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Social vulnerability and the impact of policy responses to COVID-19 on disabled people

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Abstract

In this paper, we propose a conceptual framework for understanding the impact of the policy responses to COVID-19 on disabled people. These responses have overwhelmingly focused on individual vulnerability, which has been used as a justification for removing or restricting rights. This suggests the need to shift the attention towards the social determinants of disabled people's vulnerability. We do this by bringing literature on social vulnerability in disaster risk management or 'disaster studies' in contact with key concepts in disability studies such as the social model of disability, independent living, intersectionality, and biopower. Empirically, we draw on the findings of the global COVID-19 Disability Rights Monitor (www.covid-drm. org), as well as on reports from academic journals, civil society publications, and internet blogs. We put the proposed conceptual framework to work by developing a critical analysis of COVID-19 policies in three interrelated areas-institutional treatment and confinement of disabled people, intersectional harms, and access to health care. Our conclusion links this analysis with strategies to address disabled people's social vulnerability in post-pandemic reconstruction efforts. We make a case for policies that address the social, economic, and

Abbreviations: BAME, Black, Asian and minority ethnic expert; COVID-19 DRM, COVID-19 Disability Rights Monitor; SAGE, Scientific Advisory Group for Emergencies; SARS-CoV-2, severe acute respiratory syndrome coronavirus 2.

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environmental conditions that disproportionately expose disabled people to natural disasters and hazards.

KEYWORDS

biopower, COVID-19, deinstitutionalisation, disaster studies, independent living, intersectionality, social model of disability, social vulnerability

INTRODUCTION

The infectious coronavirus disease or COVID-19, caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), spread globally at the beginning of 2020. In response, countries around the world started implementing measures to cope with the ensuing pandemic. In this paper, we propose a conceptual framework built around the concept of 'social vulnerability' to analyse critically these policy responses to COVID-19 from the perspective of their impact on disabled people. The proposed framework distinguishes between the individual impact of the coronavirus and the collective impact of the policy responses to the pandemic. In many cases, the latter have been more harmful for disabled people than the coronavirus itself, as global studies on the impact of COVID-19 on disabled people testify (Brennan et al., 2020). We propose a conceptual framework which offers an alternative to the policy focus on comorbidity and individual characteristics.

To do this, we bring social studies of vulnerability and disaster risk management (Flanagan et al., 2011, 2018; Juntunen, 2005) in contact with key concepts in disability studies such as the social model of disability, independent living, intersectionality, and biopower. The result is a comprehensive framework able to grasp in their complexity the socioeconomic, environmental, and intersectional factors that expose disabled people to the virus, including the overwhelmingly disability-exclusive public management of the COVID-19 pandemic. The need for a comprehensive approach in examining the impact of COVID-19 on disabled people is clearly identified in a study by the British Office for National Statistics (2020: 3):

"No single factor explains the considerably raised risk of death involving COVID-19 among disabled people, and place of residence, socio-economic and geographical circumstances, and pre-existing health conditions all play a part; an important part of the raised risk is because disabled people are disproportionately exposed to a range of generally disadvantageous circumstances compared with nondisabled people."

Our point of departure is the general observation that throughout the world, responses to COVID-19 have been disability-exclusive rather than disability-inclusive. Disability injustices associated with COVID-19 policies have included inaccessibility of public information and communications, inaccessibility of hygienic facilities, reductions in community supports (including personal assistance), enhanced institutionalisation and harms inflicted on disabled people in residential institutions, shortages of support staff, lack of access to food, medicines and essential supplies, ableist microaggressions and violence in public (including harassment and abuse), and discrimination in provision of health care (Antova, 2020; Brennan et al., 2020; Morris, 2021; Safta-Zecheria, 2020; Shakespeare et al., 2021). We argue that these injustices have been underpinned by individualised and medicalised understandings of vulnerability. As an alternative, we

propose to conceptualise vulnerability as a feature or outcome of social arrangements rather than as a characteristic of individual bodies and minds.

We accept that '[u]nderstanding what drives social vulnerability is an essential step toward helping communities to acquire the resources and strategies needed to minimize losses from disasters' (Bergstrand et al., 2015: 392). However, during the COVID-19 pandemic, the social construction of vulnerability has been more readily recognised with regard to other marginalised groups that have been disproportionately impacted by COVID-19 than with regard to disabled people. Research has identified a wide range of socio-economic and environmental factors that have placed people at higher risk of infection and death. Poverty, inequality, overcrowded living conditions, and the precarious conditions of low paid workers have all been highlighted as social factors that increase exposure to COVID-19 (Anderson et al., 2020; Kantamneni, 2020; Machin, 2021; Patel et al., 2020). Yet this is not unique to the COVID-19 pandemic. For decades, reports have identified that 'structural racism, which drives the social marginalization of racial/ ethnic minorities and other vulnerable populations, leads to inequities in morbidity and mortality' (Ford, 2020: 184). In their analysis of the impact of the COVID-19 pandemic on the Irish Traveller and Roma communities, Villani et al. (2021) make an important distinction between 'health inequality' and 'health inequity'. Health inequality 'simply indicates differences in health which are natural', whereas 'health inequity is a value judgment, referring to differences which are avoidable and unfair' (Villani et al., 2021: 47). Yet these perspectives have been largely overlooked in relation to disabled people who have been assumed to be inherently more vulnerable to the coronavirus, as is reflected in policy documents which emphasise the high prevalence of medical conditions among disabled people (e.g. NHS, 2020).

