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**POLICIES OF EXCLUSION: THE IMPACT OF COVID-19 ON
PEOPLE WITH DISABILITIES**

AMANDA M. CALEB* AND STACY GALLIN**

ABSTRACT

COVID-19 has had a significant impact on marginalized groups and has amplified the social and health inequalities in society, particularly for people with disabilities (PwDs), who are at higher risk of dying from the coronavirus. As such, it is vital that policies and practices include and protect PwDs, yet that is not the case across the United States. In this article, we examine policies related to COVID-19 that have further othered PwDs and that have created practical and theoretical inequity. In looking at public health strategies that are meant to protect the public, we argue that measures such as social distancing guidelines and the use of remote health care have exacerbated the challenges PwDs already face and risk further harm and exclusion for an already marginalized group. In analyzing health facilities' triage policies—both those that were in existence prior to the pandemic and those that were created in response to it—we assert that these policies can exclude PwDs from receiving care and that these policies are reflective of existing structural and social inequities. We discuss these same inequities derived from a social utility approach in the plans for distributing COVID-19 vaccines, which devalue or erase PwDs from prioritization, despite their increased health risks from the coronavirus. We conclude by offering suggested changes to existing policies that move toward true equity and accessibility for PwDs and the greater community.

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I. INTRODUCTION

“The Government should acknowledge persons with disabilities in the same time as they include others. They will go right past us, and leave us out if we don’t speak out.”¹ These words, spoken by Susan, a deafblind woman living in Massachusetts, encapsulate the feelings of many people with disabilities (PwDs): a sense of exclusion has been exacerbated by the COVID-19 pandemic and related policies, which, while intended to protect the health of the population, have led to the further marginalization of PwDs.² For the approximately 61.4 million adults (25.7% of the population) in the United States who report a disability, COVID-19 has further exposed the systemic inequities they face; these include unmet health care needs due to cost (31.4% of PwDs, ages 18-34),³ lack of internet access (54%, compared to 85% of all U.S. adults), and inadequate transportation (34%, compared to 16% of all U.S. adults).⁴ Early research from the United States and the United Kingdom suggests that people with intellectual disabilities are dying from COVID-19 at rates between three and six times higher than people without intellectual disabilities.⁵

The health outcomes related to these statistics are not, in fact, products of individual bodies (impairments) but rather of social, cultural, and political models that have historically marginalized PwDs and created the notion of disability as oppositional to normal, a statistical average of what people should be able to do.⁶ Understanding disability as a product of historical, cultural, and political discourses (i.e., systems designed to contain and control individuals as part of the body politic) complicates both the reporting about disability and our response to disability, moving it away from an individual-only issue to an issue of structural injustice.⁷ The dividing practices embedded in disability—how a PwD becomes a disabled person, linguistically, medically, and politically—is an

1. “*We Need to Speak Up or We Will Be Left Behind*”: *Story of a Deafblind Woman in Massachusetts, United States*, INT’L DISABILITY ALL. (June 2, 2020), <https://www.internationaldisabilityalliance.org/usa-deafblind-covid>.

2. Emily M. Lund et al., *The COVID-19 Pandemic, Stress, and Trauma in the Disability Community: A Call to Action*, 65 REHAB. PSYCH. 313, 319 (2020).

3. Catherine A. Okoro et al., *Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults—United States, 2016*, 67 MORBIDITY & MORTALITY WKLY. REP. 882, 886 (2018).

4. Gloria L. Krahn et al., *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH S198, S201 (2015).

5. FAIR HEALTH ET AL., RISK FACTORS FOR COVID-19 MORTALITY AMONG PRIVATELY INSURED PATIENTS: A CLAIMS DATA ANALYSIS 12 (2020). See PUB. HEALTH ENG., DEATHS OF PEOPLE IDENTIFIED AS HAVING LEARNING DISABILITIES WITH COVID-19 IN ENGLAND IN THE SPRING OF 2020, at 65 (2020).

6. See Helen Meekosha & Russell Shuttleworth, *What’s So “Critical” About Critical Disability Studies?*, AUSTL. J. HUM. RTS., 2009, at 47, 63–64; LEONARD J. DAVIS, ENFORCING NORMALCY: DISABILITY, DEAFNESS, AND THE BODY 3 (Verso, 1st ed. 1995).

7. See DAVIS, *supra* note 6.

example of Foucault's biopower, the means by which a state controls the national body by regulating the individual body.⁸ Framed within neoliberalism, disability becomes that which has decreased value because of its decreased usefulness—its dis-ability.⁹

Biopower during a pandemic is even more pronounced, particularly for PwDs who experience increased levels of control via restrictions that may impact their health and mental wellbeing.¹⁰ Pandemic responses are about regulating bodies—both “sick” and “healthy” ones—in an effort to reduce disease transmission. Quarantine and isolation strategies, social distancing policies, and shelter-in-place mandates all serve to control the movement of bodies and the movement of disease itself.¹¹ None of this is bad from a public health standpoint; however, the balance of pandemic biopower is delicate, as the very nature of these policies is built upon modes of difference (i.e. sick vs. healthy). Acts of control that are informed by a neoliberal sentiment of value and product(ivity)¹²—which are often implied in decisions such as the allocation of scarce resources and vaccination distribution—risk the further marginalization and subsequent health of PwDs.

For those in minoritized communities, the failings we are witnessing are merely a case study of the exacerbation of a broken system for which equity and justice do not apply to all people. Particularly for PwDs, the national response to COVID-19 has proven to be a continuation of our country's tendency towards structural ableism, both in practice and policy.¹³ The bioethical foundations of autonomy, beneficence, nonmaleficence, and justice have continuously been violated with respect to the care of people with disabilities, thus creating an environment of distrust of the medical profession.¹⁴ In non-pandemic times, “our

8. See MICHEL FOUCAULT, *THE HISTORY OF SEXUALITY* 140–41 (Robert Hurley trans., Vintage Books ed., 1980) (1976).

9. See Fiona Kumari Campbell, *Legislating Disability: Negative Ontologies and the Government of Legal Identities*, in FOUCAULT AND THE GOVERNMENT OF DISABILITY 108, 119 (Shelley Tremain ed., 2005).

10. Lund et al., *supra* note 2, at 315–16.

11. See Jim Sergent et al., *Social Distancing: It's Not About You, It's About Us*, USA TODAY (Mar. 16, 2020, 5:42 PM), <https://www.usatoday.com/in-depth/news/2020/03/16/social-distancing-coronavirus-isolation-quarantine-pandemic-virus-infection-symptoms/5019940002/>; see also Matt Ehling, *Shelter-in-Place Strategy for Coronavirus Poses Constitutional, Economic Problems*, MINNPOST (Mar. 24, 2020), <https://www.minnpost.com/community-voices/2020/03/shelter-in-place-strategy-for-coronavirus-poses-constitutional-economic-problems/>.

12. When used in critical theory, “product(ivity)” is a means of referring to both the relationship of value and product and value and productivity (the commodification of bodies).

13. Andrew Pulrang, *The Disability Community Fights Deadly Discrimination Among the COVID-19 Pandemic*, FORBES (Apr. 14, 2020, 5:00 PM), <https://www.forbes.com/sites/andrewpulang/2020/04/14/the-disability-community-fights-deadly-discrimination-amid-the-covid-19-pandemic/?sh=1f18e38f309c>.

14. Joseph Shapiro, *People with Disabilities Fear Pandemic Will Worsen Medical Biases*, NPR (Apr. 15, 2020, 5:00 AM), <https://www.npr.org/2020/04/15/828906002/people-with-disabili>

country has forced sterilizations of people with mental illnesses and developmental disabilities, exploited institutionalized persons with disabilities for research, and instituted routine use of prenatal genetic testing that raises concerns about devaluing and increasing hostility towards disabled people—to name a few.”¹⁵ Data on the treatment of PwDs during crises such as 9/11, the H1N1 pandemic, and Hurricane Katrina are limited, yet one glaring finding from these emergencies that has been highlighted by the media is the failure to properly care for and evacuate those with disabilities, leaving them to suffer and die in favor of saving the able-bodied.¹⁶ This history of medical mistreatment and abuse of PwDs calls into question the standards of care, policies, and practice being utilized as the world struggles to deal with COVID-19.

