

Experiences of vulnerability of people with disabilities during COVID-19 in South Africa

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People with disabilities experience significant feelings of vulnerability as a result of COVID-19 measures which are not disability-inclusive.

People with disabilities are often left behind in emergencies, and this is a risk during the COVID-19 pandemic. With approximately 3.8 million people living with disabilities in South Africa, it is not clear how they were considered during the initial and ongoing stages of strict lockdown.

Through an online administered survey study, we explored the experiences of vulnerability among and the impact of COVID-19 on people with disabilities in South Africa. One hundred people completed the survey with closed and open-ended questions to document their experiences related to the first and second lockdowns in South Africa.

Vital disability-specific health services were not regarded as 'essential services', thus placing people with disabilities at heightened risk. These included the State delivery of

medication, as well as services related to sign language, assistive devices and technology, rehabilitation, and therapeutic and developmental interventions. Inadequate disability-specific information on COVID-19 left many people with disabilities and their caregivers with limited information on how to protect themselves. As a result, they experienced heightened fears, anxiety, and worry about contracting the virus, contributing to poor mental health. This growing mental health crisis is likely to burden the already inadequate health system and mental health support structures.

Emerging lessons reveal that the right to health of people with disabilities should be protected during the COVID-19 pandemic and similar emergencies. Additional efforts are needed to ensure that pandemic responses are disability-inclusive from the planning stage.

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Introduction

People with disabilities face more barriers in accessing health care than others^{1,2}, and the one billion people with disabilities worldwide are ‘left behind’ in health care.³ There are violations of the rights of people with disabilities to health under international law (such as the UN Convention on the Rights of Persons with Disabilities, UNCRPD). Neither universal health coverage (UHC) nor Sustainable Development Goal (SDG) 3 (good health and well-being) can be achieved without better health services for people with disabilities.³

The Coronavirus disease 2019 (COVID-19) pandemic is a health crisis superimposed on existing health disparities. Past global health emergencies illustrate that poor and vulnerable people, including people with disabilities, are hit hardest by crises.³⁻⁵ Disability is a major concern during COVID-19, and not merely in terms of access to care. Because of the association between disability and poverty¹, and because of certain chronic health conditions, people with disabilities may be among the most vulnerable to contracting COVID-19. People with disabilities often have complex health needs^{2,5} which may increase the severity of COVID-19 symptoms and heighten the risk of mortality.^{7,8} This extends to mental health issues; emerging research indicates that COVID-19 may itself lead to depression and anxiety in some⁴ and psychiatric symptoms, including delirium and psychosis, in others.⁹ A study in the United States has already identified that individuals with pre-existing mental disorders are at increased risk for COVID-19 infection¹⁰ and may also experience symptom exacerbation.

As the COVID-19 pandemic spread, South Africa, like many other countries, declared a national state of disaster under Section 3 of the Disaster Management Act 57 of 2002.¹¹ On 23 March 2020, President Ramaphosa announced a national lockdown, aimed at delaying and limiting spread of the pandemic and to prepare the national health system. This was a stringent lockdown with set restrictions on all movement outside the home and limiting economic activity to essential services only.¹¹

In May 2020, the World Health Organization (WHO) released a policy brief entitled ‘A disability-inclusive response to COVID-19’, emphasising that people with disabilities commonly experience barriers in accessing health care and are one of the most excluded groups.¹² The brief highlighted that the pandemic could further compound social exclusion and would have a disproportionate impact, via direct or indirect means, on people with disabilities. For these reasons, the brief exposed the extent of exclusion, thereby emphasising the need for action to ensure disability inclusion. The brief called for an integrated approach to ensure that people with disabilities are not left behind.¹² Following this, organisations of persons with disabilities (DPOs) in South Africa released advocacy documents calling for disability inclusive responses to COVID-19.^{13,14}

In South Africa, people with disabilities are often already vulnerable due to inequalities in sectors including education, employment, transport, and access to health care.^{11,15} For example, health care in South Africa is well documented as being challenging for people with disabilities in a number of provinces.¹⁶⁻²⁰ Inaccessible health care and underlying health conditions put people with disabilities at a double risk of severe illness and death if infected with COVID-19.⁷ While there is very limited information on this because of insufficient disaggregated data, preliminary reporting from high-income countries (HIC) confirms this double vulnerability.²¹ Against this background, we posit that the COVID-19 pandemic may illuminate the magnitude of existing challenges.

