

# **“I’m Tired of Waiting”: Diagnosing Accessibility Issues and Inequality for Patients with Disabilities Within the American Healthcare System**

HALEY MOSS\*

I. INTRODUCTION.....	1012
II. THE DISABILITY RIGHTS MOVEMENT’S EFFECT ON ACCESS TO CARE .....	1016
A. <i>Primer on Disability Rights Litigation and Legislation</i>	1017
B. <i>The Rise of Nursing Homes and Long-Term Care Facilities</i> 1026	
III. THE STATE OF COMMUNICATION IN DISABLED HEALTHCARE...	1027
A. <i>Effective Communication Between Physicians and         Disabled Individuals.....</i>	1030
B. <i>Virtual Visitation and the Rise of Telehealth.....</i>	1033
IV. THE IMPACT OF IMPLICIT HEALTH CARE BIASES ON DISABLED PEOPLE .....	1034
A. <i>More Disabled Than You? The Roots of the “Disability         Hierarchy” .....</i>	1035
B. <i>Physicians’ Role in Enforcing the Disability Hierarchy</i> 1037	
V. COMPLIANCE AND EMPOWERING DISABLED PATIENTS .....	1040
A. <i>The Hidden Costs of Inaccessibility: Life, Vulnerability,         and Capitalist Criticism.....</i>	1040

---

\* J.D., University of Miami School of Law, 2018; B.S. & B.A., University of Florida, 2015. A thank you to my family for always believing in me. Access to health care is a disability issue, and I am proud of the many advocates who fight for health justice daily in terms of legislation, policy, who we elect, and more. We should not have to keep waiting to be seen within the healthcare system.

B. <i>Doctors Need More Training to Address Disability Bias in Medicine</i> .....	1041
C. <i>“Nothing About Us Without Us” Includes Our Say</i> .....	1043
1. Re-Evaluating “Meaningful Access” to Include Access to Communication .....	1043
2. Self-Determination Through Alternatives to Guardianship .....	1045
VI. CONCLUSION .....	1046

## I. INTRODUCTION

“Don’t tell him about the number of medications you have to take in a day. Don’t tell him about the specialist it took five months of drifting on the waitlist to see.”<sup>1</sup> Lillie Lainoff wrote these words as part of a fictional short story about telling someone about having a disability. However, the intricacies of medical care are some of the quiet truths that patients with disabilities know all too well. I know this all too well, as I am an autistic person who has had to decide whether to disclose to a physician or ask them to clearly detail what they are doing to eliminate any anticipatory anxiety related to sudden changes in course of treatment or examination.<sup>2</sup> These intricacies include the difficulties in the accessibility of the appointment (either physically or cognitively), finding qualified specialists or physicians along with the right course of treatment once there, and the general confusion even nondisabled people face in navigating health care in America. Ultimately, much of the difficulty comes down to communication. Being able to exchange crucial health information with a physician, friend, family member, or romantic partner effectively is no small feat.

---

1. Lillie Lainoff, *How to Tell that Guy You’ve Been Dating, Your Boyfriend, or Your Friend (Whom You’re Actually in Love with) You Have a Disability*, L.A. REV. (2019), <http://losangelesreview.org/tell-guy-youve-dating-boyfriend-friend-youre-actually-love-disability-lillie-lainoff/>.

2. I have one particular memory of a physician’s assistant noting in my chart that my autism, which is a life-long neurodevelopmental disability, was something I had in childhood. Note that rather than saying “patients with autism,” I chose to use identity-first language to respect the wishes of autistic people, including how I describe myself as an autistic woman. See *Identity First Language*, ASAN, <https://autisticadvocacy.org/about-asan/identity-first-language/> (last visited May 12, 2021).

In fact, all disability-related care focuses on communication, to some degree. It is not always simple to find access and understanding within the confines of a hospital or doctor's office, especially if your disability is marked by communication challenges.<sup>3</sup> Frequently, the disability itself is not what brings patients to the physician, though it could affect how a person experiences other symptoms and ailments. As an autistic person, my autism is not what brings me to my annual physical examination, though I might disclose it to make sure the physician's assistant and doctor will communicate more clearly with me. Furthermore, I might avoid disclosure to ensure the attending physician continues to view me as an adult patient rather than a perpetual child with a developmental disability, as may happen considering the condition is commonly associated with childhood.

The legal definition of disability is fairly broad. Under the Americans with Disabilities Act of 1990 ("ADA"), a qualified individual with a disability is someone who has "a physical or mental impairment that substantially limits one or more major life activities . . . has a record of such an impairment, or [is] regarded as having such an impairment."<sup>4</sup> The Center for Disease Control ("CDC") recognizes six of the most common disability categories: mobility, cognition, hearing, vision, independent living (difficulty doing errands alone), and self-care (difficulty dressing or bathing).<sup>5</sup> As used in this Article, "disability" will refer to persons whose impairments fall within one or more of these categories. The disabled population is far from a small group of marginalized people. Nearly one in four Americans has a disability, or about sixty-one million people.<sup>6</sup> Politically, disability comprises an

---

3. This is seen through interventions like speech or occupational therapy, daily needs like personal care assistance, routine medical appointments like annual physicals and gynecological examinations, psychiatric services, or an acute medical emergency.

4. 42 U.S.C. § 12102.

5. CDC: *1 in 4 US Adults Live with a Disability*, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 16, 2018, 1:00 PM), <https://www.cdc.gov/media/releases/2018/p0816-disability.html>.

6. Estimates of who might be an individual with a disability might be higher when factoring in Americans with, what the healthcare system and insurance companies label as, pre-existing conditions: diagnoses ranging from life-threatening illnesses like cancer to chronic conditions like diabetes, asthma, or heart disease. Because the legal definition of a disability is so broad, nearly all pre-existing medical conditions could be considered forms of disability. When using the standard of pre-

active voting bloc; previously unheard calls for equality and full inclusion are now hallmarks<sup>7</sup> of political platforms.<sup>8</sup> In fact, disability is the world's largest minority group in existence<sup>9</sup> and the only minority group that may be joined throughout life due to a change in circumstances.<sup>10</sup> Disability is also intersectional across sex, gender, race, and age; according to the CDC, one in four women has a disability, two in five non-Hispanic, indigenous or Alaska Natives have a disability, and two in five people over the age of 65 are disabled.<sup>11</sup>

And this large, heterogenous group of people with disabilities encounters numerous barriers to accessing health care.<sup>12</sup> Those barriers

---

existing conditions to measure who in America is disabled, the number swings between sixty-one million and one hundred thirty-three million Americans. *See id.*; *see also* Ashley Welch, *1 in 4 U.S. Adults Has a Disability, CDC Says*, CBS NEWS (Aug. 16 2018, 1:31 PM), <https://www.cbsnews.com/news/1-in-4-u-s-adults-has-a-disability-cdc-says/>.

7. *See* Haley Moss, Opinion, *Which 2020 Democratic Candidates Are Taking Disability Rights Seriously?*, TEEN VOGUE (Jan. 13, 2020), <https://www.teen-vogue.com/story/2020-democrats-disability-rights> (“Disability issues affect a significant number of voters . . . . If candidates lack robust disability policies or ignore disabled voters like me, they’re missing an opportunity to be an inclusive candidate for all Americans”).

8. Sara Luterman, *Biden’s Disability Policy Plan Is Surprisingly Good*, THE NATION (June 1, 2020), <https://www.thenation.com/article/politics/biden-disability-policy-plan/>; *see also* Philip Pauli, *Joe Biden Bet Big on Disability Issues and Won*, RESPECTABILITY REP. (Nov. 7, 2020), <https://therespectabilityreport.org/2020/11/07/joe-biden-disability-won/>.

9. UNITED NATIONS, FACT SHEET ON PERSONS WITH DISABILITIES 1, <https://www.un.org/disabilities/documents/toolaction/pwdfs.pdf>.

10. Joseph Coates, *Facing Facts: The Minority Group Everyone Can Join*, BALTIMORE SUN (Aug. 1, 1993), <https://www.baltimoresun.com/news/bs-xpm-1993-08-01-1993213105-story.html>.

11. *Disability Impacts All of Us*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.

12. Jessica L. Roberts, *Health Law as Disability Rights Law*, 97 MINN. L. REV. 1963, 1965 (2013).

include lower average incomes,<sup>13</sup> disproportionate poverty,<sup>14</sup> insurance coverage issues and inaccessible medical equipment.<sup>15</sup> Waiting lists for home and community-based services can last for years, effectively denying people support and necessary home health care.<sup>16</sup> The risk assessment and cost-sharing practices of the private health insurance industry frequently render people with disabilities uninsured or underinsured, presuming they do not qualify for social security programs like Supplemental Security Income or Social Security Disability Insurance,<sup>17</sup> disparities that the Patient Protection and Affordable Care Act (“ACA”) aims to address. In addition, Medicaid and Medicare often fail to cover needed health services and medical equipment.<sup>18</sup> These barriers might explain some of the large inequities in accessibility in health care for adults with disabilities; one in three disabled adults between ages eighteen and forty-four report that they do not have a usual health care provider, one in four report that they have not had a routine checkup in the past year, and one in three have had an unmet health care need in the past year due to costs.<sup>19</sup>

---

13. Income disparity is not a result of lack of education or laziness. In fact, disparities in average salaries are larger for disabled individuals with terminal, graduate degrees. See MICHELLE YIN ET AL., AM. INSTS. FOR RSCH., *LEADING THE WAY, OR FALLING BEHIND? WHAT THE DATA TELL US ABOUT DISABILITY PAY EQUITY AND OPPORTUNITY IN BOSTON AND OTHER TOP METROPOLITAN AREAS 1* (2020), [https://rudermanfoundation.org/white\\_papers/leading-the-way-or-falling-behind-what-the-data-tell-us-about-disability-pay-equity-and-opportunity-in-boston-and-other-top-metropolitan-areas/](https://rudermanfoundation.org/white_papers/leading-the-way-or-falling-behind-what-the-data-tell-us-about-disability-pay-equity-and-opportunity-in-boston-and-other-top-metropolitan-areas/).

