DISABILITY IN THE TIME OF PANDEMIC

Edited by Allison C. Carey,
Sara E. Green and Laura Mauldin

RESEARCH IN SOCIAL SCIENCE
AND DISABILITY

VOLUME 13

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INTRODUCTION TO DISABILITY IN THE TIME OF PANDEMIC

Laura Mauldin[1], Sara E. Green and Allison C. Carey

In March 2020, as the pandemic arrived in the United States and generated a new reality of fear and anxiety, disability scholars and disabled people got to work.[1] From past experience of pandemics and national emergencies more broadly, they expected that disabled people, particularly disabled people of color, would be the most likely to die from COVID-19 and among the least likely to be protected from it. Their expectations proved to be true. The United States Centers for Disease Control quickly learned that those with chronic illnesses or disabilities, as well as those over the age of 65, occupy the highest risk categories for COVID-19 (CDC, 2019). Indeed, COVID-19 disproportionately affects disabled, chronically ill, and elderly people across the globe.

DISABILITY IN THE TIME OF PANDEMIC: DIFFERENTIAL HEALTH OUTCOMES

The expectation that people with disabilities and chronic health conditions would be disproportionately affected by the pandemic was confirmed from the start and solidified as the pandemic unfolded. Cloaked in the language of "pre-existing conditions," "underlying conditions," or "co-morbidities," studies found that people in those categories, that is, disabled people, died at four times the rate of able-bodied people (e.g., Choi, 2021). Congregate settings – a broad category including sites of long-term care like nursing homes, rehabilitation facilities, elderly housing facilities, shelters for unhoused people, and prisons – were hit the hardest due in part to being unable to isolate, often combined with inadequate access to protective equipment and poor overall conditions. Here again, disabled

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[1] Laura Mauldin is lead author on this introduction. The author order for the volume is alphabetical and denotes equal contributions by the three authors to the overall volume.

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people were disproportionately vulnerable because they are far more likely to be institutionalized in some way than able-bodied people (Landes et al., 2020). Indeed, in 2020, more than 41 percent of all COVID-19 deaths in the US were linked to nursing home residents or care workers (Centers for Medicaid and Medicare Services, 2020).

Demonstrating the intersecting disadvantages associated with race and disability that pre-dated the pandemic (e.g., Frederick & Shifrer, 2019), nursing homes with higher populations of non-white residents fared worse than those with primarily white residents (Gebeloff et al., 2020; Kim, 2020). Meanwhile, disabled residents (and their care workers) in smaller congregate care settings like group homes were "dying from the virus at a higher rate than the wider populations" (MacDonald, 2020), although not all governmental bodies kept statistics on these locations (Knezevich, 2020). Tsaplina and Stramondo (2020) reported that "Congregate housing for disabled people in New York other than nursing homes also shows infection and death rates far above average that may equal or even exceed those of nursing facilities" (Tsaplina & Stramondo, 2020). In New York State, residents of group homes for people with intellectual and developmental disabilities were far more likely than the general population to develop COVID-19 and far more likely to die from it (Landes et al., 2020).

Once infected, disabled people faced additional barriers, such as discrimination in healthcare. Multiple states in the US released "triage plans" for rationing care during the crisis and disabled people as a category were planned targets of treatment denial (Ne'eman, 2020). This was evidenced in "Alabama's Emergency Operations Plan that would deny ventilators to folks with severe or profound intellectual disabilities, or Tennessee, where those with spinal muscular atrophy who require help with activities of daily living would be denied treatment in a pandemic" (Stramondo, 2020). Like the general population, many medical professionals carry with them ableist perceptions that the quality of life for disabled people is invariably and necessarily low (Iezzoni et al., 2021). Drawing implicitly and explicitly on eugenics, some politicians and other public figures advocated letting disabled and elderly people die. The Lieutenant Governor of Texas suggested that older people should sacrifice themselves so the economy would not get destroyed (Levin, 2020), and a California official suggested that the virus be left to take its natural course on "the sick, the old, the injured" (Ormseth, 2020).

Around the world, general healthcare also became more inaccessible, threatening the well-being of disabled people. Many health services went online, but access to computers and the internet are unequally distributed. Medical care that was not COVID-19 related was deprioritized, leaving many people who are dependent on treatments and therapies in the lurch. The combination of high need and limited resources created a "thin margin of health" for people with disabilities, such that accessing even vital health care became uncertain (Kennedy et al., 2020, p. 5; see also Lederer, 2020; Prior, 2020).

