



# COVID-19 AND RIGHTS OF PERSONS WITH DISABILITIES: THE IMPACT OF COVID-19 ON THE RIGHTS OF PERSONS WITH DISABILITIES IN SOUTH AFRICA

COVID-19



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Department:  
Women, Youth and Persons with Disabilities  
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# ACRONYMS

<b>CBR</b>	Community Based Rehabilitation
<b>CP</b>	Cerebral Palsy
<b>COGTA</b>	The Department of Cooperative Governance and Traditional Affairs
<b>DBE</b>	Department of Basic Education
<b>DoE</b>	Department of Education
<b>DoH</b>	Department of Health
<b>DSD</b>	Department of Social Development
<b>DPO</b>	Disabled People's Organisations
<b>DSD</b>	Department of Social Development
<b>DWYPD</b>	Department of Women, Youth and Persons with Disabilities
<b>ECD</b>	Early Childhood Development
<b>EELC</b>	Equal Education Law Clinic
<b>ICU</b>	Intensive Care Unit
<b>IED</b>	Inclusive Education Directorate
<b>NCCC</b>	National Coronavirus Command Council
<b>NCID</b>	National Institute for Communicable Diseases
<b>NDMA</b>	National Disaster Management Act
<b>NDMC</b>	National Disaster Management Committee
<b>NGO</b>	Non-Governmental Organisations
<b>OCD</b>	Obsessive Compulsive Disorder
<b>OT</b>	Occupational Therapy
<b>PDBE</b>	Provincial Department of Basic Education
<b>PPE</b>	Personal Protective Equipment
<b>ROSA</b>	Regional Office for Southern Africa
<b>SAPS</b>	South African Police Service
<b>SASSA</b>	South African Social Security Agency
<b>SASL</b>	South African Sign Language
<b>SOP</b>	School Operating Procedures
<b>TOR</b>	Terms of Reference
<b>UN</b>	United Nations
<b>UNCRPD</b>	United Nations Convention on Rights of Persons with Disabilities
<b>UNHCHR</b>	United Nations High Commissioner for Human Rights
<b>WHO</b>	World Health Organization



## EXECUTIVE SUMMARY

According to various national and international policies on the rights of persons with disabilities, persons with disabilities need to have access to healthcare, education and employment opportunities, and during periods of healthcare emergencies and pandemics these rights should be protected and accommodated (UN, 2020; WHO; 2020; DSD; 2011). The limiting or denial of these rights is in direct contradiction with the Bill of Rights found within the Constitution of the Republic of South Africa, which states that all persons have equal rights to, among other things, healthcare, education and employment. Limiting or denying these rights is also in direct contradiction with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which South Africa has signed and ratified.

Even when the world is not experiencing a global pandemic, persons with disabilities have greater healthcare needs and are more likely to experience poor health compared to persons without disabilities (Ned et al, 2020). In order to provide relevant and suitable accommodations and healthcare, persons with disabilities and their representative

organisations need to be consulted and involved in all plans and policies (McKinney et al, 2020). During the current COVID-19 pandemic healthcare crisis, the need has become even more urgent as there are life-threatening consequences. The main focus of this study was to examine the impact of the COVID-19 pandemic on the human rights of persons with disabilities in South Africa. The following thematic areas were used to gather data: Access to health; access to education; access to information; access to social services; access to safety and security; access to livelihoods and economic opportunities; participation and consultation (design and implementation period); and access to quarantine and isolation sites and other COVID-19 specific facilities.

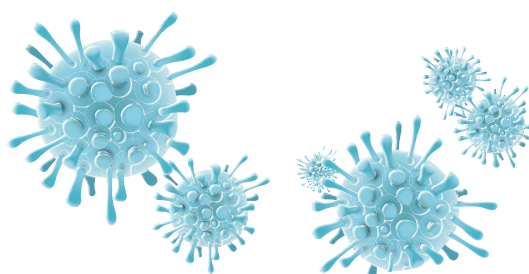
Participants in this study included adults, students and children with disabilities; parents of children and adults with disabilities; and organisations supporting persons with disabilities such as disabled people's organisations, non-governmental organisations and government departments. Of the participants, 50% identified as male; 48% as female and two percent as non-binary. Participants in this study represented the following demographics: 31% identified as being Coloured, 30% as being Black/African, 29% White, five percent Indian/Asian, while five percent of participants preferred not to disclose their race group. The youngest participant was 3 years old and oldest was 78 years old. Participants came from all nine of South Africa's provinces. A total of 192 participants were included in this study and data was collected via 114 completed surveys, four focus group discussions with 114 participants, and 17 individual interviews. Due to COVID-19, face-to-face interviews and focus group discussions were limited to the one province that had the lowest COVID-19 infections at that time, while all others were conducted via online platforms and cell phones.

The voices of persons with disabilities need to be heard to ensure that their human rights are not overlooked or excluded during future pandemic provisioning. The findings from this study showed that while there were a few positive stories and experiences shown during the COVID-19 pandemic in South Africa, the rights of many persons with disabilities are being denied or limited. These include the rights to healthcare, communication, education, safety and security, and employment. The findings from this study specifically revealed that many participants experienced difficulties following mandatory COVID-19 guidelines such as social distancing and wearing of PPE; accessing healthcare including therapy, medication, specialist care and assistive devices; communication and care from healthcare workers; accessing education for children and students with disabilities, especially those enrolled in special schools and in school hostels; being able to access COVID-19 information, social services, and safety and security; employment opportunities; inaccessible transportation and transportation challenges; and in the lack of consultation and involvement in COVID-19 design and

implementation programmes and policies, including quarantine and isolation sites and other COVID-19 specific facilities.

After the study was conducted, the findings were shared with stakeholders at a validation workshop for disability reports that was held online on the 17<sup>th</sup> of March 2021. Stakeholders included the Disability Sector (the Presidential Working Group on Disability; South African Disability Alliance), Provincial Governments (Limpopo, North West, Northern Cape, Gauteng, Free State, Western Cape and Eastern Cape with approximately 80% representation), National Departments (with approximately 80% representation); and three representatives from the United Nations Agencies and Partners (UNDP & OHRCHR). Based on the feedback received, additional clarification was made and information included.

The stories provided by participants in this study need to be read and acknowledged, and government departments need to understand the many challenges, some of which are life-threatening, that persons with disabilities face. Government departments need to consult with persons with disabilities as they implement strategies to accommodate persons with disabilities. This will help to ensure that they have human rights on a par with those of persons without disabilities. It is hoped that the findings will provide policymakers and other stakeholders in South Africa and around the globe with an awareness of persons with disabilities in future pandemics, as it highlights the need for the inclusion of persons with disabilities in all future policy and procedure decision-making. This is in line with the disability movement's slogan, 'nothing about us without us', which is especially pertinent considering that the implications of such decision-making can have life and death consequences.







# 1 STUDY BACKGROUND



## STUDY BACKGROUND

The Office of the United Nations High Commission for Human Rights (OHCHR) Regional Office for Southern Africa (ROSA) provides technical assistance on the promotion and protection of human rights to 14 countries in southern Africa, including South Africa. The Regional Office, which is based in Pretoria, focuses on protecting civic space, early warning and prevention, human rights risk analysis, human rights in humanitarian action, tackling gender-based violence and discrimination, integrating human rights in development, strengthening national protection systems, reporting on human rights and following up on recommendations by human rights mechanisms.

In the context of OHCHR's work on the rights of persons with disabilities, OHCHR provides support to the South African Department for Women, Youth and Persons with Disabilities (DWYPD) in researching the impact of COVID-19 on the rights of persons with disabilities in South Africa.

The researcher carried out research, data collection, information gathering, in-depth analysis, report writing and producing infographics on the impact of COVID-19 on persons with disabilities in South Africa.

The researcher, Dr Emma McKinney, is a Senior Lecturer and researcher at the University of the Western Cape, as well as the owner of Disability Included CC who was awarded the tender to complete this study. Dr McKinney is a person with a disability herself, and personally collected and collated the data pertaining to the impact of the COVID-19 pandemic on the human rights of persons with disabilities in South Africa. This included data on their gender and youth dimensions, and was collected from a variety of data sources that included focus group discussions and individual interviews, as well as telephonic, online and email surveys administered within institutional settings via disability organisations as well as other networks.

The researcher also examined policy interventions and positive practices recorded in terms of inclusion of persons with disabilities in the response to COVID-19 by government, organisations of persons with disabilities, service providers and/or other stakeholders. Finally, the researcher held a validation meeting where the research report was shared with relevant stakeholders. The researcher reported directly to both the OHCHR's ROSA and the DWYPD.

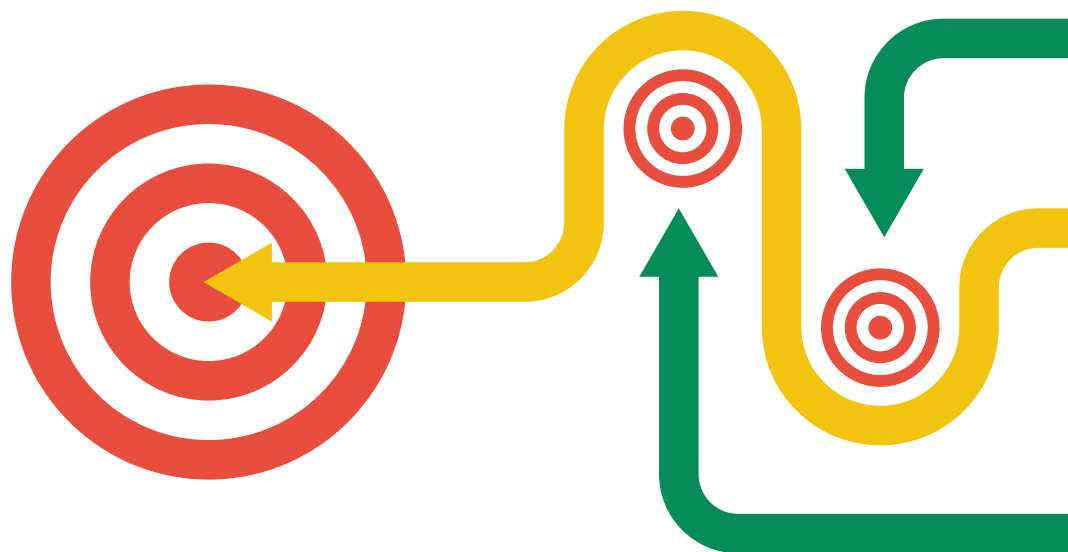
## 1.1 Study framework

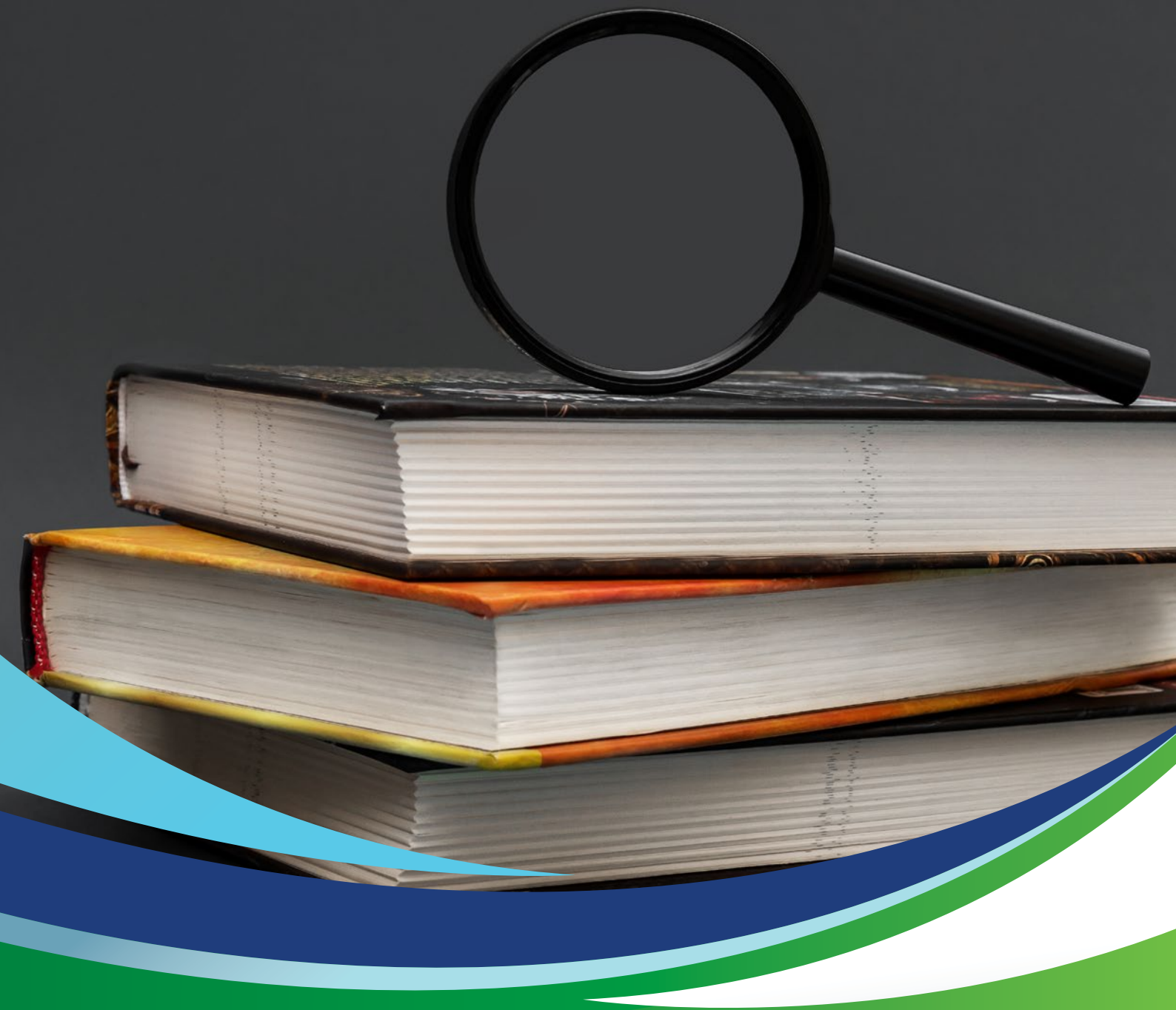
The underlining framework of this study follows a social model view of disability. This view suggests that persons with disabilities are disabled by the barriers within society and not by their impairment (Oliver, 2013; Shakespeare, 2017). In line with this view, the definition of persons with disabilities used in this study include ‘those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others’ (United Nations Convention on the Rights of Persons with Disabilities [UNCRPD], 2006, p.4).

## 1.2 Main focus

The main focus of this study was to examine the impact of the COVID-19 pandemic on the human rights of persons with disabilities in South Africa. The following thematic areas, taken directly from the terms of reference (TORs), were used to gather data:

1. Access to health
2. Access to education
3. Access to information
4. Access to social services
5. Access to safety and security
6. Access to livelihoods and economic opportunities
7. Participation and consultation (design and implementation period)
8. Access to quarantine and isolation sites and other COVID-19 specific facilities





# **2 LITERATURE REVIEW**

# LITERATURE REVIEW

This section of the report includes previously published work including policy interventions and responses to COVID-19, policy briefs and other documents by government, organisations of persons with disabilities, service providers and other stakeholders. It also includes literature from peer-reviewed journal articles relating to persons with disabilities and COVID-19 that have been published both locally in South Africa and internationally.

## 2.1 Introduction

An estimated 15% of the global population, equating to more than one billion people, currently live with a disability and prevalence rates are set to rise (World Health Organization and World Bank, 2011). In developing countries, this number is expected to be higher due to factors including undernutrition, poor health, a lack of access to education and healthcare, and challenging environments that can lead to a greater risk of disability (McKinney et al, 2020; Ned et al, 2020). Studies have shown that there is a strong correlation between disability, poverty and rurality, and that these significantly increase barriers to accessing healthcare, rehabilitation services, education and employment (Ned et al, 2020; Vergunst, 2016; Vergunst et al, 2017).

People with disabilities, even under usual circumstances, experience poorer access to services and are among the most vulnerable in any crisis-affected community. Persons with disabilities are more likely to live in poverty and to experience higher rates of violence, neglect and abuse (Kuper et al, 2020; WHO, 2020). Due to inequalities in various sectors including education, employment, transport, and access to healthcare, some persons with disabilities are already vulnerable because of their disability. As such, they may require greater care and consideration. In crisis situations, persons with disabilities tend to be excluded from emergency and pandemic responses as well as in allocating relief resource considerations, as evidenced by previous cases of pandemics such as Ebola, swine flu, cholera (McKinney et al, 2020; Sabatello et al, 2020).

According to the World Health Organization, COVID-19 is impacting societies across the globe at their very core, deepening pre-existing inequalities, increasing threats and further compounding in inequalities experienced both directly and indirectly (2020).

## 2.2 Disability-inclusive COVID-19 responses

As the COVID-19 pandemic spread across the globe, international organisations including the United Nations (UN) and the World Health Organization (WHO), published policy briefs and documents that call for the inclusion of persons with disabilities in COVID-19 responses and recovery (WHO, 2020; UN, 2020).

The WHO published *Disability Considerations During the COVID-19 Outbreak* in March 2020. This document described additional considerations that were needed for persons with disabilities during the COVID-19 outbreak. It included actions needed to ensure that persons with disabilities would be able to access the healthcare services, water and sanitation services and public health information that they required. The document detailed the specific actions the various stakeholders should take during the pandemic. These stakeholders included persons with disabilities and their households, governments, disability service providers in the community, institutional settings, and members of the community.

Actions for persons with disabilities and their households included reducing potential exposure to COVID-19; putting plans in place to ensure continuation of the care and support needed; preparing households for the instance that COVID-19 was contracted; and maintaining the mental and physical health of household members and caregivers.

Actions for governments included ensuring accessibility of public health information and communication; undertaking targeted measures for persons with disabilities and their support networks; undertaking targeted measures for disability service providers in the community; increasing attention given to persons with disabilities living in potentially high-risk settings of developing the disease; and ensuring that emergency measures incorporate the needs of persons with disabilities. Actions for healthcare included ensuring that COVID-19 healthcare is accessible, affordable and inclusive; and delivering telehealth services for persons with disabilities.

Actions for disability service providers in the community included developing and implementing service continuity plans; communicating frequently with persons with disabilities and their support networks; reducing potential exposure to COVID-19 during provision of disability services in the community; and providing sufficient support for persons with disabilities who have complex needs.



Actions for institutional settings included reducing potential exposure to COVID-19; preparing for COVID-19 infections in institutions; providing sufficient support for residents with disabilities; and guaranteeing the rights of residents during the COVID-19 outbreak.

Actions for the community included basic protection measures to be adopted by the general public; flexible work arrangements and infection control measures to be supported by employers; increased access to stores to be provided by store owners for vulnerable populations; and extra support to be provided by family, friends and neighbours for a person with a disability (WHO, 2020).

The UN's *Policy Brief: A Disability-Inclusive Response to COVID-19* was published in May 2020. The policy brief identifies four overarching areas of action: ensuring mainstreaming of disability in all COVID-19 response and recovery together with targeted actions; ensuring accessibility of information, facilities, services and programmes in the COVID-19 response and recovery; ensuring meaningful consultation with and active participation of persons with disabilities and their representative organisations in all stages of the COVID-19 response and recovery; and establishing accountability mechanisms to ensure disability inclusion within the COVID-19 response (UN, 2020).

## 2.3 Background to disability in South Africa

According to the South African census of 2011, which used questions that were based on the Washington Group questions, the disability prevalence rate was 7.5% (2,870, 130 persons with disabilities) of the total South African population (Statistics South Africa, 2014).

When it comes to the protection and rights of persons with disabilities, South Africa's overarching framework remains the Constitution of the Republic of South Africa (1996), which states in the Bill of Rights that 'Everyone is equal before the law and has the right to equal protection and benefit of the law.' The Constitution further states that no person or body, including the State and private companies, may unfairly discriminate directly or indirectly against any person on one or more grounds including race, gender, colour, age or disability. South Africa has also signed and ratified international laws and agreements relating to the protection and rights of persons with disabilities. These include the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) of 2006. South Africa ratified this in 2007, meaning that the country accepts all the legal obligations that are imposed by this convention. The UNCRPD seeks

to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities. The UNCRPD Article 11- Situations of risk and humanitarian emergencies, outlines that:

*States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*

In line with the domestication of the UNCRPD, the White Paper on the Rights of Persons with Disabilities, including the implementation matrix, was launched in 2015. This White Paper provides clear policy directives, implementation methods and guidelines for government to roll out programmes and projects that promote and protect the rights of persons with disabilities (Department of Social Development, 2015).

## **The Disaster Management Act, 2002 (Act No. 57 of 2002)**

The Disaster Management Act, 2002 (Act No. 57 of 2002) specifically provides for the protection of vulnerable communities and households. Vulnerability in the context of disaster management legislation means ‘the conditions determined by physical, social, economic, and environmental factors or processes, which increase the susceptibility of a community to the impact of hazards’. This definition encompasses persons with disabilities. In accordance with the Disaster Management Act (2002), Disaster Management Centres across the spheres of government are compelled to undertake risk assessments and implement prevention and mitigation measures including assessing the vulnerability of communities and households (and persons with disabilities) to disasters that may occur. The act also allows Disaster Management Centres across the spheres of government to give advice and guidance by disseminating information regarding disaster management in the municipal area, especially to communities that are vulnerable to disasters (including persons with disabilities).

### **2.4 South African COVID-19 situation**

On 15 March 2020, South Africa’s president declared a national lockdown. In accordance with the National Disaster Management Act, 2002 (Act, 2002 No. 57 of 2002), the South African government issued regulations on measures to prevent and combat the

spread of the novel coronavirus. These regulations were amended to include other matters regarding the protection and safety of people during the lockdown. Regulation 11B (7) published in Government Gazette No. 43199, Government Notice No. R446 of 2 April 2020, issued in terms of the Disaster Management Act, 2002 (Act No. 57 of 2002), stated that:

*Any Cabinet member may, after consultation with Ministers of Cooperative Governance and Traditional Affairs and Justice and Correctional Services, issue directions which fall within his or her line functions to provide for further conditions that will apply to activities referred to in sub-regulation (1), or other activities provided for in these Regulations, for the protection and safety of any person, including essential workers from COVID-19, provide reasonable measures for persons with disabilities and may vary the directions as the circumstances require.*

Currently, the National State of Disaster under COVID-19 lockdown has been extended to 15 April 2021.

Since then, COVID-19 positive cases have continued to rise on a daily basis. As of the 6<sup>th</sup> of May 2021, 1,590,370 positive cases of COVID-19 have been identified, with 54,620 deaths having been reported. However, South Africa is anticipated to be moving towards a third wave and the number of infections is forecasted to increase significantly (National Institute for Communicable Diseases [NICD] 2021). While the reported number of COVID-19 recoveries currently sits at 1,511,905 some people may have or continue to have significant health conditions (including lung damage, chronic fatigue and strokes), some of which may result in disabilities as a result of previous COVID-19 infection.

