COVID-19 and disability considerations: report on the experiences of people with disabilities in South Africa

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Introduction

As the COVID-19 pandemic spread across the globe, South Africa, like many other countries, declared a national state of disaster under Section 3 of the Disaster Management Act 57 of 2002 (Department of Co-operative Governance and Traditional Affairs, 2020). This was gazetted on 15th March 2020, and on 23rd March 2020, President Ramaphosa announced a national lockdown which was set to commence on the 26th March 2020, with the aim of delaying and limiting the spread of the COVID 19 pandemic as well as prepare the national health system.

People with disabilities experience poorer access to services under usual circumstances, and so are amongst the most vulnerable in any crisis-affected community (WHO, 2020). Owing to inequalities in various sectors including education, employment, transport, and access to healthcare, some people with disabilities are already vulnerable because of their disability (Hanass-Hancock & McKenzie, 2017). As such, they may require more care and consideration. It is the case then, in crisis situations that people with disabilities tend to be excluded from emergency and pandemic responses as well as in allocating relief resource considerations. This was evidenced by previous cases of pandemics such as Ebola, swine flu and cholera (Meaney-Davis, Lee & Corby, 2020). Against the background that this might be an ongoing risk in the current COVID-19 pandemic, we conducted an online study with the following aims:

i) To describe the experiences of people with disabilities and organisations of (or that serve) persons with disabilities during the COVID-19 pandemic and national lockdown period in South Africa.

ii) To identify possible strategies and recommendations for disability-inclusive pandemic responses.

This was a mixed-method descriptive study. Data was obtained via two online surveys (SUN-Surveys) which were distributed through disability persons' organisations (DPOs) and other disability networks country-wide. The first survey was for people with disabilities and the second was specifically for DPOs. We also conducted virtual in-depth follow-up interviews with people with disabilities for more narrative data; these findings will be reported elsewhere after completing the analysis. We received responses from eight out of the nine provinces with the majority of the responses being from the Western Cape Province.

This report sheds light on the impact of COVID-19 on people with disabilities and relates to: access to information on COVID-19; access to health facilities and services; access to services; participation in decision-making; and governmental involvement.

Based on the findings, this report will also serve to propose recommendations to the South African government and private sectors on how to include and make special provisions for people with disabilities to alleviate the impact, as well as to improve planning, for future crisis situations.

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NOTE: All extracts from the participants who responded to the surveys have been left verbatim and unchanged for the purposes of this study.

SURVEY 1 FINDINGS

Demographics of study participants

The online survey was accessed across eight of the nine provinces of South Africa. The percentage breakdown of participants per province is reflected on Table 1:

Table 1: Provincial breakdown of participants

Province	% of participants
Western Cape	52
Eastern Cape	11
Gauteng	17
Free State	0
Kwazulu-Natal	11
Limpopo	3
Mpumalanga	1
Northern Cape	4
North-West	1

The age range was between two years (with proxies answering for young children) and 76 years with most of the study participants between 26 and 38 years of age (See Figure 1 below).

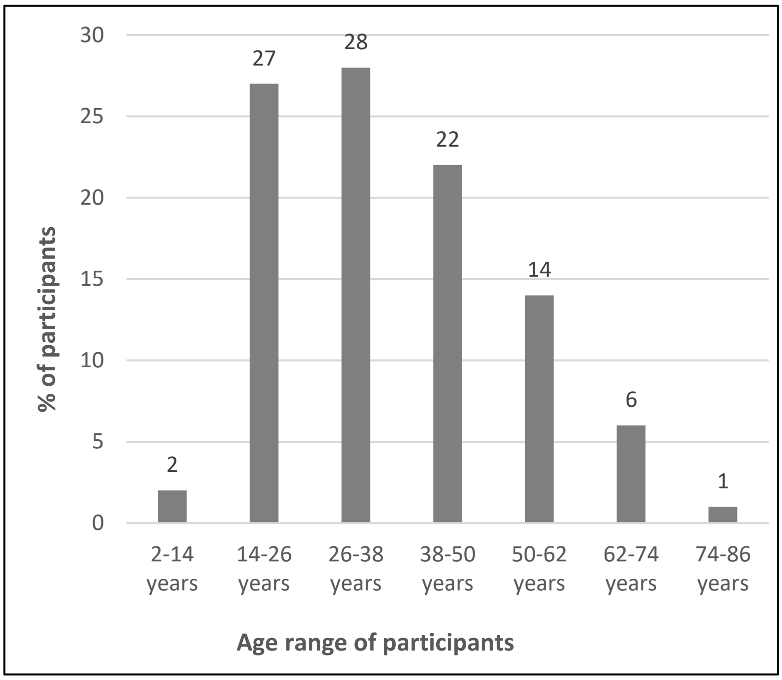

Figure 1: Age of participants

Of the total number of participants in this survey, 57 percent were female and 42 percent were male, with one percent identifying as other/non-binary. Only one percent of the participants were non-South African citizens. Regarding marital status, 21 percent of the participants were married, 58 percent had never been married, eight percent were cohabiting with partners, five percent were widowed and seven percent were separated. Approximately 42 percent of participants lived in a family home while 39 percent lived on their own. Only one percent of the participants lived in government facilities and five percent resided in private facilities.

The impairments or disability types represented in this study (See Figure 2) included the following: people experiencing difficulty walking or climbing (20 percent); people with visual impairments (16 percent); while 15 percent selected ‘other’ when describing their disability type. In addition, nine percent of participants identified as having difficulty gripping, holding or lifting, while eight percent selected feeling depressed, sad or moody. Six percent of participants identified as having hearing impairments, and six percent identified as feeling anxious. Five percent of participants selected remembering and concentrating difficulties. Four percent of participants identified as having learning impairments, four percent selected other mental health conditions, with an additional four percent choosing communication as their disability type. Lastly, two percent of participants found carrying out simple instructions difficult, while one percent identified as having intellectual or developmental impairments.