Research is needed to understand the effects of COVID-19 on the lives of people with disabilities. Documenting their experiences, gaining a deeper understanding of additional needs, and identifying solutions may assist in ensuring that COVID-19 responses are appropriately tailored and conducive for use to improve practice, policy and inclusive planning. Our study aimed to: describe the experiences of people with disabilities and organisations of (or that serve) people with disabilities during the COVID-19 pandemic and national lockdown period in South Africa, and identify possible strategies and recommendations for disability-inclusive pandemic responses.²²

This chapter presents the health-related experiences of vulnerability of people with disabilities during the first and second national lockdown periods in South Africa.

Methodology

We used an online administered survey as a virtual method, since no face-to-face research was allowed at the time of data collection. The survey was available to participants to complete either by themselves or with assistance from others (such as a family member or personal assistant) from mid-May 2021 to the end of July 2021. This virtual method was also appropriate to use at the time because, other than healthcare workers and others deemed as ‘essential workers’, South Africans were not allowed to leave their houses except for activities related to essential goods and services such as buying food and attending to urgent healthcare needs.

Data were obtained through the roll-out of two national online surveys (using the SUNSurveys platform) which were opened for approximately three months. We specifically targeted experiences related to the first and second national lockdown periods in South Africa.²² The first survey was aimed at people with disabilities; the second was conducted with staff members of organisations of persons with disabilities (DPOs). The surveys were presented in English only (as budget limitations precluded translation to all South African languages) but was compatible with disability-related software used by people with visual impairments (such as screen-readers and font size adjusters). Before distribution, the survey was piloted in two rounds and feedback was used to improve the survey. We also conducted virtual in-depth follow-up

interviews with 14 people with disabilities for narrative data, to gain further insight into their experiences. Ethics approval for this study was provided by Stellenbosch University Research Ethics Committee for Social, Behavioural and Education Research (Ethics Approval No.: REC-2020-15244). For this chapter, we report only on the experiences of people with disabilities emanating from the first survey, and focus chiefly on the factors seen to create or increase the vulnerability of people with disabilities during COVID-19.

The survey covered experiences related to five thematic areas, namely: access to information on COVID-19; access to health facilities and services; access to services; participation in decision-making; and governmental involvement. Current discussions about COVID-19 and existing literature on the status of healthcare access for people with disabilities, globally and within South Africa, informed the development of the survey. To determine the thematic areas of the survey, we drew on reviewed literature as well as key documents, such as the United Nations Report (2020) on considerations for a disability-inclusive response to COVID-19, and the World Health Organization’s 2020 report on disability considerations during the COVID-19 outbreak. The survey was distributed through DPOs and disability networks country-wide using e-mail and social media platforms such as Facebook, Twitter and WhatsApp.

People with disabilities represent a diverse, non-homogenous group, and a limitation to the study was the exclusion of those without access to electronic devices and Internet connectivity. Those living in remote settings were less able than others to participate in the research, due to a lack of technology, infrastructure and connectivity. Others similarly hampered were people living in residential care homes or institutions, whether for physical, psychosocial disabilities or any other disabilities. Another limitation was the inability

to have the survey translated to other official South African languages. Additionally, in online surveys, it is common that those with complaints are more likely than others to respond, which introduces a biased sample. We are therefore aware that our study was less accessible and inclusive than a face-to-face process would have been, especially regarding diversity of participants. As a result, the findings are not generalisable across all disability populations. Despite these limitations, we believe that the findings are strongly indicative of the challenges confronted by many people with disabilities.