14. Pam Fessler, *Why Disability and Poverty Still Go Hand in Hand 25 Years After Landmark Law*, NPR (July 23, 2015, 3:38 PM), <https://www.npr.org/sections/health-shots/2015/07/23/424990474/why-disability-and-poverty-still-go-hand-in-hand-25-years-after-landmark-law>.

15. 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, 16–17 (2008).

16. See, e.g., Sean Coffey, *Day 5: Wait Lists in Medicaid*, FAM. CAREGIVER ALL. (Nov. 5, 2001), <https://www.caregiver.org/news/day-5-wait-lists-medicaid/> (citing that at the time, Medicaid waivers for people with intellectual and developmental disabilities had an average wait time of thirty-five months while people on aged and disabled wait lists had an average wait time of six months to receive home and community-based services).

17. See Roberts, *supra* note 12.

18. *Id.*

19. *Disability Impacts All of Us*, *supra* note 11.

Patients with disabilities also experience difficulties with long waiting lists to see specialists; not being taken seriously at the intersections of race, disability, and gender; or being misdiagnosed. Further, people with disabilities must navigate the maze of health-related legislation even aside from managing symptoms and diagnoses. Most recently, issues have arisen when historic anomalies, such as the coronavirus (“COVID-19”) pandemic, worsen what is already a somewhat hostile health care environment.

This Article explores a few of the barriers to access that specifically affect disabled people when seeking medical care that is essential to their survival and offers solutions. This Introduction is Part I. Part II explains how the disability rights movement’s progress—from the passage of the Rehabilitation Act in 1973 to the ACA and corresponding disability initiatives like the self-advocacy movement—applies to the health care setting. It summarizes case law illustrating how the ADA and Section 504 of the Rehabilitation Act affect patients with disabilities seeking treatment, respect, and access in care environments of all kinds, ranging from a small-town doctor’s office to the largest metropolitan hospital system. Part III primarily focuses on meaningful access and effective communication. Part IV distinguishes the disproportionate impact that inaccessibility of care has on disabled patients, particularly in respect to marginalized persons with intellectual disabilities, mental health conditions, and physical disabilities. Part V argues that despite the issues of cost, accessibility, and compliance that alarm providers, accommodations must be made to ensure disabled patients receive sufficient care. This Part promotes self-advocacy but also notes that health care providers have a greater responsibility to ensure that (1) reasonable accommodations are granted to those who require them to understand and receive treatment and (2) disabled patients are empowered and maintain agency, rather than caregivers or those supporting the patient. In its concluding Part V, this Article offers further reflections on accessibility within healthcare for people with disabilities.

## II. THE DISABILITY RIGHTS MOVEMENT’S EFFECT ON ACCESS TO CARE

Part II delves into the effect the disability rights movement has had on access to care over the past fifty years. Section A discusses some of the achievements of the movement and why its success has been largely legislative rather than achieved through litigation. Section

B explains where both the litigation and legislation fall short at the state level, namely through restrictive guardianship statutes that impede on a disabled person's agency and ability to make health care decisions.

*A. Primer on Disability Rights Litigation and Legislation*

The disability rights movement mainly focuses on protections and advancements for the community through legislation rather than litigation.<sup>20</sup> Notably, one of the largest failures for civil rights protections for disabled individuals was sandwiched in between the landmark legislative victories of the passages of the Rehabilitation Act of 1973 and the ADA in 1990. In 1985, the Supreme Court declined to rule that people with intellectual disabilities were deserving of strict or even intermediate scrutiny under the Fourteenth Amendment in *City of Cleburne v. Cleburne Living Center, Inc.*<sup>21</sup>

In 1980, the respondent purchased a building in Cleburne, Texas to rent to Cleburne Living Center, Inc. to operate a group home for people with intellectual disabilities.<sup>22</sup> Cleburne Living Center applied for a special use permit required to operate the building as a group home but was denied.<sup>23</sup> The Center challenged this rejection, and the district court found that the city's decision was "was motivated primarily by the fact that the residents of the home would be persons who are mentally retarded."<sup>24</sup> The court determined that disability was neither a suspect nor quasi-suspect classification such that strict scrutiny was appropriate.<sup>25</sup> The Fifth Circuit Court of Appeals reversed, ruling that intellectual disability *is* a quasi-suspect class, while also noting strict scrutiny was not appropriate because intellectual disability was

---

20. Michael Waterstone, *Backlash, Courts, and Disability Rights*, 95 B.U. L. REV. 833, 833 (2015).

21. 473 U.S. 432, 435 (1985).

22. *Id.* at 435.

23. *Id.* at 436–37.

24. *Id.* at 437. The language of the case itself says "persons who are mentally retarded." Such language is outdated and offensive towards people with disabilities. Mental retardation and its variants were replaced with "intellectual disability" within federal law when Rosa's Law was signed in 2010. See Rosa's Law, 82 Fed. Reg. 31910-01 (July 11, 2017) (to be codified at C.F.R. pts. 104, 105, 222, 300, 361, 373, 385, 668, 674).

25. 473 U.S. at 437.

relevant to many legislative actions.<sup>26</sup> Nevertheless, the court noted that in light of the history of “unfair and often grotesque mistreatment” of people with intellectual disabilities, discrimination against them was “likely to reflect deep-seated prejudice.”<sup>27</sup> The Supreme Court reversed the Fifth Circuit’s determination that intellectual disability was a quasi-suspect class.<sup>28</sup> The Court held that strict scrutiny may only apply to discrimination on the basis of race, national origin, religion, and alienage.<sup>29</sup> As for intermediate scrutiny, it may be used for discrimination based on gender<sup>30</sup> and statutes that discriminate based on illegitimacy.<sup>31</sup>

In 1990, former President George H.W. Bush signed the ADA into law.<sup>32</sup> The ADA was designed “to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals [with disabilities].”<sup>33</sup> While the spirit of the ADA appears to invoke equal protection and perhaps heightened scrutiny, the *Cleburne* decision was reaffirmed after the ADA in the Court’s decision in *Board of Trustees of the University of Alabama v. Garrett* in 2001.<sup>34</sup> In *Garrett*, the Court held that people with disabilities were only entitled to rational basis review.<sup>35</sup> *Garrett* combined cases brought forth by two employees of the state of Alabama that alleged workplace discrimination under Title I of the ADA.<sup>36</sup> The Court barred

---

26. *Id.* at 438.

27. *Id.* (quoting *Cleburne Living Ctr. v. Cleburne*, 726 F. 2d 191, 197 (5th Cir. 1984)).

28. *Id.* at 442.

29. *Id.* at 440 (The classifications race, alienage, or national origin “are so seldom relevant to the achievement of any legitimate state interest that laws grounded in such considerations are deemed to reflect prejudice and antipathy . . . . These laws are subjected to strict scrutiny and will be sustained only if they are suitably tailored to serve a compelling state interest.”).

30. *See Craig v. Boren*, 429 U.S. 190 (1976).

31. *See Mathews v. Lucas*, 427 U.S. 495 (1976); *Trimble v. Gordon*, 430 U.S. 762 (1977).

32. President George H.W. Bush, Address at the Signing of the Americans with Disabilities Act of 1990 (July 26, 1990), [https://www.ada.gov/ghw\\_bush\\_ada\\_remarks.html](https://www.ada.gov/ghw_bush_ada_remarks.html).

33. 42 U.S.C. § 12101(a)(7).

34. 531 U.S. 356 (2001).

35. *Id.*

36. *Id.*



state employees from recovering damages from the state under the Eleventh Amendment for failure to comply with Title I of the ADA.<sup>37</sup> The Court held that rational basis review was appropriate when concerning disabled populations, referring back to the precedent set in *Cleburne*.<sup>38</sup> The Court most sternly advised that “if special accommodations for the disabled are to be required, they have to come from positive law and not through the Equal Protection Clause”<sup>39</sup>—explaining the trajectory of the disability rights movement.<sup>40</sup>

These cases make clear that the Supreme Court has not been a leader in advancing disability rights.<sup>41</sup> In fact, one of the only major court victories for disabled individuals in recent history is *Olmstead v. L.C.*<sup>42</sup> Two women with intellectual disabilities, Lois Curtis<sup>43</sup> and Elaine Wilson,<sup>44</sup> who both cycled in and out of state-run institutional care facilities in Georgia, brought forth the *Olmstead* case.<sup>45</sup> The two wanted to receive treatment within the community rather than institutions; their doctors agreed this was possible with appropriate support.<sup>46</sup>

In *Olmstead*, the Supreme Court held that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions when a three-prong test is met: (1) the person’s treatment professionals determine that

---

37. *Id.* at 360.

38. *Id.* at 366–68.

39. *Id.* at 368.

40. Waterstone, *supra* note 20.

41. *Id.*

42. 527 U.S. 581 (1999).

43. See Lauren Appelbaum, *Lois Curtis: Woman with Disabilities Fights for Freedom for All*, RESPECTABILITY (Mar. 15, 2019), <https://www.respectability.org/2019/03/women-disabilities-lois-curtis/> (elaborating on the inequities faced by Black disabled women such as Lois Curtis); see also *Olmstead*, 527 U.S. at 593 (noting Curtis has schizophrenia in addition to an intellectual disability).

44. See *Elaine Wilson’s Story, Continued*, OLMSTEAD RTS., [https://www.olmsteadrights.org/iamolmstead/history/item.5405-Elaine\\_Wilsons\\_Story\\_Continued](https://www.olmsteadrights.org/iamolmstead/history/item.5405-Elaine_Wilsons_Story_Continued) (last visited May 12, 2021) (elaborating that Elaine Wilson spent time within thirty-six institutions and also had profound intellectual disability and a desire to rejoin the community).

45. 527 U.S. at 593; see also *Brief History of Olmstead*, OLMSTEAD RTS., <https://www.olmsteadrights.org/about-olmstead/#Brief%20History%20of%20Olmstead> (last visited May 12, 2021).

