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# Disability and Social Inclusion: Lessons From the Pandemic

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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**

This editorial is part of the issue "Disability and Social Inclusion: Lessons From the Pandemic" edited by Owen Barden (Liverpool Hope University), Laura Waite (Liverpool Hope University), Erin Pritchard (Liverpool Hope University), and Ana Bê (Liverpool Hope University).

## 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 (Dobransky & 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.

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Article

# Risky Obliviousness Within Fragmented Services: Experiences of Families With Disabled Children During the Covid-19 Pandemic

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**Abstract**

Living on an island in a pandemic has its obvious advantages. However, in a globalised economy, border restrictions cannot keep the Covid-19 virus completely at bay. Despite coordinated efforts at infection control and extensive vaccination, Iceland, a sparsely populated island in the north, was placed among the countries in the highest risk category by the ECDC. In this article, we report a qualitative study carried out at the peak of the fourth Covid-19 wave in 2021, when the pandemic had severely hit the Icelandic social and healthcare system, with a record-breaking number of infections. Semi-structured interviews were conducted with parents with seven disabled children. Guided by feminist standpoint theory and critical disability studies, we focused on how service structures affected and shaped parents' and children's experiences during the first waves of the pandemic. The findings suggest that the pandemic intensified the already precarious position of the families. During the pandemic, the gaps in the already fragmented services widened, and the families were left to navigate this new reality on their own. Preventive measures enforced by municipalities and healthcare services centred on non-disabled people's experiences and needs. Unprepared service systems distanced themselves from the families while maintaining governance and supervision over defining their need for support.

**Keywords**

Covid-19; disabled children; family support; Iceland; social inequality

**Issue**

This article is part of the issue "Disability and Social Inclusion: Lessons From the Pandemic" edited by Owen Barden (Liverpool Hope University), Laura Waite (Liverpool Hope University), Erin Pritchard (Liverpool Hope University), and Ana Bê (Liverpool Hope University).

## 1. Introduction

In March 2020, the way of life of people living in Iceland changed instantly, with a ban on gatherings, social distancing, polymerase chain reaction (PCR) testing, quarantine, and isolation due to the Covid-19 pandemic. Restrictions were lifted and reinstated in sync with the rise and fall of the infection waves, but all domestic Covid-related restrictions were dropped in February 2022, despite high infection rates.

There are limited available data regarding the pandemic's effects on different social groups, and disabled people have remained almost invisible in the media and public documents during the pandemic. Regardless of the advice and warnings from international experts and institutions (Armitage & Nellums, 2020; World Health Organization, 2020), the official Covid-19 guidelines published by the Icelandic Directorate of Health (2022) do not identify disabled people as at risk of suffering from the serious consequences of the disease. Prior to the pandemic, it has been widely reported that disabled people have poorer health outcomes and less access to health services (Allerton & Emerson, 2012; Snæfríðar- og Gunnarsdóttir, 2017). Research on past pandemics shows that disabled people find it harder to access critical medical supplies, which can be even more challenging as resources become scarce (Campbell et al., 2009).

In this article, we report on a qualitative study grounded in the experiences of families with disabled children during the Covid-19 pandemic. These children also have long-term illnesses or underlying health conditions, increasing their risk of severe symptoms associated with Covid-19. Grounded in standpoint feminist theory (Smith, 2005; Wylie, 2003) and critical disability studies (Meekosha & Shuttleworth, 2009) we focus our critical gaze on the social structures and mechanisms that shape and coordinate the experiences of the parents. Iceland is a welfare state regime where healthcare and municipal services are universal, comprehensive, and mostly funded through taxation (Government of Iceland, n.d.). Disabled children and their families are, by law, entitled to services and assistance provided by municipalities (Althingi, 2018), and because of the children's health conditions, many also rely on a broad range of healthcare services. It is therefore important to explore how these service systems responded to the challenges that followed the outbreak of the Covid-19 pandemic.

### 1.1. Background

Prior studies focusing on the lives and circumstances of families with disabled children in Iceland have revealed that although parents value the services and support available to them and their children, collaborating with service providers often creates additional stress on family life. Services have been described as fragmented, and parents must demonstrate leadership and advocacy, taking on a supervisory role to maintain the necessary support for their disabled children (Egilson, 2015, 2022; Ingólfsdóttir et al., 2018).

According to disabled children and their parents (Egilson, 2015), an example of this fragmentation is the lack of collaboration between school and home support. Most disabled children in Iceland attend their neighbourhood school with their non-disabled peers (Ólafsdóttir et al., 2014). During school hours, assistance to disabled children is provided by the schools and funded by the municipalities, as is the support provided to their homes. However, these service provisions are organised by different departments of the municipalities, and with different budgets. Ingólfsdóttir et al. (2018) claim that parents' experiences of support and services do not align with the stated aims of the services provided by the state and municipalities. The reason for this gap, according to parents, is found in the system's structure that is centred around the professionals and the service providers instead of the children and their families. Parents in Egilson's (2015) and Ingólfsdóttir et al. (2018) call for better access to professionals and point out that increased collaboration between specialists and service providers would free the parents from the burden of serving as messengers within the service system. Although parents want to maintain an active role in meeting their children's healthcare, social and educational needs, that role must be manageable and supported (Egilson, 2015; Ingólfsdóttir et al., 2018).

According to UNESCO (2021), the pandemic has exposed the shortcomings in the education of disabled students worldwide. In the first wave of the pandemic, parents of disabled children in Iceland vocalised their fear regarding its effects, stating that many disabled children had not received the educational support to which they had a right (Einarsson et al., 2020). Icelandic law mandates that students who are either hospitalised or ill at home for longer periods should be offered education at home or in the hospital (Althingi, 2008). Björnsdóttir and Ásgrímsdóttir (2020) argue that although distance-learning solutions were used during the pandemic to help students keep up with their classwork, the implementation did not consider the children's social contexts or situations. Therefore, the use of such solutions was less available and less accessible to disabled children and children belonging to other marginalised groups. During the first waves of the pandemic, Icelandic teachers reported their difficulty in maintaining support for disabled children in schools, due to physical and social distancing rules (Björnsdóttir & Ásgrímsdóttir, 2020). Before the pandemic, these students were already at risk of missing out on learning and socialisation because of fragmented services provided during school hours (Ingólfsdóttir et al., 2018).

In recent years, there has been a shift to increased personalisation of services in Iceland. This is largely a response to the advocacy led by disabled people, calling for increased control over the services they receive as they have found traditional service arrangements to be lacking and inefficient (Snæfríðar- og Gunnarsdóttir & Arnalds, 2016). Examples of this new kind of service arrangement are direct payment contracts, which many Icelandic families of disabled children have with their municipalities. According to these contracts, the municipalities are not directly involved in service procurement, and the families themselves are responsible for hiring assistants. Such service schemes have been heavily tested during the Covid-19 global pandemic as serious questions have been raised about where the responsibility for infection control training and access to protective gear lies (Dickinson et al., 2020). In Iceland, disabled service users criticised authorities and municipalities for their inaction and slow response to the situations of disabled citizens who had to navigate pandemic-related problems on their own, such as managing support while shielding and securing assistance if they or their staff became infected (Haraldsdóttir, 2020).

Since pandemics are likely to exacerbate the precarious position of families with disabled children, it is important to gather information about how they were affected by the Covid-19 pandemic and ask what lessons can be learned from their experiences.

### 1.2. Feminist Standpoint Theory and Critical Disability Studies

Our project is grounded in feminist standpoint theory (Smith, 2005; Wylie, 2003) and the belief that centring marginalized knowledge and starting inquiries from the standpoint of disenfranchised groups in research, provides crucial knowledge about oppressive social structures. Feminist standpoint theory regards the critical reflections of marginalised groups, thinking from the outside-in, to hold a certain epistemic advantage, providing important insights into how social institutions and systems shape and affect people's experiences. This has methodological implications in our study, as we start our inquiry from the perspective of parents of disabled children and direct our critical focus outward, to the power relations and structures that coordinate and shape their experiences (Hundleby, 2020; Smith, 2005).

Furthermore, critical disability studies are a guiding framework for the study. Critical disability studies put social and cultural norms, conditions, and institutions under scrutiny as key drivers of the exclusion of disabled people (Meekosha & Shuttleworth, 2009). Ableism is a core concept within critical disability studies, highlighting the network of beliefs, social processes, and practices that produce and maintain narrow ideals of bodies as perfect and "normal." In a world of presumed able-bodiedness, disability and diversity are devalued and understood as less worthy (Campbell, 2009). Subsequently, critical disability studies provide a lens for scrutinizing and problematizing the discrimination and social exclusion typically faced by children growing up with disabilities.

Both feminist standpoint theory and critical disability studies are concerned with power relations and focus on uncovering processes of knowledge, power, and exclusion. Informed by these critical approaches we focus on the social structures and institutional processes that produce and maintain ableist social and cultural norms and shape the experiences of disabled children and their families. As academic research is not exempted from ubiquitous oppressive social relations, we wish to clarify that all the authors of this article are white, non-disabled academics with a background in social sciences, namely gender and disability studies. As Morris (1992) explains, knowledge production of non-disabled researchers in disability studies can become problematic if not grounded in reflexivity and self-awareness. We strive to work through these issues by actively engaging with reflexivity and collaborating with disabled people. We furthermore share a transformative research focus (Mertens, 2007) and aim to generate knowledge about social injustices and issues of importance for marginalized groups and use our platform to raise awareness about them.

## 2. Methods

This article draws from a qualitative study undertaken in Iceland among a group of parents with disabled children. The study is part of a larger research project where the experiences, health, and well-being of disabled people during the Covid-19 pandemic are explored. The project is funded by the Icelandic Research Fund.

### 2.1. Data Collection

Qualitative interviews were used for data collection as they provide means for gathering the thorough and detailed information necessary for exploring social processes and how they, formally and informally, organize different aspects of daily life (Smith, 2005). Interviews were conducted with parents with disabled children by the primary investigator, who is a PhD student and a seasoned researcher. The interviews were semi-structured and therefore provided flexibility to follow up on interviewees' answers while still anchored in an interview guide with predetermined topics (Braun & Clarke, 2013). The interview guide was developed by the primary investigator and revised as the project progressed. At the beginning of each interview, broad questions were asked about the family and their daily lives before the pandemic. Participants were asked about the services they had received prior to the pandemic and their experiences with different service providers, offering municipal, school, and healthcare services. The principal part of the interview focused on the family's experiences during the first waves of the pandemic, up until the time of the interviews. When all families had been interviewed once, additional interviews were carried out with the first two families, to follow up on themes that emerged in later interviews and had not been a part of the initial interview guide.

Each interview took about 60–75 minutes, through videoconferencing technologies. Consequently, it was recorded and transcribed verbatim. The interviews took place from September to November 2021 against a backdrop of a rapid spread of infections and subsequently stricter domestic prevention measures in November, following prior relaxation of prevention measures in the end of August (Government of Iceland, 2021).

### 2.2. Data Analysis

A thematic analysis approach (Braun & Clarke, 2019) was used. After being thoroughly read by all authors, the interviews were coded by the primary researcher, where in which data segments relevant to the study aims were identified and labelled. The codes were revised in collaboration with the second author, who is also a PhD student. Subsequently, themes were developed by identifying patterns among the codes, reassessed in collaboration with all authors, and reviewed by going back to the initial codes and the full dataset (Braun & Clarke, 2013; Creswell, 2008). The analysis was finalised by the primary investigator and the third author who is a professor of disability studies. In line with critical disability studies and standpoint feminist theory, the analytical focus was aimed at the social structures and mechanisms that affected and shaped parents' and children's experiences during the pandemic, to form a broad picture of the power relations affecting the lives of families (Meekosha & Shuttleworth, 2009; Smith, 2005; Wylie, 2003). Examples of critical questions that guided the analysis were: What characterizes the institutional service structure and processes that shape and affect the families with disabled children? How did service systems and institutional processes shape the participants' experiences during the pandemic? How was participants' daily life framed or coordinated by power relations during the pandemic? To validate the accuracy of our findings, we triangulated among different data sources (participants), multiple researchers (authors), and through member checking where participants in the study were asked to determine the accuracy of the findings (Creswell, 2008). The interviews were conducted in Icelandic, and direct quotes were translated by the primary investigator.

### *2.3. Participants*

In total, eight parents, six mothers and two fathers, participated in the research. In two instances both parents took part in the interviews and one family had two disabled children (Table 1). Initially, a purposeful sampling strategy was employed to recruit participants who would be able to provide in-depth information about the experiences of families with disabled children during the pandemic (Creswell, 2008). This was done by placing an advertisement about the research in a Facebook group for parents with disabled children. Five individuals answered the call, all of which participated. Snowball sampling was then used, where participants forwarded information about the research to other parents. This resulted in the recruitment of the last family. No participants opted to drop out at any time. In total, eight interviews were conducted, as two families were interviewed twice. All participants were white, native Icelanders between the ages of 34 and 52. All the children needed support in their daily lives and had physical impairments, but seven of them also had complex health issues. Three families lived in the capital region; the other three resided in towns with under 20,000 inhabitants. The children, three girls and four boys between 7 and 16 years old, all lived in two-parent households. Table 1 provides an overview of the participants.

### *2.4. Ethical Issues*

Researchers are obligated to ensure that their research is scientifically sound. Furthermore, ethical justifications for research lie in its scientific and social value (CIOMS, 2016). We affirm that we have adhered to scientifically sound and ethical research practices and believe this work to be a valid contribution to scientific and practical knowledge about the topic. The research proposal was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021–009) as is required when interviewing families from a marginalized population. As stated in their guidelines, the committee emphasises four core values in research: respect for human dignity, beneficence, non-maleficence, and justice (University of Iceland, 2014). All parents participated willingly in the research and were informed of the study's purpose and their right to terminate their participation at any time. Attention was paid to power relationships, and trust and security in interactions during the interviews were emphasised. An example of this were the measures taken to protect anonymity. This was, understandably, an important concern for participants, who many lived in tight-knit communities. In collaboration with participants, it was decided to forgo pseudonyms in analysis and published findings and omit certain demographic and background information about the families.

## **3. Findings**

Three main themes emerged from the data. The first theme, "fragmentary services," describes the support system (healthcare, school, or other municipal services) encountered by the families before the Covid-19 pandemic. The second theme, "risky obliviousness," and its subthemes, "faulty response measures," "unprepared systems," and "service providers distance themselves," depict the circumstances in which the families found themselves during the first wave of the pandemic, when gaps in the fragmentary services widened. The final theme, "on their own," offers insights into the parents' concerns about the ongoing pandemic.

### *3.1. Fragmentary Services*

All the participants described having limited trust in the healthcare system prior to the pandemic. Because of

**Table 1.** Information about the participants.

| Participants | Region | Disabled children | Siblings | Interviews |
|---|---|---|---|---|
| Mother and father | Rural | 1 | 2 | 1 |
| Mother | Rural | 1 | 2 | 1 |
| Mother | Urban | 2 | 2 | 1 |
| Mother | Rural | 1 | 2 | 2 |
| Mother and father | Urban | 1 | 1 | 2 |
| Mother | Urban | 1 | 1 | 1 |

their children's health conditions, five of the six families had regular contact with the healthcare system for monitoring their children's health. This included several doctors who all limited their interest and involvement to issues within their fields of expertise. Due to limited collaboration among these doctors, they had little oversight, resulting in fragmentary services. As one mother (id.2) explained: "I've never felt that the [healthcare] system is keeping track of us at all."

Because of this disjointed nature of services and the lack of oversight, the parents felt that it was up to them to stay vigilant and ensure the necessary follow-ups. Lapses in care could have serious consequences, as described by one mother. While a neurologist on call in the ER had recommended regular monitoring of her daughter's blood levels, her main specialist dismissed this and minimised the mother's concerns. This led to the daughter's long and dangerous seizure, which could have been avoided had her blood levels been monitored. The mother (id.6) explained:

> I said: "Well [neurologist on call] said that we need to monitor this regularly, you know. Don't we have to do that?" And he just: "No, no, no, no, no, it's all good." He just could have sent her to this damn blood test and this wouldn't have happened six weeks later. And it was just, we were so incredibly hurt and angry at him.

Other parents had similar stories to tell, of how being advocates for their children often meant that they doubted or second-guessed the doctors' opinions. Their advocacy role was often complicated by limited access to doctors and other gatekeepers. These hurdles not only lengthened the process of obtaining sufficient care and support but also cost energy for the parents. The parents were nevertheless adamant that they had to take matters into their own hands, oversee their children's healthcare and fight for the latter's rights and health. A mother (id.3) said:

> My experience of the Icelandic healthcare services is that I have to be her specialist because she has a rare disease, and no one has the time to monitor or follow up on things regarding what is best to do and ensure that everything that needs to be done gets done.

Parents' experiences with municipal service providers were also described as one-sided interactions. For example, service providers rarely showed initiative, anticipated the children's or the families' needs or provided practical information beforehand. This was a substantial barrier as it is difficult to ask for something you don't know exists. A mother (id.2) explained:

> It's a kind of a one-way street. We always have to let them know or wish for or ask for something. And you don't always know what is within your right or what you can ask for, and sometimes, I just don't know what they can offer.

Four families had direct payment contracts, where they organised the services themselves and hired assistants, with the budget from the municipality. Participants described how the support they received through these contracts was insufficient as the contract hours did not cover the needs of families. As an example, one mother explained that the municipality had assessed her daughter's support needs to be 720 hours a month, or around-the-clock care. However, citing a limited financial budget, the municipality only provided the family with a service contract that amounted to about a third of assessed hours. The mother (id.5) recounts:

> She [the social worker] said to us: "I managed to get you a 240-hour service contract." I think I remember her saying word-for-word: "Can you just please take it and be happy with it. It's the best I can do for you now. Just take it."

Although support in school is also provided by the municipality, in the parents' experience, it was organised more or less independently of the circumstances in the child's home and limited collaboration with other municipal services. The school support is tied to the school premises and limited to the school's work hours, leaving little room for flexibility. This posed a problem for children who needed around-the-clock support, as their parents had to be prepared to care for them when schools were closed due to discretionary days or when school days were shortened. One mother (id.4) explained that according to school administrators, there need to be two or three assistants available to her son at school, at all times. When assistants became ill or there was a staff shortage, the school called to let the parents know that the boy could not attend school that day, regardless of whether any assistant was at home with the child:

> Well, they [the school] believe that there should always be two assistants by his side and that….Well, they do it somehow like, there are three assistants with him and two are always by his side and the third is [elsewhere] then they change and take turns. If…well they have allowed him to come when there were only two assistants at the school, but if two assistants are off work then it's just: "Sorry, you know, it just isn't, there is no one else that can see him today."

Other parents encountered similar problems regarding the support their children were allocated at school. One participant (id.1) explained how the problem was rooted in the ways that the support was organised. Namely, rather than being arranged around children's needs the support was tied to school facilities: "Assistants belong to particular buildings; really, it's just unbelievable that it remains that way. The support needs to be more flexible.’’

The parents described how insufficient and fragmentary services before the onset of Covid-19, left them with limited trust in the different systems with which they had to interact. They had become used to taking matters into their own hands to ensure the necessary support for their children. According to the parents, these issues would become more prevalent in the pandemic. The families described themselves as in a state of shock in the first weeks of the Covid-19 outbreak. Six of the seven children had comorbidities that left them susceptible to severe infection. Their parents were particularly frightened, and so six of the families were shielded early on when news of the infection broke, before any lockdown measures had been taken by the authorities. This meant taking all their children, including siblings, out of school and taking leave from work or working from home if possible. During the first wave, these families lived more or less in isolation until May 2020, when the infection rates decreased. Although one family did not shield, their situation was similar to those of the others as they had to quarantine several times in a relatively short period and subsequently isolate themselves because of a family member’s infection. When shielding themselves from the pandemic, participants did not meet close family members who resided outside their homes or their assistants. Trying to keep up with schoolwork for their children, as well as maintaining physiotherapy schedules, housework, and remote work, many parents soon felt overwhelmed, as described by a mother (id.2): “We just closed our doors. And then we were just at home and saw to everything ourselves, and it indeed ended with the two of us having to take sick leave. It was just such awful pressure.”

### *3.2. Risky Obliviousness*

From the interviews, the theme “risky obliviousness” emerged, as parents described how seemingly unprepared support services did not reach out or provide meaningful support to the families in the first wave of the pandemic. The subthemes “faulty response measures,” “unprepared systems,” and “support providers distance themselves” depict how, inadvertently, the deprioritization of the needs of disabled children and their families in response measures, increased participants risk of isolation and exhaustion.

#### 3.2.1. Faulty Response Measures

According to the parents, neither healthcare providers nor doctors contacted the families beforehand in the wake of the pandemic. Not anticipating much support, the parents themselves did not refer to any specialist before deciding to shield. There was one exception; when news of the pandemic broke, one mother asked her daughter’s main doctor how the family should proceed. He replied that he did not see shielding as especially beneficial for her daughter, who was in fact, no different from anyone else. In the mother’s view, this response was irresponsible and most likely incorrect since the child had serious health issues and comorbidities. She explained (id.6): “I was baffled. What kind of answer is that? After that, I just didn’t talk to anyone.” Not only did the doctor dismiss her concerns, but he also did not contact her again to follow up on or revise his response when further knowledge about the seriousness of the pandemic emerged.

Parents explained how universal response measures aimed at health and safety usually did not consider disabled children’s needs. Preventive efforts sometimes served to complicate things further or create new problems. Examples include measures taken in Icelandic schools during the first two waves, when school days were shortened, and school premises were compartmentalised to limit the risk of infections. One mother described how the compartmentalisation in her son’s school resulted in his impossibility to return to school. His three assistants had been vaccinated early, being his allocated support staff. They were then separated into different compartments, making it impossible for them to work together to organise and provide him support. The mother (id.1) explained:

> He was totally forgotten in the first wave…and it was really awkward of the school to do that [split up the assistants] because then, there was never a chance for us to get any assistance. And everyone lost track, and no one made any contact because everyone was separated.

Furthermore, schools had seemingly no plans in place to provide the children with the support that they were allocated in school or to find ways to extend the support to their homes, for example through remote learning. One mother (id.3) explained how, during the shortened school days her son was sent home, without his allocated support or any consideration for the situation at home:

> They were just two hours at school or something, and then they went home. My son needs one-on-one support, both on account of his physical and emotional needs. He was sent home at twelve o’clock. His support staff was at the school, at work, probably getting paid to be at work, but the child was sent home. And we got nothing [no support].

Parents recounted several incidences of such responses and preventive measures that proved to be “awkward” or “stupid,” organised without taking the needs or considerations of disabled children into account.

#### 3.2.2. Unprepared Systems

Most of the municipal service support to the families was put on hold as soon as the virus started spreading.

As the pandemic progressed, it became clear to the parents that the municipalities and school services had no measures in place to ensure important support for the children and their families. As noted previously, support that the children were allocated during school hours was not extended to their homes. Physiotherapy, occupational therapy and speech and language therapy were cancelled, with no protocols in place to ensure these specialised services. The loss of these services could have long-term effects on the children, as one mother (id.1) explained: "He is learning to use [assistive communication device] but if there isn't continuity the training becomes unfocused and futile. We feel that we are losing precious time." Furthermore, the families had no support in their homes for extended periods. Afraid that support staff could bring infection into the home, some of the parents did not reach out to schools or municipalities for assistance. Others, however, contacted schools or municipalities to seek ways to secure support for the families. For those who had direct payment contracts, the municipalities provided little help. After much advocacy, one family was allowed to bring assistants into their home for a few days if the assistants wore protective clothing. The municipality quickly withdrew this exemption as the home was not equipped with the necessary features: two bathrooms and a special room for the assistants to change into protective clothing. The mother (id.5) explained: "There were no clear instructions on what you could or couldn't do. No one knew anything, and you always had the feeling that people were just guessing what would be okay and what wouldn't."

Because the hospitals were overloaded and the healthcare system was under pressure, some parents were concerned that their children would not be safe if hospitalised. One mother (id.3) inquired whether there was a protocol regarding the allocation of ventilators, that is, if any group was prioritised over others. The answer was that there was no protocol, but "everyone hoped it would not come to that." In her view, this was both emblematic of the system that commonly overlooked her child's needs and could probably pose a danger to him. She said:

> Worst-case scenario and all ventilators are in use, then you have to trust that the doctor you get isn't full of disability prejudice or thinks his [her son's] life isn't worth living. I mean, really? There are no protocols. I know that everyone hopes we won't get there, but this needs to be written down and decided beforehand….I mean, I don't think my house will catch fire, but I've still told my children what to do if it catches fire in the middle of the night.

Participants described their feeling of being on their own as no one seemed to have oversight or take responsibility regarding support for disabled children and their families. Although aware of the complicated situation in which the families found themselves, doctors and other service providers seemingly distanced themselves.

### 3.2.3. Support Providers Distance Themselves

In the middle of March 2020, the Children's Hospital of Iceland sent a message to the families of children with underlying risk factors, advising them to keep their children at home while little was known about the virus. At that time, the families who had decided to shield had started already. The hospital never followed up with further recommendations, and no institution or authority seemed to have oversight, take charge of streamlining information, or coordinate efforts. As a mother (id.6) pointed out: "It was like no one knew who was supposed to provide information [for families of disabled children] or, you know, take charge regarding this group."

In later waves, support from doctors proved to be important, particularly regarding vaccinations, yet quite inaccessible. Securing a place on a vaccination priority list for their children and themselves was arduous; the participants received little help from their specialists and encountered gatekeepers who were supposedly preventing misuse of the priority lists. Although they recognised the children's precarious situation, few healthcare providers showed particular interest in the families' position or provided meaningful support. In the parents' view, the Children's Hospital and healthcare specialists took a step back as the pandemic progressed, and they then withdrew, citing that this was not their field of speciality and seemingly not wanting to take responsibility. A mother (id.4) explained: "His [specialist] team just withdrew and said, 'You just have to assess the situation. If you need a medical certificate, we will write it, but you just have to assess the situation.'"

The municipal and school services also remained at a distance; nobody called to check and hear how the children were doing. Although most schools remained open, the participants chose to keep their children at home during the first wave and periodically in later waves, when infection rates rose. Some parents found it hard to send their children back to school when infections decreased, as they did not trust the schools to undertake the necessary precautions for their children's safety, such as following the two-metre distancing rule. In some cases, schools overtly shied away from responsibility. When discussing with school officials what arrangements could be put in place to facilitate their son's return to school, one family experienced limited cooperation and felt that the school staff were finding ways to bow out of their obligations. The mother (id.1) explained: "The school said at some point in time: We cannot protect anyone, that is, we cannot 100% protect anyone. And then, you know, we just backed off even more." After this response, which the parents interpreted as a distancing technique of sorts, it became difficult for them to trust that their son's needs would be considered.

### 3.3. On Their Own

At the time of the interviews, Covid-19 had lasted for many months, with fluctuations. The parents felt that during the pandemic they had been overlooked and forgotten, many using metaphors such as "on our own" or being "alone on a boat" when discussing their experiences. One mother (id.2) explained:

> I just feel like we've had to be on our toes completely to monitor and follow everything, but there isn't somehow, I don't feel like, I don't get the sense like there is someone that would possibly catch us or support us. Not at all.

The families who had shielded in the first waves of the pandemic had, now, relaxed their restrictions somewhat, although remaining very careful. With new variants posing less health threats, concerns about infections decreased among the general population, while annoyance with protective measures increased. However, the participants remained worried about their children's health and situation, and the growing dismissal of the pandemic's dangers only increased their concerns. An increasing number of people were brushing off the dangers of the virus, unconcerned about the precarious position of many people and families, as a father (id.1) explained:

> It's infuriating to hear people say that this is just a flu and that only a small percentage of people will have any problems when you precisely have someone who will have problems. You know, it's difficult listening to people talk about this so carelessly.

Some participants described similar obliviousness by healthcare staff and specialists who were quite versed in the children's situations. One mother had encountered healthcare staff's dismissive attitude and lack of understanding while she was taking strides to maintain protective measures when taking her daughter for regular bloodwork and check-ups at the hospital. Another family was asked to participate in an annual meeting and check-up at the Counselling and Diagnostic Centre, targeting families from rural towns. When the mother (id.4) declined, pointing out that her son had not been vaccinated and it would be unwise to risk infection, the specialist was surprised, seemingly forgetting about the child's situation. She believed that this probably would not have happened at earlier stages of the pandemic, when adults had not been vaccinated. "Even the specialists have forgotten. But in the earlier wave, when the infection rates were this high, everything was closed. But now, because they [the specialists] are vaccinated, everything is just supposed to be moving along."

The families criticised the authorities whom they felt had overlooked the situation of people and families who needed assistance in daily life, prioritising measures for the benefit of the economy. Many voiced their irritation and concerns about travel industry lobbyists who called for limited restrictions and more governmental support. As the parents explained, prolonging preventive measures was imperative since infection rates were still rising and the consequences on their children's health were unforeseen and potentially deadly. As one mother (id.6) explained:

> I just don't feel that anyone *needs* to go to Tenerife, you know. I think it's more important that my children get to go to school. But there is no point in discussing it because it's such a small group [who has to shield]. Naturally, if the majority was in this position [having to shield] then it would be different.

Similarly, a father (id.1) pointed out: "It is important that the government play their cards right, which we are quite scared they won't do….I think that too much money is at stake." In his view, financial and political interests seemed likely to win over the health concerns of a minority group. Being in a minority and "on their own," participants found it difficult to trust that politicians would prioritise their children's welfare.

## 4. Discussion and Concluding Remarks

In this article, we explored the experiences of families with disabled children during the Covid-19 pandemic. Consistent with previous research results (Egilson, 2015, 2022; Ingólfsdóttir et al., 2018), the findings expose a flawed system of support, prior to the pandemic, best characterised as fragmentary. Through their experience of navigating uncollaborative systems and constantly fighting for the health, education, and safety of their children, the parents had become used to taking matters into their own hands, honing the problem-solving skills that they subsequently used to tackle the difficulties that arose during the pandemic.

In our analysis, we set out to examine the service structure and processes from the standpoint of parents with disabled children and how participants' experiences were shaped and coordinated by institutional power relations. We argue that the service system responses and preventive measures taken during the pandemic were ableist in nature as they centred on non-disabled bodies and experiences (Campbell, 2009). This was particularly prominent regarding organizations of restrictions in school settings and the prioritisation in the health care system. The disregard for the importance of education and other specialised services for disabled children during the pandemic reflects ableist notions about children who are fully valued and those who are not. The deprioritisation of disabled children and their families, described by participants, is emblematic of the marginalised position they hold in society. Indeed, the problems and barriers encountered by the families during the pandemic were not alien to them but perpetuated and highlighted systemic issues and problems that they previously faced.

The parents' fear for their children's safety was exacerbated by their limited trust in healthcare and municipal services, which in many ways overlooked and underestimated disabled children's needs and complex situations. Since the interviews were conducted, the National University Hospital of Iceland (2021) published guidelines for critical care, allowing the rejection of critical care for frail patients, regardless of age, during the Covid-19 pandemic. Based on these guidelines, disabled people who rely on support in daily life, and may therefore be categorised as frail, are at risk of being refused intensive care treatment. Grounded in ableist perceptions and judgements about the quality of people's lives, such decisions confirm that the participants' anxiety regarding their children's safety was warranted. Similar issues have been raised elsewhere (Inclusion London, 2020; McKinney et al., 2021; Rockwood & Theou, 2020). Recognising that societies' structures and institutions are offsprings of existing ableist power relations, this is undoubtedly a global issue.

This article contributes to emerging literature about the experiences of disabled children and their families during the pandemic. Our findings highlight the importance of prioritising the needs and concerns of disabled people, children, and their families in policy measures taken by institutions and authorities in response to pandemics and other disasters. Covid-19 remains a threat, particularly to those with serious health issues. The long-term outcomes of the virus and the social conditions it has fostered are not yet fully known. It is important to draw lessons from the experiences of disabled children and their families and use them to improve support and ensure access to rights and social inclusion at all levels of society. The findings have implications for the service systems and institutions and indicate practical issues that need to be addressed. The fragmented nature of the service systems, established in prior research (Egilson, 2015, 2022; Ingólfsdóttir et al., 2018), remains a substantial barrier to services for disabled children and their families. Although inclusive education is the official policy in Iceland and mandated by law (Althingi, 2008), school support shows limited regard for the social or familiar context of the children. This results in a gap between the support provided in schools and in homes, which has further jeopardised the families' situation during the pandemic. It is imperative that services be more flexible and adjustable to the different needs of children. Rules must ensure children's rights to assistance and not be limited to the school grounds or particular facilities. Furthermore, service providers must fulfil their legal obligations and make certain that support is provided. Whereas direct payment contracts have introduced an important alternative to inflexible traditional service arrangements and have enhanced users' autonomy and well-being (Snæfríðar- og Gunnarsdóttir & Arnalds, 2016), in this study, current arrangements conveniently provided space for municipalities to distance themselves, seemingly exempt from legal obligations in the face of a serious event—a pandemic. This not only resulted in children and their families not receiving the support to which they are entitled by law, but also put them at risk for further marginalisation and isolation.

Limitations of the study stem from the small sample size, which is to be expected from such a small population. Notwithstanding, the study offers important insight into the experiences of these families. There was much agreement in the participants' accounts which are also in accordance with previous studies about families' experiences of services. Another limitation are the fluctuations in the pandemic and the fact it is still ongoing when this article is written. This issue is superseded by the fact that Covid-19 is an ongoing global threat. Our study is a contribution to the continuing endeavour to uncover and understand the effects of the pandemic and responses to it from institutions and service systems.

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## Conflict of Interests

The authors declare no conflict of interests.

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Article

# Same Old New Normal: The Ableist Fallacy of "Post-Pandemic" Work

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**Abstract**
The ongoing Covid-19 pandemic has catalyzed long-needed changes in accessibility and flexibility for work tasks. Disabled and chronically ill people have often experienced unprecedented inclusion during this time. As someone who is both disabled and chronically ill, I have experienced this firsthand. My work as a medical educator, public health program evaluator, and community advocate has been more accessible in recent months than at any prior time. As the pandemic escalated in early 2020, people readily embraced a "new normal" that would allow them to sustain their own livelihoods while staying as safe as possible. Yet even as Covid-19 cases increase sharply both locally and nationally with the spread of new virus variants, many abled people from both my institution and others increasingly demand a return to pre-pandemic practices. The "normal" state for which abled individuals ardently long violates the basic human rights of disabled and chronically ill people. This desire for "normalcy" is fueled by false notions of the pandemic being over. It remains preferred by many for the sake of their own comfort—even though sustaining the inclusive approaches to collaboration introduced during the pandemic often requires little effort and offers advantages for abled people as well. This experiential piece describes ableist implications of seeking "post-pandemic" work environments—and how these constitute "generic processes" in the reproduction of ableism—using both oral history from the author and emerging literature from fellow scholars. In response, it recommends inclusive strategies for anti-ableist work collaboration that achieve justice in accessibility while fostering a welcome sense of normalcy for all.

**Keywords**
accessibility; chronic illness; Covid-19; disability; inequality; justice; work

**Issue**
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## 1. Introduction

Recently I had to forego an accepted conference presentation because the organizers refused to provide accommodations for people to participate safely. After I pointed this out, the organizers not only persisted in their refusal to provide reasonable accommodations for distance participation, but also chided me for not understanding that this refusal "was stated clearly in the conference information." I reflected on how dishonoring of basic human rights is stated clearly in many laws passed in the US and elsewhere (Anderson & Philips, 2012). Including something in regulatory language does not automatically make it either ethical or just (Rioux et al., 2011). My hope that sociologists might grasp this principle readily has long since dissolved.

Indeed, all of this occurred two years into a global pandemic of monumental scale and impact. It also was not a remotely unique occurrence. I had engaged in similar exchanges with multiple other conference coordinators in recent months. Yet the "stated clearly" language from this communication lingered in my mind for days afterward. Every time I tried to figure out what to say in response, I felt impossibly exhausted. It seemed as if I literally had no words left—something anyone who knows me would consider deeply unusual. I still feel that same exhaustion weeks later. Speaking feels laborious; interactions drain me to an unprecedented degree. Emerging scholarship suggests this frazzled and overwhelmed mental state may define the "new normal" of daily living during the Covid-19 era (Hoyt et al., 2021).

As abled people romanticize "post-pandemic" life, many disabled people wonder when we will even see the basic human rights actions we have needed throughout the "pre" era (Lund et al., 2020). The notion of post-pandemic *anything* also seemed fallacious to a positively insulting degree given I sent those emails about the sociology conference presentation during the initial Omicron variant surge of SARS-CoV-2 infections. In addition to being immense as predicted (Mohapatra et al., 2022) this surge also concerned scientists because of the first Omicron variant's already substantial ability to elude both vaccine-induced immunity and available antibody treatments (Kozlov, 2021).

Many of these patterns had already become clear in public health data and publicized in national media outlets by the time I emailed the coordinators for this conference. Yet I was framed as problematic for asking—in the explicit context of my cystic fibrosis, a life-threatening and disabling chronic disease that makes me especially vulnerable to harm from this virus—about basic accommodations for remote participation. Such gaslighting behavior by people in positions of power, and the debasement involved in responding, undermines our dignity and erodes our achievement of justice (see Barclay, 2018).

Ultimately I let the email sit unanswered. I resigned myself that nothing would change no matter how many emails I sent or to whom. I would only waste my remaining energy while recovering from another surgery and the ongoing infection in my mouth that necessitated it. Available evidence also indicated I would likely reproduce my own cognitive trauma in the process (Buzolits et al., 2020). So I decided the organizers could clean up their own mess—i.e., pursue further contact if they desperately needed to know whether I would risk my life to attend in person. In this case, my silence *was* the answer.

People cannot treat us as if we are invisible (see Jung, 2002) and then expect us to have words left for them. We have been doing this for two years at peak intensity in the face of vicious oppression (Lund, 2020). Many universities now offer course content specifically focused on pandemic preparedness and response within and beyond health care (Elengickal et al., 2021) in addition to offering broader accessibility improvements across disciplines. Truthfully though, chronically ill and disabled educators spent entire lifetimes doing accessibility work before Covid-19 forced basic acknowledgement of the injustices we face every day (Hannam-Swain & Bailey, 2021). I am profoundly tired. Yet politicians, managers, and administrators continue to pontificate at every opportunity about how desperately we need to "get back to normal" (Tomé et al., 2022).

## 2. Problematizing Normalcy

For people like me, and many of my closest colleagues, normal was always anything but. Rather, it remains a violent status quo "steeped in ableism" that reinforces interlocking systems of power and inequality, especially for academics facing intersecting forms of socioeconomic oppression (Saia et al., 2021). The concept of normalcy has long served as a "generic process" in the reproduction of ableism and associated social inequality (see Schwalbe et al., 2000). Such processes comprehensively entrench inequity in both specific resources for socioeconomic mobility and general inclusion in social spaces, including professional settings (Parrotta & Rusche, 2011).

The fundamental injustice of having to work just to survive has been explored and critiqued in numerous other sociological manuscripts (Spies-Butcher, 2020). Here I focus on specific injustices related to remote accessibility and related accommodations in the context of calls for restoring "normalcy" as the Covid-19 pandemic continues.

I identify four interrelated generic processes that reproduce ableism by impairing the practice of disabled and chronically ill professionals, devoting a section of this article to each. "Going remote" describes generalized resistance to offering remote participation options for activities that include in-person components. "On 'cop shit'" details how pervasive surveillance of remote participation options that *do* get implemented penalizes marginalized individuals under the guise of promoting ethically sound conduct. "When and where we work" explores how rigid thinking about acceptable work settings restricts access to gainful employment and generative activity. "Notes on risk" highlights how framing people as "high risk" becomes a justification for purposive denial of basic human rights.

## 3. Going Remote

Physical access to conference proceedings is one of many barriers chronically ill and disabled scholars navigate in the name of maintaining normalcy for those more privileged (Reinholz & Ridgway, 2021). Providing distance participation options via videoconference platforms like Zoom is necessary for justice in event organizing (Rice et al., 2021). Although this has been true since such technologies first emerged, Covid-19 and resulting changes in resource allocation have clearly demonstrated how providing remote access increases justice in education (Xiao, 2021a).

As of July 2022, new and highly transmissible variants of the SARS-CoV-2 virus continue to proliferate unchecked. When I wrote the first draft of this article, the BA.2 Omicron strain was driving new case surges in many parts of the US (Rahimi & Abadi, 2022). There are now many major Omicron strains circulating in the US and elsewhere, each often more resistant to vaccines and antibodies than the last. Although epidemiologists and clinicians around the globe continue to urge extreme caution and continued efforts to flatten transmission curves, many communities have significantly relaxed or completely rescinded Covid-19 restrictions (Huang & Zeng, 2022). Scholars of disability justice and educational equity alike have stressed that this should be a time for bold thinking and intentional action to make learning environments inclusive and safe for the most vulnerable people in our communities via distance options (Themelis & Tuck, 2022).

Videoconference access to activities with in-person components has long since become vital. Lack of remote options is one among many pervasive and widespread barriers that chronically ill, disabled, and otherwise marginalized academics face in our work (Olsen et al., 2020). And with the advent of increasingly diverse and virulent vaccine-elusive variants of SARS-CoV-2 (for general information see Haque & Pant, 2022; for specific details about Omicron strains see Liu et al., 2022) the consequences of these willful failures of accommodation may become yet more dire for larger portions of the population.

The essentiality of remote access for justice also goes well beyond the specific context of viral pandemics. Closed captioning offers a prominent example. Providing high-fidelity automated and/or manual captioning during online meetings has never been easier or more widely achievable. Yet familiar excuses continue to abound across multiple settings and contexts for why people cannot provide these services (Lyngbäck et al., 2021). Disparities also persist in access to captioning resources, sustained in part by purely "optical" use of such tools—i.e., using them only to give the surface impression of ethical conduct rather than upholding the deeper spirit of same (Jones et al., 2021).

My university remedied similar inequities after faculty and staff campaigned to get students access to the same types of features in their Zoom suite that we had in ours from the beginning. Our central IT office also embraced general feedback about captioning being a human right. They adjusted default settings for employee accounts to activate captioning features for users who had not enabled them manually. Such pragmatic approaches can increase justice in accessibility. Even if the technology is imperfect, making it readily available and enabling captioning by default greatly increased the use of these resources during events—and thus accessibility for participants (Lazar, 2007).

## 4. On "Cop Shit"

Yet more often, technological innovations that could facilitate transformational advancements in accessibility instead get used for surveillance and punishment. Activist scholars have accurately referred to such practices as "cop shit" (Darbyshire & Thompson, 2021). The use of sophisticated digital technologies to monitor and sanction people appears widely throughout capitalist societies, with nuances specific to unique work contexts such as university education (Wan & Albracht, 2021). Teaching frequently involves pressure to maintain punitive "discipline" that supposedly facilitates student success (Aagaard, 2021). Scholars exploring these dynamics in the Covid-19 era have described a "pandemic panopticon" of carceral practices masquerading as social cohesion (Aloisi & De Stefano, 2021).

For example, Covid-19 has brought tremendous increases in online exam administration. University administrators have pressured instructors to use Web proctoring services for assessment activities conducted remotely (Hamamra et al., 2021). Many schools have also required cheating detection software. Some instructors have also contributed to these injustices in the name of "integrity" by making students keep their cameras active during exams and other assessments (Gordon et al., 2021). Forcing students to video broadcast during discussion sessions—and sometimes even lectures—has also been remarkably commonplace throughout the pandemic (Daeizadeh & Babaee, 2021).

This type of enforced surveillance is one of many generic processes reproducing social inequality under the guise of supportive teamwork (see Sumerau et al., 2021). The Covid-19 pandemic has exposed these familiar patterns in novel circumstances related to safety and accessibility (Lyon, 2021). These dynamics also offer insight into why the "just stay home" idea poses additional problems beyond its unfair burdening of already oppressed people with sole responsibility for our own survival. Home means different things for individual people. Every dwelling offers different spaces and resources—and thus different signs and signifiers of class and other elements of social location (Howlett, 2022).

Work environments outside the education sector likewise persist in toxic practices that limit accessibility and harm employee wellness (Bromfield, 2022). These include aggressively micromanaging employees' active work time while simultaneously expecting availability for tasks 24 hours a day. Many such carceral practices in remote work regulation have also followed onsite employees home during the pandemic—and even intensified in some cases, fostering a "post-trust" society (Andrejevic & Volcic, 2021).

Humiliating and otherwise punishing people for their children "interrupting" videoconference meetings offers one common example (Freisthler et al., 2021). Social and behavioral inquiry has long since explained why groups of economically and socially privileged people who have never shouldered primary responsibility for caregiving—even for their own children among those who are parents—might view such ordinary occurrences as disruptive (Shockley et al., 2021). People who have caregiving experience can readily see how meetings are interrupting activities necessary for surviving and thriving.

