

COVID-19 Pandemic and Disability: Essential Considerations

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ABSTRACT

People with disabilities have greater healthcare needs and are more likely to experience poor health, however, their access to healthcare remains compromised compared to people without disabilities. Despite this well recognised need, people with disabilities often face barriers to accessing healthcare and they face additional risks to their well-being, because of the ongoing COVID-19 pandemic. In this paper, we posit that people with disabilities are vulnerable in the context of the COVID-19 pandemic. We demonstrate this vulnerability through briefly highlighting eight key considerations, as they relate to disability and COVID-19. We conclude that both inaccessible healthcare systems and the presence of underlying health conditions put people with disabilities at additional risk. Further, vulnerability to severe illness and death, post-contracting COVID-19, is exacerbated by the interaction between impairments and personal and environmental barriers existing at different levels, resulting in a

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disproportionately negative impact for people with disabilities. It is thus not sufficient to look only at underlying medical conditions as an indicator of risk for contracting COVID-19. Additionally, the challenge posed by not routinely collecting data on disability renders potential difficulties in linking disability to COVID-19 deaths/infections. More research is needed on disability and COVID-19 to inform disability-inclusive pandemic responses.

Keywords: Disability, COVID-19, inclusion, South Africa, healthcare

INTRODUCTION

According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 1 (United Nations [UN], 2006, p.4), people with disabilities include “those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others”. Approximately 15% of the world’s population has some form of disability (World Health Organization [WHO] & World Bank, 2011; WHO, 2018). Most people with disabilities are located in the global South, because of the intersection between disability, poverty and rurality, which heightens barriers to health, rehabilitation, education and work (Grech, 2015; Grut, Mji, Braathen, & Ingstad, 2012; Mutwali & Ross, 2019; Sherry, 2015; Vergunst, Swartz, Mji, MacLachlan, & Mannan, 2015; Vergunst, 2016; Vergunst et al., 2017; Visagie, 2015). In South Africa, as per the 2016 Community Survey (Statistics South Africa, 2018), people with disabilities constitute 7.7% (3,8 million) of the total population. Consistent with international trends, the ageing population in South Africa is also disproportionately represented in disability populations (WHO & World Bank, 2011; Statistics South Africa, 2018). With the rise in life expectancy, more than half of the population aged 65 years and older, as well as approximately eight in 10 people aged 85 years and older, are reported as people with disabilities (Statistics South Africa, 2018).

People with disabilities are more likely than those without disabilities to experience poor health. For instance, an international study, across 30 countries, showed children with disabilities to be five times more likely to report illness as compared to those without disabilities (Kuper et al., 2014). However, despite experiencing a greater need for healthcare services, the one billion people with disabilities worldwide are “left behind” in healthcare (Kuper & Heydt, 2019; UN, 2018; WHO & World Bank, 2011). What further exacerbates the issue, is that some impairments require specialised services, such as medical and rehabilitation expertise and assistive devices (Kuper & Heydt, 2019), but these are not

always available for those in need residing in low- and middle-income countries (Bright & Kuper 2018; Bright, Wallace, & Kuper, 2018; Gupta, Castillo-Laborde, & Landry, 2011; UN, 2018). This is particularly concerning, considering that access to healthcare, including medical, rehabilitation technologies and assistive devices, is crucial to enabling effective and sustained access to education and employment and, thus, the capacity to earn a living to prevent hunger and poverty. The picture is similar in South Africa, where the health system is in crisis and people with disabilities remain on the margins (McKinney, McKinney, & Swartz, 2020). Within the South African context, literature shows that people with disabilities are subjected to poorer access to healthcare, are more likely to report illness and experience a greater need for these services, as compared to those without disabilities (Grut et al., 2012; Mutwali & Ross, 2019; Sherry, 2015; Vergunst et al., 2015; Vergunst et al., 2017; Visagie, 2015). Against this background, the COVID-19 pandemic may illuminate the magnitude of these existing challenges.

