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Commentary

Ever-changing but always constant: “Waves” of disability discrimination during the COVID-19 pandemic in the United States

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ABSTRACT

The ongoing novel coronavirus 2019 (COVID-19) pandemic has had considerable effects on the disability community. As the pandemic has progressed and changed, the manifestations of these effects have differed, and yet the underlying causes—ableism including the devaluation of disabled lives—have remained consistent. In this commentary, we explore the impact of the pandemic on the disability community in the United States, conceptualizing four distinct but overlapping “waves” of discrimination: 1) healthcare rationing and missed opportunities for disability inclusion, 2) access to resources, supplies, and accommodations; 3) vaccine access; and 4) long COVID and disability identity. Throughout our discussion of these waves, we detail the discrimination faced by people with disabilities, the underlying ableism that perpetuates it, and the resilience shown by the disability community. We end with a call for combating systemic ableism in healthcare and public health systems.

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The novel coronavirus (COVID-19) pandemic created a worldwide health crisis with far-reaching and ongoing effects. Marginalized communities have often been disproportionately adversely affected by the pandemic, due to historical and current systemic inequities and biases that are often further illuminated in times of crisis.^{1–3} The disability community is one such community. In this commentary, we utilize a chronological approach to explore difference ways people with disabilities have encountered ableism and its effects throughout different eras of the pandemic, with a focus on the United States. We conceptualize these different manifestations as “waves,” occurring in distinct but overlapping timeframes. Although this commentary reflects a cross-disability view, it is notable that people with some disabilities are at greater risks of negative outcomes than others. For example, after age, intellectual disability is the second strongest independent risk factor for death from COVID-19.⁴ These differences may be due to physiological factors, environmental factors (e.g., institutional housing), and social factors (e.g., pre-existing isolation) that may be more pronounced in some subgroups within the broader disability community.⁵

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Wave 1: healthcare rationing and missed opportunities

During the initial global spread of COVID-19, many governments and healthcare agencies experienced concerns or issues related to the possible shortage of medical equipment, such as ventilators, and services.⁶ This led many governments and hospitals to create healthcare rationing plans, or crisis care standards, that outlined which patients would and would not be prioritized for care in the event of a shortages.⁷ Many of these plans placed individuals with pre-existing disabilities at an automatic disadvantage, often under the presupposition that the presence of a disability de facto conveyed a lower quality of life and thus decreased the priority of saving that life.³

There was swift and strong reaction from the disability community and disability rights organizations when these plans were made public,⁷ including lawsuits and federal civil rights complaints. These complaints resulted in guidance from the United States Office for Civil Rights (OCR), stating that the growing pandemic did not suspend disability civil rights legislation. Thus, the agency advised, healthcare rationing plans that discriminated on the basis of disability were not legal.⁸

In spite of this regulatory victory for the disability community, fears about possible disability discrimination in healthcare allocation remained high.^{3,7} In the absence of formal guidance,

healthcare rationing decisions in times of crisis are typically remanded to physicians,⁶ who often hold considerable levels of implicit⁹ and explicit¹⁰ bias against patients with disabilities. Thus, many people in disability community remained concerned that the medical judgments of healthcare providers would be compromised by underlying ableism and a lack of belief in the value of disabled lives.^{5,11} These concerns were even more pronounced among disabled people of color, who experience dual and intersectional legacies of both ableism and racism in healthcare.⁵ Crisis care standards developed by teams inclusive of people with disabilities were less likely to discriminate on the basis of disability.¹² Despite this finding, input from disabled people, including disabled people of color, remains largely missing from crisis care standards, many of which are not shared with the public.

Sadly, there are some documented instances of disability discrimination in the provision of healthcare occurring during the pandemic. For example, Sarah McSweeney, a White woman with intellectual disabilities died of non-COVID-related pneumonia in May 2020, after being denied access to a ventilator and additional intensive care unit (ICU) services.¹³ According to her caregivers, explanations that McSweeney did indeed have a good quality of life were met with questions about her ability to walk,¹³ suggesting that her physicians' views of quality of life were very much grounded in ableist thinking. In an example of intersecting ableism and racism, Michael Hickson, a Black man with a spinal cord injury and traumatic brain injury, died of COVID-19 in June 20, 20.¹⁴ During recorded conversations with Hickson's wife, his physicians claimed that due his disabilities, Hickson "didn't have much of a quality of life"¹⁴ and thus saving his life was not prioritized.

To much of the disability community, the healthcare rationing controversies during the pandemic were both alarming and unsurprising. Disabled lives, especially the lives of multiply marginalized disabled individuals, have long been devalued,¹⁵ viewed as less worth living,¹⁶ and even openly targeted for genocide.¹⁷ Healthcare rationing during the pandemic was in many ways a continuation of these issues, explaining the strong and immediate backlash from disability activists when healthcare rationing plans attempted to openly codify such discrimination.⁷ Likewise, the caution around ableism in physicians' case-by-case decision-making represents the longstanding issues of medical ableism and health inequity.^{18,19} In other words, the pandemic simply shined a brighter light on pre-existing biases, discrimination, and inequity at the intersection of healthcare and disability.

