

POLICY BRIEF

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Experiences of **people with disabilities** during **Covid-19** in South Africa: The exacerbation of disadvantage



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Executive summary

The impact of COVID-19 is falling unevenly across the South African population; research quickly revealed how the worst impacts fell along geographic, racial, and gendered lines. A recent study by the Institute for Development Studies (UK), the Human Sciences Research Council, and the National Council of and for Persons with Disabilities on the impacts of COVID-19 on the well-being of South African residents with disabilities indicated that they were also disproportionately affected. Overall, the study showed that the government's response did not adequately provide for this large but significantly marginalised minority group or acknowledge its diversity of needs. Many persons with disabilities are disadvantaged in virtually all spheres of life. The inadequate response is concerning, albeit not surprising, because in pre-COVID-19 times people with disabilities constantly struggled against societal barriers – structural and social. Since COVID-19 arrived, there has been little acknowledgement of their diverse needs and how to address these inclusively.

This policy brief presents some of the economic and social well-being experiences and perceptions of people with disabilities during the pandemic, as reported by 1 857 respondents who voluntarily participated in an online survey undertaken during July and August 2021. The majority of the participants were black South Africans (83%). Types of functional difficulties included vision, hearing, mobility, communication, self-care, concentration, and memory challenges. Respondents also reported upper-body immobility, lack of use of their hands, and experiences of anxiety or fear, stress, and depression (psychosocial challenges). The study specifically aimed to reach individuals in order to hear their unique voices. Key findings included inaccessible communications relating to COVID-19, financial and employment challenges, the experience of 'abnormal' events such as food insecurity, increased inadequate access to transport and other essential services, and the psychosocial impact of the

pandemic. Based on the findings, we recommend the following: communication in all media formats must be improved to encompass the diversity of disability types; disaster and emergency planning processes must be urgently worked on to become disability inclusive; disability-inclusive baseline data is required over and above data on those who are simply social grant recipients; and there must be inclusive provision across essential and disability-specific service sectors.

Introduction – circumstances of persons with disabilities in South Africa

Approximately one in five people in South Africa over the age of five have some form of impairment that could be disabling based on the societal barriers encountered (NDoH 2019). People with disabilities are socially and structurally excluded due to challenges in accessing essential services and support. These barriers can be social because disability is not widely acknowledged, despite the Constitution and some legislation (including the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000) containing provisions aimed at promoting their inclusion in society. Furthermore, people with disabilities are often stigmatised and stereotyped by others due to cultural beliefs, misunderstandings, fear and lack of knowledge about how to accommodate and treat them with respect (DSD 2016a). Structurally, they face challenges in accessing transport services, education and health facilities, shops, and public places (McKinney, McKinney and Swartz 2021). When they travel to access these services, some are often charged extra for their wheelchairs and caregivers (McKinney, McKinney and Swartz 2021). Some of them are dependent on paid caregivers or family and friends for support to do the basic things others take for granted, including communicating with public servants, health officials and shop assistants. Rarely do public or private facilities or the staff that operate these facilities accommodate persons with disabilities or have the necessary training to interact with them. Despite often having qualifications, persons with disabilities remain unemployed, and many rely on the state for a grant. In contrast, others do not meet the clinical criteria for a grant and are unemployed, although employable (DSD 2016a). Obtaining a grant is itself a cumbersome and costly exercise with multiple visits to medical professionals as well as the Department of Social Development (DSD) and its social grants agent, the South African Social Security Agency (SASSA) (DSD 2015).

COVID-19 has brought further hardship. At the beginning of the pandemic, the United Nations reported that, worldwide, persons with disabilities 'are disproportionately impacted by the COVID-19 outbreak' (UN 2020: 4), and government or non-government responses must not undermine the fundamental human rights of persons with disabilities (overtly or otherwise), as indicated in international commitments. South Africa has been a signatory to the 2006 Convention on the Rights of Persons with Disabilities (UNCRPD) since 2007 and, in terms of the 1996 Constitution, is legally bound by its principles, which became the fundamental basis of the Cabinet-approved *White Paper on the Rights of Persons with Disabilities* (DSD 2016a). South Africa, as a UNCRPD signatory, is also legally bound to other international and regional conventions covering aspects of disability rights. The 1996 Constitution also protects the rights of persons with disabilities. The South African Law Reform Project is currently translating the UNCRPD into a possible act of parliament, but this will take some years. Seemingly, locally and internationally, the most significant gaps are between those with disabilities and their support organisations, acquainted with disability policies and legislation, and those unaware of or untrained in these policies (Liasidou and Mavrou 2017). The latter includes much of society: employers, healthcare workers, business owners and staff, public servants, and others. Within the South African government, there is a disjuncture between the two departments that drive the policies and promote the rights related to disabilities – DSD and the Department of Women, Youth and Persons with Disabilities (DWYPD) – and other departments. This disjuncture across departments is evident in at least two instances.