COVID-19 has exacerbated the already numerous challenges facing PwDs in health care. Just as it has for other minoritized groups, the pandemic has highlighted systemic discrimination and inequalities confronting those with disabilities.¹⁷ The current strain on the global health system is unprecedented in modern times,¹⁸ thus making it incredibly difficult to mandate any type of immediate reforms to a system that was already in need of repair before the pandemic hit. However, strides made in disability studies and bioethics should not be ignored in favor of “catastrophe ethics” invoked in times of crisis. As argued by multiple scholars in a recent Hastings Center Report article, “there is a moral duty to shine a light on structural disability bias that may distort how crisis standards of care are put into practice.”¹⁹ Therefore, it is necessary to examine these public health policies and standards of care policies and how they are being practically applied to ensure that the rights of PwDs are being protected and to take action if and when improvement is needed.

This Article analyzes how health policies implemented during the COVID-19 pandemic act within a biopower that further marginalizes PwDs. Divided into four sections, this Article first discusses public health policies that were

ties-fear-pandemic-will-worsen-medical-biases. See Thomas R. McCormick, *Principles of Bioethics*, U.W. MED. DEP’T OF BIOETHICS & HUMANS. (2018), <https://depts.washington.edu/bhdept/ethics-medicine/bioethics-topics/articles/principles-bioethics> (defining the bioethical foundations of medicine).

15. Katie Savin & Laura Guidry-Grimes, *Confronting Disability Discrimination During the Pandemic*, THE HASTINGS CTR. (Apr. 2, 2020), <https://www.thehastingscenter.org/confronting-disability-discrimination-during-the-pandemic/>.

16. Maya Sabatello et al., *Disability, Ethics, and Health Care in the COVID-19 Pandemic*, 110 AM. J. PUB. HEALTH 1523, 1523 (2020) [hereinafter *Disability, Ethics, and Health Care*].

17. Lund et al., *supra* note 2, at 318.

18. Erika G. Martin & Jessica Kronstadt, *No Longer Invisible: The Critical Role of Local Health Departments in Responding to COVID-19*, HEALTH AFFS. (Apr. 16, 2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200408.106373/full/>.

19. Laura Guidry-Grimes et al., *Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care*, THE HASTINGS CTR. REP., May–June 2020, at 28, 28.

implemented during the pandemic that, while intending to be inclusive, were modes of exclusion of PwDs, through social distancing guidelines and the use of remote health care. Second, this Article analyzes diagnostic care in light of triage policies for the scarce allocation of resources and the harm of such policies on PwDs. Third, this Article considers the concept of social utility as it applies to early vaccine prioritization and the ramifications for PwDs. Lastly, this Article offers recommendations for changes in policy and practice that allow for better accessibility and inclusion.

II. PUBLIC HEALTH STRATEGIES: MODES OF IN/EXCLUSION

A. Communication

The 1997 avian influenza A (H5N1) virus—more commonly referred to as “bird flu”—alerted public health officials to the need for pandemic preparation and planning.²⁰ In 2006, the U.S. Department of Health and Human Services (HHS) developed such a plan, and in the revised 2018 publication, they noted the importance of consistent and timely communication and “the use of plain language and accessible formats.”²¹ During the COVID-19 pandemic, public health officials have reiterated the need for members of the public to have timely information about how to protect themselves from the coronavirus and minimize transmission.²² However, accessible versions of this information, including Braille, American Sign Language (ASL), charts appropriate for screen readers, and the use of simple language, were delayed and have been inconsistent.²³ As such, non-profit organizations have had to take on the responsibility of quickly providing accessible information for PwDs.²⁴ This lack of accessible resources and communication is all too common in health care facilities during non-pandemic times, which contributes to the health disparities impacting PwDs.²⁵

Some of the accessible information that has been provided by the Centers for Disease Control and Prevention (CDC) and other health professional organizations have focused their messaging and language on the responsibilities of PwDs during the pandemic, which is embedded with neoliberalism. For instance, the CDC directs PwDs to take measures beyond those recommended

20. *Avian Influenza: Are We Prepared?: Hearing Before the Senate Comm. on Foreign Relations*, 109th Cong. 1 (2005) (statements of Sen. Joseph R. Biden & Sen. Bill Frist).

21. U.S. DEP’T OF HEALTH & HUM. SERVS., PANDEMIC INFLUENZA PLAN: 2017 UPDATE 6 (2017).

22. Coleen A. Boyle et al., *The Public Health Response to the COVID-19 Pandemic for People with Disabilities*, *DISABILITY & HEALTH J.*, July 2020, at 1, 2.

23. Maya Sabatello et al., *People with Disabilities in COVID-19: Fixing Our Priorities*, *AM. J. BIOETHICS*, July 2020, at 187, 188; *Disability, Ethics, and Health Care*, *supra* note 16, at 1526.

24. *Disability, Ethics, and Health Care*, *supra* note 16, at 1524.

25. Jan Withers & Cynthia Speight, *Health Care for Individuals with Hearing Loss or Vision Loss: A Minefield of Barriers to Accessibility*, 78 *N.C. MED. J.* 107, 107 (2017).

for the general populace, including instructing them to ask their direct support provider (DSP) if they have COVID-19 symptoms and requesting that they wash their hands regularly and sanitize surfaces they touch; additionally, PwDs are advised to make a plan if they or their DSP becomes sick, develop multiple communication plans, and stock up on groceries and medications for several weeks.²⁶

The language and intention of these recommendations are problematic in a number of ways, most notably in how the burden of transmission prevention is placed on PwDs, rather than their DSPs. The CDC's guidelines indicate that these recommendations are aimed, in part, at individuals who have trouble understanding public health practices or communicating their symptoms—a painfully ironic note.²⁷ So, too, is the expectation that PwDs can stockpile weeks' worth of groceries and household goods, given the interruption to their already limited access to transportation²⁸ and that they are twice as likely to live in poverty and “account for more than [half] of those living in long-term poverty.”²⁹ Stockpiling is not a realistic recommendation for many PwDs.

While the CDC's recommendations are intended to help PwDs, the rhetoric places the responsibility solely on them, with no recognition of the challenges in following these guidelines, such as extended shelter-in-place, communicative difficulties, or financial hardships, which ultimately act as a means of excluding them from COVID-19 protections, rather than including them. When compared to the CDC document produced for DSPs, the language and content is noticeably different. In the recommendations for DSPs, there is significantly more information about the spread of COVID-19 and how DSPs can protect themselves, less on how to sanitize the living space of PwDs, and a section on mental health during the pandemic—this last section is completely absent from the recommendations for PwDs.³⁰ In other words, there is an inequality in the presentation of information and the expectations, and for PwDs, no mention of services to help support the list recommendations. Contrast the CDC's recommendations for PwDs to the American Psychological Association's

26. *COVID-19: People with Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html> (last visited Sept. 11, 2020).

27. *Id.*

28. Abigail L. Cochran, *Impacts of COVID-19 on Access to Transportation for People with Disabilities*, TRANSP. RSCH. INTERDISC. PERSPS., Nov. 2020, at 1, 2; Krahn et al., *supra* note 4, at S202.

29. *Highlighting Disability / Poverty Connection, NCD Urges Congress to Alter Federal Policies that Disadvantage People with Disabilities*, NAT'L COUNCIL ON DISABILITY (Oct. 26, 2017), <https://ncd.gov/newsroom/2017/disability-poverty-connection-2017-progress-report-release>.