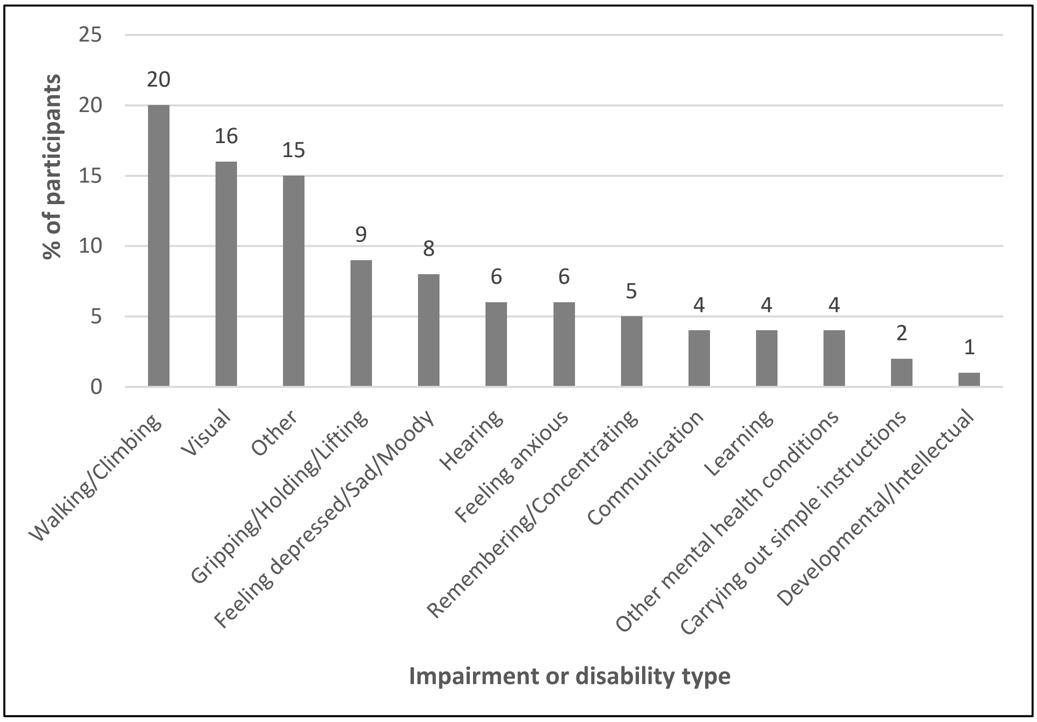

Figure 2: Types of impairments or disability types

Seventy-two percent of the participants used assistive devices or technologies while 28 percent reported to not using any assistive technologies. The following assistive technologies were cited:

Table 2: Assistive technologies used by participants

Assistive devices/technologies:	
Wheelchairs	Voice over software
Oxygen concentrators	Speech processor
Sats monitor	Read & Write programme
CPAP ventilator	Braille display
Mobility aids (crutches, walking sticks/frames)	Mobile apps for colour, text and object recognition
Sign language interpreter	Zoomtext application
PECS	Spectacles

Cochlea implants	Magnifiers
Hearing aids	Enlarge font
White cane	Guide dog
iPhone 11 Pro Max	Irlen lenses
Screen reading software	Computer with JAWS
Speech software	Fusion 2020
Above knee prosthesis leg	MacBook with its accessibility features for digital activities

While 42 percent of participants declared needing help with their daily activities, 58 percent indicated not needing assistance. Of those who were using personal assistance, paid caregivers were the most used (37 percent) followed by family members (29 percent), unspecified other (20 percent), friends (ten percent), private caregiver (one percent) and government institutional care (one percent). Twenty-six percent of the participants indicated that this support was interrupted by the COVID-19 situation, while support for 74 percent of the participants was not impacted.

Some of the reasons cited for interrupted personal assistance include:

- Restricted travel methods and not having stay-in caregivers lead to a reduction of working days for caregivers. Caregivers are also in need of public transport to get to work, which increases the risk of infection.
- Fear of contracting COVID-19 from the caregiver as they also encounter other people when running errands on behalf of the person with a disability.
- Changing caregivers and finding a reliever if another one was off-duty was risky at this time. While some caregivers were also observing lockdown regulations due to fear of the virus, others (and domestic help) could not get permits to work and some people with disabilities were not aware of how to get permits for their caregivers.
- Cash flow became a challenge and monthly costs (because of needing masks, gloves, etc.) increased to non-affordability given other disability-related costs such as linen savers, Coloplast catheters and medications. Other participants spoke about the inability to raise funds to employ caregivers.
- Virtual support is not the same as face-to-face walk-in support directly from offices.
- It is not possible to lip read with masks on.

- After testing, the waiting period of isolation interrupted some of the services and triggered stress.
- Working parents find it difficult to provide support after their own working hours.

Inadequate access to the right of information on COVID-19

Although 93 percent of participants acknowledged they received information on COVID-19, only 83 percent said they understood all the information that was given to them, while 14 percent said some information was helpful and two percent declared to have not understood any of the information received. According to 33 percent of the participants, they were not able to ask questions regarding the information they received, while 20 percent of the participants said they were able to ask some questions. Forty-seven percent felt that they were able to ask all the questions they wished to ask. This may have been due to the modes of disseminating information. For instance, this study reveals that most of the information received by participants was either through television (23 percent), social media (22 percent), cellphone (17 percent), radio (16 percent) and newspapers (10 percent). It is thus not always possible to ask questions or get direct individually-tailored answers through these platforms. The study reveals that information given to people with disabilities was not tailored to their specific disability and needs. As such, approximately 24 percent of the total participants felt that information which they received was not sufficient, while 38 percent said not all the information given was helpful to them. These mixed feelings about information received and information still required are reflected in the following comments by participants:

> *"Much of the information 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."*
>
> *"I want to know how I can resume my physical therapy in the safest manner because I have a compromised immune system and a muscle disease so have many breathing difficulties even when not actively ill."*
>
> *"Some (information) was helpful but not always able to do because your hands are touching the wheels all the time."*
>
> *"Sometimes difficult to separate facts from fiction."*
>
> *"There is a lot that the government doesn't tell people about emerging best practices such as deficiencies in zinc, cholesterol and cholecalciferol, and proning, and how these affect outcomes. I had to go and find all this for myself."*
>
> *"Information about levels and how to protect yourself"*

“Unsatisfactory answers in respect of ADHD, ASD, SMH, Down Syndrome & Learners with Physical Disability. How will teachers enforce Physical distancing with learners in Special Schools? Unsatisfactory answers when I requested a breakdown on the number of infections and deaths in terms of: Demographics, Age, Residential Location, Levels of Education and Destitute or Affluent Persons.

“Wanted to know more about symptoms of people with Spinal Cord Injuries”

“Questions I had been that if exposed to COVID-19 would the system in place inclusive enough for the nature of my disability. The testing system did not reach every corner as in a case of voting.”

“The challenge arises when I need assistance in shop when buying groceries. I am not sure whether it’s safe to hold the person’s hand or elbow. Remember that this is the very elbow we use to cover our mouth when we sneeze or cough.”

