that could strike down the entire ACA as unconstitutional,<sup>182</sup> a move that would be devastating for disabled people. Rather than dismantle the law, policymakers should consider ways to expand its protections, so that all people with disabilities are insured and can afford to access health care. Accordingly, the efforts to eliminate the ACA should cease. Alternatively, Congress should promptly enact legislation that, at a minimum, provides the same level of protection and benefits to people with disabilities as the ACA does.

Legal and policy reforms should be made to the health care delivery system, such as expanding the use of telehealth (i.e., providing health care services and information via remote technologies). Prior to the COVID-19 pandemic, people with disabilities, as well as people living in rural communities, had spent years advocating for telehealth but were told that the health care system could not accommodate a change to provide

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178. Zack Budryk, *Duckworth: Republican Coronavirus Package Would 'Gut' Americans with Disabilities Act*, THE HILL (Aug. 5, 2020), <https://thehill.com/homenews/senate/510789-duckworth-republican-coronavirus-package-would-gut-americans-with> [<https://perma.cc/D67H-PGAN>] (reporting on Senator Tammy Duckworth's concerns about the HEALS Act and its effects on people with disabilities); HEALS Act, S. 1624, 116th Cong. (2020).

179. *See generally* NAT'L COUNCIL ON DISABILITY, THE IMPACT OF THE AFFORDABLE CARE ACT ON PEOPLE WITH DISABILITIES: A 2015 STATUS REPORT (2016), [https://ncd.gov/sites/default/files/NCD\\_ACA\\_Report02\\_508.pdf](https://ncd.gov/sites/default/files/NCD_ACA_Report02_508.pdf) [<https://perma.cc/3UYK-5A79>].

180. *Id.*

181. Robyn Powell, *Despite Arrests, People with Disabilities Continue to Fight for Their Lives*, REWIRE NEWS GRP. (July 7, 2017, 12:24 PM), <https://rewire.news/article/2017/07/07/despite-arrests-people-disabilities-continue-fight-lives/> [<https://perma.cc/JX9X-KL7C>] (describing how people with disabilities have protested Congress' attempts to repeal the ACA).

182. *Suit Challenging ACA Legally Suspect but Threatens Loss of Coverage for Tens of Millions*, CTR. ON BUDGET & POL'Y PRIORITIES (Nov. 3, 2020), <https://www.cbpp.org/research/health/suit-challenging-aca-legally-suspect-but-threatens-loss-of-coverage-for-tens-of> [<https://perma.cc/T79M-26RU>].

telehealth universally, or even in a broad manner.<sup>183</sup> In light of the pandemic, however, the transition to telehealth has been quick and comprehensive, suggesting that it is indeed possible. Therefore, telehealth should continue to be available to people with disabilities. Accordingly, state and federal governments should enact statutory and regulatory changes, as needed, to expand telehealth. Congress should also allocate additional Medicaid funding for telehealth.

Finally, law and policy solutions should respond to the longstanding bias toward people with disabilities that have endured within the health care system. While the COVID-19 pandemic has shined a light on health care rationing among disabled people, rationing happened before the pandemic. For example, decisions about organ transplants are based on specific guidelines that sometimes exclude people with disabilities as recipients.<sup>184</sup> All health care providers should be trained to address their prejudice against people with disabilities. Specifically, they should receive education about ableism and treating patients with disabilities during their professional programs as well as annual training throughout their careers. Relatedly, the health care workforce must be expanded to include more professionals with disabilities. Indeed, scholars have called for more physicians with disabilities, asserting having disabled health care providers will help address biases and lead to better health outcomes for people with disabilities.<sup>185</sup> Similarly, efforts need to be made to increase the number of bioethicists with disabilities.

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183. George M. Powers, Lex Frieden & Vinh Nguyen, *Telemedicine: Access to Health Care for People with Disabilities*, 17 HOUS. J. HEALTH L. & POL'Y 7 (2017).

184. See generally NAT'L COUNCIL ON DISABILITY, ORGAN TRANSPLANT DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES (2019), [https://ncd.gov/sites/default/files/NCD\\_Organ\\_Transplant\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf) [<https://perma.cc/3LRE-RHNU>] (finding that disabled people regularly experience discrimination when needing organ transplants). See also Laura C. Hoffman, *Access to Health Care and the Intellectually and Developmentally Disabled: Anti-Discrimination Law, Health Law, and Quality of Life*, 22 J. GENDER RACE & JUST. 151, 154–67 (2019) (reviewing statistics and case law concerning organ transplants for people with intellectual and developmental disabilities).