## **2.5 Persons with disabilities at a higher risk**

Persons with disabilities may be at greater risk of contracting COVID-19 because of various factors including: barriers to implementing basic hygiene measures; difficulty in enacting social distancing because of additional support needs or because they are institutionalised; the need to touch things to obtain information from the environment or for physical support; barriers to accessing public health information. In addition, persons with disabilities may be at greater risk of developing severe disease if they become infected because of a pre-existing health condition underlying the disability; and barriers to accessing healthcare. However, the barriers facing persons with disabilities can be minimised or reduced if key stakeholders take appropriate action (McKinney et al, 2020; Ned et al, 2020; WHO, 2020).

## 2.6 Thematic areas

The literature included in this section of the report is arranged into the following eight thematic areas as they relate to persons with disabilities both globally and in South Africa: access to health; access to education; access to information; access to social services; access to safety and security; access to livelihoods and economic opportunities; participation and consultation; and access to quarantine and isolation sites and other COVID-19 specific facilities.

### 2.6.1 Access to health

In general, persons with disabilities have greater healthcare needs and are more likely to develop health-related complications compared to persons without disabilities (McKinney et al, 2020; Ned et al, 2020). Even prior to COVID-19, persons with disabilities, especially those in low-income countries, experience multiple challenges accessing healthcare. These challenges include a lack of accessible transportation; availability of healthcare and rehabilitation services; inadequate medication and equipment; high costs associated with medication and equipment; communication challenges including a lack of South African Sign Language (SASL) interpretation services for persons who are Deaf<sup>1</sup>; negative staff attitudes and behaviour towards certain disability categories such as persons with intellectual and learning disabilities; and questioning of the worth and value of surgical treatment due to discriminatory judgements about quality of life for some persons with disabilities (Ali et al, 2015; Eide et al, 2015; Vergunst et al, 2015; 2017).

According to Eide et al (2015), a lack of healthcare access for persons with disabilities jeopardises the Millennium Development Goals targets set by United Nations. The UNCRPD, the World Disability Report, the Sustainable Development Goals (SDGs), the World Health Organization (WHO), and in South Africa, the Bill of Rights within the Constitution of the Republic of South Africa, all state that healthcare is a basic human right and that persons with disabilities should have equal rights in accessing healthcare (Eide et al, 2015; McKinney et al, 2020). In March 2020, the World Health Organization (WHO) published *Disability Considerations During the COVID-19 Outbreak* which provides clear guidelines to various stakeholders including governments. Here governments were encouraged to ensure that all clinics providing testing and services

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<sup>1</sup> The word 'Deaf' has been capitalised and represents persons who use sign language as their primary means of communication and identify as members of the Deaf community.

related to COVID-19 were fully accessible to persons with disabilities. Physical barriers including uneven pathways and surfaces, stairs, hard-to-reach spaces or difficult to use equipment, needed to be addressed so that persons with disabilities could access healthcare facilities. In addition, attitudinal barriers including social stigma against disability and the denial of essential services needed to be addressed so that persons with disabilities had equal access and provisioning of healthcare.

## **2.6.2 Inaccessible transportation**

Throughout Africa, the majority of public transport such as trains, buses and minibus taxis remain inaccessible to persons with disabilities. This directly impacts on the ability of persons with disabilities to seek employment, receive an education and access healthcare thus creating economic, educational and health barriers (Vergunst et al, 2015; 2017). The lack of accessible transportation specifically negatively impacts on the ability of persons with disabilities to access healthcare services such as COVID-19 screening and testing sites, to obtain medication and receive therapeutic interventions, and to be admitted to clinics and hospitals (Ned et al, 2020).

## **2.6.3 Inaccessible built environment**

An inaccessible built environment directly impacts on a person with disabilities' ability to access healthcare, particularly if they are not able to use public transportation and are therefore left to make their own way to healthcare facilities. Other environmental factors include uneven and rocky surfaces, as well as safety concerns. These remain a significant barrier for many persons with disabilities who have mobility, intellectual and visual impairments, which result in their increased vulnerability. For example, a person with cerebral palsy using crutches may have significant difficulty navigating their way across uneven surfaces, while persons with intellectual impairments are more prone to being attacked, assaulted or taken advantage of. In addition, many buildings – including healthcare facilities – are not built with universal design principles in mind. Buildings that do not have ramps or grab rails, for example, generally pose significant challenges for persons with mobility impairments (Vergunst et al, 2017).

## **2.6.4 Access to education**

Globally, children with disabilities, especially in developing countries, experience numerous challenges in accessing and remaining in education (Donohue, 2014; McKinney et al, 2016 & 2020). When it comes to health and children with disability,



a study representing 30 countries found that children with disabilities were five times more likely to experience illness compared to children without disabilities (Kuper et al, 2014).

While there are currently no reliable global figures on learners with disabilities during COVID-19, it is probable that the pandemic has intensified their exclusion from education. This has been reported in the few studies that have been conducted during this period (Di Pietro et al, 2020; Joline et al, 2020; UN, 2020). Several factors relating to distance and online learning that widen the divide for learners with disabilities have been cited. These include a lack of support, minimal access to the internet due to a lack of (or limited) electricity, Wi-Fi and data costs, lack of accessible software and learning materials (Di Pietro et al, 2020; Joline et al, 2020).

### **2.6.4.1 South African educational challenges**

In South Africa, children with disabilities have experienced multiple layers of discrimination based on their race as well as disability. Historically, most white children with disabilities received an education in segregated special schools, while the majority of black children received an inferior education or were completely excluded from the education system (Chataika et al, 2012; Engelbrecht et al, 2016).

A study conducted in 2014 indicated that 70% of children with disabilities in South Africa were still being excluded from receiving an education. Most of the 30% of children who were receiving an education attended segregated special schools (Donohue et al, 2014). This is despite the Department of Education having adopted an inclusive education policy (Educational White Paper 6) that states that children with disabilities have the right to attend their local neighbourhood schools with support (Chataika, et al, 2012; Engelbrecht et al, 2016; Kelly et al, 2020). These educational challenges are a result of inadequate teacher training on how to accommodate the individual needs of learners with disabilities, a lack of assistive devices, teaching and learning equipment and materials, inaccessible school environments, and negative attitudes and stigma towards disability (Engelbrecht et al, 2016; McKinney, 2013).

### **2.6.4.2 School closure**

On 18 March 2020, all schools across South Africa were closed in accordance with the pronouncement of lockdown by the president three days prior. While some schools were able to provide online teaching and support for learners, the majority of learners across South Africa did not have access to devices such as laptops and computers. For many of those that did have this access, data and Wi-Fi costs remained a significant

challenge. As a result, the majority of learners across South Africa did not have access to quality teaching and learning during the COVID-19 lockdown (Adedoyin et al, 2020; Zar et al, 2020). Only approximately 20% of school children had access to online schooling; this disproportionately affected vulnerable and disadvantaged children across South Africa (Paediatrician Management Group, 2020).

According to Statistics South Africa, in 2018, 77% of children in public schools (approximately 9 million children), received a meal every school day (2019). With the lockdown preventing learners and teachers from returning to school, there were significant concerns relating to learners not receiving a daily meal (Paediatrician Management Group, 2020). An additional challenge related to learner safety, with many children being left unsupervised at home and vulnerable to child abuse, gender-based violence and other violent crime (Artz et al, 2016; Paediatrician Management Group, 2020; Zar et al, 2020).

### **2.6.4.3 School re-opening**

After consultation with parent organisations, medical specialists such as paediatricians, teacher unions and other stakeholders, the Department of Basic Education (DBE) announced that schools would reopen. On 19 May 2020 the Minister of Basic Education announced during a press briefing that all schools would be provided with COVID-19 'Essentials', which included hand and surface alcohol-based sanitisers, masks, water, sanitation, and specialised cleaning equipment before being opened (DBE, 2020).

Learners were slowly phased back into the school system with those in grades 7 and 12 returning on 1 June 2020, followed by learners in grades 6 and 11 who went back to school on 6 July 2020. Schools were reopened with strict procedures set out in directions, guidelines and school operating procedures (SOPs) that were developed by the Department of Basic Education (DBE, 2020).

However, these were only applicable to learners in 'ordinary' schools and no guidelines or SOPs were developed to ensure the health and safety of learners with disabilities attending special schools or residing in special school hostels (Hansungule, 2020).

After consultation with, from April 2020, concerned parties including parental organisations, educators, disabled people's organisations (DPOs), non-governmental organisations (NGOs) and other specialist stakeholders collectively; it was attempted to raise their concerns relating to the reopening of special schools and hostels with the DBE and the Inclusive Education Directorate (IED).

Eventually additional guidelines were published to accommodate the needs of certain disabilities (learners with hearing and visual impairments, and those with autism). However, the DBE's Directions and Guidelines excluded all categories of learners with disabilities, including learners with physical disabilities, intellectual disabilities, severe to profound intellectual disabilities, and learners with Epilepsy.

This led to legal action being taken against the DBE by concerned parties, represented by the Equal Education Law Clinic (EELC). These parties sent letters of demand to the Minister of Basic Education requesting information on the reopening of special schools across South Africa. Specific focus was on the provision of adjusted personal protective equipment including masks and sanitisers; special school hostels and special care centres, the criteria that would be used to monitor the readiness of special schools, and support for learners remaining at home.

The minister's responses to these letters were significantly delayed and unsatisfactory. This resulted in growing concerns that the specific requirements of thousands of learners with disabilities across South Africa had not been taken into consideration by the DBE in their COVID-19 directions, planning guidelines and monitoring procedures.

As a result, the EELC launched an urgent application to the Pretoria High Court in July 2020 against the minister of the Department of Basic Education. The EELC asked the DBE to publish specific guidelines for learners with physical, intellectual, and severe to profound disabilities, and those with epilepsy. They stated that without clear guidelines, the risk of contracting COVID-19 for learners from the excluded categories of disabilities would be heightened. In the EELC's press release, they stated:

*These learners need very specific educational and therapeutic support services while they remain at home, and appropriate and adjusted health and safety measures to be put in place when they return to special schools and special school hostels. It is therefore imperative that the Minister develop comprehensive guidelines for these learners (2020, p. 2).*

This court application highlighted the minister's failure to adequately provide support and proper health and safety measures during the COVID-19 pandemic. An out-of-court settlement was reached and the DBE was required to revise its directions, guidelines and standard operating procedures to ensure that the health and well-being of learners with disabilities would be protected when returning to school. As a result, the *Standard Operating Procedure for the management and Containment of COVID-19 for Schools and School Communities* was revised, it included more inclusive guidelines and was published in September 2020. While these revisions were finally made, concerns

remained. These related to continuous monitoring of the implementation of the revised directions, guidelines and standard operating procedures (Hansungule, 2020).

However, even after the DBE published revised guidelines, many parents of children with disabilities still feared for the safety of their children and did not send them back to school (DBE, 2020). Some special schools refused to open due to safety concerns as staff members felt that they were still unable to ensure the safety of their learners, teachers and non-teaching staff. Some special schools refused to reopen their school hostels citing significant concerns, including a shortage of staff, and the inability of learners and staff to social distance in areas such as dining halls, bathrooms and dormitories.

## **2.6.5 Access to information**

Global policies speak to the need for accessible information about COVID-19 as without this, persons with disabilities will not be able to take the necessary decisions, live independently, isolate or quarantine in a safe manner, or be able to access health and public services on par with those without disabilities (Ned et al, 2020; McKinney et al, 2020; UN, 2020a). Appropriate COVID-19 responses require information to be accessible, up to date with the rapidly changing knowledge evidenced during the pandemic and this information needs to be shared with persons with disabilities (UN, 2020b).

Recommendations to governments made by international organisations such as the UN and WHO state that national addresses, press briefings, and live social media relating to COVID-19 should include captioning/subtitles and sign language for all live and recorded events and communications. Public information on COVID-19 should be converted to a range of formats to ensure that they are accessible for persons with intellectual disability or cognitive impairment. These should also be available in electronic format, large print, Braille versions and formats for people with visual impairments and those who are deafblind. Governments should work closely with DPOs and NGOs that support and represent persons with disabilities to ensure that COVID-19 information is accurately disseminated to their members with disabilities (Ned et al, 2020; WHO, 2020; UN, 2020). While the Department of Health (DoH) in South Africa provided information about COVID-19, its transmission and prevention via media including television, news and media briefings, radio and social media, many persons with disabilities were still excluded from accessing information. Not all media included SASL interpretation for persons who were Deaf, closed captioning or subtitles for persons with hearing impairments who did not use SASL. Much information was

provided at a level that was not accessible for some persons with intellectual and learning impairments. Not all resources in print and online were accessible for persons with visual impairments (Ned et al, 2020).

In addition, a lack of consultation and involvement with persons with disabilities, DPOs and other NGOs supporting persons with disabilities resulted in a lack of dissemination of information and inclusion in COVID-19 related policies.

## 2.6.6 Access to social services

There is a significant interplay between poverty, ill-health and limitations in access to health services for persons with disabilities (Grut et al, 2012; Moodley et al, 2015; WHO, 2011). The World Report on Disability that was published by the World Health Organization states that 'Disability may increase the risk of poverty, and poverty may increase the risk of disability' (2011:10). Global studies have shown that in the majority of countries, social protection systems offer little support to persons with disabilities and their families, with only 28% of persons with significant or severe impairments having access to disability programmes (Kidd et al, 2018; Mitra et al, 2016; WHO, 2020). In low-income countries, this figure drops to 1% (Mitra et al, 2016).

The UN's *Policy Brief: A Disability Inclusive Response to COVID-19* states that persons with disabilities must have access to services and that measures need to be put in place to facilitate the timely access to health services for persons with disabilities, including transportation to healthcare facilities, access to sign language interpretation in hospitals, as well as the procurement of goods, medicines and services (2020).

Within the South African context, there is a strong link to the policies of apartheid, which segregated and excluded many persons, especially those who were black, disabled and residing in rural areas. However, there are still significant inequalities regarding wealth and welfare distribution, with rural areas being the most under-served and most neglected (Grut et al, 2012; Kidd et al, 2018). Persons with disabilities, especially those living in resource-poor areas, experience multiple challenges that are associated with individual as well as societal poverty (Grut et al, 2012; Moodley et al, 2015). Poverty outcomes are formed by numerous factors including gender, race, class as well as severity of impairment (Mitra et al, 2016; Moodley et al, 2015). As a result of the ongoing cycles of poverty, many families in South Africa have come to rely on the government's monthly social disability grants as their main source of income. Distribution of all social grants is made by the South African Social Security Agency (SASSA), which is a national agency of the government on behalf of the Department of Social Development (DSD).



The disability grant is means-tested and available on a permanent or temporary basis to persons who are unable to work as a result of their impairment, and who do not have sufficient other means of support (Kelly, 2013). As of January 2021, the disability grant amounted to R1,860 (approximately 56USD) per month.

However, at the end of December 2020 significant challenges were raised by the suspension of 210,778 temporary disability grants due to a lack of funds, 222,021 disability-related grants and 11,234 care dependency grants. This resulted in beneficiaries having to reapply for medical assessments during the peak of South Africa's second wave of COVID-19 infections and caused significant backlog (Daniel, 2021; South African Government, 2020). Recipients were required to visit healthcare facilities and obtain medical certificates from medical practitioners who were already inundated with COVID-19 related admissions, putting both at risk for infection. Due to the lockdown curfew hours being extended to 6am, queues at healthcare facilities resulted in thousands of desperate South Africans ignoring social distancing requirements and descending on medical practitioners in the hopes of having their suspended disability grants reactivated (Daniels, 2021; Köhler et al, 2020; McKinney et al, 2020). Due to the significant negative financial impact of COVID-19, the government provided a R350 'special COVID-19 social relief of distress grant'. This 'social relief of distress' was a temporary provision of assistance intended for persons in such dire material need that they were unable to meet their or their families' most basic needs during the COVID-19 pandemic. However, this additional financial support – which was given to over six million social grant recipients – was only originally provided for the months May to October 2020. In December, the Department of Social Development announced that this grant would be extended until 31 January 2021. However, not all applicants received payments (Köhler et al, 2020; South African Government, 2020).

### **2.6.7 Access to safety and security**

Research has shown that persons with disabilities, especially women and children, experience increased vulnerability to violence, including psychological violence, neglect, and deprivation. The stigma attached to many categories of disabilities has been identified as a key element and contributing factor to how many women with disabilities are exploited and dehumanised (Shah et al, 2016; van der Heijden et al, 2016; WHO, 2020). Furthermore, persons with disabilities are vulnerable, and at higher risk of experiencing sexual, physical, emotional, and financial abuse than persons without disabilities (McKenzie et al, 2015; van der Heijden et al, 2016). Women with disabilities are at a greater risk of experiencing violence than men with disabilities, and women without disabilities. In addition, they experience multiple forms of violence

during their lifetime, by multiple perpetrators and for longer durations (van der Heijden et al, 2016). Persons with disabilities' risk of violence is increased by societal stigma and discrimination, communication barriers, and not being viewed as credible witnesses if violence is reported; and multiple layers of abuse and neglect are experienced by persons living in residential institutions (French et al, 2009; Swedlund et al, 2000).

### **2.6.7.1 South Africa**

South Africa has unprecedented levels of interpersonal violence with many women and children, including those with disabilities, being exposed to violence during their lifetime (van der Heijden et al, 2016). A study conducted by Abrahams and colleagues showed that a woman is murdered by an intimate partner every eight hours in South Africa (Abrahams et al, 2012). In addition, South Africa has extremely high rape statistics with one in four South African men having reported rape perpetration (Jewkes et al, 2011). Women with disabilities in South Africa experience violence as a result of gender bias, which is compounded by their disabilities. This can be attributed to some of them having reduced physical and emotional defences, and being socially isolated and reliant on care givers. These increased factors of power and control make women with disabilities considerably more vulnerable than women without disabilities (van der Heijden et al, 2016).

During the COVID-19-enforced lockdown periods there has been a significant increase in reports of gender-based and domestic violence. This has been attributed to persons being under pressure, and experiencing feelings of stress, frustration and anxiety as a result of being confined in close proximity to others (Joska et al, 2020). During the first week of the Level 5 lockdown, 87,000 cases of gender-based and domestic violence were reported in South Africa (Chothia, 2020).

### **2.6.8 Access to livelihoods and economic opportunities**

Prior to the COVID-19 pandemic, the majority of persons with disabilities across the globe did not have equal access to employment opportunities. This is due to many factors including an inferior education; a lack of accessible transportation; negative attitudes towards disability by employers; unfounded assumptions of the capabilities of persons with disabilities; and a lack of assistive devices (McKinney, 2013; 2019; Lourens et al, 2016). As a result, the majority of persons with disabilities are unemployed. Persons with disabilities are also more likely lose their jobs and experience greater difficulties returning to work after natural disasters and pandemics (Mitra et al, 2016; WHO, 2020). South African studies show that over 90% of persons with disabilities are unemployed and as a result, many persons with disabilities and their families are reliant on the state

disability grant. It is feared that as a result of COVID-19, that persons with disabilities will be further discriminated against and excluded from economic opportunities (McKinney et al, 2019; Vergunst et al, 2017).

According to the UN, employment and working conditions need to be responsive to accessibility and inclusion of persons with disabilities. Those who continue to work may require specific protection or adjustments in order to stay safe during COVID-19. They recommend that employers and workplaces provide accessible environments and reasonable workplace adjustments based on the individual needs of their employees with disabilities. Alternate working arrangements and conditions made accessible and inclusive. Regarding work platforms such as online platforms and new ways of meeting need be accessible to all employees, and adequate adjustments must be in place to allow persons with disabilities to work from home (2020).

Disability-inclusive COVID-19 policies speak to the need for employers to provide specific protection, or adjustments, to ensure that persons with disabilities stay safe during the pandemic. Employment and working conditions need to be responsive to accessibility and inclusion of persons with disabilities to ensure that they are able to continue to work. It is important that accommodations and adjustments are done on an individual basis with consultation of the person with a disability (McKinney et al, 2020; Schur et al, 2020; WHO, 2020b).

### **2.6.9 Participation and consultation (design and implementation period)**

Globally, persons with disabilities are excluded from participation and consultation in the design and implementation of healthcare and disaster policies that directly impact on their lives. During pandemics and natural disasters such as Hurricane Katrina and the Haiti earthquakes, persons with disabilities were often excluded with deadly consequences (Hunt et al, 2015; McKinney et al, 2020; Stough et al, 2016).

A lack of consultation and participation with persons with disabilities via NGOs and DPOs has led to the development of policies that either excluded or discriminated against persons with disabilities. For example, South Africa's COVID-19 Critical Care Triage and Decision Tool policy, which assists healthcare workers to prioritise ICU access and ventilator support, directly discriminates against persons with physical disabilities. (Western Cape Government, 2020a; 2020b; McKinney et al, 2020; Ned et al, 2020).

According to the triage policy *Allocation of Scarce Critical Care Resources during the COVID-19 Public Health Emergency in South Africa*, persons with physical disabilities and those with intellectual impairments will be classified on the Clinical Frailty Scale as being ‘vulnerable’ (Category 4 or 5), resulting in no access to ICU care or ventilators (Western Cape Government, 2020a). According to a recent study, the current COVID-19 triage policies and practices in South Africa may exclude or disadvantage many disabled people, especially people with physical and intellectual impairments, from gaining intensive care unit (ICU) access and receiving ventilators if becoming ill (McKinney et al, 2020, p. 1).

The lack of consultation also resulted in the specific needs of learners with disabilities attending special schools and school hostels being excluded from the DBE’s TORs required for the opening of schools, and safety of learners, support staff and teachers (McKinney et al, 2020; Ned et al, 2020).

## **2.6.10 Access to quarantine and isolation sites, identified screening and testing sites and other COVID-19 specific facilities**

It is vital that everyone is able to access quarantine and isolation sites as well as other COVID-19 specific facilities, in order to access the care and medical intervention they require. The UN states that COVID-19 facilities must be accessible to persons with disabilities otherwise they will not be able to make necessary decisions, isolate or quarantine independently and safely or access these sites on an equal basis with others (2020). However, as discussed above, there are many factors that prevent persons with disabilities accessing these facilities including a lack of accessible transportation, discriminatory policies, SASL interpretation, and a lack of accessible information. No guidelines were issued by government to address accessibility for persons with disabilities at identified quarantine and isolation sites, identified screening and testing sites during the lockdown period.





# **3 RESEARCH METHODS**



# RESEARCH METHODS

## Overview

The review used a combination of desk research and analysis, key informant focus group discussions and individual interviews, as well as data obtained through an online survey. Qualitative and quantitative methodologies were used to achieve the objective: 'carry out research, data collection, information gathering, in-depth analysis, report writing and producing infographics on the impact of COVID-19 on persons with disabilities in South Africa'.

The researcher sought not just to involve stakeholders as participants, but also to enable them to play a part in directing the research process. Topics of research and methods of investigation were influenced by what stakeholders considered to be relevant and appropriate. In-depth qualitative data was collected via the focus group discussions and individual interviews and a semi-structured interview guide was used. The researcher prepared a brief inception report, outlining her approach for the research, in particular for the desk review. This included developing a template (which was approved by DWYPD and OHCHR) to ensure that the desk review included consistent and relevant information relating to COVID-19 and disability. She reviewed documents (and other media evidence) in the following main categories:

- *Policy interventions and positive practices recorded in terms of inclusion of persons with disabilities in the response to COVID-19 by government, organisations of persons with disabilities, service providers or other stakeholders*
- *International policies and academic peer-reviewed studies including, but not limited to: situation analyses; international and other convention reports; national policies; publicly available reports/guides from other NGOs working in selected countries; and relevant academic literature*

From the desk review data, a mapping of existing interventions and policies for persons with disabilities was prepared, using the template presented in the inception report. Evidence from the desk review was also organised according to the overall research areas outlined in the TOR, and guided the development of detailed questions for the survey and qualitative individual and focus group discussions with persons with disabilities across South Africa.