“I found the information to be useful but some like in the social media was so not helpful it only made me to panic (fake news).”

“Never was I sure whether the information was true due to false news out there.”

“There is a lot of contradictory research published about the virus so one has to decide for oneself what you are going to take on Board.”

“Too much bombarding with information and changes in protocols at work and on social media”

“Too much information so difficult to understand what exactly you are referring to”

“In the workplace if people could wear these clear masks or make other come of communication for the hearing. Should I detect covid-19 and recover what after effects will it leave to my hearing as I’m an ENT patient?”

“Due to the nature of my disability I need to know whether the health system in place to deal with the victims of Covid-19, does it accommodate the nature of my disability without becoming a victim of the system itself. I'm concerned about an inclusive approach for all vulnerable groups exposed, testing, medication methodology without additional cost and exposure.”

“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 (PwD). No work plan procedures/ legislation that considers the needs of PwD.”

> *"The information is helpful. I need to find out more about my illness (immunocompromised) and COVID-19. How dangerous is it to me to contract the illness and is it life threatening?"*
>
> *"I wanted to know the duration of isolation and quarantine."*
>
> *"I would love to know what is required of me to keep as a person living with a disability."*
>
> *"If persons with disabilities are part of decision-making during planning. Like example they were excluded from food parcels because of their disability grant forgetting that the costs they incurred is even more before COVID outbreak. Children with disabilities and special needs are not considered."*

Participants reported receiving information in the following ways: from other people within their circles (eight percent); from a sign language interpreter (one percent); and unnamed other sources (three percent). In terms of language, 69 percent received information in English, 18 percent in Afrikaans, five percent in isiZulu, four percent in isiXhosa, two percent in South African Sign Language, two percent in Setswana and one percent of Sesotho. There has also been significant information overload as well as false news and information linked to social media platforms. As such, in addition to experiencing a pandemic, there was also an infodemic of misinformation in the COVID-19 crisis (UN Department of Global Communications, 2020; WHO 2020).

Difficulties of people with disabilities to access health facilities and health services

Some people with disabilities have regular hospital appointments either to access medication or to receive some form of therapy. Many people with disabilities require assistive devices to function and participate in their daily lives. In this survey, approximately 59 percent of the participants required constant medical supplies, while 64 percent were on regular medication. Twenty-three percent of the participants had other illnesses such as diabetes, HIV/AIDS, hypertension, bronchitis, cluster migraines, chronic kidney disease, severe depression, cholesterol and/or arthritis. Nineteen percent of the participants had some of their hospital appointments changed and 13 percent had all of their appointments rescheduled. Twenty-one percent of the participants reported that their appointments were not changed. This was not applicable to approximately 47 percent of the participants. This caused major concern for people who require regular medication and/or therapy. Some of the difficulties experienced by participants are reflected below:

> *"There is no delivery of chronic medication. The prescriptions need to be renewed. Only certain practices are open for consultation. There is a risk that one has to bear if one goes in for physio/occupational therapy/chiro. A*

> *person wants to minimize the risk and would rather cancel appointments until there is some certainty."*

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

> *"Pharmacies are out of stock of my prescription vitamin D which I have been on for a year, and other supplements are in low supply too. I am now forced to shop around for substitutes."*

> *"I need physio (definitely) and biokinetics (but can survive with physio). Trouble is they see too many patients and people can be asymptomatic so it's dangerous. But I can't go without for much longer."*

> *"Not in the same province as my doctors at the moment. However; they have given the option of online video appointments which I declined as I am not comfortable with video chats. Script renewals are been done via email and sent directly to the pharmacy closest to me. I have not been receiving my bi-monthly vitamin b injections since the start of lockdown - some facilities requires scripts and others were out of stock and weren't sure when they would get stock in."*

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

The majority of the participants were accessing services from private facilities (52 percent), while 19 percent were using public facilities, followed by 12 percent who were using DPOs and seven percent who were using non-governmental organisations (NGOs). Eleven percent selected "other" and did not specify what this refers to.

With the COVID-19 lockdown and decreased mobility of people, transportation was cited as a significant problem for people with disabilities who rely on public transport to get to hospitals. In this survey, 16 percent of the participants expressed that they had reliable transportation before the COVID-19 pandemic, but that during the lockdown they lost their means of transportation, with15 percent saying that they sometimes would not have transportation.

> *"I used to take a taxi to see a doctor, now I haven't taken a taxi because of contact if many in a taxi and Uber transportation is expensive."*

While others still need to do collections, some participants described adaptations and accommodations, such as using delivery services, home services, etc.:

> *"My doctor organised that pathology visit me at home to draw blood."*

> *"They have given me a 6 monthly repeat prescription."*

> *"My visits to the clinic are only my six-month doctor's appointment. Medication monthly supply can be collected by a Staff member or myself on a date and time given by our clinic."*

However, this is also not without challenges:

> *"Doctors and psychologist do video calls. Pharmacy delivers. Biokinetics gave me a home programme but it's not really working without someone to motivate and help me (I have exercise intolerance)."*

Of the total number of participants, 78 percent revealed that they have not been provided with face masks and hand sanitisers by their health facility or institution, while 22 percent reported that these products had been provided. Of those who use caregivers, 59 percent revealed that their caregivers were not provided with any face masks or hand sanitisers, while 41 percent were provided. Twenty-nine percent of the participants said they had difficulty using face mask and/or hand sanitisers effectively. For instance, some individuals with physical disabilities, as well as those who use spectacles and hearing aids, expressed difficulties:

> *"Mask steams up spectacles and hooks around hearing aid", "I have difficulty because I'm only using one hand / only one side is working in my body."*
>
> *"Due to my Paraplegia, I have very limited use of my hands. I had a C5 & C6 Spinal Lesion…I need assistance to wear face mask."*
>
> *"I cannot independently put a mask on and off."*
>
> *"So there is no understanding of challenges faced by PwD. It is difficult to use hearings 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 get 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, PwD may have other pre-existing conditions that make them susceptible to COVID-19. People do not respect social distancing/practice safe practices so going out to buy medication/shopping for a PwD can be very stressful experience."*
>
> *"The face mask steams up glasses and there is a visual impairment which is further affected by the face mask."*
>
> *"Due to physical impairment/nerve damage using hand sanitizer pump bottle is difficult. Skin sensitivity to hand sanitizer"*

Some cited communication barriers related to the use of face masks:

> *"She [name protected] looks at the mouth for communication. She is 2 and cannot wear a mask."*
>
> *"No difficulty in using it myself but have difficulty with lip reading due to other people wearing masks."*