46. *Brief History of Olmstead*, *supra* note 45.

community support is appropriate; (2) the person does not object to living in the community; and (3) the provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities.<sup>47</sup> *Olmstead* protects the rights of people with disabilities who are living in healthcare facilities such as nursing homes, psychiatric facilities, and institutions, ensuring that the choice to receive services in an institutional setting is not made because they have no access otherwise.<sup>48</sup>

While *Olmstead* enshrines the right to participate in the community and receive services, this victory cannot be discussed without mention of the other aspects of state disability law that make it so individuals with disabilities are not the ones in charge of the services they receive or how they are delivered. Specifically, state law generally governs guardianship, or the process by which the court appoints a third party to make decisions for a person with a disability.<sup>49</sup> Guardianship nullifies a lot of the rights won in *Olmstead* and could be viewed as discriminatory under Title II of the ADA.<sup>50</sup> It is most commonly appointed for young adults with intellectual disabilities and older adults with dementia.<sup>51</sup> People typically are placed under guardianship following mental health crises (like the well-known case of Britney Spears),<sup>52</sup> when facing terminal illnesses, or when they have a profound intellectual disability.<sup>53</sup> A person under guardianship cannot make his

---

47. 527 U.S. at 587.

48. *Olmstead v. LC: History and Current Status*, OLMSTEAD RTS., <https://www.olmsteadrights.org/about-olmstead/> (last visited May 12, 2021).

49. Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN. ST. L. REV. 1111, 1116 (2013).

50. Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 196–97 (2010).

51. *Olmstead v. LC: History and Current Status*, *supra* note 48.

52. See Sara Luterman, *Free Comrade Britney!*, THE NATION (Mar. 31, 2020), <https://www.thenation.com/article/society/britney-spears-conservatorship/>; Sara Luterman, *The Darker Story Just Outside the Lens of Framing Britney Spears*, THE NEW REPUBLIC (Feb. 12, 2021), <https://newrepublic.com/article/161344/framing-britney-spears-review-disability-legal>.

53. Luterman, *supra* note 52.

or her own choices about medical care.<sup>54</sup> In fact, those under guardianship may not be able to make even non-medical decisions, such as choices about what they eat, who they spend time with, whether they marry,<sup>55</sup> or whether they vote.<sup>56</sup> Guardianship can also push people with disabilities back into institutions.<sup>57</sup> Several states are aware of the severity of guardianship and propose alternate models to preserve the ability to self-advocate and for individuals with disabilities to make decisions related to their care and everyday lives.

This backdrop of litigation explains why the disability rights movement has been primarily statutory. Though it has not led to many victories in court, it has resulted in legislation such as the Rehabilitation Act of 1973, the ADA, the Individuals with Disabilities Education Act, and the Fair Housing Amendments Act, among others.<sup>58</sup> The most impactful legislative enactments to result from the modern disability rights movement were the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Some also consider the ACA as not just healthcare legislation but also civil rights legislation and thus include it in this group.<sup>59</sup>

This trio of statutes aims to combat discrimination against people with disabilities in the health system, recognizing the disparate impact of inaccessible care within both the public and private systems. While the Civil Rights Act of 1964 prohibited discrimination on the basis of race, religion, gender, or nationality, disability was left out as a protected class.<sup>60</sup> However, disabled activists did not take the same mainstream, public approach as the civil rights movement. Instead, the

---

54. *Supported Decision Making & The Problems of Guardianship*, AM. CIV. LIBERTIES UNION, [aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making](https://aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making) (last visited May 12, 2021).

55. *Id.*

56. Charles P. Sabatino, *Guardianship and the Right to Vote*, 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/).

57. *Id.*

58. Waterstone, *supra* note 20.

59. Roberts, *supra* note 12.

60. Robert D. Dinerstein, *The Americans with Disabilities Act of 1990: Progeny of the Civil Rights Act of 1964*, HUM. RTS. MAG. (July 1, 2004), [https://www.americanbar.org/groups/crsj/publications/human\\_rights\\_magazine\\_home/human\\_rights\\_vol31\\_2004/summer2004/irr\\_hr\\_summer04\\_disable/](https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/human_rights_vol31_2004/summer2004/irr_hr_summer04_disable/).

disability rights movement's approach was to avoid political and public backlash as to achieve bipartisan legislation.<sup>61</sup>

The Rehabilitation Act of 1973 is the first specific piece of disability rights legislation to protect people with disabilities from discrimination and unequal treatment.<sup>62</sup> It expanded the philosophy of Title IX and Title VI of the Civil Rights Act, which prohibited federal support of programs that discriminated on the basis of gender and race, respectively.<sup>63</sup> Section 504 of the Rehabilitation Act provides that “[n]o otherwise qualified individual with a disability in the United States . . . shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.”<sup>64</sup> Federal financial assistance covers a large swath of health care providers in both the public and private sectors.<sup>65</sup> Particularly, public hospitals that are “owned, maintained and operated by a governmental unit, such as a municipality, or county, and supported by governmental funds”<sup>66</sup> often provide care to those who are impacted by a lack of quality health care services in urban and suburban areas, primarily serving people who have low income, are uninsured, or are covered by Medicaid.<sup>67</sup>

---

61. Waterstone, *supra* note 20, at 840–42.

62. 29 U.S.C. § 701.

63. Laura Rothstein, *Forty Years of Disability Policy in Legal Education and the Legal Profession: What Has Changed and What Are the New Issues?*, 22 AM. U. J. GENDER SOC. POL'Y & L. 519, 526–27 (2014).

64. 29 U.S.C. § 794.

65. See e.g., *The ADA and Health Care Providers*, NORTHEAST ADA CTR., <https://northeastada.org/resource/the-ada-and-health-care-providers> (last visited May 12, 2021); see also *Health Care Providers and Section 504 of the Rehabilitation Act*, NORTHEAST ADA CTR., <https://northeastada.org/resource/health-care-providers-and-section-504-of-the-rehabilitation-act> (last visited May 12, 2021); *Medicaid Healthcare Accessibility for People with Disabilities*, DISABILITY RTS. EDUC. & DEF. FUND, <https://dredf.org/public-policy/health-access-to-care-old/medicaid-healthcare-accessibility-for-people-with-disabilities/> (describing that Medicaid and 504 apply to state Medicaid agencies and private health maintenance organizations) (last visited May 12, 2021).

66. *Shulman v. Wash. Hosp. Ctr.*, 222 F. Supp 59, 61 (D.D.C. 1963).

67. Taressa Frazee et al., *Public Hospitals in the United States, 2008: Statistical Brief #95*, in HEALTHCARE COST AND UTILIZATION PROJECT (HCUP) STATISTICAL

Oftentimes, those patients and users are people with disabilities and include veterans with service-related disabilities<sup>68</sup> who receive care from public Veterans Health Administration services.<sup>69</sup>

Under the Rehabilitation Act, hospitals, clinics, and other healthcare agencies that accept Medicaid funds, Medicare funds, or any other form of federal funding must ensure equal access to programs and services.<sup>70</sup> The Rehabilitation Act laid the groundwork for the greatest achievement of the civil rights legislation geared towards people with disabilities: the signing of the ADA.

The ADA, modeled after the Civil Rights Act of 1964, brings about the necessary protections for people with disabilities in private and public life, regardless of federal funding.<sup>71</sup> The ADA is divided into five titles, dealing with issues from (1) employment, (2) state and local governments, (3) public accommodations, (4) telecommunications, and (5) a miscellaneous catch-all provision.<sup>72</sup>

Congress intended that the ADA must continue to address discrimination facing people with disabilities in the critical area of health services.<sup>73</sup> This goal was achieved primarily through Titles II and III, which primarily apply to health care settings.<sup>74</sup> Title II of the ADA

---

BRIEFS 1, 1 (2010) (explaining how as of 2008, 1,131 public hospitals represent 21.9 percent of all hospitals nationwide).

68. *Employment Situation of Veterans – 2020*, BUREAU LAB. STATS. (Mar. 18, 2020), <https://www.bls.gov/news.release/pdf/vet.pdf>; see also *How Common Is PTSD in Veterans?*, U.S. DEP'T VETERANS AFFS., [https://www.ptsd.va.gov/understand/common/common\\_veterans.asp](https://www.ptsd.va.gov/understand/common/common_veterans.asp) (last visited May 12, 2021).

69. The VHA serves nine million enrolled veterans each year. Twenty-five percent of all veterans have a service-related disability, and veterans face increasing rates of post-traumatic stress disorder following combat situations and military sexual trauma. See *About VHA*, U.S. DEP'T VETERANS AFFS., <https://www.va.gov/health/aboutvha.asp> (last visited May 12, 2021).

70. 29 U.S.C. § 794(b)(3)(A)(ii).

71. See 42 U.S.C. § 12132; 42 U.S.C. § 12182(a).

72. 42 U.S.C. § 12131.

73. 42 U.S.C. § 12101(a)(3).