185. See, e.g., Alicia Ouellette, *Patients to Peers: Barriers and Opportunities for Doctors with Disabilities*, 13 NEV. L.J. 645, 659–60 (2013) (“The exclusion of persons with disabilities from the medical profession affects the entire health care system in the same way that the historical exclusion of women and racial minorities affected the system. Having spent the past decade engaged in research about the experience of persons with physical disabilities in the health care system, I am convinced that including persons with physical impairments as medical professionals will help improve the health status and health care experience of all people with disabilities.”); Mary Crossley, *Disability Cultural Competence in the Medical Profession*, 9 ST. LOUIS U. J. HEALTH L. & POL'Y 89, 90 (2015) (“The under-representation of people with disabilities in the medical profession and the disparities they experience reflect just two aspects of a health care system that fall short of the goals of the Americans with Disabilities Act (ADA) . . .”).

C. *Neighborhood and Built Environment Barriers Should Be Removed*

Law and policy solutions must also address how the neighborhood and built environment affect health equity for people with disabilities during the COVID-19 pandemic and beyond. In other words, legal and policy solutions must consider where disabled people “live, learn, work, and play.”<sup>186</sup> To that end, structural disparities, which are often affected by law and policy, must be addressed so that people with disabilities can live and participate in their neighborhoods safely and healthily.

For example, local, state, and federal governments must prioritize housing and community living during the COVID-19 pandemic. Specifically, responses should include the issuance of guidance on protections for tenants with disabilities, allocations of emergency funds for rent abatement, moratoriums on evictions and foreclosures, and attention to substandard housing conditions that prevent program participants from safely sheltering in place. Local, state, and federal governments must allocate funding to increase affordable and accessible housing. Permanent housing opportunities for people with disabilities should also be increased during the COVID-19 pandemic. Notably, five homeless people with disabilities sued the City of San Diego for not providing appropriate housing during the pandemic.<sup>187</sup> Specifically, the lawsuit alleged the city forced homeless people with disabilities into a congregate setting rather than use hotel and motel rooms designated for high-risk homeless people.<sup>188</sup> Under federal disability rights laws, shelters must provide reasonable modifications to people with disabilities.

The COVID-19 pandemic has highlighted the risks of congregate and institutional settings for those with and without disabilities, for example, jails, prisons, nursing homes, psychiatric hospitals, and group homes.<sup>189</sup> The 1999 United States Supreme Court decision, *Olmstead v. L.C. ex rel. Zimring*,<sup>190</sup> requires states to eliminate unnecessary segregation of people with disabilities and mandates that people with disabilities obtain services

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186. *The Built Environment Assessment Tool Manual*, CTRS. FOR DISEASE CONTROL & PREVENTION (2019), <https://www.cdc.gov/nccdphp/dnpao/state-local-programs/built-environment-assessment/index.htm> [<https://perma.cc/H836-ZZ7F>].

187. Second Amended Verified Petition for Writ of Mandate and Complaint for Declaratory and Injunctive Relief, *Price v. City of San Diego*, No. 37-2020-00019535-CU-MC-CTL (Cal. Super. Ct. Dec. 17, 2020).

188. *Id.*

189. Gabrielle Coppola & Edvard Pettersson, *Most Likely to Be Infected: The Faithful, the Jailed or the Old*, BLOOMBERG L. (Apr. 11, 2020), <https://news.bloomberglaw.com/health-law-and-business/most-likely-to-be-infected-the-faithful-the-jailed-or-the-old> [<https://perma.cc/C7AC-2L5N>].

190. 527 U.S. 581 (1999).

in the most integrated setting appropriate to their individual needs.<sup>191</sup> Still, too many disabled people remain institutionalized. An estimated 800,000 people across the country who wish to receive home-based care and services through Medicaid are on waitlists.<sup>192</sup> States should immediately utilize Medicaid waiver authorities to expand home- and community-based services and supports to prevent the need for nursing home placements.<sup>193</sup>

Future federal COVID-19 relief legislation must include added funding to support home- and community-based services and supports to enable people to transition out of congregate and institutional settings. Tellingly, of the two trillion dollars<sup>194</sup> appropriated in the CARES Act, fewer than one billion dollars were distributed to the states to support older adults and people with disabilities.<sup>195</sup> Notably, the HEROES Act, which passed in the House but not the Senate, includes Medicaid funding to expand home- and community-based services to keep people with disabilities in their homes and out of congregate and institutional settings where they are more susceptible to COVID-19.<sup>196</sup>

Additionally, throughout the COVID-19 pandemic, local, state, and federal governments, together with disability service providers, should ensure that people with disabilities who rely on caregivers, whether in congregate and institutional settings or the community, are provided personal protective equipment for both them and their caregivers.

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191. *Id.* at 597.