30. *COVID-19: Guidance for Direct Services Providers*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/coronavirus/2019-ncov/hcp/direct-service-providers.html> (last visited June 28, 2020).

(APA) list of recommendations, and the difference is stark. While the APA advises some of the same measures, they also provide resources about advocacy and legal rights, and accessible information about COVID-19.³¹

B. Public Health Strategies

In emphasizing ways in which individuals could help mitigate the spread of COVID-19, the CDC and other health organizations adopted the three Ws slogan: “Wash your hands. Watch your distance (stay 6 feet apart). Wear a Mask.”³² Conceptually, the slogan has universal appeal, as it is simple and memorable with its alliterative Ws. However, this slogan presents challenges to PwDs, not only in how it (and its derivatives) may be presented in inaccessible or confusing ways,³³ but also in the challenge of adhering to these public health strategies.

For instance, both regular handwashing (or use of hand sanitizers) and social distancing may prove difficult for PwDs. Individuals who cannot rub their hands together would require a DSP or other care partner to be in close proximity and to regularly aid in this endeavor, which may undermine the social distancing recommendations or may be difficult due to staffing shortages.³⁴ Social distancing itself is not feasible for many PwDs who require DSPs for daily needs: sixty-seven percent of PwDs reported that their care needs were not possible within social distancing guidelines, which has created additional stress for these individuals.³⁵ For individuals living in low-income housing, which can be overcrowded, social distancing may not be possible.³⁶ Equally, PwDs have reported confusion regarding social distancing measures in public spaces, where signage is not always accessible.³⁷ This is to say nothing of the stress of prolonged social distancing for individuals in long-term care facilities, who may have little to no contact with family members and who may not fully understand

31. *How Americans with Disabilities Can Cope with the COVID-19 Crisis*, AM. PSYCH. ASS’N (May 6, 2020), <https://www.apa.org/topics/covid-19/disability-tip-sheet>.

32. CDC (@CDCgov), TWITTER (Sept. 10, 2020, 3:55 PM), <https://twitter.com/CDCgov/status/1304146374552965129>.

33. Jonathan Paul Katz, *Five Ways Social Distancing Signage Is Not Accessible—and How to Fix Them*, GREATER GREATER WASH. (June 3, 2020), <https://ggwash.org/view/77813/five-ways-social-distancing-signage-is-not-accessible-and-how-to-fix-them>.

34. *COVID-19 Poses Unique Challenges for People with Disabilities*, HUB (Apr. 23, 2020), <https://hub.jhu.edu/2020/04/23/how-covid-19-affects-people-with-disabilities/>.

35. CHARLES E. DRUM ET AL., AM. ASS’N ON HEALTH & DISABILITY, *COVID-19 & ADULTS WITH AN EMOTIONAL, PSYCHOLOGICAL, OR MENTAL HEALTH DISABILITY ONLINE SURVEY REPORT 6* (2020).

36. Lund et al., *supra* note 2, at 317.

37. *People with Disabilities Find Social-Distancing Measures Confusing*, BBC NEWS (Sept. 16, 2020), <https://www.bbc.com/news/uk-england-tyne-54158383>; Katz, *supra* note 33.

why such measures are necessary.³⁸ Finally, given the higher risks of COVID-19 for PwDs, those who are able to social distance may need to do so for longer, which can lead to increased social isolation.³⁹

Mask recommendations and requirements present a number of challenges for PwDs, including issues with communication, health protections, and stigma. Individuals with speech impairments may have increased difficulty in communicating to others while wearing a mask.⁴⁰ Conversely, for individuals who have impaired hearing, masks present communication challenges; clear masks are an effective alternative, but have been in short demand during the pandemic.⁴¹ So, too, has been personal protective equipment (PPE) for DSPs and other health care providers, particularly in the early months of the pandemic, resulting in increased risk of exposure and delayed care for PwDs in long-term care facilities and those dependent on DSPs.⁴² Finally, PwDs who cannot wear a mask—whether because of a sensory processing disorder, a facial deformity, or another medical reason⁴³—have faced a policing of disability (to confirm the “validity” of a medical condition) and stigmatization.⁴⁴

The importance of public health strategies during a pandemic should not be ignored; however, such policies should be inclusive of the needs and abilities of all individuals. Such measures need to be supported by sufficient and accessible resources, reasonable accommodations, and clear communication. While the three Ws can serve to protect the entirety of a population, they can also marginalize PwDs, with both short-term and long-term impacts on their physical and mental health.

38. See Charmaine Wright et al., *The Crisis Close at Hand: How COVID-19 Challenges Long-Term Care Planning for Adults with Intellectual Disability*, 4 HEALTH EQUITY 247, 248 (2020).

39. Lund et al., *supra* note 2, at 316.

40. *Communicating Effectively While Wearing Masks and Physical Distancing*, AM. SPEECH-LANGUAGE-HEARING ASS'N (last visited Jan. 16, 2021), <https://www.asha.org/public/communicating-effectively-while-wearing-masks-and-physical-distancing/#:~:text=Tips%20for%20Communicating%20While%20Wearing,Talk%20a%20little%20louder>.

41. Yuki Noguchi, *Demand Surges for See-Through Masks as Pandemic Swells*, NPR (July 28, 2020, 5:00 AM), <https://www.npr.org/sections/health-shots/2020/07/28/893071631/demand-surges-for-see-through-face-masks-as-pandemic-swells>.

42. TERESA MARRY & JAMIE FRIEDMAN, *NURSING HOME SAFETY DURING COVID: PPE SHORTAGES* 12 (2020); Abigail Abrams, *'This is Really Life or Death.' For People with Disabilities, Coronavirus is Making It Harder than Ever to Receive Care*, TIME (Apr. 24, 2020, 3:11 PM), <https://time.com/5826098/coronavirus-people-with-disabilities>.

43. Doron Dorfman & Mical Raz, *Mask Exemptions During the COVID-19 Pandemic—A New Frontier for Clinicians*, JAMA HEALTH FORUM (July 10, 2020), <https://jamanetwork.com/channels/health-forum/fullarticle/2768376>.

44. Andrew Pulrang, *We Need to Stop Patrolling the Borders of Disability*, FORBES (June 30, 2020, 1:12 PM), <https://www.forbes.com/sites/andrewpulrang/2020/06/30/we-need-to-stop-patrolling-the-borders-of-disability/?sh=1be1a9de2ae1>; Esmée S. Hanna, *Rapid Response: Social-Cultural Concerns on Face Coverings Must Not Ignore the Negative Consequences*, BMJ (Aug. 19, 2020), <https://www.bmj.com/content/370/bmj.m3021/rr-0>.

C. Equitable Access to Health Care

One of the logistical challenges of the pandemic is the balancing of providing health care while adhering to public health recommendations and government restrictions, specifically social distancing and shelter-in-place orders. Adoption of drive-through COVID-19 testing and telehealth were seen as ways of keeping individuals and practitioners safe while still providing necessary care.⁴⁵ However, these modifications to traditional health care present a number of hardships to PwDs that make these measures exclusionary.

Drive-through COVID-19 testing options began in mid-March 2020 as an effort to increase public health surveillance and decrease pressure on hospitals for testing, as well as create easier access for individuals seeking testing.⁴⁶ However, the very nature of drive-through testing reduces the ability of PwDs to be tested if they are unable to drive themselves and if these testing sites strictly and literally enforce the meaning of drive-through.⁴⁷ This type of testing presumes PwDs can procure transportation, which is challenging for many PwDs. For those who struggled to obtain transportation, they reported being turned away from drive-through testing sites because they were not in a car,⁴⁸ or because they arrived late to an appointment.⁴⁹ These physical barriers are echoed in the language describing the testing sites, which also serve to exclude PwDs. For instance, Nebraska Governor Pete Ricketts stated in June 2020 that the state needed “to continue to work on getting the system down for the regular customers, so to speak, if you want to think about it—the drive-up customers that the system was originally designed to serve.”⁵⁰ The dividing practice of regular vs. presumed irregular (i.e. able-bodied vs. disabled) perpetuates an othering of PwDs and can lead to inferior health care.

