

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 decisionmaking 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 pandemicrelated 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 decisionmaking 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.

References

Abrams, T., & Abbott, D. (2020). Disability, deadly discourse, and collectivity amid Coronavirus (COVID-19). Scandinavian Journal of Disability Research, 22(1), 168–174. https://doi.org/10.16993/sjdr.732

- Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *American Psychologist*, *76*(3), 451–461. https://doi.org/10.1037/amp0000709
- Armitage, R., & Nellums, L. B. (2020). The COVID-19 response must be disability inclusive. *The Lancet Public Health*, *5*(5). https://doi.org/10.1016/S2468-2667(20)30076-1
- Banerjee, T., Khan, A., & Kesavan, P. (2021). Impact of lockdown and school closure on children in special schools: A single-centre survey. *BMJ Paediatrics Open*, 5(1). https://doi.org/10.1136/bmjpo-2020-000981
- Bigby, C. (2020). The significance of research to practice during the COVID-19 pandemic. *Research and Practice in Intellectual and Developmental Disabilities*, 7(1), 1–4. https://doi.org/10.1080/23297018. 2020.1765847
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088 706qp063oa
- Campbell, F. A. K. (2008). Exploring internalized ableism using critical race theory. *Disability & Society*, 23(2), 151–162. https://doi.org/10.1080/09687590 701841190
- Care Quality Commission. (2020). CQC publishes data on deaths of people with a learning disability. https:// www.cqc.org.uk/news/stories/cqc-publishes-datadeaths-people-learning-disability
- Caton, S., Hatton, C., Gilloooly, A., Oloidi, E., Clarke, L., Bradshaw, J., Flynn, S., Taggart, L., Mulhall, P., Jahoda, A., Maguire, R., Marriott, A., Todd, S., Abbott, D., Beyer, S., Gore, N., Heslop, P., Scior, K., & Hastings, R. P. (2022). Online social connections and internet use among people with intellectual disabilities in the United Kingdom during the COVID-19 pandemic. *New Media & Society*. Advance online publication. https://doi.org/10.1177/14614448221093762
- Emerson, E., Stancliffe, R., Hatton, C., Llewellyn, G., King, T., Totsika, V., Aitken, Z., & Kavanagh, A. (2021). The impact of disability on employment and financial security following the outbreak of the 2020 COVID-19 pandemic in the UK. *Journal of Public Health*, 43(3), 472–478. https://doi.org/10.1093/pubmed/fdaa270
- Gillespie-Smith, K., McConachie, D., Ballantyne, C., Auyeung, B., & Goodall, K. (2021). The impact of COVID-19 restrictions on psychological distress in family caregivers of children with neurodevelopmental disability in the UK. *Journal of Autism and Developmental Dis*orders. Advance online publication. https://doi.org/ 10.1007/s10803-021-05132-3
- Goggin, G., & Ellis, K. (2020). Disability, communication, and life itself in the COVID-19 pandemic. *Health Sociology Review*, 29(2), 168–176. https://doi.org/

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10.1080/14461242.2020.1784020