Despite this focus on individual vulnerability, existing protections have been strategically reduced. In the UK, for example, the Coronavirus Act 2020, introduced as emergency legislation in March 2020, diminished the obligations of local authorities to assess and respond to disabled people's needs, which created 'a definite potential for many disabled people in England to not have their needs met during the period in a situation where failing to meet their needs is not considered a human rights violation' (Antova, 2020: 814). Together with this, policy documents have exclusively focused on disabled people's clinical predisposition to medical conditions. This medicalisation of disability has been a prominent feature of policy guidelines such as the 'Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic' of the British National Health Service (NHS, 2020: 2):

"People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely. At least 41% of them die from respiratory conditions. They have a higher prevalence of asthma and diabetes, and of being obese or underweight in people; all these factors make them more vulnerable to coronavirus. There is evidence that people with autism also have higher rates of health problems throughout childhood, adolescence, and adulthood, and that this may result in elevated risk of early mortality."

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To expose the impact of policy responses to COVID-19 on disabled people, we draw on evidence provided by disability organisations and disability studies scholars. Our primary source is the global COVID-19 Disability Rights Monitor (COVID-19 DRM) initiative, which conducted rapid, emergency human rights monitoring between April and August 2020. The COVID-19 DRM identified the impact of the pandemic on disabled people as 'catastrophic' and called for 'urgent action' to safeguard disabled people's rights (Brennan et al., 2020: 7). We also draw on reports on COVID-19 and disability published in academic journals (Antova, 2020; Safta-Zecheria, 2020), by civil society actors (Ferguson & Gall, 2021), and in internet blogs (Davis, 2020; Morris, 2021; Shakespeare et al., 2021).

In addition, we refer to a wealth of studies of the social determinants of vulnerability in disaster situations (Bergstrand et al., 2015; Flanagan et al., 2011, 2018; Ge et al., 2017; Juntunen, 2005; McEntire et al., 2010; Peek & Stough, 2010; Phillips & Morrow, 2007). This approach enables us to highlight the common structural features of injustices experienced by disabled people during the COVID-19 pandemic and injustices experienced by other marginalised groups that are routinely identified as 'vulnerable' (Anderson et al., 2020; Kantamneni, 2020; Kim & Bostwick, 2020; Kirby, 2020; Patel et al., 2020; Pausé et al., 2021; Platt & Warwick, 2020). It also allows for examination of the 'interaction of disasters and risk with gender, class, and other axes of inequality' including race and ethnicity (Tierney, 2007: 501), among which we focus on disability.

We first introduce our conceptual framework and then apply it to analyse the impact of the policy responses to COVID-19 on disabled people in three interrelated areas—institutional treatment and confinement of disabled people, intersectional harms, and access to health care. These three areas have been selected because of their foregrounding in the COVID-19 DRM (Brennan et al., 2020), which reflects their significance for understanding the social determinants of disabled people's vulnerability during the COVID-19 pandemic.

CONCEPTUAL FRAMEWORK: REFRAMING THE VULNERABILITY DISCOURSE

The concept of 'vulnerability' has been contentious and contested in disability studies. It has been associated with the medical model of disability, which portrays disability as an individual problem or a personal tragedy (Burghardt, 2013). Roulstone et al. (2011: 352) have argued that the concept 'play[s] down individuals' rights to independent living and full judicial rights'. Taking a different but no less critical approach, (Shakespeare and Watson 2001: 27) have advocated for universalising vulnerability: 'we are all impaired. Impairment is not the core component of disability ..., it is the inherent nature of humanity.' A related line of critique has targeted the normativity of non-vulnerability: 'It is... the normative, invulnerable body of disablist modernity that is the problem.' (Hughes, 2007: 681) In a similar vein, (Davis (2002: 31) has proposed a 'dismodernist ethics' where '[i]mpairment is the rule, and normalcy is the fantasy'.

Instead of abandoning or universalising the idea of individual vulnerability, we focus on the social determinants of vulnerability by engaging with literature on 'social vulnerability' in disaster risk management or 'disaster studies'. We believe that this approach provides the best ground for criticising policy responses to COVID-19 from the perspective of their impact on disabled people. Burghardt (2013: 558) suggests that 'it is to the benefit of disability scholarship that other disciplines have begun to deconstruct traditional, person-centred definitions of vulnerability, and to recognize socially constructed forces that contribute to its manifestation'. Such

a multidisciplinary approach to understanding vulnerability has been advocated in research on natural disasters and hazards. For instance, (McEntire et al., 2010: 52) have argued that:

"integrating field research discoveries into a more complex approach to vulnerability will assist in the analysis of what makes a hazard a disaster and uncover how we can assist all vulnerable populations in becoming more resistant and resilient."