192. *Medicaid Enrollment by Race/Ethnicity*, KAISER FAM. FOUND., <https://www.kff.org/medicaid/state-indicator/medicaid-enrollment-by-raceethnicity/> [<https://perma.cc/4JYU-P96U>].

193. MaryBeth Musumeci, *How Are States Supporting Medicaid Home and Community-Based Services During the COVID-19 Crisis?*, KAISER FAM. FOUND. (May 5, 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/E6T9-BCXC>] (analyzing how states have expanded home- and community-based services and supports during COVID-19).

194. Andrew Taylor, Alan Fram, Laurie Kellman & Darlene Superville, *Trump Signs \$2.2T Stimulus After Swift Congressional Votes*, ASSOCIATED PRESS (Mar. 27, 2020), <https://apnews.com/2099a53bb8adf2def7ee7329ea322f9d> [<https://perma.cc/S994-NSQJ>].

195. Press Release, U.S. Dep't of Health & Hum. Servs., *HHS Announces Nearly \$1 Billion in CARES Act Grants to Support Older Adults and People with Disabilities in the Community During the COVID-19 Emergency* (Apr. 1, 2020), <https://www.hhs.gov/about/news/2020/04/21/hhs-announces-nearly-1-billion-cares-act-grants-support-older-adults-people-with-disabilities-community-during-covid-19-emergency.html> [<https://perma.cc/CJ4D-3BRU>].

196. Fins & Bagenstos, *supra* note 117 (“The Democratic House version of the HEROES Act now being debated in the Senate has done much better. It includes significant funds to assist people with disabilities during the pandemic, earmarking \$10 billion to \$15 billion to pay for home and community based services for the next year. This Medicaid funding can help keep people with disabilities in their homes and out of congregate and institutional settings where they are especially vulnerable to COVID-19.”).

Similarly, workers who provide in-home support should receive additional wages, which may assist with the increasing shortage of caregivers.<sup>197</sup> Raising wages for caregivers and providing them with adequate personal protective equipment is especially important because two-thirds of in-home caregivers are women of color, another population being disproportionately harmed by the pandemic.<sup>198</sup>

Beyond the COVID-19 pandemic, laws and policies must be developed and implemented in a way that finally ends the segregation of people with disabilities and opens up a greater range of choices for disabled people who need long-term services and supports. Federal funding structures will need to be reformed so that disabled people control who cares for them and where they live. For example, Medicaid needs to eliminate the “institutional bias,” which leads to people with disabilities being unnecessarily institutionalized.<sup>199</sup> DOJ must also increase its *Olmstead* enforcement.<sup>200</sup> Likewise, the housing “crisis,” which has left people with disabilities “priced out” of appropriate and accessible housing, should be addressed.<sup>201</sup> Local and state governments must implement policies that expand housing options for people with disabilities, and the U.S. Department of Housing and Urban Development (HUD) must increase its enforcement of disability-based housing discrimination. Additional housing vouchers for people with disabilities are also critical to ensuring people with disabilities have access to affordable and accessible housing.

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197. Bob Woods, *Home Health-Care Workers in US at Tipping Point amid Coronavirus Outbreak*, CNBC (Apr. 14, 2020), <https://www.cnbc.com/2020/04/14/home-health-care-workers-at-tipping-point-amid-coronavirus-outbreak.html> [<https://perma.cc/X949-W6HV>] (“The coronavirus crisis is putting additional stress on a workforce that was already facing shortages due to the aging of America.”).

198. Benfer et al., *Health Justice Strategies to Combat the Pandemic*, *supra* note 24, at 166 (citing research about caregivers and how they are being harmed during the COVID-19 pandemic).

199. Erica L. Reaves & MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer*, KAISER FAM. FOUND. (Dec. 15, 2015), <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/> [<https://perma.cc/W4TN-G7X3>] (“Within the Medicaid program, there has been a historical structural bias toward institutional care. States are required to cover nursing facility benefits, while coverage of most [home and community-based services] is optional. As a result, Medicaid [home and community-based services] spending patterns vary among states, with states spending between 21 percent and 78 percent of their total Medicaid LTSS dollars on [home and community-based services] in 2013.”).

200. *Department of Justice Celebrates 20th Anniversary of the Olmstead Supreme Court Decision Protecting the Rights of Americans with Disabilities*, U.S. DEP’T OF JUST.: JUST. BLOGS (June 19, 2019), <https://www.justice.gov/opa/blog/departement-justice-celebrates-20th-anniversary-olmstead-supreme-court-decision-protecting> [<https://perma.cc/FR3H-LD6R>] (ensuring the benefits of *Olmstead* are enjoyed by people with disabilities, DOJ “has addressed the unnecessary segregation of people with physical, mental health, or intellectual and developmental disabilities . . . in various residential and non-residential settings, nationwide”).