These generic processes of inequality reproduction become clearer still in considering who *does* get to experience such moments without adverse consequences. Indeed, the people whose interruptions get either ignored or celebrated are those who already have substantial social and economic privilege (Clark et al., 2021). Memetic videos quickly abounded online of gender-conforming white men in lucrative professions getting interrupted by their young children during news broadcasts or transformed into cats during court hearings without facing any negative fallout (McIntyre et al., 2022).

Widespread recalcitrance about constructive technology uses such as closed captioning seems even more disturbing in this context. Considering how enthusiastically and copiously people have embraced punitive uses of technology, it feels chilling to see so much insistence on status quo practices when inclusive alternatives avail themselves more readily than ever.

## 5. When and Where We Work

Conceptualizing work away from home as the default "normal" practice also has little basis in historical context. Indeed, most subsistence activities throughout human existence have been done either specifically at home or generally in the immediate community. Even in cases where people worked for outside employers in positions of considerably greater social and economic privilege, often they lived on the same land without need for significant commuting. Living and working at nearby sites also invites greater flexibility with working hours and time management, allowing employees to maintain healthy boundaries elastic to their unique circumstances and responsibilities (Allen et al., 2021).

Covid-19 has clarified that the concept of working hours in education and other professions alike is essentially a subtle flavor of the carceral surveillance described above (Li, 2021). Some institutions seem to be grasping this more thoroughly than others—whether they have led prospectively on flexible work since the early days of the pandemic or made substantial adjustments after initially outlining harmful policies. Others now wrestle with the "technoskepticism" earned by their own punitive practices (Adams et al., 2021).

My university embraced flexible work in principle but struggled with operationalizing related details in practice. Leadership responded to critiques with improved policies highlighting the importance of such accommodations for multiple position types. Indeed, many faculties—especially those focused more on research and service over classroom teaching—have always enjoyed substantial flexibility with worksites and hours (Bhuyan et al., 2017).

I felt hopeful when leaders at our medical school developed a university-wide advocacy initiative on flexible work collaboratively with administrative staff—and more so when this initiative dissolved because our central human resources office released updated policies addressing these goals. This process illustrated a different and truly better "normal" in which leaders continually explore needed improvements and pathways to achieving them.

Of course, some work does need to occur at specific sites. Non-remote work invites significant innovation of its own within and beyond higher education settings (Xiao, 2021b). Flexible coverage for onsite staffing—basically a similar model to the remote work accommodations discussed above—can help substantially in making employment accessible. Likewise, remote work does not automatically obviate economic inequality as noted in prior examples about gender roles and intersecting oppressions (Bonacini et al., 2021).

Physical accommodations can also dramatically improve accessibility for chronically ill and disabled professionals while meeting additional needs such as sensory modulation (Rice et al., 2003). The core building access provisions of the Americans With Disabilities Act remain vital. Indeed, now-commonplace structural features such as ramps and elevators have shaped our collective concept of normalcy over time (Burch, 2020). People without personal experience of disability embrace the utility and convenience of such resources—whether attempting to transport heavy objects or simply feeling tired.

These basic ADA-mandated features also account for only a portion of physical accommodations that can improve workplace justice for intersectionally marginalized people. Covid-19 has demonstrated how actively challenging ableism, rather than simply meeting minimum requirements for reasonable accommodation, transforms employee engagement and quality of life alike (Hickson, 2021). For example, some health and functioning experiences introduce unique safety concerns that can be addressed by providing specialized personal protective equipment and other essential supplies.

Building modifications can also help to make onsite work safer for everyone while vastly improving accessibility (Mackelprang & Clute, 2009). The Covid-19 pandemic has demonstrated how many different approaches, used either individually or collectively, can bolster workplace safety. Common strategies for air quality management during the pandemic have included filtration, ventilation, distancing, and barriers.

Economic resource constraints can introduce challenges in implementing physical accommodations for workplace safety. True normalcy means prioritizing good faith efforts to accommodate people as fully as possible, as quickly as possible (Sniatecki et al., 2018). It does not mean expecting immediate perfection, but rather centering continuous growth and accountability in ways appropriate to people's unique contexts. These include considerations specific to disability as well as intersecting needs such as child care (Platt et al., 2022). Truly safe work environments require protection not only from infectious pathogens but also from oppressive social norms and policing actions that disproportionately penalize those already disadvantaged (Dhawan et al., 2021).

Indeed, safe onsite work looks different for everyone. I may be uniquely equipped to understand this as a clinical educator living with a progressive chronic disease that introduces substantial infection control requirements and contact precautions. Much of what people with cystic fibrosis do for routine health maintenance only became "normal" to other people because of the pandemic (O'Neill, 2021). For example, abled appropriation of "crip aesthetics" during the early stages of Covid-19 (Smith, 2021) has made face masks relatively familiar and nonthreatening even to those who eschew using them. I can now buy groceries while masked without people antagonizing me—or suggesting that I remain home instead of living my life autonomously. Similarly, justice does not mean "normalizing" work so that everyone's equipment and process look exactly the same. Rather, it means normalizing the adaptation of work to meet individuals' unique needs.

As suggested by the elevators and ramps example, all of this also calls into question what makes someone "need" an accommodation. When abled people "need" something, pure convenience is often the main consideration. But as Covid-19 has shown, the burden of proof on chronically ill and disabled people remains extraordinarily high for accommodations, benefits, and services (Price, 2021). The moment something inconveniences abled people, change begins to happen. Yet such change still involves privileged groups getting their demands met before awareness and support begin to reach marginalized people (Xafis, 2020).

## 6. Notes on Risk

Chronically ill and disabled Americans felt largely unsurprised when initial responses to the Covid-19 pandemic largely took the form of telling people at elevated risk for severe harm from SARS-CoV-2 to "just stay home" (Brooks, 2021). Many saw these patterns readily without formal social science training. Seeing how government officials intentionally reinforce the oppression of minority groups using coded language like "high risk" (Woods, 2022, pp. 163–216) hardly requires a sociology degree. The "normal" society continues to chase still depends on simultaneous vilification and erasure of sick and disabled people (Rutherford, 2021). Although exposing these dynamics has inspired entire subfields within the social sciences, awareness and inquiry alone have not eradicated these willful oppressions (Chen & McNamara, 2020).

Framing safety and survival as questions of individual responsibility for people who already occupy precarious positions within unjust systems is both highly intentional and deeply eugenic (Mosley, 2020). I wonder where all the people who said "never again" after learning about extermination campaigns against sick and disabled people throughout history have been during Covid-19. Their silence now sustains violence against those who have feared for our lives watching our peers perish from preventable infections. Our longstanding entreaties for people to take advantage of widely available flu vaccines and practice basic hand hygiene diligently both amplified as the pandemic began and swiftly drowned in the ire of those who valued their own convenience exclusively. These patterns continue, demonstrated by people eagerly welcoming technological innovations that punish and exclude others while resisting ones that affirm and include.

Work itself, and how we frame it in human rights context, lies at the center of this polemic. Whether we work in paid jobs ourselves or struggle to demonstrate continued eligibility for disability benefits, the so-called "right to work" touted by elected officials remains problematic and often deadly (Blume, 2022, pp. 57–86). The current system punishes those chronically ill and disabled individuals who can participate in its economy directly by denying us basic worker protections (Wilson et al., 2020). It likewise punishes those who cannot participate—because of structural features inherent in the system itself—by sustaining these barriers no matter the cost.

Framing disabled people as being somehow lucky to live on public benefits that pay barely a pittance seems a uniquely Western practice, if not a specifically American one. Public officials often add insult to injury by gaslighting disabled people receiving public assistance about how far those meager funds should go (Smith-Carrier & On, 2021). The notion that people should "pull themselves up by their bootstraps" in navigating a global pandemic and its exacerbation of poverty (O'Connor, 2020) seems especially egregious in this context.

## 7. Closing Thoughts

For chronically ill and disabled people, normalcy has always been overrated. The same things many of our peers yearn to experience again as Covid-19 gradually becomes endemic represent distinct regression for those who began to experience something resembling human rights during the pandemic. As safety restrictions ease and disappear—despite significant community spread of SARS-CoV-2 persisting—we see our lives being discounted and devalued with similar vigor. The idea that being "high risk" means we should live isolated and fearful lives, with constant reminders of our own precarity, remains normal in the minds of many. After over two years of both witnessing mass death in the news and losing several of my own friends in the cystic fibrosis community to Covid-19, this dismissal of our human rights feels deeply personal in unprecedented ways.

The toxicity of the "high risk" ethos does not end with my own disease and the functional limitations it causes, though. Indeed, disability results from the failure of society to accommodate people—not simply the presence of the limitations themselves (Donoghue, 2003). This denial of human rights sets people inexorably apart from the communities of which we are members. Like all "generic processes in the reproduction of inequality" (see Schwalbe et al., 2000), institutionalized inaccessibility not only limits opportunity and mobility (Tomaskovic-Devey, 2014) but also constrains the "informal networks" (see McGuire, 2002) that allow marginalized people to fight injustice together and support one another in the process. Perhaps most cruel of all, the denial of accessibility keeps us from one another—from the support we share reciprocally and from the simple pleasure of those connections. It requires us to keep our distance from those we love and especially from those who are best poised to understand our experiences.

I am not the only "high risk" person in my family. My father, who had a liver transplant in March 2019, has spent most of the pandemic inside his house. He and my mother even moved their porch furniture indoors as SARS-CoV-2 began spreading, understandably afraid the virus would somehow find them. Although I readily accept heightened awareness of my own mortality, I shared my parents' intense fear. The idea of losing my father just months after his life-saving transplant terrified me then and still does now. Yet colleagues who should know better often treat us as afterthoughts.

As ever, the burden falls unjustly on sick and disabled people to protect ourselves and each other (Sabatello et al., 2020). Many beneficial practices universities have adopted and sustained throughout the pandemic (see Brammer & Clark, 2020) have originated with us—those who have persistently and wearily reminded peers of danger and spoken truth to power with superiors. The transformational benefits of resulting innovations, not only in access but also in education itself, are well documented (see Almarzooq et al., 2020). Yet resistance abounds to including us in the very advancements our collective advocacy has spurred.

Two years into the pandemic, anger has given way to feelings of exhaustion and disconnection. Many educators feel this immense burnout even as we celebrate innovations this global moment has produced, such as refinement of the "flipped classroom" strategy inviting greater learner engagement (see Pokhrel & Chhetri, 2021). We cannot enjoy transformation in education without surviving to see it. Had my own departments not consistently helped me protect myself and my family, I might never have written these words.

Even in this reasonably safe and supportive context, I still cringe frequently at cavalier behavior from others. I saved my father's email to the whole school from when the original Omicron variant of SARS-CoV-2 was beginning to spread in Florida. At that point, I had only seen him once in two years—and then only at the distance behind KN95 masks. Although his experience continues to surpass those of many liver transplantees, the remaining immunosuppression still leaves him vulnerable to harm even from commonplace viruses like colds. Our family always took more virulent pathogens like influenza seriously because of my own illness, never missing routine flu shots or hand washing opportunities.

These nuances in risk management (for a general sociological overview of risk theory see Lidskog & Sundqvist, 2013; for its specific applications in sociology of health see Zinn, 2009) between different individuals highlights the importance of context in advocacy on disability justice. One of my reviewers for this manuscript thoughtfully noted that:

> For colleagues of [theirs] with physical and sensory impairments their participation in live conferences—even if accessibility is poor—is also a form of activism. In other words, for some the act of simply travelling and being out in public forces people to think about accessibility and to acknowledge the presence of disabled people in public spaces.

They reflected on how activism can take different and often equally impactful forms depending on the unique circumstances and needs of each individual.

Noting how "if conference participants with disabilities opt not to travel to conferences because of poor accessibility, nothing will change because there is little pressure to make accommodations," this referee aptly pointed out the importance of social closure in stimulating progress toward inclusivity (for a general overview of closure in professional spaces see Roscigno et al., 2009; for its specific application to academic settings see Swartz, 2008). Likewise, their feedback reflected the importance of closure in advocacy circles themselves. They noted that attending conferences in person for activist purposes "may not apply to those with conditions where catching an illness could be life-threatening…pushing for distance or hybrid conferences and teaching is one form of activism and inclusion, but the live setting is for people with other kinds of impairments." By intentionally supporting one another's risk management best practices for our own unique contexts, activist scholars can achieve collective impacts while maintaining individual well-being.

Before Covid-19, many treated these individual risk management behaviors as paranoia for myself and others in the chronic illness and disability communities (Jesus et al., 2021). I can presently buy groceries without invasive questions about high-filtration masks and hand hygiene. Awareness of the immense financial and environmental benefits of remote access options has likewise proliferated (see Klöwer et al., 2020). Yet I still cannot seem to convince abled people that my life matters as much as theirs. My CV keeps the score: asterisks alongside conference presentations I never got to make, footnotes explaining denial of reasonable accommodations, reflections on core principles my disciplines should proactively defend. These barriers to dissemination and collaboration remain widespread even among otherwise privileged scholars susceptible to adverse outcomes from Covid-19 (Rashid & Yadav, 2020).

For every professional who has managed to publish and advance and otherwise convince people of some basic value, there are countless others silenced—by persistent exclusion, by willful denial of accommodations, and ultimately by death (see Galloway et al., 2020). The fact that dying often makes others finally heed our voices (Siegel & Tani, 2021) never becomes less dystopian or grotesque. We continue to forfeit our lives in the name of normalcy never meant for us at all. Our foreshortened time upholds a status quo that not only excludes us from society overall but also denies us community with one another, curtails our access to vital supports in enduring ableism and intersecting forms of oppression (see Gil et al., 2021). The "normal" life many yearn to reclaim instead remains more of the toxic same.

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## Conflict of Interests

The author declares no conflict of interests.

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Article

# “Vulnerable” or Systematically Excluded? The Impact of Covid-19 on Disabled People in Low- and Middle-Income Countries

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**Abstract**
The Covid-19 pandemic has disproportionately affected disabled people across the globe. This review article maps the impact of the pandemic on disabled people in low- and middle-income countries (LMICs) during the first ten months of the pandemic, based on a semi-systematic review of 113 articles of empirical and “grey” literature. We highlight the multiple exclusions faced by disabled people across the sectors of health, education, economy, community, and pandemic management. Following this, we discuss the broader issues arising from the literature, including the systematic de-prioritisation of disabled people in emergency planning, the ongoing framing of disability as a medical rather than a social or human rights issue, a recognition of how the complexity of societal structures creates systematic disadvantage, and local, national, and global policymakers’ lack of engagement with disabled people during pandemic management. We identify the need for both stronger quantitative evidence on disability in LMICs to inform planning and policy processes, and the need for equitable collaboration with disabled people from LMICs across research, policy, and development programming, in the spirit of “Nothing About Us Without Us.”

**Keywords**
community; Covid-19; development; disability; disabled people; economy; education; Global South; health; low- and middle-income countries

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## 1. Introduction

The Covid-19 pandemic has disproportionately affected the 1 billion people, or 15% of the world population, who are disabled (United Nations, 2020). In this article, we present and discuss evidence on the impact of Covid-19 on disabled people in low- and middle-income countries (LMICs), focusing on the initial global emergency response during the first ten months (March–December 2020) of the pandemic. The focus on the first wave of Covid-19 was chosen to assess how the immediate response to a global pandemic took into account—or failed to account for—the inclusion of disabled people. This is particularly relevant as previous evidence strongly suggests that disabled people have been excluded during the critical phase of emergency management for previous pandemics or environmental disasters (Abbott & Porter, 2013; Battle, 2015; Gartrell et al., 2020; Görgens & Ziervogel, 2018; King et al., 2019). We argue in this article that the data which emerged during the pandemic provides clear evidence that, once again, disabled people have not just been “left behind” but have been deprioritised and had their human rights violated during the response at a global level.

The evidence presented draws on a semi-systematic literature review, carried out to inform the development of an analytical framework for a disability-inclusive recovery for the UN Partnership for the Rights of Persons With

Disabilities (UNPRPD). While we map the impacts across the five sectors of health, education, economy, community, and pandemic management, we aim to pay particular attention to the broader themes emerging across these different sectors. Our findings confirm the assertion that the impact of the Covid-19 pandemic goes far beyond health, having been described as a health, psychological, and socioeconomic "triple pandemic" (United Nations Office for Disaster Risk Reduction, 2020).

### *1.1. Disability in Low- and Middle-Income Countries*

Approximately 80% of disabled people live in LMICs (United Nations, 2020). Despite the ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) by 182 countries, in practice implementation of the Convention's rights has been inconsistent and variable. The measuring of progress towards UNCRPD implementation is complicated by the lack of accurate data on disability, which is compounded by both limited medical understandings and stigma around disability, meaning disabled people may be unwilling or unable to identify their disability status (Berghs, 2015b).

Disabled people thus continue to face discrimination and barriers, while also being disproportionately affected by poverty (Shakespeare, 2019). Disability is both a cause and a consequence of poverty (Economic Commission for Latin America and the Caribbean, 2020; Thorpe et al., 2020), which is exacerbated by a lack of social protection, with only 1% in low-income countries of disabled people having access to disability-specific benefits (United Nations, 2020). Financial burdens also are increased through a fragmented approach to public healthcare provision (Mills, 2014; Orach, 2009), leading to poorer health outcomes for marginalised groups that are financially excluded from access to healthcare (Marmot et al., 2008; Orach, 2009; Wagstaff et al., 2014; Xafis, 2020). Globally, only around 50% of primary-aged disabled children attended school prior to Covid-19, although this figure is as low as 1% for some countries (UNICEF, 2020), and in particular affecting disabled girls (Rohwerder, 2020; Said-Foqahaa et al., 2020). In addition, disabled people present the majority of institutionalised people globally, and are also overrepresented in prisons (Sakellariou et al., 2020; United Nations, 2020). In the community, a lack of formal support means reliance on informal care from family and friends for many disabled people (King et al., 2019; United Nations Economic and Social Commission for Western Asia & World Health Organization, 2020). Disabled people are also at greater risk of sexual violence and abuse (Clugston & Spearing, 2020; Giang & Huong, 2020; UN Women Africa, 2020) and violence from family members (Said-Foqahaa et al., 2020; Stars of Hope Society for the Empowerment of Women With Disabilities, 2020).

Poverty and lack of government funding for healthcare, education, and the economy means that many services are supported by development aid programmes. These often do not address disability issues (CBR Africa Network, 2020; Clugston & Spearing, 2020) and can reproduce disabling conditions if not taking emancipatory approaches or accounting for the broader geopolitical influences that contribute to disablement in the Global South (Berghs, 2015b). Research on development interventions is equally dominated by medical model approaches focussing on health interventions, with a lack of evidence on the effectiveness of rights-based approaches and empowerment initiatives (Saran et al., 2020). The limited funding available for development programmes means that there is often a focus on "quick fixes" (Shakespeare, 2019), rather than on building holistic and sustainable long-term systems (Berghs, 2015a; OECD, 2020), meaning the provision of healthcare, education, and financial support are limited and not able to withstand a global pandemic, especially in countries also simultaneously experiencing conflict or other crises.

## 2. Methods

The evidence presented emerged from a research project to assess the impact of Covid-19 on disabled people in LMICs and develop an analytical framework for the UNPRPD to enable their programming partners to conduct comprehensive situational analyses at country level and identify the key priorities for a disability-inclusive recovery. LMICs were defined as countries included on the Development Assistance Committee list of countries and territories eligible to receive official development assistance countries and territories eligible to receive official development assistance (OECD, 2022). To ensure the literature review results and development of the framework reflected the priorities and concerns of those with lived experience, an advisory group was recruited using snowball sampling through the researchers' existing networks. The group was comprised of disabled activists and scholars from LMICs (Bangladesh, Brazil, Indonesia, Jordan, Kenya, Namibia, Uganda, and Zambia).

In order to assess how disabled people in LMICs had been affected during the first ten months of the Covid-19 pandemic, we conducted a semi-systematic literature review, which combines the literature selection principles of a systematic review with narrative and discourse analysis approaches (Snyder, 2019; Zunder, 2021). The semi-systematic review methodology is better suited than a fully systematic review to mapping themes across a diverse range of evidence and theoretical approaches, as well as identifying gaps in knowledge (Snyder, 2019), and was therefore judged to be most useful to review a broad range of evidence from both empirical and "grey" literature. The literature review was carried out by a research fellow with lived experience of disability, with regular input from the project's principal investigator. The review followed the framework developed by Templier and Paré (2015) for conducting a standalone literature review, which comprises six steps:

1. formulating the problem;
2. searching the literature;
3. screening for inclusion;
4. assessing quality;
5. extracting data;
6. analysing and synthesizing data.

For step 1, the research question was formulated as: How has the first wave of the Covid-19 pandemic impacted disabled people in LMICs?

A UN policy brief on a disability-inclusive response to Covid-19 (United Nations, 2020) was used to map out four broad sectors in which disabled people experienced inequality (health, economy, education, and community). Sub-themes within these four sectors were mapped out through initial reading of emerging evidence, and this provided a rough structure for the formal literature review searches. The themes were revisited and refined throughout the literature review process. The initial sub-themes identified within each sector are included in Table 1.

The literature search was carried out in two phases. The first phase identified academic literature through searches in eight social science databases, using Boolean operators to combine search terms around disability and Covid-19 with terms covering the above-identified sub-themes. In addition, the same searches were carried out to identify literature around disability, the above sub-themes, and previous major pandemics, epidemics, or disasters that affected LMICs, to identify past literature from similar emergencies.

Backwards and forwards citation searching was employed to identify further relevant literature, and search alerts were set up to ensure any newly emerging evidence during the review period (September 2020–February 2021) was included. The second phase focused on identifying "grey" literature, including reports from NGOs and disabled people's organisations (DPOs), UN and WHO reports, national government documentation, and non-peer-reviewed research reports. "Grey" literature was identified through citations in academic literature, searches on Google scholar and on Google by country domain to identify government reports. In addition, we searched UN, WHO, and IMF databases, NGO and DPO websites, and sites where relevant reports had been collated, such as the Disability Debrief archive (https://disabilitydebrief.substack.com).

The initial process yielded 893 potentially relevant results. These were subjected to a light-touch review to identify literature meeting the following criteria and assess the quality of the data (steps 3 and 4 in the framework proposed in Templier & Paré, 2015):

- The focus was on disabled people, as defined by the UNCRPD, rather than caregivers/family members, and examining disability from a social science, rather than a medical, viewpoint.
- Disability was a major focus (i.e., there were five or more mentions of the words "disabled" or "disability").
- The focus was on disability in LMICs or was more global (papers focusing on situations specific to OECD countries were excluded).
- Academic articles were original research or review articles (exclusion of comment/opinion pieces).
- "Grey literature" reported on actual data (rather than guidance or recommendations).

Using these criteria, 113 articles were selected for in-depth review. These included 67 "grey" literature articles and 46 academic articles. Of the 46 academic articles, 14 focused on previous disasters and emergencies rather than Covid-19. Articles were coded using the subthemes in Table 1, with new themes and codes included as they emerged from the literature. In particular, a fifth broad section focussing on pandemic management

**Table 1.** Initial subthemes mapped out prior to literature review.

| Health | Education | Economy | Community |
|---|---|---|---|
| Infection and mortality | School closures | Poverty and austerity | Social care and independent living |
| Access to hygiene and protection | Home learning | Social protection and relief | Informal support systems |
| Access to treatment | Remoting learning | Unemployment and loss of jobs | Institutionalisation |
| Non-Covid-19 healthcare | Return to school | Informal employment | Homelessness |
| Public health communications | | Remote working | Public transport and infrastructure |
| | | Return to work and accommodations | Access to services |
| | | Unpaid and care work | Violence and abuse |
| | | | Religion, culture, and leisure |

generally was added to the review structure during the coding process. Coding focused particularly on recurring evidence within the themes, as well as particularly extreme cases that highlighted the stark impact of the pandemic on disabled people. While the primary aim was to produce a qualitative, narrative review report for the UNPRPD to synthesize the existing evidence, some quantitative data to understand the nature and distribution of the literature reviewed was generated by recording up to three of the most prevalent themes of each paper. The most common theme emerging within literature were either related to health (55%) or economic (48%) impacts of the pandemic. Community emerged as a major theme in around 33%, with pandemic management being a focus in 25% and education in only 16% of articles. "Grey" literature made up the majority of the evidence (59%), particularly by NGOs (31) and UN-affiliated agencies (19). While articles reviewed were published between March and December 2020, most of the evidence on the first wave emerged early on in the pandemic, with almost two-thirds (64%) of the literature reviewed published between March and June 2020. This effect was exacerbated for grey literature, whereas the publication of academic peer-reviewed literature was more evenly distributed across the 10 months of the review.

## 3. Findings

In this section, we will be discussing the major emerging findings across the five thematic areas investigated in the literature review: health, economy, education, community and, pandemic management.

### *3.1. Health: Deprioritised*

Disabled people faced significant barriers and exclusion across all aspects of healthcare, from access to public health communications, information about Covid-19 and preventative measures such as personal protective equipment and hygiene facilities, to Covid-19 treatment to essential and routine non-Covid-19 care.

Access to Covid-19-related care and treatment was affected by triage protocols which deprioritised disabled people, based on the implicit assumption of disability equalling lower quality of life, and conflating disability and frailty based on medical models of disability (McKinney et al., 2020; Scully, 2020; Singh, 2020; Women Enabled International, 2020). In addition, disabled people faced structural barriers in purpose-built Covid-19 treatment centres which did not provide facilities for disabled patients, including lack of accessible toilets and beds. Being separated through quarantine from personal assistants, caregivers, or parents in the case of disabled children, left some patients, including deaf or non-verbal people, without support to communicate with healthcare staff. The diversion of healthcare resources to Covid-19 provision disproportionately affected disabled people, with many (ranging from 19% to 70% across different surveys) unable to get their healthcare needs met. Disability-specific services were often classified as "non-essential" and therefore ceased (Disability Working Group, 2020; Goyal et al., 2020; McKinney et al., 2020).

Global shortages of personal protective equipment during the early stage of the pandemic, as well as prohibitive costs, led to many disabled people being unable to access cleaning and protective equipment. Another barrier to protection against Covid-19 was presented by lack of accessible public health communications, with the vast majority of national health authority websites not meeting minimum accessibility standards (Dror et al., 2020) and 36% of LMICs not providing sign language interpretation during press briefings (Yap et al., 2020). Technological and literacy barriers to official sources of information also put disabled people at increased risk of misinformation about the virus. In addition, the language used in public health communication reproduced ideas about disabled lives being less valuable (Abrams & Abbott, 2020; Goggin, 2020; Meaney-Davis et al., 2020), and negative healthcare messages added to mental distress for disabled people.

Two gaps identified in the health theme are around the impact of "long Covid," which has the potential to create significant numbers of newly disabled people (Wise, 2021), and access to vaccination for disabled people in LMICs, as few LMICs had begun the vaccination process at the time the review was carried out.

### *3.2. Education: Inaccessible*

The evidence reviewed suggests that Covid-19 has exacerbated disabled children's already limited access to schooling. The closure of schools in 188 countries affected 1.5 billion children across the globe (UNESCO Bangkok, 2020). As well as disrupting access to education, it also affected crucial services delivered through schools, including food programmes, access to sanitary facilities, safeguarding mechanisms to identify and prevent abuse and trafficking, and medical (including vaccination) and therapy programmes for both general health and disability-specific services (McClain-Nhlapo et al., 2020). Disabled children were both more likely to be severely impacted by the cessation of these services, and unable to access them in the first place.

Home and remote education both presented challenges for disabled children. Disabled children's families were often ill-equipped to support them with learning at home, for example, due to parents and caregivers needing to work to sustain families, or not being able to afford learning materials or necessary equipment (McClain-Nhlapo et al., 2020). The two main barriers to remote education were (a) access and (b) accessibility to technology. Firstly, internet connectivity is poor in many LMICs, particularly in rural areas, and the costs of both data and technological devices can be prohibitive (Castres & O'Reilly, 2020; Humanity & Inclusion, 2020). While remote education was delivered through TV and/or radio in some LMICs, only 18% of parents felt this was accessible or useful learning (McClain-Nhlapo et al., 2020). Secondly, major IT platforms such as videoconferencing software are not designed to be inherently accessible, and this was compounded by teachers, parents, and learners not being familiar with accessibility features. Some of the access issues reported included lack of sign language interpretation, captioning, and screen reader compatibility.

Disabled children were at increased risk of not returning to school when they reopened after lockdown, due to multiple reasons. Parents may have been concerned about the increased risk of infection if their children attend school (Pregel & Le Fanu, 2020; UNICEF, 2020), or may not believe that there is any value in attending school for disabled children (Meaney-Davis, 2020). The sharp rise in poverty during lockdowns may also increase the need for children to contribute to the household income, rather than continuing their education (Azevedo et al., 2020). Those who did return likely faced increased attainment due to the inaccessibility of home learning. With already stretched resources, many schools would have been ill-equipped to address these attainment gaps (Jones et al., 2020; UNICEF, 2020). However, the exact impact is uncertain due to a lack of disaggregated data being collected both during and before the pandemic, meaning there is no baseline data available. The literature review also identified no evidence of the impact of the pandemic on tertiary education.

### *3.3. Economy: Impoverished*

The evidence reviewed indicated strongly that many disabled people, particularly those who were also marginalised in other ways, faced increased poverty as a result of the pandemic, due to both reduced income and increased cost of living, particularly health-related costs. Food poverty was cited as the most significant type of poverty experienced, leading some disabled people to describe hunger as a bigger threat to their health than Covid-19 (Gahatraj, 2020; Humanity & Inclusion, 2020). Disabled people also faced housing insecurity and increased debt due to needing to borrow money as a result of poverty.

Most countries took relief measures to mitigate the economic impact of Covid-19, although most countries did not offer disability-specific support (Gentilini et al., 2020). Economic relief most commonly took the form of short-term or one-off cash or in-kind assistance. In practice, several barriers prevented disabled people from accessing financial support. Some relief measures specifically excluded those already in support of disability allowances or other social protection payments. Other barriers included lack of awareness about the available support, bureaucratic hurdles including the need to prove disability status in order to access payments, inaccessible distribution points, and ineffective distribution at the local level. Multiple reports (e.g., Brennan et al., 2020; Gurung & Gahatraj, 2020; Pregel & Le Fanu, 2020; Zayed et al., 2020) indicate that DPOs were instrumental in ensuring relief measures were delivered to their members at the local level, in the absence of government support.

Disabled people’s employment was also disproportionately affected by the pandemic, due to disabled people being more likely to be informal or insecure work (Banks et al., 2021; Castres & O’Reilly, 2020; Gurung & Gahatraj, 2020; Meaney-Davis, 2020). Small-scale traders, such as market traders were unable to access loans or government support due to the small size of their businesses. Disabled people were also at greater risk of having their hours reduced or cut, or being made unemployed during the pandemic, with disabled women particularly affected. Those disabled people for whom working from home was an option also faced additional barriers, including lack of accessible equipment and software (International Labour Organization, 2020). The literature review found no evidence on the impact of Covid-19 on unpaid work, including domestic and care work.

### *3.4. Community: Isolated*

Lockdowns affected 58% of the world’s population during Spring and Summer 2020 (Singh et al., 2020). These were usually implemented with short notice, disrupting the provision of both formal and informal assistance for disabled people. In a global survey, 45% of people said their governments took no action to mitigate this disruption and, as a result, a significant number of disabled people were unable to get their essential needs met (Brennan et al., 2020), including access to personal care, food and medicine, and maintenance of assistive devices and mobility aids. Lockdowns also increased isolation for many disabled people as they were cut off from their support networks, exacerbating stress and affecting particularly those in poverty and in rural areas (Light for the World, 2020; Meaney-Davis et al., 2020).

Deaths in residential homes amounted to between 42% to 57% of Covid-19 deaths in OECD countries (United Nations Human Rights, 2020). Similar data is not available for LMICs. However, reports suggest increased infection among institutionalised disabled people due to overcrowding and lack of cleanliness, along with no access to information about Covid-19 or its prevention, and increased isolation during lockdown. One report suggests that lack of oversight and breakdown of reporting mechanisms led to abuse and neglect, including human rights violations in institutions (Brennan et al., 2020). Crucially, similar conditions of overcrowding, lack of hygiene, and no access to information, were also reported in a number of other settings including informal settlements and refugee camps, prisons, and among the homeless populations, with disabled people overrepresented in all of these settings (Brennan et al., 2020; Clugston & Spearing, 2020; Jones & Tulloch, 2020; Pregel & Le Fanu, 2020; Sakellariou et al., 2020).

Violence and abuse against disabled people increased during the pandemic, particular against disabled women, girls, and non-binary people (Humanity & Inclusion, 2020; Lund, 2020; Women Enabled International, 2020). This violence took several different forms. Domestic and caregiver violence increased as disabled people became less likely to access support systems or escape violent situations. There were also reports of police violence against disabled people, with excessive force being used to enforce lockdowns and curfews (Brennan et al., 2020; Goyal et al., 2020; Panda et al., 2020). Disabled people also faced aggravated stigma and discrimination, including assumptions that they were infected with Covid-19.

Restrictions to public transport services increased barriers for many disabled people, with access to transport being identified as a significant unmet need (Hillgrove & Pryor, 2020; Zayed et al., 2020). With many essential services moving online, disabled people were more likely to be affected by digital poverty, particularly in rural areas, with cost and inaccessibility of information technology presenting major barriers. There was no discussion in the literature reviewed of how disabled people's access to public spaces, to religious practices and worship, or to leisure, culture, arts, and sport was affected by the pandemic.

### *3.5. Pandemic Management: Excluded*

General evidence on national approaches to the initial management of the Covid-19 pandemic indicates that many countries adopted a "one-size-fits-all approach" (Qi & Hu, 2020, p. 849) that neglected the specific requirements of disabled people. Where consideration was given to disability, this was not necessarily implemented locally (Sakellariou et al., 2020), or took the form of recommendations rather than being enshrined in law. There was little evidence of consultation taking place at local, national, or international levels with disabled people and their organisations, and in some cases, DPOs encountered resistance from official authorities (Gartrell et al., 2020; Poudel & Subedi, 2020) when implementing local support for their members. A major finding of our literature review was the dire lack of disability-aggregated quantitative data being collected at national, international, and global levels on the impacts of the pandemic. In particular, we identified the lack of disaggregated data relating to infections and death rates, the impact on people incarcerated in institutions, and the socio-economic impacts on disabled people.

## 4. Discussion

The results section has presented the key issues identified by sector. However, during the analysis process of the literature review, we also identified four overarching themes that emerged from and spanned these five sectors. These present the key learning points of how the pandemic has been handled in the immediate response with regard to disability. Following discussions of these four cross-cutting themes, we discuss the limitations of our study and make recommendations for further research, including several gaps in the data which have been identified.

### *4.1. Theme 1: De-Prioritisation of Disability*

Firstly, we highlight the de-prioritisation and systematic exclusion of disabled people across all aspects of planning and service delivery. While the importance of involving and consulting with disabled people in disaster and crisis management has been frequently highlighted (e.g., Abbott & Porter, 2013; Campbell et al., 2009; Görgens & Ziervogel, 2018), our literature review was not able to identify a substantial body of evidence that indicated that positive change has been achieved or lessons learned either during or in the aftermath of previous disasters or pandemics. As discussed previously, we only identified 14 relevant articles on prior pandemics and disasters in LMICs as part of our literature, and many of these describe similar failings during the immediate emergency response phase as we have identified in the literature review. This suggests that learning points and recommendations identified in the literature have not been taken on board by policymakers and therefore not translated into improved emergency management responses. Despite the widespread ratification of the UNCRPD, disability continues to be at best an afterthought, with measures to ensure disabled people's access either retrospectively or not at all implemented. We argue therefore that disabled people have not merely been "forgotten" in the pandemic response, which implies a passive kind of neglect, but that disabled people have been actively de-prioritised during the Covid-19 pandemic due to being seen as expendable. The de-prioritisation of services for disabled people as "non-essential" perpetuates the continued discrimination and stigma of disabled people as less than human.

### *4.2. Theme 2: Medicalisation of Disability*

The second emerging theme is the conceptualisation of disability as a medical issue, rather than a category of social oppression and disadvantage. Definitions of disability continue to be based on medical or deficit models, and this was replicated in some of the literature reviewed. In addition, disabled people have often been labelled "vulnerable" both in official government health communications, as well as in some of the reports reviewed, without questioning the social factors that produce disablement and make disabled people "vulnerable" (see also Abrams & Abbott, 2020), particularly when Covid-19 emergency responses both de-prioritised disabled people and often exacerbates the barriers disabled people faced. We argue therefore that a stronger focus on social models and understandings of disability, particularly those originated by disabled people from the Global South, is crucial for a more nuanced and less essentialist understanding of the experience of disability in LMICs.

### *4.3. Theme 3: Interconnection of Issues*

While the literature review was structured into the four sectors of health, education, economy, and community, the analysis and writing processes highlighted that these were not discrete categories but were often interconnected. Access to food provides a good example of this, being simultaneously (a) an economic issue due to food poverty being the most common form of poverty, (b) an infrastructural issue due to lack of transport to access markets and shops, and (c) a health issue due the lack of a nutritious diet potentially exacerbating existing and creating new impairment. It is, therefore, crucial to understand the complexity of contemporary social systems and how they work together in creating structural disadvantage, and considering this in pandemic management and development programming, rather than opting for "quick fixes" that do not affect long-term substantial change. One methodology to achieve this may be through implementing systems theory into the practical implementation and delivery of development programmes (Reynolds et al., 2018). This could support a more holistic approach that enables positive change without focusing on issues in isolation, as well as fostering cooperation and communication between different stakeholders involved in both policy and delivery of programmes.

### *4.4. Theme 4: Collaboration With Disabled People*

The final emerging theme is around the inclusion of disabled people in the pandemic management and recovery process. The evidence indicates that little consultation took place at national and international levels with disabled people during the pandemic process. While it is possible that not all consultation that took place was documented, this highlights the need for transparency and accountability in how disabled people have been involved in policy- and decision-making. Disabled people have historically been the subjects of research done by non-disabled people (Goodley, 2011) and many "disability charities" are not in fact disability-led. In this literature review, much of the "grey" evidence came from international NGOs, rather than DPOs. This risks replicating "charity model" approaches with disabled people being spoken about, contrary to the global disability rights motto "Nothing About Us Without Us."

### *4.5. Limitations*

While we have aimed to provide a broad overview of the impact of Covid-19, this literature review has a number of limitations. Firstly, it focuses on the emergency response during the first ten months of the pandemic. While therefore providing valuable evidence of how disability is deprioritised in times of acute crisis, further comparative evidence is needed on how barriers may have lessened or new barriers emerged during subsequent waves of Covid-19. For example, access to vaccination was not covered in the literature as vaccination programmes were just beginning to emerge at the time the review was concluded. Secondly, due to publishing times, particularly for peer-reviewed evidence, evidence was sparse in the early months of the pandemic. One of the challenges faced during the review was the distinction between empirical evidence and recommendations, guidance, and opinion. Thirdly, the review only focused on English language articles, meaning evidence published in other languages may have been missed, potentially further excluding knowledge from marginalised disabled people. Fourthly, the literature review took a broad approach in focussing on all LMICs, which necessitated some conflation while recognising that the Global South is not a monolith. Efforts were made to recognise where experiences were specific to a cultural context while seeking to draw out experiences common across LMICs. We hope that this literature review thus provides a particular focus on the many commonalities experienced by disabled people not just across the Global South, but also similarities to the experiences of disabled people faced in developed countries. Finally, while the researchers have lived experience of disability, they are based in the Global North. This position of privilege means that researchers do not have first-hand experience of the pandemic in LMICs. This was mitigated through regular consultation with advisory groups of disabled experts from LMICs.

### *4.6. Recommendations*

While providing an initial overview of the impact of the Covid-19 pandemic on disabled people in LMICs, this review also highlights a considerable amount of work to be done to fully understand how disabled people are continuing to be impacted and how they can be included in the eventual recovery from the pandemic.

There is an urgent need for more quantitative evidence on disability and Covid-19. This literature review has highlighted the lack of disability-disaggregated evidence that has been collected by policymakers during the Covid-19 pandemic at the national, international, and global level, making it difficult to assess the full impact of the emergency response on disabled people. Additionally, where data has been collected, there is often no baseline data available for comparison. Researchers and governments need to ensure that any general data collected can be disaggregated by disability status, and that specific research on disability issues is commissioned to generate robust evidence that can inform policy. The findings section highlighted a number of gaps in each sector where more evidence is required to fully understand the impact of Covid-19, including data on infection and death rates for disabled people, return to school and attainment gaps for disabled children, updated disability poverty rates, the impact on disabled people performing unpaid and care work, quantitative and qualitative data on the experience of disabled people in institutionalised settings, and access to leisure, religion, and public spaces. We would also particularly like to highlight the need for further data on the implementation of priority access to vaccination for disabled people in LMICs, as recommended in World Health Organization (2020) guidance.

Simultaneously, more thought needs to be given by research and development programmes, particularly those originating in high-income countries, on how to ensure a more equitable collaboration with partners in the Global South, and particularly with disabled people who are directly affected by these issues. This includes working with DPOs, whose crucial contribution to supporting disabled people has been highlighted in this review, as well as working with disabled people as co-researchers, and crucially, ensuring disabled people are remunerated for their time and contributions.

## 5. Conclusion

This article has summarised the exacerbation of existing barriers faced by disabled people across the world, and particularly in the Global South, during the first nine months of the Covid-19 pandemic. For many disabled people in LMICs, the pandemic has simply compounded existing crises and hardships; as one first-hand report puts it: "[It was] a domino-like chain reaction of discrimination and exclusion" (International Disability Alliance, 2020). We have sought to highlight how this exclusion was not rooted in inherent "vulnerability" but was socially produced through the systematic exclusion of disabled people from pandemic management and planning. It is crucial to continue to resist individual and medical approaches to disability and recognise it as a social and human rights issue A stronger focus on co-production and equitable working with disabled people and their organisations is therefore crucial for researchers, development professionals, and other stakeholders, to ensure that research and policy are fit for purpose (Gartrell et al., 2020; Görgens & Ziervogel, 2018; Pineda & Corburn, 2020; Pregel & Le Fanu, 2020). In the spirit of "Nothing About Us Without Us," disabled people need to not just be involved, but lead on everything that affects them, to ensure that the recovery from Covid-19 is disability-inclusive.

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## Conflict of Interests

The authors have no conflict of interests to declare.

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Article

# Disabled People’s Experiences of the Coronavirus Pandemic: A Call to Action for Social Change

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**Abstract**
The Coronavirus pandemic has caused significant disruption and change in most aspects of society, and there are concerns that disabled people may be particularly disadvantaged. This article, written by disabled activists and non-disabled allies, shares data extrapolated from focus groups regarding the lived experiences of twelve disabled people and disability allies during the Covid-19 pandemic, eleven of whom were based in the UK, and one based in Iraq. We describe the key issues and learning points from this data, arguing that the measures taken by the government and organisations to protect the public during the pandemic have instead brought to the fore long-standing ableist narratives regarding which bodies are valuable in society. This ableist agenda has acted to control and silence the voices of disabled people by objectifying disability and defining “pre-existing health conditions” as being more expendable, and therefore less worthy of attention during the pandemic. In presenting our position for change and call to action, we will argue that it is only when disabled people’s experiences and voices are heard in decision-making that policymakers can begin to learn from the inequalities that have been demonstrated through the pandemic. Here, we will introduce our Wellcome Trust-funded “We Are the People” Disability Research Collective programme (2021–2026). This programme develops a new disability activist-led research network, whereby disabled people can conduct research into topics that are important to them.

**Keywords**
ableism; activism; Coronavirus; disability; silencing; social change

**Issue**
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## 1. Introduction

Evidence points to disabled people potentially being at particular risk of experiencing disadvantage as a consequence of the Coronavirus pandemic that has been impacting the globe since December 2019 (Armitage & Nellums, 2020). Confirmation of the depth and extent of inequalities is beginning to be reported. In the UK, Shakespeare et al. (2022) demonstrated how the Coronavirus pandemic has affected established social practices that allowed disabled people to navigate their lives. Examples provided by disabled people included how their access to much-needed health and social care had changed, with particular therapies being cancelled altogether; or how they experienced challenges in navigating new social norms, such as people with hearing impairments being unable to lip read with opaque face masks, or when people with visual impairments found maintaining appropriate social distancing difficult. Recommended practices to help respond to the Coronavirus pandemic, such as self-isolation, can specifically disadvantage disabled people for a number of reasons, for example, when public health information is not provided in accessible formats, where disabled people require support from care workers, or where disabled people's social interactions with others are restricted due to limited digital literacy or because they do not have access to stable internet connections (Caton et al., 2022; Kuper et al., 2020; Shakespeare et al., 2022). In addition, through the Coronavirus pandemic, disabled people reported being at particular risk of experiencing financial stress and instability, such as food insecurity and needing to use food banks, as well as difficulty in accessing welfare support (e.g., Emerson et al., 2021; Inclusion London, 2020; Loopstra, 2020; Scope, 2020). It is perhaps unsurprising then that studies have shown how disabled people have reported poorer mental health as a consequence of the Covid-19 pandemic (Kavanagh et al., 2022), and significant anxiety regarding the impact that this period is continuing to have on their lives (Office for National Statistics, 2022), as well as feelings of social isolation and abandonment by the UK government (Inclusion London, 2020; Scope, 2020).