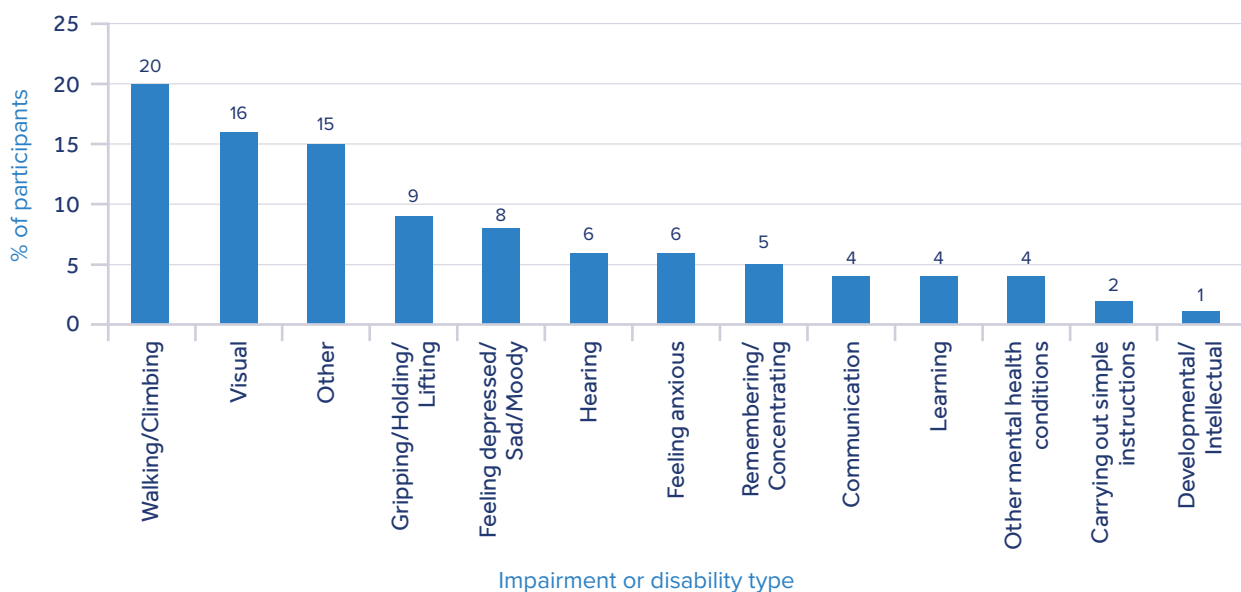
Key findings

One hundred responses were received from participants in eight of the nine provinces of South Africa, the majority being from the Western Cape Province (52). Responses from other provinces were: Gauteng (17), Eastern Cape and KwaZulu-Natal (11 each), Northern Cape (4), Limpopo (3), and North-West and Mpumalanga (one each), with no responses from Free State.

Participants’ ages ranged between two years (with proxies such as parents answering for young children) and 76 years. Most participants were between 26 and 38 years of age. Fifty-seven per cent of the participants identified as female, 42% as male, and one person identified as ‘other’ or non-binary.

The impairments or disability types represented in this study are illustrated in Figure 1. Of these respondents, 72% reported the use of various assistive devices or technologies, while 28% reported not using any assistive technologies. Participants also reported on various underlying health conditions which necessitated extra or specialised care.

Figure 1: Types of impairments or disability types



Source: Ned, McKinney, McKinney, Swartz. 2020.²²

Continuity in access to health services

Many people with disabilities have ongoing health needs which require regular access to medication, medical supplies, therapy and assistive devices. In this survey, 59% of respondents required constant medical supplies and 64% were on regular medication. While some benefitted from online services and delivery by State and other organisations, this was not accessible and/or available to all, especially for those relying on public health services. This sometimes had a direct impact on their (and their caregivers') safety and ability to receive assistance:

The medical supplies are limited. I cannot cope with the little supplies given it raises a health hazard.

My dad has to go fetch (my monthly supplies) and he is 64 and so he is putting his life also in a risk to go by that hospital.

If I send (my cousin) to go fetch my tablets... she will go about six o'clock in the morning, then she will come out three o'clock or 3:30. But then who will help me at home when she's there?

Some respondents (32%) indicated that hospital appointments had been cancelled or postponed, causing them significant anxiety. Rehabilitation services and disability-specific interventions were not initially classified as essential, and other ongoing specialised services such as wheelchair seating clinics and the provision of other assistive devices were not always available or prioritised. This had implications for those needing rehabilitation. Not being able to upgrade wheelchairs meant that some participants were in danger of developing pressure sores because of incorrect seating, or having to stay in bed all the time because their wheelchairs were no longer suitable. This negatively affected their physical and mental well-being.

I was struggling to get maintenance of my wheelchair as suppliers were closed of which I believe it should be treated as essential service.

They would keep (my wheelchair for repairs) for a long time in hospital and I then struggle without it. So now I am scared to take it to hospital because of that.

Services disrupted by the pandemic included sign language interpretation services, the provision of assistive devices (such as linen-savers, urine bags and suppositories) and technologies, medication, personal assistance, informal care or support, rehabilitation services, and therapies and development interventions.

By Tafelsig Clinic I get my tablets [to control my muscle spasms] and suppositories and by Mitchells Plain Day Hospital I get my ... urine bags and linen-savers, they don't give it here at Tafelsig (anymore).