Those with breathing difficulties or shortness of breath feel like they are suffocating:

> *"I have a very low lung capacity and use conscious diaphragmatic breathing at a rate of 32-45 breathes a minute in order to keep my oxygen levels safe. Most masks make it difficult for me to breathe efficiently and I feel like I'm getting even less co2 out the usual (I tend to focus more on getting o2 in....have had respiratory acidosis a few years ago)."*
>
> *"I can't breathe well."*
>
> *"It is difficult to breathe in especially if there is previous lung damage and other conditions."*
>
> *"My suppressed immune system makes breathing with a mask unhealthy as I take I impurities from my own breath."*

For participants who rely on the government services, very little help has been offered to assist, especially in obtaining chronic medication:

> *"No one has assisted me with anything." "They always says they will look for it and let me know but I am always the one that needs to go to the clinic and tell them I am almost out of tablets then they start to look for my file again since I was diagnosed with HIV some of them are treating me bad and they don't care."*

Measures to help people with disabilities to access food and other social services

People who were employed

While 41 percent reported that they do not work, more than half the participants in the survey (59 percent) are part of the South African workforce with jobs ranging from educators, researchers, administrators, security guards, consultants, officers, self-employed, etc. Thirty-six percent of those employed had to stop working as a result of the lockdown, while six percent had to change the nature of their job in order to continue earning an income:

> *"I lost my job - contract was not renewed."*
>
> *"The workload has dropped significantly as my main income comes from environmental consultants who cannot do their field work at the moment which means fewer reports for me to edit."*

> *"Remote working from home and loss of some income (40%)"*
>
> *"I cannot work as the restaurant is closed due to the lockdown."*
>
> *"Loss of income due to travel industry being closed."*

Regarding the unemployment insurance fund (UIF), it was not applicable to 73 percent of the total participants. While 14 percent reported to have received UIF, 11 percent of the participants who lost their jobs said they were unable to get their UIF. Three percent declared not knowing if they could get UIF and this was related to lack of information. Although compensation was not applicable to most participants (88 percent), nine percent of the participants who required compensation did not receive any compensation from their employers and only three percent reported to have received compensation. While employers were requested by government to assist their workers in the application for UIF, some of the participants in the survey said their employers had done nothing or very little to assist them with this process. Those who received UIF were successfully assisted by their employers.

Regarding social security, 30 percent of the participants receive a state disability grant and approximately five percent had not been able to receive their grant during the first month of the lockdown period. The reasons include change of dates, feelings that SASSA is inadequate, as well as avoidance of long queues. About 11 percent of those who receive grants expressed that COVID-19 and the lockdown has had a negative impact on the process of receiving their monthly grants:

> *"On collection days the lines can be hell as f--k, it's not worth the damage to my already sensitive skin. I usually wait 5-7 days to collect and shop. This is to avoid queues and possibly catching the disease since no social is practiced."*

Students

Forty percent of the participants reported to be students. Ninety-six percent of the students in this survey reported that they were able to study at home, while four percent were not able to. Like many students in the country, the studies of students with disabilities have been slowed down by the lockdown. Given that all learning has transitioned to online platforms, connectivity problems are experienced:

> *"Biggest problem is internet connection at home, usually rely on university's internet. Can't always get the assistance I need."*
>
> *"I don't have access to internet and can't do my work."*

Some students are experiencing anxiety, increased workload, poor communication and it is affecting their performance:

> *"Studies have moved to online. The weekly workload has increased as a result. Tests have been replaced by assignments which I find more*

> *challenging with my anxiety and my marks are far lower than if I had written tests as I struggle to complete assignments on time."*
>
> *"Concentration is difficult."*
>
> *"The workload has definitely intensified and I hardly get a break. I have to rush for all of my tests and have been receiving low marks for certain subjects."*
>
> *"Unisa has given me no communication on how they will accommodate students during exams. I have sent many emails to them."*
>
> *"Communication is the only obstacle, other than that I am coping with online studying."*
>
> *"It has been challenging to do all the work online and it feels like a much bigger work load."*
>
> *"I have to do most of the communication to lecturers about concessions and needed material."*
>
> *"Horrible it makes me feel so depressed and overwhelmed."*

Accessing other resources such as scanners and printers appears to be a challenge:

> *"I am visually impaired and I work and study, it is difficult for me to get hard copy books scanned. Accessing university employees for assistance was quite difficult in the beginning."*
>
> *"Unable to utilize libraries and do research and assignments properly or effective and efficient."*
>
> *"Not having a printer at home was a real disadvantage due to the fact that writing a thesis requires a lot of reading, specifically electronic articles."*
>
> *"Stressful. It is difficult to deal with the external changes as well as my emotions and anxiety that the pandemic has exacerbated. Itis difficult to focus on my studies whilst home schooling 3 children and seeing to the running of the household. I have to reorganize my life. The fear of contracting the virus is overwhelming as I am immunocompromised. Friends are going through Covid-19 experiences as well as like falling ill and death of the extended family members. It is not easy to cope I need more interaction with my supervisor and other participants in my study. I have lost my momentum because there are too many responsibilities to focus on at the same time."*

In addition, students who were conducting research which involves contact with participants, have had to pause their studies.

The survey responses show that some students were provided with laptops (10 percent), tablets (two percent), WIFI or data (31 percent) and online teaching (31 percent). However, the online learning challenges still exist:

> *“Due to being in front of the screen majority of time, my eyes have started to pain. Due to my visual impairment, I sometimes cannot read small words on my screen.”*
>
> *“It has been challenging to do all the work online and it feels like a much bigger work load. I also don't have as much interaction with my friends as I used to which has made me feel sad and lonely.”*
>
> *“The learning experience has been difficult because of the lack of consideration towards certain elements of accessibility by my department and the task that they ask of me to perform.”*
>
> *“I am not motivated as last year due to the many challenges that I experience. I would have preferred to have the contact week which was initially scheduled for May 2020. This would have assisted to engage with the lecturers and other students, this is usually a plus and a booster!!!”*
>
> *“Because of I'm a disabled person, I need assistance at all times but because of Lockdown regulations I'm required to demonstrate social distance which gives difficulties in terms of learning and teaching.”*

There were some students who receive the necessary support and reported that all is going well.