Similar challenges have also been evidenced among disabled children and those with caring responsibilities (Banerjee et al., 2021; Gillespie-Smith et al., 2021; Onwumere et al., 2021). For instance, Banerjee et al. (2021) have argued that the lockdown period and subsequent closure of schools may have had detrimental effects on disabled children's mental well-being, with parents reporting that their child was more anxious as a result of the lockdown. The uncertainty of the lockdown period may have also promoted worsened emotional and academic development for disabled children, as well as a loss of structure and routine (Banerjee et al., 2021). In addition, Shakespeare et al. (2022) have described how disabled children learning at home during the pandemic may have been provided with poor quality and inaccessible education materials. Family carers of disabled children have also reported increased psychological distress as a consequence of the pandemic (Gillespie-Smith et al., 2021). Myriad factors might be attributed to poorer mental health in carers, but there is concern that this population have faced considerable unmet care needs (Onwumere et al., 2021) in terms of difficulties in navigating unclear public health advice and reduced access to respite support and other needed disability services (Gillespie-Smith et al., 2021).

Alongside the above challenges, reports have evidenced how disabled people are concerned about whether they will receive equal access to healthcare provision and medicine (Inclusion London, 2020; Scope, 2020), specifically regarding the possible rationing of ventilators for disabled people (Abrams & Abbott, 2020). Disability health inequalities have also been highlighted in mortality rates attributed to Covid-19. For instance, disabled people commonly experience other health conditions, and potentially ill health, and may be at increased risk of health complications should they become exposed to Covid-19 (Shakespeare et al., 2022). Reports from the Office for National Statistics (2020) revealed that the vast majority of individuals who have died as a result of Covid-19 had pre-existing health conditions and that disabled people accounted for approximately two-thirds of all recorded deaths due to Covid-19 in England and Wales (see Office for National Statistics, 2021). The Office for National Statistics (2021) report also revealed the mortality rate for disabled people, particularly people with learning disabilities, was far higher than that of non-disabled people. Indeed, the Care Quality Commission (2020) expressed concern that in the UK, there has been a "significant increase in deaths of people with a learning disability as a result of Covid-19.'' Therefore, the consistent message discussed in this section is that the response from the UK to Covid-19 risks reinforcing and exacerbating existing systemic health and social inequalities already experienced by disabled people (Shakespeare et al., 2022).

While there is no single, straightforward, explanation for these inequalities, researchers in the disability studies field argue that they may be due, in part, to ableism guiding the systems, decision-making processes, and communication about disability during the pandemic era (e.g., Abrams & Abbott, 2020; Goggin & Ellis, 2020; Liddiard, 2020; Lund & Ayers, 2020; Lund et al., 2020), leading to a silencing and erosion of disabled people's voices. "Silencing" of disabled people, in the context of this article, refers to how disabled people are denied opportunities to share their experiences due to oppressive practices of powerful others (Yoshida & Shanouda, 2015). Ableism refers to the value that society places on being "able-bodied" or "able-minded,'' and how existing systems and procedures contribute to, and reinforce, perceptions of disabled people as inferior (Campbell, 2008). Goodley et al. (2014) have argued that disabled people are likely not to be viewed as fully human, which in turn, places a lack of value and worth on their lives. As Goodley and Lawthom (2019, p. 247) described, "disabled people risk becoming the collateral damage of neoliberal-ableism: justifiably excluded because they simply cannot survive the demands of everyday living." Turning to the pandemic, there are concerns that ableism is being demonstrated in multiple powerful ways. For instance, Liddiard (2020) argued that ableism may be shaping a perceived lack of worth regarding disabled people's lives in policy and discourse. Concerning the pandemic, others have suggested that ableist policies may be guiding healthcare decisions that in turn, deny disabled people's rights in the global rush to manage the pandemic (Andrews et al., 2021; Bigby, 2020). As Bigby (2020, p. 2) indicated, the Coronavirus pandemic has raised concerns "that human rights for people with disabilities are fragile and not yet deeply embedded in service systems or practice. It is too easy, in times of crisis, to slip back into paternalism and denial of rights."

This potential denial of rights is reflected through discourse applied to Coronavirus patients. In the UK in particular, discourses about disability are commonly framed with terms such as "pre-existing" or "underlying health conditions," and "vulnerable." These terms are not necessarily controversial in and of themselves, given the increased likelihood of disabled people having pre-existing health conditions (Shakespeare et al., 2022). However, while acknowledging this, researchers have argued that descriptors like "pre-existing health conditions" move away from a strict health association, to one of a paternalistic and stigmatising nature that is used to "other," devalue and segregate particular groups of people from the "healthy" norm (Abrams & Abbott, 2020; Ktenidis, 2020). This separation, effectively dividing people between those deemed "healthy" and those "unhealthy," risks creating legitimacy and acceptability about disabled people's mortality rates associated with Covid-19, due to their lives being perceived as less valuable (Abrams & Abbott, 2020; Shakespeare et al., 2022). In other words, the ableist narratives that emerge from discourse and policy regarding responses to Covid-19 risk problematising disabled people for falling outside the norm, rather than addressing the systemic inequalities that exist (e.g., in terms of healthcare funding and disabled people's access to support) in a neoliberal structure (Abrams & Abbott, 2020).

## 2. A Call to Action: An Overview

In this article, we will seek to argue two points. First, that the disadvantages that disabled people have experienced in the wake of the Coronavirus pandemic can be attributed to long-standing systemic ableism that has permeated political and social discourse. It is this ableism that has resulted in disabled people being silenced, and as well as being viewed as expendable, and as though they are less than human. Second, notwithstanding the human suffering that has taken place through the Coronavirus pandemic, this period represents a unique opportunity in time for disabled people's voices to be heard in building back a more just and equitable society than that prior to the crisis.

There are concerns within the literature regarding the apparent dearth of research to date exploring the impact of Covid-19 on disabled people (Shakespeare et al., 2022). In making our points, we attempt to address this gap and draw on empirical data we collected with disabled people and disabled allies about their experiences of the pandemic. We will first describe the methodology of this project, before discussing and applying our data according to theoretical interpretations of silencing and ableism. We will then make our position for change and call to action by introducing our ongoing Wellcome Trust-funded programme (2021–2026). We will discuss our forthcoming plans for the research programme, as well as broader recommendations for reforming the ableist exclusion that disabled people have likely encountered through the Coronavirus pandemic.

## 3. Methodology

Data for this article were collected through four focus groups with disabled activists and allies. Across the four focus groups, participants were asked to discuss their thoughts regarding different contemporary issues concerning disabled people and disabled people's research, for instance, the Coronavirus pandemic, access to goods and services, health, well-being and compassion, activism, and participation in research. The focus groups were therefore not strictly discussing experiences of the Coronavirus pandemic as a central issue, though as all data collection took place during the pandemic, the pandemic organically underpinned many of our discussions.

In total, we collected data from twelve participants across the four focus groups, of which eleven were based within the UK, and one was based in Iraq. The first three authors of this article participated in the focus groups in dual roles as researchers and as disabled activists. Some participants, such as the first three authors of this article, attended more than one focus group, though this was not a prerequisite for participation. We did not collect data about specific participant characteristics (e.g., gender, nature of any impairment, geographical location etc.) to ensure the anonymity of all participants' experiences, including those of the authors. Each of the focus groups took place virtually via Google Meet, lasted approximately 60–90 minutes, and were audio-recorded and transcribed. The School of Education Research Ethics Committee at Bath Spa University granted ethical approval for this research to take place.

For our analysis, the first three authors analysed all focus group transcripts for content that related to our central interest in disabled people's experiences of the Coronavirus pandemic. We used thematic analysis as described by Braun and Clarke (2006), which involved the construction of key codes and emerging larger themes. We were keen to ensure that the reported data did not simply become an autobiographical description of our own experiences, but rather, reflected the communal accounts of the disabled people across the focus groups. To achieve this, the first three authors each engaged in independent thematic analysis of the data regarding experiences of the Coronavirus pandemic. Following our independent analyses, the first three authors met as a team to conduct a further collective thematic analysis, whereby we discussed our thoughts on the data. This allowed for fruitful collaborative discussions about the thematic content that had emerged, resulting in the finalisation of the key collective experiences. From these discussions, three broad themes emerged from the data: (a) feeling ignored and treated as less than human in responses to the Coronavirus pandemic; (b) barriers encountered by disabled people during the Coronavirus pandemic; (c) learning opportunities for a more inclusive post-pandemic world. In the next section, we present these three themes before stating our call to action in the final section of this article.

## 4. Findings

### 4.1. Feeling Ignored and Treated as Less Than Human in Responses to the Coronavirus Pandemic

A consistent narrative across the data was that the Coronavirus pandemic has been an intensely difficult period for disabled people. A central experience from participants was that disabled people did not have a significant voice or representation in Coronavirus-related decision-making and so, at times, felt silenced and powerless. In particular, participants felt as though disabled people and carers had largely been ignored and segregated by government and organisations in responses to the Coronavirus pandemic. One participant described this sense of feeling ignored by the lack of consistent support for people with hearing impairments during government briefings in England:

> We know the real issue that we're all having at the moment is that government is not engaging with disabled people's experiences, and therefore because they're not engaging with those experiences, there is "no issue," you know? That's why we see, time and time again, [that] there is no BSL [British Sign Language] interpreter on the daily briefings, because they're [the government] not considering engaging with the disabled community. (Participant 1)

Participants suggested that this lack of representation could be attributed to at best, ignorance from government and organisations regarding the importance of making reasonable adjustments for disabled people, or at worst, viewing disabled people's lives as lacking in worth. For some participants, such as those who shared the forthcoming quotes, there was a concern that potentially long-term ableist ideals within society were being used as justification for the ongoing decisions that were being taken by the government and other organisations. Such decisions led to participants feeling a strong sense of abandonment, and at times, intense anxiety over the salience of their potential personal vulnerabilities to infection, and how disabled people would have to manage for themselves. These fears in particular were around the legitimacy of the prevailing narrative within governmental and societal discourse regarding disability and mortality due to Covid-19. One participant challenged the implication in the language adopted by government representatives that deaths due to Covid-19 were more "justifiable" if the individual was disabled and/or had a pre-existing health condition(s):

> I think that there's been a real devaluation in how modern society is viewing disabled people and I think, for me personally, I always knew that that devaluation was there, but I think in the last few years it's really been shown overtly and it's really come to the fore. Whereas, before it's kind of bubbling beneath the surface…it began really vividly with the austerity agenda…in that…disabled people were villainised…burdens, all of those things, and, you know, the nature of that was [to] justify a very brutal change in welfare policy….I think particularly with Covid, my concerns have been, as a disabled person, that…my perceived lack of value is becoming very real, in a way that I've kind of always known, but I didn't really see it as overt necessarily. So, we can talk about how the UK government has shown very little support to help the disabled community in terms of the pandemic….And actually…the UK government has shown, or [has] used disabled people as a means of justifying its mortality figures, so that we know…whenever they did the daily briefings…[they'd say that] the majority of mortalities that has come from Covid has been with pre-existing health conditions, but I've always questioned why just having a pre-existing health condition matters in mortality figures, why should that make any difference? (Participant 1)

Another participant argued that government rhetoric was based upon perpetuating a "eugenic logic" and "survival of the fittest," whereby disabled people were seen as disposable. This was reinforced by what they felt was an unwillingness from government representatives to engage in constructive discussions with disabled communities about how they were experiencing the pandemic:

> I think all this shows really is [that] this has just been a very thin veil that has been covering up really what the policy and opinion is, which is that disabled people's lives…they're not important. And actually, in the grand scheme of things, if a few thousand disabled and old people die, well, you know….It's just another form of eugenics, and, so why would they [the government] be listening to disabled people? There's no need for them because it's just part of their eugenic logic that makes sense. It's like survival of the fittest. So, I think we're maybe being a bit naïve to think that they do, would, might like to care, and they might like to involve us in the conversation. I'm getting more and more pessimistic that I just, I think it's very hard to see why they would even try. (Participant 4)

### 4.2. Barriers Encountered by Disabled People During the Coronavirus Pandemic

Participants spoke of the challenges disabled people were encountering through the pandemic. Reported challenges were many, and included factors such as difficulties in understanding and following inaccessible government pandemic guidance, accessing needed health and social care, maintaining physical and mental health, protecting against the risk of infection (e.g., for disabled people who were immunocompromised), and navigating inaccessible technologies, such as for online video communication. Some participants described how these barriers were long-standing in nature, in that they existed before the onset of the pandemic, already having been intensified during the roll-out of the UK government’s austerity agenda described above by Participant 1. However, they attributed the pandemic with bringing and exacerbating these long-standing barriers to the fore. For instance, participants spoke at length about how their support infrastructure had fundamentally changed as a consequence of the Coronavirus pandemic and gave several examples of how they would typically access support to assist them in their everyday lives, such as health and social care services. Others spoke of more social or informational support, such as in communicating with others. In some cases, participants described how their ability to access needed support had significantly reduced, and some services had stopped completely, resulting in them having to manage their health and well-being in other ways. One participant spoke of known challenges for disabled people in accessing social care, which became exacerbated through the pandemic:

> A [disabled] lady…went five days without any carers coming in, so did not get washed or change her clothing for those five days…because she had nobody to look after her, to help her. Now that, that’s treating somebody worse than an animal isn’t it?...Lots of people have become really, really isolated, because they’re not able to get out and about, because there’s no places that they would normally go to, as part of their weekly routine…disabled people, I’m speaking for myself in this…life is hard enough, but you throw something like the Covid situation into the mix, and you are back of the pile. (Participant 8)

For other participants who were able to access support, the Coronavirus pandemic provided additional challenges, stresses and concerns regarding how they managed their own health and well-being. One participant described how interacting with others placed them at additional risk of infection, but in spite of this increased risk, they were required to locate their own protective equipment in order to stay safe:

> I think relying on personal assistants means that I’m completely open to the virus when they are coming in, even though they’re so careful, so caring, so concerned themselves about potentially passing that onto me, but I haven’t been given any PPE [personal protective equipment]. I’ve just had to scramble around on Amazon and places like that to find it. So, my physical health is very vulnerable, my mental health is probably the lowest I’ve ever been, and that’s quite unusual for me, I don’t think I’ve really experienced any of these things before. (Participant 4)

This experience of poor mental health and well-being was also felt by other participants. As the previous quote indicates, participants felt intense anxiety and vulnerability over potentially being put at risk of infection. At the same time, while not wanting to expose themselves to the virus, some participants were also concerned about pre-existing issues of social isolation not only for them as individuals, but also for those around them who were similarly isolated:

> I do have a lot of people around me that have mental health issues, or are very, very isolated in their living circumstances. And I’ve found trying to keep up with everyone, and just, sort of, try and support people with their mental health issues, people who have been there for me…it’s great, I’m happy to do it, but it’s quite emotionally difficult. (Participant 6)

Other participants spoke of a broader long-standing barrier of inaccessible communication, and how they attributed reduced mental health and well-being to how the pandemic was being communicated by policymakers and politicians. Participant 5 spoke of new “social rules” that members of the public were supposed to follow, but felt lost as these rules “have been quite hard for me to understand, or to grasp quickly, ‘cause I think sometimes they haven’t always been that well-supported by evidence, or they haven’t been clearly communicated.” Some participants found the negative rhetoric and news stories around Coronavirus distressing, and so opted to avoid or reduce their consumption of news, such as via radio and television, due to mental health concerns.

### *4.3. Learning Opportunities for a More Inclusive Post-Pandemic World*

Notwithstanding the challenges described in the previous themes, many participants felt that the Coronavirus pandemic had promoted positive changes in behaviours, which in turn, could help support a more inclusive society going forward. For example, participants appreciated that there appeared to be a wider acceptance of the diversity of people’s needs. One participant gave the example of society possibly becoming more aware of mental health issues:

> I often talk about that kind of exhaustion that one has just getting [by] day to day with a disability, and I think because of the anxiety and the fear that people have actually been feeling…there’s been lots of talk about the Corona rollercoaster, and people feeling very fatigued and needing to lie down and sleep and rest a lot. I do hope that people maybe grow in understanding that that is…it’s really important to factor that in, not just for disabled people but for everybody in terms of your work-life balance. (Participant 2)

The clearest example related to the positive shift in societal discourse towards more inclusive working conditions, with Participant 6 describing how “some of the measures that were previously thought to be reasonable adjustments are now being taken up by a wider pool of people." For several participants, the pre-Coronavirus world, particularly in relation to work, such as having to deal with long commutes and fatigue, was a stressful and problematic experience. During the pandemic, and at the time of writing this article, many participants had taken up working from home. While participants did acknowledge that home-working did raise new challenges, such as those regarding their own care needs and sense of isolation, and the changing uses of technology as a means of communication, they felt that the pandemic provided a valued sense of relief for them in that some pre-pandemic work-related practices were no longer required. However, participants were concerned that rhetoric from government and organisations indicated that working from home could only be a temporary measure, and agreed that it was important that appropriate reflection take place to establish the enablers and barriers to different types of working practices:

> One of the things…[about] working from home, because, really, people who don't go to the workplace every day have been sharing that experience now with, say, 80 percent of the working population. Does that mean anything? Does that teach anything to anybody? It's a curious thing. Or, was it so awful that we just want to relegate a very small population of disabled people to having to put up with working from home? Because it's nasty and nobody else wants to do it ever again because they're all lonely and sad when they work from home, you know? It's that sort of issue. (Participant 3)

As the previous quote alludes, a particular concern from participants was that Coronavirus-related decision-making from government and organisations appeared to be focused on going back to normality, which was defined as synonymous with life before the pandemic. Participant 6 described how "at the moment, we probably do have a government that wants to go back to the normal that was, because they were the ones at the top of the pecking order in that system." For some, this rhetoric promoted an intense fear because this would mean them experiencing pre-pandemic barriers once again. Moreover, navigating the pre-pandemic barriers would potentially be coupled with pandemic-related tasks, such as involving protection of their health. For instance, Participant 3 spoke of how they may have to manage competing interests of remaining employed, and protecting themselves from being exposed to Covid-19: "So, if you're in shielding like I am, does that mean that I have to deal with, 'do I risk death, or do I keep my job?' And that's quite a tough one."

In light of the challenges and fears that disabled people had encountered through the pandemic, participants stressed the importance of hearing disabled people's voices in decision-making to challenge possible reversals back to pre-pandemic ways of working. Participant 6 described how it was important to convince government and policymakers "to understand that actually, a new normal is what is widely wanted":

> And maybe this is why…disabled people's voices [are] so important now, in order to challenge some of those before the big decisions…before everything returns back to the normal that was, now is the time to be elevating these voices that are celebrating the good aspects of the diversity and all of that.

In this sense, participants agreed that the pandemic period provided an important and unique opportunity to learn from the inequalities of the past and build a more inclusive society going forward, as described by the above participant. They acknowledged that expressing this would require significant activism and engagement from disabled people and non-disabled allies. It is this need for activism and engagement that drives our call to action.

## 5. A Call to Action: Reflections on Findings, and the "We Are the People" Disability Research Collective

What is clear from the above is that disabled people may have experienced significant hardship as a consequence of the Coronavirus pandemic, both in terms of restricted access to goods and services, as well as how they navigated a dehumanising discourse of disability rooted in a "eugenic logic" (Participant 4). Governmental responses to the pandemic have left some of our participants with intense feelings of fear and anxiety, as well as a sense of frustration and powerlessness. In reflecting on our findings, we wish to apply theoretical ideas of silencing (Yoshida & Shanouda, 2015) and ableism (Campbell, 2008), which are emerging during this era, specifically, those identifiable in the accounts that we have collected through fieldwork.

Some participants related that they were concerned about the lack of attention given to disabled people's rights in decision-making processes, and spoke of feeling silenced due to their voices and needs not being heard or considered in public responses to controlling the virus. Others spoke of the various opportunities for positive learning and meaningful social change that could develop from disabled people's experiences, if policymakers were willing to listen, such as regarding the transition from office to home-working and the advantages this may present, including reduced fatigue and better work-life balance for staff. This reliance on policy makers' willingness to listen created tension in terms of participants feeling both hopeful that positive social change was achievable, whilst also feeling great concern about a possible desire within the UK government "to go back to the normal that was" before the pandemic (Participant 6) in a post-pandemic world, due to a feeling that this previous normal best served the general population.

Other clear examples of silencing were observed in terms of disabled people feeling excluded and isolated from others. This is perhaps most evident through the imposed lockdown across the population, but, to an even longer extent, confinement to a particular place (the home) was recommended for those likely to be severely harmed by the virus. This confinement posed a further significant tension for participants, as while the imposed lockdown may have reduced their risk of infection and provided respite from potentially difficult pre-pandemic working practices, such as long commutes, this period also placed them at risk of considerable social isolation, which in turn was potentially destructive to their mental well-being. In terms of support, some participants reported being potentially unable to—or chose not to—access it. A few expressed the view that the support they conventionally received involved additional risks due to the pandemic, and reported having to manage these as best they could. Other participants, cognisant of not being simply focussed on their own challenges, described having a sense of duty towards individuals who needed support, whether this concerned giving emotional or practical physical assistance. Given that availability of health and social care services during the pandemic has been markedly affected, the ability to access essential provisions has very likely been negatively impacting disabled people.

A third form of silencing related to participants' expressed concerns that their lives were deemed as lacking value: that a "eugenic logic" was guiding decision-making processes under the pandemic emergency, which led some to consider that a regime of "survival of the fittest" (Participant 4) had been instituted. This could be considered a most extreme form of ableism whereby those bodies not considered "fit and healthy" were to be written off as unfortunate but unavoidable casualties of the pandemic. A point of real tension related to what easing of Covid-19 restrictions could mean for maintaining the well-being of disabled people in the future, for instance, disabled people within the workplace. As this created particular challenges, queries were raised as to whether the UK government and employing organisations understood disabled people's needs and potential fears, and whether clear information and support would be provided in order to allow disabled people to manage their job roles effectively. If this was not the case, then this would, in effect, be marking out disabled people as burdens, which could act as a justification for ascribing an inferior status to them (Campbell, 2008), as compared with other non-disabled members of work teams.

Taken together, the Coronavirus pandemic has brought to the fore, and potentially exacerbated, various longstanding barriers that have affected disabled people's lives, such as being viewed as less than human. It is apparent that at the societal level, particular voices have been silenced in terms of raising issues that call out ableist inequities. The isolation and removal from participating in society of certain groups of people has likewise been undertaken and justified by certain governmental authorities. As mentioned above, describing disabled people as vulnerable or as having pre-existing health conditions is, apparently, being deployed as a particularly insidious justification for problematic death rates (e.g., Abrams & Abbott, 2020), and arguably, perhaps in a similar way to justify the silencing and confining of disabled people. Notwithstanding, our findings emphasise the desire of many disabled people to raise awareness of, and challenge, deep-rooted ableist norms that have led to these practices. Specifically, the uncertain period of the Coronavirus pandemic provides an unprecedented moment in history for disabled people's voices and experiences to be heard in creating a more equitable society.

In noting these interpretations, we acknowledge that the experiences of the Coronavirus pandemic described in this article cannot be considered indicative of all disabled people, since there is considerable variation in how this period has affected different populations. Further, as we chose not to record characteristics of participating disabled people, we cannot conclude whether experiences of the pandemic are shaped by factors such as gender, impairment, and location, amongst others. For instance, it could be hypothesised that the closure of health and social care services in order to prevent the spread of infection may be more acutely felt by disabled people in rural locations owing to the spatial isolation of some communities. Moreover, it is becoming apparent that what could have been expected at first glance to have extreme impacts, positive or negative, might on deeper examination, be giving rise to a mixed pattern of experiences for individuals who are likely to be similarly situated. We recommend that further research be conducted to address these questions.

In the final part of our article, we present a call to action. This call to action centres on elevating the voices of disabled people who have been silenced (e.g., Read et al., 2021). Taking such a stance is essential for ensuring that the feelings of exclusion that disabled people have faced, and will likely continue to face, during the Coronavirus pandemic and beyond, are addressed. As Lund and Ayers (2020, p. S211) described in relation to the Coronavirus pandemic response, "disabled lives must not be sacrificed, and disabled voices must not be silenced." Academic activism led by disabled and non-disabled researchers is our proposed way forward as we seek to build on the complex experiences encountered in the wake of the pandemic, for we are convinced that this is a unique opportunity in time for disabled people's voices to be heard. We recognise that building back society to be more just and equitable will take time as social change is incremental. That is, it is not a linear process and is likely to face recurring ableist challenges in policy discourses and across conventional academia similar to those encountered prior to and during the pandemic crisis. The authors of this article are currently leading a research programme (2021–2026) entitled the "We Are the People" Disability Research

Collective, which is funded by the Wellcome Trust. This programme focuses on creating and developing a disability activist-led research network for South West England, founded upon principles of disability activism, equity, and co-production. The purpose of our network is for disabled people, disabled people's organisations, and their allies to work with a team of academic partners to co-produce and participate in accessible and inclusive research that addresses issues of importance to the region and leads to positive social change in policy and practice. Example topics include, but are not limited to, understanding the legacy of the Coronavirus pandemic for disabled people; to what extent disabled people's experiences of the pandemic are influenced by factors such as gender, race, sexuality, differences in urban versus rural environments, etc.; what positive learning and change for disabled people has emerged through the pandemic; and how change for disabled people in a post-pandemic world can be achieved and sustained. Our programme hopes to directly challenge the ongoing silencing of disabled people's voices in several ways. First, shifting power and control over research away from universities to disabled people and disabled people's organisations at the grassroots level. In so doing, we hope to understand and show how academic institutions can work better with underrepresented communities to share their experiences. Second, creating innovative research questions and new research methodologies that accurately reflect the needs of disabled people. Third, forging collaborations between disabled people and policymakers, so that ongoing norms of silencing and ableism associated with disability in discourse and decision-making can be challenged. Through forging these collaborations between disabled people and policymakers, we will seek to enact and embed positive social change in all the research that emerges from our "We Are the People" Disability Research Collective programme. In making this call to action, we welcome anyone who is interested in learning more about our programme to contact us.

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## Conflict of Interests

The authors declare no conflicts of interest.

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Article

# Re-Imagining Inclusion Through the Lens of Disabled Childhoods

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**Abstract**
The purpose of this article is to contribute new insights to critical disability and disabled children's childhood studies that center on the valuing of disabled children's lives—a guiding purpose in the disability justice movement. We use published findings from the Inclusive Early Childhood Service System project, a longitudinal, institutional ethnography of the ways that families and children are organized around categories of disability, which show social inclusions and exclusions before and during the pandemic. These findings illuminate: (a) institutional flexibility for the purpose of social inclusion and isolation during the pandemic as a result of institutional organization; (b) the impact of institutional decisions around closures, remote programs, and support on families' choices and self-determination; and (c) the ways safety is differently applied and rationalized for disabled children allowing institutions to exclude disabled children and families. We use critical disability studies and disabled children's childhood studies to interpret these findings and position the valuing of disabled children's lives with a call for disability justice actions.

**Keywords**
critical disability studies; disability justice; disabled children's childhood studies; pandemic; social exclusion

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## 1. Introduction

This article uses critical disability studies (e.g., Goodley, 2016) and disabled children's childhood studies (e.g., Curran & Runswick-Cole, 2014) to theorize social inclusion and exclusion for families and disabled children during the Covid-19 pandemic. We present new theoretical insights about social inclusion and exclusion gleaned from previously published work from the Inclusive Early Childhood Service System (IECSS) project, as well as other literature, which underscores how pandemic responses to early childhood education and care services impacted families' access to services and the choices they could make with what was on offer (Underwood, Frankel, et al., 2019; Underwood et al., 2021). We first explore institutional flexibility, which relates to how organizations structure the menu of services for families. Institutional flexibility impacts how families access, navigate, and choose services for their disabled children. We then address the "fallacy of choice," which refers to an illusion of authentic choice around accessing early childhood service systems that institutions present to parents/caregivers (Underwood, Frankel, et al., 2019, p. 146). Finally, we examine safety, whereby disabled children are both simultaneously constructed as needing enhanced protection for their own safety as well as constructed as threats to the safety of others (see Ivery & Endicott, 2018; Stoughton, 2006). We use critical disability and disabled children's childhood studies to interpret these findings, which pushes the paradigms of early childhood service systems in ways that affirm value and inclusion of disabled children and their families. We turn to disability justice (e.g., Mingus, 2011; Piepzna-Samarashinha, 2018; Sins Invalid, 2019), a movement that is implicit in its inclusion of disabled children and aims to center the valuing of disabled children's lives.

The IECSS project is a longitudinal, institutional ethnography of the ways that families and children are organized around categories of disability. Our previous findings show that exclusions through the pandemic did not account for the complexity of the closure of early childhood service systems for disabled children (Underwood et al., 2021). Rather, how early childhood service systems are structured and how they have responded to the pandemic illuminate existing ableism and other injustices. Yates and Dickenson (2021, p. 1) state that "underlying social structures and systems mean some groups are more at risk in a pandemic context and are therefore more affected [in all aspects of their health, physical, emotional, social, spiritual] than others." Specifically, our previous findings on pandemic-imposed changes to how early childhood service systems organize and deliver services to disabled children demonstrate that institutional responses led to exclusions for many families, while other institutional adaptations to the pandemic demonstrated opportunities for connection and inclusion (Underwood et al., 2021).

We begin this article by discussing critical disability and disabled children's childhood studies and describe tenets of the disability justice movement. We then offer a general description of pre-pandemic disability services in Canada and show how ableism is at the center of pandemic discourse and service changes. We hold the complexity of institutional flexibility, fallacy of choice, and safety as intricate concepts dependent on how disability is constructed and interpret these from the lens of critical disability and disabled children's childhood studies. We highlight disability justice actions for institutional responses that are more inclusive and affirming of difference with an emphasis on the implications of pushing this paradigm forward in early childhood service systems.

## 2. Theoretical Frameworks: Critical Disability and Disabled Children's Childhood Studies

Critical disability and disabled children's childhood studies offer rich theoretical and political resources to explore tensions around disability, normalcy, and social inclusions/exclusions made visible by institutional responses during the pandemic. Critical disability studies is an interdisciplinary field that rethinks impairment and disability beyond a western medical model of deficit and its emphasis on fixing or remediating individuals (Garland-Thomson, 2013; Goodley et al., 2019). Instead, critical disability studies make a "paradigm shift" (Goodley, 2011, p. xi), troubling normative conceptions of the human and re-orienting to disability as a fundamental way of being with something of value to contribute to our human life together (see also Michalko, 2002; Titchkosky, 2003). Human complexity and disability are constituted by material, socio-political, socio-cultural, discursive, geopolitical, historical, and other processes (Garland-Thomson, 2013; Goodley et al., 2019). Critical disability studies present alternatives to deficit and medical views, including more affirming ontologies and representations of disability (Douglas, Rice, et al., 2021), intersectional, global, and post-colonial analyses of disability along multiple axes (race, class, gender, sexuality geopolitics, and others (see, for example, Erevelles, 2011; Puar, 2017), interventions in exclusionary policy and practice, and the valuing of disabled childhoods (Underwood et al., 2021).

Critical disability studies thus critique and contest *ableism*—the assemblage of institutions, knowledges, discourses, policies, practices, and relationships that systemically advantage and value able-bodied/minded individuals (Campbell, 2009; Goodley, 2014; Goodley et al., 2019)—and *disablism* the systemic devaluing, stigmatizing, marginalizing, and disadvantaging of disabled people (Abberley, 1987; Thomas, 2007, pp. 13–14). Within our contemporary moment of advanced capitalism, understanding neoliberal ableism, or what Goodley et al. (2019, p. 981) term "neoliberal ableist capitalism" is particularly salient for theorizing pandemic responses to disability. Neoliberalism is the marketization of all of life through ideology, policy, and forms of governance that simultaneously compel hyper-individualism, choice, and self-reliance within ever-expanding markets, shrinking public support and increasing demands for hyper-productive, competitive, and adaptable workers (Goodley, 2014; Larner, 2000). Neoliberal ableism means austerity rules the day, casting disability as devalued, a potential drain on systems in need of a solution in which the labor of parents and custodial adults, and particularly mothers, is implicated (Douglas, Runswick-Cole, et al., 2021).

The field of critical disability studies is tied to a rich legacy of critical scholarship and activism. During the 1970s in the UK, a group of disability activists and Marxist sociologists put forward the social model of disability as a radical contention that disability is a social rather than individual or medical phenomenon: "Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS, 1975, p. 14; see also, among others, Oliver, 1996). It is not individual impairments that disable, exclude, and stigmatize people, but inaccessible physical and ideological environments. Fueled by the Black Power, feminist, Marxist, queer, and other political and academic movements of the 1960s and 1970s, proponents of the social model of disability made strategic interventions into exclusionary policies and advanced disability rights in education, accessibility, independent living, and more. This mushroomed into a vibrant field of critical work and disability models (cultural, social, relational, feminist, minority) with broad academic and political influence (e.g., Goodley et al., 2019; see also Davis, 1995; Garland-Thomson, 1997; Morris, 1991; Snyder & Mitchell, 2006; Wendell, 1989).

Critical disability studies emerged over the past decade in response to provocations (Goodley et al., 2019) by feminist, queer, crip, feminist of colour, Global South, and other scholars and activists whose work illuminates some of the limitations of the social and other disability models to substantively take up intersectionality and decenter white, male, physically disabled experiences (Bell, 2006; Erevelles, 2011; Garland-Thomson, 2013; Kafer, 2013; Schalk, 2018; Sins Invalid, 2019). It also developed to theorize impairment and lived experiences of impairment (including painful or difficult ones; see Douglas, et al., 2020; Patsavas, 2014; Tremain, 2015), decentre Global North experiences of disability, take up provocations from decolonial, post-colonial, and Global South disability studies (Erevelles, 2011; Ineese-Nash, 2020; Nguyen, 2018; Puar, 2017); and move beyond western Enlightenment ontologies centered on a humanist perspective (as opposed to relationality or the non-human; see Braidotti, 2013; Rice et al., 2021).

Disabled children's childhood studies (Curran & Runswick-Cole, 2013, 2014; Runswick-Cole et al., 2018) extends critical disability studies by centering the experiences and perspectives of disabled children and the role of (m)others, families, kin, and care, aspects of disability experience typically associated with the devalued feminine and missing within critical disability studies (Douglas, Runswick-Cole, et al., 2021; Underwood, Angarita Moreno, et al., 2020). Curran and Runswick-Cole (2014) describe the emergence of disabled children's childhood studies stemming also from childhood studies that challenge, among other things, normative assumptions of the child and human development as a universal progression toward identity with the economically productive, non-disabled, self-fashioning, autonomous individual (Curran & Runswick-Cole, 2013). The "normative" child is based on assumptions that are moored in western "psy" disciplines (i.e., developmental psychology, childhood psychiatry) and Global North deficit models of disability that also underpin institutions of early childhood including education, service systems, and care (Douglas, Runswick-Cole, et al., 2021). Ableism affects both disabled children and their families, who often experience systemic discrimination along with their children (Douglas, Runswick-Cole, et al., 2021).

According to Curran and Runswick-Cole (2014), disabled children's childhood studies have three main tenets: a conscious repositioning of disability discourse "'about' disabled children, which is so often conflated with talk of impairment, inequality, and abuse" (p. 1618); it centers disabled children's narratives and experiences in research; and it seeks to "trouble the hegemony of the 'norm'" (p. 1618). Together, these principles:

> [Create] an agenda for change [which] rejects the mythical status of the "normal" child as an end point and instead promotes ongoing action against poverty, and a recognition of the distinction between disabled children's "ordinary" and productive childhoods and their experiences of inequality, and attempts to widen understandings of children's identities in a global context. (Curran & Runswick-Cole, 2014, p. 1622)

In the next section, we use both critical disability and disabled children's childhood studies to interpret the reoccurring findings of institutional flexibility, the fallacy of choice, and safety within the IECSS project to help us understand social inclusions and exclusions during the pandemic and question whether disabled children's lives were valued. We use our new theoretical insights to contribute to disability justice in childhood, a focus that has not yet been taken up in the literature.

## 3. Arriving at Disability Justice in Childhood

Disability justice is an intellectual, political, and artistic movement that pushes beyond the whiteness of disability studies and activism, centering the experiences of Black, Brown, queer, sick, and disabled people. As such, disability justice also collectively creates worlds that affirm the difference between disability and other non-normative bodyminds alongside the right to care as a fundamental part of being human together (Mingus, 2011; Piepzna-Samarashinha, 2018). Sins Invalid (2019), a performance group that forwards disability justice states:

> Disability justice is not yet a broad based popular movement. Disability justice is a vision and practice of what is yet-to-be, a map that we create with our ancestors and our great-grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which every body and mind is known as beautiful. (para 11)

Of the 10 key principles identified that shape a commitment to disability justice work, prioritizing the following is pertinent in putting forth disability justice in childhood: (a) intersectionality, a term coined by Crenshaw (1989) that speaks to the multiplicity of individual identities that result in unearned privileges and oppressions in socio-political and socio-cultural contexts; (b) resisting capitalist notions of work and production (Sins Invalid, 2019); (c) valuing disabled individuals as a whole, and recognizing many facets to one's life; and (d) interdependence, which captures the necessity of togetherness and inclusion to value all lives (Mingus, 2022) and is contrary to concepts of independence, which on a systemic level works to maintain the status quo of ableism, disablism, and neoliberal ableism and other dominant oppressions (e.g., racism, classism, sexism). We come back to these principles in our interpretation of the findings and advocate for disability justice in childhood.

We recognize the inclusivity of the disability justice movement with its strong focus on collective liberation, its cross-movement nature, and cross-disability solidarity (Sins Invalid, 2019). We use this opportunity in theorizing about pandemic responses to disabled children resulting in social inclusions and exclusions to tie in ideas from critical disability and disabled children's childhood studies, to bring forth disability justice in childhood. We do this by first describing, albeit briefly, the pre-pandemic experience of accessing disability services in Canada to set the stage that institutions are embedded within ableist, disablist, and normative constructions of childhood. We then discuss our findings from previous IECSS work (Underwood, Frankel, et al., 2019; Underwood et al., 2021), and illuminate how the concepts of institutional flexibility, fallacy of choice, and safety are understood through the lens of critical disability and disabled children's childhood studies which informs new insights into disability justice in childhood.

## 4. Pre-Pandemic Disability Services

There is a multitude of pathways from which families access disability services which vary between provinces and territories across Canada. We present a generalized picture of pre-pandemic organizational structures of disability services in early childhood which situates the context from which changes were made during the pandemic. This organization of disability services is based on families' experiences shared in the IECSS project (e.g., Underwood, Frankel, et al., 2019; Underwood, Ineese-Nash & Haché, 2019; Underwood et al., 2021; van Rhijn et al., 2021).

Disability services are accessed through multiple sites including therapeutic services, childhood care and education, and school systems, although they are largely triggered through health services. Some families are referred to services as early as pregnancy, while others inherit service relationships from before a child was in their care in the case of adoption, fostering, or change of custody. Some families are connected with disability services later in the child's life through referrals to health or therapeutic services, early learning settings, childcare, and/or school. Some families already have experience of disability services with another child in their family and may make self-referrals to early intervention or advocate for a referral from a health care provider. Early childhood services can also connect families to developmental services. For example, "drop-in" and childcare centers can often be one of the first places where families interact with early learning professionals (e.g., Underwood et al., 2018; Underwood, Frankel, et al., 2019).

Waitlists to access early intervention and disability services are common. There is often a transition process between services for pre-school and school-aged children who access developmental services, with some families experiencing long waitlists for assessments or severance in services once they enter the school system. The IECSS project has heard from many families that services in schools look significantly different from the early years (Underwood, Frankel, et al., 2019).

Families' access to early intervention is impacted by many factors including income, geographic location, race, culture and language, housing status, disability, and the approach of service providers (e.g., Underwood et al., 2021). There are both public and private early intervention services. Some families access one or the other, while some use a combination, and many are funded through workplace benefits. Many families living outside of large metropolitan areas travel to access services. For some families, traveling to access services can involve time away from their community and can include traveling to a different province, all of which involves work for families to access travel grants, or other funds, and to coordinate care between communities. Families' initial connection with developmental services, their experiences with waitlists, and transitions between services are often shaped by external factors. In early March 2020, the Covid-19 pandemic resulted in unprecedented worldwide closures of public and social service spaces and specifically impacted how early childhood service systems responded to public health measures to mitigate the effects of Covid-19 transmission. These changes dramatically shifted which services were deemed essential and how services were accessed.

The Covid-19 pandemic has resulted in new public discourses on health care, which have illuminated inequities in our society (e.g., Mingus, 2022), but were evident prior to the pandemic. There are countless examples of blatant ableism evident throughout the pandemic discourse and response. For example, Abrams and Abbott (2020) share that, at the beginning of the pandemic, Covid-19-related deaths in care homes in the UK were not reported; Parekh and Underwood (2020) describe the long-standing systemic issues in long-term care facilities in Canada for both its residents and workers, which were and continue to be at the heart of Covid-19 outbreaks; and media reports frame deaths resulting from Covid-19 within the rhetoric of "underlying and pre-existing health conditions" (Abrams & Abbott, 2020, p. 169) as an excuse in the deaths of disabled individuals (Mingus, 2022). These examples and more simultaneously dismiss, devalue, and "other" disabled individuals and feed the socio-political context of how disability is understood and constructed, which extends to the response of early childhood service systems in the pandemic.

Throughout the pandemic, childcare and school closures and the suspension of essential services for disabled children revealed the inequitable structure of

Canadian's lives and those all over the world. In our previous work (Underwood et al., 2021), we document institutional responses to the pandemic and share the standpoint of families with disabled children navigating and accessing early childhood services since March 2020. The pandemic has accentuated how institutional decisions to delay or omit disability-specific early childhood services are rooted in ableism and constitutive, at least in part, of exclusion (Underwood et al., 2021).

## 5. Institutional Flexibility: Meeting the Needs of Families With Disabled Children

Institutional procedures are exposed when we look to the everyday experiences of individuals who navigate these systems (Smith, 2005) which reveals how institutions are organized and impact access and interactions with services for families with disabled children. The tenants of critical disability studies invite a view of disabled children's childhoods beyond services poised to normalize disabled children (Goodley et al., 2019). The expanding view of disabled children often calls for malleable approaches to supporting children to be included in ways where they are valued. As such, we see families of disabled children advocate for institutional flexibility to support their children's inclusion, recognizing the complexity, variety, and value of their children's and families' experiences (Underwood, Frankel, et al., 2019; Underwood et al., 2020; Wright & Taylor, 2014).

In our findings previous to Covid-19, institutional flexibility was needed for "programs to adapt needs to be in response to children, but also to their families" (Underwood, Frankel, et al., 2019, p. 148). Throughout the pandemic, there have been examples of greater inclusion for disabled children that "are situated primarily in interactions that are outside of the typical institutional conceptualizations of inclusion" (Underwood et al., 2021, p. 20). Inclusion often happens outside of systems working to have "normative" or non-disabled experiences, which is often the experience institutions are aiming to create through their medicalized view of disability. This undermines disabled identity which is central to critical disability studies (Curran & Runswick-Cole, 2013) and necessary in how we understand the institutional flexibility needed for disabled children's inclusion. Institutional flexibility moves inclusion beyond what Mitchell and Snyder (2020) and other disability scholars (see, e.g., Collins et al., 2022; Jones et al., 2022) have called "neoliberal inclusionism," an institutionalized, ableist, and functionalist response to disability that "tends to reify the value of normative modes of being developed with respect to able-bodiedness, rationality and heteronormativity" (Mitchell & Snyder, 2020, p. 179) and, we would add, in relation to western individualist, capitalist, and colonialist ways of being. In our previous work, we describe the role imposed on families as being "responsible for normal" (Underwood, Church, & van Rhijn, 2020, p. 89).