- Goodley, D., & Lawthom, R. (2019). Critical disability studies, Brexit and Trump: A time of neoliberal-ableism. *Rethinking History*, *23*(2), 233–251. https://doi.org/ 10.1080/13642529.2019.1607476
- Goodley, D., Lawthom, R., & Runswick Cole, K. (2014). Posthuman disability studies. *Subjectivity*, 7(4), 342–361. https://doi.org/10.1057/sub.2014.15
- Inclusion London. (2020). Abandoned, forgotten and ignored: The impact of Covid-19 on disabled people. https://www.inclusionlondon.org.uk/disability-inlondon/coronavirus-updates-and-information/ campaigns-news-during-coronavirus-crisis/ abandoned-forgotten-and-ignored-the-impactof-Covid-19-on-disabled-people
- Kavanagh, A., Hatton, C., Stancliffe, R. J., Aitken, Z., King,
 T., Hastings, R., Totsika, V., Llewell, G., & Emerson,
 E. (2022). Health and healthcare for people with disabilities in the UK during the COVID-19 pandemic. *Disability and Health Journal*, *15*(1). https://doi.org/
 10.1016/j.dhjo.2021.101171
- Ktenidis, A. (2020). Covid-19 and the implications of its ontologically violent messages. University of Sheffield. https://www.sheffield.ac.uk/ihuman/ Covid-19-blog/disability-and-Covid-19-globalimpacts/Covid-19-and-implications-its-ontologicallyviolent-messages
- Kuper, H., Banks, L. M., Bright, T., Davey, C., & Shakespeare, T. (2020). Disability-inclusive COVID-19 response: What it is, why it is important and what we can learn from the United Kingdom's response. Wellcome Open Research, 5. https://doi.org/10.12688/ wellcomeopenres.15833.1
- Liddiard, K. (2020). Surviving ableism in Covid times. University of Sheffield. https://www.sheffield.ac.uk/ ihuman/Covid-19-blog/surviving-ableism-covidtimes
- Loopstra, K. (2020). Vulnerability to food insecurity since the COVID-19 lockdown. Kings College London.
- Lund, E. M., & Ayers, K. B. (2020). Raising awareness of disabled lives and health care rationing during the COVID-19 pandemic. *Psychological Trauma: Theory, Research, Practice, and Policy,* 12(S1), S210–S211. https://doi.org/10.1037/tra0000673
- Lund, E. M., Forber-Pratt, A. J., Wilson, C., & Mona, L. R. (2020). The COVID-19 pandemic, stress, and trauma in the disability community: A call to action. *Rehabilitation Psychology*, 65(4), 313–322. http://doi.org/ 10.1037/rep0000368

Office for National Statistics. (2020). *Deaths involving COVID-19, England and Wales: Deaths occurring in June 2020*. https://www.ons.gov.uk/people populationandcommunity/birthsdeathsand marriages/deaths/bulletins/deathsinvolving covid19englandandwales/deathsoccurringin june2020#pre-existing-conditions-of-peoplewho-died-with-Covid-19

- Office for National Statistics. (2021). Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020. https://www.ons.gov.uk/peoplepopulationand community/birthsdeathsandmarriages/deaths/ articles/coronaviruscovid19relateddeathsby disabilitystatusenglandandwales/24januaryto 20november2020
- Office for National Statistics. (2022). Coronavirus and the social impacts on disabled people in Great Britain: March 2020 to December 2021. https://www. ons.gov.uk/peoplepopulationandcommunity/ healthandsocialcare/disability/articles/corona virusandthesocialimpactsondisabledpeoplein greatbritain/march2020todecember2021
- Onwumere, J., Creswell, C., Livingston, G., Shiers, D., Tchanturia, K., Charman, T., Russell, A., Treasure, J., Di Forti, J., Wildman, E., Minnis, H., Young, A., Davis, A., & Kuipers, A. (2021). COVID-19 and UK family carers: Policy implications. *Lancet Psychiatry*, 8(10), 929–936. https://doi.org/10.1016/S2215-0366(21)00206-6
- Read, S., Simmons, B., Levinson, M. P., & Bush, T. (2021). A call to action for conducting research with people with profound and multiple learning disabilities. *PMLD Link*, 33.3(100), 6–7.
- Scope. (2020). The disability report: Disabled people and the Coronavirus crisis. https://www.scope.org.uk/ campaigns/disabled-people-and-coronavirus/thedisability-report
- Shakespeare, T., Watson, N., Brunner, R., Cullingworth, J., Hameed, S., Scherer, N., Pearson, C., & Reichenberger, V. (2022). Disabled people in Britain and the impact of the COVID-19 pandemic. *Social Policy* and Administration, 56(1), 103–117. https://doi.org/ 10.1111/spol.12758
- Yoshida, K. K., & Shanouda, F. (2015). A culture of silence: Modes of objectification and the silencing of disabled bodies. *Disability & Society*, *30*(3), 432–444. https:// doi.org/10.1080/09687599.2015.1019042

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