> *“It’s not good experience but with support is doable.”*

There was also a response that additional accommodations were made with regard to being given extra time during assessments:

> *“For some of my tests, I have been given an extra time of 15 minutes to complete them”*

Impact of decision-making on people with disabilities

Forty-five percent of the participants in this survey were affiliated to or members of DPOs. Of these participants, only 50 percent reported their organisations to be involved in decision-making regarding COVID-19 responses. Some of these organisations have been involved in distributing information in the following ways: through newsletters, social media, emails or telephonically; regular check-ups on their members to ensure they are mentally and emotionally stable; providing food parcels to its members; and assisting with funds for medications and doctors’ appointments. These responses are a reflection of the participants’ experience:

> *"Within the scope of [Organisation's name protected] and the availability of funds, we support our members with food parcels and information concerning COVID-19 and are available to support our members with questions concerning COVID-19 Information that is relevant to COVID-19 is communicated with all our members electronically. All our staff members work from home."*
>
> *"Accessible material was produced about the COVID-19 situation. Online social events (a quiz) was organised for the members, to counter isolation. I'm also aware that [organisation's name protected] attempted to engage with government regarding the situation, though I don't have much information about that."*
>
> *"I am a member of several formal and informal disability networks and we have been involved in information distribution, lobbying and hooking up people with help in the community."*
>
> *"It is a support-based organisation and they have set up regular online meetings and they keep on sending useful/helpful information."*

While some organisations had resources to continue with their activities through a "work from home" arrangement, other organisations had to scale down:

> *"[organisation's name protected] had to scale down its support of people with disabilities, during level 5 & 4. Will get back to full operational capacity as and when permitted by regulations."*

From all the received responses, there was no indication of collaboration between the organisations and government on decisions of how to assist the disabled community during the period of lockdown. From the responses from participants in this survey, there is no indication that people with disabilities are involved in any way in the decisions and policy-making actions on the issues that have been raised related to the lockdown period.

Lack of awareness around government assistance for people with disabilities

Fifty-four percent of the participants were not aware of what the government was doing to assist people with disabilities during the lockdown period. Only seven percent of the participants acknowledged that the government is helping its citizens in various forms. These include: providing PPE for residential facilities; and an increase in the disability grant. While some participants said they are only aware of general support and not targeted support, another participant highlighted that people with disabilities are included when reference is made to citizens:

> *“It is within the regulations of Lockdown that government will support all the people who are currently in South Africa and its citizens who are abroad by providing all essential services and protective clothing, which means people living with disabilities are within that category of citizens of South Africa.”*
>
> *“I point my finger to that department for women, children and persons with disabilities. They are quiet around disability issues while they should be in the forefront. What have they done?”*

Participants were asked to suggest ways in which the government could further support people with disabilities. Some of the participants felt that the government should be doing more targeted and mainstream interventions to assist people with disabilities, such as financial assistance, food parcels, clean water, and domestic help. There is also an expressed need for health practitioners to be trained to work with people with disabilities and run educational programmes on COVID-19 as it relates to people with disabilities. Further suggestions included the following:

> *“There should be a dedicated disability help-line. Disability should be included in all of the programs rolled out.”*
>
> *“Consideration of people with disabilities should be an integral part of government's response to Covid19. 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 people with disabilities do not have the energy or dexterity to prepare meals on their own).”*
>
> *“From a student perspective, internet connection must be made available in order to aid studies.”*
>
> *“I would like to get a three-month supply of medication at a time to avoid unnecessary exposure at the state hospital.”*
>
> *“To make the covid19 related information available in braille.”*
>
> *“Protect specifically blind people who rely heavily on people.”*
>
> *“Provide free transport for mobility. Check regularly to offer psychosocial services.”*
>
> *“Helping people with disabilities with food parcels and deliver them.”*
>
> *“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.”*
>
> *“The legislation needs to consider PwD and their challenges.”*

> *“There needs to be specified shopping hours and days for PwD so they do not have to queue in long lines as PwD are high-risk individuals especially if there are pre-existing conditions. An option for pharmacies to have free delivery of chronic medication for PwD. Employers need to consider PwD when we return to work and implement reasonable accommodation measures. All specialists need to sterilize their consultation rooms/ physio beds/etc.”*
>
> *“Destigmatize COVID-19.”*

Fears of people with disabilities due to COVID-19

Given that people with disabilities perceive themselves as more at risk, and owing to the longstanding health inequities related to access to services, participants shared fears, anxieties and worries about themselves or their family members/caregivers contracting the virus. These fears can contribute to increasing mental health needs for people with disabilities. COVID-19 appears to have subjected participants to worries that everyday activities, such as buying groceries, coupled with their dependence on caregivers, guardians, friends and relatives, potentially threatens their health and puts them at risk of contracting COVID-19. Additionally, the heightened financial and livelihood insecurities, along with undergoing potential isolation during lockdown, trigger a range of fears and anxieties. Some of the shared concerns include:

- Fear of being infected, dying and leaving children alone
- Fear of going to the shops and not being helped at the shops
- Fear of being isolated and discriminated against
- Fear of sharing showers, tubs and toilets in communal and residential settings
- Fear of unemployment after lockdown and loss of livelihood
- Fear of not completing studies and financial implications
- Fear of dying of hunger and having inadequate medication and safety gear for caregivers for COVID-19 , e.g. gloves and mask
- Fear of not being able to seek and access medical help and healthcare upon contracting COVID-19
- Concerns about elderly parents and caregivers getting ill and the implications of not having caregivers
- Running out of funds to pay caregivers and sustain self.

SURVEY 2 FINDINGS

Responses from organisation of (or serving) people with disabilities

A total of 11 organisations responded to the survey. Seven of these organisations were mostly represented by the director of the organisation. Other participants' roles were: a caregiver in the organisation (one); a therapist and therapy coordinator (one); and national programmes managers and coordinators (two). Nine of the organisations addressed all disability types, one addressed only physical disabilities, and one addressed all disabilities except intellectual disabilities.

The services provided by these organisations covered a range: educational support; advocacy and training; economic and skills development; special care (residential and day care services); assisting with healthcare of persons with disability, including counselling; and support of groups and capacitation of people with disabilities and their families.

While some organisations had a presence in all provinces, others only worked in one or two provinces. At the time of completing the survey, none of the organisations were aware if any of their members had contracted COVID-19. However, the organisations shared that members had been affected by the pandemic in different ways.