45. Tara Bannow, *Drive-Through COVID-19 Testing Launched by Hospitals in Parking Lots, Garages*, MOD. HEALTHCARE (Mar. 11, 2020, 4:26 PM), <https://www.modernhealthcare.com/providers/drive-through-covid-19-testing-launched-hospitals-parking-lots-garages>; Andis Robeznieks, *Telehealth Keeps Care Continuity During COVID-19—That Must Continue*, AM. MED. ASS'N (July 20, 2020), <https://www.ama-assn.org/practice-management/digital/telehealth-keeps-care-continuity-during-covid-19-must-continue>.

46. Sarah McCammon, *Drive-Through Coronavirus Tests Begin to Pop Up Around the United States*, NPR (Mar. 17, 2020, 4:26 PM), <https://www.npr.org/2020/03/17/817354387/drive-through-coronavirus-tests-begin-to-pop-up-around-the-united-states>.

47. See *Blind Americans Encounter Discrimination by Restaurants and Other Services During COVID-19 Crisis*, NAT'L FED'N OF THE BLIND (Apr. 3, 2020), <https://www.nfb.org/about-us/press-room/blind-americans-encountering-discrimination-restaurants-and-other-services>.

48. *E.g., id.*

49. *E.g.,* Sarah Mizes-Tan, *Disability Activist Calls for More ADA-Accessible COVID-19 Testing Sites in Sacramento*, CAPRADIO (Dec. 14, 2020), <https://www.capradio.org/articles/2020/12/14/disability-activist-calls-for-more-ada-accessible-covid-19-testing-sites-in-sacramento>.

50. Fred Knapp, *Disabled Advocates Say TestNebraska Not Accessible*, NET (June 1, 2020, 5:38 PM), <http://netnebraska.org/article/news/1221753/disabled-advocates-say-testnebraska-not-accessible>.

The widespread adoption of telehealth during the pandemic—a form of health care that was in existence for several years, but without widespread use—has been seen as a necessary measure to reduce transmission while still allowing individuals to seek treatment.⁵¹ Telehealth is a particularly interesting study for disability accessibility. While many PwDs have been advocating for its widespread usage and availability for years and therefore see its usage during the pandemic as an act of inclusion and equity,⁵² others have been critical of its implementation and limitations.⁵³ The benefits of telehealth for PwDs are substantial: individuals are not faced with the accessibility barriers at many care facilities, such as with inaccessible medical equipment;⁵⁴ the elimination of transportation reduces potential costs and burdens, including potential coordination with a family member to attend with the patient; care from one's home can provide additional comfort and a willingness to communicate more freely; and finally, telehealth allows for continued monitoring of chronic conditions.⁵⁵ Telehealth use among PwDs who have access to Medicare or Medicaid is substantial, accounting for nearly two-thirds of all beneficiary usage in 2016.⁵⁶

The challenges, however, are several and significant, and extend beyond the pandemic, particularly regarding internet access and security. Internet access is notably less among PwDs (fifty-four percent vs. eighty-five percent),⁵⁷ and these statistics do not account for access to broadband in rural or low-income areas.⁵⁸ Given the shifts to internet-based services (e.g., health, education, etc.), internet access is a systemic inequality, one that can impact health during a pandemic if individuals are unable to receive medical care.⁵⁹ Related to internet access is internet safety. During the pandemic, the federal government has waived penalties for violations under the Health Insurance Portability and Accountability Act (HIPAA), in recognition of the inability to secure all

51. Robeznieks, *supra* note 45.

52. Kimberly Noel & Brooke Ellison, *Inclusive Innovation in Telehealth*, NPJ DIGITAL MED., 2020, at 1, 1.

53. Thiru M. Annaswamy et al., *Telemedicine Barriers and Challenges for Persons with Disabilities: COVID-19 and Beyond*, DISABILITY & HEALTH J., 2020, at 1, 2–3.

54. See Krahn et al., *supra* note 4, at S203. While the ADA requires buildings to be accessible, this does not extend to the equipment within a building, which can lead to inferior health care and health inequalities, see CTRS. FOR MEDICARE & MEDICAID SERVS., OFF. OF MINORITY HEALTH, INCREASING THE PHYSICAL ACCESSIBILITY OF Health Care Facilities 3 (2017).

55. Noel & Ellison, *supra* note 52, at 1.

56. CTRS. FOR MEDICARE & MEDICAID SERVS., INFORMATION ON MEDICARE TELEHEALTH 27 (2018).

57. Krahn et al., *supra* note 4, at S202.

58. See Annaswamy et al., *supra* note 53, at 2.

59. Rupa S. Valdez et al., *Ensuring Full Participation of People with Disabilities in an Era of Telehealth*, J. AM. MED. INFORMATICS ASS'N, Nov. 2020, at 1, 2.

telehealth connections and software.⁶⁰ Such actions could lead to increased cyber security breaches, which are particularly harmful for PwDs, “given the increased probability of potentially sensitive and stigmatizing health information in comparison to their able-bodied peers.”⁶¹

A second area of concern is that of accessibility. Most telehealth platforms are not currently accessible for some PwDs, especially those with hearing, visual, or cognitive impairments,⁶² and the accessibility requirements for telehealth under the regulations for the Americans with Disabilities Act (ADA) and Federal Communications Commissions are murky.⁶³ This is in contrast to the requirements in the ADA and Section 504 of the Rehabilitation Act requirements for reasonable accommodations for in-person visits, which include communication support, such as ASL and Braille.⁶⁴ Telehealth can also prove difficult for individuals with intellectual impairments and those who have difficulties with language or literacy.⁶⁵ The widespread use of telehealth during the pandemic is only inclusive if measures of inclusion are implemented.

A final note about telehealth during the pandemic is one of intentionality. Many of the issues of exclusion outlined above applied before the pandemic, and will potentially apply after. In other words, the opportunity to be inclusive via telehealth has been there, but there has been little action to make it fully inclusive, and measures taken during the pandemic have created further potential exclusion (such as the waiving of penalties for HIPAA violations)—despite requests from PwDs to have accessible telehealth options.⁶⁶ These unresolved issues of accessibility suggest that the decision for widespread telehealth usage was done more for the sake of the able-bodied community than for PwDs, resulting in a practice of inclusion that has continued to exclude.

60. Gabriella Weigel et al., *Opportunities and Barriers for Telemedicine in the U.S. During the COVID-19 Emergency and Beyond*, KAISER FAM. FOUND. (May 11, 2020), <https://www.kff.org/womens-health-policy/issue-brief/opportunities-and-barriers-for-telemedicine-in-the-u-s-during-the-covid-19-emergency-and-beyond/>.

61. Valdez et al., *supra* note 59, at 3.

62. Annaswamy et al., *supra* note 53, at 2.

63. Blake E. Reid et al., *Telehealth and Telework Accessibility in a Pandemic-Induced Virtual World*, U. COLO. L. REV. (Nov. 9, 2020), <https://lawreview.colorado.edu/digital/telehealth-and-telework-accessibility-in-a-pandemic-induced-virtual-world/>.