74. See *Lovell v. Chandler*, 303 F.3d 1039 (9th Cir. 2002); see also *Tennessee v. Lane*, 541 U.S. 509, 536 (2004) (Ginsburg, J., concurring) (“[I]ncluding individuals with disabilities . . . sometimes require[s] not blindfolded equality, but responsiveness to difference; not indifference, but accommodation.”); *ADA Q&A: Health Care Providers*, PACER, <https://www.pacer.org/transition/learning-center/laws/ada/health-care-providers.asp#:~:text=Title%20III%20applies%20to%20all,is%20covered%20by%20the%20ADA.> (last

ensures equal access and opportunity to participate in services and programs administered by public entities and state and local government services, including state and local public health programs, services, and activities.<sup>75</sup> Title II extends the Rehabilitation Act's nondiscrimination requirement to all public entities, including state and local public health programs, services, and activities, regardless of whether or not they receive federal funding.<sup>76</sup> Under Title II, these services must be physically and cognitively accessible, meet specific building standards, and entities are required to provide reasonable accommodations. Title III of the ADA regulates nondiscrimination and accessibility for public accommodations and commercial facilities, prohibits private places from discriminating against people with disabilities, and sets standards for accessibility at facilities and businesses.<sup>77</sup> Title III applies to private hospitals and private health care providers.<sup>78</sup>

Aware of the often-conflicting court interpretations of the ADA and Rehabilitation Act, Congress and the executive branch passed wider legislative protections and corrected Supreme Court decisions on who qualifies as disabled. One such amendment was the ADA Amendments Act of 2008. The ADA Amendments Act "emphasizes that the definition of disability should be construed in favor of broad coverage of individuals to the maximum extent permitted by the terms of the ADA and generally shall not require extensive analysis."<sup>79</sup>

Further, the ACA, also known as Obamacare and the principle legislative achievement of former President Barack Obama's time in office, can also be considered a massive civil rights victory for patients with disabilities. According to Rebecca Cokley, who previously

---

visited May 12, 2021) ("Hospitals and other health care facilities that are operated by state or local governments are covered by Title II of the ADA. Private hospitals, nursing homes, psychiatric and psychological services, offices of private physicians, dentists and health clinics are among the health care providers covered by the Title III of the ADA.").

75. 42 U.S.C. § 12131(1).

76. Pendo, *supra* note 15, at 30; *see also* 42 U.S.C. §§ 12131–12134; U.S. DEP'T OF JUST., THE AMERICAN WITH DISABILITIES ACT TITLE II TECHNICAL ASSISTANCE MANUAL § II-1.2000 PUBLIC ENTITY (1994), [www.ada.gov/taman2.html](http://www.ada.gov/taman2.html).

77. 42 U.S.C. § 12182(a).

78. *ADA Q&A: Health Care Providers*, *supra* note 74.

79. *The Americans with Disabilities Act Amendments Act of 2008*, U.S. EQUAL EMP. OPPORTUNITY COMM'N, <https://www.eeoc.gov/statutes/americans-disabilities-act-amendments-act-2008> (last visited May 12, 2021).

worked in the Obama administration, the ACA “was a game-changer for the disability community and was in some ways comparable to the ADA in terms of the impact the law had on peoples’ lives. [M]uch of the law’s importance has centered on its anti-discrimination protections for people with preexisting conditions—which do have a significant effect on people with disabilities and chronic health conditions.”<sup>80</sup>

People with disabilities historically face difficulties surrounding Medicaid and Medicare, as well as obtaining private insurance coverage. Medicaid was expanded under the legislation; poverty and Medicaid services are both common within the disability community for reasons that are outside the scope of this Article. To break down inequalities disabled people face in receiving private coverage if they do not qualify for Medicaid, the ACA prohibits health insurance companies from charging more or denying coverage to people with pre-existing conditions, or health issues that existed prior to the start of the new insurance coverage defined to include disabilities.<sup>81</sup>

The ACA builds on its predecessors, Section 504 and the ADA, in disability law and policy with civil rights protection for disabled people. Section 1557 of the ACA ensures that an individual is not excluded from participating in, denied benefits because of, or subjected to discrimination as prohibited under Section 504 of the Rehabilitation Act of 1973.<sup>82</sup> That way, patients do not face discrimination under any health program or activity, any part of which is receiving federal financial assistance, or under any program or activity that is administered by an executive agency or any entity established under Title I of the ACA or its amendments.<sup>83</sup>

---

80. Rebecca Cokley, *Repealing the ACA Would Create Chaos for the Disability Community During a Pandemic*, CTR. FOR AM. PROGRESS (Oct. 9, 2020 9:20 AM), <https://www.americanprogress.org/issues/disability/news/2020/10/09/491428/repealing-aca-create-chaos-disability-community-pandemic/>.

81. 45 C.F.R. § 147.108 (2015).

82. *Discrimination on the Basis of Disability*, U.S. DEP’T HEALTH & HUM. SERVS., <https://www.hhs.gov/civil-rights/for-individuals/disability/index.html> (last visited May 12, 2021).

83. *Id.*

B. *The Rise of Nursing Homes and Long-Term Care Facilities*

While health care providers are required to be accessible under federal disability rights laws and the *Olmstead* decision enshrines the rights of people to partake in their communities and receive services outside of institutions, one problem remains: institutions continue to exist, albeit not in the form of publicly run mental health facilities. Some long-term care facilities and providers are owned by nonprofits and government actors, contributing to the idea of nursing homes as modern institutional care.<sup>84</sup>

“No person should have to live in a nursing home or other institution . . . unnecessary institutionalization of individuals with disabilities is discrimination under the [ADA]. If I were disabled I would want this choice—and so would you.”<sup>85</sup> These words were written by former Secretary of Health and Human Services Donna Shalala following the *Olmstead* decision.<sup>86</sup> *Olmstead* provides people with disabilities with the freedom to live in their own homes and receive treatment in the community, if it is the individual’s wish and is a reasonable accommodation, in accordance with their treatment plan. However, many still do not have the freedom to live on their own or with assistance absent a nursing or residential care facility.<sup>87</sup>

Even though *Olmstead* reinforces the proposition that disabled individuals cannot be involuntarily placed in nursing facilities, that decision nonetheless is made for individuals with disabilities when they cannot meet all three prongs of the *Olmstead* test.<sup>88</sup> While long-term care facilities and nursing homes claim to be the best care settings and assist with disability-related challenges, they give rise to additional

---

84. See Muriel R. Gillick, *The Evolution of the Nursing Home*, AM. SCIENTIST, <https://www.americanscientist.org/article/the-evolution-of-the-nursing-home> (last visited May 12, 2021).

85. *Enforcing the Olmstead Decision*, CTR. FOR AN ACCESSIBLE SOC’Y, [http://www.accessiblesociety.org/topics/persasst/Olmstead\\_shalala.htm](http://www.accessiblesociety.org/topics/persasst/Olmstead_shalala.htm) (last visited May 12, 2021).

86. *Id.*

87. See *Nursing Home Care*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/nchs/fastats/nursing-home-care.htm> (last visited May 12, 2021). (citing 1.3 million nursing home residents as of 2015, scattered across 15,600 nursing homes).

88. Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid’s History*, 26 GA. ST. U.L. REV. 937, 943–44 (2010).



disparities in the healthcare system by their very nature. Infections and additional complications spread through these care settings like wild-fire; eighty-two percent of nursing homes between 2013 and 2017 had citations for failure to adequately prevent or control the spread of infection and about forty-eight percent had multiple citations.<sup>89</sup> The congregate care setting, while intentioned initially to provide welfare and benefit for people to receive home care, ultimately became a source of warehousing, abuse, and neglect of the medical needs of disabled Americans.

### III. THE STATE OF COMMUNICATION IN DISABLED HEALTHCARE

Under the ADA and Section 504 of the Rehabilitation Act, people with disabilities are entitled to reasonable accommodations in settings such as hospitals and doctors' offices.<sup>90</sup> For some patients, these accommodations are absolutely necessary to understanding their treatments or otherwise effectively communicating with their providers. But the Supreme Court has not set a standard that sufficiently addresses the variation in these needs.

In its decision in *Alexander v. Choate*, the Supreme Court held that the mandate of Section 504 is met when people with disabilities are provided "meaningful access" when they receive evenhanded treatment and have the opportunity to participate in and benefit from programs receiving federal assistance.<sup>91</sup> When Tennessee predicted a \$40 million shortfall in its Medicaid budget in 1980, the program reduced the yearly number of inpatient hospital days for Medicaid patients from 20 days to 14 days.<sup>92</sup> Medicaid patients challenged this reduction as

---

89. Letter from John E. Dicken, Director of Health Care, U.S. Gov't Acct. Off., to The Hon. Ron Wyden, U.S. Senate, *Infection Control Deficiencies Were Widespread and Persistent in Nursing Homes Prior to COVID-19 Pandemic* (May 20, 2020), <https://www.gao.gov/assets/710/707069.pdf>.

90. *Access to Medical Care for Individuals with Mobility Disabilities*, [https://www.ada.gov/medicare\\_mobility\\_ta/medicare\\_ta.htm](https://www.ada.gov/medicare_mobility_ta/medicare_ta.htm) (last visited May 12, 2021) ("Private hospitals or medical offices are covered by Title III of the ADA as places of public accommodation. Public hospitals and clinics and medical offices operated by state and local governments are covered by Title II of the ADA as programs of the public entities. Section 504 covers any of these that receive federal financial assistance, which can include Medicare and Medicaid reimbursements").

91. 469 U.S. 287, 301, 304 (1985).

92. *Id.* at 289.

discrimination against disabled patients under Section 504 of the Rehabilitation Act.<sup>93</sup> The district court found the 14-day limitation was not the type of discrimination that Section 504 was designed to protect against;<sup>94</sup> the Sixth Circuit reversed, holding any annual limitation on inpatient coverage would disproportionately affect people with disabilities.<sup>95</sup> The Supreme Court held that the limitation was not discriminatory, and the state was not required to provide additional coverage than what nondisabled users would receive.<sup>96</sup> In essence, *Choate* does not “guarantee that each recipient will receive that level of health care precisely tailored to his or her particular needs,” effectively disadvantaging people with disabilities.<sup>97</sup>

Even if a person needed additional care, they would not have been able to receive it under the *Choate* decision because both disabled and nondisabled patients would be granted the same, equal access – not equitable access based on the level of a person’s needs or taking a universal design approach<sup>98</sup> that inherently creates a system that benefits all users and people could use what they need without additional modification. Instead, the Court says that the Rehabilitation Act considers substantive areas where “the societal and personal costs of refusals to provide meaningful access” were particularly high: employment, education, and the elimination of physical barriers to access.<sup>99</sup>

Today, the *Choate* decision is met with criticism especially in light of cost control measures relating to Medicaid following the passage of the ACA.<sup>100</sup> Over ten million Americans who are covered by Medicaid are eligible as people with disabilities.<sup>101</sup> Individuals with

---

93. *Id.*

94. *Id.*

95. *Id.*

96. *Id.* at 298, 303.