As we write this in the spring of 2022, over 1 million people in the US have died and, according to the National Center for Health Statistics, the majority of these have been elderly people (CDC, 2022). In a recent National Council for Disability report on the impact of COVID-19 on disabled people, they write that "disability status as a demographic fact is not required or asked on death certificates, it is extremely difficult to establish even the bare fact of how many people with disabilities died from COVID-19" (2021, p. 40). They also argue that various studies of different disability populations indicate that disabled people were far more likely to die than nondisabled people. There "...is still not, however, an actual count of the numbers of COVID-19 infections or deaths of people with disabilities who have died directly as a result of contracting COVID-19" (NCD, 2021, p. 40).

But there are clues from one study in the UK: one study found that 17% of the population had a disability, but disabled people made up nearly 60% of COVID-19 deaths (Bosworth et al., 2021). On its face, the fact that more disabled than non-disabled people may have been affected by the COVID-19 pandemic might seem easily explainable by purely biological factors. Our goal as social scientists, and the goal of this volume, however, is to produce scholarship that improves our understanding of the social causes and consequences of the unequal distribution of disease. A social scientific approach to disability during the pandemic starts with the premise that while there may be physiological reasons for the particularly deadly effects of the virus on disabled people once they are exposed, the disproportionate spread of COVID-19, risk of infection, and other negative distal effects in these populations are the result social arrangements in which disabled people are disadvantaged.

DISABILITY IN THE TIME OF PANDEMIC: DIFFERENTIAL SOCIAL AND EMOTIONAL OUTCOMES

While evidence on the social effects of the pandemic is still accumulating, early research suggests that COVID-19 has had ramifications that reverberated throughout the economy, education, community life, and the social world. In the process, the pandemic revealed the economic and social marginality of disabled people. Economically, disabled people lost their jobs at higher rates, despite their already low employment rates. Between March and April 2020, employment fell by 24% for disabled people compared to 18% for the general population (Brooks, 2020; Maroto & Pettinicchio, 2020). Job loss was particularly severe for White and Black disabled women who tend to work in industries hit hardest by the pandemic (Schur & Kruse, 2020; Schur et al., 2021). Because recipients of disability benefits are often prohibited from saving because of program limits, they are also uniquely unprepared for economic emergencies.

Education was transformed, and these transformations were often unresponsive to the needs to disabled children and/or parents. Some disabled students needed the health protections afforded by the shift to online education, but were disadvantaged by the social isolation. Other students needed educational services that required face-to-face interaction, and even hands-on activities, in order to be successful. The individualized nature of meeting student needs often were cast aside as districts implemented hastily constructed emergency plans. Many students lost key components of their individualized education plans (Sonnenschein et al., 2022). Children and adults with disabilities also lost access to disability services outside of the school system. Many programs, such as arts and recreational programs and worship services, went online or into hiatus. Community-based direct care staffing became perilously unstable. Rarely did disabled people and their families have input into how their services and supports transformed (Schormans et al., 2021).

Early evidence also suggests that social and economic upheaval associated with the pandemic had serious consequences for the psychological health and emotional well-being of many people (Pfefferbaum & North, 2020; Rajkumar, 2020; Usher et al., 2020; Vindegaard & Benros, 2020). There is some evidence that the pandemic has increased discrimination toward people who were already targets of stigma before the pandemic – including people with disabilities and chronic health conditions (Abrams & Abbott, 2020; Bagcchi, 2020; Chen & McNamara, 2020; Maroto et al., 2021). Discrimination and stigma are known to have negative psychological consequences for people with disabilities (Brown, 2017; Ciciurkaite et al., 2021; Namkung & Carr, 2020). Lack of participation in social and recreational activities has also been shown to be negatively associated with well-being among people with disabilities (Green & Vice, 2017). Thus, the pandemic is likely to have decreased well-being through increased discrimination and social isolation.

DISABILITY IN THE TIME OF PANDEMIC: A ROAD MAP TO THIS VOLUME

The social and emotional effects of the pandemic noted above are variable, complex, and likely to extend far into the future in novel ways. As we live through the radical transformation of work, school, and family life, we need to understand how such transformations affect social arrangements that are already precarious for people with disabilities. Understanding the disproportionate effects of the pandemic on disabled people in their varied communities and across their complex identities requires that a variety of disciplinary and interdisciplinary lenses and analytic tools be put to use with data from around the world.

Authors in this volume approach their research using the insights, perspectives, and methods of a variety of social science disciplines and related areas of professional expertise. These include Anthropology, Disability Studies, Education, Physical and Rehabilitation Therapies, Public Health, Psychology, Sociology, and Women's and Gender Studies. They are affiliated with institutions in both the Global North and the Global South, and the data on which the research presented in this volume is based come from Canada, India, Poland, and the United States. The chapters in this volume also include collaborations across disciplines, among students and seasoned academics, among people in and outside of academic institutions, and among people with and without lived experience of disability. The volume includes both quantitative analysis of large data sets suitable for testing hypotheses about the relationship between disability status and various kinds of pandemic-related outcomes, and qualitative analysis of interviews, case studies, observations, and textual data to uncover nuanced patterns of pandemic experiences within the context of disability. A number of chapter authors explore complex social locations and intersectional identities that interact with disability and the pandemic in people's lives.