Scholars in other disciplines have conceptualised 'social vulnerability' as a condition of preexisting social structures where certain social factors such as overcrowded living conditions exacerbate the effects of natural disasters on marginalised groups (Bergstrand et al., 2015; Ge et al.,
2017), including the effects of disasters like the COVID-19 pandemic (Kim and Bostwick, 2020).

From this perspective, individual vulnerability is a function of social vulnerability, reflecting preexisting inequalities in that some groups are more prone to death, injury, and economic loss than
others (Peek & Stough, 2010; Wisner et al., 2004). The concept of social vulnerability is useful for
understanding the unequal outcomes of disasters and health crises such as COVID-19 by linking
social conditions and risk exposure. Structural factors such as poverty, segregation, and discrimination affect community's exposure to risk and ability to recover from disaster events (Kim and
Bostwick, 2020).

The concept of 'risk' is not innocent itself, as research in sociology of health suggests (Petersen & Wilkinson, 2007). Perceiving health in terms of 'risk' results in individualising representations that obscure the social determinants of both health risks and vulnerability. Indeed, the concepts of 'risk' and 'vulnerability' have been inseparable in public discourses during the COVID-19 pandemic. By summoning the authority of rational calculation, cost-benefit analysis, and scientific reasoning (Wilkinson, 2006: 4), representations of health risks have coalesced with representations of individual vulnerability to bolster biopower—i.e. to justify surveillance, shape identity categories, and responsibilise subjects. At the micro-level, critical ethnographies of hospital care for older people have shown how governing risk may result in defensive practice, disconnect between staff and patients, and 'othering' of patients (Hillman et al., 2013). Attempts to manage risk during COVID-19 have resulted in similar outcomes for disabled people in residential institutions. Our analysis of social vulnerability also resonates with the social scientific studies of suffering within the sociology of health (Wilkinson, 2006). Attending to the social aspects of suffering helps highlight the structural violence of the policy responses to the pandemic that have increased the social suffering of disabled people by framing them as 'being at risk' and, therefore, individually vulnerable. These insights are congruent with some of the key ideas that have shaped social scientific research on disability since the 1980s, including the social model of disability, independent living, intersectionality, and biopower.

The social model of disability and the independent living philosophy have emerged from within the disability rights movement and have been further elaborated within the academic discipline of disability studies. In its essence, the social model of disability is a critique of disabling barriers, 'a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment' (Oliver, 2009: 47). The idea has developed and evolved since its introduction in the 1980s. Within disability studies, the social model has been criticised for ignoring impairments, personal experience, and, more generally, individual difference. Critical realists have criticised the social model for downplaying the intrinsic restrictiveness of impairments (e.g. Shakespeare & Watson, 2001), and social constructionists—for ignoring the social construction of impairments (e.g. Davis, 2002). A related point is that the category of 'disability' is not homogeneous, although the social model theorists have sometimes emphasised

sameness to bolster collective identity and political purpose (Oliver, 2013: 1025). However, the category of 'disability' includes people with fluctuating conditions and is context dependent, for example, relative to the life course and age-related expectations, or geographical location. In recognition of this, we emphasise that the experiences of disabling barriers during the pandemic have been shaped by experiences of impairments, while both have been socially constructed in interaction with other axes of difference such as gender, race, age, and so forth. Notwithstanding such variations in experiences, it is the structural barriers that have driven the social marginalisation of disabled people and have led to health inequities in morbidity and mortality (Ford, 2020).

The independent living philosophy is about self-determination of disabled people through choice and control, 'an assertion that disabled people should have the same opportunities for choice and control as non-disabled people' (Morris, 2004: 427). A key obstacle to self-determination of disabled people is their institutional treatment and confinement. The social model of disability and the independent living philosophy have complemented each other—(Barnes 2007: 349) points out that the development of the social model was inspired by 'the thinking behind the concept of independent living' (Barnes, 2007: 349), while for Debbie Jolly (2009: 3), 'the social model of disability underpins the aims of the independent living movement'.

The perspective of intersectionality reveals the situation of people marginalised on multiple grounds. Originally developed to explore 'the various ways in which race and gender intersect in shaping structural, and representational aspects of violence against women of color' (Crenshaw, 1991: 1244), intersectionality could help illuminate intra-group differences in experiences of injustice within the broader group of disabled people. In disability studies, this type of analysis has been pioneered by disabled feminists in the beginning of the 1990s (Begum, 1992; Morris, 1993) and since then has become a prominent feature of disability research (Berghs et al., 2017).