97. *Id.*

98. Universal design is defined as “the concept of designing all products and the built environment to be aesthetic and usable to the greatest extent possible by everyone.” WOLFGANG F.E. PREISER & KORYDON H. SMITH, UNIVERSAL DESIGN HANDBOOK (2d ed. 2001).

99. *Choate*, 469 U.S. at 307.

100. Leslie Pickering & Anita Silvers, *Reading Alexander v. Choate Rightly: Now Is the Time*, 6 LAWS 17 (2017).

101. *Id.*

disabilities particularly utilize Medicaid benefits because they are often more extensive than private insurance plans.<sup>102</sup>

Even outside of the Medicaid contexts, courts have interpreted *Choate*'s "meaningful access" standard to mandate widely disparate levels of accommodation depending on the circumstances.<sup>103</sup> In regards to health services, meaningful access has not been interpreted to mean that each facility must be accessible and usable by individuals with disabilities.<sup>104</sup> *Choate* focuses on physical access as intentionally discriminatory.<sup>105</sup> However, each service, program, or activity when viewed in its entirety must be readily accessible to and usable by individuals with disabilities.<sup>106</sup> *Choate* fails to account for the fact that ready access can be dependent on disabilities; in other words, this may only account for cognitive accessibility and not physical, or vice versa. Physical inaccessibility is viewed as facially discriminatory,<sup>107</sup> while patterns of exclusion, even if unintentional, may violate Section 504 by holding open the door to disparate impact litigation under Section 504 in health care and in other arenas.<sup>108</sup> Barriers to access differ depending by disability. Equal treatment and opportunity to participate for people with physical, mental, and intellectual impairments may vary wildly.<sup>109</sup> Capricious application of "meaningful access" across health care settings ignores what disability advocates refer to as "access needs"—

---

102. THE IMPACT OF THE AFFORDABLE CARE ACT ON PEOPLE WITH DISABILITIES: A 2015 STATUS REPORT, NAT'L COUNCIL ON DISABILITY 1, 36–39 (Jan. 16, 2016), [https://www.ncd.gov/sites/default/files/NCD\\_ACA\\_Report02\\_508.pdf](https://www.ncd.gov/sites/default/files/NCD_ACA_Report02_508.pdf).

103. Laurence Paradis, *Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act: Making Programs, Services, and Activities Accessible to All*, 14 STAN. L. & POL'Y REV. 389, 399 (2003) (explaining the variety of settings *Choate* has been applied to in addition to healthcare. *Choate* has been applied in cases relating to education and transportation as well).

104. *Id.*

105. 469 U.S. 287, 301, 307 (1985).

106. Pendo, *supra* note 15, at 31–32.

107. 469 U.S. at 307.

108. Leslie Pickering Francis & Anita Silvers, *Debilitating Alexander v. Choate: "Meaningful Access" To Healthcare for People with Disabilities*, 35 FORDHAM URB. L. J. 447, 449 (2008); *Choate*, 469 U.S. at 293–94.

109. See e.g., Lilah Burke, *Disability as Diversity*, INSIDE HIGHER EDUC. (Nov. 12, 2020), <https://www.insidehighered.com/news/2020/11/12/could-disability-be-further-included-diversity-efforts> ("The disabled community is not a monolith.").

what a person needs to communicate, learn, and take part in an activity.<sup>110</sup> A somewhat arbitrary standard ultimately signals that some access needs are worth meeting more than others, and that some people with disabilities will end up being denied meaningful access either cognitively or physically.

A. *Effective Communication Between Physicians and Disabled Individuals*

When considering meaningful access, it is worth recognizing the unique needs of each disability subculture and subcommunity. The need for accommodations is especially paramount for Deaf individuals in need of health care services. Deaf and hard-of-hearing people primarily use nonverbal communication, including lip reading,<sup>111</sup> hand gestures, and sign language.<sup>112</sup> Not all Deaf or hard-of-hearing people want or use cochlear implants, nor are all fully deaf.<sup>113</sup> Each individual has unique access needs. Federal law requires that health care providers offer appropriate auxiliary aids to hearing-impaired patients where necessary to ensure effective communication.<sup>114</sup> Failure to do so constitutes discrimination against disabled persons.<sup>115</sup>

Deaf rights in healthcare were cemented with the Eleventh Circuit Court of Appeals' decision in *Silva v. Baptist Health South Florida*. The plaintiffs, Cheylla Silva and John Paul Jebian, are profoundly

---

110. *Conflicting Access Needs*, PAC. ALL. ON DISABILITY SELF ADVOC., <https://pacific-alliance.org/wp-content/uploads/2016/10/PADSA-Resource-Guide-Conflicting-Access-Needs.pdf> (last visited May 12, 2021).

111. See Lydia Callis, *Lip Reading is No Simple Task*, HUFFPOST, [https://www.huffpost.com/entry/lip-reading-is-no-simple-task\\_b\\_9526300](https://www.huffpost.com/entry/lip-reading-is-no-simple-task_b_9526300) (Mar. 24, 2017).

112. Sophia Waterfield, *ASL Day 2019: Everything You Need to Know About American Sign Language*, NEWSWEEK (Apr. 15, 2019, 7:00 AM), <https://www.newsweek.com/asl-day-2019-american-sign-language-1394695>. While one million people today use American Sign Language ("ASL") as their primary language, most Deaf children are born to hearing parents who do not know ASL or sign at home.

113. See Amelia Cooper, *Hear Me Out: Hearing Each Other for the First Time: The Implications of Cochlear Implant Activation*, 116 MO. MED. 469, 470 (2019).

114. Salima Ali, *Providing Interpreters for Patients with Hearing Disabilities: ADA Requirements*, 9 INNOVATIONS CLINICAL NEUROSCIENCE 30, 30 (2012).

115. 856 F.3d 824, 829 (11th Cir. 2017).

deaf and primarily communicate using American Sign Language (“ASL”).<sup>116</sup> They presented several times at hospitals operated by the Baptist Health system.<sup>117</sup> To accommodate patients with hearing impairments, hospitals use auxiliary aids such as an interpreter or an assistive device to communicate.<sup>118</sup> Silva and Jebian requested live, in-person interpreters yet were often provided only with video remote interpreters.<sup>119</sup> The technology glitched and froze with unclear video feeds.<sup>120</sup> The hospital would instead ask family members to be the interpreter or for the plaintiffs to pass handwritten notes, effectively dismissing plaintiffs’ requests for assistance.<sup>121</sup>

The Eleventh Circuit overturned the district court’s decision that “effective communication,” a form of meaningful access, was to treat and diagnose medical conditions.<sup>122</sup> Rather, the appellate court followed in the tradition of the disability self-advocacy movement when determining what effective communication is.<sup>123</sup> Self-advocacy, as a personal and political philosophy, is a movement primarily of and by persons with disabilities who are making their own decisions and speaking for themselves and for others with disabilities.<sup>124</sup> To embody this spirit of independence and self-advocacy, the *Silva* court defined effective communication as participation in one’s own medical care and the focus should be on the quality of communication leading to a treatment.<sup>125</sup> For ASL users, access to high-quality, medically-sophisticated interpreters is absolutely necessary to ensure that individuals in the Deaf community properly understand their treatment options and care plans.

While *Silva* cemented and expanded the right to effective communication beyond a misinterpretation of successful medical intervention, the ways in which we express messages and elicit important health

---

116. *Id.*

117. *Id.*

118. *Id.*

119. *Id.* at 830–31.

120. *Id.* at 830.

121. *Id.*

122. *Id.* at 831.

123. *Id.* at 833.

124. *See Parallels in Time, Part One: The Self-Advocacy Movement 1980 –*, <https://mn.gov/mnddc/parallels/seven/7a/1.html> (last visited May 12, 2021).

125. *See* 856 F.3d at 833.

information can vary greatly depending upon the type and severity of disability. Additional Deaf rights cases expand on *Silva*, ensuring that meaningful access also includes companions.<sup>126</sup> Companions can be crucial for disability communication, providing interpretation services, emotional or physical support, or helping to ensure accessibility in some way.<sup>127</sup>

Regardless of how much support someone may need, being able to participate in one's own medical care may revolve around language and communication. However, for many disabled people, communication and speech difficulties are hallmarks of their conditions.<sup>128</sup> This is especially apparent in neurological, learning, intellectual, and developmental disabilities.<sup>129</sup> For instance, the very nature of autism, a neurodevelopmental disability, is known almost exclusively for differences in communication and social interaction.<sup>130</sup> People with speech or language disabilities may not communicate verbally and have difficulty talking.<sup>131</sup> Some may be augmentative and alternative communication ("AAC") users.<sup>132</sup> AAC users either do not use speech or cannot reliably speak out loud.<sup>133</sup> AAC can include the use of sign language,

---

126. *Bax v. Drs. Med. Ctr. of Modesto, Inc.*, 393 F. Supp. 3d 1000, 1018 (E.D. Cal. 2019).

127. *Id.*

128. See e.g., Martine Smith et al., *Communication Difficulties in Adults with Intellectual Disability: Results from a National Cross-Sectional Study*, 97 RSCH. DEVELOPMENTAL DISABILITIES (2020).

129. *Definitions of Communication Disorders and Variations*, AM. SPEECH-LANGUAGE-HEARING ASS'N, <https://www.asha.org/policy/rp1993-00208/> (last visited May 12, 2021).

130. See American Psychiatric Association, *Autism Spectrum Disorders* in *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS* (5th ed. 2013); *About Autism*, AUTISTIC SELF-ADVOC. NETWORK, <https://autisticadvocacy.org/about-asan/about-autism/> (last visited May 12, 2021).

131. *Augmentative and Alternative Communication (AAC)*, AM. SPEECH-LANGUAGE-HEARING ASS'N, <https://www.asha.org/public/speech/disorders/aac/> (last visited May 12, 2021).