We have organized the volume around two broad inter-related themes. Chapters in Part 1, *Implications of the Pandemic for the Health, Well-being, and Care of People with Disabilities and their Families*, address differential vulnerability to negative pandemic-related outcomes such as access to services; social, emotional, and economic well-being; and opportunities for meaningful social interaction. In Part 2, *Implications of the Pandemic for People with Disabilities in Educational and Workplace Settings*, we turn our attention to how the pandemic affected people with disabilities in two specific contexts. Educational and workplace settings are particularly interesting because they are known to be spaces in which people with disabilities experience significant discrimination and stigma and yet they are also spaces in which inclusive programs have been intentionally developed and accommodations have been mandated.

Part 1: Implications of the Pandemic for the Health, Well-Being, and Care of People With Disabilities and Their Families

In Chapter 1, Jayajit Chakraborty reports results of a large scale quantitative study examining the relationship between county-level pandemic vulnerability and disability distribution in the United States. Findings show that not only is the percentage of disabled people in the population higher in counties that are more vulnerable to the pandemic, the most vulnerable counties also contain the highest percentage of people whose disability identity intersects with other disadvantaged social locations such as being a member of a racial/ethnic minority group, being female, living in poverty, and being unemployed. This chapter establishes a theme that runs through the entire volume – preexisting disadvantages were exacerbated during the pandemic. In Chapter 2, Valérie Grand'Maison and colleagues explore the impact of pandemic-related public policies on people with disabilities in Canada. Findings suggest a mechanism through which the pandemic reproduced preexisting inequalities. The chapter argues that pandemic-response policies that overlooked the social, economic, and housing precarity in which disabled people often live can worsen preexisting disadvantages – especially among people with disabilities from historically marginalized groups. In Chapter 3, Michelle Maroto and colleagues examine the positive and negative outcomes of social distancing – one particular pandemic response – in a mixed methods study of Canadians who live with disabilities and chronic health conditions. They found that people with disabilities felt that while social distancing measures such as avoiding contact with non-household members, avoiding public places, and transitioning to remote work/school offered vital protection against the disease, they also often resulted in increased loneliness and anxiety.

In Chapter 4, Srishti Jaitely and Gaurav turn our attention to pandemic experiences of people living in informal settlements in Mumbai, India. Using a qualitative case study approach including observations and interviews, the authors found that pre-pandemic disadvantages such as social and economic difficulties, environmental inaccessibility, limited transportation, and lack of disability-specific training among healthcare workers interacted with the pandemic in important ways and created significant barriers to the success of pandemic-related resource mobilization. In Chapter 5, Fernandes and Sarkar also address pandemic experiences in India through a critical discourse analysis of the media constructions of disabled children's lives, needs, and desires during the pandemic. They show how the disaster framing of the pandemic masked preexisting inequality and neglect and contributed to a narrative construction of disabled children as vulnerable and burdensome.

Chapter 6 ends the first part of the volume by bringing us back to the United States. Joana Milan Lorandi and Pamela Block explore the experiences of people with complex health conditions before and during the pandemic through 12 in-depth interviews with six participants. They draw particular attention to the ways in which participants imagined post-pandemic futures based on experiences before and during the pandemic. They conclude that participants felt they had been targets of ableism in the health system before the pandemic and feared that barriers to fair treatment and access to health care had been pushed to new heights by the pandemic.

Taken together, the six chapters in Part 1 tell a story in which pre-existing social, and economic disadvantages experienced by people with disabilities in Canada, India, and the United States interacted in complex ways with public policies, media coverage, and the virus to create additional layers of disadvantage and barriers to well-being for people with disabilities that may persist in a post-pandemic world. These chapters also suggest that pandemic-exacerbated inequalities intersect with those associated with other disadvantaged social locations – leaving the lives of those at the intersections in particularly precarious post-pandemic positions.

Part 2: Implications of the Pandemic for People With Disabilities in Educational and Workplace Settings

Previous research suggests that educational and workplace settings are sites in which people with disabilities often encountered disadvantages prior to the pandemic (Maconi et al., 2019; Maroto & Pettinicchio, 2014). These are also social institutions in which intentional, though far from perfect, accommodations, adaptations, and protections have been developed and/or legally mandated.

In Chapter 7, Rachel Fish and colleagues report findings of a US-based qualitative study of changes in the school experiences of disabled children as well as changes in the ways in which families engaged with schools and advocated for and/or supported their children during the pandemic. As in previous chapters, findings suggest that disability interacted with other axes of inequality in shaping these processes and that the pandemic exacerbated preexisting disadvantages at the intersections of class, disability, gender, linguistic status, and race in ways that created an uneven distribution of pandemic-related negative outcomes for children and families.