Children needing therapy could not get support while at home. The loss of income and curtailment of services affected most of the people in the organisations. This exerted pressure on the mental health of the managers who also had to be emotionally available for their employees and members whom they could not reach for support:

> *"Loss of income for staff and employees with disabilities in the protective workshop, closure of the organisation resulting in the inability to render community based services."*
>
> *"The main effect on our residents has been the restrictions on their daily lives of the National lockdown. This has meant that they cannot receive visits from friends or relatives, their regular outings have been curtailed, and volunteers who normally undertake activities with the residents have been unable to do so."*
>
> *"Unable to attend school. Unable to eat because parents can't work. Missing out on therapy appointments. Unable to participate in dance and sports activities."*
>
> *"...being at home not doing anything really hurts us because children were progressing, it means we have to start from scratch when we open."*

> *"The biggest challenge that causes stress as a manager is having to financially sustain the employees of the organisation…. I also had to manage the stress of the employees."*
>
> *"…my staff are turning to me for guidance and that places a huge burden on me and I do not have anybody to go to because of lack of clarity from government."*

Information on COVID-19

Nine organisations reported that the following information was given to them for the prevention of Covod-19: wearing of a face mask (24 percent); practicing social distancing (24 percent); and hand hygiene (24 percent). Self-quarantine (19 percent) was reported by seven organisations as part of the information given to its members while other information (11 percent) was included by four of the organisations in their information to members on prevention of COVID-19:

> *"From the broader Centre that we were linked with, general education material, notices, contact information, etc. was sent to students. We sometimes followed up with more personal contact, such as calls and had a mentor and staff members check in with individual students."*
>
> *"Discouraged fake news spreading in townships."*

Social media was the most common medium of sharing information on COVID-19 by the organisations (30 percent), followed by cell phones (26 percent), and person-to-person (13 percent). Other forms of communication were television (four percent), radio (eight percent), the internet (four percent), and a sign language interpreter (eight percent). The languages used by organisations to provide information on COVID-19 to members and volunteers were English (47 percent), isiXhosa (16 percent), South African Sign Language (16 percent), Afrikaans (10 percent), Setswana (six percent) and Sesotho (six percent).

Although organisations were able to provide information, it was not without challenges. Providing information to persons with certain disabilities such as intellectual disability and the blind was identified as challenging:

> *"There is limited information in simple language for persons with intellectual disability and little information in isiXhosa."*
>
> *"Educating blind people on social distancing and sanitizing - getting extra sanitizers for the pa's - re-educating the Deaf on social distancing. COVID 19 rules are contrary to their cultural norms. - knowing (not knowing) which sanitisers are not harmful to those with albinism."*

Some organisations do acknowledge governmental involvement in providing information on COVID-19 to persons with disability.

> *"National: Sign language interpreters during television broadcasts. Regional: WCDoH [Western Cape Department of Health] posters circulated through social media. Local government: Working alongside NPOs in Masiphumelele."*

> *"We received information from the Department of Women, Youth and Persons with Disabilities, which we then distribute via our provincial offices, who in turn circulate via social media."*

However, the majority of the organisations voiced their dissatisfaction with the government for not doing anything or not doing enough:

> *"No, government has not assisted in the development of materials such as pamphlets. Information can only be accessed electronically."*

> *"We are very disappointed by government's interaction with persons with disabilities and disability organisations. We voiced this view via media interaction (e.g. Citizen) following the webinar hosted by the DWYPD on 22 May."*

> *"Should be able to answer the staff when they ask about what to do but because of lack of clarity from government, the only thing I can say is we just have to treat each case as it arises and this is very unsettling for me."*

Other organisations were not aware of any governmental involvement on providing information to persons with disability:

> *"Am not aware of any measures implemented by any level of Government to provide information specifically to people with disabilities, other than sign language interpreters on television when Government officials make announcements regarding Covid-19."*

Access to health facilities and services

These organisations have assisted their members in accessing health care services during the pandemic and lockdown through collaborations with health forums, online counselling, and the provision of food parcels. This is reflected below:

> *"We could provide online counselling and academic support. Medical support was referred to ER24 for emergencies of the campus health numbers."*

> *"We have provided emotional support and advice remotely to support their ongoing therapy and to help them decide when to seek medical care."*

> *"We would report incidents to the SANAC Nerve Centre and to the Provincial Nerve Centres for COVID19."*

> *"Collaboration with health forums."*

However, transportation problems and poor hospital reception services were some of the challenges that organisations reported to be experienced by their members, when accessing health care services on a day to day basis. Others reported unavailability of medications:

> *“Not enough PPE's. Some of their medications are not available.”*
>
> *“Transport challenge”*
>
> *“Accessible transportation. People have to sit and wait for assistance for very long hours without anything to eat or drink and then they get send home to come back the next day and the next and the next.”*
>
> *“Transport distance and cost. Waiting lists. Queues.”*
>
> *“Long queues and people are often turned away from the health facilities, timeous access to medication as a result of the crowding at health facilities.”*
>
> *“Long waits at hospitals for doctors' visits and to collect medications, which create discomfort and can be distressing for people in wheelchairs.’*

Three out of eight organisations (38 percent) reported that these challenges were worsened by the pandemic and lockdown:

> *“On campus services had to mostly be done online. Whereas campus health was accessed easier, once off campus this could not access. Some clever students asked to stay on campus, and this enabled better service access, such as campus health services, and any other emergency ER24 services.”*
>
> *“Shortage of medication”*
>
> *“We have concerns about the Critical Care Decision Tool and its impact on persons with disabilities. Their rehab and non-emergency medical appointments have been cancelled.*
>
> *“They have been scared to travel on public transport.”*

Additionally, organisations perceived the government as not doing enough in assisting people with disabilities during the pandemic. The disability sector’s call for “nothing about us without us” seemed forgotten as organisations of, and people with disabilities expressed concern for inadequate consultation and not being included in the initial plans of addressing the pandemic. As such, there were certain expectations from government such as having a disability act in place and building real partnerships with disabled people’s organisations:

> *“Government should engage with DPOs for assistance in managing access to health facilities. DPOs should be mandated to monitor challenges experienced at the health facility and to provide support when required.”*

> *“Give us money ring-fenced for disability support only - not just via NSFAS. And put a Disability Act in place.”*
>
> *“Improved communication and a "real" partnership rather than lip service.”*
>
> *“Train and deploy SASL interpreters - sensitization workshops for health workers.”*

Furthermore, organisations reported that their members faced certain challenges when accessing other services such as social grant services and food parcels. Some voiced significant concerns about services not reaching those whom they are meant to benefit as a result of corruption:

> *“Difficulty to access food parcels, especially in families with no income.”*
>
> *“Access to social grants”*
>
> *“Services they usually use, such as the library for internet access and school for education and food, have been closed.”*
>
> *“The government did their own food relief programmes, our people were sadly excluded.”*
>
> *“There was no relief funding for the organisations and for persons with disabilities, except the disability grant.”*
>
> *“We think government is trying to help but the help doesn’t reach everybody because since we applied for food parcels and nappies, nothing has ever reached us up to this far.”*

However*,* one organisation acknowledged the generous support offered by individuals and the corporate sector:

> *“We literally sent out a message that we need money and our supporters have been extremely generous ... without the private sector help we could have been swamped.”*

Overall concerns and fears

The pandemic has imposed certain fears for the disability community. For instance, anxiety about the uncertainty of the end of the pandemic and its effects, which include: deepened poverty implications; fear of being infected and not getting medical help; and fear of unemployment.