If I have to go to the toilet you have to use pills like dulcolax suppositories because you can't go for yourself which goes with other things like Senokots so that your bowel system can work.

That's another thing, nobody is allowed to accompany me (in hospital), you know being disabled or being immunocompromised or being sickly, you need that support.

Restrictions in access to essential services had dire consequences for some. Limited access to medicines and the interruption of rehabilitation and therapies placed people with disabilities at a significant disadvantage:

A quad (raplegic) died in hospital because he couldn't get assistance. The medication was cut off because they couldn't even assist him until he died. Right of life has just been taken away because he's not like anybody else."

During lockdown, even where services were available, little to no transportation was available, and this impeded access for the majority of respondents who rely on public transport to reach hospitals for services. During the first month of lockdown, public transport was often limited to the early hours of the morning and late hours of the afternoon, and modes of transport that were still available were not accessible. Standard mini-bus taxis, for instance, generally do not accommodate wheelchairs.

Like now I do not have a (manual) wheelchair. I use the electric one so now it does not have a battery. I cannot get it (new battery) and so do not have any transport at present and therefore cannot go anywhere (in my wheelchair).

Personal assistant services for persons with disabilities requiring additional care were also interrupted, for several reasons. Firstly, restrictions on travel and not having live-in caregivers led to a reduction of working days for caregivers who needed public transport to get to work. Travelling by public transport also increased caregivers' risk and fear of contracting the Coronavirus. Secondly, people with disabilities and their families were concerned about the risk of contracting COVID-19 from the caregivers, as they encountered other people when using public transportation.

Some caregivers observed lockdown regulations due to fear of infection. A number of DPOs provided permits for caregivers which identified them as healthcare workers in case they were stopped by police or other authorities when on their way to work. However, some caregivers (and domestic helpers) could not obtain these permits and some people with disabilities were not aware of how to access caregiver permits. In addition, personal protective equipment (PPE) was not allocated to caregivers, and/or or persons with disabilities and their families who relied on caregivers. Changing caregivers and/or finding a relief caregiver if a particular caregiver was off-duty was risky at

this time because of contact exposure when using public transport as well as the challenges already stated.

Others reported difficulties related to the use of masks and other protective equipment:

I cannot independently put a mask on and off.

So there is no understanding of challenges faced by people with disabilities. It is difficult to use hearing aids and a facemask as the hearing aids get hooked onto the elastic bands and ties. The people's voices are muffled and I can't hear them. The Irlen lenses get steamed up because of the mask and my vision gets obstructed. So, with both senses being obstructed it's very difficult to go shopping, pick up medication, try to communicate, try to walk downstairs. Furthermore, persons with disabilities may have other pre-existing conditions that make them susceptible to COVID-19. People do not respect social distancing/practise safe practices so going out to buy medication/shopping for a person with a disability can be (a) very stressful experience.

Due to physical impairment/nerve damage using hand-sanitiser pump bottle is difficult. Skin sensitivity to hand-sanitiser.

In addition to experiencing communication barriers, some respondents experienced breathing difficulties:

No difficulty in using it myself but have difficulty with lip-reading due to other people wearing masks.

It is difficult to breathe in especially if there is previous lung damage and other conditions.

Most masks make it difficult for me to breathe efficiently and I feel like I'm getting even less co2 (than) the usual (I tend to focus more on getting oxygen as I have had respiratory acidosis a few years ago).

Some participants with spinal cord injuries used a chin-control mechanism with a joystick placed directly under their chin to steer their motorised wheelchairs, which proved difficult when they had to wear a mask:

It is very difficult because (the mask) moves up and down and sometimes I can't control properly.

Mental health concerns

Respondents shared anxieties about themselves or their family members/caregivers contracting the virus, and in relation to everyday activities, such as going to buy groceries and not being helped at shops. Others described a fear of sharing showers, tubs and toilets in communal and residential settings, including hospitals. These concerns were amplified because of their dependence on caregivers, guardians, friends and relatives.

Significant fears prevailed in terms of not being able to seek and access medical help and health care upon contracting COVID-19, dying of hunger, and having inadequate medication and PPE for caregivers, such as gloves and masks. Many were deeply anxious about the financial implications of being unemployed and loss of livelihood after lockdown, as well as not being able to complete studies. Others were frightened of isolation and discrimination.

It's stressful and it's exhausting to actually go out if I need to go and see the doctor.