While devastating, the early weeks and months of the pandemic afforded multiple opportunities to include disability in data collection and monitoring efforts that were largely, and unfortunately, missed. Data collection about infection rates and outcomes of various marginalized groups in the United States began to provide important insights to direct the COVID-19 response.²⁰ Despite urging from advocates,⁵ government agencies,²¹ and legislators,²² disability identifiers were often omitted from surveillance and data collection systems monitoring outbreaks at both the state²¹ and federal²² levels. It would not be until 2021 that the Centers for Disease Control and Prevention would update their identifiers to include one question about disability.²³ Left to rely on circumstantial information and inferences, disability was often an afterthought in the public health emergency response rather than a part of the early days of planning. Although it was almost immediately known that individuals residing in congregate facilities, like carceral settings and group homes,²⁴ were at an increased risk of infection with COVID-19, the public health emergency response to this knowledge varied widely, and there were not urgent efforts to move people with disabilities out of congregate settings. A lack of representation on COVID-19 response teams, led by states, contributed to this problem.¹²

Wave 2: access to resources, supplies, and accommodations

In addition to the explicit issues of healthcare rationing described above, there were also secondary issues of access to resources, supplies, and accommodations among people with disabilities during the pandemic.⁵ Because healthcare supplies were directed to hard-hit hospitals, many people with disabilities who use medical supplies as part of their standard care routines found it more difficult to access the supplies they needed.¹¹ Some individuals with disabilities also struggled to access routine medical care, either online or in-person. Because many people with disabilities are at high-risk of adverse outcomes of COVID-19 due to primary or secondary health conditions^{19,25}, many followed stay-at-home guidelines strictly and chose not to seek face-to-face care.²⁶ Although telehealth was an option for some, others struggled to access this care due to lack of reliable high-speed internet, privacy, or disability-related considerations that made it difficult to access telehealth platforms.² These issues were often heightened for people with disabilities due to the strong connections between disability and poverty, and the connections between poverty, lack of reliable internet access, and crowded living spaces.^{1,5} As a result, people with disabilities were often faced with the impossible decision to either seek care and risk contracting—and potentially dying of—COVID-19 and not seeking care but risking the exacerbation of a serious illness. These barriers, combined with PPE and testing shortages,²¹ heightened reliance on others for personal care,² and heightened likelihood of residing in group or institutional residences,^{5,21,22} increased the barriers to accessing safely medical and personal care for many disabled individuals.

Likewise, the need to strictly isolate and socially distance increased the risks of social isolation for people with disabilities, exacerbating a pre-existing issue in the disability community.⁵ People with disabilities for whom home was not necessarily safe due to interpersonal and domestic violence were often forced to isolate with perpetrators of abuse and to rely on these individuals for life-saving care and assistance.² In the quick shift towards digital care, connection, and education, accessibility issues were often an after-thought, resulting in many programs and supports not being immediately accessible to individuals with disabilities, especially those who have difficulty accessing digital media.²⁷ As a result, because disability-related access needs were often considered only after initial plans were put into place, people with disabilities often contended with poor access to services and supports for longer periods of time than did their non-disabled peers.²⁷ Ironically, people with disabilities have also faced issues around the expedited push to "return to normal". For example, the pandemic established teleworking as a viable and reasonable accommodation for many jobs,^{28,29} reducing access barriers for individuals whose disabilities make in-office work more challenging. However, many companies have pushed "return to office" policies at various points during the pandemic,^{28,30} potentially re-creating access barriers for employees who were helped by telework, including those who are at high risk for complications from COVID-19 and thus would likely be safer continuing to work from home.

The isolation necessitated by the pandemic was simultaneously necessary for the continued health and survival of many people with disabilities and a significant detriment to their mental health and well-being. Social isolation and the fear of contracting COVID-19 negatively impacted the mental health of people with disabilities³¹ while simultaneously creating barriers to accessing care. For many people with disabilities, the pandemic created a situation where the usually implicit devaluation of disabled lives and the general lower priority given to the needs of disabled individuals was explicit^{3,7}. On a practical basis, this impacted things like access to services, care, education, and support^{1,11} while also putting the

prevalence and depth of ableism on full display,⁵ thus acting on both physical and psychological determinants of health.