Families have always had to maneuver early childhood systems; however, new protocols initiated in response to the pandemic created opportunities for greater inclusion, for some families. Before the Covid-19 pandemic, many families and kin, in more rural and northern communities, were required to travel to access services. When closures occurred as a response to the pandemic, many health services moved online or to phone appointments, and some therapeutic services offered virtual services, while some private providers continued to offer in-home in-person services (Underwood et al., 2021). Through the lens of disabled children's childhood studies, these changes align with valuing families' time, safety, other services, and relationships, both in valuing disabled children and their families' experiences (Curran & Runswick-Cole, 2013; Runswick-Cole et al., 2018). These remote options, pulled forward by the Covid-19 pandemic, act as an example which demonstrate how flexibility in accessing services is in accordance with valuing all the other activities, services, relationships, joy, work, pace, etc., that are involved in disabled children and their families' lives, recognizing the wholeness of disabled children and their families and pushing inclusion beyond inclusionism (Sins Invalid, 2019).

Though some institutions have adapted and offered flexibility within services during the pandemic, it has not necessarily resulted in greater inclusion for all children. For example, flexible learning is a concept that requires individual students to be more adaptable to environmental changes (Huang et al., 2020). Increased learning flexibility can mean less structured routines which blurs work and leisure and can put more work on individuals to create the structure for themselves. Removing structure and access to people outside of homes does not prioritize the interdependence that can exist for disabled children. Many parents took on additional roles in remote settings, including creating routines and supporting children to participate in online schooling and therapy programs (Underwood et al., 2021). The expectation that families (predominately mothers) take up work in supporting children's participation in school and therapy has long existed and is something disabled children's childhood studies have highlighted (Curran & Runswick-Cole, 2013; Runswick-Cole et al., 2018). The closures resulting from the Covid-19 pandemic exasperated the demands and workload placed on families for their disabled children to connect with school and therapies. The anti-capitalist political principle of disability justice values the often invisible work families (predominately mothers) carry out on behalf of institutions, while current capitalist values exploit them (Sins Invalid, 2019). The pandemic brought the hidden labor of inclusionism and frictions around access to the surface.

Participants in the IECSS project living with disabled children during the pandemic describe rigid institutional policies that exclude them from a variety of programs and services (Underwood et al., 2021). For example, remote options were not offered to everyone, leading to exclusion from programs, including school, early years programs, early intervention services, recreation programs, etc., meaning that some programs were paused and did not offer services for a time, while other programs closed (Underwood et al., 2021). Disabled children's lives and experiences were not centered. Disability justice calls for justice for all and recognizes that any exclusion is injustice (Sins Invalid, 2019). We hold onto the glimpses of institutional flexibility during the pandemic that moved inclusion beyond inclusionism and in so doing, value disabled children and families. The result is altered ways of being, through interdependence, relational autonomy, and flexibility. We see possibility in applying disability justice to the programs that children and families are accessing and recognize how flexibility is needed for their inclusion. We contend that flexibility can be carried out at various levels, including institutional levels that can facilitate access and inclusion (Gordon, 2014) in a way that values disabled children and their families.

## 6. Is there Authentic Choice in Accessing Early Childhood Services for Disabled Children?

The structure of early childhood services is limited in scope—families are required to fit into a pre-determined menu of available services. We coined the term "fallacy of choice" in our previous work, where our research findings illuminate a "fallacy in the claim of choice[s] that families have" (Underwood, Frankel, et al., 2019, p. 146). In reference to accessing disability services in schools, "parents are able to gain access to services if they comply with the procedural aspects of the system, which often requires multiple forms of privilege" (Underwood, Frankel, et al., 2019, p. 146). Indeed, while choice is forwarded as a site of freedom within neoliberal discourse and capitalist education and service systems, critical disability studies scholars (among many others) have shown how choice operates instead as an instrument of ableism and inclusionism (Mitchell & Snyder, 2020; Underwood, Frankel, et al., 2019). Conforming with the expectations of service systems to gain access to pre-set offerings hinders choice and highlights "conflicts that can arise for parents who are forced to make a choice, given the dilemma of [often choosing between] two [or more] less than desirable options" (Bartlett & Rice, 2019, p. 56).

Thus, institutions set the stage and create the structures that shape early childhood services. Early childhood services are informed by "ableism [which is] inherent in [institutional] decisions that lead to disabled children being pushed out of the institutions of childhood" (Underwood et al., 2021, p. 25). Institutional structures also impact and constrain how families can make choices for their disabled children. The reality of constrained choice precedes the pandemic, and families and disabled children have had to contend with the outcome of such choices made in accessing developmental services including learning loss, school disruption, as well as cross-sectoral barriers and integration in a way that the rest of society is only adjusting to as a result of the pandemic.

Institutional responses to the pandemic have further constrained choice and self-determination for families with disabled children. For example, the choice to send children to school or early intervention programs was limited during the closures of services deemed non-essential by governments, which provided evidence of a false narrative of self-determination around accessing services and programs for disabled children. The limitations in the options that were available from the predetermined menu of early childhood services during the pandemic led to social exclusions within organized programs (Underwood et al., 2021). The choice to send disabled children to school was, in many cases, not a choice at all as disabled children's realities were not considered in plans for school re-openings. Restricting school and the very act of deeming services for disabled children as non-essential magnifies both ableism (Campbell, 2009; Goodley, 2014; Goodley et al., 2019) and disablism (Abberley, 1987; Thomas, 2007). This devaluing of disabled lives as discardable is a point disability activists have long articulated and fought against (see, for example, Church et al., 2016), and we extend this point to pandemic disabled childhoods here. During the pandemic, non-disabled children were advantaged and disabled children were disadvantaged in accessing educational and developmental services.

Additionally, an intersectional framework is needed in discussing social inclusions and exclusions as "disability cuts across and is at times indistinguishable from age, gender, race, mortality, class, trauma or sexuality [which] are ripe for cross-movement building work and has the potential to deepen and expand our understanding of oppression and violence like never before" (Withers et al., 2019, p. 182). In our previous research findings, it was noted that privately funded services, including schools, saw less disruptions and were largely accessed by middle- to high-income families (Underwood et al., 2021). This example ties in with how multiple oppressions work together to marginalize individuals, which was evident during the pandemic. Taking power and privilege into consideration and using an intersectional framework in understanding the institutional design of accessing and choosing early childhood services is an important part of disability justice in childhood. Mingus (2011) states:

> We need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and "we are just like you" to a model of disability that embraces difference, confronts privilege and challenges what is considered "normal" on every front. (para. 5)

Furthermore, in thinking with Mingus (2011) it is evident that choices concerning access in the pandemic follow the same pattern of "institutional control over development, social participation, family engagement, and accommodation or adaptation" (Underwood, Frankel, et al., 2019, p. 149) where government allocations of "essential" and "non-essential" presented a landscape of unequal and unfair choices. Disability justice challenges inclusionism, or access, and focuses on justice and valuing disabled children's childhoods.

## 7. Navigating Safety: Whose Safety Matters?

Disabled children are persistently centered in debates around safety. Disabled children's childhood studies provide theoretical resources to explore how pandemic responses have been shaped. Normative understandings position the disabled child as simultaneously vulnerable (to disordered development, for example) and in need of support, and dangerous (a threat to already scarce resources within a neoliberal context of austerity; see Curran & Runswick-Cole, 2013; Douglas, Runswick-Cole, et al., 2021; Underwood et al., 2020). For instance, the calls for greater resources in schools to support student safety with eating, mobility, and personal care is often juxtaposed against the calls for greater resources to protect staff from their students (see Miller, 2019). Although Stoughton (2006, p. 147) was referring to children identified with "emotional disturbance," their observation that such children "can become the focus of fear and moral concern" could be applied to the experience of many disabled children in school. The perception of threats to safety and well-being also extends to the threat to normative school programming, where disabled students are often removed to reduce their perceived impediment to the success of their peers (Danforth et al., 2006; Erevelles et al., 2006). Concerning Covid-19, disabled children have been identified to be at increased risk of serious health outcomes, while at the same time being positioned as contributing to the increased risk of transmission to school staff (Viau, 2022). Throughout the pandemic, policymakers have been attempting to respond to the evolving science and rhetoric around safety—what constitutes safety, whose safety should be prioritized, and how.

For many disabled school-aged children, services and therapies are accessed through special education programming in school. Over the pandemic, schools across Canada have been frequently shuttered due to rolling lockdowns. For example, schools in Ontario were closed for 20 weeks between March 2020 and May 2021 (Gallagher-MacKay et al., 2021) while other early childhood services were closed for an even longer period. Even when schools re-opened, there were continued interruptions and limitations in early childhood and school-related activities.

At the same time families were asking for authentic choice, the discourse around the reopening of schools in Ontario in September 2020 was driven, to some extent, by an equity-based discourse. The narrative suggested that in-school learning was key to the equalization of learning opportunities, particularly for historically marginalized communities. Yet, when the demographic data were reviewed within Ontario's largest public board of education, the Toronto District School Board (TDSB), communities that were largely racialized, lower-income, and had been impacted more significantly by Covid-19 (for more on the intersection of race, class, gender, and precarity of work during the pandemic see Kantamneni, 2020) were the least likely to opt for in-person schooling (Crawley, 2020; TDSB, 2020). Withers et al. (2019) remind us that "systems of oppression come into existence in and through one another" (Fellows & Razack, 1997, p. 335, as cited in Withers et al., 2019, p. 180) and "ableism [specifically] is both dependent on and necessary for every other oppression to exist" (Withers et al., 2019, p. 183). Intersectionality (Crenshaw, 1989; Sins Invalid, 2019) helps us see why the return to school privileged abled, white, wealthier families who lived in communities that were more protected from infection (Timmons et al., 2021). Families with privilege were more likely to manage and keep up with the demands of online learning, such as having devices for every child, separate spaces where each family member could work flexible work schedules to accommodate supporting children during remote learning, their own computer literacy and the uploading and printing demands that were put on many families during remote learning, thus even in remote settings online school was inequitable (Timmons et al., 2021).

Additional concerns around the implications on children's health and safety because of extended school closures (SickKids, 2020) emerged from concerns around school safety and the conditions in classrooms that were exacerbating Covid-19 transmission (Fox, 2021). Questions raised around learning loss, the implications on child development and socialization as well as mental health arose, with some analyses including particular attention to disabled children (Engzell et al., 2021; Gallagher-MacKay et al., 2021; Whitley et al., 2021). Examinations of what disabled children have lost over the pandemic have been well documented and demonstrate the significant disruption in and loss of programming and services (Underwood et al., 2021). However, the risk of contracting Covid-19 within schools was and remains an important safety consideration. For many disabled children, who access self-contained special education programming or schools, consistent masking and social distancing may not be possible. Therefore, policymakers have had much to consider in weighing the safety risks of facing the heightened risk of transmission of a potentially fatal virus with the ongoing risks associated with interruptions of service, support, and programming. As such, even when schools were closed to the general population, many continued to offer in-person, self-contained, special education programming (Bowden, 2021), in part because there was no mechanism to provide the range of services in online environments.

Maintaining in-person learning for disabled children, when deemed too dangerous for the general population, was a strategy aimed to mitigate the risk of delays or interruptions in development and socialization. Conversely, disabled children accessing in-person learning were simultaneously positioned as contributing to the heightened risk of Covid-19 transmission, particularly to the teaching team and their classmates (Sharpe, 2021; Wong, 2021). The narrative of returning to in-person learning also positioned the return to school as necessary for the families of disabled children who may be in a heightened need of respite (SickKids, 2020). However, in many discussions around the return to school, disabled children are positioned as the locus of risk to families' well-being as opposed to advocating for the reorganization of a care system that ensures families are adequately supported. Despite this push, when TDSB families were asked to indicate whether their children would return to in-person schooling, special education schools had, overall, notably lower response rates with lower proportions of students confirmed returning compared to the system average (TDSB, 2020b, 2020c). As the section addressing the fallacy of choice argues, this finding suggests that families were not really presented with an authentic choice; instead, families whose children could not participate virtually were often presented with two options—in school or no school—neither of which offered support and protection for their children. The false choice presented to families in the form of binary options for school results in exclusion. It also undervalues the work that families are doing in assessing risk for their children, family, and communities, while they imagine, create, and advocate for something outside of the binary options they are presented with. If systems adopted the tenets of disability justice, particularly anti-capitalist principles and principles of interdependence, support would be organized in a way that recognizes the critical knowledge families hold and enhances families' authentic choice over how they access support while overall reducing safety risks for disabled children.

An examination of how capitalist values intercede and hinder disabled children is illuminated by Hall's (2022) observations of schooling during the pandemic: "the problem of sending some disabled students into schools at this time is a similar problem to long term care homes—an inability and/or unwillingness to imagine something different for disabled people that doesn't use cost as an excuse." In addition, a return to school also alleviates systems of educational governance from having to ensure access to support disabled children and their families through other, arguably more responsive, means. For instance, tying access to supports and services to in-person attendance in congregated care or classroom settings at the height of a viral pandemic results in three key outcomes and considerations: The responsibility to conceptualize, evaluate, and navigate all "safety" considerations related to in-person learning is placed onto the families of disabled children, creating a false sense of choice for families coupled with less than ideal options; attitudes of ableism and the devaluing of disabled lives emerge, where safety appears to play into the "unwillingness [of systems] to imagine something different" (Hall, 2022); the positioning of disabled children as both vulnerable and in need of protection, as well as contributors to risk and unsafe conditions both at home and school continues to be reflected through the return-to-school approach. Either way, Covid-19 responses have not and do not center disability or disabled children.

## 8. Concluding Thoughts: Re-Imaging Inclusion and Moving Towards Disability Justice

As highlighted by many disabled advocates and researchers, disabled lives, including disabled children's lives, were not considered essential during the pandemic (Gurza, n.d.; Mingus, 2022; Parekh & Underwood, 2020; Thorneycroft & Asquith, 2021). The devaluing of disabled lives has also persisted in the wake of ending the pandemic and the narratives around the economic toll the pandemic has had and continues to have. Capitalist neoliberalism is continued through the demands that are placed on disabled children and their families during the pandemic and in the broad call for "a return to normalcy" to end the pandemic. In all, critical disability studies and disabled children's childhood studies help us theorize (a) the ableism and disablism of pandemic responses to disability, (b) the intersectionality of disabled childhoods and how this played out in pandemic responses, (c) the implication of institutions in maintaining systemic discrimination through recruiting parent/family labor to "solve the problem" of disability, (d) the fallacy of choice produced through neoliberal ableist discourse and policy, and alter conceptions of the child beyond vulnerability and danger. Disability justice calls for the re-imagining of inclusion throughout all systems and emphasizes valuing disabled children and their families

Adopting the principles of disability justice in childhood means challenging the sense of neutrality through which policies and practices around care and access to services are delivered and urges us to recognize and reconcile the underlying ableism, racism, and colonialism in shaping our early childhood services and the rigidity of our institutional practices. In forwarding disability justice in childhood, we have shown how understanding intersectionality (Crenshaw, 1989), resisting neoliberal capitalism, and implementing concepts of interdependence (Mingus, 2011; Piepzna-Samarashinha, 2018; Sins Invalid, 2019) creates the opportunity to re-imagine dismantling early childhood systems that place explicit value on disabled children's childhoods.

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## Conflict of Interests

The authors declare no conflict of interests.

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Article

# Neurodiversity, Networks, and Narratives: Exploring Intimacy and Expressive Freedom in the Time of Covid-19

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## Abstract

The Narratives of Neurodiversity Network (NNN) is a neurodivergent academic, creative, and educator collective that came together with allies during the Covid-19 pandemic to create a network centred around emerging narratives about neurodiversity and exploring new ways of learning and socialising. The network focuses on exploring the roles of written, spoken, and visual narratives across cultural locations about neuro-atypical experiences in generating improved agency and self-advocacy for those who have been subject to pathologization through neuro-normativity and intersecting oppression. During the last year, widening access to digital platforms has provided a space to explore these issues outside of traditional academic spaces. We run a monthly "Salon," our mixed-media "reading, listening, and watching" group, in an effort to find positive representation within contemporary culture. Discussions have moved beyond mimesis and into a consideration of how narrative and storyworlds can question the supposed naturalness of certain ways of being in and perceiving the world. This article interrogates the network's core principles of nonhierarchical co-production, including the roles of creativity, community, identity, and emancipatory research which were animated by the new techno-social context. We consider the cultural lives of neurodiversity in the West and beyond, including ethical and aesthetic dimensions. We share a faith in the power of storytelling to inform new social identities for neurodivergent people and to inform scientific understandings of atypical cognition. In exploring this, we speak through a porous first-person plural narrator, to unsettle the idea that there is a hegemonic "we" speaking on behalf of all neurodivergent people.

## Keywords

autism; collaboration; narratives; neurodivergence; neurodiversity; online community; self-advocacy; social networks

## Issue

This article is part of the issue "Disability and Social Inclusion: Lessons From the Pandemic" edited by Owen Barden (Liverpool Hope University), Laura Waite (Liverpool Hope University), Erin Pritchard (Liverpool Hope University), and Ana Bê (Liverpool Hope University).

## 1. Introduction: A Note on Neurodiversity, Narrative Diversity, and Method

> I'm into neurodiversity, communication, and representation in a lot of ways. There is no one home for *all* my research interests at once but this space holds some interests that don't live in any of the academic departments I've been in or any of the jobs I've had. Neurodiversity in the divergent universe? Creative nonfiction about neurodivergent experiences? Yeah, those go *here.*

Narrative is central to this article. It represents both a shared interest that united our network's members during the Covid-19 pandemic and an emancipatory means of neurodivergent self-fashioning. It is also integral to the research for and presentation of this article. When we say "narrative," we capture how our members use narrative and storytelling to connect, self-advocate, navigate, and engage within an online space. We invite readers to view this article as a meta-discourse, as we place individual members' words in dialogue with one another and with our overarching themes. We also use "narratives" to place equal value on the varied viewpoints (or narratives) as a reminder of the pluralities and divergences even under a collective (and largely co-produced) piece and to reject the neuronormative primacy of spoken verbal conversation implied in "voices" or "polyphony" (Wood, 2021). The first-person plural "us" and "we" signal our collective positionality. Relatedly, the article is divided into subsections that represent differing relationalities to the concept of narrative, but we acknowledge this article's narrative might occasionally appear to be non-linear, tangential, or even contradictory. This is calculated and purposeful as we communicate the nuances and variations of expression inherent in a neurodivergent-majority space within the constraints of an academic article and reject the neuronormative expectation of linearity (Yergeau, 2018, p. 19). By uniting diverse perspectives under a collectively written article, we are consciously enacting the key tenet of the larger neurodiversity movement (Kapp, 2020, p. 330) by acknowledging the myriad embodied affective and cognitive differences among humans, which exceeds the currently recognised medical categories of neurological difference due to the dominance of a singular ideal of subjectivity.

We wanted to give all network members the opportunity to contribute during production. To logistically manage to co-write with 317 network members, this article's main body (text not marked as quotation) was written collaboratively by some co-founders of the Narratives of Neurodiversity Network (NNN) to capture responses to questions members were invited to respond to. Importantly, this invitation was also extended to those drafting the article. This configuration moved us away from the "academic as observer" model, to foreground shared community, and work towards a model of co-production. While the development of our methodology for this research (and later its dissemination) was inspired largely by our efforts to centre the lived experience of our members outside of traditional participatory research models, we acknowledge our debt to previous scholarship that foregrounds neurodivergent co-writing (Bertilsdotter Rosqvist et al., 2019, 2020a; Fletcher-Watson et al., 2019). The nuance within our approach is part of the network's broader aim to acknowledge and disrupt systemic power imbalances, where those with more educational or cultural capital (here, academics), often appear to be doing "all the work," even when others are subtly shaping the group (for example, engaging with other members and providing humour, references, interpretations, or passion). We acknowledge this approach is not true co-production, as those who drafted the article maintained a level of editorial privilege as they decided which questions were put to the wider network, which discussion points to focus on, and which responses were quoted. To mitigate this privilege, we invited all network members to respond to the article and suggest edits during drafting. Thus, network members were not greeted with a finished product and the implication that we had already decided how to present their insights. Similarly, all member quotations are attributed anonymously to "one member." We only identify context when relevant and with permission. All network members who contributed to the article's formulation or the discussions around its content are named—even if not quoted directly. We also, therefore, follow the alphabetical authorship convention common among many-author papers and when determining relative contributions is impractical (Fernandes & Cortez, 2020) or, in our case, undesirable.

## 2. Narratives of Neurodiversity Network: Beginnings, Aims, and Technology

For many disabled and/or neurodivergent people, the initial months of the pandemic were a highly contradictory period. Many were designated "clinically vulnerable" and subject to stricter lockdown protocols while media discourses on issues, such as vaccination, mask-wearing, the lifting of lockdown legislation, and what kind of people would be more likely to experience a greater adverse reaction to Covid infection, often centred on disabled persons (Imperatore, 2021). Additionally, previously utilised health and social care were often not provided during the pandemic (Flynn & Hatton, 2021). However, alongside these narratives of disempowerment, the necessary shift to remote working meant accommodations that had seemed impossible or impractical prior to the pandemic were suddenly found feasible (Ryan, 2020). Accessible technology and home working and studying became a requirement for the abled majority, and, through this fundamental reconfiguration of labour models, many found these pandemic adaptations enabling. As workspaces became online spaces in this unprecedented moment of lockdown, the possibilities for fostering community, cultural life, and connections with others from across the world seemed more tangible.

In August 2020, while the world was in the throes of the first Covid-19 wave, one of the founders of what is now the NNN sent a tweet looking to develop a network for writers and creatives interested in neurodiversity. To gauge interest, she wrote: "I'd love to hear from other people who are working on autism or neurodiversity and literature or creative writing. I think there are quite a few of us." "Neurodiversity," the notion that all brain types are valid and that neurological differences cannot and should not be "corrected" or "cured," and "neurodivergence," a term developed by neurodivergent communities to describe themselves, were developed in the late 1990s (Arnold, 2017; Asasumasu, 1999). The term "neurodiversity" is often attributed to Singer (1999), but we wish to acknowledge that the term was emerging simultaneously within online autistic spaces. The field has since expanded, and "neurodiversity" has become a central theme in the work of many writers, theorists, and creatives in the UK and is also gaining some traction around the world (Manalili, 2021). It also denotes an activist position and investment in advancing the equalising agenda of the neurodiversity movement (Walker, 2021). Outside of more formal discourses, neurodiversity is an empowering term used by many neurodivergent people, who contest the idea that their way of being is lesser. Despite the growing popularity and awareness of neurodiversity as a concept, we felt that there was a scarcity of majority neurodivergent spaces where we could share resources and support one another. The series of tweets that followed received engagement from users from a wide variety of backgrounds, disciplines, geographical locations, and neurodiverse positionalities (we include neurotypical allies within our space and our neurodivergent members have a variety of diagnoses, including, but not limited to, autism, ADHD, dyslexia). Significantly, several literary scholars answered the initial call for connections. Together, we realised our interest in neurodiversity was mediated through our engagement with fiction and creative writing. We soon refined this initial observation as we learned narrative's implicit and liberating role as a vehicle for exploring neurodivergent identity, developing a community united by shared understandings, and enabling self-advocacy.

The subsequent idea was to create some sort of neurodivergent-led communication channel and resource hub where people in these areas could both reach out and provide support and/or solidarity to others. The network began—as many academic networks do—with a Jiscmail list as the Listserv Neurodiversity and Literature. The server became a limiting space, rather than a liberating one, as the longer time scales of monitored email exchanges could not support the rapid influx of new members engaging at their desired scale. Members expressed a desire to forge connections outside the "formal" constraints of email and to interact without "copying in" the entire group, as required by the server. Additionally, Listserv's firm association with academia was becoming an issue. While anyone with an email address can access Jiscmail lists, these servers are synonymous with higher education institutions. Acknowledging this, many members from outside the academy began with the caveat: "I am not an academic but…." This phraseology signalled that, despite our desire to create a community of interested persons irrespective of formal academic credentials, we had inadvertently created a hierarchy through our choice of a more traditional academic model of online networking. Aided in part by the new technological norms of pandemic working models, we sought online services that supported greater conversational immediacy. We found Zoom an invaluable asset in this sense for our mixed-media reading/listening group, the Salon, and to enable direct conversation. Eventually, we established our network on Discord, an instant message and digital distribution platform that supports a variety of access needs and communication mediums, including asynchronous and instant messaging (including text and voice), video calling, and photo sharing across simultaneously existing channels. Typically, a singular Discord server has many channels, and members may select which discussions they contribute to, which has enabled smaller communities to form within the network of members with specific foci, such as creative writing, academic discussions, and general socialising. One member explained that, since becoming more familiar with the Discord server and its functions, they now find it less demanding than other communicative formats:

> I was completely new to Discord at the time when our network migrated to it. I am really not tech savvy, but I got used to it fairly easily and I find it much easier to keep track of than some other formats such as email. It suits me to be able to read a comment and respond in my own time (or not respond).

The alternative pacing of Discord encourages members to respond out of keenness or shared interest rather than obligation. By supporting multiple, coexisting discussions on a vast array of topics, more academic and potentially exclusionary discussions are decentred and positioned as only one of many aspects of the network's engagement with narratives of neurodiversity.

By situating our interactions in a shared online space, we acknowledge the important history of this model as a site of early autism advocacy and activism in the late 1990s and early 2000s. Our Discord channel is indebted to this legacy of networked communities formed by and for the neurodivergent. Historically, the removal of the need for face-to-face and verbal interactions enabled many neurodivergent individuals to take to online blogging and forum creation as a safer and more comfortable method of expression (Blume, 1997; Davidson, 2008). Most of the contributions to the Autism Self Advocacy Network's anthology *Loud Hands: Autistic People, Speaking* were taken directly from the blogs of autistic writers such as Julia Bascom, Nick Walker, Remi Yergeau, and Mel Baggs, a practice that indicates the impact that the free expression and comment-based interchange of blogging had on the formulations of the neurodiversity paradigm. Indeed, adapting digital spaces for the needs of an emergent community has become something of a particular talent of the neurodivergent who have been led, in part, by social necessity (Sinclair, 2012). For our network, adopting a somewhat more private forum space on Discord has allowed us to take a digital step away from the current dominance of social media such as Twitter and Facebook. Neurodivergent presence remains strong and useful in these spaces, but often finds itself acutely exposed to the toxicities, biases and ignorance of worldwide users. While we remain braced for challenging exchanges, as reflected in our co-written constitution, the creation of a partially enclosed app-based digital space in Discord allows members to feel unplugged from the exposure of a site like Twitter, in turn enabling safer and more open interaction (Creechan et al., 2021).

As we began to grow, we realised we needed to reassess who the network is for and who its beneficiaries are. Having started within academic strictures, we recognised the unethical and appropriative stakes of discussing neurodiversity without broader community input. As neurodiversity studies is developing as a critical field, the academic membership needed to engage with the paradox of advocating for "diversity" while being complicit in a system that privileges the perspectives of white, middle-class, autistic academics from the Global North, who have had access to formal diagnosis (Betilsdotter Rosqvist et al., 2020b). As such, we broadened the purview of the network to include anyone with an interest in the relationship between neurodiversity and narrative. Some of our most active members are situated outside of the academy but are fully engaged in current scholarship and research conversations on the Discord server. One such member explained:

> As a person who isn't a traditional academic and who doesn't have access to academic discourse, the network means I no longer feel isolated in my interests.

Similarly, another member described the space as "a bit of an online oasis" and reflected on their ease within a space where being neurodivergent is a majority position. When establishing the network, we decided not to limit membership to individuals who identified as neurodivergent or to doubt the validity of self-diagnosis. It was agreed that, so long as the network remained neurodivergent-led (in practice, a consistent and significant majority of neurodivergent administrators) and inclusive for our neurodivergent majority, those who identified as neurotypical were welcome to contribute to the server. There was a slight concern about the need to negotiate a means of "cross-neurotype communication" (Hillary, 2020a) when we decided to open the space to neurotypical allies, but we found that by actively decentering the expected norms of online communication, we mitigated the need for performative neuronormativity and, as such, our neurotypical members learned to respect the flexibility of our space and there was no need to institute additional supportive measures or "translation" practices for those unused to being in the neurological minority. It was striking that when asked about the network, members commonly referred to the space as "affirming" and "freeing," as the neurodivergent majority meant members could "think through ideas without the pressure of the "NT gaze" of academia" (McDermott, 2022). Indeed, others commented that, within the network, academic ideas could be articulated according to communication preference, a rarity in conventional academic spaces. One member commented that they "feel more articulate in text, compared to in-person," a communicative choice that is easily supported by the server (Donaldson et al., 2021). Time and again, members positioned the network in opposition to the academy and to traditional models of scholarship and knowledge production. It was particularly striking that network discussions could cover the same material, but that they were perceived as different and, as such, liberating—as one member observed:

> General and academic contributions in this space feel a lot more relaxed for me because of the inclusive social expectations—I don't feel nearly as self-conscious about stuff like rambling, over-apologizing, bringing up things that the conversation has moved on from etc. At the same time, I feel like there's a bit of a gap where I have to consciously stop self-policing by neuronormative standards? Like if I want to keep popping on/off and/or keep my camera off in a call I feel the urge to apologise or power through the fatigue and just stay on and then I have to remind myself that people in this space probably don't care that my camera is off.

Some of us have expressed loss and frustration that, having been taught to manage our neurodivergence for neuro-majority spaces, traditional educational systems had affected and even stifled our ability to think and express ourselves naturally (Freire, 1970; Wood, 2019). We lament the loss of creative and intellectual potentialities offered by our divergences that we could have harnessed had we been encouraged to embrace them.

This article celebrates the creative and emancipatory possibilities of an online neurodivergent-majority space that prioritises peer support, mutual aid, and community formation. As the pandemic mainstreamed remote collaboration to an unprecedented level, we realised the possibilities an online space could offer neurodivergent individuals outside the oppressive and pathologising strictures of societal institutions, including the classroom, the courtroom, the psychiatrist's chair, and the academy. The network will continue to evolve as our understanding of one another and what it means to be neurodivergent develop. Within the social sciences, discussions of neurological differences actively resist the dominant medical framings of neurodivergence, which has led to important discussions of harms perpetuated by dehumanising research practices (Pellicano & den Houting, 2022). Nonetheless, to focus solely on the impact of institutions and social structures on neurodivergent persons situates us only as subjects and/or victims of neurotypical society or of our own neurological difference. By recognising the power of narrative as a means of exploring our differences, we have found an alternative, empowering approach through which we can connect with one another and advocate for ourselves. Each strand of our regular network activities foregrounds narrative and storytelling: our discussions of fictional narratives in our monthly mixed-media reading/watching groups, our "show and tell" sessions, our work-in-progress research discussions, and the sharing of thoughts and opinions on Discord forums are all mediated through narrative. This mosaic of narratives enables us not only to celebrate the intellectual outputs of our members but also to share in pleasurable activities and hobbies they enjoy, supposed frivolities which are so often discouraged or dismissed by capitalist dynamics that focus resolutely on productivity and use-values. Instead, we believe in the value of personal narratives. By cultivating a space to share these narratives, we have established a community of care through which we can begin to tackle epistemic injustice (Chapman & Carel, 2022).

## 3. Narratives of Neurodiversity

Our early identity as the Neurodiversity and Literature Network, which had connotations of specialist (and therefore exclusionary) forms of writing, was soon changed to the NNN. This shift allowed us to conceive of literature more broadly, encompassing all sorts of stories about neurodiversity, from various perspectives and in myriad formats. The shift from "literature" to "narratives" signified a sort of plurality, where neurodiversity could be recognised and discussed beyond mainstream or canonical representations, allowing alternative writing formats such as blogs, social media posts, zines, and pamphlets. Recognizing our members' varied access needs, we were inspired by this broadened focus to extend beyond written formats to include performance art, film, television, podcasts, and stand-up comedy. The discussion of these narratives would become integral to the network's community focus, but formal consideration also inspired us to conceive of the content published within the group—posts, comments, and dialogues—as narratives in their own right that signalled a burgeoning neurodivergent counterculture. In this way, "narrative" came to be understood within the network as involved in the active construction of new stories and modes of articulation through which we can engage with identities and experiences that were previously marginalised in representations aimed at the neuro-majority.

The shift from the conjunctive "and" of our original name to the prepositive "of" also signalled the network had become a space for exploring how neurodiversity itself is narrativised both culturally and as a lived experience. Many of our members are acutely aware of the stories constructed through the medical model of disability, where neurological difference has been figured as a "disordered" way-of-being in need of mitigation, change, or eradication. After all, what is a list of symptoms, if not a form of narrative? This predominant rhetoric continues to proliferate through public consciousness, manifesting as stigma and discrimination, and subsequently placing neurodivergent persons under intense scrutiny and impossible pressures. As a reaction in part to the strictures of the medical model, the neurodiversity movement has typically understood neurodivergence through the social model of disability, which posits that it is not the neurological difference that constructs disability, but ableist social structures (Oliver, 1983). The social model, however popularised, has its limitations, is often invoked to focus on structural failing, and thereby downplays the physiological and cognitive elements that create challenges no matter the structure of the wider society. We believe that narrative offers a third model for thinking about neurodivergence. Narrative gives credence to the expertise of lived experience and resituates the neurodivergent person as the subject, as opposed to the object, of the model. We refer, in particular, to any narratives that unsettle the dichotomization of human perspectives into cognitive types or discrete discourse communities that conform to existing networks of power (Yergeau, 2010). We are particularly interested in those stories—personal, collective, or speculative, which convey agency, rather than passivity and subjugation, upon those who are regarded as neurologically "atypical.'' As one member, who is a SEN educator, comments:

> There's a huge clash between the pathology and neurodiversity paradigms/narratives…and one of the ways in which the neurodiversity paradigm is making headway (this is in itself a narrative element!) is through the critical exploration of narratives of many types. Ugh, I didn't express any of that well, but I hope I am conveying the idea of living in and with a bunch of narratives and also seeing narratives as having the potential to change education for the better. So narratives are both the what and the how??

For this reason, our network functions as a long-form, open-ended and non-hierarchical arena to explore the nuances of our own narratives via interpersonal communication and engagement with an array of media. Relatedly, adding a proactive "creative writing" channel helped foster a culture of narrative-making for members keen to express or explore their stories through their own craft, while also providing a space for the mindful and escapist decompression creativity can enable.

But, what are these narratives specifically? And, why is storytelling so important to neurodivergent people? Contrary to common medical-model assumptions, neurodivergent readers empathise, take perspectives, and participate in communal thinking in reading stories (Chapple et al., 2021). The successes of contemporary neurodivergent authors, such as Elle McNicoll, Katherine May, Joanne Limburg, and Rivers Solomon, have been the subject of network discussions and are deemed to actively demonstrate the value and possibility of neurodivergent storytelling. When we invited our members to respond to the questions "what do stories give us?" and "how do stories enable us to think about our neurodivergence?" responses were often interwoven with concerns around identity formation. Stories give us "reality," writes one member, who refines this definition as "a consensus story; the story we, they, or you tell ourselves about ourselves." Narratives can both offer empowerment and expose abuses of power. One member describes how their autism and ADHD diagnoses were insidiously "predicated on the idea—literally in the diagnostic report—that I have no imagination and can't create stories or think creatively." These diagnostic reports are themselves narratives, relying on an authoritative medical rhetoric in their (increasingly futile) attempts to define and categorise neurodivergence. One member notes the importance of following diagnostic shifts, positioned as:

> A story about the conflict between clinic and constitution: Who defines what we are made up of? How do we define what we are made up of? What mediums and expressions allow us to write the stories that ensure our cultural, economic, political, and social freedom to define our value on our own terms?

Within the context of these wider societal pressures, allowing neurodivergent persons to narrativise as a mode of creation or self-exploration becomes a political imperative and, for some, engagement with stories and storytelling can be a means of self-care. As one member notes, writing stories "has saved my life on more than one occasion. I know I am not mentally well when I can't read or write. I write fiction and non-fiction, to help me process information and explore my feelings." Academic discourse suggests stories can place too many communicative demands on neurodivergent individuals to have a wholly positive effect on wellbeing, but through discussions with the network, we are inclined to agree with Hilde Lindemann Nelson's assessment that narratives can be good for us insofar as they allow us to create new counter-stories that reject normative understandings of our identities (Nelson, 2000). By foregrounding narrative exploration *and* creation, the network offers a space where storytelling is valued as a fundamental element of neurodivergent lived experience rather than an activity seen as beyond the capacity of those with certain neurodivergent diagnoses.

## 4. Narratives of Identity

> Personally, neurodivergence is itself a story. As a story, I have a sceptical relationship with it and I'm more than aware it's a story of contestation.

Organically, our focus on fictional narrative became enmeshed with discourses of self-exploration (Hillary, 2020b). We see this tendency as an ironic and empowering reversal of the neurotypical tendency to "story" autistic (and other neurodivergent) persons that Yergeau (2018) observes in *Authoring Autism*. New members introducing themselves often explain they are joining partially to make sense of their neurodivergence. As such, we recognise peer support and shared experience as important values for self-understanding (Rose, 2005). Exchanges between members provide respite from dominant cultural scripts that typically align with medical or pathological interpretations of neurological difference. Here, they find empowering terms, concepts, and stories that support a positive and an affirming sense of self that embraces their neurodivergence. As one member puts it, the network grants us tools and resources to "learn *with* each other" rather than from each other, as we continue to develop our individual and collective understanding of our respective identities. Indeed, members frequently remark that the network fosters thinking-with and feels like a site of thinking-together which, in Erin Manning's words, allows "a coming into itself of thought through a coming out of it-self of the individual" (Manning, 2020, p. 7). One member's introductory post read:

> I'm a second-year social anthropology undergraduate who only recently (a few months ago) realised I was neurodivergent. I haven't been formally diagnosed and have decided not to seek diagnosis but think that I now understand myself better and find it really affirming to connect with other ND people.

These reflections are common on the server as many members use the space to explore their respective diagnoses or challenge the categorisation of these criteria. That said, some members find these diagnostic narratives helpful, but only once reconfigured by their own thinking: "For me, I prefer autistic and allistic as terms; you're either autistic or you're not"; they elaborate to say that the creation of this autistic/allistic binary enables autistic persons to create an empowering independence from the equalising agenda of the wider neurodiversity movement where their specific needs could be negated. Other members express dissatisfaction with diagnostic labels as they find them limiting and totalising. "Being someone who doesn't see themselves as neurotypical I identify with autism rather than as autistic (I consider myself non autistic)," one member writes, "I appreciate how [the] celebration of our uniqueness doesn't depend on labels or diagnostic status [on the server]." This member's hesitancy to identify as autistic is predicated more on their "fundamental issue with the idea of neurotypicality" which they consider a similarly constructed social narrative. Their comfort in "a sense of familiarity with certain aspects of neurodivergence" demonstrates how self-narrativization empowers, a conclusion reached through conversations and reflections within the network space. Here, members create shared understandings—even if not shared by everyone; for instance, in response to the question "what does it feel like to be part of the network?" one member joked about the "joys of alexithymia" and, in reaction, another member gave their response to the same question as "still alexithymic!" This shared understanding of aspects of neurodivergence can create humorous inter-relations while establishing feelings of belonging and community (Bertilsdotter Rosqvist, 2012).

Although neurodiversity is an empowering concept in many ways, it is nevertheless mired in the values and knowledge practices of the Global North and the centring of anglophone constructs, meaning that some narratives of neurodiversity are better represented than others both within the network and in culture more broadly. This poses challenges for those whose identities do not conform to these dominant paradigms, and the individualist and cognitivist values that they impart. As it stands, neurodiversity remains Global North-centric as the disparity of published works on the subject from the Global South attests. One member, who is Tagálog, explains that while she identifies with the aims and values of the Network, she is still working out how neurodiversity harmonises or intersects with other aspects of her identity:

> It's still unclear to me how I can integrate my autistic identity with my Tagalog identity. I don't even know how to translate or if I can even translate how being autistic is in Tagálog. It's not a matter of disliking that the emancipatory concept of being autistic came from the Global North. I accept it and I acknowledge how it's now one of the conceptual tools that help me understand myself. I just feel at a loss on how to relate this with my local identity that won't erase my Tagálog identity. English/American influence already did so much damage to our collective Tagalog identities here in the Philippines. I do hope this network can connect me with people who can relate with these issues in their local contexts.

This comment reminds us that the neurodiversity movement was not birthed in a vacuum, and is inextricable from the social, cultural, and political contexts of its emergence. While neurodiversity is a cross-culturally salient *human* phenomenon, the neurodiversity movement is fundamentally grounded in Western Europe and North America. Frameworks, terms, and schemas that dominate discussions (especially diagnostic terms) may be oblivious to the contexts in the Global South and can be awkward superimpositions onto unique and incommensurable ways of understanding human diversity. Neoliberalism, colonialism, and racism have not just shaped hegemonic ideas of the "normal" or the "neurotypical," they have also interacted in multidimensional and frequently violent ways with Global Southern approaches to neurodivergence that are often grounded in local spiritualities. While the deep and profound influence of culture in shaping voice-hearing experiences has now been well-established (Luhrmann & Marrow, 2016), there is a striking gap on research that explores how other forms of neurodivergence in the Global South shape unique subjectivities and forms of belonging. As a collective involved in discourses regarding the future of neurodiversity, we must acknowledge our biases, limitations, and contexts. For example, we must recognise that when we talk about challenges of being neurodivergent, we tend to imagine that these challenges occur only within our majority geopolitical and cultural context (in the case of the network, there is a large UK majority), even if they are more widely applicable. As a member writing from "an urban and privileged context in India" explains: "When it came to being diagnosed with ADHD, dyslexia, autism, etc., in an educational context it really wasn't pursued unless you were a 'problem' kid." While there are some parallels here across countries and continents, the assumed point of comparison is situated within the contexts of the Global North. While it is possible for some members to identify themselves as being part of the network, cultural nuances and Western biases mean that their perspectives are not always represented under the "us" of our collective identity. Shaping a group identity means recognising plurality within a shared social space, placing emphasis on difference, paying attention to our social, cultural, and political situatedness, and acknowledging that some of us have better access to cultural narratives of neurodiversity than others. While the network is a space for those with similar experiences and shared social identities to come together, we are inevitably implicated in the broader systems we aim to resist and must therefore be mindful of the potentially exclusionary natures of the narratives we share to actively commit to cultivating a more intersectional space. For example, the scheduling of our live Salon discussions tends to align with the availability and time zones of the UK-based administrators who most often coordinate them. This adherence to European norms arguably exerts an exclusionary structural influence on non-Europe-based members that requires addressing.

## 5. Fostering Care Amidst Austerity and the Pandemic

While we have tried to develop an inclusive, neurodivergent-led online community, administrators have sought to understand their responsibilities to the members and each other as we recognise the disproportionate effects of austerity and the pandemic on disabled people. For this reason, we have compiled support materials that connect to our broader "networks" of care.

As many of us are also educators, we also recognised our privilege in accessing texts, spaces and social networks others are excluded from on the basis of their perceived identities and capacities. However, Discord has itself served as a "facilitator" that enables us, admins, to participate in the network as equals, and to disclose our own narratives of neurodiversity. Although it is a digital server, it also makes human connections possible, with one member writing about its "potential for collaborative work, esp. in the vein of academic discussion, news and current affairs vis-à-vis neurodivergence." As this comment suggests, the app itself is an extension of our community, enabling new stories and relations to form between those who would not be able to connect in the same way without it. It is also an affective space, where we can share not only words and fully formed judgements but images that half-formed ideas that excite us or perplex us, frustrate us, or which just puzzle us. As in the real world, there is often a sense of "not knowing," which makes it quite different to "academic space."

Unlike many platforms that we engage with in our lives, Discord was not developed to improve productivity in education or work. Discord was instead designed to connect players of online games around the world. Zoom offered a free peer-to-peer communications tool that did not require an institutional account, at least for shorter meetings. Both channels provide a greater range of non-speech expressive tools via emoticons and hand-gesture symbols than many other platforms. The multiple chat channels on Discord remain live after meetings, allowing individuals to communicate at a pace that suits them, and to loop back to ideas introduced six months ago. There is no need to time-limit questions or answers, nor to see any answer as definitive. So, while intimacy is often assumed to be something produced within private as opposed to community spaces, we discovered the beginnings of real friendships through the server. At the same time, however, we do not see the Network as a utopian project because the connections we have facilitated have no doubt excluded some. For instance, we often rely on academic language and we rely on technology that is inaccessible to some. While some have adjusted to its format, some people still find Discord "too busy" and/or overwhelming.