201. SCHAACK ET AL., *supra* note 88.

#### D. *Economic Stability Should Be Achieved*

Law and policy responses must also address economic stability, a critical social determinant of health. People with disabilities experience strikingly high poverty rates<sup>202</sup> and food insecurity,<sup>203</sup> which detrimentally affects their health outcomes. To address disparities relating to poverty and employment, significant legal and policy reforms are needed.

Legal and policy responses should address the high unemployment rates among people with disabilities during the COVID-19 pandemic.<sup>204</sup> For example, the U.S. Equal Employment Opportunity Commission (EEOC) should continue to issue guidance for employees and employers about how federal disability rights laws, such as Title I of the ADA, apply during the COVID-19 pandemic.<sup>205</sup> The EEOC should also increase enforcement of ADA violations in the employment context because disabled employees are increasingly reporting discrimination as businesses reopen. For instance, some employers deny people with underlying medical conditions the opportunity to work from home as a reasonable accommodation.<sup>206</sup> Companies should ensure that employees are receiving reasonable accommodations, as required by law. Moreover, some people who had COVID-19 may qualify as disabled and be legally entitled to reasonable accommodations.<sup>207</sup> States should also implement policies that encourage employers to allow all employees to work remotely where possible, irrespective of disability, throughout the

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202. Brucker et al., *supra* note 86, at 273.

203. Brucker & Coleman-Jensen, *supra* note 87, at 109.

204. *See supra* section I.C (discussing unemployment among disabled people during the COVID-19 pandemic).

205. *What You Should Know About COVID-19 and the ADA, the Rehabilitation Act, and Other EEO Laws*, U.S. EQUAL EMP. OPPORTUNITY COMM'N (Dec. 16, 2020), <https://www.eeoc.gov/wysk/what-you-should-know-about-covid-19-and-ada-rehabilitation-act-and-other-eeo-laws> [<https://perma.cc/R8DZ-UQAL>] (providing guidance on the ADA and Rehabilitation Act).

206. Ellerbeck, *supra* note 126.

207. *See Silver v. City of Alexandria*, 470 F. Supp. 3d 616, 621–22 (W.D. La. 2020) (finding that plaintiff's cardiovascular condition in the context of a COVID-19 environment established both a disability and a need for an accommodation); *Busby v. Bonner*, 466 F. Supp. 3d 821, 830–831, 833–34 (W.D. Tenn. 2020) (finding that people vulnerable to COVID-19 are individuals with disabilities under federal law); *Fraihat v. U.S. Immigr. & Customs Enf't*, 445 F. Supp. 3d 709, 736–741, 736 n.21 (C.D. Cal. 2020) (certifying class, granting injunctive relief, and finding that that people with the following medical conditions posing COVID-19 risks are likely people with disabilities under the Rehabilitation Act: cardiovascular disease (congestive heart failure, history of myocardial infarction, history of cardiac surgery); high blood pressure; chronic respiratory disease (asthma, chronic obstructive pulmonary disease including chronic bronchitis or emphysema, or other pulmonary diseases); diabetes; cancer; liver disease; kidney disease; autoimmune diseases (psoriasis, rheumatoid arthritis, systemic lupus erythematosus); severe psychiatric illness; and history of transplantation).

pandemic. Federal, state, and local governments should also consider ways to aid businesses in providing reasonable accommodations to its employees.

Local, state, and federal responses should also ensure that COVID-19 economic stimulus relief funding includes disabled people. Notably, the CARES Act, which provided economic stimulus monies for individuals, initially excluded people with disabilities who receive Supplemental Security Income (SSI).<sup>208</sup> Indeed, it was only after the disability community's advocacy that the federal government clarified that SSI beneficiaries could receive stimulus and that it would not be considered income for purposes of their eligibility to receive SSI.<sup>209</sup> Future COVID-19 relief legislation that includes economic stimulus should explicitly include people who receive SSI or Social Security Disability Insurance (SSDI).

Beyond the COVID-19 pandemic, legal and policy responses must more broadly address economic disparities that have endured for disabled people. For example, efforts to address the low employment rates among people with disabilities are warranted and should include greater enforcement of disability-based discrimination by the EEOC and more funding for vocational rehabilitation. Businesses should reconsider opportunities for disabled people to work from home even after the pandemic. Indeed, the COVID-19 pandemic has demonstrated that working from home is possible and something people with disabilities believe can increase employment opportunities.<sup>210</sup> Similarly, the EEOC should consider issuing guidance that urges employers to allow employees to work remotely as a reasonable accommodation.