The idea of biopower has been imported into disability studies from the work of Michel Foucault and its commentators (Tremain, 2005). Biopower is power that works primarily by managing (regulating, transforming, enhancing, monitoring, categorising) life, as opposer to 'sovereign power' that works primarily by restricting (taking, denying, impairing, seizing, suppressing) life (Foucault, 1978). The concept illuminates 'what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life' (Foucault, 1978: 143), which gets to the core of disabled people's experiences of different forms of professionalised 'care'. In (Foucault's 1978: 139) original account, biopower has two forms—disciplining individual bodies to enhance their vitality ('anatomo-politics of the human body') and regulating the vitality of whole populations ('bio-politics of the population'). Both these forms of biopower are relevant for discussions of disability, and particularly of disabled people's experiences of access to health care during the pandemic.

In our present analysis of the policy responses to COVID-19 from the perspective of their impact on disabled people, we combine all these perspectives. We make recourse to the social model to argue for a reframing of the mainstream vulnerability discourse to focus on the social arrangements that force disabled people into states of vulnerability. We draw on the independent living philosophy to criticise the institutional treatment and confinement of disabled people during the pandemic that has itself been justified by the policy makers by presenting disabled people as individually and medically vulnerable. The perspective of intersectionality helps explore intragroup differences in experiences of the policy responses to COVID-19 within the broader group of disabled people. Such intra-group differences are sometimes exploited by the mainstream vulnerability discourse to justify exclusion (as in the idea that some disabled people necessarily require institutional care because of the extent of their physical or mental vulnerabilities). Finally, analyses of biopower illuminate how professional interventions, underpinned by individualised

understandings of vulnerability and aimed at 'caring' for disabled people's health and wellbeing, amount to controlling disabled people's lives in non-exceptional times, and, moreover, why such 'caring' interventions have been denied to some disabled people during the exceptional period of the pandemic. We focus primarily on examples of policies in the United Kingdom, but we also make global observations by drawing on the findings of the COVID-19 DRM (Brennan et al., 2020).

INSTITUTIONAL TREATMENT AND CONFINEMENT

Historically, the institutionalisation of disabled people has been a preferred policy response to disabled people's perceived individual vulnerability, challenged only partially by the reform of 'deinstitutionalisation' (Mladenov & Petri, 2020). The concept of 'social vulnerability' and the critique of institutionalisation articulated by the advocates of independent living (Evans, 2002; Jolly, 2009; Morris, 2004) make it possible to expose institutionalisation as a flawed response to the social vulnerability of disabled people that actually enhances their individual vulnerability. The latter is precisely what has happened during the COVID-19 pandemic. As evidence, a study by the (Office for National Statistics, 2020: 3) found that living in care homes or institutional settings has been the single biggest risk factor for people with learning impairments in England. Indeed, all the socio-economic and geographical circumstances and pre-existing health conditions considered have made some difference to the risk of people with learning impairments, but the largest effect has been associated with living in a care home or other congregated settings.

The problems that characterise residential institutions in general (Mladenov & Petri, 2020) have either worsened or become more visible since the time of the first COVID-19 lockdowns in March 2020. These problems have included grave violations of the rights to life and liberty of the institutional residents. The right to life in residential care has been undermined through neglect, denial of access to health care, failure to implement social distancing and to provide personal protective equipment (PPE), understaffing or inadequate staffing, overmedication, and lack of mental health support. The right to liberty of the residents has been violated through intensification of internal surveillance and control, as well as through bans on leaving institutions and on visits that have enhanced individual suffering. In Britain, the campaign 'Rights for Residents' has appealed to the politicians to 'find a more humane and nuanced solution that balances the risk of contracting Covid-19 against the devastating mental and physical deterioration we are witnessing [amongst institutional residents]' (Morrison & Mayhew, 2021: 12). The campaigners have reported that many residents have 'stopped eating and drinking as they exercise the only liberty left to them and choose to give up the will to live' (Morrison & Mayhew, 2021: 12).

Evidence collected by the COVID-19 DRM from different countries confirms that during the COVID-19 pandemic, the consequences of forcing people to live in congregated settings to receive support have been catastrophic. A respondent from Canada characterised a residential institution in Quebec as 'dangerously understaffed. There were people dead in their beds, others laying on the floor and some others with three layers of diapers and dehydrated' (Brennan et al., 2020: 23); a Greek respondent characterised psychiatric institutions in Greece as 'hermetically sealed with more absolute restrictions than before, with no possibility of visits, with no advocacy services and with no independent monitoring' (Brennan et al., 2020: 24); a respondent from India speculated: 'Perhaps they [the residents] don't even know what is going on outside!' (Brennan et al., 2020: 25) In the early days of the pandemic, residential institutions in Southern and Eastern Europe have been exposed as infections hotspots due to international flows of migrant care workers (Safta-Zecheria, 2020: 840).

Notably, in some cases, COVID-19 policies recognised the social vulnerability of homeless people who were identified as vulnerable due to overcrowded living conditions in hostels or homeless shelters and the ensuing inability to socially distance. As a result, in the UK, the voluntary sector, local and central governments, doctors, and other agencies worked together to decongregate homeless persons and ensure that they were housed in places where they had their own bedroom and bathroom to avoid outbreaks (Kirby, 2020). Across the world, policy responses to disabled people living in overcrowded institutions were strikingly different. Rather than implementing emergency deinstitutionalisation, institutions around the world were sealed off from the outside world. Furthermore, there were reports that homeless disabled people were rounded up, detained and sent to institutions (Brennan et al., 2020). It seems that the mere presence of impairment is enough to obscure the social dimensions of one's vulnerability.