Equally, we recognise we could not have imagined the network space's possibility without the affective, intellectual, and creative labour of the members. As feminist critics of science and technology studies demonstrate, the connections and exchanges fostered by these forms of networks are typically seen as too "subjective" to constitute the basis of knowledge (Latimer & López Gómez, 2019). Some see caring about those we work with and think alongside as introducing bias. They claim our ties to each other may obscure the supposedly "objective" view typically expected in academic knowledge production. Yet what we are studying, as literary critics or cultural theorists, is produced by people and through socially enacted material arrangements. As much as we are responsible to others for the work we produce—many of us aim to flourish as a means of advocacy for neurominority people—we need to be open to the vulnerability of being challenged and changed by others, and to be transparent in our communicative acts. We may struggle to participate in the spaces dictated by our professional status, or we may find ourselves able to access certain spaces only if we mask our differences and access needs. Technological mediation does not, contrary to conventional ideological constructions of "individuals'' and "relations," inhibit either intimacy or autonomy. The network instead provides energy and opportunity to pursue our work within an environment somewhat closer to equality. This article, therefore, offers a space to consider the affective constraints on our own ethical practices and the power relations within which we are enmeshed.

## 6. Afterword

To reflect on the article's collaborative production, this brief afterword details the access considerations made during the process. Tasks, such as refining research questions, inviting and collating network responses, writing, and copyediting, were divided according to strengths and expertise; for instance, one dyslexic co-founder struggles with writing from a blank page, so was responsible for re-drafting and later edits. Scholars from the Global South had editorial control over the sections discussing the eurocentrism of the neurodiversity movement. Regarding our approach, feedback from members has been overwhelmingly positive, as one comments:

> I like that we were given the opportunity via draft feedback to qualify the answers we gave to the questions and also understand the specific context in which our words will be going out (which can be a source of special anxiety to many ND folk, I think). Also helped reinforce the sense of being research collaborators not subjects.

We wanted to make each stage of the publication process as transparent and as participatory as possible, but we found that aspects of the academic publication process made this ethos more difficult to follow. When it came to the peer-review, one reviewer pointed to the irony that the review process is not quite as collaborative as our working method. In order to facilitate a collaborative revisions process, we gave editing privileges to all network members and asked that the track changes function was used to identify small textual amendments and that the comment function was used to ask broader questions or for larger points of clarification that had the potential to change the direction of the overarching discussion. We used an additional document to present the reviewer feedback to the network and for members to assign themselves to revisions that intersected with their personal investment in the discussion; this document then became the response to our reviewers. Where revisions prompted significant further discussion, members were invited to share their thoughts on our Discord server, and we used the forum function to untangle ideas. Although it may seem oddly utopian, we experienced no significant difficulties encountered during the co-writing process. We have reflected upon this relative ease, and we think that the inter-personal relationships that we had developed through previous network activities, our commitment to discussing our respective needs, and our willingness to place equal value on contradictory views may have contributed to the level of positivity experienced by our members in the preparation of this article. We hope that we have managed to capture the nuances, understandings, and collective empowerment that we have felt through our continuing pandemic (and future) project, the NNN.

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## Conflict of Interests

The authors declare no conflict of interests.

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Article

# National Theatre in My Kitchen: Access to Culture for Blind People in Poland During Covid-19

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**Abstract**

This article reflects on the phenomenon of the virtualization of culture and its significance in providing accessibility to people with visual impairment. From this point of view, virtual culture becomes a space of negotiation between social inclusion and exclusion. By examining the experiences of participants in cultural events and the planners of such events, I try to identify possible advantages as well as dangers related to the process of transferring cultural life to the Internet. The scope of my research embraces accessible cultural events offered by selected institutions and non-governmental organizations in Poland. Research data was collected by interviewing both employees and participants of events with visual impairment. I have also drawn upon my own experiences as a blind admirer of culture and a worker in the sector of cultural accessibility. My main research question is: Does the virtualization of culture make events more accessible for people with visual impairment, or does it increase already-existing barriers? A further issue is explored—namely new solutions that are appearing in the accessible remote events on offer. The theoretical framework for this study includes accessibility studies and disability studies.

**Keywords**

culture; disability studies; virtualization; visual impairment

**Issue**

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## 1. Introduction

The Covid-19 pandemic has changed human life in nearly every way. To limit the spread of the disease, many countries decided to introduce lockdowns, the length and scope of which varied from country to country. In the meantime, living habits have changed all over the world, as people have shifted many of their activities to virtual spaces. Information and communication technologies (ICT) such as computers, smartphones, and tablets became the principal means of carrying out multiple functions, for millions of people. Groups who are traditionally more vulnerable in crises, such as people with disabilities, were especially affected by these changes. Much has been already written about the impact of lockdowns on this group concerning work (Aydos et al., 2021), healthcare (Schotland, 2021), personal security (Katz, 2020; Lund, 2020; Shelton, 2021), and more. In this article, however, I address an area that has not been thoroughly examined to date, namely the participation of people with disabilities in cultural activities. Except for very few and fragmentary examples that focus on Western Europe (Gentry, 2021; Reason, 2022; the audience agency, 2021), we lack research on this topic.

To fill this gap, at least minimally, I examine how the virtualization of cultural life impacted accessibility for persons with visual impairment. I present the findings of a study that I conducted in Poland among individuals with visual impairment and employees of cultural institutions and NGOs. I present and discuss the various solutions being implemented in order to make virtual cultural events accessible and indicate the main difficulties from both the participants’ and the organizers’ perspectives. I ponder on the benefits for both sides and take into account the cognitive, entertaining, and social dimensions of one's contact with culture based on the very broad range of the examined events, starting with cooking workshops and ending with theater performances.

My main research question is whether the virtualization of culture makes events more or less accessible for persons with visual impairment. In other words, does it contribute to producing new and inclusionary mechanisms, or does it merely increase already-existing barriers? Generally speaking, "access can be divided into physical access (e.g., to objects and places) and intellectual access (e.g., to ideas and information)" (Jaeger & Bowman, 2005, p. 63). This article centers on the latter aspect and—for the sake of clarity—it is necessary to define the extent of this access. The focus here is on the issue of accessibility of culture for persons with visual impairment: Where I use the term "accessibility," I refer only to the accessibility of culture and only for this group of people. In search of an answer, I analyze examples of various remote cultural events and divide them into two categories, which I refer to as online and offline. The former are virtual meetings with patrons which are held in real-time, also called streaming, organized on a given internet, social media, or video-conferencing platform. These are often interactive meetings, though the degree of interaction may vary. The latter category includes various audiovisual materials, including films and performances, which can be downloaded or accessed at one's convenience. In this category, I also include activities that do not use the internet directly, such as the practice of sending CDs with films with audio descriptions to viewers.

## 2. Access to Culture and Accessibility Studies

According to the Universal Declaration of Human Rights, the chance to freely participate in cultural life is a fundamental human right (United Nations, 1948). However, people with disabilities often face considerable difficulties in exercising this right. This particular issue was also addressed in the Convention on the Rights of Persons With Disabilities, which imposes on states parties the obligation to take all appropriate measures to ensure that persons with disabilities may take part in cultural life on an equal basis with others (United Nations, 2006).

Making culture accessible to persons with disabilities is a long process, comprising numerous stages and including factors such as architectural accessibility, digital accessibility, the accessibility of events, the training of staff, and many others (Come-in, 2019). Persons with various disabilities might need various accessibility services, and accessibility itself might work differently depending on the sphere of life. The main accessibility service for persons with visual impairment is audio description, which can be defined as "a verbal commentary providing visual information for those unable to perceive it themselves. AD helps blind and partially sighted people access audiovisual media and is also used in live settings such as theatres, galleries and museums" (Fryer, 2016, p. 1). Other accessibility services are related to the sense of touch and include 3D models, tactile graphics, touch tours, and others (Hayhoe, 2017; Kleege, 2018).

The accessibility of culture in Poland does not have a long history, as the first screening of a movie with an audio description took place in 2006, in Bialystok (Jankowska & Walczak, 2019). Since then, accessible cultural events have appeared in various cities, though the choice of accessible cultural events in Poland is still not very wide-ranging. For a long time, the need for access was addressed predominantly by NGOs, who were involved in preparing audio descriptions and closed captions for selected films and performances. The situation appears to have changed at least in theory: In 2019, after years of efforts from people with disabilities and their allies, the Act on Ensuring Access for Persons With Special Needs was adopted. This new legislation imposed an obligation on public institutions and cultural sites to adapt their activities to the needs and abilities of a diverse audience. This is a big step towards increasing social awareness about accessibility. However, in practice, many institutions have still not implemented the guidelines of the Act.

Until recently, the process of making culture accessible had received little scholarly scrutiny, and when examined, it was mainly in terms of technical guidelines. Audiovisual translation, which includes audio descriptions and closed captions, has aroused the interest of scholars for some time. Nevertheless, as Matamala and Orero (2016, p. 2) assert, "the object of study and its methodology have outgrown the field where they were initially studied." They point to the need for the emergence of a new research field, namely accessibility studies composed of audiovisual translation, assistive technologies, new media technologies, audience development, tourism management, and many others.

Accessibility studies in Poland, especially research into the accessibility of culture for people with visual impairment, have hardly been explored. The majority of works on this topic have considered it within the rehabilitative paradigm and highlight its compensatory and therapeutic dimensions (Kłopotowska, 2016; Paplińska, 2016; Szabała, 2019). This approach strengthens the medical model of disability, which is based on the assumption that disability is a dysfunction that should be eliminated through a process of rehabilitation or medical intervention. This methodology was criticized years ago by members of the disabled persons' rights movement and scholars from the field of disability studies (Barton, 1989; Oliver, 1983) as it is considered a harmful and oppressive approach with a devastating impact on emancipatory and empowerment processes. Disability studies and the closely-related area of accessibility studies are based on the social model, the principle assertion of which is that disability is not a result of the bodily dysfunction of an individual, but a social construct triggered by defects in the social environment, which is designed to satisfy the needs of a privileged group of users only (Finkelstein, 1981; Oliver, 1983; Shakespeare, 2006).

Accessibility studies suggest considering accessibility as a human right (Greco, 2016). When thus conceptualized, accessibility goes beyond the narrow structures of adaptive or rehabilitative tools for a specific excluded group. It resonates with the concept of universal design, defined as “the design of products and environments to be usable by all people from all ages to the greatest extent possible, without the need for adaptation or specialized design” (Mace, 1985, p. 147). The use of universally designed spaces and products is equitable, flexible, simple, and intuitive. It provides perceptible information, shows tolerance for error, and generates low physical effort. Understood in that way, universal design is a fundamental principle of social inclusion.

Establishing standards for designing universal and accessible solutions urgently requires the development of an interdisciplinary field for knowledge transfer (Greco, 2018). It is necessary to reflect on what solutions support the development of accessibility and which merely seem to perform a task. Therefore, it is hoped that this article will contribute to the process of developing theoretical considerations and practical solutions.

## 3. Methodology

The study discussed in this article was conducted between 1 November 2020 and 30 June 2021. First and foremost, the examined material includes structured interviews with the participants of cultural events and representatives from institutions and NGOs that offer accessible cultural events. It is supplemented with the autoethnographic material based on my own experiences as a blind participant in cultural events online (Anderson, 2006), which were collected in form of short diary notes taken after each event in which I participated (Anderson & Glass-Coffin, 2016). Furthermore, the core ethnographic material is complemented by the information acquired from the websites and social media profiles of cultural institutions. Due to safety concerns at the time, related to the ongoing pandemic, all interviews were conducted by telephone.

The group of participants in cultural events numbered 20; there were 14 blind and six low-vision people (12 women and eight men), ranging from 25 to 52 years of age. The interlocutors came from the following cities: Ciechocinek (north of Poland, ca. 10000 habitants), Gdynia (north of Poland, ca. 240000 habitants), Lublin (east of Poland, ca. 340000 habitants), Łomianki (central Poland, ca. 25000 habitants), Otwock (central Poland, ca. 45000 habitants), Poznań (central Poland, ca. 530000 habitants), Sieradz (central Poland, ca. 41000 habitants), Skierniewice (central Poland, ca. 48000 habitants), Warsaw (the capital, central Poland, ca. 1800000 habitants), Wrocław (west of Poland, ca. 640000 habitants), and Zduńska Wola (central Poland, ca. 42000 habitants).

The study was conducted following the ethical standards of qualitative research. Before starting the interviews I contacted all potential interlocutors, presenting myself, the aims of the project, and the conditions of the interview, namely: the approximate length of the interview, the fact that I would be recording them, and the general topic of the interview. All the interlocutors were informed that they could withdraw their consent at any moment during the research and that they could skip any question if they found it uncomfortable. Each interview took place only after prior consent has been obtained.

In the case of blind and visually impaired interlocutors, I ensured all of them that I would not use their true names. However, I asked them for consent regarding using true demographic data and wrote about them only after this consent was granted. The names of visually impaired interlocutors will not be disclosed throughout this article: Their sex, age, and city of provenance will be provided instead.

Demographic data, including age and place of living, are important information that allows the reader to situate a given respondent in a context, which may be pertinent to the numerous issues discussed in this article, such as the digital divide.

In the case of representatives of cultural institutions and NGOs, their personal names won’t be disclosed either. Demographic data, in their case, were found to be irrelevant. When referring directly to their statements, I provide the name of the institution or organization they are related to.

Participants in my research were reached through announcements posted on two Facebook groups for the blind and visually impaired in Poland: Niewidomi i Niedowidzący—Bądźmy razem (The Blind and the Visually Impaired—Let’s Be Together) and Trzecie Oko—Niewidomi i widzący razem (The Third Eye—The Blind and the Sighted Together).

The group of accessible culture providers was composed of six people, representing the following cultural institutions and NGOs: Zachęta Narodowa Galeria Sztuki (Zachęta National Gallery of Art), Fundacja Kultury bez Barier (Culture Without Barriers Foundation), Fundacja Wielozmysły (Multisenses Foundation), Okręgowe Muzeum w Nowym Sączu (The District Museum in Nowy Sacz), and Centrum Sztuki Współczesnej Łaźnia (Łaźnia Centre for Contemporary Art). It should be noted that all of them had previous experience working on issues of accessibility to culture before the pandemic.

Participants from this group were known to me before the research started, and I reached them through my private network.

The collected empirical material was subjected to a thematic analysis. To examine the data for the most relevant themes, a six-step analytical process was implemented: (a) familiarizing with the data; (b) initial coding; (c) searching for recurring themes; (d) reviewing themes; (e) identifying themes, and (f) producing the final research report (Braun & Clarke, 2006; Madden, 2010; Saldaña, 2011). The recurring subjects were initially organized into topical themes—such as events organized by a particular institution—and subsequently grouped into broad categories of overarching themes—such as advantages of remote participation in cultural events (Bailey, 2018). Finally, five main categories were defined and are examined below: The first two categories embrace the analysis of the variety of techniques to make remote cultural events accessible depending on the type of event; the remaining three categories refer to the challenges, advantages, and disadvantages of a remote contact with culture.

## 4. The Accessibility of Remote Cinema and Theater

It is worth mentioning that the process of making culture accessible in a remote form for persons with visual impairment had begun in Poland long before the Covid-19 pandemic started. The "De Facto" Association sends CDs to its members by traditional mail, with an audio-described film that may be viewed at home. After a certain period, it must be returned ("De Facto" Association, n.d.-a). The Barrel Organ Foundation carries out a similar initiative: It established and runs the website Adapter (https://adapter.pl/filmy), where films with audio descriptions and closed captions are systematically uploaded. Unlike the "De Facto" Association, the Adapter website offers access to its resources without any restriction on time or quantity. Moreover, theater lovers may visit the website of the Polish national film archive (https://fina.gov.pl) and view selected plays from The Television Theater provided with audio descriptions and closed captions (https://ninateka.pl).

In 2020, these activities turned out to be far from sufficient; therefore, audio descriptions were prepared for many new performances and films. Theaters put them on platforms such as YouTube or VOD, free of charge (Teatr Kamienica, 2020; Teatr Polski w Bielsku-Białej, n.d.). The 17th edition of Millennium Docs Against Gravity Festival took place in the autumn of 2020 in a hybrid form, and spectators could watch selected films provided with audio descriptions in theatres as well as on the internet. Watching films on the website was free of charge and made possible during the entire festival: "After logging in, you have 24 hours to start watching and then, after you start, [you have] about four hours to finish," explained a representative of the Culture Without Barriers Foundation.

The 10th Culture and Art for Blind Persons Festival (https://fkison.defacto.org.pl), organized by the "De Facto" Association was held entirely online; it is one of the most representative cultural events for the blind in Poland, lasting one week and providing participants with culture in every form—mainly film, though it included concerts, performances, and meetings with writers. While usually based in the city of Płock, in 2020 it took place on an internet platform called BigBlueButton.

The shifting of cultural life towards the remote mode has introduced cultural events to the internet that do not need accessible services for the blind, for example, author's meetings or concerts. It has thereby contributed to broadening the scope of cultural life for audiences with visual impairment. Interestingly, as my interlocutors indicated, they often found out about certain kinds of cultural activities for the first time when they were made online. One participant (female, 52, Otwock) said:

> In the first lockdown, I discovered stage reading online. Kwadrat Theater, for example, did that. It was an event completely open to the wide public, but also accessible to us because they read stage directions as if it was an audio description.

## 5. The Accessibility of Remote Museums and Galleries

The most common activity organized by museums and galleries during the lockdown was virtual visits, both online and offline. In Zachęta National Gallery of Art, in the spring, educators recorded audio descriptions for whole exhibitions, as well as particular works. Although recordings of that kind were usually prepared by professional narrators, in this case, the institution decided that the recordings would be done by employees from the gallery, out of a desire to create the most faithful impression of being at the place: "In order to make it more natural, to provide a familiar voice, it is recorded not by lectors but by the educators who usually guide the tours for persons with visual impairment," a representative said.

During the autumn lockdown, the gallery expanded its activities and organized online visits. I had the opportunity to participate in one of them. During such events, the educator was in the gallery, walking around the spaces and speaking about the exhibition on the Zoom platform. Again, the need to represent "being" in the exact place was addressed. By listening to the educator, we could experience an audio description of certain objects and hear sounds from the exhibition, sounds of the gallery space, that varied depending on where the educator was walking. Offline accessible visits were also carried out by the Łaźnia Centre for Contemporary Art.

In the spring, a unique form of online event that emerged was "the workshop" (for example, on cooking). The Culture Without Barriers Foundation organized them in collaboration with various other cultural institutions. I participated in the one arranged by the Royal Łazienki Museum, during which the educator first spoke about the culinary customs of the royal court, presented historical pictures, and audio-described them. Secondly, she cooked according to a recipe from the cookbook of the royal chef and participants were cooking along with her in our own homes, in front of our laptops and phones. She observed us on Zoom through our cameras and gave us feedback and tips.

## 6. Challenges to Making Remote Culture Accessible

Researchers on the issue of digitalization concerning disability have indicated various underlying challenges to the process (Ellis & Kent, 2011; Good Things Foundation, n.d.; Jaeger & Bowman, 2005). The findings of my study highlight two of them in particular. The first of these is related to the fact that some people with visual impairment do not have access to the internet or have very limited abilities in navigating it. It is the so-called "digital divide" or "digital exclusion" (Castells, 2001), a phenomenon usually associated with poor countries that have no digital infrastructure. It can, however, be observed in well-developed countries like Poland. Here, there is a gap between digital natives and digital immigrants (Prensky, 2001). Additional demarcation can be seen between people living in major urban centers and those from rural areas (Steele, 2019).

Young urban digital natives with visual impairment, who seamlessly incorporate new technologies, are well-accustomed to getting information in that manner and are more often aware of opportunities for participating in accessible cultural life in their cities. Therefore, after shifting to a "remote cultural mode," it is natural that they find and enjoy new possibilities. To some extent, they feel that culture has become more accessible, as they are able to participate in events far away from their homes. For those on the opposite side of the digital divide, however, this new status quo is not as positive: Their exclusion has become even greater. One participant (male, 38, Skierniewice) explained:

> In the big cities, in Warsaw and Lodz, many institutions do audio descriptions and people are used to it. In my city there is nothing. There is no accessibility in real life, even less so in the digital one. Our city has 50000 habitants, persons with the disability certificate [are] about 400, a few dozen of them should walk with a white cane, but only six of them do. So how are they supposed to [consume] digital culture? They do not know how to use a smartphone.

One of the elements of digital exclusion is insufficient knowledge of English. The Zoom platform, while frequently used by various cultural institutions, did not have a Polish language version for some time. It was mentioned by several of my interlocutors as a significant factor that hindered their participation in remote cultural life. One woman (46, Warsaw) said: "I have a problem because I do not always understand the commands in English." A representative of the District Museum in Nowy Sacz complemented this idea: "During the first visit, some elderly people were connecting with the USA instead of connecting with us, because they did not understand what was going on."

To face this challenge, organizations and institutions tried to offer active technical support. The case of the "De Facto" Association can serve as an example: Before their annual festival, the organizers provided all participants with a brief training session about how to manage the BigBlueButton platform where the festival was taking place. A woman (46, Warsaw) recounted:

> We received instructions on how to use it. If you had a problem, you could call them. They prepared short instructions on how to turn the microphone on and off and so on. Thanks to that, many elderly people took part in it.

Since the elderly are more likely to experience computer anxiety and frustration with user interfaces (Gallistl et al., 2020), referencing well-known analog technologies might be also an accessibility service. That was the path the Multisenses Foundation chose when implementing the project of accessible walks; the format of "radio play" was used. "We don't call it a podcast so as not to frighten elderly people. We call it 'radio play,' as if it was on the radio. Radio is a well-known space," said a representative. Another form of adaptation to the digital capabilities of the audience is a choice of medium less problematic to recipients than the internet. Another representative explained: "We sent the CDs to the Polish Association of the Blind because there are many elderly people in this project and most of them don't know how to use the internet."

The second main challenge, as Ellis and Kent (2011) observe, is the inaccessibility of selected websites and internet platforms for screen readers used by persons with visual impairment to manage ICTs. Here, the most challenging turned out to be platforms for selling tickets online:

> I know that there was a kind of film festival. It was free of charge. But you had to generate free tickets on the website. And many blind persons couldn't deal with that because the platform was inaccessible. (male respondent, 41, Poznan)

> Calendars are usually inaccessible to me. So when I want to buy the ticket and I have to choose the date, I can't. (female respondent, 46, Warsaw)

> Buying a ticket on the internet…is always problematic for me. I just ask my friend to do it for me. (female respondent, 28, Warsaw)

> I struggled a lot with the website of the Philharmonic, first to buy the tickets and then to turn on the concert. I finally managed to do it, but it is not very accessible. (female respondent, 40, Łomianki)

These quotes clearly indicate how digital inaccessibility is a factor of exclusion that pushes persons with visual impairment back into the medical paradigm. The responsibility for participation again rests on the individuals with disabilities, who personally have to struggle with websites or look for the assistance of non-disabled persons. As creators of the social model claim, the disability (or, in this case, digital disability) is constructed by the inaccessibility of the common social space, in this case, a digital space (Oliver, 1983; Shakespeare, 2006).

## 7. Advantages of Making Remote Culture Accessible

Although all of my interlocutors eagerly awaited to enjoy cultural life again in person, they also reported many benefits of having a virtual cultural life. For persons with visual impairment, one of the most essential aspects was the increased independence in managing their own time. Offline accessible cultural events have allowed them to choose what film or performance they watch, as well as where and when they do so. Non-disabled spectators can usually go spontaneously to the theater or cinema whenever they want. However, persons with visual impairment who would like to participate in the city's cultural life are forced to subordinate all their plans to this desire. Accessible screenings are not common and frequent events. They are available only for an exact date, in an exact place. If a person miss the accessible screening or performance, she or he will probably have to wait several months until there will be next opportunity of enjoying it. Offline accessible cultural events, such as the audio-described films and performances that are available on the internet for several days, are a way to overcome these limitations. It significantly increases the probability that persons with visual impairment will reach it. It may also apply to offline museum and gallery visits. "For guided tours in person there were usually eight or ten people coming, and now these recordings on YouTube have tens or even hundreds of displays," said a representative from the Łaźnia Centre for Contemporary Art.

Additionally, such arrangements allow a spectator to see the material more than just once, which turns out to be another type of accessibility service. "A blind person, after watching a film sometimes doesn't know what it's going on. And it is necessary to watch it twice or even thrice in case of difficult films," said a male respondent (41, Gdynia).

A further, indisputable advantage of having a "remote cultural life" is the reduction of geographical barriers. Both the participants of cultural events and their organizers have stated that due to the virtualization of cultural life, the rate of participation in cultural activities beyond one's place of living increased significantly. "Now, on our online visits, we have many people from outside of Warsaw," said a representative from Zachęta National Gallery of Art. A male respondent (35, Wrocław) agreed: "In one day, I can participate in events that take place in various cities in Poland or [around] the world." I personally was able to participate in accessible cultural events of several European institutions for the first time, thanks to their remote form.

The removal of this physical, spatial dimension increased the autonomy of persons with visual impairment:

> I have never been to the National Theatre before. I will probably never go there in person because I don't have anybody who will go with me. But now I have the National Theater in my kitchen. (male respondent, 49, Lublin)

> One person told me during the online workshop that she had never gone to that institution before because she was afraid of getting lost. (representative from the Culture Without Barriers Foundation)

Accessible remote cultural events are especially significant to persons living in small cities, who are particularly vulnerable to cultural exclusion. For those who do not have an opportunity to watch an audio-described film or attend a performance in person, the internet is the only space for contact with culture. For this group, the increased number of accessible, virtual cultural events in 2020 resulted in much better access to culture, in general.

> I live in a small city. There is no cinema here. Films are shown in the theater and of course without audio description. So I have always watched films on the internet. The pandemic forced everybody to shift to the internet and much more accessibility appeared. (female respondent, 50, Sieradz)

It appears that accessible, remote cultural events have great potential. The virtualization of cultural events favors the development and expansion of accessibility in certain aspects. Nevertheless, there are also inherent flaws that will be addressed in the following section.

## 8. The Disadvantages of Making Remote Culture Accessible

Although remote cultural life creates many promising opportunities, it may deprive us of many others. Some of my interlocutors frankly admitted that remote participation in cultural life has much less value to them: "It definitely doesn't satisfy my need for theatre. I'm not as focused as in a real theatre where everything is happening here and now," said a female respondent (28, Warsaw). Even people who appreciated various new possibilities created by this situation were not uncritical towards it. The claims that come up address technical and social aspects.

The first of those is related to the fact that within the cases of remote accessibility, the scope of accessibility services that can be utilized is restricted. In a virtual theatre, there is no opportunity to touch decorations or costumes. In a virtual museum, visitors cannot touch tactile graphics and blind participants can only rely on their hearing; due to the low quality of the recordings, this is sometimes very challenging. When participating in a live theatre performance, blind people can understand much more of what is happening on stage than when merely listening to a recording:

> When you sit in the theater, even without audio description, thanks to rustles and puffs you can more or less see the plot. And in virtual theatre you cannot. (female respondent, 52, Otwock)

I remember that my sensation was quite similar. While watching several audio-described theater performances on my computer I thought frequently that deprived of all the embodied experience of being in the place, the audio-described show becomes, in fact, nothing more than a radio play. An interesting strategy of overcoming these limitations was adopted by The "De Facto" Association. In the project dedicated to the figure of Irena Sendler various accessibility services were combined. The participants could watch the documental movie with audio description, but also received via traditional mail the tactile graphics representing, for example, the medal of the Righteous among the Nations and others images related to the theme ("De Facto" Association, n.d.-b).

The second aspect is related to the social dimension of participation in cultural life. For many people, the actual theater or museum is not only the physical space one gets in contact with art; it is also the space one gets in contact with other people, where social relationships are established and maintained:

> I don't feel this atmosphere. I know that I won't meet them in person. (male respondent, 38, Ciechocinek)

> After these theatre performances, my two friends and I always went to have a glass of wine. I can now have a drink at home, but, you know, it is not the same. (female respondent, 33, Warsaw)

It is necessary to stress, however, that a cultural event is not only an excuse for meeting others; experiencing art together is a matter of producing and strengthening interpersonal relations. In the case of a group that is especially vulnerable to social exclusion, such as persons with disabilities, an experience that can be shared with people outside of the group is especially important. Cultural life is a space of social life where raising awareness and breaking stereotypes leads most naturally and smoothly to better inclusion. The exchange of opinions and discussion about films and performances that have just been experienced is a motive that appeared in the remarks of many of my interlocutors, as a component of the cultural event and their social lives. One respondent (female, 50, Sieradz) said: "I need people. I want to meet my friends. Go out and talk to the others about what we have just seen."

The next drawback pointed out by my interlocutors is the lack of interaction with the artists themselves. As it turns out, for many, the opportunity to express their applause is an important element of participation in a cultural event. It is perhaps related once again to the issue of creating and fostering a sense of belonging to the community: "I miss the opportunity to scream 'encore!' I miss the applause," said one of my female respondents (47, Zduńska Wola).

Moreover, for many people, participation in cultural events is a source of rituals that organize the world and separate the space of festivities from that of everyday life. By going out, one draws a natural divide between what is private and what is public. When participating in cultural events, people usually enter a public space dressed elegantly and behave in a specific way. By watching films and performances at home, one relocates culture to a private space. Simultaneously, ICTs that were rather associated with privacy before the pandemic have become the main carriers of "publicness" (Soriano & Cao, 2017). The boundaries between the private and public spheres become fluid and eventually blur. It results in dissonance and longing for the return to pre-pandemic life:

> When I go to the Philharmonic, I can wear high heels. At home I can also [do this], of course, but it's not the same. I can dress perfectly, wear high heels, makeup, sit on the sofa, and I will still feel stuck. (female respondent, 40, Lomianki)

> When I watched this online spectacle I wore a shirt and jacket. I turned off the phone. I tried to feel the atmosphere. (male respondent, 35, Wroclaw)

My interlocutors have tried to recreate old rituals to feel included in the community of spectatorship again, but in the remote mode, it has proven very difficult.

## 9. Discussion

The data collected and discussed in this article are undoubtedly insufficient to make definitive diagnoses. Due to the recruitment method, the group of interlocutors I have cited is surely not a representative sample. In fact, I interviewed only those persons with visual impairment who are more or less active and functioning well in digital spaces and employees from those cultural institutions that have already some experience with accessibility questions. Nevertheless, the material collected seems to provide interesting insights into the functions of accessibility of remote culture in Poland, providing a starting point for the discussion on the positive and negative aspects of virtualization.

Speaking of positives, it should be noted that, in some cases, the virtualization of cultural events resulted in the creation of completely new, experimental forms of accessibility. The radio plays prepared by the Multisenses Foundation fall into this category.

Furthermore, it contributed also to creating new standards of providing digital access. The practice of individual IT support for the festival participants offered by the "De Facto" Association can serve as a good example.

To some of the visually impaired interlocutors, the virtualization of cultural life was also a factor that significantly expanded their knowledge and competencies. Some of them reported that they developed their digital competencies significantly during 2020. Others mentioned that they had gotten to know many cultural institutions that they had not known before. Another aspect that is worth mentioning, is the partial reduction of the financial and geographical barriers. Last but not least, a benefit of virtualization—partially related to the former—is its emancipating dimension, namely the increase of autonomy and agency it means for persons with visual impairment. In Poland, accessible screenings and theater performances are not frequent events, though in big cities they take place a few times a year. A spectator with a visual impairment has no impact on where, when, and which piece might be prepared with an audio description. As a consequence, they have no way of choosing what to watch and have to gratefully accept whatever is offered. This situation corresponds to the charity model of disability, in which a person with a disability is reduced to a passive subject of assistance by the non-disabled (Shapiro, 1993). This also resonates to some extent with the medical model of disability, which requires an individual with a disability to adapt themselves constantly to external conditions designed only with the non-disabled in mind (Barton, 1989; Oliver, 1983).

Concerning the negative sides, the main problem from the point of view of institutions and NGOs is the fact that preparing a remote accessible cultural event is much more time-consuming than live events. Nevertheless, all of my interlocutors from this group declared that they positively assessed the remote form of organizing events and that they would like to introduce virtual events to their permanent programs, even though live events are being held again. This opinion was shared by the participants in their events. When asked if they would still participate in virtual events, 17 persons answered positively. Most of them pointed to the geographical aspect as the main reason.

Among the main disadvantages of remote cultural events, from the point of view of participants, the first and foremost is the lack of social dimension. It turns out that even the best digital technologies are incapable of substituting real human presence (De Kerckhove & Rowland, 1997). Further issues can be considered under the umbrella of technical flaws or limitations. Digital communication proved to be much more unreliable and—in several cases—inaccessible for people with visual impairments than we could expect. Additionally, there is an impoverished sensory range in online accessibility services. At the same time, one cannot neglect the problem of digital exclusion. For many, the shift towards the virtual only deepened existing inequalities instead of raising accessibility levels.

## 10. Conclusion

It would be beneficial to broaden the scope of my research and interview employees/representatives from institutions that started their accessibility arrangements during the pandemic. Furthermore, it seems necessary to interview much more visually impaired event participants to consider the sample as representative of the community of persons with visual impairment at large in Poland. However, I believe that, with due care, useful tips and suggestions may be found in the discussed material. Single individual testimonies of the challenges faced by my respondents, as well as the new possibilities they have discovered, can serve as a warning or inspiration respectively. Aware of the limitations and shortcomings of this study, several conclusions can be drawn.

First and foremost, it is noteworthy that accessibility is already well-grounded in several cultural institutions in Poland. Shifting towards a remote mode did not interrupt this long and dynamic process; on the contrary, to some extent, it had a stimulating effect. Some institutions and organizations saw developmental potential in it. Furthermore, further reflection on the virtualization of culture contributes significantly to expanding the general knowledge about digital accessibility, understood not only in what concerns accessibility for screen readers but also in the broader context of universal design.

Last but not least, it is often overlooked in studies concerning the functioning of people with visual impairment that this is a very diverse group, in which representatives have very different needs, capabilities, and preferences. Since disability is an intersectional and coconstructed concept, it should be always taken into consideration together with a wide range of demographic factors, including gender, age, and place of living.

In light of the presented study, the accessibility of a remote cultural life seems to have an ambiguous nature. On the one hand, it is conceived of as an inferior version of accessibility to live events, as it is deprived of many key accessibility services. On the other hand, it is an interesting and promising alternative for persons excluded from a more varied cultural life due to geographical or financial factors. This leads me to conclude that my research question remains, to a point, unanswerable. However, I hope this study contributes, if only partially, to the intellectual debate surrounding the inclusion of visually impaired persons as consumers of culture in Poland. All of my interlocutors seemingly appreciated the value of remote cultural life, while at the same time indicating its flaws. I believe that the issue of remote cultural life requires extensive further research, though it can already be claimed that it is a very important component of the current accessibility panorama.

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## Conflict of Interests

The author declares no conflict of interest.

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Article

# Pandemic Lived Experience, Crip Utopias, and Dismodernist Revolutions: For a More-Than-Social Model of Disability

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**Abstract**

At its height, the Covid-19 pandemic dispersed across society a perception of bodyminded contingency that ushered in modes of "building community" that were unimaginable in pre-pandemic times, alongside an intensification of health and social inequalities. From the start, disabled people intervened on social media to stress the considerable extent to which the pre-pandemic knowledge derived from their lived experience, disability theory, and disability rights' organising could contribute both to the critique of how in pandemic times people were *made* differentially disposable and to the creation of new relationalities, mostly online, around the principle of accessibility. This article explores how a critical perspective rooted in the lived experience of disability builds on these interventions to excavate the role played by the lived experience of bodyminded contingency and vulnerability during the pandemic in generating a radical transformation of modes of living (together). First, it will suggest that this radical transformation powerfully resonated with the politics of accessibility associated with disability politics. It will do so by delineating the critical significance of commentary produced during the pandemic by disability theorists and activists, as well as the relationship between the perception of widespread bodyminded contingency and vulnerability and the development of "crip utopias of accessibility" and "dismodernist revolutions" during the pandemic. It will then locate this experiential spread of bodyminded contingency and vulnerability at the core of pandemic infrastructural sensibilities. I will conclude by reflecting on its relevance for the development of a "more-than-social" model of disability which attends to the crip world-making power of disability as fundamentally entangling the social and the biological.

**Keywords**

Covid; crip; dismodernism; infrastructures; lived experience; models of disability; more-than-social; posthuman; revolution; utopia

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## 1. Introduction

At its height, the Covid-19 pandemic dispersed across society a perception of bodyminded contingency that ushered in modes of "building community" that were unimaginable in pre-pandemic times, alongside an intensification of health and social inequalities. From the start, disabled people intervened on social media to stress the considerable extent to which the pre-pandemic knowledge derived from their lived experience, disability theory, and disability rights' organising, could contribute both to the critique of how in pandemic times people were *made* differentially disposable and to the creation of new relationalities, mostly online, around the principle of accessibility. On the one hand, these interventions spotlighted the relevance of the lived experience of disability for understanding people's experiences of the pandemic. On the other, the pandemic conjuncture was defined by the de-linking of the reorganizing of collective life in a more accessible manner from the disability histories and theories through which a politics of accessibility has been developed. For years, in drawing upon my crip lived experience and knowledge to help make the spaces I inhabited more accessible, I had performed a similar de-linking by disconnecting my actions from any overt connection to crip politics. To explore possibilities for undoing this de-liking in 2019 I applied to participate in the Lived Experience Leadership pilot scheme offered by the disabled people organisation Inclusion Scotland. The aim of the programme was to help participants explore what being disabled and a leader could mean in their individual life journeys, and how as disabled leaders they could make a positive change in the world.

I had applied to join the Lived Experience Leadership programme before the onset of the Covid-19 pandemic when face-to-face teaching in academia, besides activism, provided the horizon of my thinking around the ways in which I could use my experience of disability to crip the world I was part of for the better. When the Lived Experience Leadership programme started, however, the pandemic was in full swing, as was lockdown; I had lost my job and the world I wanted to crip for the better was constituted by the online spaces of autonomous learning that had become my learning communities. These spaces were more accessible to me than any other space I had encountered in my life (apart from the spaces of the activist groups I am involved with). Their accessibility seemed to me to simultaneously materialise a crip utopia and index a relationship between disability politics and the pandemic reorganizing of social relations online. By the end of my Lived Experience Leadership journey, I was keen to explore how the lived experience of disability could link to pandemic lived experience by contributing a critique rooted in its own politics and history, and by encouraging the pursuit of accessibility as a crip world-making endeavour.

This article will unfurl this spirit by exploring how lived experience of disability and lived experience of bodyminded contingency and vulnerability during the pandemic are connected. Its focus will be on how a critical perspective rooted in the lived experience of disability afforded a position from which to critique the institutional abandonment of unwanted populations during the pandemic, but also to illuminate the materialization of crip ways of reorganizing society during lockdown. The first section of this article will therefore discuss the significance of the lived experience of disability in understanding the pandemic lived experience of bodyminded contingency and vulnerability, as well as emancipatory possibility. The lived experience of disability is defined by a double encounter with oppressive social structures and with alternative ways of being (together). This afforded a critical lens during the pandemic for illuminating the differential vulnerability and disposability the governmental management of the pandemic was creating, as well as the potential for alternative ways of organizing relations in an emancipatory direction to develop.

Drawing on commentary provided by disability theorists and activists, the second and third sections of this article will instead explore how the disruption of normalcy that the pandemic involved might allow us to contemplate disability as "both a signifier of inequity and the promise of something new and affirmative" (Goodley et al., 2019, p. 972). They will discuss how the reorganization of relations in the context of social distancing and lockdown materialised what I will call "crip utopias" and "dismodernist revolutions." Both are crip visions of a different world that originated out of the grassroots responses that people made to the universality of bodyminded contingency and vulnerability. The second section will address "crip utopias" of accessibility as already existing forms of life that fit the description of "concrete utopia" proposed by Ernst Bloch to distinguish a world-changing anticipation of the future in the present from the discredited abstract utopias which merely operate as wishful thinking. The third section will argue that the crip utopias of pandemic times can be read as "dismodernist revolutions" that emerged out of the spreading out across society of lived experience of bodyminded vulnerability and contingency. Lennard Davis' concept of dismodernism is particularly apt to capture the pervasiveness of this experiential spread.

However, the lived experience of disability is fundamental not only for critique but also for remaking the world in an emancipatory direction. As Sandhu (2017) suggests, lived experience can provide an ideal position from which to make a positive change in the world. The fourth and fifth sections of this article will delineate how the radical transformation of understandings and practices generated from the widespread lived experience of bodyminded vulnerability and contingency during the pandemic connects to a revised social model of disability. Section 4 will locate this experiential spread of bodyminded vulnerability and contingency as the biological core which animates the sensibilities of care and vulnerability that became thinkable during the pandemic, which I will call infrastructural to express their rootedness in the material conditions of collective life. Section 5 will connect the infrastructural (post-)pandemic understanding of bodyminded contingency and vulnerability that these sensibilities express to critical disability studies models of disability which locate bodyminded phenomena of non-normativity within a world in which the human and the non-human, as much as the social and the biological, are entangled. Underpinning this section is an argument for the usefulness of embracing a "more-than-social model of disability" to theorise the possibilities afforded by the lived experience and materiality of disability to make worlds and remake the world. To delineate what this model might look like I will draw on Dimitris Papadopoulos' exploration of the experiential practice and reconfiguration of the material conditions of existence that underpins the transformation of political and social movements into "more-than-social'' movements.

Mine will be an attempt to capture the glimmers of the crip world (re-)making power that appeared in pandemic times. It will be driven by the intent to take a stand against the unfurling post-pandemic consensus that we are back to the pre-pandemic normal, and that there is nothing we can do to stop the retreat away from the crip utopias of accessibility and dismodernist revolutions that pandemic times witnessed. My reflections on what happened during the pandemic, thus, ultimately re-affirms a belief in the power of crip lived experience to expand outwards and meet others to contribute to the continued undermining of normalcy in post-pandemic times.

## 2. Sick and Crip Lived Experience in Pandemic Times

Discussing pandemic contingency and vulnerability as “bodyminded” identifies “the imbrication (not just the combination) of the entities usually called ‘body’ and ‘mind”’ (Price, 2015, p. 270) as grounding experiences of oppression as well as resistance, while disentangling their lived experience from association with a specific set of impairments, medical conditions or identification. Efforts to delineate what or who lived experience of bodyminded contingency and vulnerability during the pandemic included, thus, marks out an experiential field inhabited by individuals and groups holding a variety of disability identifications, if any. It offers the possibility to link the expertise derived from pre-pandemic lived experience of disability into an expansive pool of lived experience of body-minded contingency and vulnerability. It also contributes to explaining why the commentary issued from a perspective of the lived experience of disability during the pandemic was in tune with the widespread lived experience of bodyminded contingency and vulnerability that defined pandemic times. It did so, I would argue, precisely because it recognised as familiar both the unequal distribution of healthcare inequalities and socioeconomic hardship that characterised the pandemic conjuncture and the attempts to sustain and build community in conditions where “normal” face-to-face interaction was precluded.

The critical edge possessed by commentary on the pandemic produced by disability theorists and activists derived from the connection between theory and lived experience of disability in ways that lend support to Lois McNay’s recent engagement with the nexus between theory and lived experience. McNay traces out the possibilities for critique of oppression this encounter opens up, and the intersectional, situated, and anti-essentialist framework within which this critique unfolds: For McNay (2022, p. 7), “theorizing from experience” is an approach that “affirms the pivotal importance of the lived reality of those directly affected to an unmasking critique oppression.” This unmasking starts from within heterogenous life-worlds to produce a “wider, multivalent or intersectional account of power”; its aim is not to posit an “original truth of oppression, but to render critique alive to latent, unrecognized, or emergent dynamics of power that often fall below the threshold of public visibility” (McNay, 2022, p. 9). The visibilisation of “emergent dynamics of power that often fall below the threshold of public visibility,” and of emergent understandings and practices that undo these dynamics, is precisely what was performed during the pandemic by perspectives rooted in the lived experience of disability.

Significantly, however, this lived experience shaded into the proliferation of life-worlds of bodyminded contingency and vulnerability generated by the pandemic. A continuum could be imagined between those of us who experienced bodyminded contingency and vulnerability for the first time and those of us who had already been inhabiting ill or crip bodyminds. Speaking from the perspective of the former, medical humanities theorist Felicity Callard reflected upon the epistemic disruption and expansion allowed by the lived experience of thinking from a sickbed in pandemic times—an epistemic experience and reality that she describes as separate from those pertaining to the sphere of health. She said: “What we perceive, and how we think, depends on where we are and how our body is positioned. In thinking about epidemic time, I want to think from a body that is positioned on a sickbed” (Callard, 2020, p. 728). The ways in which Callard’s positionality was critical as much as it was embodied exhibited the features proper to a phenomenology of impairment that, according to Jonathan Sterne, furnishes a “critique of naturalization” from a perspective defined by “contingency and situatedness” (Sterne, 2021, p. 11).