In Chapter 8, Julia Jansen-van Vuuren and colleagues explore how family-school partnerships in Canada were affected by the pandemic through interviews with 18 parents in Ontario. Findings suggest that parents value frequent, open, personalized communication about their children, and felt that they experienced a less than optimal degree of this kind of communication during the pandemic. They also expressed hope and optimism about the potential for developing effective future partnerships with their children's schools in the future.

In Chapter 9, Madeline Burghardt and colleagues report on a highly creative emancipatory research project conducted in collaboration with staff and participants of a disability-based arts program in Ontario, Canada. Findings suggest that social distancing and the pivot to online activities within the arts program created barriers to social inclusion for program participants that were not equally distributed. While many participants found that the pandemic provided opportunities for learning and growth, others remained disengaged and "lost" due to lack of technological access and personal support.

In Chapter 10, Giermanowska and colleagues report on a qualitative study based on interviews with 25 university students from across Poland who use assistant support services provided in private and public universities. Again, findings indicate that the negative effects of the pandemic were unequally distributed and that the pandemic exacerbated preexisting segregation and inequality in ways that heightened the social isolation of students who rely on personal supports for social engagement and community participation. As in other chapters in this section, however, the authors point out that some students found value in the pivot to online education in that it provided them with a sense of self-reliance and independence.

In the final chapter in this section and the book (Chapter 11), we move from the classroom to the workplace. Courtney Mullin and colleagues explore the role of disability-based employee resource groups in implementing disability inclusion strategies within large organizations and corporations in the United States, and the ways in which the pandemic changed the workplace experiences of disabled employees. Interviews with members of disability-based employee resource groups and diversity, equity, and inclusion officers suggest that the responsibility for disability inclusion shifted to employee resource groups at the start of the pandemic and that these groups played an important role in enhancing disability awareness and responding to instances of ableism. Findings also suggest that, as in the classroom, there were unequally distributed benefits and costs of pandemic-related changes. Some participants reported that the pandemic created a heightened awareness of disability issues that resulted in a growth in inclusive policies and practices, but others reported a near erasure of disability-inclusion efforts during the pandemic.

Taken together, chapters in Part 2 provide evidence that even within social institutions in which disability accommodations and support services have been mandated and in which programs specifically designed to enhance disability inclusion have developed, measures taken to reduce the spread of the physical disease had unequal consequences for people with disabilities. Some students and workers found that changes and challenges associated with the pandemic provided opportunities for individual and collective growth, while others lacked the support or infrastructure needed to take advantage of these opportunities.

DISABILITY IN THE TIME OF PANDEMIC: SUMMARY AND DISCUSSION

While this volume is being produced at a time in which social science understandings of the consequences of this ongoing pandemic are just beginning to develop, the research reported in this volume tells a compellingly consistent story. Far from a narrative in which the COVID-19 pandemic is a natural disaster or universal phenomenon that united the world through shared adversity, the research presented in this volume provides a narrative of differential access and differential impact. The narrative is remarkably similar across research settings, geographic locations, disciplinary backgrounds of authors, and epistemological and methodological approaches. The disadvantages and barriers experienced by people with disabilities before the pandemic tended to be heightened by the policies and practices designed to reduce its impact, but the pandemic and related changes also brought some opportunities for enhanced inclusion for some people with disabilities. Disabled people with other marginatized identities, however, were the hardest hit and the least likely to be able to benefit from the opportunities the pandemic provided. Chapter authors offer some clear and specific policy implications and make suggestions for future research that will enhance our understanding of how disability operates as a social location and axis of inequality around the world - as well as a deeper understanding of disability in the time of pandemic.

Our premise is that the disproportionate effects of the pandemic on disabled people that are described in this volume and other early work aren't inherent or "natural." Rather, these social patterns are symptoms of systemic ableism at work. Understanding this system and its effects on disabled people and communities in the context of the pandemic are what prompted the idea for this volume. Ableism, similar to and in conjunction with other "isms" such as racism and sexism, involves discrimination toward members of a social group, but it goes beyond discrimination to also encompass the value placed on certain attributes (Wolbring, 2008) and ways in which these values are codified in the daily doings of programs and institutions (Lewis, 2022). The idea that disabled lives are less valuable than other lives is codified in policies that deprioritize funding for homecare that would enable disabled people to live in their homes rather than institutions. It is reflected in the failure to prioritize mental healthcare so disabled people could receive treatment rather than incarceration. During the pandemic, the devaluation of disabled lives was blatantly reflected in "triage plans" that were proposed around the world in which disabled people *as a category* would be allowed to die in order to ration care, saving treatment for those whose lives were deemed to be more worthwhile.

The need to take up disability as a category of social experience worthy of analysis cannot be overstated; this must be the starting point if we want to