132. See MaryAnn Ronski & Rose A. Sevcik, *Augmentative Communication and Early Intervention: Myths and Realities*, 18 INFANTS & YOUNG CHILD. 174 (2005); see also *id.*

133. *Augmentative and Alternative Communication*, *supra* note 131.

facial expressions, communication applications or devices, or a combination of methods.<sup>134</sup>

### B. *Virtual Visitation and the Rise of Telehealth*

For people with mobility impairments, doctors' offices are inaccessible along with the medical equipment often used for routine examinations.<sup>135</sup> Telehealth makes access easier for people with disabilities.<sup>136</sup> There is less reliance on outside transportation, competing for limited accessible parking spots, mental health concerns, or the assistance of caregivers and companions at appointments.<sup>137</sup>

The ADA still applies to telehealth, so providers may not skirt their responsibilities and compliance obligations.<sup>138</sup> The ADA protects the right of people with disabilities to access electronic information technology ("EIT").<sup>139</sup> The Health and Human Services' Office of Civil Rights guidance states that "covered entities must offer people with disabilities full and equal access to the EIT they employ, unless those individuals are provided reasonable accommodations or reasonable modifications that permit them to receive all the benefits provided by the EIT in an equally effective manner."<sup>140</sup> Further, Section 1557 of the ACA is interpreted to require "covered entities to ensure that health programs and services provided through EIT be accessible to individuals with disabilities unless doing so would result in undue financial and administrative burdens."<sup>141</sup> Section 508 of the

---

134. *Id.*

135. Margaret A. Nosek et al., *The Meaning of Health for Women with Physical Disabilities: A Qualitative Analysis*, 27 FAM. CMTY. HEALTH 6, 16 (2004).

136. Kimberly Noel & Brooke Ellison, *Inclusive Innovation in Telehealth*, 3 NPJ DIGIT. MED. 89 (2020); Daniel Young & Elizabeth Edwards, *Telehealth and Disability: Challenges and Opportunities for Care*, NAT'L HEALTH L. PROGRAM (May 6, 2020), <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

137. Young & Edwards, *supra* note 136.

138. *Telehealth*, ADMIN. FOR CMTY. LIVING, <https://acl.gov/ada/telehealth> (last modified July 26, 2020).

139. *Id.*

140. *Id.*

141. Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,376, 31,426 (May 18, 2016) (to be codified at 48 C.F.R. pt. 92).

Rehabilitation Act has been the standard for websites and technology in federally funded programs and federal government entities.<sup>142</sup>

Telehealth, however, does not fix or address the issues associated with inaccessible medical equipment or exams. Thus, the need for reform and greater accessibility in-person is still necessary. Telehealth providers and methods both need to rise to provide adequate accessibility and appropriately meet each individual patient's needs.<sup>143</sup>

#### IV. THE IMPACT OF IMPLICIT HEALTH CARE BIASES ON DISABLED PEOPLE

Perhaps more alarming than the legal maze people with disabilities must navigate through to have accessible health care is how these disparities affect different groups of people with disabilities. When factoring in other aspects of identity, such as gender, sexual orientation, and race, the picture remains grim as to who has access to care. Members of minority racial and ethnic groups with disabilities face further barriers to access: language barriers, quality interpretation services, a higher lack of cultural competence among health care providers, conscious and unconscious biases as well as stereotyping and discrimination.<sup>144</sup> Further, disabled people of color have an inherent distrust of physicians and health systems due to unethical treatment and institutionalized racism.<sup>145</sup> Women with disabilities, as well as disabled people who were assigned female at birth, have additional health needs such as gynecological care and report these services are inaccessible due to the exam tables and equipment utilized.<sup>146</sup> These biases are at full effect for Angel Miles, a Black woman who is a wheelchair user,

---

142. 29 U.S.C. § 794(d).

143. Young & Edwards, *supra* note 136.

144. Jana J. Peterson-Besse et al., *Barriers to Health Care Among People with Disabilities Who are Members of Underserved Racial/Ethnic Groups: A Scoping Review of the Literature*, 52 *MED. CARE* S51, S52 (2014).

145. *Id.*

146. Pendo, *supra* note 15.



has a Ph.D., and is a health policy analyst.<sup>147</sup> “I’m often ignored,” she says.<sup>148</sup> “I’m often spoken at, and not to.”<sup>149</sup>

While this is more profound for intersectionally marginalized disabled people, disability bias, both implicit and explicit, in healthcare affects all people with disabilities with major health and wellness consequences, even ending in premature, unwarranted death.<sup>150</sup> Implicit bias refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner.<sup>151</sup> Explicit biases are conscious where a person is clear about their feelings or attitudes, and their actions reflect them.<sup>152</sup> Disability bias can be both implicit and explicit for medical professionals and has grave consequences for disabled people navigating the healthcare system.

#### A. *More Disabled Than You? The Roots of the “Disability Hierarchy”*

An unspoken truth of disability community and who is seen as more or less disabled comes down to the presence of a disability hierarchy or a system that values people with specific disabilities more so than others.<sup>153</sup> Disability hierarchies are based on the idea that some impairments are “worse” than others and are therefore stigmatized.<sup>154</sup> Under this social construct, certain kinds of disabilities are more

147. Joseph Shapiro, *People with Disabilities Fear Pandemic Will Worsen Medical Biases*, NPR (Apr. 15, 2020), <https://www.npr.org/2020/04/15/828906002/people-with-disabilities-fear-pandemic-will-worsen-medical-biases>.

148. *Id.*

149. *Id.*

150. *Assisted Suicide Kills People with Disabilities*, CTR. FOR DISABILITY RTS., <https://cdrnys.org/assisted-suicide/> (last visited May 12, 2021); Shapiro, *supra* note 147.

151. *Understanding Implicit Bias*, PERCEPTION INST., <http://kirwaninstitute.osu.edu/research/understanding-implicit-bias/> (last visited May 12, 2021).

152. *Conscious and Unconscious Bias in Health Care*, NAT’L CTR. FOR CULTURAL COMPETENCE AT GEO. UNIV., <https://nccc.georgetown.edu/bias/module-3/1.php> (last visited May 12, 2021).

153. See Mark Deal, *Disabled People’s Attitudes Towards Other Impairment Groups: A Hierarchy of Impairments*, 18 *DISABILITY & SOC’Y* 897 (2003).

154. Rachel Stewart, *The “Really Disabled”: Disability Hierarchy in John Hockenberry’s Moving Violations*, 1 *REV. OF DISABILITY STUDS.* 1,1 (2014).

acceptable than others.<sup>155</sup> Historically, physical disabilities were seen as the bottom of the ladder, with “ugly laws” on the books to get poor and disabled people out of the public view.<sup>156</sup> Today, people with physical disabilities may be at the top of the ladder because their experiences are more readily visible: the performance collective Sins Invalid notes that the disability rights movement historically centers the experiences of those with mobility impairments, often ignoring and marginalizing people with other types of impairments and disabilities.<sup>157</sup>

All disability hierarchies are rooted in ableism.<sup>158</sup> “Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be ‘fixed’ in one form or the other.”<sup>159</sup> Ableism, after all, feeds upon the medical model of disability and the pre-existing biases that the medical profession has towards disability.<sup>160</sup> The medical profession often views disability almost solely as a form of impairment and problem to be fixed. Disabled and chronically ill patients may view disability as a part of their identity that can also be exacerbated by access barriers. This social view of disability can be conflicting given the medical profession’s role being to help alleviate barriers and improve quality of life.<sup>161</sup> Quality-of-life improvements are not the same as making a patient into a nondisabled

---

155. Kim Sauder, *Fighting My Internalization of the Hierarchy of Disability*, CRIPPLEDSCHOLAR (Aug. 23, 2015), <https://crippledscholar.com/2015/08/23/fighting-my-internalization-of-the-hierarchy-of-disability/>.

156. See generally SUSAN M. SCHWEIK, *THE UGLY LAWS: DISABILITY IN PUBLIC* (2009).

157. SKIN, TOOTH, AND BONE: THE BASIS OF MOVEMENT IS OUR PEOPLE, A DISABILITY JUSTICE PRIMER 11 (2016).

158. *The Problem with the Disability Hierarchy*, INCLUDE NYC (July 26, 2017), <https://www.includenyc.org/content/perspectives-the-problem-with-the-disability-hierarchy>

159. Leah Smith, #Ableism, CTR. DISABILITY RTS., <http://cdrnys.org/blog/uncategorized/ableism/> (last visited May 12, 2021).

160. See Eric Shyman, *The Reinforcement of Ableism: Normality, the Medical Model of Disability, and Humanism in Applied Behavior Analysis in ASD*, 54 INTEL. & DEVELOPMENTAL DISABILITIES 366, 368 (2016).

161. See generally *Medical Futility and Disability Bias*, NAT’L COUNCIL ON DISABILITY (2019), [https://ncd.gov/sites/default/files/NCD\\_Medical\\_Futility\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf).

person, especially if the disability is a life-long condition the person was born with, or a later onset chronic illness.<sup>162</sup>

Disability hierarchy and ableism reinforce and hinge upon the medical model of disability, insisting that disability is an undesirable quality, something to be fixed and cured. While this view may be dominant amongst physicians, the reinforcement of the medical model can lead to disparate treatment, with physicians and medical personnel deeming some disabled people “worthier” of intervention than others. A person with a disability, like any other person, should not have to prove that they are “worthy” of their lives or how they will contribute to society in order to receive life-saving or life-sustaining care.<sup>163</sup>

### B. Physicians’ Role in Enforcing the Disability Hierarchy

The disability hierarchy is primarily perpetuated by nondisabled people, especially physicians and medical staff.<sup>164</sup> It spirals throughout rationing care, embodies the debate of physician assisted suicide and also deters disabled people from receiving medical care.<sup>165</sup> The biases lead to a mistrust and misunderstanding between what disabled patients want and what their health care providers think is best for them. Doctors think their patients are worse off than they actually are,<sup>166</sup> thus suggesting end-of-life options that nondisabled people may not receive, or denying preventative care or treatment altogether.