When the insights generated by crip lived experiences of the pandemic are concerned, manifold directions of inquiry emerged to tease out the relevance of disability politics to the injustices and potential for emancipatory change that marked pandemic times. The epistemic possibilities afforded by crip lived experience allowed an appreciation of how the pandemic offers a privileged lens through which to denounce the differential disposability of life. Starting from the fact of high death rates of disabled people and seniors, disability theorists denounced how Covid-related deaths were the result of populations having been made vulnerable by socio-economic relations and structures. Within an anti-essentialist and intersectional framework, Tremain (2020) expanded the parameters of critique to contend that “vulnerability isn’t a characteristic that certain individuals possess or embody. Like disability, vulnerability is a naturalized apparatus of power that differentially produces subjects, materially, socially, politically, and relationally”; within this framework, “it is by and through the contingent apparatus of vulnerability and other apparatuses that certain members of the population are vulnerableized” (Tremain, 2020). In a similar spirit, contributors to the I Human blog denounced how “who lives and who dies then during this pandemic is not just a matter of biology, but a fundamentally (bio)political matter” (Ktenidis, 2020) and how the societal devaluation of certain categories within the population provided the basis for their “vulnerableization” (Tsakiri & Mavrou, 2020). Ignagni et al. (2020) captured through the hashtag #ICUEugenics dynamics whereby “disabled and chronically ill people are being viewed as vulnerable, potentially expendable, and a lower priority, when access to life-saving healthcare and medical equipment are limited," and situated their analysis within a wider intersectional framework attuned to "the amplification of this frame of disposability along interlocking markers of marginalization." Importantly for the discussion of this article, Rice et al. (2022) contrasted the violence of medical triage protocols in Canada with the possibility of lively worldmaking carried by digital story-making.

Indeed, oppositional critique contributed by disability theorists and activists was fundamental for unpacking the ways in which proliferating lived experience of bodyminded contingency and vulnerability had made more readable, within the wider society, what had been hitherto occluded disability perspectives. First, the contestation of processes of devaluation was put forward as simultaneously speaking to wider dynamics and situated within the confines of disability politics and history. As Wong (2020) put it:

> In this critical time, when scarcity is a reality, you see the hierarchy. Certain groups are valued over others. This is the world that so many disabled and chronically ill people already live in. Our lives are still seen as expendable. Now the magnitude is much greater.

Secondly, the fact that the pandemic upended the illusory power of ableism was theorised as significant for society at large, not just for disabled people. As Altermark (2020) argued, also on the I Human blog, "our societies are confronted with the fact that bodies are fragile and open to injury. As a result, ableist ideals of self-sufficiency and self-mastery suddenly appear as illusory." Third, a critique of the individualistic framing characteristic of the discourse of pandemic governance was performed as an entry point into the delineation of forms of crip world-making grounded in opposite logics and relationalities. As Schippers (2020) noted, "the current public health measures are rooted in a merely individualistic approach, as reflected by its main feature 'social distancing'" and developing a "counterstory of solidarity" is what "will keep the (disability) community alive in this time of crisis." Fourth, the call for accessible structures to be embedded within all forms of practice was voiced as key for identifying the bases of alternative forms of social organization. Commenting on how the pandemic had witnessed the development of a degree of commitment to accessibility that disabled people had been advocating for already, and the risk for this commitment to lapse as soon as a post-pandemic moment would be entered, Wong (2020) reflected:

> My hope for coming out of this pandemic is that we don't return to the status quo. Many don't realize that "normal" was actually not great for a lot of people. Just because all of the nondisabled people go back to work—or to Burning Man, or to Coachella—that doesn't mean we should stop thinking about accessibility.

If, as Goodley et al. (2021, p. 33) suggest, "living through a geopolitical moment where many people are dealing with matters of life and death inevitably raises existential questions"—and they go on to question "what is it that we want…how might disability disrupt normative desires? How might we desire disability?"—then Wong's and Schippers' reflections indicate the extent to which the alternative order of accessibility and solidarity that perspectives rooted in crip lived experience called for during the pandemic is what may make crip worlds desired in post-pandemic times.

## 3. Crip Utopias in Pandemic Times

At the start of the pandemic Ignagni et al. (2020) speculated that "Covid time might allow a particular kind of crip world making that engages crip practices that may have seemed impossible five weeks ago." This becoming possible of the seemingly impossible indeed panned out as online spaces structured around multiple access needs flourished in ways that materialised the Blochian conception of "concrete utopias," or "collective movements" towards the materialization of emancipatory futures "in the here and now" (Dinerstein, 2017), as this section will explore. Titchkosky (2011, p. 4) argues that "access not only needs to be sought out and fought for, legally secured, physically measured, and politically protected, it also needs to be understood—as a complex form of perception that organizes socio-political relations between people in social space." Since online meetings became the main form of participation and community building during lockdown, access was the main form of perception underpinning their design and operation, thus turning them into a microcosm for the alternative order of accessibility and solidarity that underpinned community building during the pandemic.

In particular, the organisation of these meetings to meet the participants' diverse and changing needs since the first lockdown entrenched access as a form of perception that operated as a fundamental lens through which to "see" each other's needs and dignity. In so doing, it conjured the "access intimacy" that Mia Mingus talks about; namely, the feeling that one's access needs and those of others are not only understood but welcomed as belonging within a given space. Access intimacy was what, during the pandemic, brought people close as the tool that most effectively "builds and deepens connection" (Mingus, 2011). Turning the perspective of a crip lived experience on the development of access intimacy in online meetings during the pandemic would read it as constituting a form of crip politics aimed at remaking the world in more inclusive directions. It would also value the role of lived experience of bodyminded vulnerability and contingency during the pandemic as having possessed "intrinsic as well as instrumental value" in bringing to the table a specific form of experience around which to "rebuild our systems and structures" (Sandhu, 2017, p. 123).

Indeed, the materialisation of emancipatory futures through the reorganization of collective spaces around multiple access was inseparable from the dispersal of bodyminded contingency and vulnerability across society during the pandemic. The alternative realities, rhythms, perceptions and life-worlds that our crip life-worlds have always been entangled with had finally found resonance with collective realities that could include but were not confined to the space of a disability identification. The merit of lived experience of pandemic bodyminded contingency and vulnerability in making these alternative realities come true was captured by medical humanities scholar Monica Greco. Greco (2020) maintained that seizing the crisis that the pandemic constituted originated from an oppositional and embodied assertion of the epistemic validity of the knowledge produced by lived experiences of illness. She reflected:

> So here we find ourselves, at ground zero, observing the experience of illness and the pandemic as if our lives depended on it. The "lay perspective" and stories of sickness acquire new meaning, new status, a new kind of relevance....The crisis must be seized, and not wasted.

Greco's anticipation of radical change as brought on by the owning of and acting upon our lived experience of illness, and as something that already exists, evokes utopian thinking of the Blochian kind, where "utopian" indicates not something abstract but something emerging from "the contents of...most immediate nearness" that "still ferment entirely in the darkness of the lived moment" (Bloch, 1986, p. 12).

In seeking to rehabilitate utopia from wishful thinking into the ground for a world-changing practice operating in the present, Bloch maintains that:

> We need the most powerful telescope, that of polished utopian consciousness, in order to penetrate precisely the nearest nearness. Namely, the most immediate immediacy, in which the core of self-location and being-here still lies, in which at the same time the whole knot of the world-secret is to be found. (Bloch, 1986, p. 13)

The perspective of crip lived experience can function as a telescope through which to grasp the organisation of online spaces around multiple access needs as a form of crip politics that belongs within the order crip utopias. Crip utopias—from Mingus' (2015, p. 118) imagination of the "Unperfects" building, a city in which it was possible to live "with pride and ease," to Piepzna-Samarasinha's (2019) celebration of a disability justice community that has long "dreamed new ways of creating and accepting care as a pleasure, not a chore"—are always set against a world where "disability is unwelcome, its presence in utopia" is an unsettling reality (Smith, 2021). It is in this way that thinking towards the future through the lens of crip lived experience becomes a conduit to seeing how survival, both individual and collective, "is hopefully what's next" (Piepzna-Samarasinha, 2020). If for Bloch (1986, p. 8) utopian thinking is "directed towards changing the world and informing the desire to change it," crip utopian thinking possesses a collective orientation that makes visible the collective realities that emerged out of widespread bodyminded contingency and vulnerability during the pandemic.

## 4. Dismodernist Revolutions for (Post-)Pandemic Times

The crip utopias of accessibility that I had encountered in online meetings and learning groups during the pandemic materialised responsiveness to my access needs that I had never encountered in life as a crip person, researcher, or teacher (only as an activist). Most importantly, it was not only the exigencies of my crip bodymind that were being accommodated. Access intimacy was fed by the simultaneous welcoming of myriad other access needs within the design and management of online spaces. In pandemic times, the principles of universal design that I had sought to apply in my teaching practice were being employed as matter-of-fact technologies for building community. Whether we identified as ill or healthy disabled or unhealthy disabled, during the pandemic collectivized life-worlds of bodyminded contingency and vulnerability were what provided a starting point for remaking society in its entirety. If "any crisis asks questions of common sense...[it] exposes the problems with existing arrangements, provokes responses that were previously unthinkable and collectively reminds us that all that appears to be solid can very easily melt into air" (Parker, 2020, p. 8). The pandemic was a crisis that still offers potential for the remaking of our worlds precisely on the basis of the crip utopias it witnessed. The fact of the pervasiveness of bodyminded vulnerability and contingency within pandemic society is captured by Davis' famous description of the world we inhabit as one in which "we are all nonstandard, and it is under that standard that we should be able to find the dismodernist ethic" (Davis, 2002, p. 32). Davis' work is crucial for building expansive conceptions of disability, attuned to the access intimacy that during the pandemic operated as the ground for crip utopias of accessibility to develop in online spaces. For this reason, I suggest, the world-changing power that pandemic crip utopias and lived experience possessed is usefully envisaged as having been rooted in their operation as "dismodernist revolutions"; namely, as a re-organisation of everyday practice and relations that transforms a society by undoing the boundaries that separate the sick and the crip from the healthy and the abled.

Lived experience of widespread bodyminded contingency and vulnerability during the pandemic unsettled these boundaries by naturalizing understandings opposite to those that define "ontologically violent messages" (Liddiard, 2020) such as the notion of "risk group" that reassured "'normal' people that someone else will die" and that individualized risk to protect the "ableist fantasy of independency and full functioning" (Altermark, 2020). This points to the need for an emancipatory perspective rooted in crip lived experience to start with, but reach beyond, lived experience of illness and disability to challenge power and imagine different worlds. To grasp its operation what is required is what Goodley et al. (2021, p. 35) call a "bifurcated analysis" that acknowledges the "possibilities offered by disability to reshape and re-fashion the human (crip ambitions) while at the same time asserting disabled people's place within common humanity (normative desires)." This perspective significantly predicates a form of critique that, by drawing on interdisciplinary and intersectional orientation, starts but does not end with disability.

This perspective resonates with Ignagni et al.'s (2020) reflection that, on the one hand, it is easy to think that, during a pandemic, "we are all a little bit crip, [that it] is [easy] to assert that we are all living in crip time now, as we zoom into meetings, work from home, and prioritize comfort over maintaining an ableist level of professionalism"; on the other hand, "Covid time is not the same as crip time. Covid time is emergency time that must be endured rather than settled into" (Ignagni et al., 2020), as it is defined by unequal vulnerableization. Covid time was crip time because it was "polyrhythmic" (Kafer, 2021, p. 15) and thus incompatible with clock time and the temporalities of normalcy; it was also crip time because it provided the basis for imagining the future as crip in the expansive dismodernist sense by overturning imaginaries in which "the very absence of disability signals a better future" (Kafer, 2013, p. 2). Davis' concept of dismodernism grasps both the vulnerableization to which people are differentially exposed and the possibility for re-making the world along lines of support and solidarity by starting from an understanding of the world as a space in which "impairment is the rule, and normalcy is the fantasy. Dependence is the reality, and independence grandiose thinking" (Davis, 2002, p. 31). While differential vulnerableization defines both pandemic and non-pandemic times, crip utopias during the pandemic proliferated "prototypes" of experience that "disassemble the regnant fantasies of wholeness and completion" (Davis, 2013, p. 16) and, in this way, materialized a dismodernist re-organisation of society.

This dismodernist re-organisation of society created an ideal scenario in which to put to work the power for critique as well as coalition building that crip identification affords. As Kafer (2021, p. 15) notes, crip operates as "as a word, an orientation, an affiliation, a feeling" that has dragged many of us into a community we did not know existed, were not sure we wanted to join, "but needed, desperately." It also continually forces reflection on which bodyminds we include in our crip politics and see as belonging within its imagined futures. This, in turn, prompts the question: "How do my failures to imagine others as crip restrict the coalitions to come?" (Kafer, 2021, p. 416). Deploying the insights derived from the lived experience of disability to examine pandemic lived experience of bodyminded vulnerability, contingency, and the societal change these demanded, it becomes possible to approach pandemic lived experience as having sparked possibilities for crip world-making practices that spilt over the abled/disabled and healthy/ill divide by superseding its very ontological underpinnings and by delineating a dismodernist field of relationalities.

The crip utopias of accessibility that developed during the pandemic indexed the unfolding of dismodernist revolutions in Eva von Redecker's sense of the term. Von Redecker (2022, p. 1) understands "revolution" as disentangled "from the inevitable associations with the storming of the Bastille" and as associated with "a form of radical change that is initiated in the interstitial spaces of a social order and that leads, through lengthy processes of transfer, to a new constellation." This sense of revolution captures how crip utopias and the lived experience that defined pandemic times operated by "rehearsing the future and repurposing the present" to generate new constellations in which "the unthinkable comes to be taken for granted" (von Redecker, 2022, p. 1). This dismodernist form of interstitial change is defined by a "path-breaking persistence" that holds hope for persistence in (post-)pandemic time but only on the condition of creating the infrastructure necessary to sustain crip utopias beyond the delimitation of "pandemic times" defined by governance (von Redecker, 2022, p. 20).

## 5. Crip Lived Experience and (Post-)Pandemic Infrastructural Sensibilities

A crip lived experience perspective yearns for and contributes to bringing about access intimacy through a politics of access that builds community as a form of collective survival (Piepzna-Samarasinha, 2018). This is what constituted the sensibilities that underpinned and were nourished by the unfurling of crip utopias and dismodernist revolutions during the pandemic. As this section will explore, they can be defined as infrastructural because they tied collective survival into the creation of infrastructures that would support it, while taking responsibility for this creation. Pandemic infrastructural sensibilities of this order resonate with a conception of natural disasters as preventable "by reducing vulnerabilities" (Kelman, 2020, p. 154). From a similar perspective, Bratton argues that the pandemic has made urgent the need for a "positive biopolitics" that takes responsibility for devising the "governmentality through which an inevitably planetary society can deliberately compose itself" (Bratton, 2021, p. 12). In other words, he calls for the emphasis to be placed on how society "knows itself, models itself, and attempts to compose, organize, and care for itself through various mechanisms, be they public, personal, private, or scientific" (Bratton, 2021, p. 2). The flourishing of self-organised initiatives to re-compose society through online gatherings that I have discussed through the lenses of crip utopias of accessibility and dismodernist revolutions is a prime example of this. The centrality of access intimacy to their constitution lends support to a theorisation of the pandemic as having made visible the entangled nature of human existence. As Martin Parker notes, "Covid-19 has also allowed us to see infrastructure more clearly….Human beings have made a world that is profoundly entangled" (Parker, 2020, p. 3). For Bratton, the biological in the infrastructural spawns a conception of entangled vulnerableization that views "society as epidemiology does, not as self-contained individuals entering into contractual relationships, but as a population of contagion nodes and vectors" (Bratton, 2021, p. 33). This in turn calls for the emphasis to be shifted "from personal experience and toward responsibilities couched in the underlying biological and chemical realities that bind us" (Bratton, 2021, p. 34). Within this framework, awareness of "our common biological circumstance" should underpin sensibilities that "override, other subjective cultural divisions and associations" (Bratton, 2021, p. 33). It was precisely the common biological circumstance of the lived experience of bodyminded contingency and vulnerability that made necessary, and possible, the development of crip utopias of accessibility and dismodernist revolutions during the pandemic.

Pandemic crip utopias of accessibility and dismodernist revolutions can in this sense be re-visioned as having been woven together by infrastructural sensibilities of solidarity and care, and as infrastructural phenomena that belong within the order of the posthuman as it has been discussed in critical disability studies as a "complex fusing of human and non-human entities that mark the 21st-century citizen" (Goodley et al., 2021, p. 30). In parallel to Bratton's view, this view of the posthuman is predicated by an ontological perspective which places a focus on how "materiality and immateriality are entangled with one another" and, as a consequence, on how "human beings (and the non-human entities which we come into contact with) are capacitated through their interconnections" (Goodley et al., 2021, p. 31). It also yields a political perspective that works towards "a convergent model of social justice" to explore "the productive alliances, sustainable assemblages and affirmative connections that exist between humans and non-humans'' (Goodley et al., 2021, p. 45). It is this political perspective that valorises the politics of access that generated crip utopias of accessibility and dismodernist revolutions during the pandemic as both infrastructural and, fundamentally, crip.

## 6. The Lived Experience at the Core of (Post-)Pandemic More-Than-Social Models of Disability

A crip infrastructural vision for (post-)pandemic times speaks to a further aspect of Bratton's reflections around the place of the biological within infrastructural models. To capture the ways in which the biological operates a disruption of normalized patterns of organizing life, Bratton develops the concept of "the revenge of the real." Through this concept, he wants to capture how "the most difficult lessons to be learned are those that come when reality—in the form of a virus, of our vulnerability to it, of our inadequate governing responses to it—crashes through comforting illusions and ideologies" (Bratton, 2021, p. 1). The pandemic effected "a revenge of the real" as a conjuncture which forced us to confront the "real" as a "non-negotiable reality that upends comfortable illusions, no matter how hard some may try to push back with their chosen form of magic" (Bratton, 2021, p. 3). Situating crip utopias of accessibility and dismodernist revolutions within this framework illuminates the political flourishing that the disruption of normalcy that Bratton reads as "a revenge of the real" allows.

The idea of "a revenge of the real" carried by biological intractability particularly resonates with materialist conceptions of disability that seek to rescue it as an "active, dynamic, and substantive materialization" (Mitchell et al., 2019, p. 4) by attending to the logic of trans-corporeality by which it is animated. Alaimo proposes "a trans-corporeal paradigm that interconnects disability and environment," anchored by the disability sense that "one is always immersed within that which must be reckoned with" (Alaimo, 2017, p. xv). From this perspective, for example, environmental hazards and disability appear not as "individual health problems of bodies or environments gone astray but rather [as] shared continuities of each other" (Fritsch, 2017, p. 375). Disability is entangled, on this view, in a space of trans-corporeal "interconnections between the human and the more-than-human world" (Alaimo, 2010, p. 2) that are "not merely social but material" and that crucially unfold the "landscapes of interacting biological, climatic, economic, and political forces" (Alaimo, 2010, p. 2). This perspective can be read as infrastructural as it conceives of disability as a trans-corporeal phenomenon defined by participation in the creation of "alternative biologies, alternative subjectivities and viable nonnormative modes of life (human, animal, organic, inorganic)" (Mitchell et al., 2019, p. 2). The possibility for this perspective to contribute to radical change resides in its apprehension of embodiment's "productive, proactive expressive capacities" (Mitchell et al., 2019, p. 4), as what allows us "to inhabit the world as vulnerable, constrained, yet innovative embodied beings" (Mitchell & Snyder, 2017, p. 371). Crip utopias of accessibility and dismodernist revolutions during the pandemic sedimented into an alternative organisation of social relations with multiple attempts to inhabit the world through the lived experience of bodyminded contingency and vulnerability.

It is in this way that their constitution resembles that which Papadopoulos associates with more-than-social movements. Papadopoulos (2018, p. 1) uses the term "posthuman culture" to refer to a "decentering of the human (and the humanist subject and its politics) into its relations to other living beings and the material world." He introduces the concept of "more-than-social movements" to propose an alternative to social movements which, on his view, fail in proportion as there is not an adequate "infrastructure that could hold together and protect the communities and perpetuate and multiply the effects of their actions" (Papadopoulos, 2018, p. 2); to correct this flaw Papadopoulos develops "an ontology of community and infrastructures of communal connectivity" (Papadopoulos, 2018, p. 2) that refer to "something much greater than social relations" (Papadopoulos, 2018, p. 3). Crip utopias of accessibility and dismodernist revolutions during pandemic times were precisely rooted in infrastructures of communal connectivity that were cripped by their emergence in response to the need to build collective survival out of a shared bodyminded contingency and vulnerability. In this way, the autonomous experimenting with worlds and with "the materiality of life" (Papadopoulos, 2018, p. 3) that attended the formation of crip utopias of accessibility and dismodernist revolutions performed the hallmark function of more-than-social movements to "change the materiality of the lived spaces and the bodies, human and nonhuman, of communities" (Papadopoulos, 2018, p. 3).

It is on this basis that they call for analysis through the lenses of critical disability studies concerned to attend to the biological core that lies beneath the social model of disability. In an attempt to upgrade the traditional social model of disability there have always been proposals in disability studies to build "a conceptual model that will enable an appreciation of difference and embed the plurality of lived experiences into a frame of action" (Owens, 2015, p. 388). An early example of this was Swain and French's (2001, p. 569) "affirmation model," which addressed "the limitations of the social model through the realisation of positive identity encompassing impairment, as well as disability." Another early example was Crow's (1996) "renewed social model of disability," which aimed to encapsulate "the total experience of both disability and impairment" by bringing back impairment for analysis alongside social disablement. Common to these explorations was the intent to contest the dualism that the traditional social model of disability originally set up between biological impairment and socially-constructed disability (or disablement), and to attend to the plurality of lived and embodied experiences of illness and non-normative bodyminds in their socio-economic, cultural and political contexts through the re-insertion of "an embodied ontology" as an ideal starting point for disability studies (Shakespeare & Watson, 2001). A re-connection of the biological and the social through a "more-than-social model of disability" captures their interconnection in the formation of crip utopias and dismodernist revolutions that emerged out of the lived experience of bodyminded contingency and vulnerability in pandemic times. It also spotlights lived experience of bodyminded contingency, vulnerability and inaccessible worlds as the core from which crip modes of world-making can originate in post-pandemic times. Within a more-than-social model, disability is not only defined by its socioeconomic, political, and experiential constitution but it is apprehended as a phenomenon itself constitutive of both individual life-worlds and collective ones.

## 7. Conclusion

In retrospect, 2020 marked a pivotal threshold in the history of disability; one in which the Covid-19 pandemic dispersed bodyminded vulnerability and contingency unequally across society, opened up space for a reconfiguration of realities and understandings of health and illness, and fostered possibilities for de-centering conceptions of permanent able-bodiedness within these. At the time of revising this article, August 2022, this reconfiguration seems to be crumbling under the pressure of the lifting of all government measures that sought to contain the spread of Covid and, in so doing, defined the contemporary conjuncture as a pandemic. It also seems to be crumbling in the face of widespread enthusiasm for the return to ways of living according to the rules of normalcy that this lifting has allowed. Mingus (2022) expressed "disabled rage" at the "stunningly self absorbed levels of abled entitlement" in January 2022, and declared: "We will not trade disabled deaths for abled life. We will not allow disabled people to be disposable or the necessary collateral damage for the status quo" (Mingus, 2022). In what has been declared the post-pandemic times, the "eugenic abandonment" Mingus talked about has been normalized and cherished as part of the new normal.

Crip lived experience developed before or during the pandemic affords the tools and perspective needed to challenge the post-pandemic return to normalcy by refusing to let the re-organisation of life and relations around access needs that was mainstreamed during the pandemic recede to its pre-pandemic exclusively crip dimension. As disabled people, it is in this refusal that we can take leadership, and a more-than-social model of disability allows us to do so by rooting disability at the centre of any crip world (re-)making endeavour. A powerful example of the stance we can take is provided by Tischer's (2022) recent call for "safer eventing" to remain a priority: This is fundamental for a variety of reasons, including the need to guarantee the safety of self and attendees and because hosting in-person events conveys the "implicit message that the pandemic is over and things are back to 'normal'" It is equally important because the return to in-person modes of finding community causes many of us "grief in being sent back to the margins" where attending events "is tiring, stressful, and expensive," and fear that "the ease that was the saving grace of the last 2 years is going to inexorably dwindle away."

The power to resist this dwindling away resides, whether in pandemic or post-pandemic times, in the owning of our lived experience of disability or bodyminded contingency and vulnerability as possessing a revolutionary potential for remaking the inaccessible worlds that we live in. This is because the reconfiguration of realities and understandings of disability and bodyminded contingency and vulnerability occasioned by disability as much as by the pandemic cannot be decoupled from the potential to create accessible collective realities and spaces. A more-than-social model of disability provides the theoretical framework for grasping as much because it identifies the biological materiality that infuses lived experiences of illness and disability as what contains the power to disrupt social structures and received understandings. Locating crip matter at the core of (post-)pandemic more-than-social movements allows us both to centre within these a disability perspective and presence, and to contribute to debates around models of disability a position that centres the world (re-)making power of bodyminded non-normativity as well as vulnerability and contingency.

On the one hand, thus, to value how pandemic lived experience and crip utopias of accessibility unfolded as dismodernist revolutions can be a useful starting point for the development of more-than-social models of disability. On the other hand, carrying forward the legacy of these utopias and revolutions involves a refusal to let them recede as a post-pandemic pursuit of normalcy asserts itself. One of the legacies of the pandemic might be the appreciation of how staying with the uncomfortableness that crip lived experience brings is entangled with sharing it with others, with re-encountering it through other bodyminded lived experiences, and with collectivising the myriad alternative realities it originates. Sandhu (2017) argues that owning lived experience may place us in a position to change the world for the better. From this perspective, the emancipatory possibilities afforded by crip lived experience and pandemic lived experience of bodyminded contingency and vulnerability may just reside in the epistemic revolutions that they animate when we turn outward, armed with new understandings of our world (re-)making power, to create crip post-pandemic worlds, with others.

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## Conflict of Interests

The author declares no conflict of interests.

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Article

# Putting on Intersectional Glasses: Listening to the Voice of the Vulnerable

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**Abstract**
Many share the concern that the Covid-19 pandemic has had devastating impacts on the vulnerable who are already disproportionately at risk of social exclusion. The health-related risks that the pandemic entailed and the challenges that resulted from the associated measures have led to new vulnerabilities for specific groups such as persons with disabilities, persons from a (forced) migrant background, and women/girls. This article will discuss the complexity of the multiple vulnerabilities during the Covid-19 pandemic by relying on data collected from immigrant women with disabilities. To this end, data from two women with disabilities who are members of the historically marginalized Turkish immigrant group in Austria were analyzed with regard to their experiences during the pandemic. Their accounts are analyzed from an intersectional perspective in order to document the effects of peri-post-pandemic measures on the lives of people with multiple disadvantages. The interviews and audio diaries by two immigrant women with disabilities recorded over seven months are used to delve into latent oppression structures and overlapping mechanisms of difficulties embedded in their experiences. The findings show how the multiple identities and struggles of the two women were affected during the pandemic by building upon each other.

**Keywords**
disability; gender; immigrant; intersectionality; pandemic; vulnerabilities

**Issue**
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## 1. Introduction

The Covid-19 pandemic has created global stress and changed the social landscape remarkably. Mitigation measures such as staying home, reducing social contact, school closures, or home office regulations have altered the lives of people all over the world (Kickbusch et al., 2020). On the one hand, these mitigation efforts achieved the deceleration of the spread of the virus; on the other hand, they entailed social, economic, psychological, and health-related consequences (Altig et al., 2020; Gostin & Wiley, 2020; Senjam, 2020). Although the pandemic did not leave anyone unaffected, when compared to the people without disabilities, the pandemic generated greater vulnerabilities and challenges for people with disabilities (Ciciurkaite et al., 2021; Kickbusch et al., 2020; Landes et al., 2020). Depending on their employment, personal relationships, economic situation, gender, or disability status, people with disabilities experienced the pandemic-related limitations in differently disadvantaged ways. However, it is safe to say that the Covid-19 pandemic has affected people with disabilities more negatively than people without disabilities (Armitage & Nellums, 2020; Pineda & Corburn, 2020; Senjam, 2020). In this article, the data retrieved from immigrant women with disabilities show how the pandemic has affected their lives in relation to their disability, immigrant status, and gender separately as well as in an interconnected way.

### *1.1. Disability and Pandemic*

Similar challenges to those that people with disabilities faced during past crises such as natural disasters, outbreaks, and earthquakes (Andrews et al., 2019; Godfrey, 2020) were observed during the Covid-19 pandemic.

Measures and regulations during the Covid-19 pandemic mainly targeted the general public and failed to consider the specifics of people with disabilities. The challenges that people with disabilities faced were due to their disability, but also due to intersecting vulnerabilities experienced during the pandemic. The pandemic showed how different demographic and identity categories (e.g., gender, poverty, and race) magnified the jeopardy for people with disabilities. The intersection of racial trauma (Comas-Díaz et al., 2019), systemic social inequalities (Lund, 2020), material hardships, and poverty (She & Livermore, 2009) was aggravated by the pandemic's harsh consequences.

There were several abrupt structural changes that people had to adapt to in their daily lives, such as wearing masks, isolation, and strict health protocols that were challenging for people with disabilities. In the early stages of the pandemic, concerns centered on ableist health care and the needs of the disabled were neglected during preventative decision-making (Lund & Ayers, 2020). People with disabilities were concerned with the ableist perspectives of health care providers when making clinical judgments. In addition, the infection risk was another stressor for people with disabilities. Several global institutions (e.g., Center for Disease Control and Prevention, United States Office for Civil Rights, United Nations) also mentioned the higher likelihood of contracting the virus and falling sick due to pre-existing health issues as well as the precariousness of their living conditions. Similarly, the mortality rates of people with disabilities were higher than those of people without disabilities (Abedi et al., 2020; Landes et al., 2020; Turk et al., 2020), which may result from a lack of timely and high-quality care or chronic stress.

As Rajkumar (2020) explains, the consequences of the pandemic created a shared trauma that had mental impacts on many. Similarly, several studies (Ettman et al., 2020; Zhang et al., 2020) documented increased anxiety, insomnia, and eating disorders among the general public. Among other shared traumas such as the September 11 attack, the Ebola outbreak, the Tsunami, and the Great Recession, Ciciurkaite et al. (2021) consider the Covid-19 pandemic as the most recent large-scale shared trauma, which makes the pandemic a macro-level stressor for all. As Shakespeare (2006) suggests, people with disabilities experience such shared trauma in a disproportionally drastic way. When the effect of Covid-19 on the whole population is considered, the pandemic is framed as a stressor that can result in long-term health issues and disabilities (Ciciurkaite et al., 2021), which makes it a greater stress factor for people with pre-pandemic disabilities.

The disruption of access to health care services or treatments was another pandemic-related consequence for people with disabilities. Access to hospitals and health care facilities is vital for people with disabilities and chronic diseases. However, the pandemic put a hold on several domains of the healthcare system. At times, hospital visits were canceled and medication could not be prescribed. The sudden discontinuation of required therapies, personal assistance, or support from others left many people with disabilities in a difficult situation emotionally and health-wise. Assistance for body care, but also the care of assistive devices, ceased, leaving several people with disabilities without the equipment required for daily life. Hospital visits were categorized as a high risk of infection, which created fear and a psychological burden on people who could not cancel their hospital visits (Leocani et al., 2020). Both situations disrupted the routine of people with disabilities.

When compared to people without disabilities, people with disabilities more often suffer from loneliness and experience a lower level of social bonds (Emerson et al., 2021; Olsen, 2018). Prolonged social distancing during the Covid-19 pandemic, on the other hand, increased the stress level for all (Lee, 2020; Rajkumar, 2020), but to a larger degree for marginalized groups, who are less likely to have supportive social networks (Goldmann & Galea, 2014). People with disabilities had to go through a long time of isolation and loneliness due to a lack of social interactions. Besides entailing loneliness, social distancing also disrupted the assistance that people with disabilities had relied on. The social distancing guidelines affected the support from either professional workers, volunteers, or family members in a negative way (O'Connell et al., 2020). While some people were left with no support or very limited support, others had to continue relying on professional support knowing that this could put them as well as those supporting them at a greater risk. In both ways, social distancing posed additional challenges and resulted in health-related, psychological, and emotional challenges for people with disabilities.

The financially precarious situation of people with disabilities was another dimension that was severely impacted by the Covid-19 pandemic. As She and Livermore (2009) discuss, people with disabilities suffer from long-term poverty and experience material hardships more than individuals without disabilities. People with disabilities are mainly associated with poor socioeconomic status and several other underlying health problems due to a lack of sources and medical care (Jaggernath et al., 2014). Similarly, disability is associated with exposure to harsher life situations, lack of resources, and more vulnerability to health problems. A lower likelihood of being employed, dependence on expensive assistive technology and medication, and employment in low-paying jobs are some of the factors that put people with disabilities at a greater disadvantage. This economic insecurity of people with disabilities was aggravated by the Covid-19 pandemic due to business closures, shrinking economies, and increasing prices for equipment and medication.

Another factor that put people with disabilities at a disadvantage was access to information. The sudden changes, measures, and stress factors were accompanied by a limited amount of knowledge, most of which could not be relied on, which increased the level of fear and concern among the public. The lack of accessible information about the virus, protective measures, or prevention techniques was an issue for people with disabilities reported from several contexts such as India (Senjam, 2020), Italy (Leocani et al., 2020), and the USA (Landes et al., 2020). The lack of barrier-free information and the excessive focus on the general public rather than specific groups resulted in lacking access to the necessary information regarding regulations, procedures, exceptions, or measures. Furthermore, the situation of immigrants with disabilities was marked with language and cultural barriers. Accessing the required information and remote support through phone or e-mail communication could lead to additional hurdles for immigrants with disabilities who had language difficulties. A lack of language skills or knowledge about the health care system and support services put immigrant communities in a challenging situation and immigrants with disabilities suffered from cultural and linguistic barriers during the pandemic (Geuijen et al., 2021; Piérart et al., 2020).

Gender was another remarkable disadvantage during the pandemic. The OECD's 2020 Risks That Matter Survey showed that the Covid-19 pandemic could be characterized as a "shecession" due to the disproportionately negative effects of the pandemic on women. Several studies (Couch et al., 2022; Nishimura, 2022; Siddiqa, 2020) reported the severity of the pandemic's consequences for women including increased sexual abuse, domestic violence, labor market exclusion, and forced marriage. This longstanding marker of difference and dimension of oppression—gender—intersects mainly with race and poverty, but also disability. The intersection of having a disability and being a woman, as Hancock and Daigle (2021) call it, is a "double jeopardy" for the risk of victimization. Having a disability, therefore, increases discrimination against women, which was aggravated by the risks created by the pandemic.

## 2. This Study

This article reports on a research project in Austria by employing a longitudinal and participatory research design. The research project, Cov_enable, funded by the Austrian Science Fund (FWF) documents the effects of peri- and post-Covid-19 policies and regulations on the lives of people with disabilities. Cov_enable (P 34641-G) tries to understand how the conceptions of vulnerability are experienced and reshaped and how these impact people with disabilities.

Similar to other countries, the Austrian Government implemented the first lockdown in mid-March 2020 to mitigate the spread of severe acute respiratory syndrome. With the first lockdown, harsh measures and rules were introduced, which increased the challenges for persons with disabilities. Globally observed consequences for people with disabilities (e.g., the disruption of therapy and treatment, financial problems, increased stress) have been reported in Austria as well. However, in the Austrian context, some other challenges aggravated the situation for people with disabilities from a migrant background. Although later on, some steps were taken to provide information on rules, regulations, and measures in the languages of the main immigrant groups (in Turkish, Arabic, Serbian/Bosnian/Croatian), the information provided in these languages was very limited. To understand how the Covid-19 pandemic affected the lives of immigrant women with disabilities, the following research questions were recruited:

- How is the Covid-19 pandemic experienced, documented, and shared by immigrant women with disabilities?
- What changes in the lives of immigrant women with disabilities occurred and are expected during the Covid-19 pandemic?

## 3. Methods

Addressing these questions demanded a creative, flexible, but still ethically sound and rigorous research approach. The research strategy in Cov_enable is framed as a grounded theory approach (Charmaz, 2014) that uses an intersectional lens (Bowleg, 2008). Throughout the research process, basic principles of grounded theory methodology such as iterative and constant comparative procedure, theoretical sampling, coding, and memo-writing were applied (Charmaz, 2014).

The participants were reached through an association that supports immigrant people with disabilities in Vienna. After reading the information flyer of the project, they contacted the researcher and shared their willingness to learn more about the project. All steps of the data collection and other details about the project were provided; confidentiality and anonymity of the data as well as of participants were assured by informed consent. One participant was in her mid-20s (henceforth pseudonymized as Elmas), and the other was in her mid-40s (henceforth pseudonymized as Semra). Both arrived in Austria from Turkey as teenagers. While Elmas graduated from a vocational school in Austria and now works part-time (however, not during the lockdowns) at an organization where she counsels other immigrants with disabilities, Semra never attended school in Austria and is unemployed. However, competency in German is still an issue for both of them and both do not feel comfortable speaking German. Both are in wheelchairs and live with their parents.

Intensive interviews wherein a retrospective perspective was adopted to hear their experiences of the first year of the pandemic were the first data collection tool adopted. Later, digital video/audio/written diaries (Bates, 2020) were produced. Participants submitted 4–5-minute audio/video diaries in Turkish twice a month and recounted how their week was over seven months. Participants reported their week by answering questions such as: What does my life look like at the moment? Where did I go? Whom did I see? What made me excited this week? What made me sad? When and where did I feel vulnerable? The data retrieved are presented in Table 1.

As first-order constructs, these diaries offered rich data in the form of highly self-representational narratives of individuals (Bates, 2020). To this end, the data were transcribed verbatim, and the text material was analyzed using grounded theory (Charmaz, 2014) and Bowleg's (2008) intersectionality approach. With an intersectional lens, the patterns and themes were made explicit by exploring how mutual identities intersect and how they relate to social inequality.

The data were coded to interpret the meaning of the values and perspectives that both participants attach to their experiences (Charmaz, 2014), hence assuring that the analytic ideas developed during the analysis were based on the data was the target. The data analysis included a variety of tools such as a preliminary examination of the data to locate the relevance, line-by-line coding, building categories for refinement purposes, and comparing the findings and the accounts. In addition, several writing tools and activities such as mind-maps, notes, diagrams, or clustering were used. During the data analysis, no digital tools or software were used. However, the codes and categories were all kept track of electronically. The lines were coded by asking questions to make sense of what is meant and suggested in a line and what it is about.

In grounded theory, the aim is to define what is happening, as well as to make meaning of what is happening (Charmaz, 2014). Initial coding started with the preliminary data collection. Initial codes are mainly comparative and provisional, and especially grounded in the data. During this process, as Glaser (1978) suggests, the codes were active and alive, which made it possible to go back and forth in the data for constant comparison. Focused coding followed the initial coding to locate the most significant initial codes. Focused coding did not reduce the codes in a statistically significant way, but the codes were handled in a way that asks "what they tell about the world they are embedded in" (Buroway, 1991, p. 281). In the next step, categories were created by looking for similarities and differences among the data, clustering the codes, and using visual drawings. As Kelle (2005) suggests, the categories were developed from the data itself and were not forced. Through categorizing, grounded theory analysis led to an inherent pattern very closely related to the main concern or issue (Halton & Walsh, 2017). However, due to the intersectional perspective, there were several interconnected concerns, and the process of reaching the core categories resulted in more than one category. As the aim was to reach a social phenomenon, it was expected that the data analysis would lead to the development of a central point that explains a bigger part of the data. As Charmaz (2014) suggests, revealing the social process that is studied was the target, and core domains were looked for. As the last step, theoretical coding was performed to raise these core domains to theoretical concepts, which helped to theorize the findings and identify their relationship to the literature.

## 4. Findings

Three major themes emerged at the end of the analysis. The first theme was related to the consistency of being vulnerable as an immigrant woman with a disability. This theme showed how existing oppression was aggravated through the newly introduced measures during the pandemic. The fluctuation of the severity of the measures affected the severity of the patterns of oppression. The second theme was related to the cultural perspective of the Turkish community, which is more protective of/interfering with women/girls and especially women/girls with disabilities. The third theme emphasized the individual struggles during the pandemic as an immigrant woman with disabilities as (self)advocates of the disabled community fell short and did not reach out to the marginalized groups within the marginalized groups. The themes will be accompanied by quotes from the interviews as well as from the video/audio diaries.

### *4.1. Accompanying Vulnerability*

The first theme showed how being vulnerable is a part of the life of people with disabilities, which is a situation that changes over time but never ceases. The concept of vulnerability has different levels experienced by people with disabilities, and especially those who experience an intersection of markers of difference (disability, gender, migrant background). Being vulnerable can be characterized as a fluid (or liquid) that was more visible or invisible, depending on the complexity of the accompanying social situations such as measures during the pandemic. The right or need to be accompanied by

**Table 1.** Summary of the data retrieved.

| | Semra | Elmas |
|---|---|---|
| Period | October 2021–April 2022 | September 2021–March 2022 |
| Photos | No photos | 3 photos |
| Audio diaries | 13 audio diaries | 11 audio diaries |
| Written data | No written data | 3 written diaries |
| Videos | No video diary | 1 video diary |

someone during hospital or doctor visits was differently affected by the measures several times in a short period. The information about the rules of accompanying someone to the hospital was difficult to access. As the updates were published in German, participants' family members or friends had to call beforehand to ask about the current rules. Elmas, who required her mother's help during her regular therapy, explained this situation the following way:

> It was difficult to follow what they allowed. One day yes, next day no. Anyways, I never understood when they talk on the phone [she means their German is hard to understand]. They talk in a way that you do not understand. But you know what, they do it on purpose. So you stop calling. All the time the same thing.

Not having an accompanying person during hospital/doctor visits removed the physical support required in buildings that are not fully accessible for people in a wheelchair. Due to the increased social distancing at the hospitals, there was also no support while getting (un)dressed. Additionally, this regulation also removed the emotional support required during treatment in a medical facility. The routine of going there with their mothers was disrupted and the feeling of loneliness and being unprotected was observed. Elmas has had always difficulties in the hospital she goes to regularly and the presence of her mother next to her had always provided emotional support:

> Everyone was scared of the other people. Especially when they see a woman in a hijab, they do not like it anyways. There was a man who created issues for me all the time. But my mother would shout back at him in Turkish. It does not matter if he understands. But I could not. I am a shy person. My last visit to the hospital was a very bad one. I was all alone.

The persistence of vulnerability in the lives of people with disabilities intersected with several other factors, such as wearing a hijab, not being able to understand German, or having a migrant background. The findings showed that the feeling of being vulnerable or disadvantaged was already well-known to the participants before the pandemic. The difficulties in accessing information, the lack of feeling welcome, and the lack of cooperation by the medical professionals had been experienced before the pandemic. The pandemic had an impact on the severity of these issues and made the situation more unbearable. Similarly, Elmas was explaining her experiences by referring to the comparison of before and during the pandemic:

> Today I was at the tram station and an old tram (not barrier-free) came and I could not get in. No one wants to come closer to you. They avoided helping me all the time, especially men (referring to her wearing a hijab). Now with Corona, everyone is staying away.

### *4.2. Interference of the Family*

The second theme revealed how family dynamics changed during the pandemic. As both women live with their families, the perceptions of the family members were very relevant in terms of how these women experienced the measures, rules, or regulations during the pandemic. Decisions on going out, staying indoors, going shopping, or avoiding social contact were made by the family collectively. This interference, however, was preexisting. Yet, it became more visible during the pandemic as it was justified as a "protective measure" by the family:

> My father was telling me that even the healthy people are falling sick and dying. This virus is very dangerous for me. I know. If I catch it, hmmm not good. Yet, I want to go out to get some air. (Semra)

The increase in interference also reflected the families' ableist perspective and how disability is considered a vulnerability to falling sick. The justification made by the families relied on the assumption that disability increases the risk of falling sick and also the resulting mortality. The participants seemed to agree with this assumption and preferred staying indoors:

> This week, I was home all day. In my situation, it is better to stay home. My brother lives nearby; he buys the things we need for us. I would not be able to carry this stuff anyway. (Semra)
>
> I am keeping myself busy with my hobbies. My parents want me to stay indoors and safe. I would not like to fall sick. In my case, that would be difficult for my parents. (Elmas)

The families of both women compared people with and without disabilities in terms of what the consequences would be if they caught the virus and got hospitalized. Fear of not being taken care of well at the hospital, being discriminated against due to their immigrant background, and having to eat food that may not be halal at the hospital were some of the concerns shared by the families. Although some of these concerns were also shared by the participants, both women were not fully convinced. Semra explained it the following way:

> I told my father: Why are you going out? You are not healthier than me. You are 70 [laughs].

Semra recounted:

> I even got Corona. The fact that I stayed home did not help. My father brought it to us. When you are vaccinated, you have mild symptoms. And I am young.