> *“Poverty, unemployment, vulnerability as a result of co-morbidities, social distancing particularly for persons who require personal support e.g., wheelchair users and care attendants.”*
>
> *“They will not get the assistance and help they need losing their jobs, lack of funding.”*

> *“There is a fear of contracting the virus due to the vulnerability of our residents and the likelihood of a more severe reaction than the average person, and the fear of rapid transmission should the virus enter one of our facilities, due to the necessity for close contact between residents and caregivers.”*
>
> *“The fear they might get infected, as COVID-19 virus is invisible. The fear of dying alone, when infected.”*
>
> *“Shortage of medication and inaccessibility of treatment. Inability to respond appropriately in a crisis (e.g. seizures and especially Status Epilepticus and SUDEP).”*

A concern was also raised about the inability of organisations to support affected families and caregivers who do not get any form of income at this time:

> *“We have two students who are infected by COVID19, one was admitted in hospital and due to her condition, she is very aggressive, got discharged to the care of the grandmother… then the grandmother also tested positive. We don’t have anything to meet them halfway as the organisation.”*
>
> *“We are worried about the caregivers who work on a voluntary basis. Our concern is what if they get sick.”*

Financial impact

The pandemic and lockdown has had an impact on the financial status of the organisations that participated in this survey. Two specific issues identified were donations and fundraising strategies. The organisations emphasised that donors are seemingly taking longer to respond to funding applications and in their capacity to deal with the volume of applications, all this while organisations are going through a financial crisis. The organisations describe the impact as devastating and fatal:

> *“Fatal impact! Alternative sources of income through manufacturing and SETA learnership programme income, rental income and training income.”*
>
> *“It has had a devastating effect on our funding strategies, as up to 40% of our funding is typically derived from these sources, which have all but dried up since the start of Lockdown.”*
>
> *“Negative. Some funders have redirected funds to feeding and some funders are struggling themselves so cannot continue to support us. Lucrative fundraising events have had to be cancelled and only small-scale online fundraising has been possible.”*
>
> *“We could do any awareness and promotion We list out on fundraising. We had to stop all services due to Financial constraints.”*

> *“Normally our fundraising is in the form of events which we couldn't do in the light of lockdown and social distancing, so by April we were already in trouble…and yet we only received response on our funding application by July.”*
>
> *“Our application was declined on technical basis, we appealed but it doesn’t help if it comes too late after you’ve closed down.”*

The organisations report that the pandemic has also had an impact on the future sustainability of their organisations. It seems that, with limited fundraising and technical skills needed, including the global economic impact of COVID-19, organisations have been severely affected:

> *“Inability to source alternative income streams. Staff members receive UIF/TERS only which affected their personal economic circumstances. Staff members might be retrenched because of inability to pay salaries after the lockdown. Risk of resignations as professional staff (social workers) seek alternative employment.”*
>
> *“We have to relook and rethink our way of implementing programmes and projects, as it is not possible to have gatherings and events.”*
>
> *“The future sustainability of our homes is in serious jeopardy due to the sudden and unexpected loss of a major part of our funding. Without alternative intervention, some of our homes may well face closure.”*

Strategies used to address challenges

In discussing strategies used to address the challenges, five of the participating organisations explained how they were not set up for the current situation posed by COVID-19 and lockdown. They explained how their organisations had no new funding as a result of the pandemic. Many of the initiatives and fundraising events were suspended. During this time, efforts have focused on seeking support from private donors and local businesses as they needed immediate support to survive:

> *“As NPOs, we could not apply for small business funding and by the time NRC funding came, I am sure a number of NPOs had already closed their doors. So funding is our biggest challenge.”*
>
> *“We have not received help since June and the centre has no funds anymore, we are worried because we have kids who need assistance with nappies.”*

Thirty-four percent of the organisations have had the opportunity to collaborate with the government in making decisions for people with disabilities during the pandemic:

> *“Through especially the Faculty of Medicine and Health Sciences, as far as I know. And some research entities too are collaborating.”*
>
> *“We have received requests for information relating to persons with disabilities from DBE and Social Development (City of Cape Town).”*
>
> *“Our organisation represents the disability sector on the SANAC Nerve CENTRE for COVID19.”*

However, there are organisations that feel the government has not put adequate provisions in place or has done nothing to protect persons with disability against COVID-19.

> *“There seems to be very little done to protect persons with disabilities.”*
>
> *“Nothing”*
>
> *‘Nothing. Most DPOs are in lockdown due to financial constraints and persons with disabilities were denied access to services.”*
>
> *“None that I am aware of”*
>
> *‘Closed schools, stopped visitors to institutions, topped up SASSA grants.”*
>
> *“Very minimal”*
>
> *“They didn’t come to us before they decided on the 150 mil, they might have had better idea in terms of scale of need.”*

A call for government intervention/recommendations to government

The participating organisations suggested some ways in which the government could provide more assistance to people with disabilities. These include, advocating for collaboration and exchange of information between government and non-profit organisations (NPOs) who are already working closely with the communities they serve:

> *“Effective communication and consultation (not rubber-stamping). Sorting out ongoing SASSA problems.”*
>
> *“Collaborate with DPOs to form support clusters so that individuals could be assisted within their homes.”*
>
> *“Funding assistance, guidance on how to deal with Covid-19 in a care home environment, provision of PPE, screening and/or testing.”*
>
> *“Consider their needs as a starting point and not an afterthought.”*
>
> *“Consult more with persons with disabilities, to ensure that they are not left behind.”*

> *"If they can assist us with food parcels, nappies and PPEs that will be helpful."*
>
> *"It is important to involve participants on what support is needed, though provider will be government."*
>
> *"Volunteers have been amazing, they were visible... That is a big thing we need, to build collaborations because the NPOs are specialists, we know what's going on in the communities, we know our clients and we will be able to render services."*