Benefits programs that disincentivize working must also be

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208. Initial legislation excluded SSI beneficiaries. See *The Senate Stimulus Proposal in Response to Coronavirus Fails to Meet the Moment*, CTR. FOR AM. PROGRESS (Mar. 20, 2020, 3:50 PM), <https://www.americanprogress.org/issues/economy/news/2020/03/20/482079/senate-stimulus-proposal-response-coronavirus-fails-meet-moment/> [<https://perma.cc/VPA3-FAWS>]. Eventually, SSI beneficiaries were deemed eligible to receive an economic stimulus check. See Andrew Saul, *Supplemental Security Income Recipients Will Receive Automatic COVID-19 Economic Impact Payments*, SOC. SEC. ADMIN. BLOG (Apr. 15, 2020), <https://blog.ssa.gov/supplemental-security-income-recipients-will-receive-automatic-covid-19-economic-impact-payments/> [<https://perma.cc/MRH8-ZBDH>].

209. SSI benefits decrease based on “earned” and “unearned” income. See *Understanding Supplemental Security Income (SSI)—2020 Edition*, SOC. SEC. ADMIN., <https://www.ssa.gov/ssi/text-income-ussi.htm> [<https://perma.cc/8NTX-C45R>].

210. Zoë Beery, *When the World Shut Down, They Saw It Open*, N.Y. TIMES (Aug. 24, 2020), <https://www.nytimes.com/2020/08/24/style/disability-accessibility-coronavirus.html> [<https://perma.cc/WE4Y-UGWX>] (“Still, many hope that some of these accommodations can outlast the pandemic and make way for a hybrid model where physical and virtual access are universal.”).



reformed.<sup>211</sup> For example, people with disabilities must be able to work while keeping Medicaid benefits. Specifically, Medicaid is the only health insurer that funds home- and community-based services and supports for disabled people.<sup>212</sup> Nonetheless, some disabled people are forced to choose between working and receiving necessary services and supports because of Medicaid's income limits. Hence, the federal government should expand Medicaid eligibility so people with disabilities can work and still receive benefits. Relatedly, government benefits programs, such as SSI, must update their asset limits and increase monthly benefit amounts so that people with disabilities are not forced to live in poverty.<sup>213</sup> In other words, systems need to be reformed so that poverty is not an inherent consequence of having a disability.

#### *E. Education Must Be Accessible*

Educational attainment is strongly linked to health and wellbeing.<sup>214</sup> Nonetheless, people with disabilities experience persistent educational inequities, which the COVID-19 pandemic has exacerbated. Notably, while Congress committed to pay 40% of the additional costs of special education when they passed the Individuals with Disabilities Education Act (IDEA) forty-five years ago, the federal government has never come close to that pledge, currently covering about only 15% of the expenses.<sup>215</sup> To respond to COVID-19 related inequities, immediate legal and policy responses should ensure that students with disabilities receive appropriate and accessible educations throughout the pandemic. Moreover, broader

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211. Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 32 (2004) (“[P]ublic health insurance programs themselves impose serious impediments to the participation of people with disabilities in the labor force.”); *see also* See GOV'T ACCOUNTABILITY OFF., MODERNIZING FEDERAL DISABILITY POLICY 1 (2007), <http://www.gao.gov/new.items/d07934sp.pdf> [<https://perma.cc/D7Y7-AVYK>] (noting low rates of return to work for individuals with disabilities receiving cash and medical benefits); U.S. GEN. ACCT. OFF., SSA DISABILITY: PROGRAM REDESIGN NECESSARY TO ENCOURAGE RETURN TO WORK 39–47 (1996), <http://www.gao.gov/archive/1996/he96062.pdf> [<https://perma.cc/K48B-599A>] (noting that the benefit structure provides disincentives to low-wage work and impedes the return to work).

212. Reaves & Musumeci, *supra* note 199.

213. SSI beneficiaries are not allowed to have assets above \$2,000. *See Understanding Supplemental Security Income (SSI) Resources—2020 Edition*, SOC. SEC. ADMIN., <https://www.ssa.gov/ssi/text-resources-ussi.htm> [<https://perma.cc/BT23-S6GN>]. The monthly SSI benefit is \$783, totaling less than \$10,000 per year. *See* SOC. SEC. ADMIN., *supra* note 209.

214. Editorial, *Education: A Neglected Social Determinant of Health*, 5 LANCET PUB. HEALTH e361 (July 2020) (“The evidence behind the importance of education as a determinant of health is amongst the most compelling.”).

215. *IDEA Full Funding: Why Should Congress Invest in Special Education?*, NAT'L CTR. FOR LEARNING DISABILITIES, <https://ncl.org/news/policy-and-advocacy/idea-full-funding-why-should-congress-invest-in-special-education/> [<https://perma.cc/US62-AYTW>].

legal and policy reforms to address the causes of long-lasting disparities are necessary.