Mentally, it started to affect me – because will it be a benefit to me to be, be alive or to see tomorrow because I don't see the country is improving.

Participants with pre-existing mental health issues expressed their difficulty in accessing services before and during lockdown.

I called the South African suicide hotline and nobody answered... and then they phoned me back the next day but I thought that was very bad because I mean I could have been dead by the next day. It's supposed to be a 24-hour line.

I need to go to a psychiatrist to help me but to seek that kind of help is very expensive.

A number of those with psychosocial disorders felt stranded by the slow response of the government during lockdown.

I applied for that R350 (special COVID-19 grant) you know that the government is giving to unemployed people and whatever and I never ever heard back from them.

I mean you know with the disability grant right, from the government, you need to provide them with a psychiatrist statement... like, how do they (government) think that we're supposed to get that sort of information (for disability grant application) from a doctor when we can't even see them.

The heightened fear and anxiety about contracting the virus is contributing to the rise of mental health challenges. Additionally, those with pre-existing mental health issues may experience symptom exacerbation. This growing mental health crisis is likely to increase pressure on the already overburdened public mental healthcare system and other mental health support structures. Additionally, people with mental health conditions exacerbated or triggered by COVID-19 may not receive support.

Access to rapid information

A lack of information about the spread of the disease in relation to disability puts people with disabilities at increased risk of infection. Information in accessible formats, such as Braille, large print, sign language, captions, audio provision and graphics was not always provided.

While generic information on COVID-19 was found to be helpful, there was little to no targeted information provided to people with disabilities addressing their specific disability and needs.

Much of the information was useful but I feel I was excluded as a blind person since I rely on people guidance and touching, putting me on high risk not knowing how to protect myself.

Some (information) was helpful but not always able to do because your hands are touching the wheels all the time.

The information was general. It is not clear to whom we direct questions to. There is currently no information on assistance provided to persons with disabilities. No work plan procedures/legislation that considers the needs of persons with disabilities.

Additionally, no information was given to carers and personal assistants on how they could protect themselves and obtain permits to continue as carers.

Government involvement

Fifty-four percent of the respondents were not aware of available governmental assistance for people with disabilities during the lockdown period. Only 7% acknowledged some governmental contribution, namely the provision of PPE in residential facilities and the increased monthly disability grant. Some respondents were critical of the provision of general support, and identified the need for disability-targeted support. Suggestions for improvement were as follows:

Train people on dealing with individuals with hearing disabilities. Twice (!) had the situation of people unwilling to assist me due to not being able to lip-read while they are wearing masks.

Consideration of persons with disabilities should be an integral part of government's response to COVID-19. I don't think enough was done to protect vulnerable people, especially with grant payments, etc. Some services that were banned during the lockdown are essential to people with disabilities, like food deliveries – some persons with disabilities do not have the energy or dexterity to prepare meals on their own.

There should be a dedicated disability help-line. Disability should be included in all of the programmes rolled out.

Discussion

As is common among low- and middle-income countries (LMICs)²³, the weak South African health system had arguably already failed people with disabilities long before COVID-19. Information from this study suggests that the COVID-19

pandemic may have deepened the multiple layers of vulnerability to poorer health and challenges to participation and accessing services. As the number of COVID-19 cases grows and restrictions continue, the vulnerabilities of people with disabilities, already at risk, are likely to increase. Essential and specific health services for people with disabilities, as outlined in article 25 (b) of the UNCRPD, were disrupted due to not being regarded as essential services^{24,25}, generating potentially severe implications across the life course. For example, lack of intervention at critical stages for children and adults may result in secondary problems, such as joint and/or muscle contractures, respiratory conditions, and skin ulcers. Similarly, those with psychosocial disorders, strokes and other neurological and/or degenerative conditions may face situations as life-threatening as the pandemic²³ in the short and long term. Failure to regard such services as essential (as opposed to optional) increases the susceptibility of people with disabilities to contracting COVID-19, as a consequence of the absence of targeted planning and their pre-existing medical conditions. Additionally, the restrictions imposed when purchasing medical supplies and the limited provisions from the public sector exacerbated their vulnerabilities to decreased physical health and mental well-being.

