

Editorial

Disability and Social Inclusion: Lessons From the Pandemic

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Abstract

The coronavirus pandemic necessitated rapid, radical changes to global systems, structures, and organisations across all areas of life, including education, healthcare, and social services. These changes were something of a double-edged sword. On the one hand, widespread adoption of the kinds of remote-working technologies long advocated for by disabled people opened up possibilities for inclusion. On the other, some people’s inability to access such technologies, together with increased social isolation, exacerbated forms of exclusion. This thematic issue considers what lessons can be learned from the pandemic in striving to design a future which is more inclusive for all. In this editorial, we provide a brief overview of some of the major challenges the pandemic created for disabled people, who were disproportionately negatively affected by it. We also suggest that a disability rights lens is a useful way of highlighting both the contingency of disability and the need for more responsive and humane healthcare systems. The editorial goes on to outline the opportunities to challenge entrenched ableism and create a “new normal” the pandemic afforded. It concludes by offering a thematic overview of the articles in this thematic issue, which together reveal a complex pattern of inclusions and exclusions, interdependence, and intersectionality.

Keywords

ableism; coronavirus; Covid; education; intersectionality; technology

Issue

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1. Introduction

The coronavirus pandemic marked us all deeply, but in many ways disabled people bore the brunt. The pandemic not only highlighted the continuing social and health inequalities encountered by many disabled people; pre-existing austerity measures, which disproportionately impacted disabled people, exacerbated the impact of Covid-19 on them (Arrieta, 2022). The prejudice and discrimination they so often face have in many cases been magnified considerably by Covid-19. In the UK, for example, where we editors are based, the Office for National Statistics reported in February 2021 that disabled people were three times as likely as non-disabled people to die from coronavirus. Learning-disabled people’s risk of death from Covid-19 in the UK was four times

greater than non-disabled people’s. These figures were updated in May 2022 and showed that although rates of death had decreased, disabled people remained significantly more likely to die. Inclusion London’s February 2021 report *Locked Down and Abandoned: Disabled People’s Experiences of Covid-19* detailed a range of negative impacts across mental health, employment and finance, social care and support, healthcare and community access (Inclusion London, 2021). It outlines contributory factors, including discriminatory attitudes resulting in disabled people being given low priority for treatment and vaccination, and increased likelihood of “do not resuscitate” orders, on top of pre-existing socio-cultural, health, and economic inequalities. The roots of these inequalities can be traced back through a long history of prejudice, discrimination, segregation, and oppression.

2. Challenges

The pandemic thus amplified many challenges to disabled people. Some of these are reflected in this issue. It was known relatively early that the virus could have catastrophic consequences for many people, including death. This meant that health systems could easily become overwhelmed, due to shortages of ventilators and other specialised equipment, and of medical expertise. There were strong arguments for protecting populations to try and stop transmission. Some governments faced difficult decisions between protecting people and “business as usual.” However, many disabled people who had underlying conditions were more at risk of contracting the virus and of death, and lack of protection measures put them even more at risk (Dyer, 2022, p. 19). This was further compounded when questionable decision-making was coupled with old age and vulnerability. In the UK, when there was a sudden need for NHS beds, then Secretary of State for Health and Social Care Matt Hancock mandated that people who may have Covid could be discharged to care homes, unleashing a deadly wave of Covid cases in disabled older people living in such homes (Dyer, 2022). This exemplifies some of the carelessness and poor decision-making affecting some of the most vulnerable in our population. Similarly, people with learning disabilities who had Covid-19 encountered what charities described as “shocking discrimination,” as those in the hospital were given “do not resuscitate” orders (Tapper, 2021). Cuts were made to social care and it took a very long time for people with learning disabilities to be prioritised in access to vaccinations, despite them being at greater risk of death.

It was also quickly found that Covid-19 could result in a post-viral syndrome where people develop symptoms that greatly affect them long-term; this became known as “long Covid.” This is yet another example of how any one of us can travel from non-disabled to the realm of disability at any time, yet again dispelling the myth that impairment is something unfortunate that happens to a few unlucky individuals. However, it was staggering to see how so many lessons that should have been learned previously with similar illnesses such as ME, fibromyalgia, and many others were simply forgotten here. Studies immediately came out suggesting that long Covid was supposedly only psychological in nature, or suggesting interventions that research has shown to have failed for similar conditions before (Hunt et al., 2022). This was a very real betrayal of millions of newly chronically ill people that had entered the disability experience. This new community found itself having to grapple with a lack of support in health care, social care, and employment: again, experiences that had previously been well documented for similar communities (Hunt et al., 2022). We argue that this was completely unnecessary and that our society had the tools to help support this new wave of people in more positive ways. Although we understand that not everyone who has long Covid

will want to conceptualise their experience through a social oppression and disability rights lens, we argue that this lens allows for an important understanding of this illness. Looking at it through a disability rights lens means we understand that better access to healthcare which is responsive to the needs of the people is essential. It means that we understand access to social care and appropriate support in employment are essential tools for supporting people. It means we understand a pandemic could happen again and that people deserve to inhabit this experience in better and more equal ways. It means experiences like long Covid are also about political decision-making and societal support.