First, the Disaster Management Act 57 of 2002 (DMA) makes no mention of persons with disabilities or disability-inclusive approaches to managing disasters. Second, the long-overdue inclusion of persons with disabilities as a specific vulnerable group under section 3.5 of the *White Paper on the Rights of Persons with Disabilities: Implementation Matrix 2015 – 2030* (DSD 2016b) in the Disaster Management Framework of 2005 (DMF) has yet to occur. At the time of writing, there is no evidence of progress in this regard, and there was none before the COVID-19 outbreak. Yet, the DMA and the DMF inform the disaster management and mitigation measures of the National Coronavirus Command Centre (NCCC). Inexplicably, one of the NCCC regulations prevented carers of persons with disabilities from accompanying them when seeking healthcare, placing a definitive barrier on those who require extra assistance to engage with healthcare workers (McKinney, McKinney and Swartz 2021). The promulgation of this regulation indicates that before the outbreak there was a lack of disability inclusiveness and awareness brought about by ignorance and inadequate understanding of human and disability rights by those tasked with ensuring the safety and well-being of citizens under the Constitution. Disability mainstreaming in all spheres of life is still a dream, and South Africa's ill-preparedness to accommodate persons with disabilities during the pandemic has worsened their circumstances.

Findings from the online survey – mitigation measures are disability exclusive

Accessing pandemic-related information

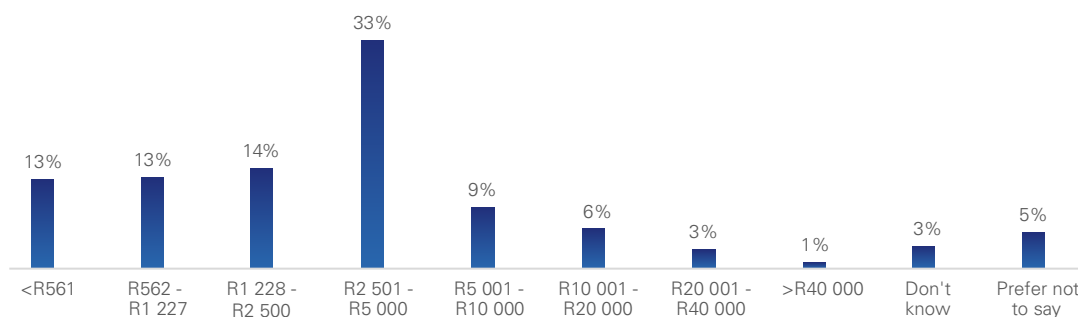
Of the 1 857 participants surveyed, 6 out of every 10 said they had some difficulty accessing information about the pandemic. Poor access was often related to the inability to read print material or hear radio broadcasts. It also included television broadcasts not having captions and the sign language interpreters not being sufficiently visible. Where the government offered assistance – for example a temporary increase in the disability grant, food parcel delivery at community centres, and sign language accompanying televised COVID-19 messaging – this information did not always reach the intended beneficiaries. About half of the survey respondents were unaware of any focused government effort to support persons with disabilities. The third who were aware of such actions noted the temporary nature of the increase in the grants and the emergency Social Relief of Distress (SRD) grant. The remaining 20% reported that they were unsure if there was any government assistance. The evidence indicates that communication was inadequate, and awareness was reported mainly by those who received increased government grants, suggesting that being a previous grant recipient has some benefits beyond simply receiving financial aid. For example, being on the social grant recipient list might ensure that relevant information is conveyed to those on the list, or at least those caring for them.

Changing economic experiences

Although 79% of respondents received a social grant from the government, only 31% received a disability grant, and 33% received the temporary COVID-19 SRD grant of R350 per month. The remainder received the elder-person grant (10%) and child support, care or foster grants (5%). In South Africa, those who receive a disability grant lose it at the age of 60 years and must apply for a state elder-persons grant. They cannot receive both. This suggests that the high disability-related costs to households that include a person with a disability and individuals with disabilities (DSD 2015) are ignored from the age of 60 years. Interestingly, 21% of respondents said they had been denied a disability grant by the state because of the income means test (19%) or because the state did not recognise their disability (2%).