This has happened against the background of having the social vulnerability of disabled people enhanced through disintegration or reduction in community supports. For many disabled people around the world, access to food and medication has become more difficult since the beginning of the pandemic: 'Respondents from high-, middle- and low-income countries reported remarkably similar barriers to accessing essentials'. (Brennan et al., 2020: 42) Information about COVID-19 concerning prevention, testing, treatment, restrictions, and support has been missing, inadequate, confusing, or inaccessible. Social distancing and other restrictions have undermined both personal assistance for disabled people and support for informal carers. Opportunities for independent living have drastically deteriorated. In Scotland, the disability advocacy organisation Inclusion Scotland reported that 'early in the pandemic many people had their care packages withdrawn overnight or severely reduced' (Nisbet, 2021: 18). A respondent to the COVID-19 DRM from Italy stated: 'I am afraid that my mum will die of exhaustion and then I will die without her assistance.' (Brennan et al., 2020: 29) Lack of community supports has contributed to enhanced institutionalisation. As a result, flawed responses to disabled people's social vulnerability have enhanced individual vulnerability in a vicious cycle of self-justification.

INTERSECTIONAL HARMS

Scholars of disaster risk management have explored intersectionality in conjunction with social vulnerability to highlight the multiplicity of factors that disproportionately expose some people to natural disasters and hazards. The perspective of intersectionality has enabled social scientists to understand people's vulnerabilities during disasters in structural rather than individual terms, as 'the result of different and interdependent societal stratification processes that result in multiple dimensions of marginalisation' (Kuran et al., 2020: 2). Moreover, combining the ideas of intersectionality and social vulnerability allows for a complex and nuanced understanding of the social structures that force people marginalised on certain grounds into states of vulnerability:

"Different axes of inequality combine and interact to form systems of oppression – systems that relate directly to differential levels of social vulnerability, both in normal times and in the context of disaster. Intersectionality calls attention to the need to avoid statements like 'women are vulnerable' in favour of a more nuanced view." (Tierney, 2019: 127–128)

However, most policy documents on populations that are at high risk of contracting coronavirus focus on single demographic factors such as age, race, ethnicity, or weight in isolation, instead of examining the complex intersections between these characteristics (Peek & Stough,

2010; Phillips & Morrow, 2007). Studies that treat demographic factors in this way fail to acknowledge the multiple identities of disabled people. Such studies risk representing people as one-dimensional or defined by a single characteristic—in the case of disabled people, this is usually their impairment. Moreover, the focus on single demographic factors is problematic because it diverts attention from cross-cutting structural issues (inequality, exclusion, social control) by foregrounding individual traits, which dilutes the responsibility of health systems and governments to make systemic changes (Pausé et al., 2021). This approach is also dangerous because it stigmatises certain body types (the 'fat', or 'frail', or 'impaired' bodies). It has led policy makers to adopt a medical model of risk and vulnerability by:

"targeting people with multiple comorbidities after identifying them as the most vulnerable. However, this medical model of disease risks ignoring social factors, which can increase exposure to and mortality from coronavirus" (Patel et al., 2020: 110).

Intersectional issues tend to be overlooked in commonly available statistics about infections, deaths, hospitalisations, and vaccinations. Current reporting of COVID-19 in policy documents is based on aggregate figures which hide underlying social and economic inequalities that increase susceptibility and exposure of marginalised groups (Ali et al., 2020). For example, ethnic minority groups in the UK (with the exception of white Irish people) have been more vulnerable to contracting and dying from COVID-19 because they are more likely to live in overcrowded housing conditions, more likely to work in health and social care roles, and more likely to be economically vulnerable under the pandemic restrictions:

"Simply comparing mortalities with overall populations fails to take account of key characteristics of different groups that we would expect to lead to different outcomes in the aggregate, such as demographics and place of residence. ...some are more likely to be economically vulnerable under current restrictions than others, and this dimension is crucial for painting a full picture of ethnic inequalities arising from COVID-19." (Platt & Warwick, 2020: 2)

In addition, despite the disproportionate impact of COVID-19 on ethnic minorities, they have not been well represented in the policy making bodies that designed the responses to the pandemic. For example, (Yarrow and Pagan (2021: 92) point out that in the UK, the Scientific Advisory Group for Emergencies (SAGE) is 'made up primarily of [white] men (16 men and seven women) and only one black, Asian and minority ethnic (BAME) expert'.