Other shared stories

The participating organisations reflected on the impact of the pandemic on their organisational members. The stories highlighted the impact, ranging from increased levels of fear to disrupted learning, including the violation of the rights of people with disabilities:

> *"We consider ourselves extremely fortunate that Covid-19 has not yet entered any of our 16 homes around the country, while at the same time being acutely aware that it is likely only a matter of time before this does happen. We live in fear of this happening as we are fairly certain that even one positive case in one of our homes is likely to be extremely difficult, if not impossible to control."*
>
> *"Most of our beneficiaries have reported difficulties with adjusting to studies and experiencing stress (a well-known seizure trigger)."*
>
> *"A mother and child with autism and epilepsy were confronted and almost arrested by SAPS in a public space because they were not social distancing!!!"*
>
> *"One of our members, who has a speech impediment and who are physically disabled were not assisted by SAPS when she laid a compliant of abuse against her by her family. Our Provincial Manager had to intervene and ask for the assistance of the Police Commissioner, before the case was taken up."*
>
> *In one incident a member that is blind was abused by her caretaker and the social grant was used by the caretaker. We were able to assist the member to go to the police and lay a charge. The matter was resolved and the person is now staying with someone else."*

Limitations of the study

This study was not without limitations. With COVID-19 being a recent and sudden global pandemic, there is limited data on how this affects the lives of people with disabilities. We recognise that many individuals with disabilities, especially those who reside in institutions or group homes, as well as those residing in rural areas, may experience access and connectivity challenges and, consequently, many people were unable to participate. This survey is therefore limited to those who have access to the internet and social media. Additionally, it is possible that many people were experiencing research exhaustion as there were many studies taking place during lockdown, all aiming to understand the impact of the pandemic.

Given the short period required to obtain information and the nature of the lockdown, our survey was also unable to reach as many people with disabilities as originally aimed. Some individuals with learning or intellectual disabilities, for example, might not have had the opportunity to participate in this survey, if they do not have a caregiver who is willing to help them. The results reflect only a portion of what some people with disabilities in South Africa experienced during this COVID-19 lockdown period.

Similar to Survey 1, only limited organisations who had access to the survey online were reached. Thus, with the relatively low numbers of participants, findings cannot be generalised. However, experiences shared by organisations outline vital issues affecting them and their members with disabilities. These experiences can inform disability-inclusive responses to COVID-19. It is hoped that policy makers, in particular, will benefit from our findings.

Conclusions and recommendations

While prior evidence shows that the health system has been failing people with disabilities, this study shows that the COVID-19 pandemic may have deepened the multiple layers of vulnerability and challenges faced by them. As COVID-19 cases increased and restrictions continued, so are the vulnerabilities of the already vulnerable people with disabilities.

On the one hand, some participants shared an inability to access disability-specific important information in relation to COVID-19. For example, questions on what it would mean if they contract the virus as people with disabilities, would service providers be able to assist, what if they cannot lip read because of mask-use, will they be able to get immediate help, etc., came up often. Universal access to information about COVID-19 should therefore be both general and targeted.

On the other hand, other participants shared not receiving adequate food supplies or medical care. Some people with disabilities found themselves without personal support, due to the imposed restrictions. Communication, for Deaf and hard of hearing individuals, was greatly impacted by the safety step of wearing face masks as they left behind those who rely on lip reading. These findings demonstrate that the vulnerability of people with disabilities is exacerbated by various contextual barriers which may lead to a disproportionate impact for people with disabilities, if left unaddressed. For people with disabilities, it is not only an underlying condition that indicates higher risk but contextual factors, such as attitudinal, environmental and institutional barriers and the prevailing systemic issues, equally positions them at higher risks of contracting the virus.

The study also highlights mental health challenges, following the COVID-19 pandemic. People with disabilities are experiencing fears, anxiety, worry and obsessing about contracting the virus, contributing to poor mental health. Issues such as the imposed limited safety of spaces (especially communal or residential settings), the associated risk of doing everyday activities, as well as the threat to their already limited personal assistance, heightens fear and anxiety. Additionally, fears of either losing or not finding employment post COVID-19, or not completing their studies due to the added strain of online learning, were seen to cause tension and great difficulty.

These added fears and anxieties places extra strain on the mental and emotional well-being of people with disabilities. This growing mental health crisis is likely to burden the already inadequate health system and other mental health support structures. Consequently, the gap in accessing mental health care by people with disabilities is possibly growing and the health system needs to plan for this need. Further research on access to mental health services for people with disabilities is needed to inform inclusive responses to mental health care.

The pandemic has also threatened the social, educational and livelihood opportunities for people with disabilities. For some students, it emerged that the online learning experiences still presented various challenges, despite the support provided. Of those who were employed, some experienced pay cuts while others lost their jobs, and thus had their livelihoods threatened. DPOs also mentioned financial challenges, which means that jobs are at risk. This is particularly concerning given that the food parcels and the financial stimulus packages did not reach many who were in need. DPOs are greatly concerned about addressing poverty resulting from their members and employees losing their employment. Therefore, the pandemic has not only brought huge survival costs to the surface but has also placed issues related to access under the spotlight.

In light of these findings, preventive measures which accommodate people with disabilities may require targeted planning. Specifically highlighted are the following:

- Access to essential support services, personal assistance, as well as physical and communication support should be prioritized.

- Mental health responses should be embedded in the COVID-19 response for people with disabilities, with specific focus on adapted and redesigned mental health support services at community level.
- There is a need to promote disability-inclusive health systems through tapping on the services of community-based rehabilitation care workers to support both people with disabilities and their families. This is particularly important because the load of caring has shifted heavily to many families during this time of COVID-19.

Learning from experiences shared by the DPOs regarding financial support is key to ensuring the sustainability of DPOs and NPOs. With limited fundraising skills, including technical skills necessary to run and manage organisations through COVID-19 and beyond, organisations will struggle to survive. The multi-sectoral collaboration that DPOs are strongly advocating for could offer a better platform to address challenges, share knowledge and channel resources in a transparent and inclusive approach.

Through adopting a bottom- up approach in addressing COVID-19 challenges, Community Action Networks showed that people manage better when working collectively and with collaboration. This power of community collaborative action to help themselves suggests that a bottom-up approach enhances sustainable solutions in addressing COVID-19-related challenges.

There is a need to build economic resilience through private, corporate and public sector cooperation and participation and value chain resilience, that is, to be able to provide at least food security to vulnerable groups while building collaboration across the regions.

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