Data for this paper was obtained from a research project, where a rapid review of key considerations for people with disabilities, as informed by both current discussions about COVID-19 and existing literature about the status of healthcare access for people with disabilities, globally as well as within the South African context, was conducted. Key documents, which informed these thematic areas, against the reviewed literature, for the deductive analysis were the UN report (2020) on considerations for a disability inclusive response to COVID-19 as well as the WHO (2020) report on disability considerations during the COVID-19 outbreak.

DISABILITY INCLUSION AND THE CONTEXT OF COVID-19

It is important to note that, while people with disabilities experience greater healthcare needs to those without disabilities, during pandemics such as COVID-19, the healthcare crisis and needs of people with disabilities are more far reaching. In addition to all the general issues of healthcare access for people with disabilities, during the COVID-19 pandemic, there are a number of additional considerations, which we will discuss briefly. In keeping with the social model of disability, we have deliberately not categorised people with disabilities into specific groups (i.e. all people with physical disabilities), since no two people with disabilities experience disability and barriers in the same manner. Most barriers faced by people with disabilities are a result of external factors such as societal negative attitudes towards disability, a lack of accessible transport or appropriate communication rather than general intrinsic factors (Barnes, 2012; Shakespeare, 2013).

1. **People with disabilities are among the most vulnerable to contracting COVID-19** and may experience severe morbidity and greater risk of mortality following the infection. As WHO (2020) announced recently, people with disabilities (and, more so, those with underlying conditions) are at higher risk of developing serious illness following COVID-19 infection and are more likely to die. Many adults and children with disabilities have a compromised immune response or respiratory function (e.g., people with cystic fibrosis or quadriplegia), or risk factors for COVID-related mortality, such as cardiac disease, hypertension or diabetes mellitus. Older people are at greater risk of becoming seriously ill from COVID-19 and, given that many older people are classified as having disabilities, their risk is potentially compounded. This is supported by data from both China and Italy (Guan et al., 2020; Nurchis et al., 2020). In addition to the above inherent vulnerabilities, other studies show that people with disabilities are four times more likely to die or be injured during COVID-19, due to a lack of disability inclusion in health policies, planning and practice (Armitage & Nellums, 2020; Pineda & Corburn, 2020).
2. **The health risks posed by COVID-19 may be worse for people with disabilities in some contexts with underresourced health systems** (Whiting & Handley, 2020). For example, in South Africa, access to healthcare has been documented as a challenge for people with disabilities in underresourced areas, such as the Eastern Cape (Grut et al., 2012; Vergunst et al., 2015; Vergunst et al., 2017), Northern Cape (Visagie, 2015) and other provinces (McKinney et al., 2020; Mutwali & Ross, 2019). Such underresourced contexts place people with disabilities at a higher risk for morbidity and mortality. Increased pressure on regional health systems, due to rising COVID-19 infections, may result in people with disabilities not receiving adequate or appropriate medical attention. Due to a number of differing factors, including a lack of awareness, language and communication barriers, cognitive and communicative impairments, dexterity challenges and technological challenges, many people with disabilities were not able to access therapeutic services via telephone or online platforms.
3. **People with disabilities may find it harder to access routine medical and rehabilitation services and may be de-prioritised if critical care resources such as intensive care unit (ICU) beds and ventilators are limited**, which, consequently, violates their right to equal healthcare access (Liddell et al., 2020; McKinney et al., 2020). As Moodley (2020) states, the rationing of critical care facilities is a reality where there are resource constraints and rationing decisions may disproportionately affect people with disabilities. However, attitudinal and systemic barriers are likely to leave people with disabilities behind. Such attitudes may disproportionately shape

decisions on distribution of resources and services during COVID-19, in contexts characterised by inadequate health resources and limited capacity. Various studies already revealed the lack of capacity among service providers to treat people with disabilities and address the stigma, exclusion and discrimination that people with disabilities are subjected to, across health sectors (Kuper & Heydt, 2019; Leocani, Diserens, Moccia, & Caltagirone, 2020; Ned & Lorenzo, 2016).