Similarly to people from ethnic minorities, disabled people have been more vulnerable to contracting and dying from COVID-19 because of their social and economic marginalisation: '[f]or disabled people in general, measures of deprivation were the biggest factor accounting for some of the increased risk of catching and dying from the virus' (Morris, 2021: n.p.). Moreover, those disabled people who have deviated from the intersectional norm of the able-bodied, adult, male, financially secure urban dweller in multiple ways have experienced stronger marginalisation in comparison to those whose deviation has been restricted to being 'disabled'. Such intragroup disparities have been exacerbated by digital divides and inaccessible COVID-19 policy briefings (Shakespeare et al., 2021). As we already noted, the category of 'disability' is itself non-homogeneous and is characterised by impairment/disability hierarchies (Sherry, 2016) where physical impairments tend to get most attention by policy makers and researchers, whereas intellectual and psychosocial impairments get least attention.

During the COVID-19 pandemic, multiple deviations from the intersectional norm identified above have conditioned subgroup-specific injustices. For instance, Irish 'Traveller women residing in women's refuges, and single mothers living in trailers with several children with no running water, toilets and electricity', were found to be excessively affected by the lockdowns (Villani et al., 2021: 51). Moreover, certain subgroups have experienced not only enhanced but also idiosyncratic injustices. Let us consider several examples from the COVID-19 DRM. First, the intersection between disability and age has conditioned exclusion of disabled children from education due to shifts to online schooling characterised by inaccessible online teaching: 'respondents from Malawi and Moldova described how children with disabilities were excluded from remote learning because they did not have access to technology' (Brennan et al., 2020: 36; see also Shakespeare et al., 2021). A related problem experienced by disabled children and their families has been exclusion from disability supports available in educational settings (e.g. therapy, rehabilitation and counselling provided at schools).

Second, the intersection between disability and gender has conditioned exposure to gender-based violence due to lockdown restrictions and inaccessibility of support for victimised disabled women: 'There were reports of sexual assault, domestic violence, and police brutality against women and girls with disabilities.' (Brennan et al., 2020: 37) Third, the intersection between disability and financial status has conditioned exposure of homeless disabled people to measures of compulsory institutionalisation, compounded by lack of adequate community supports: 'homeless persons with disabilities were detained against their will and moved to institutional settings that were inaccessible and unsafe' (Brennan et al., 2020: 38). The COVID-19 DRM has reported cases of compulsory institutionalisation in Uganda, Rwanda and India (Brennan et al., 2020: 38).

Finally, the intersection between disability and place of residence has meant that disabled people living in remote and rural areas have experienced enhanced levels of digital exclusion during lockdowns. The access to other services and essential goods such as food and medication has also been more difficult for this subgroup of disabled people: 'there were concerns that they did not have adequate access to information in areas without access to the internet, phones, and other technologies' (Brennan et al., 2020: 39). In all of these cases, considering disabled people's vulnerability from an intersectional perspective makes its social dimension more conspicuous. In other words, the approach of intersectionality helps prevent the individualisation and medicalisation of disabled people's vulnerability.

ACCESS TO HEALTH CARE

Michel Foucault's (1978, 1991) work on biopower has helped expose social support provided in the form of education, employment support, health care, social care, and psychological counselling as an exercise of power, a means of control, 'conduct of conduct' (see also Lupton, 1995; Rose, 1999). Disabled people's subjection to biopower (including anatomo-political disciplining of individual bodies and bio-political regulations of whole groups) has been more conspicuous than the subjection of non-disabled people because disabled people have been immersed in biomedical practices such as diagnosis, treatment, and biomedical research to a much greater extent (Tremain, 2005). The obstinacy of perceiving disabled people as *individually* vulnerable stems from this immersion.

During the COVID-19 pandemic, being recognised as individually vulnerable has drastically restricted disabled people's freedom of movement and/or has imposed new mechanisms of surveillance, as in the case of 'shielding' in the UK, where disabled people have been ordered to stay

at home.² The extreme case of this use of the category of individual vulnerability to control disabled people's lives has been, of course, the institutional treatment and confinement of disabled people (Brennan et al., 2020).

This use of the concept of biopower to understand disabled people's situation is commensurate with, yet distinct from critical sociologies of biopower in public health (Lupton, 1995). Indeed, the policy responses to the pandemic were so successful in reconfiguring individual rights because during COVID-19, people were mostly governed through consent—in many instances (e.g. with regard to hygiene, face masks, vaccinations), self-management has largely superseded external constraints. We accept that, despite the emergency measures and restrictions, public health approaches to COVID-19 have been grounded in consent rather than coercion—a feature of biopower that, according to (Lupton 1995: 10), constitutes the essence of health promotion. Indeed, most people have been regulated through voluntary self-management rather than involuntary restrictions during COVID-19. However, we argue that in the case of disabled people, the strategies of managing public health during the pandemic have also made recourse to a more sinister, negative and life-negating aspect of biopower that has supplemented and, in some cases, displaced the injunctions to self-manage and self-regulate.

The general corollary is that biopower works differently on different groups in different contexts and in different historical periods.