Figure 1 shows that at the time of the survey most participants were struggling financially, despite government pandemic interventions: 13% lived on an income below R561 per month and 13% on R562 – R1 227. Another 14% lived on R1 228 – R2 500, and 33% on R2 501 – R5 000. In 49% of cases, respondents reported that they struggled to cover their disability-related expenses during the pandemic.

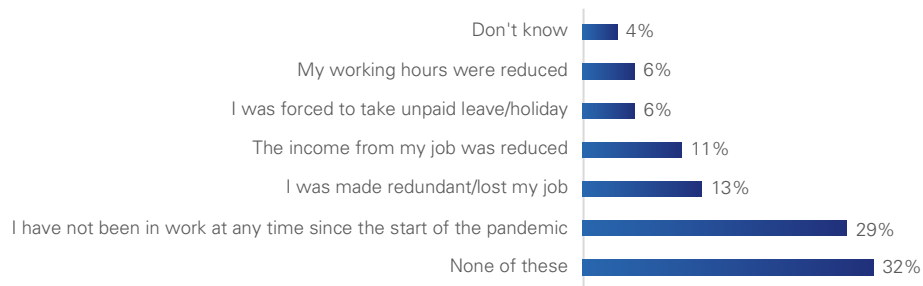
Figure 1 Respondents' monthly average incomes (%) (N = 1 857)



Respondents work status

Only 37% of the participants reported being in full-time, part-time, casual- or self-employment when lockdown was introduced on 27 March 2020, while 35% were unemployed. This figure for unemployment is higher than the official Statistics South Africa figure for the first quarter of 2020, which was estimated at 30.1% (Stats SA 2020). However, official estimates do not include people in the population who are no longer looking for work (ie they have given up seeking employment). This may not be the case for persons with disabilities. However, 11% of the respondents reported being unable to work due to their disability or health. Some were doing unpaid care work (6%), while the remainder were students or pensioners when lockdown started. In a follow-up question that asked if employment conditions had changed at any time during the pandemic, as Figure 2 shows, 13% reported having lost their jobs, 11% said their employment income had been reduced, 5% reported a reduction their working hours and 6% had to take unpaid leave or vacation leave at some point during the pandemic. Three out of four respondents (76%) had difficulty paying for their basic living expenses due to changes in their financial situation because of lockdown measures and government COVID-19 mitigation regulations. About half of the participants expected their financial situation to worsen in the next months because of the pandemic's economic consequences.

Figure 2 Change in employment circumstances because of the pandemic (%) (N = 1857)



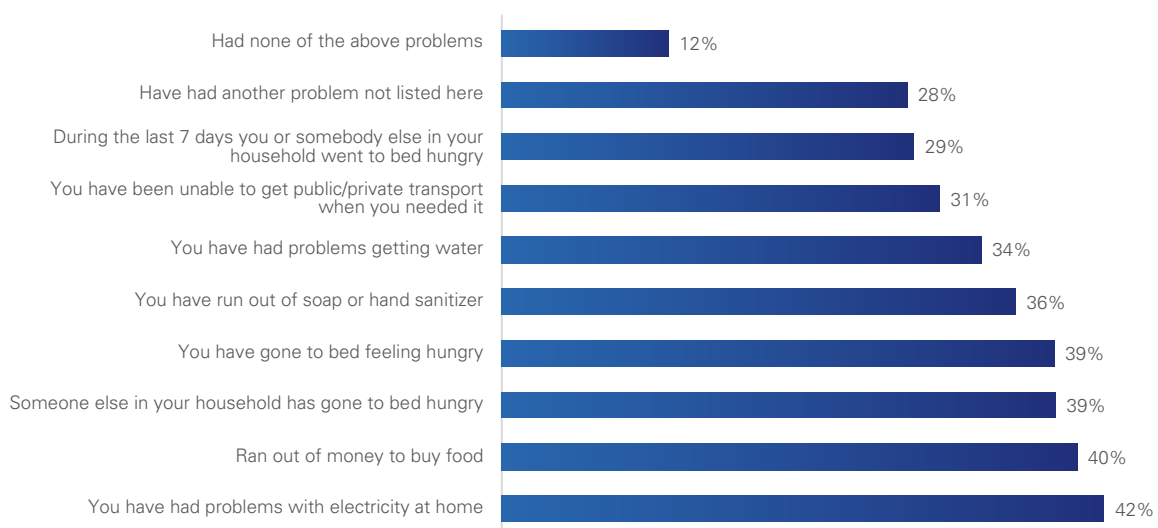
The experience of 'abnormal' events during the pandemic