Medical bias towards people can lead to untreated conditions, emergencies, and cause additional pain and inaccessibility in everyday

162. See generally Afia Ali et al., *Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers*, 8 PLOS ONE 1 (2013); *The Current State of Health Care for People with Disabilities*, NAT’L COUNCIL ON DISABILITY (2009), <https://www.ncd.gov/publications/2009/Sept302009> (last visited May 12, 2021).

163. *Medical Futility and Disability Bias*, *supra* note 161, at 18.

164. See *id.*; Sauder, *supra* note 155; Meriah Nichols, *Disability Hierarchy Is Real and It’s Holding Us Back* UNPACKING DISABILITY WITH MERIAH NICHOLS, (July 22, 2019), <https://www.meriahnichols.com/disability-hierarchy/>; Shapiro, *supra* note 147.

165. *The Current State of Health Care for People with Disabilities*, *supra* note 162 (“competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care”).

166. *Medical Futility and Disability Bias*, *supra* note 161, at 27.

life. Lex Friedan, a quadriplegic professor, landed in the emergency room following a broken hip.<sup>167</sup> He explained to *NPR*:

The doctor who was attending me said: “You’ve got a badly broken injured hip. We’ve also observed that you’re not walking.” And I said, “No sir, I broke my neck in 1967, and I haven’t walked since then.” And he said, “Well, we’re not going to repair the hip then.”<sup>168</sup>

The broken hip remained untreated, which led to years of extra pain and mobility issues.<sup>169</sup> Friedan’s story echoes what the National Council on Disability found in their study on disability bias and “medical futility,” that health care providers critically undervalue life with a disability where they deem treatment “futile” or “nonbeneficial” and oftentimes do so despite the contrary wishes of the patient.<sup>170</sup>

Underestimating quality of life happens often, especially for those viewed at the bottom of the disability hierarchies which are often people with intellectual disabilities and profound or life-altering mobility impairments.<sup>171</sup> Several studies have demonstrated that health care providers’ opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people.<sup>172</sup> For example, one study found that only seventeen percent of providers anticipated an average or better quality of life after a spinal cord injury compared to eighty-six percent of the actual spinal cord injury comparison group.<sup>173</sup> Even with this knowledge, researchers and physicians alike struggle when measuring quality of life for profound, intellectual, and multiple disabilities, citing that nonverbal communication or a perceived inability to express themselves is a barrier in

---

167. Shapiro, *supra* note 147.

168. *Id.*

169. *Id.*

170. *Medical Futility and Disability Bias, supra* note 161, at 27.

171. *Id.*

172. Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 GA. STATE U. L. REV. 893, 900–01 (2017).

173. Kenneth A. Gerhat, et al., *Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers*, 23 ANNALS OF EMERGENCY MED., 807, 807–12 (1994).

measuring.<sup>174</sup> Yet these studies fail to account for meaningful access and effective communication strategies, or AAC methods, further exacerbating the lack of quality of life. Physicians then try to measure quality of life based on emotional wellbeing and serious physical ailments, but in the cases of severe disability, might have been hesitant to comment.<sup>175</sup> These problems have been put on public display in the time of the COVID-19 pandemic. Public health workers in overcrowded hospitals have been forced to decide who gets access to limited life-saving equipment,<sup>176</sup> often having to choose between disabled people or seemingly healthy people.<sup>177</sup>

Overall, people with disabilities' perception of their quality of life reveals that physicians' measures of quality of life is inaccurate.<sup>178</sup> Disabled people have families, friends, jobs, hobbies, among other fulfillments.<sup>179</sup> Most report a high quality of life and level of happiness, especially when they have access to sufficient health care services and supports.<sup>180</sup> Disabled people, primarily those who have mobility impairments, physical differences, or use equipment such as home ventilators, are aware of the ways that physicians underestimate their quality of life.<sup>181</sup> Yet physicians' misperceptions have negatively influenced physicians' medical futility decisions, resulting in the withdrawal of necessary medical care from people with disabilities.<sup>182</sup>

---

174. See generally Appolonia M. Nieuwenhuijse et al., *Physicians' Perceptions on Quality of Life of Persons with Profound Intellectual and Multiple Disabilities: A Qualitative Study*, 45 J. INTEL. & DEVELOPMENTAL DISABILITIES 176 (2019).

175. *Id.*

176. Mike Baker & Sheri Fink, *At the Top of the COVID-19 Curve, How Do Hospitals Decide Who Gets Treatment?*, N.Y. TIMES (Mar. 31, 2020), <https://www.nytimes.com/2020/03/31/us/coronavirus-covid-triage-rationing-ventilators.html>.

177. *Id.*

178. Ron Amudson, *Quality of Life, Disability, and Hedonic Psychology*, 40 J. FOR THEORY OF SOC. BEHAV. 374 [pin cite needed] (2010); see also *id.*; Shapiro, *supra* note 147.

179. Baker, *supra* note 176.

180. *Medical Futility and Disability Bias*, *supra* note 161, at 10 (2019).

181. See Alice Wong, *I'm disabled and need a ventilator to live. Am I expendable during this pandemic?*, VOX (Apr. 4, 2020, 10:20 AM), <https://www.vox.com/first-person/2020/4/4/21204261/coronavirus-covid-19-disabled-people-disabilities-triage>; Shapiro, *supra* note 147 (“[Alice Wong] says people, including medical providers, see her and underestimate the quality of her life.”).

182. Wong, *supra* note 181.

## V. COMPLIANCE AND EMPOWERING DISABLED PATIENTS

The inaccessibility of the American healthcare system—from access barriers, legal mazes, communication difficulties and challenges, and thriving systemic ableism and medical bias—reinforces that there is “no end in sight” regarding healthcare hurdles for people with disabilities. Yet, while the law may have failed at addressing every loophole, there is a way to go in reducing waitlists for specialists, Medicaid waivers for home and community-based services, and bridging gaps to access for public and private health providers. Eliminating bias is the most effective first step to be taken for physicians and non-lawyer health care workers.

*A. The Hidden Costs of Inaccessibility: Life, Vulnerability, and Capitalist Criticism*

Following the Supreme Court’s decision in *Choate* and the inconsistently-applied standards of meaningful access, courts have turned to the accessibility of doctors’ offices and access to services.<sup>183</sup> While the meaningful access standard continues to be capriciously applied, there are severe consequences to noncompliance and inaccessibility as discussed throughout this Article. Meaningful access should apply to all aspects of health care, rather than merely physical accessibility. Physicians have an obligation and swear a solemn oath to save lives and should uphold that no matter how disabled someone is. Health care providers instead could worry less about costs of care by providing the full spectrum of available choices for disabled patients, thus allowing them to make their own decisions to thrive and stay alive.

Instead of focusing on cost of accessibility, which has proven to have long-term costs including the ultimate price of life and further health complications, physicians must grant reasonable accommodations to those who require them in order to understand and receive treatment, ensuring that these patients truly have meaningful access to care. Granting reasonable accommodations to people with disabilities who require them to understand and receive treatment should not be viewed as unduly burdensome or too expensive. While this standard has come to be associated with the *avoidance* of accommodations in the

---

183. Francis & Silvers, *supra* note 108, at 470.

workplace under Title I of the ADA, a similar standard should be applied in health care settings. Under Title I, employers are required to make reasonable accommodations for disabled job applicants and employees unless there is an undue hardship. Undue hardship can be due to excessive financial costs or fundamentally altering the nature of the business.<sup>184</sup> The same should be true for disabled patients seeking medical care of any sort because it eliminates the chance element associated with meaningful access; cognitive and physical access to care should be more often than not be considered reasonable for those seeking treatment. Take Professor Lex Friedan, whose broken hip went untreated: the costs of fixing it later in life could be much greater financially, let alone the physical and emotional effects. Those costs would result in Friedan having to adapt all over again and suffer through unnecessary pain.<sup>185</sup> It would not be an undue burden to treat a broken hip, and the complications that come from ignoring it, such as more direct support workers, home- and community-based services, or physical therapy, may also become more costly financially. Under a standard of this sort, physicians would have no choice but to treat a patient with an emergency regardless of disability status, though Title II and Title III of the ADA alongside Section 504 of the Rehabilitation Act already speak to nondiscrimination.<sup>186</sup>

*B. Doctors Need More Training to Address Disability Bias in Medicine*

Diversity, equity, and inclusion conversations in the medical field should include greater disability awareness and training. The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care.<sup>187</sup> Health care providers currently do not have sufficient education or training in disability competency, specifically in areas of actual life experiences of people with a wide range of disabilities.<sup>188</sup>

---

184. See 42 U.S.C. § 12111(10); 29 C.F.R. § 1630.2(p) (1997).

185. Shapiro, *supra* note 147.

186. 42 U.S.C. § 12132; 42 U.S.C. § 12182(a); 29 U.S.C. § 701.

187. *The Current State of Health Care for People with Disabilities*, *supra* note 162.

188. *Medical Futility and Disability Bias*, *supra* note 161, at 10.

Due to the prevalence of disability, such trainings should be a part of diversity, equity, and inclusion initiatives in care settings or required to maintain active provider licenses. According to the National Council of Disability, “[d]isability 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.”<sup>189</sup>

Diversity and inclusion initiatives are increasing in a number of public and private organizations nationwide. Including disability in those trainings—especially within healthcare—helps create a more equitable patient experience. Patients should not be forced to continue to explain their disability to their physicians and try to combat those biases themselves when seeking care, especially if care is unrelated to the disability itself.

However, disability trainings and education need to go beyond simply preparing providers to see patients with disabilities. Diversity and inclusion focus should also include advocating for individuals with disabilities to enter the field themselves. Disability diversity within health care providers could also lead to greater empathy, reduced bias, and more understanding.<sup>190</sup> Doctors with disabilities make up a minority of providers, and ableism views medical workers as the pinnacle of health and able-bodiedness.<sup>191</sup> For disabled doctors, the most “able” physician of the 21st century is the one who can relate to all patients, whatever they are facing, and has the skills and creativity to give them the best care.<sup>192</sup> In the healthcare profession, disability should be

---

189. *The Current State of Health Care for People with Disabilities*, *supra* note 162.