64. *Id.*

65. Annaswamy et al., *supra* note 53, at 2.

66. Noel & Ellison, *supra* note 52.

III. STATE POLICIES, TRIAGE GUIDELINES, AND THE ALLOCATION OF SCARCE RESOURCES

A. *Triage and Crisis Standards of Care in Disaster Scenarios*

When the need for health care resources overwhelms available resources, triage protocols are enacted to help distribute resources in a fair and equitable manner.⁶⁷ Although triage protocols were invented to help army medics determine which soldiers were more likely to be saved from medical intervention on the battlefield,⁶⁸ current triage protocols are typically invoked in response to a public health disaster that triggers the need for a crisis standard of care.⁶⁹ Crisis standards of care differ from regular standards of care because they “must balance a number of competing considerations: health care professionals’ duty to care, equitable distribution among a population with diverse health needs, accountability of public agencies and health care systems to serve the public interest, and preserving health care systems adequately so that recovery remains possible after the disaster.”⁷⁰ While a physician’s primary role is usually treating and advocating for an individual patient, crisis standards of care must take into account the public good, thus marking a substantial paradigm shift in the foundations and ethics of medicine to incorporate utilitarianism (doing the most good for the most people) while still providing equitable care.⁷¹

The most common triage protocols focus on clinical outcome: which patients are most likely to survive with treatment who otherwise would not?⁷² In disaster scenarios in which crisis standards of care must be enacted, there are often many people in need who would benefit equally from treatment and not enough resources to care for them all.⁷³ At this point, a “tie-breaker” is used to choose which patients will get the scarce resources.⁷⁴ There are many different frameworks that have been suggested for determining the allocation of scarce resources, including a first-come, first-served process; a random lottery; and prioritizing those who work in health care or minority groups who have historically been victims of discrimination.⁷⁵ For most clinicians, “the most

67. See Nathan A. Bostick, et al., *Disaster Triage Systems for Large-Scale Catastrophic Events*, 2 DISASTER MED. & PUB. HEALTH PREPAREDNESS S35, S35 (2008).

68. Shruthi Sivakumar, *History of Triage – The Indispensable Tool in Emergency Medicine*, FIRSTCLASS, <https://www.firstclassmed.com/articles/2018/triage-history> (last visited Jan. 9, 2021).

69. See *id.*

70. Savin & Guidry-Grimes, *supra* note 15.

71. See NANCY BERLINGER ET AL., THE HASTINGS CTR., ETHICAL FRAMEWORK FOR HEALTH CARE INSTITUTIONS RESPONDING TO NOVEL CORONAVIRUS SARS-CoV-2 (COVID-19) 2 (2020).

72. Jackie Leach Scully, *Disability Disablism, and COVID-19 Pandemic Triage*, 17 J. BIOETHICAL INQUIRY 601, 602 (2020).

73. *Id.*

74. *Id.*

75. *Id.*

ethically justifiable move however is to continue along the path of best possible clinical outcome, by refining the clinical inclusion criteria in order to identify an increasingly narrow core of people most likely to benefit from treatment.”⁷⁶ This typically involves looking at a person’s overall health and determining if there are any other factors that would make it more or less likely that the person would benefit from treatment.⁷⁷

B. COVID-19 Specific Triage and Standards of Care

The situation with COVID-19 triage and standards of care differs from the traditional scenarios because of the nature and progression of the coronavirus. Many of the most serious complications associated with COVID-19 affect the lungs and respiratory system.⁷⁸ Therefore, the availability of ventilators quickly became the main area of focus for triage protocols during the pandemic.⁷⁹ In addition to ventilators, there has also been concern over preserving the health of those who have the expertise to operate the ventilators, such as respiratory therapists, anesthesiologists, and other medical specialists.⁸⁰ The lack of PPE to keep these frontline workers safe and mitigate the spread of COVID-19 has further exacerbated these issues, leading to the need not only to allocate scarce resources but also to create policies to “flatten the curve” and reduce the burden on health care facilities.

With so many factors unique to COVID-19, crucial questions arose regarding how crisis standards of care would be determined and who would be responsible for making these decisions. Due to a lack of preparation on the part of the federal government, no national guidelines exist, leaving the burden to organizations and individuals. There are a number of different factors that can be used to create these protocols depending on which values are prioritized by those in power. Because of an absence of national guidelines and an urgent need to respond to the pandemic, “[s]tates and individual hospitals started to draft or reveal previously developed scarcity policies that either explicitly or implicitly excluded people with disabilities...not just on an individual basis, and not only as a secondary, knock-on effect ... but in some cases categorically, by diagnosis

76. *Id.*

77. Scully, *supra* note 72.

78. See Panagis Galiatsatos, *What Coronavirus Does to the Lungs*, *JOHNS HOPKINS MED.* (Apr. 13, 2020), <https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/what-coronavirus-does-to-the-lungs>.

79. Robert D. Truog et al., *The Toughest Triage—Allocating Ventilators in a Pandemic*, 382 *NEW ENG. J. MED.* 1973, 1973 (2020).

80. Chethan Sathya, *Respiratory Therapists Are Keeping Many Covid Patients on Ventilators Alive*, *WASH. POST* (Apr. 7, 2020), <https://www.washingtonpost.com/outlook/2020/04/07/coronavirus-ventilators-respiratory-therapists/>; Amanda S. Xi et al., *Rapid Establishment of an ICU Using Anesthesia Ventilators During COVID-19 Pandemic: Lessons Learned*, *CRITICAL CARE* (June 30, 2020), <https://ccforum.biomedcentral.com/articles/10.1186/s13054-020-03107-x>.

and certain arbitrary measurements that have little to do with COVID-19 survivability.”⁸¹ As early as March of 2020, individual state policies discriminating against PwDs began garnering attention.⁸² By April, complaints had been filed with HHS Office of Civil Rights (OCR) against COVID-19 protocols being put forth in Alabama, Kansas, New York, Pennsylvania, Tennessee, Utah, and Washington.⁸³

Alabama’s policy dictated that hospitals could deny ventilators to patients with “severe or profound mental retardation,” “moderate to severe dementia,” or “severe traumatic brain injury.”⁸⁴ Utah’s guidelines included a phrase “excluding patients with advanced neuromuscular disease ‘requiring assistance with activities of daily living or requiring chronic ventilatory support.’”⁸⁵ These guidelines are the most controversial because of their blatantly discriminatory language and practices. Policies of exclusion based on disability are unethical and legally questionable. As stated by HHS, “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities.”⁸⁶ Biases related to the quality of life of PwDs have often been taken into account when drafting policies related to health care, including the design and implementation of Medicaid.⁸⁷ In addition to public policy concerns, there are moral considerations involved in using quality of life as a value judgment on which to base medical decisions and triage policies: “(i) that disability may not decrease personal satisfaction; (ii) that [quality-adjusted life-years (QALYs)] oppress individuals with disabilities; (iii) that QALYs neglect to represent contrasts between what patients with a similar condition value.”⁸⁸ Nonetheless, quality of life has been used as a determining factor to prevent people with intellectual disabilities from receiving organ transplants or other forms of care.⁸⁹

Crisis standards of care policies in Tennessee, Colorado, and Minnesota consider anticipated or documented duration of need as a method of prioritizing

81. Andrew Pulrang, *The Disability Community Fights Deadly Discrimination Amid the COVID-19 Pandemic*, FORBES (Apr. 14, 2020, 5:00 PM), <https://www.forbes.com/sites/andrewpulrang/2020/04/14/the-disability-community-fights-deadly-discrimination-amid-the-covid-19-pandemic/?sh=423bc786309c> [hereinafter *Disability Community Fights*].

82. Michelle M. Mello et al., *Respecting Disability Rights – Toward Improved Crisis Standards of Care*, NEW ENG. J. MED., July 30, 2020, at e26(1), e26(1).

83. *Id.*

84. *Id.*

85. *Id.*

86. *Id.* at e26(3).