Wave 3: vaccine access

As COVID-19 vaccinations became more widely available, vaccination access among people with disabilities continued to lag.²³ Various issues contributed to this, including reliance on skeptical caregivers for assistance in accessing the vaccine,³² lack of prioritization of many disability groups in vaccine roll-out plans³³ and hesitancy about the potential side effects of vaccination in people with pre-existing conditions.³⁴ Additionally, many people with disabilities, especially disabled people of color, expressed concerns about potentially being targets of medical “experimentation” with the vaccine.³² This is likely reflective of the long history of medical maltreatment and dehumanization of both people of color^{1,5} and people with disabilities³ and reflects the inherent difficulty of trusting a system that has often affirmatively showed that it cannot be trusted. Such historical grounding likely also contributed to the spread of misinformation about the vaccination and resulting hesitancy among some people with disabilities,³⁵ although people with disabilities were still more likely than non-disabled people to express a desire to be vaccinated.²³

Among people with disabilities who wished to receive the vaccine, systemic access barriers often made this more challenging. For example, vaccine appointment systems were often not screen-reader accessible,³³ individuals with rare disabling conditions were overlooked during the vaccine prioritization process as being “high-risk” due to a lack of research specific to the intersection of that condition and COVID-19.³³ Disability groups were often not consulted about specific issues facing their communities during the initial vaccine roll-out.³⁴ Researchers found hundreds of errors concerning COVID-19 testing, treatment, and vaccination identified hundreds of persistent errors on states’ public health websites,³⁶ potentially contributing to confusion and lack of access among the disability community.^{33–36} Many of the issues are again reflective of the general marginalization of the disability community during times of crisis—disability access is often an afterthought in broader plans.^{3,5,7,12} At the same time, disabled advocates are often deprioritized in favor of non-disabled professionals who are presumed, correctly or incorrectly, to have expertise on disability,¹⁸ thus creating a continual, systemic silencing of disabled voices and perpetuating health inequity.

Wave 4: long COVID and disability identity

An increasing concern during the pandemic has been the potential for people to acquire “long COVID”, often formally referred to as post-acute COVID syndrome (PASC). PASC refers to a heterogeneous cluster of potential renal, pulmonary, cardiovascular, neurological, and psychiatric symptoms that may linger for weeks or months after an individual has recovered from an acute COVID-19 infection.³⁷ The potential for post-acute effects of COVID has been described throughout the pandemic,³⁷ with cardiovascular, pulmonary, neurological, and psychiatric symptoms being perhaps the most well-noted. The pathophysiology and treatment of various PASC effects is not yet well-understood,³⁷ putting healthcare providers in an often-challenging situation when supporting patients reporting sometimes debilitating PASC effects,^{38,39} and, like other medical research,¹⁸ research on PASC often fails to come from a disability-informed lens.

To some people experiencing severe PASC, the symptoms become disabling, forcing them to confront the potential reality of being disabled, possibly for an extended period of time.³⁸ A lack of established and effective protocols for PASC³⁹ means that people

experiencing functional limitations related to PASC often must consider environmental accommodations to address the impact of their symptoms in addition to seeking medical care. This essentially introduces them into the disability community—although not all individuals with disabling chronic illnesses may identify as disabled⁴⁰—and increases the importance of educating people with functional limitations related to PASC on issues like disability rights, terminology, and accommodation requests. Because physicians and other healthcare providers may not be well-versed in the psychosocial aspects of disability,^{10,41} this potential lack of connection between PASC and the existence of the disability community may in fact create another avenue for disability marginalization in the pandemic and places the task of educating and mentoring newly disabled individuals solely on the disability community. This creates both an opportunity for community building and a potential burden on the disability community, as activists provide time, resources, and support to help newly disabled individuals with PASC navigate the day-to-day realities of living with a disability, including navigating interpersonal, medical, and systemic ableism and disability discrimination. Illness and resulting functional limitations do not stop at the clinic door, and disabled peers often provide support when medical answers are lacking, limited, or difficult to find.¹⁸

Conclusion

The waves of discrimination experienced by people with disabilities throughout the COVID-19 pandemic illustrate the rapidly changing landscape of the pandemic and common themes of failure in the public health response. The devaluation of disabled lives was first evidenced by policies to withhold care or equipment as policymakers grappled to ration equipment and healthcare capacity. While society has rapidly gained knowledge about this previously unknown disease, we have repeatedly failed to capitalize on the opportunity to collect data about disability, which could lead our response in protecting the lives of this vulnerable group. This erasure has been present from the initial lockdown responses, to the vaccine rollout, to the response to PASC—data on disability and the inclusion of disabled individuals has been a continual afterthought through the pandemic.^{1,5,7,12,21,22}

Although the manifestations of these impacts have varied throughout the pandemic, all are ultimately rooted in the pervasive ableism in our healthcare, public health, and emergency response systems, and in society at large. It is important to note both the great burden placed on the disability community during the pandemic, as well as the resilience, advocacy, and strength that the disability community has demonstrated. Also critical is the urgent call to integrate lessons learned from the illumination of ableism during this pandemic so we may discontinue rather than perpetuate it in our future responses. Disability must be actively included public health responses from data collection to messaging to interventions, and the structural, political, and social factors that contribute to the marginalization of disability in public health and pandemic responses must be acknowledged, challenged, and fixed.

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