The emergency created by the COVID-19 pandemic has shifted the biopolitical interventions that have shaped the lives of disabled people towards *thanatopolitics*—the politics of administering death. The strong link between biopolitics and thanatopolitics has been most powerfully made in the work of the Italian philosopher Giorgio Agamben (1998), who has argued that Nazi concentration camps have revealed the true thanatopolitical face of biopolitics (for a discussion, see Tierney, 2016). This radical perspective suggests that every biopolitics is essentially thanatopolitics, not least because enhancing the life of some entails decisions about letting or making others die (see Nasir, 2017). Drawing on this intellectual tradition, the disability studies scholar (Davis 2020: S138) has criticised triage practices during the COVID-19 pandemic as expressions of thanatopolitics:

"Any metric used for determining who should get limited resources will inevitably be drawn into a eugenics sinkhole. It is here that biopolitics and thanatopolitics display a unity that might have seemed to have been in opposition. The urge to let live and the urge to let die morph nicely into each other. In order to let live, doctors must let die."

For the purposes of the present analysis, it suffices to argue that in times of emergency such as the one created by the COVID-19 pandemic, the biopolitical principle of enhancing life tends to shift towards the thanatopolitical principle of letting or making die in practices that concern the life and health of those disabled people considered particularly frail. This process is conditioned by an ontological invalidation of disabled people (Hughes, 2007) whose expression in disability policies is the overwhelming focus on disabled people's individual vulnerability. This focus has disastrous effects when disabled people get subjected to utilitarian calculations. Looking at the guidelines for allocation of medical resources in the UK, (Antova 2020: 815) has made the point that 'there are instances in the NICE and BMA guidelines that allow for unequal treatment to potentially take place disguised as an attempt to prioritise insufficient resources, or as a utilitarian concern for maximising health outcomes for that part of the population considered healthier (having a higher chance to survive or benefit from treatment)'. The COVID-19 DRM report has also revealed and criticised the allocation of limited medical resources during medical triage for discriminating against disabled people:

"Several written testimonies from Canada, the UK, the USA, Austria, Luxembourg, the Netherlands, Georgia, France, and South Africa said that their governments indicated that hospital triage should discriminate against COVID-19 patients with disabilities in the event of a shortage of hospital places. Triage guidelines explicitly or implicitly instructed health workers to decide on a person's right to life based on their disability." (Brennan et al., 2020: 42)

This discrimination in access to health care suggests that a biopower-aware analysis of policy responses to COVID-19 from the perspective of 'social vulnerability' needs to consider both the mechanisms for controlling disabled people through biomedical and healthcare practices, and the mechanisms for letting disabled people die through policies based on a utilitarian calculus (on utilitarianism in COVID-19 policies, see Delanty, 2020). In the prolonged state of exception imposed by governments around the world as a response to the pandemic, conspicuous surveillance and disciplining of bodies has co-existed with conspicuous decisions to let die or even make die (thanatopolitics). We may even go a step further with Davis (2020) and argue that it has been the immersion of disabled people in practices of biopower that has rendered them vulnerable to thanatopolitical interventions. Finally, linking this argument to our preceding discussion of intersectionality adds a layer of complexity, for both biopower and thanatopolitics tend to work differently on different sub-groups within presumably homogenous groups. Thus, for example, considering disabled women as more 'individually vulnerable' than disabled men is likely to lead to both enhanced regulation and greater likelihood of being denied health care in a situation of emergency such as the one created by COVID-19.

CONCLUSION

In this paper, we developed a conceptual framework for understanding the impact of the policy responses to COVID-19 on disabled people that revolves around the notion of 'social vulnerability'. We thus recognise the salience of the more general category of 'vulnerability' for disability studies, but only when its social dimension gets emphasised. In the past, disability scholars have sought to appropriate this category for the purposes of disability research by arguing that 'we are all impaired' (Shakespeare & Watson, 2001). This universalisation of individual vulnerability has been used to expose autonomy, self-possession, self-control, and self-sufficiency as modern or, more recently, neoliberal myths. However, to posit individual vulnerability as a common ontological ground of humanity 'adds pessimism to essentialist naturalism' (Hughes, 2009: 402) by asserting the reality of pre-social, purely natural bodies.

Hughes's (2009) point is that universalising individual vulnerability or 'frailty' may (wittingly or unwittingly) reaffirm perceptions of biology as destiny, obscure the social construction of the body as 'lived' in everyday life, and trivialise disabled people's experiences of disability-specific oppression. Elsewhere, Hughes (2007) has argued that, instead of affirming the universality of individual vulnerability, disability studies needs to deconstruct the modern opposition between vulnerable and invulnerable by making recourse to postmodern analyses of the 'wounded', the 'monstrous' and the 'abject'. We are sympathetic to this project but, as (Hughes 2007: 408) also points out, it remains more concerned with 'the imaginary and the symbolic' rather than with 'the painful material realities of exclusion and oppression that are the ubiquitous bedfellows of disability'. The concept of 'social vulnerability' helps focus on the latter while avoiding both biologism and one-sided culturalism.