A multiple-response question asked survey participants to select from a list experiences or events they normally would not experience but had experienced during the pandemic (Figure 3). Responses relating to access to food indicate that 40% reported having run out of money to purchase food and 39% had gone to bed hungry or someone else in their household had gone to bed hungry (also 39%). The greatest concern around hunger and an indication that food relief measures were insufficient was that 29% indicated that they or a member of their household had gone to bed hungry in the week before, ie more than a year after the first hard lockdown. This illustrates the inadequacy of provisioning food relief for many people with disabilities. In response to qualitative questions some respondents indicated that food parcels were often inaccessible to those with some degree of immobility, as they could not get to the collection points at community centres and supermarkets.

Just under one-third (31%) reported having been unable to get access to public or private transport when this was needed. Initially, this was caused by the restrictions on using public transport but later on, as restrictions eased, transport operators were unwilling to transport them or their equipment, which was feared to be unsanitary.

People who required rehabilitative therapy and medication were unable to obtain these at times, either due to transportation challenges or because these services were not initially deemed to be essential services. More than one-third (36%) reported having run out of soap and sanitiser. This was linked in some cases to transportation issues, reduced income and lack of supplies at shops and health centres. However, personal situations worsened due to unprecedented water shortages (34%) and more frequent cuts in electricity (42%). Water, soap and sanitiser are essential not only for COVID-19 hygiene but also for general hygiene and specifically for those whose impairments require extra hygiene. While electricity is important for heating water for sanitary purposes, certain persons with disabilities require electricity to recharge assistive devices including wheelchairs, hearing aids and communication devices.

Figure 3 Events experienced during lockdown not normally experienced prior to the pandemic (MR) (%) (N = 1857)



Psychosocial implications of the pandemic on the respondents

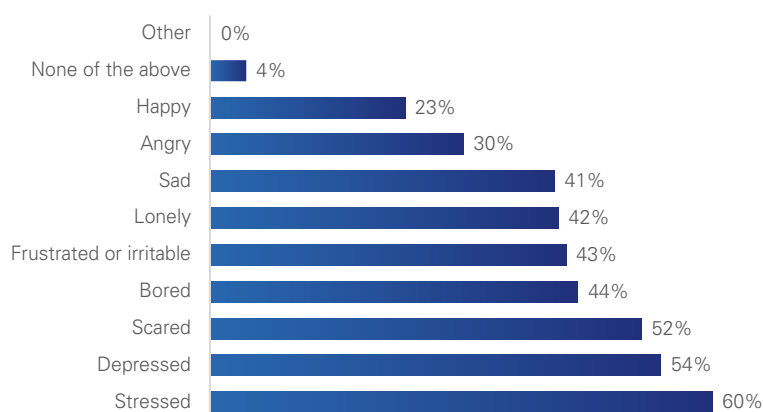
Some respondents relied on state facilities (37%) to access disability-related services, 25% on organisations such as non-governmental organisations and 20% on family and friends. Interestingly 51% of respondents said they were newly reliant on support from disability service organisations. Almost half (45%) reported interruption in their disability-specific services since the pandemic started, as many service providers were not initially considered to be essential-service providers and were prevented from operating. Less than 20% said they had not needed to use disability-specific service providers during the preceding 17 months.

With 60% of respondents having relied on the services of a caregiver to support their daily activities, many of these respondents (73%; N = 1 112) experienced disruptions of this care during lockdown. In most cases, the services were unavailable for only a day (61%), but in some cases for weeks (10%) and months (18%) and in exceptional cases (9%) still unavailable at the time of the survey. The absence of a caregiver not only imposes daily hardship but also can increase psychosocial challenges, particularly loneliness if the carer is the only source of companionship.