## Ethics statement

Prior to the study being conducted, the participant information sheet, consent forms, interview sheets, interview schedules, and online survey that were used in the study were approved by the OHCHR and DWYPD. The participants were required to give informed written consent prior to participating in this study. This included participants who attended face-to-face individual interviews and focus group discussions, as well as those who participated in telephonic and online Zoom interviews. Learners and children under the age of 18 provided assent prior to their participation in interviews and focus group discussions, which only took place after written consent was obtained from the parent or caregiver. Participants with visual impairments were offered electronic and braille versions of the documentation once interviews and focus group discussions were confirmed. Information letters provided background information to the study, and included what would be required if they chose to participate. These letters also stated that as far as possible anonymity would be maintained; listed the advantages and disadvantages of participation in the study; described the right to terminate the interview or focus group discussion at any time; and gave the researcher's contact details. All participants were provided with a copy of the information letter as well as their signed consent forms. The researcher read through and summarised the content of the documents with participants aloud before interviews and focus group discussions took place to ensure that they understood and were happy to participate.

Participants who were Deaf were offered a sign language interpreter of their choice to translate the questions from spoken English into SASL and to translate their answers from SASL into spoken English. The sign language interpreters were required to sign a code of conduct for sign language interpreters (agreeing to confidentiality, accuracy of translation etc.) prior to interviews being conducted. All interpreters were reimbursed for their services. While there was no reimbursement for participation in the study, participants over the age of 18 were provided with a cell phone airtime or data voucher, which was automatically uploaded onto their cell phones for accessibility purposes. Learners and children were provided with a meal and cool drink rather than cell phone airtime or data because many schools have a zero-cell phone policy, and because carrying a cell phone can put learners at risk of being attacked or robbed of their cell phones while they are traveling home after the interview or focus group discussion. Participants who were unable to provide consent were not included in this study.

## **Recruitment**

As part of the recruitment process, a number of organisations and groups across all nine of South Africa's provinces were approached and invited to complete the online survey and participate in the study. These included DPOs; NGOs supporting persons with disabilities; various government departments; known employers of persons with disabilities; disabilities services and units for students with disabilities in higher education institutions; initial schools for learners with disabilities; mainstream schools accommodating learners with disabilities; and parents of children with disabilities. Additional participants were recruited through snowballing techniques. Participants were purposefully selected on the basis of either being an adult with a disability, a student with a disability, a child with a disability, a parent or caregiver of a child or adult with a disability, a DPO representing persons with disabilities, or an NGO supporting persons with disabilities.

## **Inclusion and exclusion criteria**

Participants with physical, sensory, psychosocial, learning, intellectual and multiple disabilities, aged between one and 70 years old were included in the study. The study also included participants without disabilities, such as parents and caregivers of children and adults with disabilities; teachers and support staff working in special schools for learners with disabilities and mainstream schools accommodating learners with disabilities; and persons working in NGOs and DPOs. Only persons residing in South Africa during the COVID-19 pandemic were included. In order to be eligible for inclusion in the study, participants had to agree to participate in the study and sign a letter of consent providing permission to use their data.

## **Procedures**

Data for this study was obtained via three methods. Firstly, an online survey containing quantitative and qualitative questions was developed and completed by 114 participants. Secondly, four focus group discussions took place. Three were conducted face-to-face with participants, while a final focus group discussion took place via Zoom. Finally, individual interviews were conducted with 76 participants face-to-face, telephonically, via Zoom as well as WhatsApp video. An interview schedule was used during focus group discussions and individual interviews with participants to gather in-depth qualitative data. The data collection phase of the research took place between November 2020 and January 2021.

## **Interviews and focus group discussions**

The original TORs required the researcher to conduct face-to-face focus group discussions with participants in five of South Africa's nine provinces. However, this was reduced to four separate focus group discussions that took place in one province of South Africa, which was at the time the province with the lowest number of active COVID-19 cases. The remaining focus group discussions involved participants from other provinces, and were conducted remotely via online platforms such as Zoom. An additional challenge was the very tight time frame, which was as a result of some administrative challenges relating to the signing and authorisation of contracts. These challenges had an impact on the number of interviews that were conducted. The delays meant that all students in higher education institutions had completed their studies for the year, and only one week was available to conduct focus group discussions with learners, teachers and non-teaching staff in schools.

While individual interviews were not originally planned, the researcher was able to conduct individual interviews with participants face-to-face in the one province. In addition, moving to online platforms enabled the researcher to conduct qualitative individual interviews. This added to the richness of the study.

Face-to-face interviews and focus group discussions were held in selected venues that were wheelchair accessible, had accessible bathrooms, were close to public transportation or within walking distance to participants' homes and places of employment or education, and were away from noise and distractions.

Strict COVID-19 safety protocols were followed, including the researcher sanitising her hands, all surfaces and all stationery used before and after each interview; requiring all participants to sanitise their hands upon entering the interview venue; ensuring that seating was compliant with the 1.5 m social distance requirements; maintaining ventilation at all times; and wearing masks. Individual interviews and focus group discussions ranged from 45 minutes to two-and-a-half hours.

The semi-structured interview schedule included questions relating to accessing healthcare; education; information relating to COVID-19; employment opportunities; and quarantine facilities. As mentioned previously, these questions were approved by the OHCHR and DWYPD when submitted in the inception report.

Some participants requested telephonic interviews due to comorbidities or fear of contracting the virus and infecting their children with disabilities. A number of parents of children with disabilities chose to be interviewed telephonically in order to protect

their children from possible infection. Others were persons with disabilities who had comorbidities while some preferred telephonic interviews over online platforms such as Zoom or WhatsApp calls. All face-to-face and telephonic interviews and focus group discussions were audio recorded using a digital voice recorder, while online interviews and focus group discussions were recorded with both video and audio functions. These were downloaded onto the researcher's computer and saved in a password-protected folder. All identifying features such as names, locations and employers were removed and a pseudonym allocated to each participant. Additional field notes that were taken during the interviews and focus group discussions were stored in a locked safe. The interviews were transcribed verbatim. All participants over the age of 18 signed that they had received the airtime or data voucher, and learners and children under the age of 18 signed that they had received their meal and cool drink.

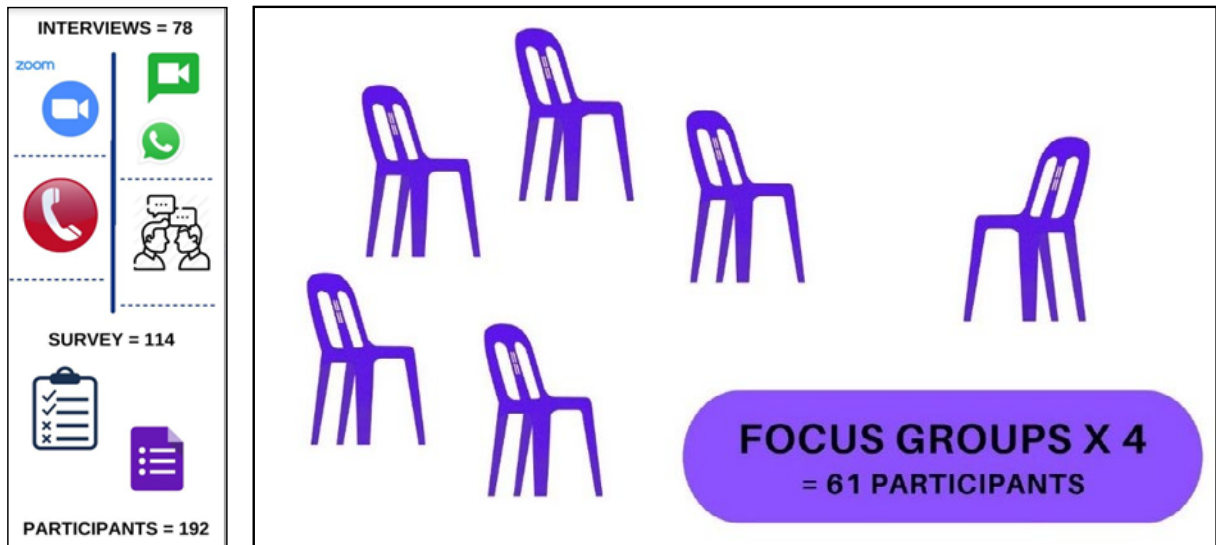
## **Random online survey**

A collection of disaggregated data in relation to the human rights impacts of COVID-19 on the rights of persons with disabilities in South Africa was collected via a random survey. This survey was administered via online survey, phone and email for persons with disabilities who required assistance with completing the survey.

The online survey was aimed at four different audiences and completed by adults with disabilities, students with disabilities, parents and caregivers of children and adults with disabilities, and organisations supporting and representing persons with disabilities. Semi-structured and open-ended questions were included in combination of biographic data in the survey that came directly from the TOR document. Information including participants' race, gender, age and province of residence was included. Using the Washington Group questions, participants selected their impairment limitations and provided more details about their condition or that of their child/adult with a disability (Washington Group on Disability, 2020).

Random sampling was used to select participants, and the sample size included a total 114 participants. The researcher ensured that the survey was accessible to people with differing disabilities and that it was compatible with assistive devices that they might use (such as JAWS). She also informed prospective participants that she was available to assist any person who might require help completing the survey (i.e. through reading the questions, typing answers, explaining any questions if required etc.). At the end of the survey those completing were asked if they would like to participate in focus group discussions or individual interviews.



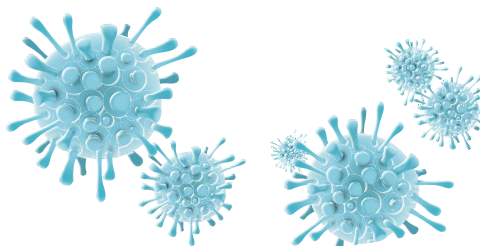


## Participants included in the research

The total number of participants that were represented in this study totalled 192, which included 114 completed surveys, and 76 participants taking part in focus group discussions and individual interviews.

## Difficulty and disability

The Washington Group set of questions were used in this study and participants were encouraged to select categories that best described their conditions. 18% of participants found walking and climbing stairs difficult; 10% found hearing difficult and used lip reading or use Sign Language to communicate; seven percent found seeing difficult even when wearing glasses; five percent had a psycho-social or mental health condition; nine percent had difficulty holding, gripping and lifting things; nine percent felt depressed, sad, anxious or moody; seven percent had difficulty remembering and concentrating on things; six percent had difficulty communicating with others or being understood; five percent had difficulty reading and writing; two percent had difficulty in carrying out simple instructions; four percent had developmental or intellectual disabilities; three percent were on the autism spectrum; seven percent had a neurological condition; and eight percent had multiple disabilities.



### Difficulties and disabilities

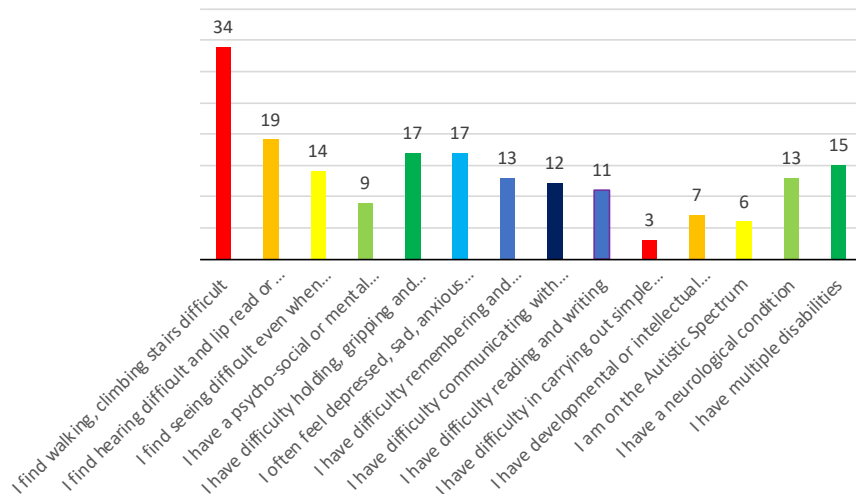


Chart 1: Difficulties and disabilities

## Participant's age

When it came to the age of persons included in this study, the following age categories were represented: Three percent were children between the ages birth to 10 years; 10% included both children and youth aged 11 to 20, and 11% for persons ranging in age from 21 to 30. Persons ranging in ages between 31 and 40 represented 21% of participants while the largest represented group included persons 41 to 50 years in age. 13% of participants ranged in age from 51 to 60 and six percent were between the ages of 61 and 70.

### Participant Age

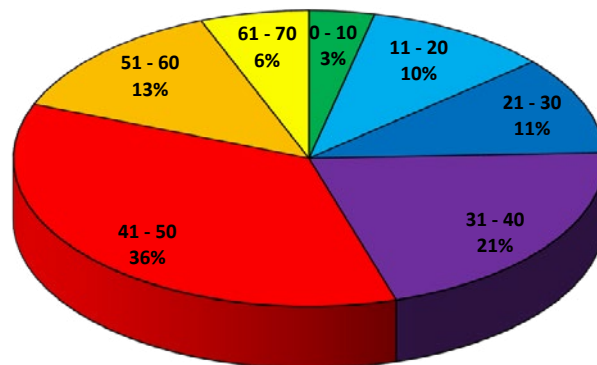


Chart 2: Participant age

## Gender

In this study, 50% of participants identified as being male, 48% as female, and two percent as being non-binary.

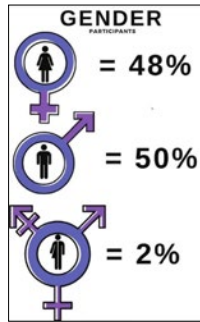


Chart 3: Participant gender

## Race

Participants in this study represented the following demographics: 31% identified as being Coloured, 30% as being Black/African, 29% White, five percent Indian/Asian, while five percent of participants preferred not to disclose their race group.

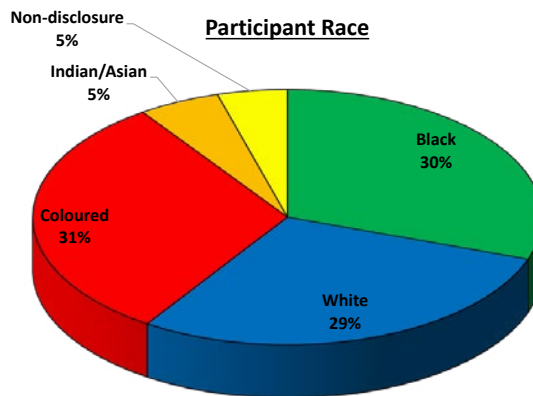


Chart 4: participant race

## Provincial inclusion

Participants included in this study resided in the following provinces across South Africa: 69% in the Western Cape; 57% in the Northern Cape; 19% in Gauteng; 15% from KwaZulu-Natal; nine percent from the Eastern Cape; and seven percent in Limpopo. Four percent of participants resided in the North West, Mpumalanga and Free State provinces of South Africa.

## Questions

All questions on disability that were used in the survey and the focus group discussions were aligned with the Washington Group set of questions and categories adopted by Stats SA in data collection on persons with disabilities as part of the 2011 Census and General Household Surveys to ensure comparability. Data disaggregation included gender, age, race, province, and type of disability. Data was gathered via thematic

areas and included access to health, access to education, access to information, access to social services, access to safety and security, access to livelihoods and economic opportunities, participation and consultation (design and implementation period), access to quarantine and isolation sites and other COVID-19 specific facilities.

The samples for qualitative and quantitative data collection methods reflected the diversity of the population of persons with disabilities in South Africa, and included persons in private and public closed institutions. Data was suitably weighed to ensure it was representative in line with available census and other relevant baseline data.

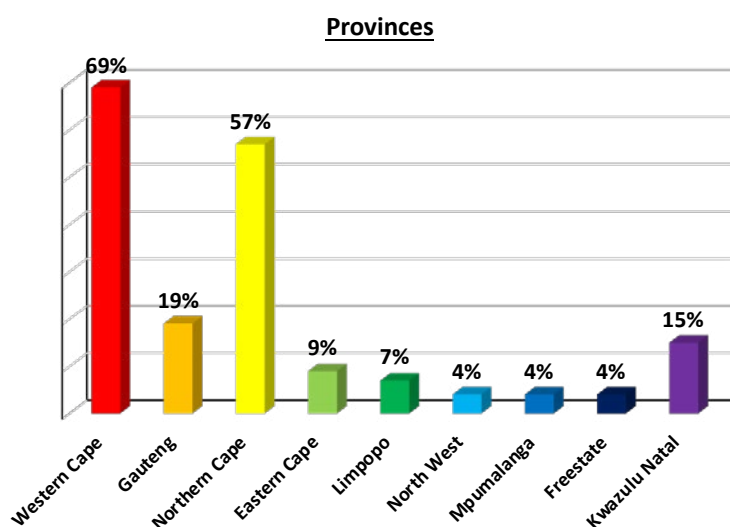


Chart 5: Provinces

## Analysis

Analysis of the interview and focus group discussion transcripts was performed using thematic analysis. The transcripts were read and reread several times by the researcher in order to become familiar with the data. She then arranged the data into the eight differing thematic areas that were identified as being key in the TORs.

## Validation Workshop

After the study was conducted, the findings were shared with stakeholders at a validation workshop for disability reports that was held online on the 17<sup>th</sup> of March 2021. Stakeholders included the Disability Sector (the Presidential Working Group on Disability; South African Disability Alliance), Provincial Governments (Limpopo, North West, Northern Cape, Gauteng, Free State, Western Cape and Eastern Cape with approximately 80% representation), National Departments (with approximately 80% representation); and three representatives from the United Nations Agencies and Partners (UNDP & OHRCHR). Based on the feedback received, additional clarification was made and information included.



# 4 FINDINGS

# FINDINGS

The findings from this study are arranged into the following eight thematic areas relating to persons with disabilities: access to health, access to education, access to information, access to social services, access to safety and security, access to livelihoods and economic opportunities, participation and consultation (design and implementation period), and access to quarantine and isolation sites and other COVID-19 specific facilities.

In addition to sharing the challenges experienced by persons with disabilities during the COVID-19 pandemic in South Africa, participants also shared positive stories and experiences and provided recommendations that they felt were required. These are vital, especially when many of their voices were not heard or acknowledged, and their input was not sought by the policy-makers.

## 4.1 Background to participants

*'I truly have my doubts as to whether I'm going to be able to make it for another year. It puts a lot of pressure psychologically on one to try and figure out how, in the face of this, this valley of the shadow of death, do I just sort of carry on walking?'*

This section of the findings provides data relating to the experiences of participants with disabilities during the COVID-19 pandemic. It begins with providing some of their experiences relating to adherence to government regulation personal protective equipment (PPE), obtaining support, contracting COVID-19, life during lockdown Level 1, lack of independence, vulnerability and difficulty coping, and the impact of COVID-19 on families with persons with disabilities.

### PPE challenges

A significant challenge to participants with disabilities in this study related to the adherence to PPE regulations. This section highlights some of these challenges and includes the wearing of masks and face shields, social distancing, and hygiene concerns.

An organisation supporting persons with disabilities commented:

*The world's forgotten about people with disabilities and PPE. It's carnage really. Government just wasting money in huge volumes of rubbish – PPE was just thrown everywhere. But even in that throwing, it wasn't thrown towards people with disabilities. They weren't considered.*



## Mask and face shield challenges

Some participants with hearing disabilities who relied on lip-reading shared the difficulties they experienced in completing their jobs because they were required to wear a mask. One respondent said:

*I had difficulty with communication especially with clients and work colleagues due to mask covers.*

A participant who was Deaf shared:

*I struggle to read people lips as they wear masks as they don't want to take off and can't follow them even if they shout behind the mask and makes communication difficult unless a sign language interpreter is available which is not easy to arrange.*

An adult who was Deaf and relied on SASL taught at a school for deaf children. This respondent highlighted the challenge of not being able to sign correctly due to wearing a mask or even a clear face shield:

*Certain signs happen on your face and when you wear a shield you can't touch your face. Sometimes I have to take it off sign and then put it back on again. It's a lot of problems.*

A participant with a hearing disability shared her experiences of trying to understand people who were wearing a mask:

*I always say to people, 'You got to look at me when you talk to me, otherwise I can't hear you.' But I didn't realise quite how much that mask makes it muffle the sound. And I'm clueless, half the time I have no idea what people are saying to me.*

A parent of a child with a disability shared her experiences:

*Some people with disabilities are not able to comply with strict laws. My son cannot wear a mask due to over-sensitivity. He rips it off the second it goes on. He is three. He doesn't understand the importance or the reason or anything regarding the mask. He doesn't understand that he has to stay at home and he really misses going out. It has limited my movement as I have to stay home with him.*

## Social distancing

A number of participants who were deaf shared concerns about social distancing:

*Social distancing for many people who are deaf is challenging. For facial*

*expression and eye contact it is difficult. Deaf people need to be close to each other as a result we cannot observe the social distancing. The law says we must be one and half metres but when you are deaf it is hard. You can try but you cannot. You have to come closer.*

Adults who were Deaf shared some concerns regarding specific aspects of Deaf culture that require physical touch:

*Deaf people, when they want your attention, it is appropriate to touch you on the shoulder, to touch you on the arm. That is Deaf culture. They tap and touch you. That is how they were taught in Deaf schools.*

A number of participants, especially those who were wheelchair users and those with visual impairments making use of guide dogs, shared challenges related to people not adhering to social distancing regulations.