87. Mello et al., *supra* note 82, at e26(3).

88. Satendra Singh, *Disability Ethics in the Coronavirus Crisis*, 9 J. FAM. MED. & PRIMARY CARE 2167, 2169 (2020).

89. *Disability Community Fights*, *supra* note 81.

patients for the allocation of scarce resources.⁹⁰ The duration of need can factor into the original assessment or subsequent evaluations and that may result in a reallocation of resources.⁹¹ Resource intensity alludes to the amount of time, effort, and resources a person will require to potentially survive COVID-19.⁹² PwDs often require more resources than those without disabilities, which is true during non-pandemic times as well as during the COVID-19 pandemic.⁹³ Disability rights activists argue that providing reasonable accommodations in COVID-19 triage protocols would acknowledge that PwDs have greater resource intensity and allow for extra time on a ventilator if necessary.⁹⁴ The American Association of People with Disabilities has lobbied Congress to prohibit the use of anticipated or documented resource-intensity as a factor in allocating ventilators or other scarce resources.⁹⁵ There has also been concern that people with conditions requiring long-term ventilators could be forced to give up this scarce and valuable resource in favor of someone who has a better chance of survival.⁹⁶ As Ari Ne’eman has maintained, “[e]ven in a crisis, authorities should not abandon nondiscrimination.”⁹⁷ Doing so “interferes with the trust in the medical system that we need to combat the virus: Chronic ventilator users may have reason to avoid seeking hospital care if they become infected, based on a well-founded fear of being sacrificed ‘for the greater good.’”⁹⁸ The New York State Task Force on Life and the Law has argued that chronic ventilator users should be explicitly protected from reallocation because doing so “fails to follow the ethical principle of duty to care and could be construed as taking advantage of a very vulnerable population.”⁹⁹

Rather than solely taking into consideration the medically accepted standard of short-term prognosis, Pennsylvania and Massachusetts included long-term life expectancy in their triage protocols.¹⁰⁰ Incorporating the number of life-years saved, rather than focusing only on maximizing the number of lives saved,

90. Ari Ne’eman. *When It Comes to Rationing, Disability Rights Law Prohibits More than Prejudice*, THE HASTINGS CTR. (Apr. 10, 2020), <https://thehastingscenter.org/when-it-comes-to-rationing-disability-rights-law-prohibits-more-than-prejudice> [hereinafter *When It Comes to Rationing*].

91. *Id.*

92. *Disability Community Fights*, *supra* note 81.

93. *See When It Comes to Rationing*, *supra* note 90.

94. *Id.*

95. Ari Ne’eman. *I Will Not Apologize for My Needs*, N.Y. Times (Mar. 23, 2020), <https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html> [hereinafter *I Will Not Apologize*].

96. Mildred Solomon et al., *Covid-19 Crisis Triage – Optimizing Health Outcomes and Disability Rights*, NEW ENG. J. MED., July 30, 2020, at e27(1), e27(2).

97. *I Will Not Apologize*, *supra* note 95.

98. *Id.*

99. Guidry-Grimes et al., *supra* note 19, at 29.

100. Mello et al., *supra* note 82, at e26(3).

is an ethically questionable decision that was met with objection from many different advocacy groups.¹⁰¹ Long-term life expectancy is influenced by a number of factors; just as some disabilities can impact long-term life expectancy, social determinants of health, such as poverty and access to health care, can also play a role in these predictions.¹⁰² Thus, long-term life expectancy is notoriously difficult to calculate accurately and much more susceptible to bias than short-term prognosis.¹⁰³ In addition, attempts to maximize the number of life-years saved ultimately leads to prioritizing younger patients over older ones solely due to their age, an ethically controversial practice.¹⁰⁴ Long-term life expectancy also negatively impacts those with chronic, progressive illnesses which do not affect their ability to recover from COVID-19.¹⁰⁵ As a result of these ethical concerns, Pennsylvania and Massachusetts revised their guidelines by mid-April to remove these value-driven considerations.¹⁰⁶

In a bulletin published on March 28, 2020, entitled, “Civil Rights, HIPAA, and the Coronavirus Disease 2019,” OCR stated in no uncertain terms that despite the unprecedented situation facing the United States, discrimination of PwDs would not be tolerated.¹⁰⁷ This bulletin stated that “the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights law.”¹⁰⁸ The bulletin also served as a reminder that despite the unique circumstances, abandoning laws and civil rights statues cannot be an option. Roger Severino, OCR Director, maintained, “[o]ur civil rights protect the equal dignity of every human life from ruthless utilitarianism.”¹⁰⁹ Other scholars in the field have subsequently reinforced this message: “Antidiscrimination mandates exist for a purpose, and they may not be completely waived during health emergencies—in fact, they are even more important at such times, when individuals who are marginalized by society experience heightened vulnerability.”¹¹⁰ Despite these messages, there are accounts of PwDs being denied rights by way of hospital triage policies. In May 2020, Sarah McSweeney, who had quadriplegia and cerebral palsy, developed non-coronavirus-related pneumonia and her guardian reported being pressured by the

101. *See id.* at e26(2).

102. *Id.* at e26(3).

103. *Id.*

104. *Id.* at e26(2).

105. Mello et al., *supra* note 82, at e26(3).

106. *Id.* at e26(2), e26(3).

107. *BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)*, DEP’T OF HEALTH & HUM. SERVS., OFF. FOR C.R. 1 (Mar. 28, 2020), <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

108. *Id.*

109. *Id.*

110. Guidry-Grimes et al., *supra* note 19, at 31.

lead physician to alter McSweeney's Do Not Resuscitate request in order to save a ventilator for another patient.¹¹¹ While stories like this are rare, they raise questions about a willingness to suspend civil rights during a pandemic, even in the face of ethical and legal requirements.

IV. VACCINATION PLANS AND PRIORITIZATION

In conjunction with HHS's development of a pandemic response plan, the CDC, in collaboration with the National Center for Immunization and Respiratory Diseases, developed a vaccine prioritization plan for pandemic influenza, which was most recently updated in 2018.¹¹² This plan relies on a narrow social utility in emphasizing the essential functions of certain individuals; as such, in instances of low, moderate, or very high pandemic severity, most health care workers and emergency services personnel are prioritized, as are the manufacturers of the vaccine and deployed military personnel.¹¹³ However, the plan also prioritizes pregnant women and toddlers under three years old, which is indicative of a broad social utility in the valuing of the individual worth to society.¹¹⁴ This prioritization indicates a social value for health care services, national security and military interests, and the future population. Adults ages nineteen to sixty-four with high-risk conditions—this includes PwDs—are considered a tier two priority for low severity, tier three for moderate severity, and tier four in very high severity: in each scenario, they are only one tier above healthy adults, ages nineteen to sixty-four.¹¹⁵ In cases of very high pandemic severity, adults with high-risk conditions are prioritized below all military personnel, all critical government personnel, all communications and electricity personnel, and all banking, agricultural, shipping, and transportation personnel.¹¹⁶

While an influenza pandemic is different from the current COVID-19 pandemic, this type of social utility prioritization informs components of plans for allocating the coronavirus vaccine.¹¹⁷ In July 2020, the CDC commissioned

111. Joseph Shapiro, *As Hospitals Fear Being Overwhelmed by COVID-19, Do Disabled Get the Same Access?*, NPR (Dec. 14, 2020, 3:47 PM), <https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc>.

112. *Interim Updated Planning Guidance on Allocating and Targeting Pandemic Influenza Vaccine During an Influenza Pandemic*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/flu/pandemic-resources/national-strategy/planning-guidance/index.html> (last modified June 2, 2020) [hereinafter *Interim Influenza Allocation Guidance*].

113. *Table 1. Category, Vaccination Population Groups, Estimated Number in Population Group, and Tiers for Low, Moderate, and High/Very High Pandemic Severity*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/flu/pandemic-resources/national-strategy/planning-guidance/guidance_508.html#table-1 (last updated Oct. 24, 2018).