The embeddedness of people's bodies and minds in structures of power, economy, and discourse is a key lesson to be learned from our critical analysis of the impact of policy responses to COVID-19 on disabled people. From such a perspective, in most cases, the vulnerability of individual bodies and minds during the pandemic has been a function of the social and political structures that have prevented people from acting or from exercising choice and control, or that have disciplined them into acting in specific ways that have gone against their interests. In essence, we argue that the catastrophic impact of the policy responses to COVID-19 on disabled people throughout the world can best be understood through a social conception of vulnerability.

Our purposed conceptual framework draws on key ideas that have shaped disability studies over the last several decades, including the social model of disability, independent living, intersectionality, and biopower. However, it also goes beyond disability studies by engaging with studies of disaster risk management to reframe the vulnerability discourse towards focusing on the social determinants of disabled people's vulnerability. That said, we agree with the sociologists of health that the concept of 'risk' itself should be approached critically because of its individualising potential and biopolitical resonances, clearly evident in policy responses to the pandemic. In addition, it is important to emphasise that COVID-19 has not happened in a vacuum. Other disasters, including armed conflict, humanitarian disasters, and natural disasters, have coincided and overlapped with the pandemic. We have indicated how the studies of social determinants and policies responding to such crises could contribute to our understanding of the impact of COVID-19's policies on disabled people.

Policy responses to the pandemic provide examples of how different understandings of vulnerability are applied in practice. Policy responses that focus on impairment and individual vulnerability justify the segregation, isolation, institutionalisation and denial or removal of basic human rights, including the right to life itself (Brennan et al., 2020). These policy responses are based on the presumption that disabled people are inherently more vulnerable to the coronavirus. In contrast, our framework purposes that policy responses should focus on social vulnerability and disabling barriers that force disabled people into states of vulnerability (overcrowded institutions being one example of this). Such an approach is commensurate with analyses of the social determinants of health, and the concept of health inequity (Villani et al., 2021) is particularly valuable for understanding the structural inequalities that determine social vulnerability. Such an approach also calls for a rights-based response to disasters such as the COVID-19 pandemic that is in line with the UN Convention on the Rights of Persons with Disabilities, which is grounded in the social model of disability and supports the independent living philosophy.

In more general terms, policy responses to disasters and post-disaster reconstruction that are guided by an understanding of the social determinants of vulnerability espoused in this paper would prioritise universal and unconditional support, as opposed to conditionality, benefit sanctions, and corrective and punitive interventions. Examples of policies that recognise social vulnerability are 'housing first' approaches to homelessness and 'universal basic income' approaches to social security. Free and universal access to health care is key—we need 'to help unconditionally, irrespective of costs, those who need help, to enable their survival' (Žižek, 2021: S5). However, survival is not enough—the disability studies perspective suggests that we need to emphasise 'the duty to empower' on a par with 'the duty to care' (Elder-Woodward, 2021: 13). Policy responses to disasters and post-disaster reconstruction that emphasise 'the duty to empower' would prioritise community services based on independent living principles, refuel deinstitutionalisation programmes, and provide additional and targeted support to people with intersecting needs. Such policies would ensure equal access to health care unprejudiced by the identification of extensive

support needs, thus undermining thanatopolitics, but would also remain vigilant towards biopower in care by highlighting and challenging surveillance, victim-blaming, and responsibilisation in policy interventions aimed at restoring and maintaining health and wellbeing.

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AUTHOR CONTRIBUTIONS

Ciara Brennan: Conceptualization (equal); Formal analysis (equal); Writing-review & editing (supporting).

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available at https://www.covid-drm.org.

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ENDNOTES

- The COVID-19 Disability Rights Monitor resulted from a concerted effort of seven disability rights organisations to assess the impact of the national governments' responses to the pandemic on disabled people throughout the world. The initiative has included collecting and analysing data on the impact of COVID-19 on disabled people, maintaining a dedicated website (www.covid-drm.org), writing and publishing a report in October 2020 (Brennan et al., 2020), and organising webinars and other events to disseminate the findings. Data collection took place between 20 April and 8 August 2020 through a survey consisting of 40 closed and open-ended questions formulated in consultations among the implementing organisations. The survey received 2,152 responses from 134 countries, with the voices of disabled people (n=863) and disability organisations (n=525) clearly dominating the responses. The COVID-19 DRM arguably created 'the largest internationally comparable data set on the experiences of persons with disabilities during the COVID-19 pandemic' (Brennan et al., 2020: 19).
- ² See: https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19
- ³ Notably, this has also been the case with older people during the pandemic: 'Ambulance staff were told to reduce admissions by not taking the elderly to hospital.' (Findlay, 2021: 7) The treatment of older people in the times of COVID-19 is described by (Findlay, 2021: 7) as 'the greatest human rights scandal to face older people in Scotland in my lifetime'. Utilitarian approaches to COVID-19 policies have subjected both older people and disabled people to an ontological invalidation with deadly consequences as argued by Morris (2021: n.p.), 'in the case of disabled (and older) people, pre-existing prejudices about the quality, or indeed value, of someone's life can get in the way' of co-producing decisions about treatment. Moreover, the parallel injustices experienced by disabled people and older people during the COVID-19 pandemic have converged in cases where disability and old age intersect.

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