3. Opportunities

At the same time, we editors had a sense—but not the evidence—that the pandemic offered opportunities for the flourishing of expression, creativity, resourcefulness, sturdiness and interdependence that Garland-Thomson (2015), amongst others, has written about in arguing the case for the conservation of disability. Early on in the pandemic, disability scholar and activist Alice Wong characterised disabled people as “cyborgs and oracles” in her Disability Visibility Project blog (Wong, 2020): *cyborgs* because of their frequent intimate relationships with technology; *oracles* because they know what it means to be vulnerable and interdependent, and therefore have a vision of what a future in which lives which are increasingly both precarious and interdependent might be like. Alice argued that this is why everybody should listen to disabled people; and of course, Covid-19 is not currently the only threat humanity faces. War, climate change, and biodiversity loss continue to render us all vulnerable and life on Earth increasingly precarious. And so it is more important than ever to listen to disabled people.

Although it is inarguable that the pandemic disproportionately negatively impacted disabled people, some aspects of responses to the pandemic exposed and challenged normative social structures and behaviours in positive ways. For example, the switch to home-working was a benefit to some disabled people. As a result, disabled people have pushed for a “new normal” (Tiago et al., 2020). This “new normal” challenges traditional ableist practices, which despite disabled people trying to fight against them for many years, remained unchanged—until these changes were required for the protection of non-disabled people. A number of employment opportunities, including telework, arose for disabled people (Tiago et al., 2020). Prior to Covid-19, disabled people had already been using the internet more than non-disabled people for daily tasks and social interactions, and so when disabled people became more reliant on the internet, it was found that they were more engaged with information about Covid-19 (Dobrzensky & Hargittai, 2021). The switch to increased telehealth—the provision of health and rehabilitation services via the internet—has been of benefit to some disabled

people and parents of disabled children. Rosenbaum et al. (2021) report that the provision of online health and rehabilitation services for disabled children has reduced both the time and economic costs associated with travelling to appointments. Educational institutions also quickly switched to distance learning, which has often been seen as a benefit for disabled learners, who find traditional learning environments exclusionary. However, caution must be taken, because as Covid-19 becomes less of a threat to the population, society is quick to return to the old normal, ignoring the needs of disabled people. The picture is further complicated by the fact that the switch to remote learning and working did not benefit all disabled students and employees.

4. Thematic Summary of the Issue

We, the academic editors of this thematic issue, are affiliated with the Centre for Culture and Disability Studies (CCDS) at Liverpool Hope University. When we were invited to produce this thematic issue, we saw it as an opportunity to begin to try and make sense of the pandemic, whilst honouring our commitment to fully acknowledging the ontology and epistemology of people who are disabled. This thematic issue offers international perspectives on disability and Covid-19, with a good mix of empirical and narrative accounts. Disturbing and distressing as some of the stories these articles tell are, we are proud of the contributions to our understanding of disability, culture, and the pandemic that this evidence makes. The global nature of Covid-19 has meant that we have been able to assemble a range of research from around the globe including Austria, Canada, Iceland, Norway, Poland, the UK, and the US. As disability studies academics, we recognise the continued issue of the dominance of westernised perspectives in researching disability. Kubenz and Kiwan (2023) contribute a useful counter-perspective with their systematic literature review of the impact of the pandemic on disabled people living in low- and middle-income countries.

Some of the articles in this thematic issue provide solid evidence of the disproportionately negative impact of the pandemic on disabled people. Balter et al. (2023) examine the impact of institutional decisions during the pandemic and draw attention to how these were differently applied to young disabled children and the impact this has had on families. Similarly, Snæfríðar- og Gunnarsdóttir et al. (2023) highlight how disabled children were completely overlooked in planning and implementing measures to deal with the effects of the virus. Möhlen and Prummer (2023) reveal how the move to digital learning, while having the potential to increase the inclusion of disabled learners, only increased their marginalisation.

The pandemic also offered opportunities to strengthen the arguments against ableist practices in society that result in exclusion. Furthermore, it demanded imagination, ingenuity, and served as a

reminder of the interdependent state in which we all live. Evidencing this is the contribution by Betts et al. (2023), which reflects on the development of a “techno-social” space to increase agency and self-advocacy, and that of Nowakowski (2023), which confirms the experience that many disabled people had, in terms of increased accessibility and inclusion in work. Finally, a number of the articles in this issue emphasise the importance of intersectionality in any assessment of the impact of the pandemic. Klette-Bøhler et al. (2023) and Singh (2023) both demonstrate the multidimensional nature of discrimination—when disability intersects with gender, race, class, and migration status.

We hope you find this issue as thought-provoking as we did.

Conflict of Interests

The authors declare no conflict of interests.

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Owen Barden is an associate professor in disability studies at Liverpool Hope University and a core member of the Centre for Culture and Disability Studies. He has published widely on the topics of learning disability histories, qualitative research methodology and methods, participatory research, and relationships between disability, technology, literacies and learning. He has a particular interest in using participatory methods with co-researchers with learning disabilities.

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Erin Pritchard (PhD) is a senior lecturer in disability studies at Liverpool Hope University and core member of the Centre for Culture and Disability Studies. Her most recent book, *Dwarfism, Spatiality and Disabling Experiences*, engages with theories within human geography and disability studies to unpack the socio-spatial experiences of people with dwarfism. She has published work on dwarfism in key disability journals, including guest editing a thematic issue on representations of dwarfism for the *Journal of Literary and Cultural Disability Studies*.



Laura Waite is a senior lecturer in social sciences at Liverpool Hope University and a core member of the Centre for Culture and Disability Studies. She has made a number of contributions to its work, including a chapter in *Disability, Avoidance and the Academy* (Routledge, 2016) and papers at seminars and conferences. Her research has a particular focus on people described as having profound and multiple learning difficulties, people with Down syndrome, and students and staff who identify as “mad” in higher education.