A participant who was a wheelchair user shared her experience:

*People don't respect the fact that I also need my two meters of space. I have to ask them to move away from me. It's almost like you're a non-person sometimes.*

Some persons with disabilities used humour to educate people about the need to social distance:

*I tend to use humour to get through somebody else. 'Oh, excuse me I can't get through, my butt is too big.' Then they get it and it makes them realise that I'm human.*

Another participant shared his frustration at some people's ignorance and exclusion of his needs and personal space:

*Excuse my horrible language but I'm not some kind of vegetable. I hate having to be the teacher to ignorant people. Sometimes I have to use my teacher voice, or the voice I use when my kids are being naughty and don't listen.*

A participant who uses a wheelchair and who has an acquired spinal cord injury shared how much longer it took to do basic tasks such as shopping because his family could not assist him and because of the additional time it took to sanitise his wheelchair. This exposed him to the virus for a longer period of time:

*Everything takes me three times longer than it used to. If it was a half hour into the shop and back, it takes an hour and a half. Now it's COVID-19 it takes even longer.*

A participant with a visual impairment spoke of the challenges of being unable to social distance during COVID-19:

*For us who are blind we are depending on the Almighty Father because when I am walking here getting lost I need someone to help me. There is no social distancing when it comes to being helped. You have to touch them [sighted persons] with your hands.*

An employer of persons with disabilities shared some of the challenges relating to persons with disabilities:

*Even our staff we've got some of our staff who have 15 people living in a house. They stay at home but it's the others. Those people go out partying, that the guy with a disability just has to stay there and live in those circumstances. They are not considered.*

An organisation supporting persons with disabilities including parents of children with disabilities shared:

*I think he's found the ability to social distances impossible. That has been a big concern and parents have been very stressed by that.*

## **Hygiene concerns**

While the government encourages people to wash their hands with soap and water a number of participants shared their concerns relating to many persons with disabilities:

*We are supposed to wash our hands, share water facilities and toilets. That type of thing is really stressful and a lack of access to PPE. Parents were not given PPE. These are for various of children with severe disabilities. This is everywhere, not just in rural areas.*

A participant with a visual impairment said:

*I do follow everything that [President] Ramaphosa is saying. Wash your hands or 20 seconds with warm water. I do it. But it is no use. My hands are my eyes. I am going to touch all of the surfaces.*

A participant with multiple disabilities shared her frustration at the inequalities within South African societies and her worry about persons with disabilities who are not as privileged:

*For me I sit in my nice little middle-class bubble. Outside the when people are sharing shacks with several other people and there's no running water, and so*

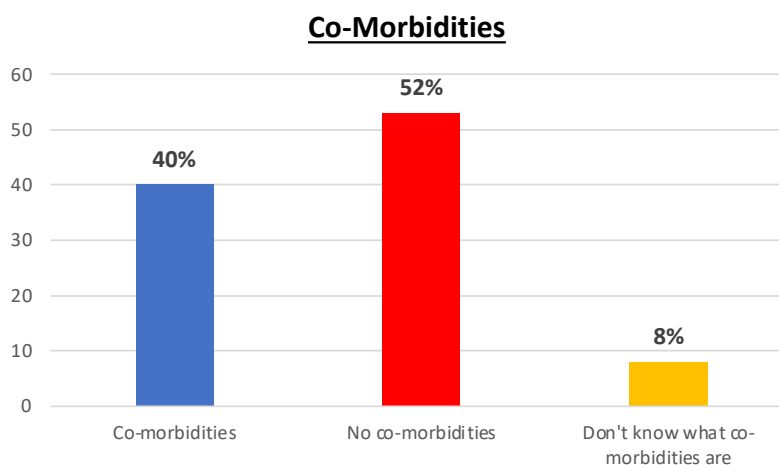
*on. It's a disaster waiting to happen. And it's also a humanitarian issue. It's an offense such, it shouldn't happen like that.*

A staff member working in a special care centre shared her experiences of having to educate residents with severe intellectual and multiple impairments on keeping safe:

*We had to repeat and repeat about handwashing and sanitising. We had to practise and demonstrate. Giving them a piece of paper and saying read would never work! When COVID-19 started, [manager's name] demonstrated during assemblies practically. We would use a rhyme of how you must wash your hands for 20 seconds. Then they would remind each other and if one didn't do it, they would tell on. They are now in that routine of washing their hands, sanitising and cleaning all the time.*

## Co-morbidities

Participants were asked whether they had co-morbidities and whether they felt at greater risk of contracting COVID-19. All participants responded and while 52% of participants stated that they did not have comorbidities, 40% shared that they did and that many were fearful of contracting the virus as a result. It was concerning that eight percent of participants were not aware of what co-morbidities were.



**Chart 6: Participant co-morbidities**

Some participants with co-morbidities shared their fears of contracting COVID-19:

*I am more compromised, than I'd be if I wasn't taking my medication for my immune condition. My doctor said my medical condition makes me more vulnerable.*

Another participant spoke of how if he contracted COVID-19 that there may be severe consequences:

*'The risks are higher.'*

*It's a combination of the things they said one just has to accept that if you get sick. 'You will get sick more quickly and you'll stay sick longer and it may be more severe.'*

A mother of a child with multiple disabilities shared that her daughter had numerous health challenges and as a result, was extremely vulnerable during COVID-19:

*She is classified as cerebral palsy and profoundly disabled. She suffered hypoxic ischemic event at birth. So, for lack of a better diagnosis she is classified as cerebral palsy. She's got global developmental delays. She's also visually impaired. She can hear but because of the brain damage she is not able to translate messages into meaningful things. With that global developmental delay, she is at a stretch maybe at about a six-month old cognitive and development level. She's wheelchair bound. She obviously it's not able to feed herself. She's got swallowing issues, chewing issues.*

## **Chronic health conditions**

A number of persons with chronic medical conditions were included in this study as they were unable to work as a result of their conditions and received a disability grant. In addition, a number had additional disabilities. A participant shared:

*I've got chronic kidney disease. I am had a transplant 29 years ago and it's been stable and successful. But transplant is a therapy, not a cure. You have to take anti-rejection meds to manage which lowers your immune system and or reduces your immune response. But obviously under current circumstances [COVID-19] that's not quite the same.*

A person with chronic health condition shared:

*A friend of mine who's on dialysis. He's was supposed to be a chef, but he's on disability because of his condition. He can't hold down a proper job. H is living in a one room with a flat with in semi poverty. He goes on public transport to get to dialysis and sometimes he walks. Sometimes it's to save money. Because of his condition he's afraid of getting COVID-19.*

Many persons with chronic health conditions spoke of being vulnerable:

*Now so already, you're vulnerable because and you see people dying for your*

*reasons of your condition and now you've got the pandemic and that's killing them too. There are more of us than I think they realised. Many people have invisible vulnerabilities or chronic medical conditions that are going to render them more vulnerable than most under the circumstances, even if our conditions are not disabling or disabling at this point.*

Some participants spoke of the need to adhere to strict lockdown measures in order to keep themselves healthy and not contract the virus:

*It was extremely frightening. When we went into lockdown. I was actually relieved because I thought I felt safe. I mean, look in my situation. I have my own home. I have control over who comes into it. That was really helpful in that regard. And I managed to create a sort of a little safe bubble for myself. It is safer. The only person I've had in my home since other than me since March has been a person who fixed a broken tap.*

## **Obtaining support**

Clear differences between participants were reported relating to the support they received from family, friends, carers, work colleagues, healthcare workers, NGOs and DPOs as well as their local community during COVID-19. Some participants spoke about positive support structures:

*I'm really lucky because I am quite privileged and I have got family who support me emotionally.*

*I have had some amazing friends and colleagues who really helped me. If I hadn't been in a situation where I know the people who I do, I don't know how I would have made it through.*

A participant who contracted COVID-19 spoke of the support she received from her doctor and how this assisted her and her family in understanding and dealing with the virus:

*My doctor was an email or a phone call away. He came back and gave us a lot of information. And that was really useful. So, we could actually be prepared in advance for what we would probably have to deal with.*

On the other hand, some participants shared how a lack of support created significant challenges in keeping safe, minimising contracting the virus, receiving food and accessing healthcare. A participant who was blind shared her fears:

*Contracting COVID-19 – it's a big worry for us. For my parents and I, we don't*



*really have a support system. Once again, the lack of independence, it's difficult for me.*

Many participants, especially persons with physical disabilities and parents of children and adults with disabilities, spoke of the fear of contracting COVID-19 from their carers. Many shared feelings of vulnerability arising from being reliant on others for daily care. Participants mentioned the complexities around the cost of COVID-19 testing, and requiring carers to social distance and follow guidelines when they were off duty and travelling to and from work.

A person with paraplegia shared:

*While we have been isolating and living in our bubble, we have no control over what our carers do when they are off.*

Another wheelchair user shared her experiences of having contracted COVID-19 from her carer:

*My greatest fear came true. My carer went home not feeling well. She stopped at the chemist and got some dry cough mixture as that's what the pharmacist recommended. She said it didn't sound like COVID-19. She came back the next day and I said she must leave straight away. I ended up being positive. She probably gave it to us before it got to that point because you contagious before you even showing sometimes.*

A participant with a physical disability shared her experiences of both her and her carer contracting COVID-19 and having to rely on help and care from her children:

*I was coughing up blood. I was so weak. I had no one to help. I am a single mom. The kids helped me with the cooking and keeping me healthy, help me with the everything. My carer was in hospital with COVID-19.*

A number of participants with psychosocial disabilities spoke of their difficulties accessing care and support, and how some healthcare professionals did not accept their disabilities:

*Persons with epilepsy are not viewed as persons with disabilities.*

A participant with a visual impairment spoke of how isolated and fearful she felt, and how she had no support:

*I don't have a choice, I have to ask others to help me in the street. I am scared. I don't have friends or family here. I ask each and every individual that I meet on*

*the street for help because I stay alone. I cook. I clean. I do everything myself. You don't know if it got corona or not but you need help. So, I just go with them. If I had a choice I would just hibernate in my room. I wish food and medicine would just come there and my home but it does not. You have to move out of your home to get food.*

## **Contracting COVID-19**

The greatest fear that many participants shared was of contracting COVID-19. A single mother with a physical disability who had two children on the autistic spectrum shared her experiences of contracting COVID-19 and being reliant on their care:

*My one son, he gets totally overwhelmed, very emotional, and then has meltdowns which you have to deal with as well. The last thing I want to do is to hold somebody when I was so ill but this is what he needs to calm down. He needs to be held.*

A participant spoke of his experiences of having contracted COVID-19 from his carer:

*My heart stopped when on the Sunday night I got a call from her daughter saying she [carer] was in the hospital and on oxygen. On the Monday, I went to go get tested because I was really not feeling great by that stage. Then it really hit me.*

Another participant who uses a wheelchair for mobility after a car accident contracted COVID-19, and spoke of how she was left with significant pain even after she was no longer COVID-19 positive:

*The nerve pain was horrible. Even now if I don't take my medication, I can't even put my feet down and because of the pain.*

## **Lockdown Level 5 challenges**

When South Africa first went into hard lockdown during Level 5, no one was permitted to leave their homes other than to buy food or receive medical care. There was a lack of clarity regarding carers' ability to leave their homes to assist persons with disabilities. This resulted in significant challenges and stress in the lives of many persons with disabilities who were reliant on personal care for survival. Another significant challenge was that public transportation was shut down so carers who did not have their own transportation were unable to make use of buses and trains to get to and from work.

A participant who was a wheelchair user shared:

*Because of my significant health challenges, I normally make use of three carers on a rotational basis. Because of the lockdown, I could only use one as she lived close to me and could walk. The other two could not come in because of transport. This was very stressful for me and the only carer.*

A participant with paraplegia shared her experiences of having to have physical care:

*Because I get terrible back pain, my carer has to massage my legs and back. While I was strict about masks and washing hands, we just could not social distance. That is how I caught it [COVID-19].*

A participant who had quadriplegia spoke about the need for his carers to assist him physically with intimate and personal bodily care:

*Because of the nerve damage, my muscles go into spasm and then there's nothing I could do about it. He has to assist me. We can't social distance.*

A mother with a severe physical disability shared her experiences of parenting young children during lockdown after her partner walked out on the family. She was not permitted to have her carers travel to work:

*I've had wild children lately; they have become free-range children. I don't have a choice. They have watched too much TV but I don't have a choice.*

A student with a disability shared that being in lockdown was not new for her and that she experienced many years of being isolated:

*Lockdown for me was actually not that weird because my life was like that, in any case, staying at home.*

Another participant with a visual impairment commented:

*I chatted to my friend [with a disability] every day and the one thing we said was all the people without disabilities are moaning about being stuck down in their homes saying 'we can't do anything'. We basically said, 'welcome to our world, we know about this isolation'. This is what it feels like to be disabled, especially visually impaired.*

## **Lack of independence, vulnerability, difficulty coping and anxiety**

A number of participants reported feeling frustrated with their loss of independence, being vulnerable, and having difficulty coping during the COVID-19 pandemic.

A participant shared his feelings of being overwhelmed and anxious:

*It is very difficult and it's not a good feeling. As somebody who was always brought up to be a very independent person and very having to be very strong. I've had no option but to be struggle.*

A wheelchair user who contracted COVID-19 shared his difficulties of having to rely on others:

*To have to sit there and be vulnerable has been very hard.*

Some participants with mood disorders spoke of the increased anxiety surrounding keeping safe and how this often became overwhelming:

*There were days, which was, it was more than I could cope with.*

Another participant with a mood disorder shared:

*I bought myself some so much chocolate and comfort food and stuff because I knew I would start unravelling.*

A participant with diagnosed obsessive compulsive disorder (OCD) shared how difficult the pandemic had been for him:

*COVID-19 is my worst nightmare because I have OCD tendencies and so handwashing is now enforced. There is so much anxiety surrounding all this is hygiene. It's very scary for me. I'm very scared and my life changed completely because of COVID-19. Completely.*

A participant with a visual disability shared:

*It has been more than 30 years. It is still hard accepting my disability, even now I cry. People say 'accept, accept' but there are daily challenges. The world is not kind to us, especially during COVID-19.*

Numerous participants with visual impairments spoke of their fear of contracting the virus while trying to move around in society and having to rely on people to guide them or using a white cane or a guide dog. One participant with a visual impairment shared:

*The anxiety of catching the virus through touching things was real. I am physically reliant on touch. It is a big issue.*

A participant with a visual impairment shared:

*Especially at first, I was scared. For me I have to eat. I have to work. I have to rely on people to help me in the taxis. There is nothing I can do. If corona comes I have to say 'Heavenly Father it is Your will that I die'.*

A number of people with visual impairments who made use of a guide dog for independence also chose not to use her guide dog as they were concerned of contracting the virus via people touching their dog's harness, lead or collar, or physically trying to guide them:

*For the first five months of lockdown I didn't use my guide dog in public. I had to rely on my mother, which was very frustrating. It was just too risky.*

A participant with a visual impairment who used a guide dog shared her fear around people touching her guide dog:

*People say, 'oh look at the doggie'. Then they just go ahead and touch him without my permission. That terrified me. I know I can trust my guide dog when we walk together. I never bumped into things or people. But now during COVID they don't understand that I could catch the virus from them if they touch her halter.*

Another participant with a visual impairment spoke about how not all family members stood up for them during challenging situations in public when support was needed:

*A lady, she bent down and she touched her [guide dog]. And I was like, 'Please, please, don't touch my dog. You know, we happen to be experiencing a global health crisis.' I controlled myself and said it nicely. But my mom was so embarrassed about her 'rude blind daughter'. I kept on saying, 'Look, I'm not being rude to you, but you can't touch my guide dog without my permission.' My mom stepped in between and spoke to spoke to her and apologised. Basically, I was blowing against thunder.*

The same respondent explained that she did not want to cause trouble and only wanted to collect her medication from the clinic:

*I don't saddle up my dog and go out to town, thinking, 'oh today I'm going to blow someone's head off their shoulders'. I'm not looking for a fight. I'm not like that. I just want to go to town, do my things I need to do, and go back home. That's, that's all I want to do.*

A participant with multiple disabilities shared their fear of contracting COVID-19 as they would not be able to have the COVID-19 vaccine because of their multiple health challenges:

*I am at a significantly higher risk of contracting COVID-19 and if I do, I'm probably not going to make it. It's anxiety provoking being around people who don't care.*

A number of participants with chronic health conditions shared their experiences of having to keep themselves safe. A participant shared:

*Anti-vaccine and COVID-19 denialists are particularly prevalent here. They want to feel like they able to choose for themselves. But I don't always feel like it's safe for me to go to places or to interact with people because I can tell that the community isn't really taking these things seriously. That exposure risk could eventually come back to me and kill me.*

Another participant with a chronic health condition spoke about the challenges of having to defend themselves among people who do not understand their conditions:

*It's been very stressful. Sometimes the conversations that people have on social media where I am trying to hold my own as a person with a chronic illness is hard. Especially in a community where people sort of shame or have fear-based reactions to my condition.*

A person with multiple health conditions as well as multiple disabilities that placed her at high risk of contracting COVID-19 shared:

*It's very, very, very difficult for me to cope with the stress of having to constantly confront people and assert myself and my boundaries. It takes an enormous amount of effort and energy. Where I see people in public places being irresponsible, I have to say, 'I will not socialise with you. I cannot be in this space. I will not interact with you unless you comply with regulations.' It is so freaking stressful.*

Some participants lived in fear of contracting COVID-19 and this has a significant impact on their mental wellbeing:

*I truly have my doubts as to whether I'm going to be able to make it for another year. It puts a lot of pressure psychologically on one to try and figure out like how, in the face of this, this valley of the shadow of death, do I just sort of carry on walking?*

Many participants, especially those with psycho-social disabilities spoke of the increase in anxiety, stress and mental health complications as a result of COVID-19:

*My anxiety levels and depression levels are up and down, and up and down. There'll be periods where everything's fine and I can carry on as normal. Then I sort of emotionally flatline and have become like a slug. I can't get simple things done. I just wanted to sort of lie on my bed.*



Many participants spoke of their difficulties buying food and medication during lockdown. Only 1.7% of participants were able to access food parcels from government departments, while 3.4% were hungry or were unable to get the medication they required.

### Buying of food or medicine during lockdown

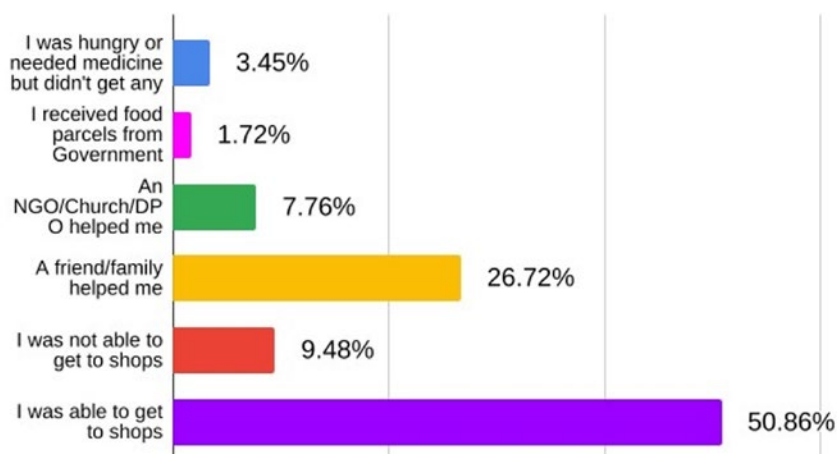


Chart 7: Buying food or medicine during lockdown

### Impact of COVID-19 on persons residing in special care centres and institutions

A number of participants and persons caring for adults residing in or attending special care centres and institutions shared that COVID-19 was significantly challenging. A manager working at a special care centre that accommodated adults with intellectual impairments, multiple disabilities and mental health conditions shared some challenges that they experienced and what they did to accommodate and support their users:

*Our day workers are 40 and our service users in the hostel are around 220. During COVID-19 our residents stayed. But some of those that were here stayed while some who were home when lockdown happened in March unfortunately had to stay at home. There are some that have not been here for the best part of the year. Our day workers we also had to stop them from coming in, which was hard for them and is still hard for them. It's hard for us too as we need their hands and skills here. But throughout, we assisted them with food parcels. We took them cooked food, we are constantly on the phone and WhatsApp groups with them and their families. We had to get a WhatsApp platform for all our parents to get information out quicker. We have always used the telephone and emails with them but now with WhatsApp it is quicker. It helps them as well as if they send a message, we get it straight away and are on it.*

A social worker shared that many of the residents and service users were vulnerable:

*Our primary disability is severe intellectual, but many have multiple disabilities and mental health conditions. Over one hundred of our residents are on psychiatric medication, which is a co-morbidity, as well as blood pressure and diabetes. All these things make them more vulnerable.*

One special care centre built a fence around their facilities in order to keep the residents safe as the area where their buildings were located was not secure:

*Some of mental health service users find being restricted in our facilities, especially in our frail care, very difficult. Having a fence around us to keep us safe makes them feel like they are in prison. They feel cut off. When the fences went up around the buildings it was very traumatic for them. They just don't understand. They feel like they have lost their freedom.*

## **Impact of COVID-19 on families**

The impact of COVID-19 had a ripple effect not only on the lives of persons with disabilities, but very often on the lives of their family members. A student with a disability who relied on a bursary to survive had to take in and look after his parents after they lost their home. He commented that:

*The parental roles have been reversed. For me it's very difficult.*

A participant with a visual disability spoke of the challenges of having to support her family during COVID-19:

*I also discovered, to my horror, that my father is an addict. I basically had to set up counselling sessions and try to track down NGOs or NPOs who could help in that regard, because we didn't have the funding for rehab. All state rehabilitation facilities as part of lockdown were closed. That was [...] very hard. I to take charge of the finances, because otherwise we wouldn't have made it.*

Another participant with a disability who was supporting his family said:

*We would go hungry on a monthly basis. In week number two of the month.*

Other participants with disabilities spoke of the stress and anxiety of having to support their families. A participant who was supporting a family member with an addiction said:

*The person he himself is not bad or evil or anything, but the behaviour that comes with the addiction. The lying and manipulating and I've never ever experienced something like that in my whole life. I put on my big girl panties very fast.*

Some participants with mental health conditions spoke about the numerous challenges that changes in routine, job losses and the fear of contracting COVID-19 had on their lives. A participant shared how they were forced to move after being retrenched:

*I particularly wanted to move into a deeper rural area because my wife has various other neurological issues and mental health conditions and living in the city during COVID-19 from a sensory perspective was really very difficult for her.*

One respondent acquired a physical disability after a severe car accident, resulting in her having spent significant time in hospital and rehabilitation when her son was young. Her son has a disability, and she spoke of the trauma he experienced when she was admitted to hospital with COVID-19:

*He was so nervous about it and because he'd been through me being in hospital. He was even more anxious and stressed about it.*

Some participants with disabilities were also required to support other family members who lost their jobs due to COVID-19, while others had to resign due to comorbidities:

*My also disabled mother had to quit her job though so I have additional financial responsibilities to help her and added pressure.*

Participants identified a number of challenges that excluded them from being employed. These included:

*A lack of accommodations, poor access to places of work due to lack of transport and few positions suited for me.*

A mother of a child with multiple disabilities spoke about the impact that COVID-19 had on her family and the changes that they had to make in order to protect their daughter from contracting the virus:

*In terms of contact when my husband returned from work initially, he came home through the back door, got undressed, and showered. He stayed away. He wouldn't feed her until the next day. In terms of family, our immediate family, they know you come in you wash your hands. You don't kiss [daughter's name] You don't touch her hands because in terms of development. Her sensory stimulation is through our hands. Her hands are still very much in a mouth, her fingers go into her mouth, her hands rubbing all over her face and into her eyes. Everything that COVID-19 guidelines say you must not do, she does. There's no way that I can stop this.*

## 4.2 Access to health

*‘The pharmacists are so overworked that when you talk to them, you get a very negative picture and it creates a lot of anxiety. It was very scary because I need my medication to survive.’*

This section of the findings focuses on the healthcare experiences of participants with disabilities. It includes participants’ experiences of receiving therapeutic assistance, assistive devices and specialised care, communication and care from healthcare workers, experiences of having a COVID-19 test, using public transportation to get to healthcare facilities, accessing medication during the pandemic, and finally their thoughts on the COVID-19 vaccine.