114. *Id.*

115. *Id.*

116. *See id.*

117. *Interim Influenza Allocation Guidance*, *supra* note 112.

the National Academies of Science, Engineering, and Medicine (NASEM) to develop a framework for vaccine distribution, which was released on October 2, 2020.¹¹⁸ The document uses the ethical principles of “maximum benefit, equal concern, and mitigation of health inequities” alongside the procedural principles of “fairness, transparency, and evidence-based.”¹¹⁹ In applying these principles, NASEM maintained the narrow social utility of prioritizing high-risk health workers and first responders in their Phase 1a vaccination plan, but, in applying a broad social utility, also included people with comorbidities that significantly increased their risk of severity and death from the coronavirus and “older adults living in congregate or overcrowded settings” in Phase 1b.¹²⁰ PwDs living in group homes are included in the Phase 2 vaccination plan, but other PwDs are not explicitly mentioned, though individuals with chronic conditions (such as cystic fibrosis and neurological conditions) are included in Phase 2.¹²¹ The Disability Rights Education & Defense Fund, critical of the draft version of this document, sent recommendations to include and prioritize PwDs, but these recommendations were not added to the final document.¹²² The document acknowledges the increased risk for PwDs because of chronic health conditions, an inability to adhere to public health guidelines, and communication difficulties, but they are omitted from key impact data due to a dearth of COVID-related research.¹²³ In other words, the CDC and others’ failure to adequately research the impact of COVID-19 on PwDs has resulted in a devaluing of them in vaccine distribution plans.

The lack of clear guidelines regarding PwDs outside congregate settings has trickled down to state-sponsored vaccination plans: only twelve states specifically identify PwDs in their proposed plans, despite evidence that COVID-19 is impacting PwDs at disproportionate rates.¹²⁴ This omission is glaring, particularly as several national disability advocacy groups have

118. NAT’L ACADS. OF SCIS., ENG’G, & MED. & NAT’L ACAD. MED., FRAMEWORK FOR EQUITABLE ALLOCATION OF COVID-19 VACCINE 2 (Helene Gayle et al. eds., 2020) (ebook) [hereinafter NASEM FRAMEWORK]; Press Release, Nat’l Acads. of Scis., Eng’g, & Med., National Academies Release Framework for Equitable Allocation of a COVID-19 Vaccine for Adoption by HHS, State, Tribal, Local, and Territorial Authorities (Oct. 2, 2020).

119. NASEM FRAMEWORK, *supra* note 118, at 92.

120. *Id.* at 11.

121. *Id.* at 12.

122. *People with Disabilities Not Counted in Guidance Aimed at Equitable Allocation of a COVID-19 Vaccine*, DISABILITY RTS. EDUC. & DEF. FUND (Oct. 15, 2020), <https://dredf.org/2020/10/15/people-with-disabilities-not-counted-in-guidance-aimed-at-equitable-allocation-of-a-covid-19-vaccine>.

123. NASEM FRAMEWORK, *supra* note 118, at 4, 39–40.

124. Megan McNeil, *Advocates Call for People with Developmental Disabilities to be Some of First to Get a COVID-19 Vaccine*, KOLD NEWS 13 (Dec. 7, 2020, 7:04 PM), <https://www.kold.com/2020/12/07/advocates-call-people-with-developmental-disabilities-be-some-first-get-covid-vaccine>.

repeatedly contacted federal and state agencies to stress the importance of expressly including PwDs in vaccination planning documents and to prioritize these individuals for vaccination.¹²⁵ Such plans demonstrate a neoliberal view of product(ivity) that continues to marginalize PwDs through a social utility that devalues the contributions of PwDs to society.

V. RECOMMENDATIONS: POLICY AND PRACTICE

The emergence of COVID-19 was an unprecedented public health crisis that required a rapid response.¹²⁶ Those in health care and bioethics have worked tirelessly to rise to the challenge facing them with little to no preparation.¹²⁷ Their efforts are nothing short of miraculous, and their achievements should be applauded. However, in times of crisis we cannot abandon our commitment to justice and nondiscrimination. Ethically and legally, we have a responsibility to care for the most vulnerable. This section will offer five recommendations for improvement in the creation and implementation of crisis standards of care for PwDs.

A. *Plan Ahead*

Crises such as 9/11, the H1N1 pandemic, and Hurricanes Katrina and Rita highlighted the need for emergency guidelines that provide specific assistance to PwDs.¹²⁸ However, crisis response recommendations by the CDC and the Federal Emergency Management Agency have proven relatively futile in dealing with the unique challenges of COVID-19.¹²⁹ For example, suggesting that in times of crisis PwDs should rely on a “personal support network” comprised of multiple people has not been possible due to the need to mitigate the spread of the virus using social distancing measures.¹³⁰ While COVID-19 has wreaked havoc on the daily routines of most people, those with disabilities have been particularly devastated. Residents of congregate care settings are especially vulnerable during a public health crisis.¹³¹ Changes in routine, including less/different staff members, dwindling resources, the inability to self-

125. *DREDF's Comment Letter on the NASEM COVID-19 Vaccine Allocation Framework*, DISABILITY RTS. EDUC. & DEF. FUND (Oct. 15, 2020), <https://dredf.org/2020/10/15/dredfs-comment-letter-on-the-nasem-covid-19-vaccine-allocation-framework/>.

126. *NIH Director: Defeating COVID-19 Requires Unprecedented Action and Collaboration*, NAT'L INSTS. OF HEALTH (May 18, 2020), <https://www.nih.gov/news-events/news-releases/nih-director-defeating-covid-19-requires-unprecedented-action-collaboration>.

127. See Sara Berg, *4 Ways COVID-19 is Causing Moral Distress Among Physicians*, AM. MED. ASS'N (June 18, 2020), <https://www.ama-assn.org/practice-management/physician-health/4-ways-covid-19-causing-moral-distress-among-physicians>.

128. *Disability, Ethics, and Health Care*, *supra* note 16.

129. *Id.* at 1524.

130. *Id.* at 1523–24.

131. *Id.* at 1526.

monitor or accurately communicate symptoms, and the inability to social distance, coupled with restrictions on the “personal support network” of visitors, has been devastating.¹³² Death rates in congregate care settings are disproportionately higher than almost anywhere else.¹³³ As of November 24, 2020 forty percent of all COVID-19 related deaths in the U.S. occurred in long-term care facilities.¹³⁴ These concerns were identified by disability scholars and activists long before the pandemic as being discriminatory and potentially dangerous, yet nothing was done.¹³⁵

While advanced planning alone may not have been enough to completely remove these obstacles, it certainly would have gone a long way towards improving the living conditions of PwDs during COVID-19. Suggestions include:

Significant investment in congregate care settings is required to rethink their architectural design (such as the need for separate toilet facilities to reduce contagion), improve remote forms of communication and recreation, carry out advance planning in case of public health disasters, obtain resources that will diminish the hazards of catastrophic events, and establish protocols for ombudspersons to safely monitor facilities, even under pandemic restrictions.¹³⁶

Home and community-based services are essential for some people with disabilities. For those relying on home health care, designating DSPs as essential workers in advance of the pandemic would also have offered some protection, both to PwDs and providers, allowing them access to PPE and other scarce resources.¹³⁷ Proactive policies that protect not only PwDs, but those who care for them are critical.¹³⁸

Inclusive planning could also help address the inaccessibility of remote health care by providing appropriate training to individuals staffing testing sites, increasing the number of accessible testing sites, providing location-based testing (such as in a congregate care setting), and improving security and accessibility features of telehealth.¹³⁹ These are all expected and reasonable accommodations in non-pandemic times, in adherence to the protections laid out in the ADA.¹⁴⁰ Planning ahead would ensure that these protections are honored

132. *See id.* at 1524–26.

133. Priya Chidambaram et al., *Long-Term Care Residents and Staff*, KAISER FAM. FOUND. (Nov. 25, 2020), <https://www.kff.org/policy-watch/covid-19-has-claimed-the-lives-of-100000-long-term-care-residents-and-staff/>.