In South Africa, de-prioritisation was also evident in how key disability-specific health services were not considered as essential services during the initial stages of lockdown (McKinney et al., 2020). De-prioritisation also left some people with disabilities without personal assistants, while others were without assistive devices and technology services, rehabilitation services, therapeutic and developmental interventions, and without sign language interpretation services for people who are deaf (McKinney et al., 2020; Mulibana, 2020).

4. Given that access to information remains a barrier to healthcare access (Meyiwa, 2010; Ned, 2013; Ned & Lorenzo, 2016), **people with disabilities may fail to access health information and communication on prevention measures, as it is often not provided in accessible formats.** This emerged as a serious issue in a rapid review on the impact of COVID-19 on people with disabilities (Meaney-Davis, Lee, & Corby, 2020). Such lack of access to information on prevention and transmission, as Kuper et al. (2020) and Mulibana (2020) put it, may subject people with disabilities to a higher risk of contracting COVID-19. For instance, people who are deaf often face medical challenges due to unavailability of sign language interpreters in hospitals and as a result of service providers not knowing or understanding sign language (Huisman, 2020). Not all national televised broadcasts relating to COVID-19 information on transmission, prevention or statistics had sub-titles, which resulted in many people with hearing impairments being excluded (McKinney et al., 2020). In addition, not being able to lip-read service providers, due to the compulsory wearing of masks, and low levels of literacy among many people who are deaf, resulted in additional communication challenges (Andrade & Baloyi, 2011; Glaser & Van Pletzen, 2012).

5. Additionally, **access to water, sanitation and hygiene facilities remains disproportionate for some people with disabilities,** compared to people without disabilities (Department of the Presidency [DoP], 2020; UN, 2018). While efforts from the Department of Water and Sanitation to ensure water provision through the distribution of water tanks are duly noted, not all people with disabilities may have been reached, due to South Africa's poor infrastructure and spatial

challenges. This is particularly concerning, given that the majority of people with disabilities, especially in rural and informal dwelling settings, live in homes with no running water, taps that are inaccessible to those with certain disabilities, and rivers that are situated far from residential areas and oftentimes risky for people with disabilities (Grut et al., 2012), thus making frequent handwashing difficult (McKinney et al., 2020). More importantly, this may have an impact on sanitation practices, which are central to containing the spread of the pandemic.

6. Social distancing and isolation may be unrealistic for some people with disabilities who live in residential institutions or who are dependent on personal assistants or carers. It is well established that in institutions, such as homes for the aged or care facilities for people with disabilities, where people live in close proximity to one another, there is a high risk of substantial virus outbreaks (DoP 2020; Meaney-Davis et al., 2020; Minkowitz, 2020). Additionally, some people with disabilities, such as those with visual impairments, rely on touching surfaces to navigate everyday activities, such as reading Braille and using shared assistive devices. In the context of self-isolation and social distancing, these may present survival challenges. For example, some wheelchair users require close-proximity care from others for feeding, positioning, washing, getting in and out of bed, and other kinds of personal assistance. Without this personal care, some may not be able to function or survive. People with mobility devices, such as crutches and walkers, who live in institutions of care, might not have access to the sanitising equipment required to sanitise their devices, or they may not be physically able to do this themselves (McKinney et al., 2020; WHO, 2020). This shows that many prevention and treatment measures undertaken to reduce transmission of COVID-19 may not be adequately inclusive of people with disabilities (WHO, 2020).

7. The above issues may collectively evoke fears and anxieties among people with disabilities, not only regarding contracting COVID-19, but equally due to the implications of potential isolation and negative economic impacts (Armitage & Nellums, 2020). As such, **mental health conditions may become prevalent among people with disabilities as a result of COVID-19 and pre-existing mental health conditions and psychosocial disabilities may deteriorate.** The pandemic has resulted in a complete change to the psychosocial environment, including isolation and contact restrictions, which have the potential to negatively impact on the mental health of many people with disabilities (Fegert, Vitiello, Plener & Clemens, 2020; Patel, 2020).