Most South Africans have been negatively emotionally and psychosocially impacted by COVID-19 and the mitigation measures promulgated to control the spread of the virus. The situation for persons with disabilities is often exacerbated. They have lost jobs, which are difficult for them to get at the best of times, or have had salaries reduced. Their food security, sanitation and access to rehabilitation, medication or carer services have been badly disrupted by lockdown measures despite limited government interventions. Furthermore, inaccessible communication about the virus and mitigation measures has often denied them awareness of what is occurring and denied them access to relief measures. Perhaps more importantly for those living alone or those who relied on a caregiver, curfew and associated travel restrictions resulted in lengthened experiences of loneliness. The lack of electricity, combined with limited services to ensure working hearing aids, wheelchairs and other assistive devices, would be deeply depressing. The inability to receive rehabilitative care and necessary medication could result in the heightening of physical and psychosocial impairments. These circumstances place a greater emotional and psychosocial toil on some people with disabilities, who may have particular requirements to function on a daily basis and retain their usual level of socialisation, independence and dignity.

Figure 4 shows the various emotional and psychosocial experiences that participants encountered during the first 17 months of the pandemic. About 6 in 10 participants reported having felt stressed, and half reported having experienced depression (54%) and fear (52%).

Figure 4 Emotional experiences of respondents under lockdown (MR) (%) (N = 1 857)



Using a six-item response rating scale, ranging from 'very bad job' to 'very good job' or 'don't know', respondents were asked to indicate their perceptions of how different sectors of society were accommodating the needs and rights of persons with disabilities in their responses to the pandemic. About half of participants indicated that they believed the general government (51%), the government's social and health sectors (49%) and non-governmental institutions (48%) were doing a 'a very bad' or a 'bad job' in accommodating the needs and rights of persons with disabilities in their responses to the pandemic.

Conclusion

The diverse needs of persons with disabilities must feature in pandemic preparedness, interventions, disaster mitigation measures, and planning for recovery phases. The study illustrates that while the circumstances of persons with disabilities are generally disadvantageous and that these are generally unacknowledged, during the pandemic their situation and circumstances have worsened.

The results of the study indicate that it is crucial for government to take an intersectional- and disability-inclusive approach in mitigating the impact of disasters and should be aware of the impacts of their mitigation regulations on vulnerable members of society, including persons with disabilities who have been excluded from many forms of support and services. The general experience across South Africa is that regulations and mitigation measures have focused mainly on controlling the spread of the virus. Consequently, little and belated thought was given to whether these regulations would benefit or have unintended negative impacts on certain groups, and particularly persons with disabilities. Mitigation measures have not been disability inclusive across an array of domains.

Recommendations

Considering these findings, we make the following recommendations:

1. *Accessible communication.* The mainstreaming and awareness of disability must be standard at all facilities. This includes ensuring that accessible communication through all public media is provided in diverse formats that accommodate all people with a range of access needs. For example captioning, sign language interpretation, braille and easy-read versions.
2. *Inclusive disaster and emergency planning processes.* The disaster and risk framework for persons with disabilities is far from complete and government must immediately address the gaps that currently exist to ensure that persons with disabilities are explicitly included in the discussions about pandemic mitigation and the recovery processes.
3. *Inclusive baseline data.* When lockdown was introduced, there was and still is no official baseline data about persons with disabilities, their diversity and their different needs. There is no evidence that existing official datasets have been used in the pandemic beyond those that focus on social grant recipients, which datasets do not include everyone. Furthermore, there is no evidence of initiatives to begin compiling comprehensive datasets across the different state departments and engaging with disability service organisations to pool datasets. Disability service organisations are in direct contact daily with persons with disabilities through provision of services, even to those in the most remote parts of the country. Consultation and involvement of these organisations will assist in the mitigation of most of the access challenges faced by persons with disabilities that were unearthed in this research. This is even more critical in all COVID-19 recovery plans. Consequently, comprehensive mapping and tracing, to ensure far-reaching disability-inclusive interventions, are virtually impossible. To supply necessary services to those most in need and to those persons with disabilities who are most vulnerable, work must be undertaken urgently along with improved collaboration between government and disability-representative civil-society organisations.
4. *Inclusive service provision across sectors.* Given their pre-existing disadvantaged contexts, future interventions must ensure that persons with disabilities receive necessary disability and health services, food and nutrition security, and improved access to hygiene.
5. The psychosocial fallout of the pandemic will remain with us all for some time and, without excluding other citizens, a particular effort needs to be made to address the negative impacts of such crises for persons with disabilities, whose already difficult lives have been placed in further turmoil because of disability-exclusive mitigation measures and regulations.

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