134. *Id.*

135. Guidry-Grimes et al., *supra* note 19, at 29.

136. *Id.*

137. *Id.*

138. *Id.*

139. *Id.* at 30; *Disability, Ethics, and Health Care*, *supra* note 16, at 1524, 1526.

140. Solomon et al., *supra* note 96, at e27(3).

and that vulnerable populations are not marginalized by a failure to prioritize access to health care.

B. *Improve Communication*

As referenced earlier in this article, there have been myriad issues regarding communication for PwDs during this pandemic, from inaccessible information and insufficient PPE to inaccessible remote health care.¹⁴¹ In addition to many of these examples being blatantly discriminatory, if “communicating the risks, measures of prevention and treatment options before, during and after the emergency are key to slowing down a pandemic and improving health outcomes,”¹⁴² then these measures are also a threat to the health of the general public. Accessible communication is an expectation set forth by the ADA, and many of these issues had been identified and could have been addressed prior to the pandemic.¹⁴³ It is clear planning for multiple methods of communication, such as requiring captioning or ASL interpreters, is standard practice and not something that is abandoned in times of crisis.¹⁴⁴ The ADA requirement of “reasonable accommodations” should provide assurances that people with communication or mobility impairments will not be left behind by ensuring that there are policies in place before a crisis hits.¹⁴⁵ The neglect to provide effective communication for PwDs is both exclusionary and antithetical to the goal of preventing and mitigating the spread of COVID-19.

C. *Be Transparent*

The rationale behind the creation of crisis standards of care should be as transparent as possible. While all people would benefit from knowing what to expect in a crisis situation, those communities that have historically been mistreated by the medical community, in particular, need to know as much as possible about the process of creating and implementing crisis standards of care. Because there are no national guidelines, the perception of triage protocols as being determined based on the whim of an individual or group of people in power is dangerous for a situation that requires trust in the medical community. Without transparency, the tendency for vulnerable populations and minoritized groups to avoid seeking medical care for fear of bias and discrimination can increase.¹⁴⁶

141. Guidry-Grimes et al., *supra* note 19, at 29; *Disability, Ethics, and Health Care*, *supra* note 16, at 1524.

142. *Disability, Ethics, and Health Care*, *supra* note 16, at 1524.

143. Solomon et al., *supra* note 96, at e27(3).

144. *See Disability, Ethics, and Health Care*, *supra* note 16, at 1524.

145. Solomon et al., *supra* note 96, at e27(3).

146. Guidry-Grimes et al., *supra* note 19, at 30.

Transparency is also needed with regards to reporting COVID-19 statistics, particularly if such data is being used to determine care and vaccine prioritization—the absence of such data for PwDs can be fatal.¹⁴⁷ While there has been recognition of the need to create better emergency guidelines and crisis standards of care for PwDs, there is limited data to work with.¹⁴⁸ Federal agencies and public health organizations need to ensure that data is being accurately collected on COVID-19 and its relation to disability status. This should include testing, diagnoses, care guidelines, care received, and deaths. This data needs to be aggregated, analyzed, and published in an open-access and accessible format to allow for transparency both in response to the current pandemic and as a way to prepare for future crises.¹⁴⁹

D. Create Triage Committees to Oversee Decision-Making

Without any type of consistent, national framework guiding decision-making processes, determinations over the allocation of scarce resources and crisis standards of care protocols are increasingly difficult to monitor and regulate.¹⁵⁰ Creating triage committees to oversee the decision-making process can provide a barrier against personal bias. Principles of justice and equality call for triage considerations to be made based on medical assessments of each individual patient, free of “any information about patients that could be stigmatizing, such as name, socioeconomic status, ethnicity or any disability that is medically irrelevant for the particular decision being made.”¹⁵¹ With a triage committee comprised of several people, ideally none of whom are directly involved in the care of the patient, the only factors that are pertinent to the case are ones that are medically based.¹⁵² Any and all characteristics not directly applicable to the clinical outcome are omitted from committee review, thereby substantially reducing the potential for personal bias and discrimination.¹⁵³

E. Respect Disability Rights

Michelle M. Mello, Govind Persad, and Douglas B. White offer six guideposts for respecting disability rights in the creation of crisis standards of care.¹⁵⁴ Four are related to decision making, while the other two are policy-based.¹⁵⁵ The first recommendation is to prohibit the use of categorical exclusions, particularly those based on disability or diagnosis (which often leads

147. *Id.*

148. *Disability, Ethics, and Health Care*, *supra* note 16.

149. Guidry-Grimes et al., *supra* note 19, at 30.

150. *See id.* at 29.

151. *Id.* at 30.

152. *Id.*

153. *Id.*

154. Mello et al., *supra* note 82, at e26(3)–(4).

155. *Id.* at e26(4).

back to disability).¹⁵⁶ Their second suggestion is to reject quality of life as a value judgement on which to make medical decisions.¹⁵⁷ Third, they advocate for the use of near-term prognosis as opposed to long-term life expectancy.¹⁵⁸ Fourth, they argue that chronic-use ventilators should not be permitted to be re-allocated to other patients in the hospital.¹⁵⁹ These four recommendations are practice-based and echo the sentiments put forth earlier in this Article by disability scholars and activists.¹⁶⁰

Their fifth recommendation is procedural and relates to the training and implementation of triage officers who are familiar with disability rights.¹⁶¹ These officers would be tasked with respecting the rights of PwDs and ensuring that only objective medical information is used in patient assessment and evaluation.¹⁶² Their final recommendation is to include disability rights advocates in the development and dissemination of policy.¹⁶³ They argue that “[d]oing so shows respect, helps avoid paternalism, augments procedural fairness, and may produce substantively better guidelines. It may also help avoid ambiguities in guidelines that invite misapprehension and speculation.”¹⁶⁴ Disability rights advocates have rallied behind the phrase, “Nothing about us, without us.”¹⁶⁵ Including people with disabilities in the planning, implementation, and dissemination of crisis standards of care policies would preserve, to the greatest extent possible, the integrity, justice, and equality of medical decision making during a crisis.¹⁶⁶

Respect for disability rights goes beyond crisis of care, however; it needs to be foundational to all care during a pandemic and beyond. This includes a fair consideration of health care needs (such as masks and ventilators), reasonable accommodations for remote health care, and equitable consideration when it comes to vaccine prioritization. While PwDs are afforded a number of protections under the ADA,¹⁶⁷ the COVID-19 pandemic has revealed two disturbing realities about those protections: a willingness by society to deprioritize them and the limitations of those very protections. There is an opportunity to learn from this pandemic about how to strengthen the ADA and

156. *Id.*

157. *Id.*

158. *Id.*

159. Mello et al., *supra* note 82, at e26(4).

160. *See Disability Community Fights*, *supra* note 81; Singh, *supra* note 88.

161. Mello et al., *supra* note 82, at e26(4).

162. *Id.*

163. *Id.*

164. *Id.*

165. Guidry-Grimes et al., *supra* note 19, at 28

166. *See Disability, Ethics, and Health Care*, *supra* note 16, at 1524, 1526.

167. *See Solomon et al.*, *supra* note 96, at e27(3).

adherence to its requirements so that PwDs are not mistreated during a crisis of care and beyond.

VI. CONCLUSION

Rather than viewing COVID-19 as a once-in-a-lifetime pandemic for which global health systems could not adequately prepare, we need to understand it in light of systemic inequalities that have exacerbated the health impacts on marginalized groups, especially PwDs. It is important that we do not allow a crisis situation to be an excuse to further marginalize a group by neglecting their moral and legal rights to fair treatment and care. As the one-year anniversary of the discovery of the coronavirus approaches, society has begun to acknowledge the unjust, unethical, and ineffective methods that have been haphazardly put into effect to deal with this crisis and the effect these policies have had on the disabled community. The challenge we now face is to remedy these policies of exclusion.