### **Accessing therapy, assistive devices and specialised care**

A number of participants with disabilities, as well as parents of children with disabilities, spoke of how there had been reductions in accessing therapeutic services, or mentioned that they were not able to access them at all. A parent of a child with a disability shared that her child received remote occupational therapy (OT):

*We had telehealth for his OT only.*

Another parent spoke of how her child had not been able to access therapy that he required since June 2020:

*My son used to have physical therapy once a week and swimming therapy once a week. Although he had some therapy at first lockdown in March, it was far less than usual as his physical therapist came to the house but he couldn’t go for aquatherapy. Then funds ran out as both parents lost jobs and medical aid ran out.*

With government rehabilitation centres being closed, there were significant shortages of specialised mobility devices such as wheelchairs being provided to persons with disabilities, especially new patients:

*There’s many, many people who haven’t received their devices. They have already been waitlisted for two or three years; are now delayed another year or so for their devices.*

Some participants spoke of how there was a shortage of specialised care available:

*Rehab services have been closed or drastically cut back as resources have been allocated to COVID-related care.*

Therapists working with persons with physical disabilities experienced significant challenges with providing rehabilitation as well as therapy during COVID-19. Some therapists spoke of the steps they put in place to keep themselves and their clients safe:

*We had to conduct therapy wearing full PPE.*

With government regulations preventing early childhood centres from reopening, many children with disabilities were not able to access the therapeutic services and early intervention that they required. An organisation providing support to learners and their parents/caregivers said:

*All our early childhood development work stopped because all the DSD [Department of Social Development] closed. All our 'let's talk disabilities' and all our advocacy and awareness stigma work stopped.*

A parent expressed her worry that persons with disabilities would not be able to receive the medical assistance or therapy they required:

*A lot of them [specialised healthcare workers] have been moved to other areas. So they are not going to get the normal support they would get.*

The lack of availability of medical specialists such as psychiatrists in the state system was highlighted as a significant challenge for a number of participants with mental health conditions:

*I have been accessing a state psychiatrist before COVID-19 and last year she told me that my meds have to be adjusted, but she is no longer available. The hospital told me psychiatrists are few and far between, and especially now they are overworked and they don't see patients so I'm forced to see a doctor that issues scripts. He is a GP with some other licence to be able to issue schedule five and up. He adjusted my meds and I'm like, 'Oh, no, no, no! That was not good for me.'*

Another participant with a mood disorder shared her experiences of not being able to access a state psychiatrist:

*It seems to be worse during COVID-19. I don't know what other people with mental health challenges must be going through. It's terrible.*

Some participants, especially those with physical disabilities, spoke of the many challenges they experienced trying to access medical care in hospitals during COVID-19. A wheelchair user explained that the situation had changed since the start of the pandemic:

*Going to [name of hospital in the Eastern Cape] hospital was very problematic because after going there for three years with no problems they just decided that people with wheelchairs or walking aids will not get preferential treatment in any form when at the hospital.*

Another participant with a physical disability spoke of a lack of care while in hospital and that he was asked to provide his own assistant to help him after healthcare staff refused to do so:

*At hospitals then they want to know where is your carer?*

Many participants spoke of the significant price increases of certain medications and materials that they required on a daily basis. A mother of a child with a disability said:

*I told the lady at [name of national pharmacy chain] that I can show her the prices for the past 16 years for gloves, bioscrub, degerm, syringes and nappies as we've been buying the same products all these years. The price increases are astronomical.*

## **Communication and care from healthcare workers**

Some participants shared the challenges that they had in communicating with and accessing care from healthcare workers. This was especially highlighted from participants with hearing impairments who relied on lip-reading:

*I really battled to understand what my doctor was saying. His voice was muffled and I couldn't lip-read because of his mask.*

While teleconsultations and online health consultations were conducted between patients and healthcare workers in order to reduce the risk of COVID-19 infections, this form of consultation was not always accessible to all persons with disabilities:

*She [colleague who was Deaf] asked me to call in the doctor. I called the doctor and she gave me the information. I then had to explain it to her.*

Another significant challenge for participants who were Deaf was healthcare workers being unable to communicate in SASL and the lack of SASL interpreters within the healthcare system in South Africa. A parent of a child who was Deaf raised her concerns:



*If she goes into hospital there are no visitors, who is going to help her? Who is going to explain to her?*

Some residents of a special care centre had severe intellectual and psychosocial disabilities and were hospitalised after contracting COVID-19. A participant described how they were accommodated in hospital:

*Our nursing sister was well connected so she knows a lot of the doctors and staff. Even if she didn't know them, she would phone them each and every day. They could put her through to 10 different people and she would stay on that line until she spoke to the right person. She maintained relationships with doctors, especially for the resident who ended up in ICU. Also, our centre is well known in the area so if they hear it is a patient from [name of facility] then they will help them. It's not always that nice, you do have those bad cases, but often if they know it's one of our people then they help.*

## **COVID-19 testing**

A number of participants shared that they had not gone for COVID-19 testing even after experiencing COVID-19 symptoms because of long lines at state testing sites, fear of contracting the virus from those waiting in the line if they were negative, being unable to access public transportation to get to testing sites, and the high cost of private testing.

Two participants, both wheelchair users, spoke of how the drive-through testing sites were the best option for them. However, they both reported over a two-hour wait and the high cost of having the tests conducted privately:

*I had two, one nasal and one throat due to my husband testing positive. It was a drive-through facility so stayed in car which was preferable.*

A participant who suspected she had COVID-19 was concerned with the 10-day turnaround time (at the start of the pandemic in South Africa) but could not afford to be tested at a private testing facility. She commented that:

*To be honest, I think the cost of testing has been quite prohibitive.*

A participant who was deaf and relied on lip-reading found the experience very challenging:

*The staff were not friendly and mostly rude in a way. I had to get them to understand that I am deaf and that I need to lip-read. I had to force them to write down on what they are saying.*

Another participant who was Deaf and who tested positive said:

*I went for a test but nobody explained what was happening. Only one doctor tried a little to me but once she left the doctor's room I was on her own. There was no interpreter, no nothing.*

Participants who had a COVID-19 test conducted were asked to share information regarding the test results. 75% of participants who took the COVID-19 tests received their results and understood what they meant. When asked, participants shared their SMS messages 'SARS-CoV-2 (COVID-19) was DETECTED from the sample taken' and said that the words were confusing and difficult to understand. Four percent of participants did not understand the SMS they received; 17% never received their test results, while four percent received an SMS a week or more after they took the test.

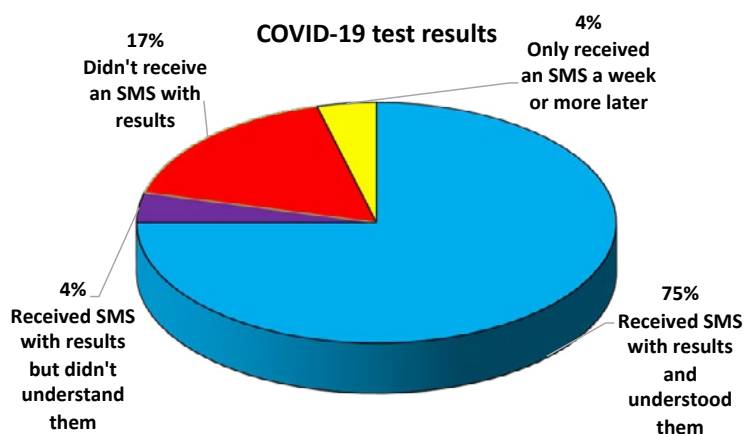


Chart 8: COVID-19 test results

Only a very few number of participants had a COVID-19 test conducted in a State healthcare facility, with the majority of those having had them conducted after being admitted to hospital after exhibiting COVID-19 symptoms. Many participants shared that the long queues at State facilities had not been given priority, inaccessible transport to get to healthcare facilities, communication concerns especially by participants who were Deaf and those who relied on lip-reading, as well as significant delays in receiving their test results, were cited as significant challenges that prevented participants from being tested.

These factors resulted in some participants feeling like they had no choice but to have tests done via private healthcare. A significant challenge that was raised by participants was the associated cost of having a COVID-19 test conducted privately. A participant who was a wheel chair user shared:

*I cannot rely on the State testing. The lines are so long and the waiting times for results were up to 3 weeks. I cannot wait that long. I am forced to pay to have tests done privately and this costs an arm and a leg.*

Another participant shared:

*The private test costs R850 which is way out of most disabled people's range. Most cannot pay for what they need let alone for tests. If you think that the disability grant is only R1,860 per month. Many of us have no choice.*

Some participants who relied on carers and family members for their care shared their challenges of trying to get them tested for COVID-19. A participant who was a wheelchair user who was reliant on carers shared:

*Normally we change carers every five days. If I catch COVID-19 there is a very good chance that I could die. I need to have my carers tested before they come on shift. Who is going to pay for these tests? A disability grant won't cover that. Also, I tried to get them tested at the [name of State hospital] but they said that because they do not have any COVID-19 symptoms that they would not test them. It is only for sick people and they are healthy. I wrote letter explaining my situation but they [State healthcare workers] wouldn't budge.*

A parent of a child with multiple disabilities shared:

*Having to pay for our carers to be tested to keep our daughter safe is an expense we hadn't budgeted for. It has resulted in a complete change in our routine which is very difficult for our daughter who needs routine to feel safe. Normally they [carers] work two days on, two days off. Because of the cost, and having to isolate after the test while waiting for their results, we now only change once a month. This is very tough on our poor carers but financially we have no choice.*

## **Transport**

A number of participants shared their concerns about how persons with disabilities were discriminated against in being unable to get to healthcare facilities due to accessibility challenges:

*In the beginning, they couldn't get to the hospitals, because there wasn't a transport.*

Others spoke about the health risks of using public transportation as a person with a disability:

*They cannot get to the hospitals, because it was too dangerous to use it [minibus taxis].*

A mother of a child with a disability expressed the financial challenges relating to getting children with disabilities to healthcare facilities:

*Now they can't get to it [hospital] because they can't afford to, because they've been getting no money that unable to work. I mean, parents with a kid with a disability is not going to turn work now. There are many different layers of various barriers they've been experiencing.*

## Medication

A number of participants shared that they were not able to obtain the medication and materials that they required during the COVID-19 pandemic, or that they were no longer able to afford them due to unemployment or increases in prices. A participant requiring schedule five medication for a chronic condition said:

*There was a stage where my medication wasn't available in the country because of the borders having been closed and stuff like that. And even now I have to buy my medication from a chemist, because my meds aren't available at the moment through this state.*

**Accessing medication during lockdown**

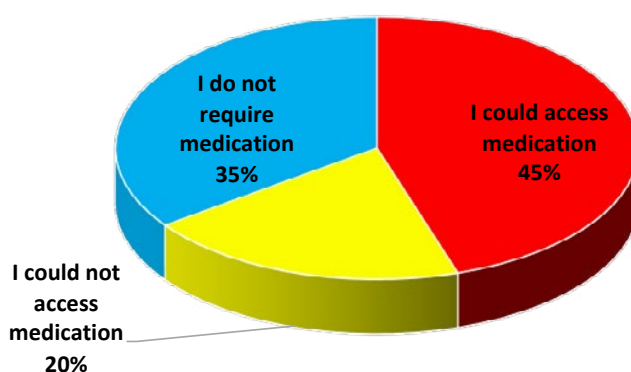


Chart 9: Accessing medication during lockdown

Another participant shared how anxious he became when he was unable to access his medication:

*That was very scary and, you know, we would go to the clinic to collect our medication. Then they would always be IOU, which means certain meds weren't in stock and you need to come back later and collected. But, you know, we would we would go back with our IOU letters and that would be like, 'Well, you know, there's no stock and we don't know when it's going to get any better.'*

This was echoed in the comments of another respondent:

*The pharmacists are so overworked that when you talk to them, you get a very negative picture and it creates a lot of anxiety. It was very scary because I need my medication to survive.*

Not being able to access medication also had a significant effect on mental health:

*Going to clinic the lines are so long. They don't give all my tablets right and it's hard to get a doctor appointment. At the moment I don't work I just lay everyday with a lot of regrets in my mind and don't know what to do with my life.*

A participant who was the recipient of a kidney transplant spoke of the life-and-death situations for transplant patients who were not able to access their medication from the government and had no funds to pay for them privately:

*Many of my friends with my condition have been told that there are no medicine stocks available as the borders were closed. Some can pay for medicines privately, but the majority who are on newer medications do not have the money. It is unethical.*

Some interviews were conducted in institutions accommodating persons with psychosocial and mental health conditions, and the topic of access to psychiatric medications was raised. Some participants shared that there were shortages of medication. One participant shared that they were fortunate to have a resident nursing sister who had built up a good relationship with healthcare workers from surrounding healthcare facilities and was able to call on their support when they were not able to access medication directly:

*Our nursing sister would drive to the local depo to collect the medication. If there wasn't stock, she would talk to other clinics in the area who would give her some. So fortunately, thank God, we didn't have any stockouts.*

## **COVID-19 vaccine**

During the study, many participants shared their feelings towards being vaccinated against COVID-19. There were very differing opinions among participants:

*There are a lot of strong opinions and a lot of contradicting information regarding the vaccine. There are many concerns. But nothing based in facts.*

Some participants were desperate for the vaccine:

*Persons with disabilities should be first eight in line to get the vaccine.*

Some wanted to have it but spoke about their concerns whether they would have access to the vaccine:

*Will I have access?*

*My greatest fear is that the government will screw up the roll-out of the vaccine. They are so hopelessly useless at any initiative that involves careful planning and organisation.*

Other participants were strongly opposed to being vaccinated:

*I oppose forced vaccination even though I understand the need for vaccination and agree with a vaccine program being created.*

*I don't think we should be injected with this vaccine.*

*My concern is if it does not work what then? Why is government taking so long to implement the vaccine and why must it be rolled out to certain groups first? I don't know. Government is playing with lives.*

*I doubt its effectiveness.*

*I am not interested in this vaccine because I have heard many negative things about the outcome.*

A few participants said that they did not believe that they would be able to have the vaccine due to health conditions:

*I have an immune condition common in those with autism (MCAS) and cannot be vaccinated at present but I fear they may attempt to penalise those who refuse unless they can produce expensive medical documents which I cannot afford to obtain proving it is not safe for me. I fear them violating my bodily autonomy with some excuses about public safety.*

*It may be unsafe for disabled people with prior conditions but many cannot afford to see doctors and get evidence of such conditions and may be forced to vaccinate even against their will.*

Many participants worried about the safety of the vaccine:

*I feel a bit worried about the vaccine because there is so much information going around about it. I'm not sure what is true and what is false?*

*I am not too sure if it is 100% guaranteed.*

*I would like to see if there are negative reactions to the vaccine and worried that not all the strains will be covered.*



*I am worried about safety.*

Other participants spoke of the damage that conspiracy theorists were creating via spreading 'fake news' and incorrect information:

*The conspiracy theory stuff that actually makes me so angry. You know, I used to. I started off by sort of laugh loudly. Then reprimanding people on Twitter. I was getting so angry about it. But now I've stopped because it was causing me too much stress.*

A mother of a child with multiple what she called 'severe' disabilities shared:

*Our access to things, there's times that we could still have that we could that should be given to our children and our people with disabilities. We should not have to scrounge and scratch and fight and argue and all of those things for on a daily basis.*

## 4.3 Access to education

**'School, it was halted just because of his disability. I felt bad because his other two brothers in mainstream, they had online classes and even returned normal schooling.'**

This section of the report provides information on the educational experiences of learners with disabilities attending special schools for learners with disabilities and mainstream schools, as well as those residing in special school hostels during the COVID-19 pandemic. It also includes the experiences of students with disabilities attending higher education institutions. It describes the impact of school closures on the education of learners with disabilities, some positive home-schooling experiences, online and home-schooling challenges, the lack of support and communication from the DBE, the impact of COVID-19 on teaching and learning, provisioning of PPE, mask wearing, social distancing, school hostel COVID-19 safety challenges, transparency and communication between DBE, schools and parents, and the experiences of students with disabilities in higher education institutions.

### 4.3.1 Learners with disabilities

While South Africa's DBE stated that remote teaching and learning of all learners must continue during the COVID-19 pandemic, many special schools accommodating learners with disabilities opened later than mainstream schools. This was attributed to

them not being able to physically keep learners, teachers, teaching assistants and other staff members safe from the virus, because it was not possible to eliminate physical contact. Some learners required physical assistance such as being transferred from wheelchairs, there were communication challenges with social distancing and mask wearing for learners who were deaf, some learners needed to share assistive devices such as braille machines, and learners with visual and physical disabilities needed to touch surfaces such as grab-rails.

## Impact of school closures

A number of parents of children with disabilities spoke of the negative impact that school closure had on their children. Many spoke of increased anxiety, stress and mental health conditions brought on by isolation. In some cases, this led to developmental and academic regression.

A parent of a child on the autism spectrum spoke of how difficult home-schooling was, as it involved changes in their child's regular routine and a lack of clear communication on school opening dates for special schools:

*It was very difficult for him to adjust to the new schedule when he went back as the school alternated days to reduce the number of kids on the premises. He thrives on routine. During the hard lockdown he struggled to complete his work at home as worksheets are not the best way to teach him. He just got more anxious.*

Another parent of a learner with mental health challenges said:

*He is an introvert so he preferred being at home, however the isolation made him reclusive and affected his mental health. It was a struggle to get him to go outside or leave his room for anything.*

A significant challenge identified by a number of participants was the poverty of many families with children with disabilities. Many special schools provide meals as part of school feeding schemes and with school closures, this no longer took place. During an interview with a principal of a special school (who was an adult with a disability herself), it was clear how much she cared for her learners:

*We worry so much for our children. Many only got their one meal of the day at school. Now that the school is closed, we know many are hungry. We send our school bus and driver to the homes of parents that we know are struggling once a week. We make up basic food parcels as they have nothing.*

## Positive home-schooling experiences

Some parents with disabilities reported that they were able to provide their children with home-schooling and had positive relationships with their child's school and teachers. Other parents shared that while their school had not provided their children with work, they were able to create their own work or purchase resources from their own pockets. One mother said:

*I am a stay-at-home mom. I have focused on his education using a subscription worksheet service for his developmental age.*

A number of parents shared how their children who would normally become very ill during the winter months and who regularly missed school or were hospitalised shared how being in a 'bubble' and not attending school resulted in their children remaining free of illness:

*Ironically my child has been the healthiest he has ever been. Not being exposed to the other children's bugs has kept him healthy and illness free.*

A few participants – including principals and parents – praised their educators for putting in significant amount of work to support their learners. A principal shared:

*They are so hardworking. The love for their learners is so strong. Sometimes they would pay for things from their own pockets to help their children.*

A number of parents spoke of the support they received from their children's teachers:

*They tried so hard. They started WhatsApp support groups with all of us parents. They gave us ideas on how to work and help our children. They were so encouraging. They really cared.*

Some teachers shared that because their learners' parents did not have devices such as laptops, computers, smartphones, or data, they had to develop creative and relevant strategies to support their learners:

*Once every two weeks, our school bus would deliver a pack of work from each teacher to a few homes in various communities and parents would collect their children's work.*

A parent shared how her child's teacher held her accountable for ensuring that her daughter completed her work each week and that how this helped to her remain motivated:

*We had to submit our work to her [teacher] every Monday. We knew that if we had problems that we could WhatsApp her and she would help us. This really worked.*

A teacher working at a school for learners with visual impairments spoke of how she missed being able to teach her learners:

*Just knowing that my children are sitting at home doing nothing is so painful.*

## Home-schooling and online challenges

Interviews with parents of children with disabilities, some teachers, NGOs and DPOs supporting learners with disabilities showed that not all teachers provided remote teaching and learning to all learners with disabilities. Numerous reasons were provided, including a lack of accountability among teachers working in special schools, parents being unable to assist their children, parents residing far from the school and not being able to physically collect work-packs, as well as a lack of online teaching because of a lack of devices, electricity, internet and WIFI data challenges.

A teacher shared:

*I work so hard but there are others [teachers] who are so lazy. They think, 'because we teach the special ones [learners with disabilities] we can do what we like. The department won't do anything to us.' They gave the learners nothing. They sat at home and did nothing.*

A number of teachers expressed that many of their learners' parents were uneducated, or were only able to read and write at a basic level. As a result, they were unable to assist their children with work that was sent home:

*I made up packs of work but the children didn't do it. I sent WhatsApp messages and they said they didn't know what to do so we stopped.*

A teacher of learners with vision impairments shared some of the challenges she experiences with parents of the children she teaches:

*They are unable to read braille. Some parents are illiterate. Others are just not interested. They are interested in their normal nondisabled children, but not their children who are blind. Even if we give them a simple task, like go do this to help your child. No, they won't do it.*

Many parents who had children who were deaf spoke about their lack of fluency in SASL as being a major challenge in being able to assist their child with completing their work. A father shared:

*I just don't know the specialised signs for things so I cannot help my boy. It is so frustrating especially when I can help his brother with his work but I cannot help him as I can't sign.*

The most common barrier teachers raised related to parents not having devices such as laptops or computers. For those who did, data and a lack of internet connectivity remained a barrier to children not receiving or completing work:

*They [parents] don't have fancy devices. Most don't have data to download the work. That is the main challenge.*

A mother whose child has photosensitive epilepsy spoke about some of the challenges she had trying to support her son with home-schooling as his school only provides online teaching:

*If you catch him having a seizure he's not functioning and not responding. Having to spend a lot of time on the computer just it became really difficult because of the photosensitivity.*

A number of parents interviewed chose not to send their children back to school when schools reopened, while others sent them back later. Some parents cited fear of their children contracting the virus, or because of their children having medical or health-related challenges:

*He [child with a disability] was not in school. His paediatrician advised us in 2017 not to send him back to school due to his lung problems.*

Many parents spoke of the very difficult decision of whether to send their children back to school, especially for those with comorbidities.

A mother spoke of how her son's mental health had deteriorated while at home and how she was so grateful when his school reopened:

*This is why I decided to send him back to school. His mood improved dramatically while he was back at school. It was brief unfortunately as his father caught COVID-19 so my son was no longer allowed to return to school and was home for exams until the school closed.*

Support and communication from the DBE Teachers working in special schools shared their frustration at the lack of guidance from their Provincial Department of Basic Education (PDBE) officials regarding the reopening of special schools, what would happen to learners with disabilities who were not able to return to school, and how evaluations and assessments would take place:

*There was no guidance from them [the PDBE]. We were waiting for guidance from them. Term One we have evaluations. Term two there were no evaluations. Term Three we closed, there was nothing. We didn't know. It was still the same as if it was a normal school year. But it wasn't a normal year.*

Another teacher with a disability shared her frustration:

*The Department of Education don't care for us. They don't even come to our school to help us to know what to do to help the children with disabilities. They don't ask us what our challenges are, or tell us how they can help us. They don't come near.*

Another teacher shared how the lack of clarity regarding the number of teaching days in special school and how teachers were required to complete the curriculum was challenging:

*We basically had two months to teach. Not even a full two months. But we went, but nothing was done. They compress the curriculum but up until now everyone is confused.*

Teachers raised the issue of a lack of clarity regarding the reopening of special schools from the DBE and how not being able to provide information to parents was very difficult:

*The parents are looking at us and saying that you lied to us all the time. But we didn't get any information from the department.*

Parents of children with disabilities were asked whether they were satisfied or unsatisfied with the education their child received from their teachers and schools during lockdown. 57% of parents stated that they were unsatisfied while 43% stated that they were satisfied.