Throughout the COVID-19 pandemic, legal professionals and policymakers must ensure that all students, including those with disabilities, receive a suitable education. It is becoming increasingly clear that primary, secondary, and post-secondary schools have trouble accommodating students with disabilities while teaching remotely. The U.S. Department of Education (ED) and DOJ should issue guidance for schools and universities on their legal obligations under the IDEA, section 504, and the ADA, as well as ways to follow the laws during the pandemic. For example, the federal government should issue guidance for schools and universities about how to ensure remote learning is accessible for disabled students. Moreover, future federal COVID-19 relief legislation should allocate additional funding to support schools in providing students with free and appropriate public educations during the pandemic.

Long-term, law and policy must also respond to the pervasive education disparities that disabled people experience. Unquestionably, special education must be fully funded—meaning Congress must live up to its promise of covering 40% of special education costs, a benchmark that has never been met.<sup>216</sup> ED, and DOJ, as appropriate, should also increase its enforcement of the IDEA, section 504, and the ADA in primary, secondary, and post-secondary schools. Students with disabilities must receive equitable educations, and all violations of federal disability rights laws must be addressed. Additionally, racial and ethnic disparities, which lead to significant inequities relating to students of color with disabilities having higher rates of discipline and contributing to the school-to-prison pipeline, must be addressed through the issuance of guidance by ED and greater enforcement by the federal agency.<sup>217</sup>

#### *F. Social and Community Context Injustices Should Be Eliminated*

Finally, law and policy efforts must address issues relating to the social and community context—i.e., civic participation, discrimination, and social cohesion—an essential social determinant of health.<sup>218</sup> Specifically, immediate legal and policy responses should address COVID-19 related inequities, while longer-term solutions need to focus on ensuring broad

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216. *Id.*

217. See generally NAT'L COUNCIL ON DISABILITY, BREAKING THE SCHOOL-TO-PRISON PIPELINE FOR STUDENTS WITH DISABILITIES (2015), <https://ncd.gov/publications/2015/06182015/> [<https://perma.cc/2UBU-KKLY>].

218. Off. of Disease Prevention & Health Promotion, *supra* note 18.

access to social and community life for people with disabilities. To that end, attention to how existing laws affect opportunities for community participation is warranted.

People with disabilities face several inequities relating to social and community context during the COVID-19 pandemic. Given that the pandemic occurred during an election year, barriers to voting for people with disabilities were especially concerning.<sup>219</sup> According to the American Association of People with Disabilities, “[w]hile many voters with disabilities regularly face accessibility barriers and other forms of voter suppression, COVID-19 has made voting even less accessible.”<sup>220</sup> Voting accessibility is an essential aspect of social and community context and warrants immediate attention by legal professionals and policymakers. Notably, in October 2020, the United States Supreme Court granted Alabama election officials’ request that allows Alabama to ban curbside voting, which the dissent believes violates the ADA and will “forc[e] voters with disabilities, for whom COVID-19 is disproportionately likely to be fatal, to risk unnecessary exposure to the virus if they wish to vote in person.”<sup>221</sup> To address voting inequities during the COVID-19 pandemic, local, state, and federal governments must take immediate action. For example, local and state governments should ensure that mail-in voting is accessible to people with disabilities.<sup>222</sup> The DOJ should also issue guidance for local and state governments about how the ADA and other federal laws apply to mail-in voting and what states must do to ensure all people with disabilities can vote privately and independently.

Legal and policy responses should also address other barriers to social and community context. As restaurants and other places of public accommodation reopen in outdoor settings, local and state governments should ensure that businesses remain in compliance with state and federal disability rights laws. For example, restaurants should not block sidewalks

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219. *See generally* AM. ASS’N OF PEOPLE WITH DISABILITIES, COVID-19 AND THE DISABILITY VOTE (2020), <https://www.aapd.com/wp-content/uploads/2020/09/COVID-19-and-the-Disability-Vote.pdf> [<https://perma.cc/HB8Q-6N8P>] (describing barriers to voting encountered by disabled people during the COVID-19 pandemic).

220. *Id.* at 1 (footnote omitted).

221. Order Granting Application for Stay, *Merrill v. People First of Ala.*, 592 U.S. \_\_\_, 141 S. Ct. 25 (2020) (No. 20A67), 2020 WL 6156545 (Sotomayor, J., dissenting).