The extended time spent at home was not fancied by both participants and it strengthened the feeling of emptiness or highlighted the lack of purpose. With the changes in everyday life during the pandemic, the participants had to go through radical changes such as lockdowns where the whole family was at home. Yet, sometimes they were able to have a seemingly "normal" day, just like before the pandemic. However, here "before the pandemic" does not mean "no vulnerability or oppression." Staying home while other family members went out reminded them of the lack of goals in their lives:

> Today was like any other day. I spent the day at home. Yeah, just another day. (Elmas)

> There have been times like this before in my life. I am depressed and I stay home. I do not find any joy. Just stay home and wait for the night. (Elmas)

Their everyday life was monotonous but very structured. It was mainly considered a task that must be completed as soon as possible. The day is marked by errands that follow one another systematically, with most of the day spent without any activity inside the home. Having a disability is viewed as a limitation on the activities one can engage in. This situation creates a feeling of emptiness. The lack of social networks and connections to the outside world other than family is seen as a consequence of a disability. The decisions are made and errands are run by family members and were considered a protective behavior even prior to the pandemic:

> I am anyways used to doing nothing. I do not need to. I am grateful that I live with the family. They do everything. It is always the same. I just sit. It is boring though. (Semra)

> My father told me not to bother about a driving license. He said he will drive me everywhere I want. But he is old. (Elmas)

The pandemic also reduced the number of attempts to change this situation. Attempts to go out and engage in various activities no longer take place as often as before. Reasons include the fear of getting sick or lack of family support and encouragement. In any case, the feeling of aimlessness or having nothing to do is reinforced by the family. Taking responsibility for a person with a disability can have many reasons, but it has a strong impact on the individual. The battle between gratitude and motivation to get involved is challenging. As explained by Elmas, this ends by giving: "Well, what to do? In my case, I think it is the best it can get."

### *4.3. Lack of Community Support*

The third theme that emerged over the seven months is related to the social network and support systems for immigrants with disabilities. As discussed earlier, the rules and regulations were difficult to follow for the participants and the support through telephone was not inclusive and understandable either for them or their families. In such a case, they tried to refer to other community members to access information. However, the specific information on the exceptions for people with disabilities was barely known:

> There is this lady who helps disabled Turks, but she kind of disappeared. I guess, she did not want to take responsibility. What if she says something that is wrong? (Semra)

> We, disabled people, needed help and proper information. I wanted to apply for a job. I did not know how to. My Austrian friend knew. He is working now with no problem. I did not know and there was no help. (Elmas)

Although the Turkish community is connected through several platforms (social media, print media, or the support line of the Turkish embassy), the situation of people with disabilities was not an area where information was provided. The participants tried several times to reach these support services; however, that did not help. It is important to mention that this surprised the participants as well:

> As if we are not Turkish. They help all the time, normally. They did not know anything this time. (Elmas)

> I called the embassy again, they are saying something, but then also saying maybe it is not updated. Check yourself. How can I? (Semra)

Based on the data, it can be concluded that the participants refer to these information channels in their community for other questions including unemployment benefits, family support, health service, and the education system. The lack of attention paid to the disabled community by the Turkish community was mentioned several times by both participants:

> My parents call them for everything and they help all the time. When it comes to us [referring to the disabled community], they are silent. (Semra)

Another important finding related to prioritizing the information channels of the Turkish community and avoiding or not trying to access information provided by the Austrian ministries, municipalities, or Covid-19 hotlines:

> Our embassy [Turkish embassy] knows everything. They help better than Austrians. They understand us. (Elmas)

> I follow the Facebook groups. There are many from our community. People would help and they know everything. Austrians won't help. (Semra)

## 5. Discussion

The findings showed how various dynamics of inequality interact with each other and that they require more attention. As several scholars (Choo & Ferree, 2010; Crenshaw, 1991) discussed, single-axis analyses cannot account for the disadvantages and challenges these participants go through. The lived experiences of these people showed how they are systemically discriminated against and oppressed. Hence, the socially constructed axes of social stratification, such as race, gender, disability, and class, should be examined together to delve into the structured discrimination in society (Bowleg, 2008; Frederick & Shifrer, 2019).

As discussed so far, people with disabilities are often victims of negligence and ignorance in society (Presler-Marshall et al., 2020) and experience intersecting vulnerabilities (Lund, 2020; Piérart et al., 2020), as demonstrated by the findings of Cov_enable. The focus laid mainly on the interaction of gender, poverty, and race should not neglect disability as an intersectional category of inequality (Frederick & Shifrer, 2019; Garland-Thomson, 2005; Gerschick & Stevens, 2016). Indeed, disability is also one of the dimensions of the interlocking inequality system. People with disabilities experience the interplay among different forms of oppression such as poverty, racism, ableism, and classism.

People with disabilities are routinely excluded from the decision-making process. This exclusion sometimes takes place in terms of social policy on people with disabilities (Andrews et al., 2019). They are mainly spoken for and not actively included in the conversation. As seen, being spoken for also takes place at the micro-level, in the family. As the voices of people who are identified as vulnerable are prone to neglect while taking decisions and establishing crisis management, people without disabilities take over the conversation and overshadow the lived experiences of people with disabilities (Lund & Ayers, 2020), such as their families. Advocating for the disabled community, a sign of allyship, should not push marginalized perspectives to the side. This would perpetuate the longstanding devaluation of people with disabilities (Petersilia, 2001). The repetition of this overshadowing process could be observed during the current Covid-19 pandemic, as ableist social norms and policy were the focus of the regulations and measures (Lund & Ayers, 2020).

## 6. Conclusion

The pandemic has increased vulnerabilities, and the life situation of people from historically marginalized groups (immigrant women with disabilities) was exacerbated. The findings showed that the existing vulnerabilities and disadvantages were more visible due to the measures introduced and the intersection of various markers of difference such as gender, migration background, and disability. As Barnartt (2010) discusses, disability and the disadvantages that it entails can be considered a non-stable fluid. They fluctuate over time and they can be more visible or invisible depending on their interactions with the complexity of other social categories and social environments. In this study, the ableist perspective (Shakespeare, 2006) of the families, the protectiveness towards women/girls in the Turkish community, and lived experiences of racism led to new vulnerabilities. The women being spoken to and decided for were justified as support, which turned out to be a sign of passivation for the participants. As Forber-Pratt et al. (2019) explain, not listening to the disabled community and speaking for them does not challenge ableist policies as much as required.

The lack of preparation of the system to provide information in languages other than German was another challenging factor for the immigrant community. However, this seems to be accepted among the Turkish community, as they came up with alternative information channels. Nonetheless, the negligence towards the disabled immigrant community was recognizable. Other areas where vulnerabilities were aggravated included health care and access to disability-specific information. As Ingravallo (2020) points out, banishing visitors from hospitals harmed the people who needed support during their hospital visits, which is mainly the case for people with disabilities. Previously experienced discriminatory practices and lacking physical and emotional support turned hospital or doctor visits into a traumatic experience for the participants, who sometimes ended up postponing the visits.

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## Conflict of Interests

The author declares no conflict of interests.

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## About the Author

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Article

# Vulnerable Students, Inclusion, and Digital Education in the Covid-19 Pandemic: A Qualitative Case Study From Austria

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**Abstract**

Worldwide, more than 1.5 billion students had to switch to distance learning in 2020. Education took place at home, where parents attended to their children, and teachers taught their students in digital mode, while minors were physically and socially isolated from their peers. Concerning the situation in Austria, several quantitative studies expose two central challenges: First, the comprehensive lack of digital infrastructure disrupted (digital) distance learning. Second, the Covid-19 pandemic particularly affected vulnerable students and extended educational inequality. The state of the art emphasizes a lack of qualitative studies demonstrating different perspectives on the educational situation of vulnerable students in general and with SEN in particular during the pandemic. This leads to the following research question: How do professional actors map the situation of inclusive and digital education during the Covid-19 pandemic in Austria? To research this unprecedented situation, four focus groups with diverse stakeholders (teachers, principals, psychologists, and school board employees) discussed their experiences in the school years 2019–2020 and 2020–2021. Data were analyzed according to the Grounded Theory method of the postmodern approach referred to as "situational analysis." The study visualizes various parallel discourses and voices within the situation of (digital distance) learning during the Covid-19 pandemic. The theoretical context of the intersection of inclusive and digital education frames the empirical findings. Central findings relate to missing or discriminatory guidelines and policies, a lack of digital infrastructure, and altered professional-pedagogical support that minimized or disrupted inclusive education during (digital) distance learning.

**Keywords**

Austria; Covid-19 pandemic; digital divide; distance learning; exclusion; inclusive education; SEN

**Issue**

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## 1. Introduction

Due to the Covid-19 pandemic and related policy decisions, more than 1.5 billion students worldwide were forced to switch to distance learning in the spring of 2020 (UNESCO, 2020). Unlike in former educational settings, learning and teaching took place at home. Teachers were supposed to teach in digital mode and guardians were responsible for education and had to accompany their children 24/7. Students were physically and socially isolated from their friends and peers. These pivotal circumstances characterized the next 1.5 years. This situation affected the education system's sustainability as well as students' educational path. The Covid-19 pandemic and its associated systemic inadequacies have demonstratively reinforced social inequities, particularly among vulnerable students:

> Because of the inequitable impacts of the pandemic upon children with disabilities, children from economically poor backgrounds, and second language learners, this international crisis brought renewed

> focus and attention to the pre-pandemic disparities of access to quality education. (Porter et al., 2021, p. 44)

As exemplified by digital distance learning, the reinforcement of social inequality became particularly evident in the 21st-century phenomenon of the "digital divide" (OECD, 2001) during the Covid-19 pandemic. Within this context of social inequalities caused due to and reproduced by the digital divide, this article focuses on the digital inclusion of vulnerable students in general and students with special educational needs (SEN) in particular.

In Austria, 1,142.342 students were affected by the Covid-19 pandemic (Statistik Austria, 2020). Among them, 5.1% were attributed SEN in the spring of 2020 (Statistik Austria, 2020). SEN is the official Austrian diagnosis to promote and facilitate quality education for students with "permanent mental or physical disability" (Republic of Austria, 2022, Article 8). Although Austria ratified the Convention on the Rights of Persons with Disabilities in 2008, only 61% of all SEN students have access to mainstream schools but modified with special curricula, alternative grading systems, and additional courses (Statistik Austria, 2020). More than a third of all SEN students (13,679) still attend segregated SEN schools (Statistik Austria, 2020). Buchner and Proyer (2020, p. 89) conclude that "the move towards inclusion did not lead to a transformation of the dual structure" in the Austrian education system. Moreover, the target group of students with "permanent mental or physical disability" (Republic of Austria, 2022, Article 8) leads to the dilemma that "most policies concerning inclusive education are reduced to the focus of disability" (Buchner & Proyer, 2020, p. 83). Even if ethnic minorities are overrepresented among SEN students, i.e., due to insufficient German language skills, policies do not consider this dimension of social inequality (Subasi Singh, 2020). Buchner and Proyer (2020) emphasize that students at risk often do not have equal access and equitable opportunities as their peers. The SEN framework is lacking a broad understanding of inclusive education that considers all students' needs and capacities regardless of, inter alia, disabilities, gender, and migration background (Biewer, 2017; Florian, 2014; Göransson & Nilholm, 2014).

## 2. State of the Art and Research Gap

An Austrian, German, and Swiss cross-country study showed that students at risk (in German-speaking contexts often subsumed as students with low socioeconomic status [SES], second language learners, and students with disabilities) were affected the most by distance learning (Huber, 2021). In the case of Austria, a quantitative online survey with teachers (n = 2,285) pointed out that students at risk were challenged by high demands, academic underachievement, a decrease in their competencies as well as dropouts (Steiner et al., 2020). Jesacher-Rößler and Klein (2020) surveyed Austrian school principals (n = 532) on school development during the Covid-19 pandemic. Principals of schools in socio-spatially disadvantaged areas were less positive toward distance learning, had lower expectations of their students' academic achievements, and were less strategical in implementing (digital) distance learning than their colleagues. In their study, Kast et al. (2021) focused on "teachers' attitudes and their self-efficacy beliefs about students at risk during the first home learning period" (Kast et al., 2021, p. 1). Teachers' attitudes were less positive toward students with low SES than their peers were. The lowest positive beliefs were found toward students with first languages other than German. Another study surveyed the situation of students with disabilities in (digital) distance learning (Besic & Holzinger, 2020). Teachers (n = 142) from inclusive primary schools reported positive experiences: Students with and without SEN were motivated by using digital media in terms of self-regulated learning. A review of the literature identified three main research gaps: (a) missing theoretical approaches on the intersection of inclusive education and digitalization; (b) a lack of qualitative research approaches toward the inclusive and digital education of students with SEN; and (c) the missing integration of diverse perspectives on inclusive and digital education during the Covid-19 pandemic.

These gaps lead to the following guiding research question: How do professional actors map the situation of inclusive and digital education during the Covid-19 pandemic in Austria?

By answering this question, this article contributes to the scientific discussion on the intersection of inclusive and digital education with a focus on SEN students during the Covid-19 pandemic. The theoretical implications depict the intersection of inclusive and digital education. Aiming at a holistic approach, this article takes account of the perspectives of professional stakeholders across all relevant levels in the Austrian education system: members of the school board, teachers (for special education), school principals, and school psychologists. The data did not include students' and guardians' perspectives due to ethical reasons (German Sociological Association, 1992). All students and especially those with SEN were under enormous psychological and social pressure during the first Covid-19 peak in the school year 2020–2021 (March 2020 until January 2021).

## 3. Theoretical Implications

Relevant terms such as digital inequalities, the digital divide, and digital exclusion are difficult to delineate. All concepts describe the relationship between social dimensions and digitalization. Nevertheless, the concepts differ from one another on a theoretical level. The first wave of research activities addressed social inequalities and the digital divide (cf. Reisdorf & Rhinesmith, 2020). The second wave characterized the impact level and policy-driving research activities under the umbrella term of digital inclusion (cf. Nemer, 2015).

The digital divide is a "gap between individuals, households, businesses, and geographic areas at different socio-economic levels with regard both to their opportunities to access ICT and to their use of the Internet for a wide variety of activities" (OECD, 2001, p. 32). From their research on the digital divide, Kim and Kim (2001) concluded that four dimensions of social inequalities—class, sex, age, and region—mainly affect digital media and literacy. However, they refer to the "multidimensionality of the multiplicity of the digital divide" (Kim & Kim, 2001, p. 81) as a "recursive and thus a dynamic phenomenon where gaps close at one stage and open at another" (Hacker & van Dijk, 2003). Inspired by Kim and Kim (2001), Hohlfeld et al. (2008) identified three levels of the digital divide in educational contexts:

1. Educational infrastructure, like hardware and software, but also access to the Internet and technology support structure;
2. Students' and teachers' use of technologies, application skills, and competencies;
3. Empowering and participating in learning processes.

The first level is widely used by policymakers to argue for successful implementation and challenges the consideration of levels 2 and 3 at the same time (Nemer, 2015). Levels 1 and 2 are preconditions for the third level reflecting on inclusive values such as empowerment and participation (Hohlfeld et al., 2008). It follows the idea of inclusive education as a "process of increasing participation and decreasing exclusion" (Florian, 2014, p. 288) in both offline and digital settings.

Digital exclusion focuses on the nexus of social inequalities and digitalization. It is related to sociological theories of social inequalities (Bourdieu, 1986), but also the capacity approach (Nussbaum, 2006; Sen, 1999). Thus, the concept "should always be seen as embedded in a person's offline circumstances, and for this reason, this analysis of digital exclusion is grounded in the prior analysis of social exclusion" (Helsper, 2012, p. 405). Helsper (2012) developed a theoretical model regarding the link between offline and digital fields of exclusion. She considers four main areas—economic, cultural, social, and personal—that exist both offline and digitally, and correspond with one another. Mediators frame the correspondence between offline and digital fields and can decrease the risk of exclusion. On the one hand, social impact mediators such as access, skills, competencies, and attitudes influence the risk of digital exclusion (Helsper, 2012, p. 411). On the other hand, digital impact mediators such as relevance, quality, ownership, and sustainability influence the risk of social exclusion (Helsper, 2012, p. 415). The interplay between offline and digital levels in consideration of the mediators draws a complex situation that influences digital exclusion. Rahamin (2004) demonstrates that ITC usage can reduce social and digital inequalities, overcome the digital divide, and decrease social and digital exclusion simultaneously.

Digital inclusion is the antonym of digital exclusion. Scholars point out the misconception that digital inclusion only includes access to technology and the Internet for all, as called for in the first digital divide (Nemer, 2015). However, only the interplay among all three levels of the digital divide can promote digital inclusion. "Digital inclusion is the process of democratization of access to ICTs to allow for the [social and digital] inclusion of the marginalized in society" (Nemer, 2015). While digital exclusion mainly focuses on the analysis of social inequalities and digitalization, digital inclusion deals with initiative and solution-based approaches, but also implications for policy-making (Reisdorf & Rhinesmith, 2020)—especially to promote the second and third levels of the digital divide. "The more inserted and participatory into the contemporary dynamics…the faster the people will understand and be familiar with the digital process" (Nemer, 2015, p. 6). Hereby, the enrolment of schools becomes a pivotal point. Next to appropriate infrastructure, it concerns the adaption of digital literacy curricula relating to inclusive values, as well as support for teachers and educators (Lowenthal et al., 2020).

This study is contextualized within the paradigm of digital inclusion. It addresses the research field of inclusive education and analyzes the inclusiveness of (digital distance) learning during the first crucial periods of the Covid-19 pandemic in 2020 and 2021.

## 4. Data Collection and Methodical Approach

The empirical data consist of four focus group interviews conducted during the first and second school closures and returns in April 2020, June 2020, and the mid and end of January 2021. After conducting and analyzing the first two interviews according to the approach by Clarke et al. (2015), focus groups 3 and 4 accentuate the topics of digitalization and inclusion. The diversity of stakeholders aimed to represent different levels of the education system: Eleven teachers and special educators (quotes marked with T1–11) represent the in-service level and the work with students. One school psychologist (P1) provided insights into the in-service level from a multi-professional and interdisciplinary perspective. Two school principals (SP1 & 2) represent the management level, while two policymakers (PM1 & 2) from the school board acted for the administrative policy level. Due to social distancing, the interviews were held online and varied between 1.5 and 2.5 hours. All participants received and signed written informed consents to guarantee their anonymity, confidentiality, and data protection (cf. German Sociological Association, 1992). The recorded sessions were transcribed and prepared for analysis.

The analysis of the data followed the Grounded Theory method and its postmodern approach to situational analysis (Clarke et al., 2015). It aimed to visualize various parallel discourses, structures, and voices within the unprecedented situation of the Covid-19 pandemic. Clarke et al. (2015) developed five different mapping strategies to lift blank data to an abstract level. For the sake of completeness, all five strategies are briefly introduced, but only two strategies are elaborated on in this article.

The first strategy called "situational map" captures all codes in an unordered way to scheme and overview the situation. Mapping strategy 2 is a situational map, but in an ordered way that aims to categorize the codes for the first time (individual human actors, non-human actors, collective human actors, implicit and silent actors, discursive human actors, discursive non-human actors, political and economic-driven elements, socio-cultural elements, historical elements, debates, spatial elements, related discourses). The third mapping strategy is referred to as the "relational situational map" and structures the data throughout the research process, accompanied by constant memo writing (Clarke et al., 2015; see Figure 1). It aims to clarify important elements of the researched situation and in a second step, their relationships (Clarke et al., 2015). The core questions regarding the relational situational map are: Who or what is present in the situation? Who or what is not? The relational situational map presents the eleven main human and non-human elements within the researched situation (light blue circles). Central human actors are teachers, school authorities, students with(out) disabilities, and parents. The data contains narratives about individual actors, i.e., when interviewees underlined their experiences with specific examples. Collective actors appeared with policymakers, and with those identified as students at risk. The non-human elements occurred with digital devices, (digital) learning materials, digital literacy, diversity management, representation in the media, information flow, and social aspects. The coding of the material offered relational structures that frame, affect, define, and influence the (non-)human elements (white circles).

Mapping strategy 4, presented in Section 5, is called "map of the social arena" and focuses on the actors within the relevant social world (Clarke et al., 2015). It bears mentioning that participation in these social worlds is not necessarily voluntary. Several questions guide the creation of this map, which refers to the participants, their work, and commitments, as well as to places of silence and controversies. It addresses the questions: Why are some actors more relevant than others? What elements or discourses are related to it? Based on the relational situational map, we mapped the social arena of inclusive and digital education during the Covid-19 pandemic. Figure 2 presents the topic-related social arena and structures the empirical findings in line with the three following subchapters.

The fifth mapping strategy is the "positional map" (Clarke et al., 2015). This map aims to reveal both the key positions of the researched situation and controversies. The abstract level uncovers occurring positions on important discursive issues but does not represent individuals, groups, or other elements. Hereby, the following question is of interest: Which positions are not considered?

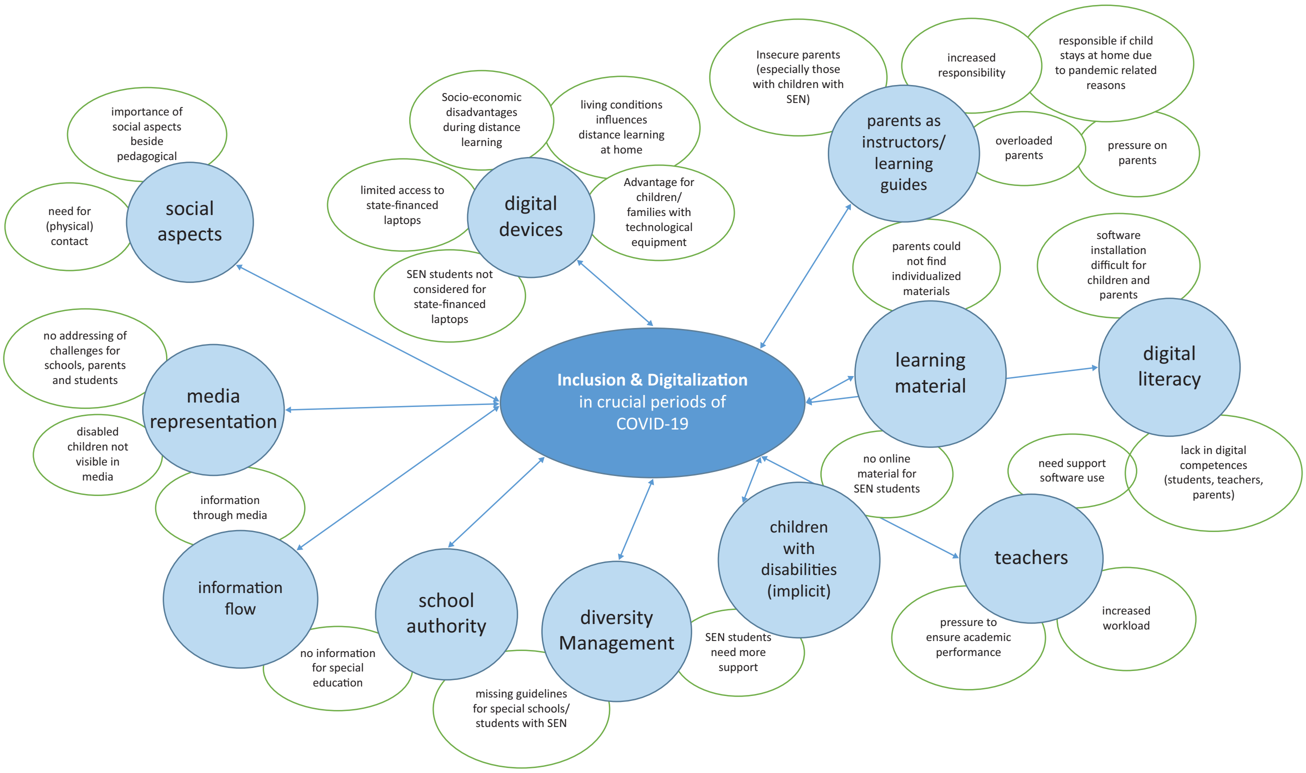

Figure 1. Relational situation map.

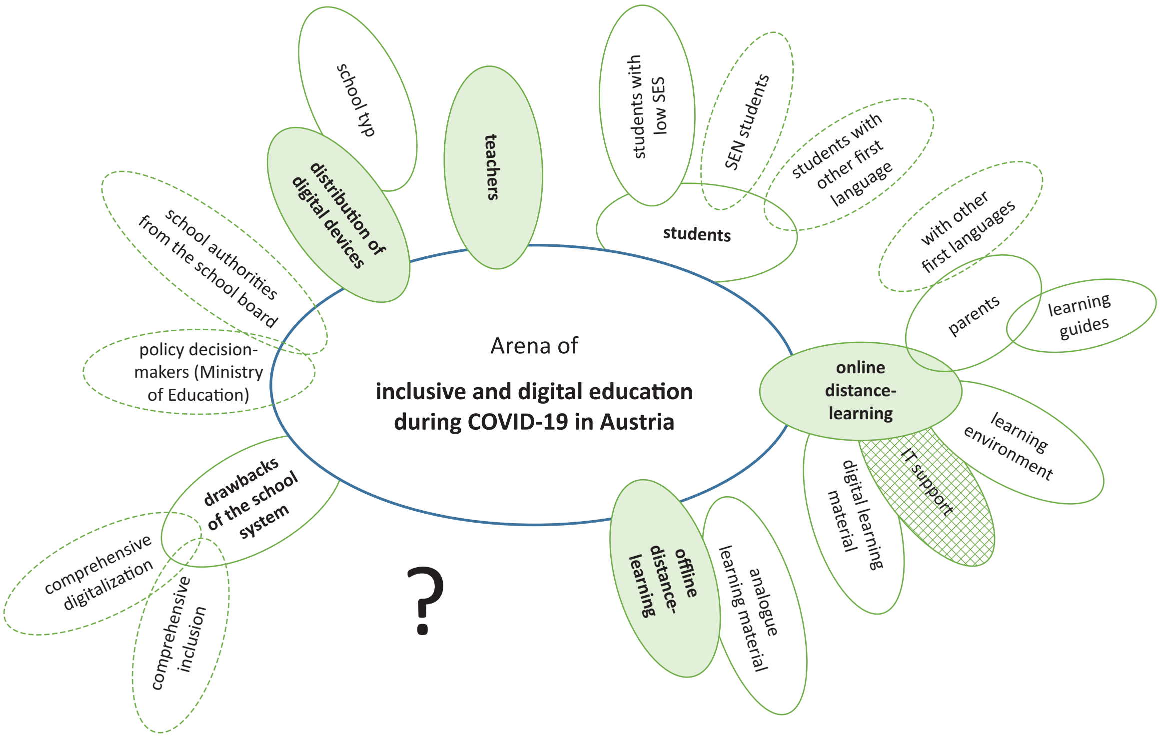

**Figure 2.** Social arena map.

It aims to identify vulnerabilities, but also precarious situations. The positional map will be the next step, but needs yet to be carried out in the ongoing research process. It will include data collected from students and parents to comply with a holistic perspective of the researched situation.

## 5. Empirical Findings

### *5.1. Digital Devices and Their Distribution to (SEN) Students*

(Digital) distance learning depended on the provision of equipment and learning materials in a short time, literally overnight. The distribution of devices passed three organizational levels: the school authority board, the school management at the institutional level, and the in-service distribution. The Austrian government funded "only 5,000 devices for City A" (Focus Group 2, T2). As a reference, nearly 250,000 students attended school in City A in 2020. This means that only 2% of all students received a digital device. As a result, distribution criteria were required, which led to an assessment of who needed a digital device and who did not—e.g., "a smartphone was considered as sufficient infrastructure" (Focus Group 1, T2). The procedure encountered criticism from the in-service actors (Focus Group 2, SP2). Other respondents said:

> The cynicism…that the Ministry of Education buys computers for federal schools. [They] have the opportunity to get computers…and the compulsory schools are supposed to look where they get it from, that's a form of discrimination. (Focus Group 3, T9)

The interviewed policymakers agreed on this self-critically (Focus Group 1, PM1; Focus Group 2, PM2). Furthermore, the quote shows a hierarchical order concerning administrative responsibilities: The Ministry of Education is responsible for all federal schools, while the local school authority boards administrate compulsory schools. Nevertheless, the local school authority boards were administratively relocated to the Ministry of Education in 2019. At the same time, the Ministry of Education is directly responsible for the distribution to federal schools and the distribution regulations for the school authority boards. In-service actors did not differentiate between both actors but assessed the regulations and distribution criteria as insufficient and discriminatory. In particular, the mentioned discrimination came to the fore in the case of SEN schools:

> If school leaders of SEN schools had not actively said, hello, we exist, too. We would not have been given any devices. It's not as if the quality managers [of the school board] are aware of…students with SEN. (Focus Group 1, SP1)

> And we were lucky because I said that our children with SEN are in a secondary school as well. Therefore, we got ten laptops. Because they [the students with SEN] would not have been considered, because SEN means they don't need devices anyway. (Focus Group 2, SP2)

The arena of inclusive and digital education during the Covid-19 pandemic demonstrates how different actors evolve in the situation. Policymakers and school authorities had the power to regulate and influence how inclusive digital learning took place. They were in control of the distribution processes and regulations. In other words, their actions and decision-making influenced the inclusion of students (with SEN) as well as their overall access to education. While the position of policymakers and school authorities as collective actors seemed to be clearly defined from the point of view of the in-service actors, none of the interviewees holding such a position considered themselves responsible or even able to influence the situation. Policymakers and school authorities partly considered students with low SES. It makes the collective actors of students with low SES more visible than the collective actors of SEN students. Students with SEN can be considered silent actors without any political lobby (Focus Group 1, PM1; Focus Group 2, SP2). The discourse still keeps individual perspectives, experiences, and needs in the background. The analysis uncovered that in-service actors like school principals and teachers were the actors gaining active agency in the arena. Only the in-service actors considered (SEN) students' real or assumed needs and perspectives due to their active involvement.

### *5.2. Challenges With Technical and Professional-Pedagogical Support*

Not only the provision of digital devices, but also the elements of digital literacy, maintenance, and IT support impacted (digital) learning during the school closures. The massive lack of digital support infrastructure hindered the implementation of digital distance learning. Thus, teachers managed the technical support on their own with students' private hardware. In the beginning, the implementation of digital learning caused problems because especially younger students did not possess enough digital literacy:

> We installed the apps on the students' smartphones, explained it to them, and were then able to assign tasks from our…devices to the children. (Focus Group 2, T4)

The situation visualizes massive data protection issues due to the usage of private devices:

> During the very first lockdown…there was no offer at all. The teachers organized it themselves and a few already worked with Zoom….Again, the difficulty, because they [a school authority] said…you have to adjust to MS Teams." (Focus Group 4, T10)

Since the school board did not set up any requirements on what software and learning materials to use, teachers had to decide these matters on their own in order to be able to continue teaching. After some weeks, the Ministry of Education published official guidelines. Thus, the in-service actors were forced to adjust and partly reorganize their former tools of choice. This caused a recurring lack of implementation and interrupted digital distance learning. Teachers faced a higher workload than before, which increased due to the additional—but required—digitalization, among other things. The interviewees discussed these elements as underdeveloped and too time-consuming during times of crisis.

The situation was framed by uncertainty, time pressure, lack of digital literacy, and missing infrastructure, which caused a switch towards offline distance learning and the use of analog materials. Again, school authorities and policymakers were considered by others as powerful, but could not define or even manage the situation properly:

> [And] if I want teachers to work digitally, then something like a digital education observer is needed. Then, it needs 1,000 employees who are responsible to make it run. (Focus Group 3, T8)

It underlines the nationwide need for infrastructure to implement digital education and demonstrates the omission of digital infrastructure over the last decade.

In addition to digital infrastructure, another essential support structure influenced (inclusive and digital) education during distance learning: The in-vivo-code *parents as learning coaches* describes this unprecedented situation (Focus Group 2, SP 1). However, the demands exceeded the parental role, tasks, and time resources (Focus Group 2, T4). The analysis shows two main elements: Parents suffered from an overload, and their digital literacy was the most crucial factor for their children's participation in digital distance learning. It bears mentioning that the interviewees tended to generalize their experiences, e.g., when claiming that parents of students with SEN or with low German language skills (Focus Group 4, T11) were less capable of offering support to their children:

> The parents of SEN students…couldn't provide the support. (Focus Group 2, T3)

> When you have parents who don't speak German well, explaining anything on the phone, and telling them that the child has to come to school…now with the school attendance and so on….It is almost impossible. (Focus Group 2, T5)

According to these statements, the lack of parental support caused challenges for digital distance learning. The social background and thus the environment at home were pivotal elements for students' learning and academic performance. There was a common sense throughout all interviews that there is an interdependence between academic performance in (digital) distance learning and the environment at home (Focus Group 3, T9). Other respondents said:

> It was also very different [depending on] which parental home the children come from. So, it differs from the super supported child and the child I had to call twice a week so that any workbook was picked up at all. (Focus Group 2, T4)

This narrative highlights that in Austria, education (still) depends on the social background. The pandemic situation demonstrated these effects extensively.

Regarding challenges with technical and professional-pedagogical support, teachers and parents gained central agency. Due to missing support infrastructures, teachers were responsible for ensuring digital distance learning in cooperation with parents. The collective actors of parents were constructed based on their children's dis/abilities. The interviewees transferred their assumptions about the students' disabilities or language skills onto their parents' abilities. Thus, parents of students with SEN were collectively judged as digitally or linguistically incapable. Again, students were not considered in an active role. Again, the collective actors of policymakers held a passive position, although they were in power and in control of regulations. However, the moment they took charge of the situation through official guidelines, this rejected teachers' laborious efforts and engagement. The interviewees reported that these steps entailed a reproduction of traditional teaching with analog learning materials. It "catapults us back into the 1970s" regarding teaching and didactics (Focus Group 3, T9). All these circumstances indicate serious drawbacks of the Austrian school system that became visible in the arena of inclusive and digital education during the Covid-19 pandemic.

### *5.3. SEN Students Are Obligated to Attend School Physically*

As already discussed, the lack of comprehensive inclusive and digital education preceded the crisis. Ambivalent acts regarding the implementation of inclusive education during the Covid-19 pandemic mirror those omissions. The first policy agenda did not take inclusive education and students with SEN into account. Policymakers had the key role of regulating the situation. However, they provided neither sufficient guidelines nor information "regarding inclusive agendas. Zero. There's nothing at all, it's just overall statements" (Focus Group 1, PM1). Other respondents said:

> Like, for example, they were not able to provide risk guidelines for us to understand which children can go to school and which cannot. What are pre-existing conditions that apply to students and which ones don't? (Focus Group 2)

The missing guidelines, not only for SEN students, led to nationwide suspensions of digital attendance. This forced policymakers to regulate these developments during the second lockdown. As the Austrian Ministry of Education stated in a decree:

> In special education schools, face-to-face instruction continues. Pupils who, for reasons related to the Covid-19 pandemic, are unable to attend or participate in class, may be granted permission to remain absent from class. (BMBWF, 2020, p. 3)

Focus Groups 3 and 4 reflected on this regulation and concluded: "That it is discrimination again, because why can't SEN children study from home?" (Focus Group 4, T10). The narrative argument addresses the collective level. Political agendas assess SEN students and their social environment collectively as unable or not appropriate to stay in (digital) distance learning. Interestingly, school authorities could make exceptions for distance learning at all times during the pandemic (e.g., BMBWF, 2021, p. 2). Such exceptions only applied to the collective actors of students with low SES (Focus Group 4, T11). In the case of students with low SES, the narrative argued that physical attendance compensates for disadvantages due to low SES. This led to contradictory outcomes: On the one hand, the collective actors of students with SES were recommended to attend school in case of insufficient infrastructure or the need for additional support. On the other hand, the collective actors of students with SEN were obligated to attend school. Political agendas did not consider SEN students as individual actors compared to the collective actors of students with low SES. It weakened SEN students' voices and made them even less heard than they already were as collective actors. Again, teachers and school principals took an active role. While policies offered the possibility for students to attend school, school authorities, but also principals, could make exceptions and decide on students' physical participation. While the regulations concerning SEN students were seen as discriminatory, the construction of "SES reasons" (Focus Group 4, T11) as a hindering factor for digital distance learning seems to be less reflected and contributes to discursively framing families and students affected by it.

Nevertheless, the potential of digitalization for inclusive education can be highlighted by the following quote:

> Digitization has made a lot possible in the field of inclusion, or makes a lot possible, so many things, we can't yet imagine what else will be possible. (Focus Group 4, T8)

Interestingly, these opportunities were considered an active part of dealing with digital distance learning. Students with(out) SEN who did experience advantages during digital distance learning are rarely mentioned in the focus groups. It is also worth mentioning that the point of interest lies in disadvantaged collective groups of students—with SEN, low SES, and fewer German skills—while other dimensions of disadvantages (such as psychological issues or gender) that framed, arose, worsened, or continued during the Covid-19 pandemic could not be identified as a part of the social arena.

## 6. Discussion

The empirical findings show two remarkable disconnections within the situation of inclusive and digital education during the Covid-19 pandemic. On the one hand, the disconnection occurred between the two levels of activities: the level of political decision-making and the level of action (see Section 6.1). On the other hand, the disconnection appeared due to contrary discourses on the research topic of inclusive and digital education (see Section 6.2).

### *6.1. Disconnection Between the Relevant Levels of Activities*

The provision and distribution of digital devices demonstrate the disconnection between the two levels of activities. The political decision-making level was responsible to close the massive gap between required demands and available resources. Resources can be defined as a precondition to digital learning (Hohlfeld et al., 2008). Since the political decision-making level could not provide this comprehensively, it was not possible to bridge the first digital divide during the crucial periods of the school year of 2021–2022. At the same level, the split competencies impeded the distribution process. The administration of Austrian schools is not centralized. Instead, the competencies are split over communal and federal state control. The regulations led to intransparent distribution criteria that the interviewees assessed as hindering and discriminatory to SEN students and schools. Accordingly, it deepened the first digital divide and led to the interpretation that students were affected by digital exclusion at a very early stage. Following the phases model of Hohlfeld et al. (2008), the second and third levels of the digital divide were only bridged in individual cases at the level of action (Besic & Holzinger, 2020), but not across the Austrian school system. However, only the interplay among all three levels would promote digital inclusion across the digital divide (Nemer, 2015).

Due to the mismanagement at the political decision-making level, the responsibility for bridging the first digital divide was shifted to the level of action. School principals had to manage the connection between the political decision-making level and the level of action. The results show that strategies and ways of implementation at the two levels of activities differed greatly from one another. The political decision-making level tried to regulate the risk of dropping out, while the level of action dealt with individual-based academic, but also social needs. Even if in-service actors showed extraordinary engagement, this disconnection could not overcome the structural challenges and thus the digital divide. The maintenance necessary for digital (distance) learning was not provided due to missing hardware and technical support structures (Hohlfeld et al., 2008). Thus, teaching and learning had to switch to (part-time) offline distance learning.

Hereby, the dimension of low SES came to the fore. As quantitative research already indicates, socially disadvantaged students were most affected (Kast et al., 2021; Steiner et al., 2020). The findings confirm that the complexity of digital exclusion increased due to the consideration of offline circumstances (Helsper, 2012). Not only access, personal skills, competencies, or attitudes, but external conditions influence the risk of exclusion (Helsper, 2012). It shows an interplay between digital and social exclusion that is embedded in economic and social pre-existing conditions like infrastructure, (digital) learning materials, an adequate learning environment, and parental support.

### *6.2. Disconnection on Discourses of the (Digital) Education of Students With(Out) Disabilities*

Through the multi-professional perspective, two underlying discourses were identified: special education (Ahrbeck, 2014) and inclusive education (Biewer, 2017; Florian, 2014; Göransson & Nilholm, 2014). The whole process of decision-making and actions concerning inclusive and digital education during crucial Covid-19 periods demonstrated the disconnection of the two main discourses.

The discourse on special education occurred at all levels of activities, but especially at the level of political decision-making. Since the applicable regulations did not consider students with SEN in distribution processes, they seemed to follow an ableist narrative. Underlying assumptions seem to have been made, based on discriminatory and biased viewpoints on SEN students' abilities (Goodley, 2014) and their digital literacy (Lowenthal et al., 2020). The narrative is so deeply rooted that decision-makers either ignored institutions of the public school systems collectively or forced SEN students to attend school physically even when peers were allowed to stay in (digital) distance learning. Students with SEN were seen as a collective group with no individual differentiation regarding their digital and social needs and capacities (Buchner & Proyer, 2020). The distribution criteria mirror the special education discourse due to another circumstance: It seems that decision-makers applied a distribution system comparable to the medical triage model. In doing so, they consciously take the risk of social and digital exclusion for some students. The hierarchization of vulnerable target groups prioritized students with low SES. The prioritization is based on the argument that students with low SES need external support to prevent a high dropout rate. The SES narrative, again, is closely connected to the discourses on school failure because even before the pandemic students with low SES were rated as more at risk of school failure (Bourdieu, 1986; Sandner & Ginner, 2021). In contrast to the target group of SEN students, the distribution system does consider the individualized situation of students with low SES. Also, physical attendance was only recommended and depended on the individual case, but it was not compulsory as it was for SEN students.

Even if this contribution focused on the target group of SEN students, it acknowledges the dilemma of differentiation and categorization of students against the inclusive demand of considering every student (Göransson & Nilholm, 2014). Interestingly, only one quantitative research project (Besic & Holzinger, 2020) researched the target group of SEN students, while the others subsumed vulnerable students under the umbrella term "students at risk." The qualitative empirical findings highlight the lack of a common understanding. Various definitions, like students with SEN, students at risk, with other first languages (than German) or migration backgrounds, were conflated with the main aim to express students' precarious situation. It mirrors an inclusive understanding that education considers every student regardless of social categorization (Göransson & Nilholm, 2014).

The discourse on inclusive education was mainly present at the level of action, but especially at the management level represented by school principals. Their (extra) engagement reflects a positive attitude towards inclusive education because children with SEN are considered as abled students with digital literacy and the right to equal access to devices (Lowenthal et al., 2020). Inclusive structures are characterized by paying less attention to individual deficits and taking a holistic view of the situation, considering both digital and social circumstances (Helsper, 2012). Thus, the findings agree with the understanding of digital inclusion as the "democratization of access to ICTs in order to allow for the inclusion of the marginalized" (Nemer, 2015). In conclusion, digital inclusion only happened through the engagement of in-service actors. There are no systematic structures in place due to (a) the lack of digital infrastructure and (b) the lack of implementation of inclusive education over the last decades.

## 7. Conclusion

This contribution maps the main discursive challenges of the unprecedented situation regarding inclusive education during digital distance learning in Austria. The empirical results show that inclusion and digitalization are not comprehensively implemented in the Austrian education system, even if single actors rated it as fostering in terms of social inclusion. The reason for a missing intersection can be seen in the omissions of implementation of both digital and inclusive education over the last decades.

The qualitative findings indicate major challenges with implementing digitalization and promoting inclusion for all students at the same time during the Covid-19 pandemic. The political focus lay on students' academic achievement and thus keeping the dropout rate as low as possible. In Austria, education and academic success are highly dependent on social background. Accordingly, the target group of students with SES was prioritized. These procedures and related assumptions follow the special education discourse, which categorizes students by their abilities as well as backgrounds. In this study, it is shown that those categorizations are partially adopted and transformed into prejudiced images of students and their families. The prime example mirroring the special education discourse was the distribution process of digital devices. The distribution criteria did not include SEN students as potential users. All stakeholders assessed this as structural and systemic discrimination.

Another challenge was the disconnection between the different cooperating levels. Since the policy-making level was not able to provide digital devices and thus deepened the first digital divide, the in-service actors had to cover it. The engagement of individual stakeholders could not bridge the digital divide. This visualizes the omissions of implementing digital and inclusive education over the last decades once again. Nevertheless, there were sporadic findings on digital inclusion, but only at an individual (school) level.

Even if students (with SEN) are the main actors, the results show a constant ignorance of their voices. Unfortunately, this contribution was not able to consider students' perspectives due to ethical and administrative guidelines either. The importance to conduct further research including students (with SEN) is to be highlighted.

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## Conflict of Interests

The authors declare no conflict of interests.