**Education received during lockdown**

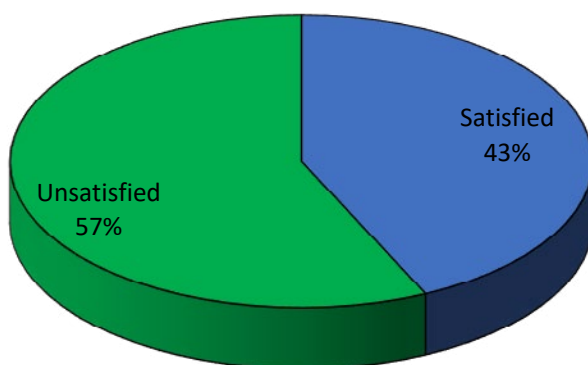


Chart 10: Education received during lockdown

## **Impact of COVID-19 on teaching and learning**

As a result of the challenges identified in this section, many learners in special schools would be required to repeat the year again:



*Those in Grade 5 this year must come back and be in Grade 5 next year.*

A mother who had a daughter on the autism spectrum in matric spoke of how they decided to remove her from school during COVID-19 and repeat the year in 2021:

*She couldn't cope with the home-schooling, the work, the anxiety, the changes.*

Another parent also decided to remove her son from school:

*He just got so depressed, so anxious, not knowing with the changes that were going on. Not knowing what to expect, what was going to happen.*

The impact of home-schooling a child with a disability took a significant emotional, physical and mental toll on many parents of children with disabilities. Parents found the multiple roles of being a carer, parent, financial provider and teacher challenging. A single mother of two children with disabilities said:

*I had to see a psychologist and it was just too much.*

A teacher working in a special school that only provided schooling for two months shared her anger and frustration towards the DBE for not ensuring the safety of her learners with disabilities and the ensuing late reopening of her school:

*This is not right. This is not fair. It is only because they go to a special school. If they went to a mainstream school, they would have been back in their classrooms learning.*

Parents were asked about whether their children with disabilities returned to school after lockdown. 55% of parents stated that their children returned to school, 27% selected not to send their children back to school because of comorbidities and safety fears, while 18% of parents shared that the school their children attended did not reopen.

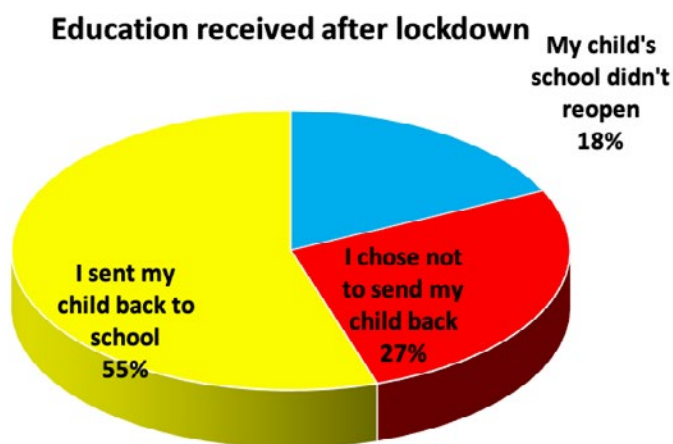


Chart 11: Education received after lockdown

## Provisioning of PPE

According to the Department of Basic Education (DBE) all schools were required to screen all learners and staff, ensure that surfaces were sanitised and provide PPE to learners and all staff. After lobbying and legal actions by organisations supporting persons with disabilities, additional school operating plans (SOPs) were put in place to ensure the safety of learners with disabilities, educators and support staff working in special schools as the existing SOPs were not inclusive of their needs.

Special schools were informed that additional PPE would be provided. This included clear face shields so that learners with hearing impairment could lip-read, those relying on SASL could follow facial cues, and those with intellectual impairment or sensory difficulties could see their teachers and staff. They were informed that there would be an increase in the quantity of PPE such as masks and face shields provided. This included the equipment required to physically assist learners with toileting, feeding and other close-contact activities. They were told that they would also receive additional sanitiser volumes to ensure that personal devices such as standing frames, braille machines, crutches and wheelchairs could be sanitised.

However, some participants working in schools that accommodated learners with disabilities shared that there was not sufficient or appropriate PPE available. Other principals shared that while the DBE informed them of what they were required to have, that there was no budget available and that the funds had to be taken from the schools' own budget. As a result, some schools that did not have funds available were not able to provide the necessary PPE or were forced to purchase inferior products.

A principal of a special school stated:

*It was so hard. We had to borrow from Peter to pay Paul. They told us we had to buy PPE but provided us with no money. 'Sorry we didn't budget for COVID.' It's now our problem.*

An educator working in a special school for deaf learners shared that each educator was only allocated one clear shield and that this was not sufficient:

*I use one all day but it doesn't stay clear. When you are using sign language you need to see facial expression. It is a barrier. When you clean it, it gets foggy. It looks like a window that is not washed properly. That is a problem visually.*

## Mask wearing

Some learners, parents, teachers, school managers and support staff shared that compulsory mask wearing posed a significant challenge for some learners and adults with disabilities working in special schools.

Parents of children on the autism spectrum and those with children with severe intellectual impairments shared some challenges relating to mask wearing.

A mother of a child on the autism spectrum shared:

*My son was very, very frightened of the masks. We tried everything. We wore them at home to try get him use to them but he would just scream. His teacher wore fun masks with kiddie pictures but nothing worked. It was just too different for him. He didn't understand.*

A father of a child with cerebral palsy spoke of how while he understood the compulsory mask wearing regulations, due to health and hygiene reasons, mask wearing was very difficult for his son, who had cerebral palsy (CP):

*Because of my son's condition of CP he drools a lot. This makes his mask very wet and we don't want him developing chest infections and other complications.*

## **Social distancing**

Teachers – both deaf and hearing – and support staff who were deaf working in a school shared that social distancing was significantly challenging when teaching and communicating with learners who were deaf.

An educator teaching learners with severe intellectual impairments shared her concern and fear about not being able to follow social distancing guidelines:

*Distance is a problem. You cannot have the one and a half metres. Some learners learn slower so you need to be near them to be able to help them to concentrate. But it is a challenge. It is very dangerous for us to work here.*

While many teachers shared the challenges of being required to social distance from their learners, some found creative solutions, such as teaching outside their classrooms. They expressed some of the benefits:

*It would be better if we could teach outside. Then we wouldn't need to use our masks. Visually it would be clearer.*

However, many stated that this wasn't always possible:

*Unfortunately, where we live it is hot. Very hot outside.*

Another teacher stated,

*If you are outside then it is fine. But when you come into the classroom to teach that is a problem.*

A teacher with a visual impairment working in a special school for children with visual impairments spoke of her challenges with social distancing, sanitising of braille materials and mask wearing:

*When I am teaching a child who is blind in the classroom, there is no social distancing. The book she is reading I am going to read. Where it as she reads, I have to follow with my finger because of braille. You cannot sanitise because the paper will get soggy. I cannot wear a mask because I have to hear if she says an 'E' or whatever. I have to be near to articulate. As a result, us teachers are running the risk of getting COVID-19. There is nothing we can do.*

Another teacher with a visual impairment shared:

*Even if I sanitise my hands 20 times, I am going to hold the same book. I am going to hold her hands to show her how to type on the braille machine to check what she is writing is the correct thing. I have to feel her hands. I can't sanitise but I am working in danger.*

A teacher of learners who were deafblind raised the concern regarding how to communicate and keep both learners and educators safe:

*What about the deafblind children? They have tactile sign language. How is that going to work? They need to be close. They need to touch their hands.*

## **School hostel COVID-19 safety challenges**

When the DBE announced that all schools would close due to COVID-19, school hostels that accommodated learners with disabilities were also closed in order to prevent the spread of the virus and to keep learners and staff safe. However, when schools reopened, significant COVID-19 safety challenges were raised by parents of children with disabilities, teachers, principals, support staff, DPOs, NGOs and other stakeholders. These concerns resulted in legal action being taken against the DBE. As a result of this legal action, the DBE was required revise the SOP to focus on the needs of learners with disabilities, teachers and support staff in the school and hostel environments; and to provide additional PPE.

However, many parents still chose to keep their children at home:

*As a mother of a child with severe disabilities, I do not feel that the school hostel is equipped to keep my daughter safe. I cannot take the risk. This is my daughter's life we are talking about. Not just a number.*

In some provinces and districts, teachers, support staff and principals supported the decision to keep the school hostels closed. They cited reasons including COVID-19

safety concerns and continued lack of PPE; not being able to comply with social distancing requirements especially in dormitories, bathrooms and eating areas; and insufficient number of support staff. A teacher working in a special school shared:

*If the hostels would have opened, we would've had deaths on our hands. The principal of the hostels really cares. It was the best decision.*

A head of department shared that she, other teachers and their principal approached their teacher unions and lawyers for legal advice and refused to reopen:

*We cannot keep our learners safe. They will die.*

A support staff member working in the school hostel shared:

*Working in special school hostels is not the same as others. We have to physically carry, turn, toilet and transfer many disabled learners. How do we keep them [learners] safe? How do we keep ourselves safe?*

Another stated that:

*We were understaffed before COVID-19. Now it is even worse. Some staff are too scared to come to work. Others have comorbidities or have family with comorbidities. Some come but leave because they are sick. We cannot cope.*

A principal working in a special school shared:

*We know that in the hostel there are problems such as social distancing in the bathrooms and eating areas. There are too many children. And a sleeping space for social distancing is a problem.*

A staff member who previously worked in the school hostel spoke about the difficulties she had social distancing and not having sufficient PPE:

*Those of us working in the hostels will not be able to social distance. We don't have enough staff. Now the hostel is in a COVID-19 mode. They didn't appoint screeners; there is no extra masks.*

A staff member working in a different school hostel said:

*We can't take the masks that they gave us at school and wear them for the whole of the rest of the day. These are the things the department did not think of.*

A teacher working in a special school that previously accommodated learners with disabilities spoke of how hard her principal had to fight to keep the hostel closed due to safety concerns of his staff and learners, many of whom had severe disabilities and comorbidities:

*The department said the hostels must open. The principal stood his ground and said the hostels will not open. They sent the circuit manager to him. Then they sent the one above her. Then they sent [...] in the MEC to him and he still said the hostel will not open unless you deep cleaned this hostel. Unless you deep cleaned all these hostels. Unless you can make sure that there will be social distance in the sleeping eating and toilet areas. Even the infrastructure in these hostels.*

One of the most significant results of some school hostels remaining closed was for the matric learners with disabilities residing in rural areas not attending school. Learners who could not stay in the hostel and lacked online teaching were required to repeat their final year of schooling. A HOD shared:

*The deaf and blind children in matric have to come back next year. They couldn't come in to write their exams.*

Parents and teachers spoke of the difficulty facing learners who resided far from the school. Because school hostels were closed, they had no option of receiving schooling:

*Some of the parents would have sent their children back, they would have. They would have sent them back if they had any other place for their children to stay other than the hostel. But they don't have.*

## **Transparency and communication between DBE, schools and parents**

A number of participants raised the issue of the DBE's lack of transparency and communication with parents and learners with disabilities who attended special schools or resided in school hostels. An educator working in a special school that provided hostel accommodation to more than half of the learners at the school shared her concern about the lack of transparency regarding the opening of school hostels:

*There is a challenge for children living in the hostel. The hostel closed in March. The children thought that it was closed because of school holiday, they didn't know that it was because of COVID-19 and that they wouldn't be going back till next year.*

A teacher raised the question of whose responsibility it was to inform parents that school hostels would remain closed:

*Who should share this information with the parents were for deaf children? Who is responsible? The department [DBE] are responsible, they should intervene. Now even in the first week of December the deaf children are still at home. There*



*are about 45 out of the 75 deaf children are still at home because they stay in the hostel. The only reason for them not coming back to school is because the hostel is closed.*

A school head of department shared her frustration at not receiving clarity on the reopening of school hostels from the DBE:

*We were waiting, waiting, waiting for the department to let us know what was going to happen for the deaf learners. We as teachers want to know what do we do with the learners who are not coming to school? The [provincial] department said they were waiting for national Department of Education so we must wait. It was all very confusing.*

Teachers working in special schools whose hostels did not open shared how the lack of information and communication from the provincial DBE damaged their relationships with parents. Parents no longer trusted them or believed that they had had their children's best interest at heart:

*The parents called and called each and every week saying, 'When can my child come back to school?' 'Why don't you want to tell us?' 'Why are you hiding this information?' 'Why don't you want to get answers from the department?' 'Don't you care about our children?' This was very, very hard. I cried a lot as I love my children but I didn't know what to tell them.*

## **Transport**

Another significant challenge highlighted by parents, teachers and NGO's supporting children with disabilities was the inability of special school busses to operate due to COVID-19 safety concerns. As a result, many children, especially those with physical disabilities who cannot access public transport, have been forced to remain at home. A teacher shared:

*We just cannot safely operate the school busses. Our children have severe disabilities and have to have carers and assistants on the busses to keep them safe. We don't have space to social distance and have the funds to sanitise our busses*

Many special schools had lost funding as well as income from school fundraising projects such as annual golf days due to COVID-19. A parent said:

*Our accessible busses are not funded by the department. The funds come from our 'Friend of [school name]' and because we couldn't fundraise, we cannot run our busses as there is no money. Parents don't have the money or accessible*

*cars to bring in their children. It is so sad that they are missing out on education just because they cannot get to school.*

### 4.3.2 Students with disabilities in higher education

A number of students with disabilities shared their experiences of accessing teaching and learning remotely during the COVID-19 pandemic.

A lecturer with a disability working in a higher education institution shared her experiences of online teaching during the COVID-19 pandemic:

*It was triple the amount of work. We've been doing face-to-face lectures and suddenly we now had to take everything, the modules and put them on the online platform. It was just a tad bit of crazy. You know what? I got through it.*

Another lecturer spoke of how working online enabled her to build closer relationships with many of her students with disabilities:

*I've become closer to some of my students with disabilities. We've actually developed some great bonds. Some of my students – we have a really close working relationship now.*

Another student shared her positive experiences of enrolling for online distanced education:

*I was actually quite relieved that I was doing online because I have been able to continue through COVID-19. It's been very hard. But what's actually been amazing is that we've got an incredible support group. It is a fellow student support group from all over the world. It's quite funny, if you've got a problem at any time of day or not, you can actually post something somebody will be awake.*

A student with a visual disability shared her experience of making the decision to leave her university residence due to fears that she would not receive support if she contracted COVID-19:

*When lockdown was imminent, I told my parents, look and I need to come home now, because what if I get sick and no one wants to help me? The university said, 'Once you – once you go, you can't come back.' I panicked and packed minimal winter clothes. I left in such a rush, even leaving food in my fridge.*

Students with disabilities who returned home to stay with family members due to the university's lack of support stated that that this move had its challenges. One student who was visually impaired spoke of having her independence withdrawn once she moved in with her parents:

*When I am back home my own life is very disabling. I can't even do my own washing. When I want to make coffee, I have to always ask first.*

She further shared how difficult it was to fit into her parents' routines and rules after being independent at university:

*[University name] was heaven because I could go to the to the shops on my own. I could go and drink coffee and do what I wanted to do. But it's unfortunately how it is with my parents. It's very dysfunctional.*

A student with a disability spoke of how she was forced to find emergency accommodation because her home was not safe:

*I had to live with my uncle who is an alcoholic and has very bad rage issues. It was very traumatic for me living with him. I held out for two and a half months but I knew I had to create an escape plan, so to speak. I couldn't stand it any longer.*

## 4.4 Access to information

***'It is better for us to have a sign language interpreter. We don't understand the meaning of the word. Whereas if there is a sign language interpreter then we understand.'***

This section of the findings shares the experiences of participants relating to the accessibility of COVID-19 information, specifically during news briefings, COVID-19 information updates, and presidential and premier briefings.

### Sign language interpretation

At the start of lockdown there was an outcry from members of the Deaf community regarding the lack of SASL interpreters during official government addresses and COVID-19 related broadcasts. Officials from the DWYPD shared how they ensured that access for persons using SASL were accommodated:

*When the National State of Disaster was first announced, our initial measures were to make sure that sign language interpretation was available.*

Numerous participants who were deaf shared their challenges in accessing COVID-19 information on television because there was no consistent SASL interpretation:

*Sometimes there is an interpreter on the TV. Other times there is not. I then have to try lip-read. I have to try very, very hard to concentrate on what is being said but most of the information it goes missing. It is very, very important to have an interpreter.*

Other participants who were deaf highlighted that even when interpreters were provided, on some television channels the interpreter was too small and information was lost as a result:

*Sometimes they have an interpreter but she is so small on the screen that I can't see well and then I miss out.*

Other participants who were deaf and relied on SASL interpreters shared that access to information differed across the lockdown levels:

*When it was locked down Level 5 there was an interpreter all the time for the news and for some information such as meetings with the president. It was so good. But when it came to Level 3 the interpreter went away. By the middle of August access for the deaf went away. Where is the information? We couldn't understand. We want to know.*

When participants who were deaf were asked if they had raised their concerns, some shared that they had sent messages and emails to ICASA (the official regulator of the South African broadcasting and telecommunications services sectors) but they received no response to their messages:

*The law says, ICASA must provide information such as the news in an accessible format. If it is not accessible there is R100,000 fine if they don't comply to the law. They ignored the law. Many deaf WhatsApp and email their problems to the broadcaster but they always get lost then never get response. When the deaf sent messages to that number they give on their website they get ignored.*

## **Subtitles**

Not all persons with hearing impairments use SASL to communicate. Some persons follow an oral/aural approach using lip-reading and speech to communicate and make use of assistive devices such as hearing aids, cochlear implants and bone anchored hearing aids. During interviews with persons using this form of communication, the majority spoke of the need for subtitles to be provided, especially during the news and important COVID-19 media briefings:

*We need captions on the news when our president talks.*

Other participants with intellectual and learning disabilities spoke of the need for subtitles to be included as some did not understand some of the terminology used during briefings and on the news. They spoke of the need for the words that were used in the subtitles to be simplified:

*I wish they used more simple and easy to understand words so we can follow as I don't understand some of what people are saying.*

Another participant concurred:

*It is good to have subtitles but sometimes they have big words that I don't understand.*

Many participants requested a SASL interpreter over subtitles, due to low literacy levels among certain persons who are deaf.

A parent of an adult who was deaf reported:

*Most of deaf people in South Africa cannot read and write at the same levels as hearing people. This is not their fault. Rather it is because there is no written form of SASL. Also, many teachers cannot sign. That is a really big problem.*

An official from the DWYPD shared the importance of planning and accountability regarding accessibility of information:

*Spheres of government and institutions to start making that information available, but it's not just the information itself. It's the whole planning process, the budgeting process. The who is responsible for this and will be held accountable if it's not done.*

## **Accessible information from employers**

It was vital that COVID-19 information was provided for employees returning to work. Some participants with disabilities were employed as teachers, teacher assistants, cleaners and general workers. Many raised concerns relating to a lack of accessible COVID-19 safety information provided by the DBE. This affected their safety, the safety of other staff members, and the safety of learners with disabilities. A teacher shared her challenges in having to assist fellow staff members who were deaf:

*The information that the Department of Education gives our school is sent to us but there is no interpreter. Our deaf staff and teachers don't understand. Sometimes the information comes in Afrikaans. I have to translate it to English and I have to shorten the information. Sometimes the information is a voice note. I have to tell that deaf what it says. While it should be the department's responsibility these are my colleagues. I work with them closely.*

A participant with a disability shared her concerns that many of her colleagues with disabilities did not have an adequate understanding about COVID-19 when they returned to work:

*There is nobody that cares. Our colleagues with disabilities need to know. They do not know when to come back to work. They were confused.*

A hearing teacher shared his anger at the DBE and blamed them for not providing his colleagues who were deaf with adequate information; this led to a number of positive cases of COVID-19 so severe that hospitalisation was required.

*The Minister of Education failed the deaf. She failed everybody and mostly them. Especially the provincial Department of Education. The Department of Health said that schools need to have information on how to prevent the coronavirus and that we as teachers need to practise. The province failed us. They taught at the other hearing schools how to clean. They were all given workshops. We here never received anything.*

Another teacher working in a special school said:

*Schools for the disabled got nothing. It was the responsibility of the teachers to teach the children that we were never taught. We need to know the challenges of helping a disabled child. The principal did not give us any training. We knew nothing.*

## Suggestions

During a focus group discussion with a group of participants representing a DPO, support persons who were deaf shared the importance of having an interpreter:

*It is better for us to have a sign language interpreter. We don't understand the meaning of the word. Whereas if there is a sign language interpreter then we understand.*

When participants were asked what they felt was needed to provide more accessible COVID-19 information, they provided the following suggestions:

- *We need more accessible media like pictures that we understand*  
*Door-to-door information sharing or at least printed information that is clear will help*
- *Some people do not have access to social media. Catalogue with detailed information to be distributed within our community is needed*
- *They could reach out to small towns, like rural in the areas where they need it most*



- *Using social stories, child friendly illustrations, and audio visuals would be great to share information*
- *For people who are deafblind, education and training will assist us. We need face-to-face training; we believe in touching or seeing*
- *They need to consult with NPOs and not service providers to really understand the needs of disabled people*

## 4.5 Access to social services

This section of the findings provides accounts of how persons with disabilities and parents/caregivers of children with disabilities accessed social services during the COVID-19 pandemic.

During interviews the DWYPD shared some of the concerns raised by persons with disabilities relating to COVID-19:

*I think there was a lot of confusion there was a lot of panic amongst the disability sector and understandably so. They raised number of issues and we responded to it or we saw to engage particular departments in order to get some kind of relief.*

A participant with a visual disability shared that she was not able to access support from the DWYPD:

*I believe there is an office for the disabled people in the president's office. I believe there are somewhere there may be in the premier's office but they don't come near our school. We get no support.*

Another teacher with a disability said:

*Sometimes they [DWYPD provincial official] come to our school they signed the register, they talk talk, but when they go, we never hear from them. They close their books and do nothing.*

An official within the DWYPD shared some of the collaborative practices that had taken place between government and civil society during COVID-19:

*We received a number of letters from the presidential Working Group on Disabilities and from disabled persons individually. These highlighting issues which we had raised with other departments, as well issues such as food distribution social grants.*

They further shared how this collaboration brought about change:

*You would have seen that the Department of Social Development made*

*provision for there to be one special day that persons with disabilities come to collect grants.*

However, they acknowledged that there were challenges with implementation of this directive:

*They [persons with disabilities] could try and observe the protocols in place to avoid COVID-19 but there was a delay during the initial period in terms of some of the officials on the ground.*

Additional areas that the DWYPD wished to share included how they assisted in changing guidelines to allowed guide dogs and service dogs to be walked and exercised during lockdown:

*So, we had raised a number of these issues with the departments including access to guide dogs, which you'll see in the legislation we were very clearly say that is allowed. You would have heard Minister Zulu from Social Development saying that that guide dogs are allowed and service animals are allowed.*

However, the DWYPD shared that they experienced some challenges:

*There were glitches and red tape, because it is ministers that needed to sign off, or there was confusion around processes because according to our understanding, we did the directions, however there was, I think, miscommunication in government, to that extent. But having said that, we have to the greatest extent possible engaged and all the issues.*

Media reports and other sources have revealed that food distribution to those in desperate need has been severely challenges as a result of many factors including a lack of coordination in the distribution of food parcels, the need outweighing the resources available, as well as corruption. However, an DWYPD shared:

*Although food distribution was a crisis, there were measures put in place to accommodate children who were a part of feeding schemes through community nutrition centres.*

There appeared to be some confusion regarding the eligibility of social grants and government's criteria for food parcels amongst participants in this research. Many were not aware that if persons with disabilities received a disability grant, then they would be excluded from receiving food parcels. An official from DWYPD said:

*The Social Relief of Distress Grant is for people who are disabled, who do not qualify to receive the disability grant.*

Of the 94 participants that provided data regarding Department of Social Development monthly disability grants, 33% of participants stated that they accessed disability grants during COVID-19.