222. For example, in Massachusetts, voters with disabilities can vote by mail using an Electronic Vote by Mail Ballot through an Accessible Vote by Mail System. *See Accessible Electronic Vote by Mail*, SEC’Y OF THE COMMONWEALTH OF MASS., <https://www.sec.state.ma.us/ele/elevv/early-voting-by-mail-accessible.htm> [<https://perma.cc/KZN9-9TLC>].

with tables and chairs.<sup>223</sup> The DOJ should also issue guidance about the ADA and section 504's requirements in COVID-19 related policies adopted by local and state governments as well as places of public accommodation. Moreover, the DOJ should issue guidance clarifying how federal disability rights laws apply to mask-wearing policies. Specifically, some people are inappropriately trying to use the ADA to justify not wearing a mask while other disabled people legitimately cannot wear a mask because of their disabilities.<sup>224</sup> Guidance could help alleviate some of these tensions. Furthermore, laws and policies must address transportation barriers, which have been further compounded during the COVID-19 pandemic, leading to even fewer options for disabled people.<sup>225</sup> For example, states must continue to provide accessible public transportation during the pandemic.

Long-term, legal professionals and policymakers must consider ways to address structural barriers that hinder people with disabilities' participation in the communities. For example, legal and policy solutions should improve civic engagement among disabled people, such as voting, volunteering, and participating in community activities.<sup>226</sup> Beyond the COVID-19 pandemic, the DOJ should prioritize voting accessibility, as studies continue to find that voting remains inaccessible for many people with disabilities.<sup>227</sup> Mail-in voting, which gained popularity during the 2020 election, may be an appropriate method for voting in the future, and

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223. Erika Mailman, *As Restaurants Take Over Sidewalks to Provide Pandemic-Safe Dining, People with Disabilities Encounter Barriers*, WASH. POST (Aug. 23, 2020, 6:00 AM), [https://www.washingtonpost.com/health/coronavirus-sidewalk-seating-disabilities-barriers/2020/08/21/02ede6b8-e24c-11ea-8181-606e603bb1c4\\_story.html](https://www.washingtonpost.com/health/coronavirus-sidewalk-seating-disabilities-barriers/2020/08/21/02ede6b8-e24c-11ea-8181-606e603bb1c4_story.html) [<https://perma.cc/NQ9T-5WD7>] (“Many restaurants have added sidewalk seating during the pandemic to take advantage of the open air . . . . Doing so, however, may put up barriers for people with disabilities and come into conflict with the Americans With Disabilities Act.”).

224. *See generally* Elizabeth Pendo, Robert Gatter & Seema Mohapatra, *Resolving Tensions Between Disability Rights Law and COVID-19 Mask Policies*, 80 MD. L. REV. ONLINE 1 (2020) (describing tensions concerning mask-wearing and federal disability rights laws).

225. Letter from the Consortium for Citizens with Disabilities to Elaine Chao, U.S. Sec’y of Transp., U.S. Dep’t of Transp. (Mar. 24, 2020), <http://www.c-c-d.org/fichiers/CCD-USDOT-COVID-Letter-032420-FINAL.pdf> [<https://perma.cc/LVH5-QPP9>].

226. Off. of Disease Prevention & Health Promotion, *Civic Participation*, HEALTHYPEOPLE.GOV, <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/civic-participation> [<https://perma.cc/5TN9-9MQL>] (identifying civic engagement as a critical component of the social and community context).

227. U.S. GOV’T ACCOUNTABILITY OFF., GAO-18-4, *VOTERS WITH DISABILITIES: OBSERVATIONS ON POLLING PLACE ACCESSIBILITY AND RELATED FEDERAL GUIDANCE* (2017), <https://www.gao.gov/assets/690/687556.pdf> [<https://perma.cc/VN8Z-DPMG>] (finding that 60% of polling places that were inspected had at least one access barrier); *see also* Matt Vasilogambros, *How Voters with Disabilities Are Blocked from the Ballot Box*, PEW CHARITABLE TRS. (Feb. 1, 2018), <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/02/01/how-voters-with-disabilities-are-blocked-from-the-ballot-box> [<https://perma.cc/8VBW-KZM6>].

policymakers should ensure that it is accessible for disabled people moving forward. Likewise, legal professionals and policymakers should address the voting inequities that people with disabilities who have guardians experience.<sup>228</sup>

Attention to expanding access to other aspects of the social and community context is also important beyond COVID-19 related inequities. For example, the DOJ should increase its investigations and enforcement of ADA violations by places of public accommodation, including website accessibility which remains a notable barrier for some disabled people.<sup>229</sup> Moreover, transportation inequities, which limit disabled people's ability to work and participate in their communities, need to be addressed. Specifically, "[p]ublic transportation provides many people with disabilities a lifeline to active participation in their communities. The ability to leave one's home to go to work, to visit friends, or to access critical services is fundamental to one's quality of life."<sup>230</sup> Despite Title II of the ADA, which mandates accessible public transportation, many public transit systems remain mostly inaccessible.<sup>231</sup> Transportation through ride-sharing (e.g., Uber and Lyft) is also unavailable to many people with disabilities, an issue that courts are currently considering.<sup>232</sup>