190. Elana Gordon, *Doctors with Disabilities Push for Culture Change in Medicine*, NPR (Aug. 6, 2018, 5:38 PM), <https://www.npr.org/sections/health-shots/2018/08/06/635414552/doctors-with-disabilities-push-for-culture-change-in-medicine>.

191. *Id.*

192. *Id.*



viewed as a form of diversity among providers as well.<sup>193</sup> Hiring providers with disabilities should be of diversity and inclusion initiatives, rather than viewed as a sign of weakness or incompetence.

C. “Nothing About Us Without Us” Includes Our Say

Disability rights often focuses on the adage, “nothing about us without us.”<sup>194</sup> This has been a touchstone of self-determination and self-advocacy, where people with disabilities are able to speak for themselves and others, including making decisions that affect their lives.<sup>195</sup> Often, the decision-makers prove time and again to be parents, caregivers, and companions.<sup>196</sup>

1. Re-Evaluating “Meaningful Access” to Include Access to Communication

Rather than a capricious application of *Choate*, “meaningful access” should explicitly include communication alongside physical accessibility. Allowing and accommodating the use of AAC as a form of meaningful access under the ADA and Section 504 allows patients who are typically written off as incompetent, unable to understand, or advocate for themselves the opportunity to have their medical concerns heard and addressed.

Public and private entities alike should put communication first. Without the ability to communicate in a doctor-patient relationship, patients lack the autonomy to advocate for themselves, address their own medical needs, or even be aware of their own information. Simply

---

193. LISA M. MEEKS & LESLIE NEAL-BOYLAN, *DISABILITY AS DIVERSITY: A GUIDEBOOK FOR INCLUSION IN MEDICINE, NURSING, AND THE HEALTH PROFESSIONS* 1, 101 (2020).

194. See JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* 1, 3 (1998).

195. *The Self-Advocacy Movement 1980*, *supra* note 124, at 1.

196. See, e.g., Joseph Shapiro, *Teaching Parents of Kids with Disabilities to Fight Back*, NPR (June 29, 2018, 1:35 PM), <https://www.npr.org/2018/06/29/620337603/teaching-parents-of-kids-with-disabilities-to-fight-back>; see also Eric Garcia, *I’m Not Broken*, THE ATLANTIC (Dec. 4, 2015), <https://www.theatlantic.com/politics/archive/2015/12/im-not-broken/446550/> (“The question of who should speak for those with autism is a divisive one in the autism-advocacy community”).

punting to companions or ignoring health needs on the basis of disability is discriminatory. In the same way that utilizing remote video interpreters and handwritten notes in *Silva* was insufficient, stripping AAC users of the right to use those communication alternatives is not appropriate in a health care setting, especially when such populations frequently have additional health needs from their co-occurring conditions.<sup>197</sup>

For people with intellectual and developmental disabilities as well as cognitive disabilities, effective communication may come from utilizing technology or sharing critical information with patients in plain language.<sup>198</sup> However, this form of language simplicity benefits more than merely people with disabilities.<sup>199</sup> It is a form of cognitive equality and accessibility for marginalized populations, such as nonnative English speakers, immigrants, or those who lack medical sophistication or education.<sup>200</sup> Plain language scholar Sarah Luterman notes, “There are many reasons someone might not know the right words. Sometimes it’s because of a disability. Sometimes English is the person’s second language, and second languages are just harder. Sometimes, people don’t have equal access to education. Sometimes,

---

197. Co-occurring conditions for autistic people are plentiful, including mental health conditions, or gastrointestinal issues. See Elaine Y. Hsiao, *Gastrointestinal Issues in Autism Spectrum Disorders*, 22 HARV. REV. PSYCH. 104, 108 (2014), [https://journals.lww.com/hrpjournal/fulltext/2014/03000/gastrointestinal\\_issues\\_in\\_autism\\_spectrum.5.aspx](https://journals.lww.com/hrpjournal/fulltext/2014/03000/gastrointestinal_issues_in_autism_spectrum.5.aspx); see also Emily Simonoff, et al., *Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample*, 47 J. AM. ACAD. OF CHILD & ADOLESCENT PSYCHIATRY 921, 928 (Aug. 2008), <https://www.sciencedirect.com/science/article/abs/pii/S0890856708600593>.

198. See Andrew Pulrang, *Plain Language Writing – An Essential Part of Accessibility*, FORBES (Oct. 22, 2020, 03:52 PM), <https://www.forbes.com/sites/andrewpulrang/2020/10/22/plain-language-writing—an-essential-part-of-accessibility/?sh=14453e87935a>; Sue Stableford & Wendy Mettger, *Plain Language: A Strategic Response to the Health Literacy Challenge*, 28 J. OF PUBLIC HEALTH POL’Y 71, 75-77 (2007).

199. Stableford & Mettger, *supra* note 198 (explaining the benefits of plain language to increase health literacy for all populations); see generally Beth Marks et al., *Health Services, Health Promotion, and Health Literacy: Report from the State of the Science in Aging with Developmental Disabilities Conference*, 1 DISABILITY & HEALTH J. 136 (2008).

200. *Plain Language in Health Care*, PLAINLANGUAGE.GOV, <https://www.plain-language.gov/resources/content-types/healthcare/> (last visited May 12, 2021).

it's all three.”<sup>201</sup> Plain language not only includes and empowers people with cognitive disabilities, but it also has the potential to increase medical and health literacy for all. Nearly thirty-six percent of adults have low health literacy, and people with lower incomes and who are on Medicaid have disproportionate rates of low health literacy.<sup>202</sup> Thus, it increases access to care through the “curb-cut effect”: improvements that are intended to benefit one group of people ultimately benefit other groups of people.<sup>203</sup>

## 2. Self-Determination Through Alternatives to Guardianship

The right to individual self-determination and decision-making can easily be stripped through guardianship proceedings, which give a caregiver the power to make decisions for incapacitated people ranging from serious medical decisions to routine appointments.<sup>204</sup> Guardianship proceedings remove the right for people with disabilities to determine which medical care they receive—if they receive care at all.<sup>205</sup> To combat the confines of guardianship, lawmakers have developed less restrictive options for people with disabilities, such as supported decision making.<sup>206</sup> From a public health perspective, supported decision-making has the potential to improve the overall physical and psychological well-being of persons with cognitive and intellectual

---

201. SARA LUTERMAN, *PLAIN LANGUAGE TRANSLATION OF DISABILITY VISIBILITY: FIRST-PERSON STORIES FROM THE TWENTY-FIRST CENTURY* (2020).

202. Roopa Mahadevan, *Health Literacy Fact Sheets*, CTR. FOR HEALTHCARE STRATEGIES 4 (Oct. 2013), <https://www.chcs.org/resource/health-literacy-fact-sheets/>.

203. Angela Glover Blackwell, *The Curb-Cut Effect*, STAN. SOC. INNOVATION REV. (2017).

204. Karna Sandler, *A Guardian's Health Care Decision-Making Authority*, 35 BIFOCAL 97, 106 (Mar.–Apr. 2014) (“One role of the guardian is to make or assist the individual with health care decisions, ranging from routine appointments to serious surgical procedures and end-of-life decisions.”).

205. *Supported Decision Making & The Problems of Guardianship*, AM. CIV. LIBERTIES UNION, [aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making](http://aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making).

206. See Zachary Allen & Dari Pogach, *More States Pass Supported Decision-Making Agreement Laws*, 41 BIFOCAL 159, 160 (Sept.–Oct. 2019) (“Supported decision-making is often defined as supports and services that help an adult with a disability make his or her own decisions by relying on trusted friends, family members, professionals, and others.”).

disabilities by creating a sense of empowerment, which in turn has been linked to positive health outcomes.<sup>207</sup>

Less restrictive alternatives to guardianship ensure people with disabilities have a say in what care they receive, who their providers are, and to ask questions and communicate with medical staff as much or as little as they well please. Ending guardianship in these cases is in agreement with *Olmstead* and offers the fewest restrictions for people with disabilities to meet their needs.<sup>208</sup> Currently, supported decision-making is becoming increasingly popular and signed into law in more states.<sup>209</sup>

Physicians and medical staff hold positions of privilege and thus can empower self-advocacy, allowing patients who are often wary of the healthcare system to speak for themselves. Believing patients with chronic ailments and disabilities is a start, as is ensuring that disabled persons have access to visits, offices, and whose voices are uplifted and concerns are validated rather than ignored. This especially should be the case for multiply-marginalized disabled people who may also be people of color, LGBTQ+, or gender minorities.

## VI. CONCLUSION

“Nothing about us without us” includes disabled patients playing an active role in their care as well as protecting rights and access under the ADA, the Rehabilitation Act, and the ACA. Disabled persons are tired of waiting for equity merely from the law. Disability activists view the ADA as a floor, not the ceiling.<sup>210</sup> With that in mind, accessibility should be at the forefront to ensure people with disabilities have access to private and public healthcare, reasonable accommodations including effective and meaningful communication options. The right to self-determination is paramount, though self-advocacy is not enough; disabled persons deserve medical providers who act as

---

207. Kohn et al., *supra* note 49, at 1127.

208. *Beyond Guardianship: Toward Alternatives That Provide Greater Self-Determination*, NAT'L COUNCIL ON DISABILITY 1, 119 (2018), [https://ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf).

209. Allen & Pogach, *supra* note 204, at 161.

210. Marc Climaco, *Activism Across Generations*, FORD FOUND. (Jul. 23, 2020), <https://www.fordfoundation.org/just-matters/equals-change-blog/posts/activism-across-generations/>.

partners and advocates for equitable and effect treatment and care. To entirely leave people with disabilities out of their own care is the most disabling aspect of the American healthcare system. It festers unmitigated bias, fear, and causes death of the largest minority group that has to fight for the mere right to be alive.

\*\*\*