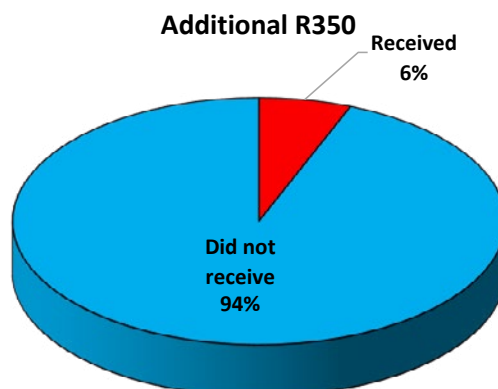


Chart 12: Disability grants

Of the total number of participants who received a monthly disability grant during COVID-19, only six percent received an additional R350 payment.

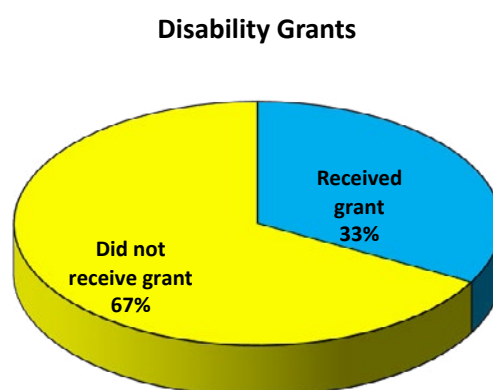


Chart 13: Accessing additional R350

A person with a health condition and disability shared his experiences of having to wait in line to collect his disability grant:

*People with diabetic cannot stand long on their feet hence the long queues cause them to experience painful feet.*

Another participant with a physical disability mentioned that no preferential treatment was provided to some persons with disabilities while waiting for their grants:

*Security want us to queue in those long line.*

A number of participants spoke of how they were not treated well and their needs were not accommodated:

*I have been discriminated against by not be helped in a way, that one can understand what is going on and not being support enough based on your disability as mostly we get treated that we are dumb or stupid.*

A participant shared how many persons with disabilities were not able to access services that they required as mentioned in the World Report on Disability:

*People fail to provide the necessary services as per the WRPD 2015 and more so during COVID-19 pandemic, which has highlighted this discrimination.*

Some participants felt that more social grants should have been provided:

*Grants should have been given to all people with disabilities.*

Participants who experienced abuse and assault during COVID-19 shared that they felt the government should:

*Provide respite care and safe houses.*

A number of participants shared experiences of significant challenges trying to access disability grants during the COVID-19 pandemic. A participant shared:

*The government should have given us proper answers as to why certain things just didn't happen during COVID-19. I didn't receive my disability grant for six months during the lockdown and when I finally got my paperwork resubmitted the clerk at SASSA just said that my six months of disability grants fell away with no reason why.*

A number of participants with disabilities expressed the need for departments such as the DSD to provide support to persons with disabilities:

*They should reach out to people with disabilities by having task teams that specifically check and ensure that they have the necessary stuff needed to survive during this pandemic.*

A participant spoke of the need for government departments to provide specific COVID-19 training to persons with disabilities:

*At least one workshop in a quarter, so that information can be spread to other disabilities people because not everyone has smartphone or have access to social media. I suggest face-to-face training. That will assist us.*

The DWYPD shared how they had developed partnerships in order to access materials

that persons with disabilities required:

*We were able to get a partnership with [name of American consumer goods corporation] and they gave us supplies to the value of around two million. They gave us nappies. We'd asked them for adult nappies but they were not able to assist us with that so they gave us children's nappies, washing powder, toothbrushes and wet wipes.*

In some provinces, 'dignity' sanitary packs were included as well as food distribution in the form of food parcels. These products were distributed amongst the disability sector in three provinces as instructed by the deputy minister. However, none of the participants interviewed said that they had received food parcels or supplies that were mentioned above.

## 4.6 Access to safety and security

***'I can't get into the courtrooms for the trial because they've put up a security gate. It makes the door too narrow for my wheelchair.'***

This section of the findings focuses on the safety and security experiences of participants during the COVID-19 pandemic. A participant with a psycho-social disability spoke of how she felt safe during COVID-19:

*My home is safe. Its secure. I've got a burglar alarm. I've got, you know, I'm on good terms of my neighbours. I've got internet access. I've got all the things that allow me to be safe or safe as possible because nobody ever is completely safe.*

However, many participants in this study spoke of feelings of vulnerability as a result of their disabilities and how many did not feel safe both from contracting COVID-19 but also from factors including abuse and violence.

A woman with a visual disability shared her experiences of having being attacked and robbed and how the SAPS refused to open a case:

*As a blind person they [SAPS] said I cannot open a police case. I was robbed here [place of employment]. Someone put a knife around my neck and said, 'I'm going to kill you.' I told the police but the first question they asked me was: 'How does that persons look like? You can be of no help. You will not be able to identify him. Because you can't see there is no case for a blind person.'*

She further spoke of the urgent need to disability sensitivity training on how to accommodate persons with disabilities:

*The police people should be taught how to be sensitive when asking questions. They mustn't just ask, What did that person look like? What was she wearing? How will I know that? I was praying for my life. I thought I was going to heaven.*

A woman with a physical disability reported poor handling of her case by a SAPS officer and how she was not supported:

*I went directly to the minister working with safety in my province. I spoke to her and I explained the situation and what happened. She said she would do something but she did nothing. We are not safe. There supposed to be persons with disabilities in each and every government departments to help with these type of things but there are not.*

A participant with a visual impairment shared her experiences of not feeling safe in her local community:

*I was walking down the road using my cane because I cannot see. There was someone walking in front of me but I did not see him. I think that all my cane must've touched his shoe. He turned around and said: 'You have made me angry.' He hit me on the chest with his fists. I said. 'But I didn't see you I am blind.' I said: 'I am so, so sorry.' People just don't know about disability, about my life. No one came to help me. Nobody came. Nobody cared. They just don't know. They haven't seen a blind person in their life before.*

Some female participants disclosed that they had been physically assaulted and abused, while two mothers with disabilities reported that their children also with disabilities had been assaulted by partners in their homes during lockdown:

*He has a drug and alcohol problem, and he was becoming more and more aggressive and verbally abusive with everybody. Eventually he hit my son [with a disability] in the face.*

A participant with a son on the autism spectrum expressed relief that a detective from her local South African Police Service (SAPS) was disability-sensitive and allowed her to accompany her son and speak on his behalf when needed when he was required to give a statement after being assaulted:

*It was because he's on the autistic spectrum. And it's because of the disability he couldn't speak clearly.*

A participant with a physical disability shared that he was contacted and requested to physically come to his local SAPS station to open a case of assault. When he explained to the officer that he had a physical disability and that he had concerns about



using public transportation during COVID-19, the officer agreed to come to his house:

*The detective phoned and he wanted me to come down to the police station to do an interview. I said I am disabled. He came to me which was good. Although the problem is that I did sit around waiting for him for two days before he did actually arrive.*

A mother shared her feelings of vulnerability of not being able to protect her children as she was a wheelchair user and her partner was physically strong. Another mother shared that she had obtained a protection order against her partner but spoke of how traumatic the event was:

*I was so stressed that he would lose his sight. There was blood everywhere. He couldn't see for hours. I was worried that his eye might have detached after being hit by my now ex-partner. We had him checked out. Fortunately, it healed. They said it was probably just some bruising within the eyeball.*

A mother spoke of how as a result of lockdown and not being able to leave the house that she became aware of how her partner had been abusing her children:

*As it actually turns out, I now know, I can confirm that things have been going on because with COVID I was home all the time. I stopped seeing what he'd been hiding and the abuse that had been going on. And you know, I was able to see what was happening because the kids [with disabilities] didn't tell me.*

Another mother spoke of how she developed a closer relationship with her daughter with a disability. This led to her daughter disclosing that she was being abused:

*The stuff [abuse] was going on too long ago. But, you know, if you don't know what's going on. And people are hiding things from you. I mean, I knew, I knew there was friction between them, but I didn't know what was actually happening.*

A participant with a visual impairment spoke of how vulnerable she felt making use of public transportation and having to be reliant on the public to assist her:

*When I wake in the morning my taxi to go to work, I just have to sing sweet Jesus and hope that I will get a taxi it will take me. I just paid my R12 and pray that I get to work. Every day is a challenge. Some days I get good drivers and when I say stop at [road name] they take me there. Other drivers stop short and drop me off somewhere. When I get out, I recognise that I'm not where I need to be. Then I have to find someone to help me. This is the problem with COVID-19. I need help. I have to say: 'I'm sorry please help me where am I?' They say let me help you. I don't know maybe they are a tsotsi. Maybe he's taking you to the nearest forest to do horrible things to you. You don't know. I feel so vulnerable*

*as a woman with a disability. When a person offers to help you, all I can do is pray that he is really going to help me. Maybe he's going to be the one to grab you or your bag.*

A mother shared her experiences of trying to obtain supervised visitations for her ex-partner who had assaulted another of her children during lockdown as she feared for her child's safety:

*I've had to go through Child Welfare and asked if they will do supervised visitation. This was hard as a mother with a disability during COVID. Eventually they agreed to do supervised visitation with him. So, she sees her father once a week for a couple of hours and supervised.*

A woman with a disability felt that she could not obtain the support that she required in order to leave an abusive partner from government departments during COVID-19 and how she had to rely on friends to assist:

*They [Department of Social Development] don't answer their phones or emails and aren't in their offices. I called a colleague from work. She literally walked me*

*through the steps doing everything [of getting a restraining order]. I honestly I don't think that I could have done this if it hadn't been for the fact that she went with me.*

A participant who was a wheelchair user spoke of some of the accessibility challenges he faced when he tried to access the magistrate's court building after being assaulted during COVID-19:

*I can't get into the courtrooms for the trial because they've put up a security gate. It makes the door too narrow for my wheelchair.*

The same participant spoke of how he was required to sit outside the courtroom at the entrance and give his evidence there, because he could not gain access. When asked whether this occurred in other courtrooms, he said that all the rooms in that particular magistrate's court had security gates, meaning that no venues were accessible.

*Ironically, they are only used to lock the courtrooms at night not to keep us safe. Who would want to break into an empty room?*

A participant shared her experiences of having to complete a statement after an assault on her child with a disability at a local SAPS station and how frustrating this process was. It was made additionally challenging as she was a wheelchair user. Getting to the police station was challenging and she was afraid of contracting COVID-19:

*I had to go twice. The first time I got in the police station and they said, oh, no, the lady who does the children's stuff wasn't there to do the interview, I must come back the next day. So, went back the next day, but it was a public holiday and she wasn't there either.*

Another participant who was also a wheelchair user described how she had to find a back entrance to the police station in her area because it was inaccessible:

*I couldn't get in the normal entrance. I had to hunt to get in. No one helped me.*

A woman with a disability said that she felt directly discriminated because of her disability by a SAPS officer when she tried to open a case of assault during the COVID-19 pandemic:

*When we went there to make the statement that the one officer just wrote us off and after we told him what happened said, 'Whatever.' He didn't take me seriously.*

There were a few positive stories. A woman participant with a disability shared her experiences of having a magistrate who she felt listened to her story and took her case seriously:

*I had some photographic evidence [of the abuse] but you know I take my hat off to the magistrate that we saw. We did the protection order because we had to go and get an interim protection order and then you have to go back. I had to say it was terrible. But the magistrate he listened and granted us.*

Another participant spoke of how she made a conscious effort to engage with the magistrate. At first, he seemed dismissive but then provided a significant amount of support:

*After a while his whole demeanour changed, and he started asking a whole lot of questions. He actually added a whole lot of stuff to the protection order. He added in psychological and mental and emotional which I did not know about. It was really weird it was like we broke through a bit of a barrier.*

## **4.7 Access to livelihoods and economic opportunities**

***'COVID-19 has changed the way we will work in the future.'***

This section of the finding relates to the experiences of persons with disabilities who

were employed, actively seeking employment or lost their jobs during the COVID-19 pandemic. It also includes feedback from employers – those with disabilities, as well as those employing persons with disabilities. Not all participants in this study were employed or actively seeking employment; those who were employed reported mixed experiences relating to working during the COVID-19 pandemic.

Some participants reported positive employment experiences:

*My work have been incredibly supportive and proactive in supporting vulnerable staff. I have felt very safe.*

An employer of many persons with disabilities who were classified as essential workers said that keeping their employees safe was vital. The company assisted with private transportation to and from work:

*In terms of our staff obviously first priority was to keep them safe as they were coming back to work. We put on private transport for them.*

Another participant shared that she had no challenges with her work:

*I had no difficulties. I was working from home.*

## Transport challenges

Many participants including persons with disabilities as well as employers who employed persons with disabilities shared some of the challenges relating to transportation. A participant with a physical disability shared his feelings towards inaccessible and unsafe public transportation and how this affected the employment of persons with disabilities:

*For the guys with disabilities, it is certainly a nightmare. It really is. I honestly think one of the biggest challenges in this country has been public transport.*

A wheelchair user described a significant challenge:

*Getting to work because the public transport could only take eight passengers by that time so when they get to me, they are always full to capacity.*

Another participant spoke of some of the challenges of public transportation and accountability:

*The inaccessibility of it. With the fact that they have been noncompliant. I mean, the government's been bending over backwards to accommodate the taxi industry and in doing so, I think put many, many people at risk. We packed up taxis with closed windows. There's no regulations on it and no enforcement.*

One employer spoke of the significant financial and time cost of providing safe and accessible transportation for their employees with disabilities:

*They couldn't take public transport. That was hugely expensive because as we had to pay the drivers' overtime. A round trip to collect them was like four hours every time, every day.*

A participant with a visual impairment who relies on catching a taxi to get to work shared:

*Every morning I am coming to work by taxi. I am going to touch the taxi. Who has touched the seat before me with their hands? For a blind person my hands are my eyes. I cannot use it wearing a glove. When I touch things with my bare hands, I am running the risk of getting the virus.*

Additional challenges relating to social distancing within vehicles transporting employees meant that reductions in working hours occurred as multiple trips were

required to collect all employees:

*You had to have few people in each car and bus. It was quite a performance.*

An employer shared that:

*It was a lot of extra cost. Yeah. But keeping them [employees with disabilities] safe was priority.*

## **Employer retrenchments or resignations**

A number of participants shared that they had either lost their jobs after their employers were no longer able to pay their salaries, or resigned due to factors such as a lack of accessible transportation or safety risks. A participant with multiple disabilities who previously worked in the hospitality industry said:

*They [company] had to shut down. They were too small to be able to afford the additional measures that would be required to open up again. They basically were like, 'Look, we're sorry. We're gonna have to ask you to leave.'*

A number of participants with physical disabilities shared how they were forced to resign from their places of employment due to feeling unsafe using public transportation:

*I stopped traveling on public transportation and I was the only person with a severe disability.*

## Safety at work

Many participants spoke about the changes that employers had made in order to be COVID-19 compliant:

*The way we were working at the office was changed. We upped our hygiene at the office significantly and took temperatures four times a day.*

An employer spoke of the changes that the company made as an essential service employer to keep their employees safe:

*We really put stringent rules in place and we employed two people just clean constantly.*

Some participants shared how they were required to complete a risk profile and that employers used these to determine who should work from home:

*We had to complete the risk profile form so that I could stay working from home to keep safe.*

A company shared how they had shifted how they work to ensure the safety of their employees:

*We've really been running our organisation completely remotely. There's hardly anybody in in the offices, except production.*

An employer of persons with hearing impairments shared:

*We need our employers to provide face shields instead of masks for staff so I can lip-read.*

Another manager with multiple disabilities shared that after weeks of no one wanting to make a decision about whether to return to work, she made the call:

*I said, 'Sorry, I'm taking an executive decision, we're not working, face to face, we're going to keep doing this till the end of the year. I know it's not what you would have liked, but it is what it is, how we're living now. We have to keep everyone safe.'*

However, not all participants felt that their employers took COVID-19 seriously. An employee with a disability shared her experiences. Two of her colleagues with disabilities contracted COVID-19 and both were hospitalised:

*He [employer] said COVID-19 it's not that important. Because he doesn't know the SOP he speaks of things he doesn't know. Because he's in management you don't contradict the leader in front of you, and in front of the staff. So you*



*keep quiet. He has a nonchalant attitude, 'Agh what? Nothing will happen. It's fine, don't worry.'*

An employee with a disability described how three employees tested positive for COVID-19 after coming to work. Despite this, there was no deep cleaning of their workplace areas:

*No nothing was done. We just had to return to work like normal. Our boss didn't take it seriously.*

Another employee spoke of the lack of training given to cleaning staff and what the outcomes were:

*Our cleaners did not go for that specialised training on how to sanitise after a positive case in the school. [Name of cleaning supervisor] was training [name of general worker] to use this sprayer but he used it wrongly. It went in one of the class assistant's eyes. He also has a disability. He moves a bit slower because he has CP. There was no PPE. No eye protection or gloves given.*

## **Financial concerns**

Many employers of persons with disabilities experienced significant financial challenges. One employer who provided specialised mobility devices shared her experiences:

*Our therapists couldn't see private clients because of the risk to the private clients unless it was really urgent and that of course has a huge impact on our financial annual turnover.*

An employer with a disability spoke of his challenges of having to retrench a number of persons with disabilities during COVID-19 due to significant financial challenges:

*We've also had to retrench a lot of staff. It is so tough knowing that persons with disabilities are already discriminated from jobs. How will they find new ones in this climate?*

Participants with disabilities spoke of the stress surrounding reduction in pay and uncertainty of whether their jobs were safe from closure:

*Our salary has been reduced.*

Another participant mentioned the stress caused by financial uncertainty:

*I have had a cut in salary. Uncertainty of the future of my employment due to finances is stressful.*

## Creative solutions

A number of employers of persons with disabilities and entrepreneurs with disabilities shared how they had to find creative solutions to keep working.

A company that previously provided face-to-face training and support shared their experience:

*We repositioned all our work for remote training and that's been really successful, but of course you can't charge people for [that] so it's all free.*

An employer spoke of how his employees have remained positive, worked extremely hard and developed creative ways to provide services to persons with disabilities:

*They have been amazing. They've taken on the change. We had all the therapists designing online training and making home videos. They really have worked hard to make whatever they can during this time.*

An employer of persons with disabilities said:

*COVID-19 has changed the way we will work in the future. We wouldn't go back to traveling so extensively, like before. Our training is now all online.*

## Accommodation of individual needs

Some employees with disabilities spoke about employers not being willing to accommodate their individual needs. A participant with a mental health condition that was aggravated by stress and anxiety said:

*I had difficulty to get agreement to work shortened hours.*

A participant with multiple disabilities said:

*I lost my previous job and now I'm freelancing but I had to take the first job I could find and my boss is not understanding of my mental health.*

A number of parents of children with disabilities spoke of their difficulties in trying to work while looking after their children, especially when special care centres, ECD centres and many special schools remained closed even when the mainstream schools reopened.

A mother of a child with a severe disability expressed her frustration with her employer not allowing her to work remotely:

*My employer refused me to stay at home during COVID-19 period with my child.*

*I got all the necessary documentations and still they refused. They knew about my son's disability and his health issues.*

## **Online platforms**

A few participants shared that they experienced the same challenges that many South Africans faced with working remotely and having to familiarise themselves with online platforms:

*I had to work from home and needed to make adjustments, like familiarise myself with virtual platforms such as MS Teams and Zoom.*

Some participants with visual impairments found that some software used for online meetings were not accessible:

*Online meetings software such as Zoom and MS-Teams is not particularly accessible for blind computer users.*

Another challenge expressed by some participants was the cost of using online platforms:

*I had a lack of adequate support in respect of data to work remotely.*

## **Employers not following COVID-19 protocols**

A number of participants shared their concerns of having employers who chose not to follow COVID-19 governmental policies and how difficult this was for them:

*When I was diagnosed with COVID-19, my employer was adamant that I had to submit all my documents within three days although I was under quarantine and I was not able to walk due to shortness of breath and weakness. If wanted to go to toilets I had to ask for assistance from my wife. It was very difficult during this time.*

A teacher working in a special school described how general workers responsible for deep cleaning and sanitising schools had not received adequate training and how this led to some significant negative health and safety effects:

*The only one in our whole school who went to training was head of maintenance which was less than two hours long. This was only after the department didn't want to pay private contractors to come sanitise our school with machines. I went on training but it wasn't only on how to use the sanitising machine but most of it was about their company business.*

*A general worker with a disability working in a large company shared: I was only given training for five minutes on how to use the machine. I then had to come back to [name of company] and show the other staff how to use the machine. I did not learn how to keep myself safe. It was just on how to use the spray.*

Some participants with disabilities shared how their employers did not take confirmed cases of COVID-19 seriously. They did not close their places of employment and deep clean:

*We had corona cases here twice. In the mainstream the school would be closed to be deep cleaned. But at our school, no. There were two teachers who got sick. They were sick on Friday, my principal knew. They had a normal school day on Monday.*

## **Losing their jobs**

A number of participants lost their jobs due to companies closing as a result of the COVID-19 pandemic. A participant shared:

*I lost my job. The company I worked for closed.*

Some participants lost not only their jobs but also their places of accommodation as a result of the COVID-19 pandemic:

*I lost my job in the hospitality industry due to lockdown. I had to move as I lived on the premises as a barter–trade agreement tied to my job.*

A few participants resigned from their jobs because their employers did not take the actions required to ensure their safety:

*I left my job due to conflict over COVID-19 regulations that were not enforcement at work.*

## **4.8 Participation and consultation (design & implementation period)**

***“I believe if persons with disabilities were involved the committees that were established to combat the pandemic, valuable insights could have been shared with response to our plights. “Nothing about us, without us.”***

This section of the findings relates to participants’ experiences of participation in and consultation on the designing and implementation of COVID-19 responses affecting persons with disabilities. Many persons with disabilities spoke of the significant need

for participation and consultation of persons with disabilities, and that without this, there would be serious and even life-threatening consequences. A participant shared her frustration:

*They [government] exclude us naturally.*

## **Lack of consultation**

Very few persons with disabilities stated that they were consulted by government during the COVID-19 pandemic. Those that reported that they were consulted said that this consultation happened far too late, and most saw no improvements after they had provided suggestions:

*I was somewhat consulted but little came of that.*

*I was consulted for a time by people in government but little was done and I became disillusioned and withdrew to save my energies for more effective work.*

A participant with a physical disability shared his experiences of being consulted by government:

*It was all just window-dressing, ticking boxes to say that they had consulted with us.*

Workers at DPOs and NGOs shared their anger and frustration at not being consulted on issues directly affecting the lives and safety of persons with disabilities:

*The representation of the disability sector was inappropriate and ineffective as the so-called representatives made no effort to contact and include organisations of and for persons with disabilities.*

A member of another organisation supporting persons with disabilities said:

*We really need help from government because we as NPOs wanna help but we are excluded.*

A member of a DPO shared the sentiment that:

*If we could have been involved, we could have helped many people through this pandemic.*

## **Lack of awareness**

Many persons with disabilities wanted to make a difference and be part of the consultation process relating to COVID-19 but found this difficult:

*There was not a platform to make a contribution.*

Another participant reported that:

*I was not sure where to give my inputs.*

A person with a disability said:

*I'm not aware if there were any active consultations towards the design, implementation and the monitoring of the measures to protect persons with disabilities that we could have participated in.*

## **Inter-governmental departmental communication**

A participant representing the DWYPD shared some of the disability accessibility and inclusivity challenges they experienced with the implementation of the National Disaster Management Act (NDMA) and its implementation by the National Coronavirus Command Council (NCCC) and how as a result, they were required to put measures in place. An example provided spoke to the challenges of a lack of SASL interpreters during COVID-19 related broadcasts:

*Because they [NDMC] didn't act as smoothly as we would have liked for them to act, we then put in a measure in place, knowing it would be temporary.*

During interviews with DWYPD officials it was reported that there was a lack of response from various government departments:

*We send out emails to them again. Asking what kind of inclusion there would be. Their response was, they'll come back to us, which they never really did.*

As a result of a lack of response, the DWYPD had to provide their own interventions to accommodate persons with disabilities:

*We had to put in other measures, interventions and communications in order to follow that up with various departments including COGTA [the Department of Cooperative Governance and Traditional Affairs].*

## **Inclusion in government**

During interviews with DWYPD officials shared how they were represented in various technical COVID-19 related national committees:

*We are represented on the COVID-19 Command Council and various technical committee workstreams.*

Government departments were all involved in COVID-19 workstreams that worked on strategies for interventions and included legal and regulatory; public health containment;



safety and security; economic; social impact; and transport and tourism workstreams. These workstreams:

*Coordinate all the inputs and then advise the president. They also reported to the president on the work that they have done on matters related to the national disaster.*

The DWYPD provided guidance for a number of workstreams including:

*In terms of residential facilities and what guidelines are put in place. We assisted the Department of Social Development in developing the directions to make sure it was inclusive.*

*We guided Health [Department] in terms of quarantine sites being accessible. [Name of DWYPD official] had started putting together a checklist of what was needed to comply with in order for them to be fully accessible.*

*We also looked at economic work stream where we said that they need to make sure that all the interventions were inclusive of persons with disabilities in terms of not just targeting, but the reporting as well.*

The DWYPD spoke about how they have been providing online support and training to departments during COVID-19:

*We've done presentations to assist departments with strengthening the systems. We have been working more closely with Social Development to assist them with strengthening their systems in terms of reporting, because it seems as though they are doing work. Unfortunately, it's not coming out in their reports. A system's approach is really important in trying to embed the disability mainstreaming in the planning in the budgeting.*

## **Implementation of policy and inclusion of persons with disabilities**

A participant representing the DWYPD spoke of some of the challenges they experienced with a lack of implementation of disability inclusion within government departments policies and guidelines, specifically the NDMA:

*We had been working with the NCCC over a number of years. We had already started the process of advocating also assisting them with policies and guidelines in terms of including persons with disabilities into the interventions and their responses. There was a commitment that came from them that they would be inclusion and they would put together an advisory committee.*

It appears that establishing an advisory committee for the NDMA was also highlighted as lacking by the UN Committee on the Rights of Persons with Disabilities:

*We had a constructive dialogue with the UN Committee and there again, they raised the issue. The response that we got from them [NCCC] was that they were putting together a committee and advisory committee of persons with disability.*

The DWYPD shared that they were involved in providing information on the rights of persons with disabilities on governmental platforms:

*We developed a resource page which includes the April 2 amendments that specifically speaks about ability inclusion and reasonable accommodation and universal access to all the interventions that that was implemented during this time.*

An official from the DWYPD captured the importance of implementation of policy within government departments and how this remains a challenge:

*I think perhaps as the president has said in some of his statements as well, although we have really good policies and directives, people seem to be acting without protocols and at times without sensitivity towards particular groups.*

## **Disability-specific desegregated data**

During interviews with a number of participants, the issue of a lack of disability-specific desegregated data was raised as a significant challenge in planning for and monitoring services and support for persons with disabilities.

A participant spoke of the need for the government to obtain disability-specific data:

*Official data on COVID-19 ought to be desegregated by disability so as to see how COVID-19 affects people with disabilities to inform evidence-based interventions.*

A DWYPD official said:

*We struggled to get the segregated data during this time and this has been a challenge for a number of years where we've been trying to clean up the data and standardise it across all administrative data. We know Stats SA is not bringing in the level of information that we would like them to.*

However, it was mentioned that an attempt at gathering disability-specific data is being made:

*The project that we're doing that is being supported by the World Bank, we are*

*now going to create a standard for the measure of disability, which will make it easier for departments to report on disability.*

Others shared this would not happen overnight:

*It will still take some time in terms of institutionalising it, but there has been a challenge in terms of getting that data coming through. So even with the provinces. We work not just with national department, but with provinces as well.*

Having disaggregated data on disability is vital in order provide appropriate support and interventions. With Government departments not having this information available goes against the UNCRPDs Preamble and Article 6 which states that this information is required by all states who have signed and ratified the convention.

Some examples of the negative impact of not having disability desegregated data included that were provided by the DWYPD included:

*Even Social Development – from the information that we received – is not able to desegregate to tell us how many food parcels went to people with disabilities. We do not have data of what’s going on in residential facilities. We were aware that there’s guidelines that needs to be made. We don’t know what the infection rate is at the residential facilities that we had also requested. Similar information from Health [Department of Health] in terms of psychiatric institutions is lacking.*

*I think what we’re seeing is definitely a challenge in terms of getting the information that we need. There may be pockets of excellence but it’s coming out very, very clearly in terms of what the reporting that we’ve received.*

## **Lack of disability representivity in government**

A number of participants mentioned that one of the factors relating to the lack of participation and consultation of persons with disabilities by government was the lack of disability representation within government departments:

*The government still represents us by using able bodies.*

Another participant said:

*They needed to ask us for advice in making their plans about us.*

## Systemic challenges

In interviews with members of the DWYPD, they spoke of how they were putting monitoring frameworks in place but that there were significant systemic challenges:

*Over and above that we've been liaising with the national departments, as well as the provincial departments where we put monitoring frameworks in place so that we could get reports from national departments and provinces. Unfortunately, they've not been forthcoming with as much information as we would like.*

Long-term systemic relating to disability-specific information challenges were mentioned:

*That actually points to a systemic issue that we struggled with for a number of years. Since the White Paper and the Rights of Persons with Disabilities, all institutions, especially public institutions, are meant to be reporting on progress on the inclusion of persons with disabilities. But we were only able to put out the first annual report as a baseline, even though we only received about 50% slightly over 50% responsiveness.*

The impact of some government departments working in silos results in many concerns raised by persons with disabilities not being dealt with or addressed by the responsible departments. Instead, these are then forwarded to the DWYPD:

*The buck keeps coming back to us because the whole system is still not responsible and responsive enough. What the disability sector tends to do is come back to us rather than going to the line function departments and pressuring them.*

The importance of having disability-inclusive policies came through strongly in interviews:

*All policies must have the disability mainstreaming component to it so that we can build the system in terms of inclusive planning, implementation, consultation and ownership with the disability sector. That comes out in the reporting as well. Unfortunately, and very frustratingly, that that kind of information has not come through to the extent that that we would like to see.*

In addition, a decline in reporting was also reported:

*Now in the coming year [...] in the following years, we see that is a declining quality as well as responses. And that's something that we need to find a way of reenergising. Our portfolio committee is key to making sure that happens.*

A DWYPD official shared her concern about a lack of disability desegregated data:

*What is clear is that the desegregation is not coming through. It's hard to measure the impact of an inclusive mandate for each department in terms of what the impact is the planning is weak. We started a process where we analyse the annual performance plans.*

Other challenges identified was late submission of documentation and its negative impacts:

*We are also supposed to be analysing the strat [strategic] plans, but those processes inevitably become delayed. When the departments don't meet a deadline in terms of a draft strat plan, so we have a number of approaches that we've taken in order to try and get the planning more inclusive.*

Another participant raised an additional barrier:

*The reporting, even now, doesn't very clearly show us the planning or the progress that has been made.*

While the DWYPD spoke of committees that were set up to ensure disability inclusivity, there were a number of challenges in terms of institutional arrangements:

*We have the National Disability Rights machinery which is represented by all national departments as well as provincial departments and we generally ask for the highest level of representation. The challenge on that forum is that we get mid-level management, junior-level management that comes who doesn't have influence in terms of decision making. So, the intervention that we have been looking at for that and are busy with is the professionalization of our disability.*

## **4.9 Access to quarantine and isolation sites and other COVID-19 specific facilities**

This section of the findings includes the experiences of the few participants with disabilities who accessed COVID-19 specific facilities. Not one participant in this study made use of a COVID-19 quarantine or isolation site, however one special care centre was converted into a field hospital.

Two participants made recommendations. One said that government should:

*Make special provision for testing and accessing health care in the event persons with disabilities test positive for COVID-19 and need to be isolated.*

The other participant suggested that government should help persons with disabilities who tested positive for COVID-19:

*Give us support with a caretaker, food vouchers, supplies and put us in a safe facility where people can help and assist us.*

A staff member working in a special care centre that accommodated adults with severe intellectual impairments and mental health conditions shared their experiences of having staff and residents contracting COVID-19 and being converted into a field hospital:

*We had over 70 positive cases of COVID-19. The majority were service users [adults with severe intellectual impairments]. We had everything closed, no one other than staff could come in and out. One of our residents had to go for a COVID-19 test as he needed to have an operation. That is how we found out that he had COVID-19. Everything is closed. PPE is worn by all staff. Everything is done. Temperature checked. And here someone who wasn't outside, never outside tested positive. That is how we found out. That day in June when it happened our whole lives changed. Literally. We had to jump. These are the most vulnerable people. He was one of those in our frail care centre. Just thinking about it makes me relive all those emotions again. We had to get the staff tested and many of the staff tested positive working in the frail care centre. Then we called the Department of Health [DoH] and they came in as we obviously had to report to them. Then the District Department of Health came in. We are so thankful that they came in and tested all those with symptoms. We had to set up a field hospital here in our ward. Everything was closed off. It was a terrible, terrible month. The parents weren't allowed in. No one was allowed in. It was so so terrible.*

When participants were asked about the support and services provided by the DoH after they were turned into a field hospital a participant shared:

*They came in and told our nursing sister what to look for. She then told our housemother look for this, look for that, then they identified people who they felt were positive and they [DoH] tested them. They couldn't test everyone. They just tested random people who had symptoms and those with comorbidities. They [DoH] were quite loving and caring and treated our people very good with respect. It wasn't like they came in and said, 'why don't you want to sit still?' No. They allowed the housemothers to be in the areas where they were testing to help them calm down. For the residents just knowing that I can hear my housemother's voice and that she was with me really helped and at least gave some comfort.*



However, when it came to the conversion of the facility into a field hospital, they shared that they were not provided with support:

*We had to move the beds and everything. The DoH just came in to do the testing and giving of results. But the setting up of the field hospital was us, the workers, ourselves. They did not give us anybody to help us. They gave us nothing, no equipment. We did everything. They did not come back. Everything was done telephonically. Our poor sister did everything. They came once to see how it looks and said: 'Yes that looks good, nice.' They just ticked the box and left. We did not get any PPE, nothing from DoH.*

However, as traumatic as it was, parents of service users and residents expressed that they were happy that they were kept safe:

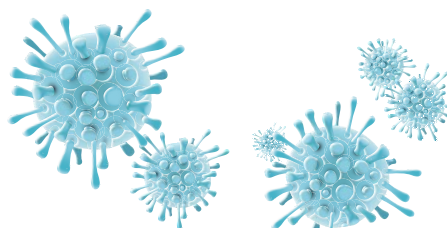
*They [staff] were constantly on the phone giving us feedback. They had cell phones to keep in contact with us.*

It was established that although the facility had been extremely cautious and COVID-19 compliant, a staff member had transmitted it:

*We looked at where this thing [COVID-19] could have come in. After we did the tracing it appeared that a staff member brought it in after a family gathering. A number had been to various family gatherings. One of our residents went to hospital and passed away. He didn't make it. It was a big wake up call for many of our staff who thought our manager was being too overbearing, too overwhelmed, too scared. But when this hit, their eyes were opened. We were so careful. We were so careful and then this happened. We took every precaution.*

A social worker shared her difficulties of not being able to provide face-to-face counselling to residents and staff after 70 persons contracted COVID-19:

*The residents were traumatised after the virus hit. We as social workers couldn't get in to talk to them. We had to talk through the house mothers. For the houseworkers and staff it was very overwhelming and very terrible. It was for themselves and their families and the service users isolated in the hostels.*



COVID-19 TESTING





# **5 RECOMMENDATIONS**

## 5. RECOMMENDATIONS

*‘They should have asked us for help designing the help they offer instead of just deciding for us.’*

During interviews and focus group discussions, as well as in the survey, participants were asked what recommendations they had for the government to ensure that the human rights of persons with disabilities were upheld.

Recommendations came from persons with disabilities, parents and caregivers of children and adults with disabilities, children with disabilities, and NGOs and DPOs representing and supporting persons with disabilities.

### 5.1 Acknowledgement and involvement of persons with disabilities

Many participants spoke of the need for persons with disabilities to be acknowledged by government. A parent of a child with a disability commented that if government had:

*Remembered they [persons with disabilities] existed would have been a good start.*

Not all persons with disabilities felt heard or acknowledged. A person with epilepsy shared that she wished that there was:

*Recognition of persons with epilepsy as part of the disability sector, and solutions regarding medication shortages.*

Person with invisible disabilities and those with chronic health conditions shared their experiences of feeling vulnerable due to their conditions:

*People like me who have a invisible medical condition which is something that can be a disability or sometimes isn't a disability. I mean it makes them feel vulnerable because one doesn't fit in one spot or the other. You're not obviously a vulnerable person, but you are vulnerable. I'm grateful that most people I encounter have been pretty considerate but I would just love the people higher up [government] to understand that people like us need to be protected.*

Having direct involvement with persons with disabilities, parents of children and adults with disabilities, and the organisations representing them was highlighted as a significant need:

*They should have asked us for help designing the help they offer instead of just deciding for us.*

*Ask people with disabilities more for advice on how to help us and then actually listen.*

## 5.2 Inclusion in planning

Extending from the lack of acknowledgement described above, most persons with disabilities felt excluded in COVID-19 planning and interventions:

*Understand and consider their needs, and then included this understanding into disaster planning and budgeting.*

Another participant shared the opinion that:

*‘the lethargy and lack of professionalism and strategy in the government social-work sector is absolutely shocking.’*

## 5.3 Developing partnerships

Many NGOs and DPOs supporting persons with disabilities expressed frustration at the lack of involvement, engagement and partnering between themselves and government departments. One participant recommended:

*Partnerships with organisations, specifically allocated resources e.g. food parcels etc., support for NPOs who lost funding.*

A participant expressed that the government should have assisted persons with disabilities by forcing companies to make accommodations for persons with disabilities who were employed:

*Businesses should be obligated to provide adjusted services to people who are at high risk and be held liable if they force people into dangerous situations.*

## 5.4 Provisioning of resources

Some participants expressed that they felt persons with disabilities were excluded from resources:

*People with disability need more support from government with medicine, food and transport and job creation for youth and education studies.*

Another participant spoke of the need for food:

*Supply them [persons with disabilities] with food parcels and to deliver it to them.*

A parent of a child with a disability shared:

*They [government] could have helped us. Many children slept hungry cause their parents doesn't work. No PPE equipment for us to assist. No money, no food, no assistance.*

Provisioning of appropriate access to information was highlighted among many participants with hearing disabilities and people who were deaf, who wanted the government to:

*Make use of sign language interpreters.*

'Home-based services' were requested by some participants with physical disabilities who were not able to get to healthcare facilities during the COVID-19 pandemic.

Provisioning of PPE was mentioned a number of times as being vital:

*Give adequate support and free PPEs to persons with disabilities.*

*Specifically including people with disabilities in the emergency planning, PPE provision. We are talking about millions of families affected by disability This is not a minority population! Over eight million individuals with approximately four family members each.*

Participants who were Deaf mentioned the need for SASL interpreters being available in healthcare facilities:

*Having interpreters available on site at hospitals or at least available immediately online via WhatsApp video call etc. to assist in communicating with medical personnel will be such a great help when we get to medical facilities on our own the personnel do not understand what we say nor do we understand them or the doctors. Training ER medical personnel with basic Sign Language will also be good.*

A participant saw the need for provisioning of resources across all areas:

*As part of the disability community, I hear the experiences of others less fortunate than myself. It is simply shocking.*

## **5.5 Providing accessible COVID-19 information and support**

Other participants felt that government should have targeted persons with disabilities and provided them with more COVID-19 related information and support:

*Maximising communication and providing measures to approach persons with*



*disabilities. Especially during hard lockdown when movement was restricted. More online information and guidance if you find yourself stranded with a disability.*

*We need to workshop or receive training to educate people with disabilities about COVID-19, or any general disease.*

Another suggestion was to develop a database of persons with disabilities:

*An up-to-date registry of people with serious disabilities living alone, with adequate social-work follow up and support.*

Many participants with hearing impairments focused on ensuring that information was accessible. Participants who relied on lip-reading highlighted the need for subtitling during broadcasts:

*Ensuring that information is accessible to all persons with disabilities. For example, persons with hearing loss not using SASL were excluded from information as no subtitling/captioning was available. This still continues despite ongoing complaints.*

Participants who are Deaf shared:

*Being Deaf, having interpreters on TV and social media every time new information becomes available or when government makes announcements will be a great help to us.*

## 5.6 Higher level recommendations

### **a) Consultation and participation of persons with disabilities (Self-representation)**

- In accordance with the internationally adopted disability slogan ‘nothing about us without us’, it is recommended that persons with disabilities must be fully consulted and involved in all government planning processes, policy development and decision-making structures established to manage current and future national disasters
- Relationships need to be built and maintained with DPOs and NGOs supporting persons with disabilities

### **b) Safety and protection of persons with disabilities**

- It is recommended that the safety and protection of persons with disabilities



is prioritised during the state of disaster and situation of humanitarian emergencies

- Prioritise safety and protection of persons with disabilities especially in institutional settings and care centres
- Prioritise safety and protection of women and girls with disabilities experiencing gender-based violence during the state of national disaster

### **c) Accessibility to government services, information and communication, and public environments**

- It is recommended that government must ensure access to basic services, information and communication, and access to identified screening and testing sites, quarantine and isolation sites for all persons with disabilities during the national state of disaster
- Information and communication must be made available and be offered in all accessible formats to all persons with disabilities (braille, audio-visual, large prints, electronic and print media, social media, online education and training, sign language interpretation services, close-captioning, subtitles etc.)
- Department of Cooperative Governance and Government Communication Information Services must set aside a budget to ensure that all national/public briefing platforms on national disasters have sign language interpretation services, close-captioning and subtitles for persons with disabilities

### **d) Access to employment and economic opportunities**

- It is recommended that government must ensure that persons with disabilities benefits equally to all announced employment and economic relief measures during the national state of disaster
- Employment environments need to provide reasonable accommodations to those that require it, especially to those with comorbidities

### **e) Access to social services**

- Provisioning of psychosocial support services
- Provisioning of social grants and social relief of distress
- Provisioning of food parcels

### **f) Access to health**

- Provisioning of PPE
- Screening methods and procedures must be accessible

- Healthcare information must be accessible
- Transportation barriers need to be addressed

#### **g) Access to education**

- Accessible online education including assistive devices, data and devices
- Prioritise special schools and school hostels
- Safety and protection of learners

#### **h) Having disability-specific desegregated data**

- All government departments need to obtain specific disability data in order to develop evidence-based and appropriate interventions and support

#### **i) Benchmarking and partnerships**

- Establish partnerships and benchmark on international and continental disability practices and interventions





# 6 CONCLUSION

# CONCLUSION

According to various national and international policies on the rights of persons with disabilities, persons with disabilities should have access to healthcare, education and employment opportunities, and during periods of healthcare emergencies and pandemics they should be protected and accommodated (UN, 2020; WHO; 2020; DSD; 2011). Even when the world is not experiencing a global pandemic, persons with disabilities have greater healthcare needs and are more likely to experience poor health compared to persons without disabilities (Ned et al, 2020). In order to provide relevant and suitable accommodations and healthcare, persons with disabilities and their representative organisations need to be consulted and involved in all plans and policies (McKinney et al, 2020). This is true at all times, and it becomes even more urgent when the world is facing a healthcare crisis on the scale of the COVID-19 pandemic.

The voices of persons with disabilities need to be heard to ensure that their human rights are not overlooked or excluded during future pandemic provisioning. The findings from this study showed that while there were a few positive stories and experiences shown during the COVID-19 pandemic in South Africa, the rights of many persons with disabilities are being denied or limited. These include the rights to healthcare, communication, education, safety and security, and employment.

This was evident in the difficulties participants faced in following mandatory COVID-19 guidelines such as social distancing and wearing of PPE; accessing healthcare including therapy, medication, specialist care and assistive devices; communication and care from healthcare workers; accessing education for children and students with disabilities, especially those enrolled in special schools and in school hostels; being able to access COVID-19 information, social services, and safety and security; employment opportunities; and in the lack of consultation and involvement in COVID-19 design and implementation programmes and policies, including quarantine and isolation sites and other COVID-19 specific facilities.

The limiting or denial of these rights is in direct contradiction with the Bill of Rights found within the Constitution of the Republic of South Africa, which states that all persons have equal rights to among other things, healthcare, education and employment. It is also in direct contradiction with the UNCRPD, which South Africa has signed and ratified.

The stories provided in this study need to be read and acknowledged, and government departments need to understand the many challenges, some of which are life-threatening, that persons with disabilities face. Government departments need to consult with persons with disabilities as they implement strategies to accommodate persons with disabilities. This will help to ensure that they have human rights on a par with those of persons without disabilities.





# **7** STUDY STRENGTHS AND LIMITATIONS







# 8 IMPLICATIONS OF THE STUDY

## IMPLICATIONS OF THE STUDY

Discrimination in accessing health, education, information, social services, safety and security, livelihoods and economic opportunities, participation and consultation, as well as access to quarantine and isolation sites and other COVID-19 specific facilities are global issues with life-threatening consequences.

It is hoped that the findings will provide policymakers and other stakeholders in South Africa and around the globe with an awareness of some of the needs of persons with disabilities in future pandemics, as they highlight the need to include persons with disabilities in all future policy and procedure decision-making. This is in line with the disability movement's slogan, 'Nothing about us without us', which is especially pertinent considering that the implications of such decision-making can have life and death consequences.



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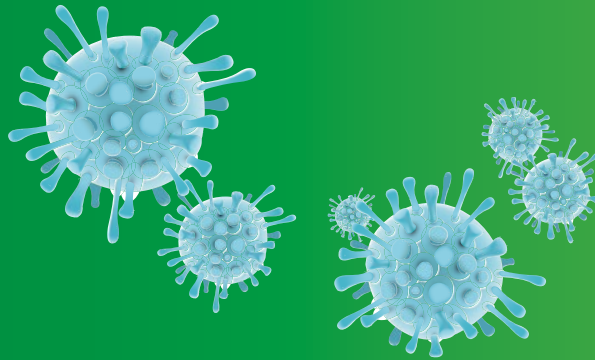






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