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Article

# How Did Children With Disabilities Experience Education and Social Welfare During Covid-19?

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**Abstract**

Research suggests that children with disabilities have been systemically marginalised during the Covid-19 pandemic as contamination measures complicated some social policies. School closure, quarantine, and the increased use of social media in remote schooling have placed children with disabilities in a vulnerable situation. This article explores the subjective consequences of such processes through the analysis of qualitative interviews with parents who had children with disabilities. To contextualise our analysis, we also draw on expert interviews with bureaucrats and social workers and data from a survey that was sent out to parents who had children with disabilities. Taken together, these data sources provide a rich empirical context to study how the pandemic influenced the access of children with disabilities to education and social services in Norway. We also pay attention to how the pandemic influenced parents' perception of social welfare in Norway and discuss how issues of race, class, and socio-economic background were reflected in their experiences. Both interview data and survey data were gathered during the pandemic. Conceptually we take inspiration from the capability approach with a particular focus on theoretical work on "conversion factors." These theoretical perspectives invite us to identify and analyse specific mechanisms that prevented and/or enabled children with disabilities to live a life according to their own visions and values during the pandemic. Through this study of how children with disabilities experienced education and social welfare in Norway during the pandemic, we shed new light on how one of the world's most advanced welfare states operates during a time of crisis.

**Keywords**

capability; children with disability; education; Norway; pandemic; social welfare

**Issue**

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## 1. Introduction

Research suggests that children with disabilities have been systemically marginalised during the Covid-19 pandemic as contamination measures complicated some social policies (Asbury et al., 2021; Ferguson, 2021; Nøkleby et al., 2021; Orsander et al., 2020). School closure, quarantine, and increased use of social media in remote schooling have placed children with disabilities in a vulnerable situation (Orsander et al., 2020). This article explores the subjective consequences of such processes through the analysis of qualitative interviews with parents who had children with disabilities in Norway. To contextualise our analysis, we also draw on expert interviews with social workers and welfare bureaucrats working in the field. In addition, we analyse data from a survey

(N = 150) that was posted online on the website of key disability organisations in Norway. Taken together, these data sources provide a rich empirical context through which to study how the pandemic influenced the access of children with disabilities to education and social services in Norway. In interpreting these data, we pay particular attention to how the pandemic influenced parents' perception of social welfare in Norway and discuss how issues of race, class, and socio-economic background were reflected in their experiences. Both interview data and survey data were gathered during the pandemic in 2021.

Conceptually we take inspiration from the capability approach (Sen, 1992, 1993, 2009) with a particular focus on theoretical work on "conversion factors" (Assmann et al., 2021; Bøhler, 2021; Hvinden & Halvorsen, 2018; Robeyns, 2005). These theoretical perspectives invite us to identify and analyse specific mechanisms that prevented and/or enabled children with disabilities to live a life according to their own visions and values during the pandemic. Both the 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the 1989 UN Convention on the Rights of the Child (United Nations, 1989, 2006) underscore the importance of such theoretical arguments as they draw attention to the importance of organising society in ways that allow persons with disabilities to partake on equal grounds. We argue that the capability approach offers a useful theoretical frame with which to study how children with disabilities experienced education and social welfare during the pandemic as it provides new insights into factors that hampered and/or facilitated structures of social inclusion and exclusion. At a more general level, the present study may be considered a stress test of how Nordic social welfare states, modelled on universalism (Esping-Andersen et al., 2002), work during times of crisis. Through a study of how children with disabilities experienced education and social welfare in Norway during the pandemic, we hope to shed new light on how one of the world's most advanced welfare states operates during a time of crisis.

## 2. Covid-19 in Norway and Its Impact on Society and People with Disabilities

During a press conference on 12 March 2020, Norwegian Prime Minister Erna Solberg argued: "Today the Norwegian government will announce the strongest and most intrusive measures we have ever made in Norway during times of peace. However, these measures are necessary to fight the spread of the virus" (Regjeringen, 2020). All welfare services which involved physical contact between people, and which did not have a critical function for society at large, were shut down to prevent the spread of the virus. As a consequence, the Norwegian Directorate of Health decided to close kindergartens, schools, and educational institutions. Only some healthcare services and institutions, which the government defined as having "critical societal functions," were allowed to run normally. The prime minister argued that marginalised youth and children, and people with disabilities more broadly, should receive an adequate offer of educational and social services despite the shutdown of large sectors of Norwegian society. However, this was not how NIM, the Norwegian Human Rights Institution, perceived the closure of education and social welfare following the pandemic. In a letter written to the Ministry of Health and Care Services, the Ministry of Modernization, the Norwegian Directorate of Health, and the National Institute of Public Health on 6 April 2020, NIM warned officials about the potential negative consequences of various infection-control measures. They argued that the closure of important social welfare services jeopardised Norway's social and political commitment to persons with disabilities according to the UNCRPD, which had been signed and ratified by the Norwegian government. Following the convention, Norway was committed to ensuring that people with disabilities enjoy "all human rights and fundamental freedoms." While Solberg and other politicians kept insisting that the measures should not disproportionately impact marginalised or vulnerable people (Regjeringen, 2021), researchers, disability organisations, and activists have identified a systematic neglect of children with disabilities during the pandemic (Bøhler, 2021; Bossy & Hervie, 2021). One report (Bøhler & Ugreninov, 2021) suggests that children with disabilities were marginalised in multiple ways as contamination measures complicated physical contact with their personal assistants, educators trained in special education, and physiotherapists. Taken together, the shutdown of educational institutions and welfare services complicated Norway's commitment to offering "varied forms of assessment, learning resources, learning arenas and learning activities so that everyone gets the best possible benefit from the education" (UDIR, 2022). People with disabilities, both young and adult, experienced several barriers that placed restrictions on their ability to partake in society on equal ground with their non-disabled peers.

## 3. Situating Norway's Covid Policies in a Broader International Context

Together with Iceland, Norway had the lowest Covid-related mortality rates in Europe during the pandemic and among the lowest mortality rates in the world (Karlinsky & Kobak, 2021; Wang et al., 2022). While changes in mortality rates are the product of complex processes, some studies suggest that pre-existing healthcare policies in Norway, and the aforementioned mitigation measures (e.g., lockdown, social distance, focus on hygiene), contributed to a general decrease in influenza, infections and other illnesses which influence mortality on an annual basis (Helgeland et al., 2021; Juul et al., 2022). The influenza virus alone is an important driver of mortality rates in Norway (Gran et al., 2010; Hauge et al., 2019) and internationally (Schanzer et al., 2007;

Simonsen, 1999), and the decrease in influenza during the pandemic may partly explain the low mortality rates in 2020. However, even if mortality rates were low, the socio-psychological costs were high for both marginalised groups (Nesset et al., 2021) and the population at large (von Soest et al., 2022). Several recent studies have elaborated on the contribution of the lockdown and social distancing to an increase in mental illness and loneliness in Norway during the pandemic (Blix et al., 2021; Hoffart et al., 2020; Reme et al., 2022). Other studies have addressed how these policies hampered the economy, both in Norway and internationally (Ibn-Mohammed et al., 2021). Importantly, we are still recovering from the pandemic as well, and some of its consequences remain to be seen. Therefore, more research is required here.

One of the marginalised groups which were influenced by the mitigation measures consists of children with disabilities (Bøhler, 2021; Bøhler & Ugreninov, 2021). Below, we develop a conceptual framework inspired by capability theory to investigate the extent to which children with disabilities were able to live a life according to their own interests during the pandemic. Such a conceptual framework can shed light on whether the shutdown of important social welfare services jeopardised Norway's social and political commitment to people with disabilities following the UNCRPD.

## 4. Capability as a Theoretical Framework

Amartya Sen's capability theory starts from the premise that every individual should be able to live a life in line with their own needs (Sen, 1992, 1993, 2009). The theory draws attention to a person's relative freedom and possibilities to live a life according to his or her visions and values in specific contexts. To study how capability operates in practice, Sen (1992, p. 40) developed the related concepts of "functionings," which are different realisations of one's sense of capability in specific contexts. Functionings can vary over time and may be influenced by a wide range of what Sen (1981, pp. 26–30) calls "conversion factors." Conversion factors refer to how people can convert the characteristics of their resources to improve their capability set (Robeyns, 2005, p. 99). In short, conversion factors are the contextual features which shape a person's sense of capability in practice, and they may be social, personal, material, or made up of other dynamics, depending on the context. The concept refers to the specific interactions between a subject and their environment, as well as the ways in which these interactions influence that subject's ability to realise their capability. Recent elaborations upon this concept have addressed the fact that conversion factors may both be negative and positive concerning the realisation of capability (Halvorsen & Bøhler, 2017; Hvinden & Halvorsen, 2018).

In recent decades, capability theory has been used widely in the interdisciplinary field of disability studies to underscore the importance of developing educational tools and policies which allow people with disabilities to partake in society as equal citizens (Halvorsen & Bøhler, 2017; Halvorsen et al., 2017; Hvinden et al., 2017)—work often inspired by the UNCRPD, as described above (Sépulchre et al., 2017). Sen himself has often used people with disabilities as an illustrative case when arguing for the importance of developing special educational policies and practices, as well as different forms of social security and welfare services (Nussbaum & Sen, 1993; Sen, 1994). Universal design, for example, improves the sense of capability for persons with mobility impairments and allows them to participate in society on equal terms with their non-disabled fellow citizens.

In the following analysis of qualitative interviews and survey data, we draw on capability theory as a conceptual frame to look at how positive and negative conversion factors facilitated or hampered social welfare and education for children with disabilities during the pandemic. First, however, we will outline data sources and methods which were used in the present study.

## 5. Methods and Data

Our data sources consist of eight semi-structured qualitative interviews with parents who had children with disabilities (8–15 years old) and 28 expert interviews organized as semi-structured, together with a survey ($N = 150$) posted online on the websites of important disability organisations in Norway. The survey was designed for parents of children with disabilities and 150 people responded.

The study was approved by the Norwegian Centre for Research Data (NSD) and follows all national requirements with regard to the handling of research data. Due to NSD regulations and the General Data Protection Regulation, we were not able to interview the children themselves, as the understandably extensive permission process was not possible to undertake within the timeframe of this study. It is also true, however, that some studies suggest that in-depth qualitative interviews with parents can still provide important insights into children's educational experiences (Brett, 2002; Wiart et al., 2010). Parents provide the perspective of an adult "third person" and shed light on mechanisms and aspects of the educational experience which are difficult to grasp from the viewpoint of the children themselves. More importantly, the new home-school context propelled by the pandemic created new relationships between parents and children with disabilities that are important to explore in detail because many parents acted as teachers, mentors, and supervisors for their children. The eight informants (three men and five women) included two parents with immigrant backgrounds and six native Norwegians. They encompassed a diverse socio-economic landscape, including high- and low-income families, as well as a range of academic experience and training levels. Five of the interviewees had pursued higher education and secured permanent employment. During the interviews, they gave the impression of being relatively well-off. Three of the interviewees had not completed higher education and had fewer resources. Two of the interviewees lived in a relationship where one parent or both parents stayed home to take care of the child. One interviewee was divorced and lived with his new girlfriend; another was a single mother. All informants self-recruited after we posted an invitation to participate in the research project on websites frequently visited by people with disabilities. They also signed an informed consent form before the interviews, which were carried out on Zoom, recorded, and later fully transcribed. To enhance comparisons across the qualitative data, all the interviews followed a semi-structured interview guide (Brinkmann & Kvale, 2018) organised around key questions that explored their experience with social welfare and education.

While all the interviews followed the same interview guide, they were also shaped by the internal dynamics of the social interaction between the researchers and the informants and varied considerably in length (some lasted an hour, others almost two hours). While capability theory did not inform the interview guide as such, we explored it both explicitly and implicitly through follow-up questions linked to that guide. Below, we briefly introduce the key informants and their children. In our analysis of the research data, we focus mainly on quotes and fragments from the interviews which shed light on how children with disabilities experienced social welfare and education during the pandemic. However, we also discuss how these experiences were intertwined with issues of race, class, and socio-economic background, and discuss parents' perceptions of social policies during the pandemic. As part of our analytical strategy, we also paid attention to how capability theory, defined as the children's ability to live a life in line with their own views, values, and visions during the pandemic, manifested during the interviews.

## 6. Characteristics of Key Informants, Sampling Criteria, and Analytical Strategies

In our analysis, we focus particularly on three interviews with parents of children with disabilities. To anonymise the informants, we use the following pseudonyms:

- Farah was Maria's mother and was single. She had arrived in Norway from East Africa already pregnant and had very poor economic circumstances, relying on student loans and social support from the government while she studied to become a secretary. Maria was nine years old and went to a special school and had multiple disabilities (both physical and cognitive).
- Ada was Grete's mother. Ada had been staying home to take care of her daughter since 2018 while her husband worked; the family was well-off. Grete was nine years old and had multiple disabilities (both physical and cognitive).
- Turid was Therese's mother and lived together with her husband and two other non-disabled children; the family was well-off. Therese was 10 years old and had multiple disabilities, both physical and cognitive.

These informants represent three different socio-economic strata of Norwegian society. Ada is representative of upper-middle-class families, as her family enjoyed a good income which allowed for one parent to remain at home. Turid is representative of a typical middle-class family in which both parents work. Farah brings with her the experiences of economically marginalised single mothers with immigrant backgrounds who rely on support from the Norwegian welfare administration. By analysing and comparing these three narratives, we hope to gain insight into how class and socio-economic background were intertwined in how children with disabilities experienced education and social welfare during the pandemic. Such a perspective is important because a growing body of evidence suggests that differences in socio-economic background have increased in Norway (Hansen & Strømme, 2021; Hansen & Toft, 2021) and across the Nordic countries (Jonsson, 2004) in recent decades. In addition, new flows of migration and increased globalisation have placed Oslo among the fastest-growing cities in Europe, with an immigration rate which has increased from under 10 percent of the population in the 1990s to over 33 percent today. More importantly, some studies suggest that people with immigrant backgrounds face more economic hardship and discrimination in the labour market than Norwegians without immigrant backgrounds (Midtbøen, 2014; Reisel et al., 2019), thus adding evidence to theories about the interplay of race and class in modern societies. In addition, some studies suggest that socio-economic differences increased in Norway during the pandemic because vulnerable population groups which relied heavily on social welfare services found themselves yet further marginalised (Blikstad-Balas et al., 2022; Reme et al., 2022). In-depth interpretive analysis of the ways in which Ada's, Turid's, and Farah's children experienced education and social welfare during the pandemic and the extent to which they were able to live a life according to their own visions can provide important insights into how children with disabilities experienced the pandemic.

## 7. Additional Data from Expert Interviews and Survey

While these three interviews constitute the primary focus for our analysis, we also rely on other data sources, such as survey data and additional expert interviews, that help to contextualize our interpretation and provide a deeper understanding of the situation. One of these was an expert interview with Fakhra Salimi, the Pakistani-Norwegian activist and expert on minority politics, black feminism, and social exclusion. Salimi was awarded the Ossietszky Prize of PEN (poets, essayists and novelists) from Norway in 2005 and the prestigious St. Halvards medal in 2015 for her ground-breaking work on the rights of women with immigrant backgrounds and black feminism more generally. She is a prominent and outspoken intellectual in the public sphere in Norway and presently leads the MiRA Center: Resource Center for Black, Immigrant and Refugee Women. Our discussion of the key interviews with Salimi inspired important additional interpretations which we include below. We also analyse an interview with Aiden, who worked in the implementation of social services for the Norwegian Welfare Administration during the pandemic. This interview brought nuance to our analysis by providing insights into the complex factors that influenced the management and allocation of social welfare services in practice.

One challenge with qualitative interviews is that they offer limited possibilities for generalisation as interpretations are often based upon a small number of in-depth observations. One way to overcome this is to combine in-depth qualitative interviews with the analysis of survey data (Woolley, 2009). We, therefore, complemented the aforementioned qualitative interviews with a survey sent to crucial disability organisations in Norway which posted the survey on their websites and, in some cases, sent it out through email lists. The survey arose from a pilot study, a critical review of the literature and discussions with experts in the field. The target group consisted of parents who had children with disabilities; respondents had to be over 18 years old. In all, 150 respondents completed the survey, most of whom (87 percent) identified as Norwegian with no immigrant background. In addition, 71 percent of the respondents were mothers of children with a functional impairment, and only 9 percent were fathers. Twenty-six percent of the respondents had children with disabilities in kindergarten, 41 percent had children in primary school, and 31 percent had children in secondary school. The survey consisted of 20 questions concerning how the pandemic influenced the access of children with disabilities to social services. In our analysis of the survey data below, we focus particularly on questions exploring parents' experiences with access to social services before and after the pandemic, respectively.

Because we have gathered and analysed both quantitative and qualitative data (with a focus on the latter), our research design is firmly situated within the growing field of mixed-method research (Hesse-Biber, 2010).

## 8. Social Welfare Programs Were Shut Down Due to the Pandemic

The survey clearly revealed that children with disabilities experienced decreased access to social welfare programs after the pandemic. Figure 1 shows how many parents who argued that their children's access to social services was severely hampered by infection-control measures:

Further inquiry clarified the ways in which the pandemic complicated the access of children with disabilities to personal assistance, care assistance, support at school, physiotherapy, home care support, and other social services (see Figure 2).

As illustrated in Figure 2, some social welfare programs were almost completely shut down during the pandemic (e.g., care assistance, which went from 28 percent to 0.7 percent), whereas others were substantially reduced (home care assistance, which went from 21 to 2.7 percent). Overall, the trend was toward less access to everything.

The qualitative interviews indicated this same trend, as in the following quote by Turid, Therese's mother:

> Therese was surrounded by a great network prior to the pandemic. She had a speech therapist, a physical therapist, an occupational therapist, and an assistant who helped out. In addition, various physicians were involved. But then all of this collapsed on March 13 [2020]. It was very hard. The pandemic made our situation chaotic….The specialised teacher tried to organise teaching online through digital platforms, but it didn't work. Because our life became so difficult,

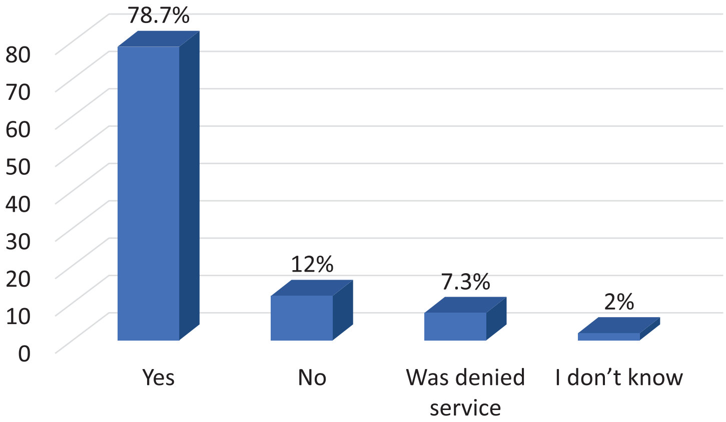

**Figure 1.** Parents of children with disabilities who experienced severely hampered access to social services during the pandemic (N = 150).

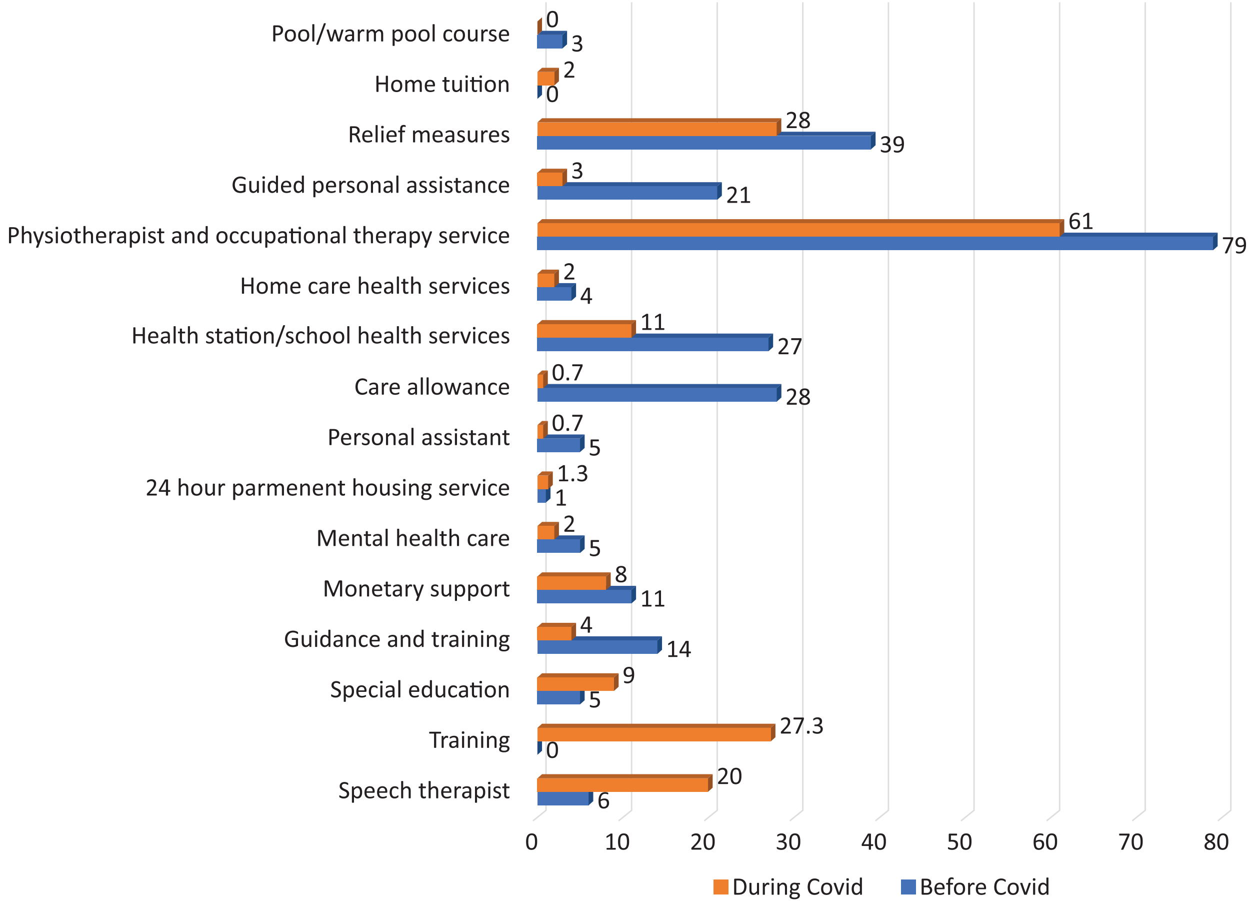

**Figure 2.** The level of access of children with disabilities to different kinds of social welfare before and during the pandemic in percentage (N = 150).

> we asked NAV [the Norwegian Labour and Welfare Administration] if we could have an assistant, but NAV responded: "No, you cannot, because your jobs are not critical to society." When we asked again, they said: "Would you really expose the assistant to the risk of getting the virus?" Covid was the most important thing. Our children were neglected. It felt like we were putting the lives of others at risk every time we asked for the support that we needed. We were not seen nor heard. Our needs were of secondary importance. It almost makes me cry when I talk about this. It was very hard [she cries for a bit, and we take a short break from the interview]. We were to a large extent left to ourselves. It would have ended badly if we didn't have a good relationship [referring to Turid and her husband]. We argued a lot about who should sit where. All four of us had to stay at home, under the same roof, and the apartment is not very big. And me and my husband constantly discussed who should skip today's work meeting. Stress, stress, stress, and stress. It was too much!

Turid's quote illustrates the social and affective costs of the pandemic, before which she felt that her family had been taken care of by the Norwegian state and its various social welfare programs. Turid's sense of the pre-pandemic system is echoed by the many studies that point to high levels of satisfaction with the social welfare programs in Norway as opposed to other states (Andress & Heien, 2001; Esping-Andersen et al., 2002), and to a general sense of social trust between citizens and the state (Christensen & Lægreid, 2005; Miller & Listhaug, 1990). For Turid, at least, this all changed during the pandemic, when she felt that her daughter was "neglected" by the system and that her family's needs "were of secondary importance." This difficult situation generated anxiety about the wellbeing of the family as a whole and even started arguments between Turid and her husband. The repetition of the word "stress" at the end of the quote captures these affective costs, as Therese, Turid, and their family could no longer live a life they had reason to value.

## 9. Interviews With Social Workers Reveal New Complexities

Professionals working in the field such as Aiden echoed Turid's argument:

> Researcher: How do you think the lockdown affected families with children with disabilities? Did they get the support they needed?

> Aiden: We were discussing this a lot; it is an important question. Kindergartens and schools were closed to the public, and none of the vulnerable children received any replacement offers or additional support. And then the government said that children with special needs should get access to education, in addition to children with parents in socially critical occupations. However, many [parents] did not [pursue this]—particularly those who had children with special needs. And it raised difficult and important questions. Where should the line be drawn for who should get an offer? But it was complex. Many parents of children with special needs should have received [it] but did not, partly because they were afraid of infections and Covid. In short, I remember how many parents kept their children at home, even though they could in fact get an offer. However, in the most severe cases we reported this further to the child protection services, but they often closed the[se] cases and refused to follow up. I think this was very, very unfortunate. We were very worried about these children and the extent to which they would get the follow-up they needed. But it is a complex issue.

Aiden's argument helped us see Turid's frustration in a broader context while also supporting her argument that children with disabilities were marginalised during the pandemic. However, as Aiden insists, it was complicated for social services administrators to decide where the threshold should be. What kind of special needs should be covered or excluded? More importantly, while any given welfare bureaucrat could argue that a family was entitled to special assistance, the larger bureaucratic structure could potentially work against this (see the description of the child protection services above).

## 10. Digital Schooling Hampered Capabilities for Children With Disabilities

Turid's observations were echoed by healthcare professionals who worked with social services at the municipal level, such as Ana from West Norway:

> The social services that were offered during the pandemic were not good enough….All children suffered because of the infection-control measures. However, I think that children with disabilities suffered the most. They are dependent on various healthcare services….Most children with disabilities do not have the prerequisites to make home-school work through digital means. It either functions well or it does not function at all. I think that children with disabilities had to pay a very high price during the pandemic. They should be given some compensation because they suffered the most during the lockdown.

Ana's observation that all children were affected by the pandemic has been borne out by recent studies in education (Azevedo et al., 2021; Blikstad-Balas & Klette, 2020; Bubb & Jones, 2020) and childhood research (Bryant et al., 2020). Other studies likewise indicate that children with disabilities suffered the most because the social services on which they relied were no longer available (Bøhler, 2021; Bøhler & Ugreninov, 2021; Greenway & Eaton-Thomas, 2020). More importantly, the increased use of social media during pandemic-driven home-schooling placed children with disabilities in a particularly vulnerable position by enabling new social hierarchies and forms of exclusion, as Turid points out:

> One problem seemed to be that the teacher was not able to organise and handle the new digital classroom—for example, both socialisation after class and talking in class were very chaotic. They organized a "class chat" [*klassechat*] with the aim that everybody should talk with each other. But it was complete chaos. The teacher struggled with this concept. She tried to say to the children: "Everybody has to talk to each other, and everybody should be included." However, it became clear that the most popular children dominated the conversation. In this context, Therese struggled and was excluded. Therese struggles to understand the social codes of social media—she posted things that others didn't understand, or that they disliked, and she was sad and disappointed. We, as parents, would like to have some guidance with regard to how children with disabilities like Therese can use these social media platforms, [so as] to avoid social exclusion. What digital social codes do you have to follow as a nine-year-old kid on Facebook? And what should be done so that children with disabilities can participate on social media and avoid exclusion? What does she need to know socially, on social media, to be part of the class? There are several great digital platforms available, but we should also have some guidance with regard to the use of such platforms. If not, these new digital social spaces can be new spaces for bullying and social exclusion. I miss more guidance from the school.

Toward these important ends, public institutions should develop guidebooks, policies, and models for teachers so that they can create a socially open and healthy environment online. Teachers must also establish a sense of order and ethics related to children's interactions on social media platforms to avoid chaos and social exclusion. Several studies have elaborated on how social media, and digital technology more generally, can lead to new forms of social exclusion of people with disabilities (Bøhler & Giannoumis, 2017; Bøhler & Ugreninov, 2021). In light of capability theory, such conditions may be theorised as negative conversion factors because they hinder the ability of people with disabilities to participate fully in society. More importantly, these conditions complicate the implementation of the UNCRPD (The Convention on the Rights of Persons with Disabilities) and the UNCRC (The United Nations Convention on the Rights of the Child), both of which underscore the importance of organising society in ways that enable the full recognition and integration of children with disabilities at all levels.

## 11. Intersectional Capabilities During Home-Schooling: Race, Class, and Socio-Economic Background

The interviews also indicated that white ethnic Norwegian couples with middle-class backgrounds in which only one of the partners worked were able to dedicate more time to the educational support of their children than couples of other races, classes, or socio-economic backgrounds. The following quote by Ada, who had been out of work since 2018 to help her disabled daughter while her husband continued to work, captures this situation:

> You know, we have been living quite isolated for two and a half years now [since she quit her job], so, in a sense, we were used to this situation of the pandemic. But all this was only possible because I was at home and could dedicate time and care to our daughter, while my husband worked. We could afford it. I could assist her in home-schooling….In the beginning, it was very difficult, but then we started to structure our own school at home. We often started with two classes in Norwegian. Then one class in English. After every class, which lasted 45 minutes, we had a 15-minute break and a longer break during lunch. It was just like the school. First one more class in mathematics. Afterward, we had a class for physical exercise, followed by [classes in] science and social science education. We used the timer on the smartphone to organize the day. We tried to follow the teaching plan provided by the school. In our home-school the bell rang for break-out time [smiles]….In retrospect, I actually think Grete learned more during this period of home-schooling than at the ordinary public school. In mathematics, we were able to go through all the curriculum for the second grade and even spent some time on the third-grade curriculum. We were also able to get quite far in the science and social science curriculums. I think we were very creative. But there was one cost. I had to dedicate all my time to following up. For example, sometimes we followed the teaching plan provided by the school, and other times I had to be creative and rearrange and organise the teaching material in new ways….However, we got little support from the school and the teachers. I am very glad I had the time and energy to act as a substitute teacher. If not, I think Grete would have struggled a lot during this period.

Here, we see that the physical school itself, as well as the support from assistants and special education teachers, were not part of Grete's life due to infection-control measures. Thanks to her circumstances, however, Ada was able to serve as Grete's "substitute teacher" while both were stuck at home. While this may have been to Grete's advantage in the end, this was not an option many families enjoyed during this time, and, indeed, studies have pointed to the complex ways in which socio-economic background can shape learning outcomes even outside of pandemic conditions (Holmes-Smith, 2006; Tieben & Wolbers, 2010; Perry, 2012;). In families where both parents worked, for example, it was much harder to adapt to pandemic-driven restrictions to educational resources and life in general, as we see in Turid's tears and emphasis on "stress, stress, stress, stress."

As a native Norwegian, however, Turid was at least able to voice her frustrations with the system and communicate with representatives of the welfare apparatus and school in her mother tongue. She also knew how the system worked and what she was entitled to, and she could file a complaint when necessary. For Farah, who was black and had arrived in Norway as a single mother and refugee from East Africa, it was more difficult to contend with such circumstances. Farah had lived most of her adult life in East Africa and was less familiar with the Norwegian welfare state and school system as the pandemic brought about its changes in her daughter's education:

> Everything became very difficult because of the shutdown of public transportation and the school and all of it. For me, it was particularly difficult, as I am in the process of learning Norwegian, and it is difficult for me to communicate with NAV and the school system. I am very grateful for the support I get, and I think the special school for my daughter [who has disabilities] is amazing, but during the pandemic much of this was placed on hold. Also, I am alone, and I must take care of my daughter even though we live on a student loan and with support from NAV….When the school closed, I had to do everything. But I am no teacher. I am a single mother. I study Norwegian and [study] to become a secretary….It was difficult. The home-schooling had a strong impact on Maria [her daughter]. She loves her school, and she loves her friends there. Maria enjoys the music classes, the social interaction, and all of that. But she hates social media, iPads, and computers. She wants physical contact with teachers and students. Social interaction. It was very hard for me to deal with all of this. Most of the assignments they gave us from school did not work. However, some did, particularly the ones that were more practical. For example, yesterday we got the assignment of going out in the woods to find a beautiful flower that we should take a picture of and then learn about. That was very enriching. However, the pandemic-school situation made everything unstable. First it was this,

> then it was that. It was hard to deal with for Maria, as she needs stability. It is part of her diagnosis. She hates disruptions.

While the pandemic clearly hampered her daughter's ability to cope with the world, Farah still saw the value (literal and figurative) of the Norwegian welfare apparatus, which perhaps provided her with better social services than what she was used to in East Africa. In contrast, both Ada and Turid criticised what they saw as the systematic neglect of children with disabilities in Norway during the pandemic. When we discussed this discrepancy with Fakhra Salimia, a leading activist in the field, she framed Farah's perspective within what she called the "depth of gratitude" one often encountered among mothers with immigrant backgrounds:

> I think many immigrant and refugee families often express a strong sense of "depth of gratitude" [*takknemlighetsgjeld*] because they compare the Norwegian system with their countries of origin—for example, Pakistan, Somalia, or elsewhere—where the social welfare benefits are almost non-existent. Therefore, many tend to be very grateful in terms of what they receive here. However, this is problematic, because we know that, in order to get a number of welfare benefits, you often have to struggle [first] and prove that you are entitled to these benefits. The "depth of gratitude" sometimes prevents many from applying, or fighting, for their genuine welfare rights. In addition, many immigrant and refugee women have limited knowledge about the benefits provided by the Norwegian welfare state and the school system, so they don't know what to expect. Norway is a welfare state and compared to many other countries we have generous welfare benefits. This became very clear during the pandemic. It is therefore very important that all citizens have access to the same benefits regardless of their immigrant or refugee status. There are many women who do not get adequate help and we are working daily to help these women in accessing their rights within the welfare system. I think that it is very important to make it clear that equal rights are not some charity [that] the government is doing for us immigrants. The person in your interview [Farah] is overwhelmed by this depth of gratitude and is not aware of the fact that these are her rights. I meet many women like her through my work, and it is our responsibility to inform them that they are Norwegian citizens and thereby eligible for equal rights.

While it is difficult to find strong empirical evidence for this "depth of gratitude" hypothesis, research carried out by the MiRA Centre where Salimi (2004) works, as well as several other studies (Hagelund, 2005; Næss & Moen, 2015), suggest that immigrants indeed know less about the welfare rights to which they are entitled than native Norwegians. Translated into capability theory, we can say that proficiency with the Norwegian language and familiarity with the Norwegian educational system and welfare state are perhaps the most important conversion factors hindering Farah and Maria from living a life following their own needs, values, and visions during the pandemic. If the Norwegian welfare state, including its educational structures, is most accessible to the white native-Norwegian middle class and less accessible to Norway's most vulnerable citizens (for example, black immigrant single mothers with children with disabilities), this represents a racial bias that is important to address in future studies and policy development. In any case, we can see that race, education, language, and economic resources contribute as conversion factors to a negative feedback loop that constrains the sense of capability in, for example, a black Norwegian woman and her child with disabilities.

## 12. Conclusion

The aim of this study was to explore how children with disabilities were influenced during the pandemic, with a particular focus on social welfare and education. We focused on the in-depth analysis of semi-structured interviews carried out with parents who had children with disabilities. Findings from our analysis suggest that pandemic home-schooling impacted families differently depending upon their socio-economic and ethnic backgrounds. Well-off families which could afford to have one parent stay at home were less affected than those who had to work and help their children with disabilities at the same time. The virtual schooling situation was also particularly challenging for parents with immigrant backgrounds who might find it hard to communicate with the school and teachers, as well as the relevant parts of the welfare system. Scarce economic resources probably added further to these parents' burdens. This placed single mothers and parents with few resources and/or immigrant backgrounds in a vulnerable situation as they struggled to make ends meet while simultaneously taking on the new responsibilities of home-schooling. Another finding from our study was that the new virtual classroom was seen as chaotic by many, and this further marginalised children with disabilities, who experienced trouble in terms of handling social codes online. In short, digital schooling created new forms of social exclusion that need to be studied more deeply and systematically.

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## Conflict of Interests

The authors declare no conflict of interest.

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Commentary

# Remnants of Community: What I Learned in the First Year of the Pandemic

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**Abstract**

This commentary reflects briefly on 10 of the many lessons that defined the Covid-19 pandemic. These reflections are taken from one disabled person's experience but resonate with many. As such they give a flavour of the thematic issue as a whole, while offering a highly personal contribution to the publication project.

**Keywords**

ableism; activism; coronavirus; disability; silencing; social change

**Issue**

This commentary is part of the issue "Disability and Social Inclusion: Lessons From the Pandemic" edited by Owen Barden (Liverpool Hope University), Laura Waite (Liverpool Hope University), Erin Pritchard (Liverpool Hope University), and Ana Bê (Liverpool Hope University).

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Disability futurity is a concept that, in 2018, I adopted for a project in the Centre for Culture and Disability Studies at Liverpool Hope University. Many internal and external colleagues were ultimately involved (e.g., Murray, 2022; Penketh, 2022) and the research followed various directions in Canada and the UK (Patterson, 2022; Worthington, 2022). My starting point was an extrapolation from epistemology gained from disability, elsewhere called cripistemology (Johnson & McRuer, 2014), as a knowledge base for a future in which increased life expectancy would bring about widespread dependence on accessible technology and a true appreciation of interdependency. This prediction seemed a bit far-fetched, as noted by some colleagues, and in all honesty I was thinking decades down the line. Conversely, to explore my position I harked back to a cultural product of 1957, Samuel Beckett's *Endgame*, which reduced the final phase of humanity to four disabled people whose very existence relied on what remained of community (Beckett, 1957/1964; Bolt, 2021; Davidson, 2007; Quayson, 2007). These Beckettian ponderings acquired pertinence when in March of 2020 I found myself, a lone disabled figure, navigating the desolate landscape of the usually lively Liverpool suburb in which I had lived and worked for more than a decade. Any speculation I had made about disability futurity was consumed in that primal pandemic moment from which I could only learn.

The first lesson I learned was that I was part of a high-risk group. Because I have an autoimmune disease called psoriatic arthritis, I take a disease-modifying antirheumatic drug, Methotrexate, which works by suppressing my rogue immune system (Bolt, 2021). Panic led me to infer that my chronic disease might be preferable to the treatment in the fearful context defined by the coronavirus. I figured I might be better off bearing the full, life-changing force of arthritis (Felstiner, 2005), rather than rendering myself prone to the life-threatening virus Covid-19. My inference was far from original, as I realised when I rang the rheumatology nurses to hear an answer-machine message about being inundated with similar enquiries. The pre-recorded advice was to keep taking the tablets and "follow government guidelines." This predicament worsened day by day with news of more cases and more deaths among which I could not help noticing a proliferation of references to the high-risk group that embodied the very reason for lockdown.

The second lesson was that eating out was not a fool-proof means of sustenance. I have an eye disease called retinitis pigmentosa that has long since progressed to the point of sightlessness, which combines with my psoriatic arthritis to complicate the preparation of all but the most basic of meals. I had addressed this situation by making my way to a local eatery each day. In lockdown, however, I could only lament reliance on these short but regular visits for good food, drink, and exercise, not to mention community beyond work.

The third lesson was that even huge supermarket chains could not necessarily provide timely supplies. Given that, apart from a fifteen-minute walk each morning, I was self-isolating, I required a shopping delivery each week. However, it was thanks only to my daughter's diligence, checking the websites throughout the day and into the night, that I secured a delivery slot every third week. I contacted one famously high-end supermarket several times to explain that even before the pandemic I relied on deliveries for basic household items; alas, neither my manifest desperation nor years of custom carried any weight at all.

The fourth lesson pertained to unexpected sources of support in the local community. One restaurant helped me by setting up a tab, accepting orders via text message, and agreeing to collect and deliver my prescription each month; another, in between lockdowns, allowed me to eat outside set hours and settle the bill retrospectively. Given that work had taken me away from family and friends more than a decade earlier, and the university around which I had structured my life was all but deserted, it is no exaggeration to assert that a few people in the locality constituted a lifeline.

The fifth lesson was that years of extended time on campus had resulted in a far too basic workstation at home. I found myself working on a decade-old laptop with a poor internet connection, which meant I had no access to Zoom or anything similar. As such, during the first lockdown, in order to join meetings I had to ask a helpful colleague to call me on the telephone, meaning I could just about listen in and be heard. No stranger to access issues, I felt rather outside some discussions but was nonetheless glad of this substandard communication.

The sixth lesson was about the extent to which a visual perspective was taken for granted (Jay, 1993). Shielding letters and other medical correspondence aside, I was at a loss when my trusty laptop broke down and was deemed irreparable, which left me with no means of writing or reading. My institution loaned me a replacement, which was gratefully received but meant I had to learn how to use new versions of all the software, ranging from the operating system and screen-reader to Word, Outlook, Chrome, and Zoom. This would have been difficult enough with sighted assistance but on my own it was frustrating to the extreme. Nevertheless, on more than one occasion I was saved by a kind colleague who made the route to my house part of her *daily exercise allowance* and stood outside my window just to look in and tell me what was on my screen. This being so, in subsequent lockdowns it was necessary for me to meet and work face-to-face with my academic support worker, in what became known as a *support bubble*.

The seventh lesson was that some educators deemed it impossible to teach students without seeing their faces. This ocularnormative assertion was made by tutors who encountered difficulties when giving sessions via Zoom. The issue was that many if not most students took to switching off their cameras for the duration of taught sessions. I discouraged this practice in my own classes, well aware that visual cues and body language were helpful to many people (Barthes, 1992). More concerning were the pedagogical implications for educators who teach without seeing the faces of students as standard (Michalko, 2001). Had the assertions of impossibility been followed by requests for experiential knowledge, there could have been productive connections; in the absence of such discourse, the normative divide differentiated and distanced my understandings from those of others.

The eighth lesson related to the fact that the deserted pavements soon became cluttered with e-scooters, as a result of a rental scheme endorsed by the City Council. The pleasure principle was not lost on me but the normative positivisms translated into non-normative negativisms. Where the main obstacles once were badly parked cars and unkempt trees, I now needed to beware of more random tests of patience. The e-scooters seemed to take many forms, depending on how they were parked, and could turn up on just about any pavement. More than being an obvious hazard, for a long-cane user they proved disorientating when having to be stepped over or walked around. Although I never forget that disabled people's knowledge tends to be dismissed as "complaining" (Wendell, 1989, p. 104), I did wonder what would happen if comparable obstacles became a feature on the roads. I knew for sure that, for the foreseeable future, I would need to walk at a markedly slower pace to avoid sustaining serious injury.

The ninth lesson pertained to haptic perception. Having recently started to use the long-cane for mobility, after more than three decades of guide dogs, I was becoming increasingly aware that the human sense of touch was indeed underrated (Classen, 2005). After all, I was learning fine details about the local environment that had previously passed me by. The trouble was that in pandemic times all contact had become problematic. For instance, a banister that once reduced the hazard of steps or stairs was now a hazard in itself. This fear of contagion extended to people, manifest in social distancing, which translated into anxieties if not guidelines about a person who perceives by other than visual means taking someone's arm when walking somewhere unfamiliar or busy.

The tenth lesson was that, even though its spectre had lurked at the back of my mind since childhood, the death of a parent is not something for which anyone can prepare. My father had been having varied and multiple cancer treatments for a few years and so was deemed clinically extremely vulnerable. Because we were both in high-risk groups, I did not spend much time face-to-face with him even between the lockdowns of 2020 and 2021. We had our final conversation via telephone, which my brother made possible by ringing me from the hospital. Selfless and understated to the end, my father tried to put my mind at rest by saying he was okay. It seemed perplexing as much as upsetting that I was not there in person and this unique mix of emotions persisted when he died a couple of days later. Despite the number of times I had rehearsed it in the dreadful corners of my mind, the bizarre reality was completely unexpected, for I donned my suit and attended my father's funeral via the laptop in my living room. Instead of being just fifty miles away with my mother, brother, daughter, and the rest of the tiny gathering allowed at the crematorium, I was joined by my academic support worker of only six months, who silently and sensitively stood to one side but made and maintained my online connection with the funeral service.

Based on 12 months, from March 2020 to February 2021, these lessons from the pandemic are indicative of dozens more; they are profoundly personal but likely to resonate with disabled people lucky enough to have lived to tell the tale. The lessons have been hard learned by a deflated if not defeated professor of disability studies who, just a few years ago, was enthused about the idea of a great tomorrow in which disabled people would share knowledge and experience as a pivotal means of progressing society. Granted, in the first lockdown, I noticed signs that predictions of such non-normative positivisms were not just rhetorical, as disability was indeed recognised as a knowledge base (Bolt, 2021). However, the sheer violence of pandemic categorisation ultimately emphasised the normative social order and deepened the normative divide. Deaths were announced in daily if not hourly news reports with qualifying references to *underlying conditions*, from which most people drew a huge sense of relief. Moreover, the future to which we were all meant to look was the *new normal*, something very different from my non-normative imaginings of disability futurity. What my ten lessons do demonstrate, though, is that in troubled times even remnants of community are vital.

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## Conflict of Interests

The author declares no conflict of interests.

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