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228. Charles P. Sabatino, *Guardianship and the Right to Vote*, AM. BAR. ASS'N: HUM. RTS. MAG. (June 26, 2020), [https://www.americanbar.org/groups/crsj/publications/human\\_rights\\_magazine\\_home/voting-in-2020/guardianship-and-the-right-to-vote/](https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/voting-in-2020/guardianship-and-the-right-to-vote/) [<https://perma.cc/K483-DS89>] ("Today under federal election law, there are only two groups that states may exclude from voting—felons and persons categorized in some way as having mental impairments. Restoring the right to vote to felons who have served their time has gained much-needed attention in recent years, but access to the polls by persons having mental impairments who are under guardianship is rarely seen as a priority inquiry. The inattention is inexcusable.").

229. See generally Elizabeth Sheerin, Note, *Inaccessible Websites Are Discriminating Against the Blind: Why Courts, Websites, and the Blind Are Looking to the Department of Justice for Guidance*, 92 ST. JOHN'S L. REV. 573 (2018) (describing website inaccessibility and calling on the DOJ for guidance).

230. Todd Bromberg, *Lessons Learned on the Paratransit Litigation Front: Equal Rights Center v. WMATA*, AM. BAR. ASS'N: HUM. RTS. MAG. (July 1, 2007), [https://www.americanbar.org/groups/crsj/publications/human\\_rights\\_magazine\\_home/human\\_rights\\_vol34\\_2007/summer2007/hr\\_summer07\\_brombe/](https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/human_rights_vol34_2007/summer2007/hr_summer07_brombe/) [<https://perma.cc/W2Q5-9BVD>].

231. See, e.g., Elyse Wanshel & Lena Jackson, *New York City's Public Transit Is a Nightmare for People with Disabilities*, HUFFPOST (Oct. 9, 2018, 4:00 PM), [https://www.huffpost.com/entry/new-york-public-transit-disabilities\\_n\\_5bae4cd1e4b09d41eba11f08](https://www.huffpost.com/entry/new-york-public-transit-disabilities_n_5bae4cd1e4b09d41eba11f08) [<https://perma.cc/76UJ-K83P>] ("Most subway stations [in New York City] lack elevators, ramps and visual and audible indicators that allow *everyone* to garner basic information, including schedule changes. Public buses, for instance, rarely announce the name of a stop, making it difficult for someone who is blind or has low vision to know where they are." (emphasis in original)).

232. Eric Westervelt, *Ride-Hailing Revolution Leaves Some People with Disabilities Behind*, NAT'L PUB. RADIO (Aug. 21, 2019, 7:27 AM), <https://www.npr.org/2019/08/21/753034337/ride-hailing-revolution-leaves-some-people-with-disabilities-behind> [<https://perma.cc/AN4V-TLZF>] (radio interview with disability rights advocates describing problems using ride-sharing).

### G. Summary

This Part called for legal and policy responses to address the many inequities people with disabilities encounter during the COVID-19 pandemic and beyond. In particular, this Part identified legal and policy implications that address health and health care, neighborhood and build environment, economic stability, education, and social and community context. Increased enforcement of and compliance with existing federal disability rights laws is crucial. Policymakers must also reform systems and allocate additional funds to address disparities. Moreover, people with disabilities must be directly engaged in the development and implementation of laws and policies. Finally, increased litigation may be necessary to enforce existing legal protections. Thus, expanded access to legal services for people with disabilities should be considered. To that end, Congress should allocate additional funding for the protection and advocacy (P&A) system, which provides free legal services to people with disabilities in a range of issues.<sup>233</sup>

## CONCLUSION

The COVID-19 pandemic has wreaked havoc on the lives of millions of people, both in the United States and across the globe. For socially marginalized populations, including people with disabilities, the virus has been particularly devastating, exposing longstanding and pervasive health and social inequities. As such, legal professionals, policymakers, and scholars should undertake a comprehensive examination of the inequalities that people with disabilities experience and how law and policy affect such disparities. This Article, therefore, builds on, incorporates, and extends the existing scholarship about COVID-19 and disabled people by positioning it within the health justice framework and proposing normative legal and policy solutions to address deeply entrenched inequities that affect people with disabilities during the COVID-19 pandemic and beyond.

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233. Gary P. Gross, *Protection and Advocacy System Standing—To Vindicate the Rights of Persons with Disabilities*, 22 MENTAL & PHYSICAL DISABILITY L. REP. 674, 674–76 (1998).