8. Lastly, **COVID-19 may exacerbate the cycle of poverty and disability as a secondary impact.** Some of the long-term effects of COVID-19 include loss of work, lack of income and increased

hunger, in addition to lower rates of sustainable livelihoods (DoP, 2020), as well as the increased likelihood of impairments associated to related infections and/or co-morbidities. While there was a stimulus package provided by the South African government, a Statistics South Africa (2020) online study revealed that many people with disabilities did not receive food parcels. There is, therefore, a likelihood that people with disabilities may remain poor in respective contexts, leading to a burden of perpetual inequality and poverty (Hanass-Hancock & Mitra, 2016). This suggests that, without addressing disability inclusion, people with disabilities are exposed to more health risks, which increase their susceptibility to contracting COVID-19 (Sherry, 2015), and they remain subjugated to poverty and inequality (Hanass-Hancock & McKenzie, 2017). This is particularly concerning within the South African context, where prevailing social protection mechanisms do not necessarily take cognisance of the economic impact of diverse conditions, types and severity of impairments and the extra costs related to disability (Hanass-Hancock & McKenzie, 2017). The need for support may thus be higher post-COVID-19, given the higher vulnerability of people with disabilities.

As our themes were deductively selected, based on this rapid review, we do not claim that these issues are exhaustive. There are a range of additional issues affecting the lives of people with disabilities during this COVID-19 outbreak, but we could not elaborate on this, in this paper.

CHALLENGES OF DISABILITY DATA AND THE NEED FOR FURTHER RESEARCH

South Africa currently experiences a significant under-reporting of challenges related to disability – to date, there is no disaggregated data for disability and COVID-19 (Loeb, Eide, Jelsma, Toni, & Maart, 2008; Sherry, 2015). The current recording system does not indicate how many cases represent people with disabilities. Neither is it recorded who develops complications leading to impairments associated with co-morbidities. It may be that future planning for resources will thus exclude people with disabilities, due to this lack of data, as, often, what is not counted does not count. It is therefore critical to collect data on disability within the COVID-19 response. A disability measure could be included in data collection to facilitate the tracking of vulnerability of people with disabilities to contracting the virus, becoming critically ill or dying, compared to those without disabilities, using the Washington Group set of survey questions (Madans, Loeb, & Altman, 2011; Washington Group on Disability, 2020).

Additionally, more research is needed on COVID-19 and disability (McKinney et al., 2020; Sabatello, Burke, McDonald & Appelbaum, 2020). The authors are currently collaborating on and conducting a study to understand the effects of COVID-19 on the lives of people with disabilities. Our study is focusing on health-related access issues, livelihood and educational issues, anxiety and mental health or life and death issues, which may be facing people with disabilities as well as perspectives about the rationing of resources as they relate to disability. We are also documenting experiences, additional needs and suggested solutions, which may assist in ensuring that COVID-19 responses are appropriately tailored and used to enhance inclusive policy, planning and practice. These results will be published at the conclusion of the data analysis process.

CONCLUSION

The issues highlighted above demonstrate the multidimensional risks facing people with disabilities and emphasise that focused attention must be paid to their rights, which are at risk of violation. While both inaccessible healthcare systems and the presence of underlying health conditions put people with disabilities at additional risk, vulnerability to severe illness and death, post-contracting COVID-19, this vulnerability is exacerbated by the interaction between impairments and personal and environmental barriers at different levels, resulting in a disproportionate impact for people with disabilities. This suggests that it is not sufficient to look only at underlying medical conditions as an indicator of risk for contracting COVID-19. Rather, contextual factors, including attitudinal, environmental and institutional barriers, together with prevailing systemic issues, need specific investigation.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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