Mental health was flagged as a priority area in need of urgent attention. The physical and mental health of people with disabilities may have deteriorated due to lack of access to health services, especially for those needing various therapies, being unable to afford hygiene products to protect themselves from COVID-19, isolation and reduced contact with others, and the stress of the situation overall. Even before COVID-19, the national mental healthcare system was overburdened and under-resourced.²⁶ Given these findings, there is a significant risk that the goal of equal services for people with disabilities will remain on the back-burner, and that the gap in accessing mental health care by people with disabilities will widen.

Many people with disabilities experienced discrimination through their exclusion from health communication because of technological and communication (including language and literacy) barriers.⁹ The study data reinforce the view that the inclusion of people with disabilities is vital in planning responses to health crises and the quest to achieve the SDGs.^{2,3,21} Achieving the goal of global health and well-being requires that healthcare systems address as a priority the needs of people with disabilities who lack or have limited access to care. Lack of interaction with those living in remote areas and residential homes (acknowledged earlier as a limitation to the study) remains a key concern, as they lack opportunities to give feedback on their experiences during COVID-19 and at any time. This increases their vulnerability through diminished access to information and capacity for self-agency. These findings, combined, reflect the multifaceted nature of the impact on people with disabilities as a result of the halted service access.²⁷

Public transport, particularly accessible public transport, is a major challenge in accessing health care in South Africa.^{28,29} The findings highlight transport challenges as impacting on access to personal assistants which in turn render people with disabilities' participation in day-to-day activities. Community-based rehabilitation (CBR) services could alleviate some of these problems. However, CBR workers have not been prioritised within public health care, even before the pandemic. Compounding the issue is that DPOs were also closed or had reduced their CBR services - a consequence of poor governmental support.²² While some services have been provided online, the South African context and infrastructure means that this option was accessible only to some. For example, expensive home-delivery services are not feasible for the majority of people with disabilities who live in poverty, whether in rural or urban areas. Online health services rely on strong Internet connection, and this is problematic when loadshedding is in place, and requires people to afford mobile data for connectivity. Given that instances of community networking and support have previously helped people with disabilities, strengthening such networks at grassroots level would help to alleviate the burden on larger healthcare systems. CBR workers could be better suited to filling such gaps and ensuring uninterrupted service provision to people with disabilities in their homes. However, these workers require information on how to protect and maintain their own health and the health of people with disabilities.

The vulnerability of people with disabilities during emergency situations escalates not only as a result of their pre-existing conditions, but also due to lack of consideration, inclusion and targeted planning for their needs. Restricted access to essential services and medicines, and the interruption of rehabilitation due to lockdown, place people with disabilities at greater disadvantage. Therefore, targeted and collaborative planning, including comprehensive collection and monitoring of data on people with disabilities²⁶, is imperative. This could include tailoring protective equipment according to impairment type and integrating accommodative measures in this situation.

Conclusions

People with disabilities experienced disproportionately negative impacts from the COVID-19 pandemic, and the pandemic has significantly increased their vulnerability to poorer health care. These findings not only expose a health system that has been failing with disability inclusion, but also reveal that equity cannot be achieved without proper access for all to health systems. The demands of COVID-19 have also overstretched the already pressured health system - a reality which has underpinned the basis for heightened fears within the disability community. To ensure quality healthcare for all, it is critical that disability-inclusive health systems are created to address the needs of these vulnerable groups. A combination of mainstream and disability-specific measures are needed to ensure systematic inclusion.

Recommendations

We provide the following recommendations:

- In order to reach out to and involve people with disabilities, particularly those in remote areas, in inclusive programmes, we call for the incorporation of CBR practices within public health care; currently these services are generally driven by non-governmental organisations, non-profit organisations and DPOs. This would promote de-institutionalisation and develop strong community-based healthcare approaches to integrate prevention, promotion and care services.
- Availability of services at community level is particularly needed for mental health care. Services, information and programmes should be accessible at grassroots level.
- Disability must not be an afterthought. The health system must promote disability-inclusive universal health coverage to improve the availability of disability-specific services and ensure that people with disabilities are able to access all services.
- There is a need to collect comprehensive disability-disaggregated data in order to track the impact of COVID-19 on people with disabilities, and to inform and facilitate effective planning and budgeting, ongoing monitoring and evaluation of service delivery.
- It is crucial that the health system applies a universal access and design approach in planning health infrastructure projects, including for accessible transport and mobility. Collaboration with people with disabilities is essential from the outset.
- For inclusive responses, the government's COVID-19 disaster management mechanism should include members of, and regularly consult with, national, provincial and local disability rights organisations of people with various disabilities, including DPOs.

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