

Literature Review to Support a Survey to Understand the Socio-Economic, Wellbeing and Human Rights Related Experiences of People with Disabilities During Covid-19 Lockdown in South Africa

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Abstract

The COVID-19 pandemic and associated national responses have had ramifications for societies around the world, including South Africa. The marginalisation of people with disabilities is well documented in pre-COVID times, and emerging evidence suggests that the crisis has made this worse, as well as presenting new challenges for people with disabilities. This paper presents a review of published research and grey literature of relevance to the proven or anticipated socio-economic, wellbeing and human right related impacts of COVID-19 on people with disabilities in South Africa and other contexts. Its purpose is to summarise evidence to inform a study on the experiences of South Africans with disabilities during the COVID-19 pandemic and the development of an improved inclusive framework for future management of such crises in South Africa.

After a brief introduction, the paper is structured around four main sections. Context is provided by considering COVID-19 and disability both globally and in Africa. Then the literature focused on Humanitarian Disaster Risk Reduction and disability inclusion is discussed. Finally the South African policy and legislation environment on disability and humanitarian action is explored.

The review finds that globally there is a limited but growing body of work on COVID-19 and disability. There is a particular dearth of evidence focusing specifically on Africa. The evidence that does exist tends either to be focused on a few particular countries or form part of large global surveys. Much of the global level grey literature published early in the pandemic and subsequently anticipates exacerbated negative experiences for people with disabilities, including exclusion from services, stigma and discrimination and lack of inclusive approaches to relief and support by governments and others. Advisory materials, sometimes focussed on specific subgroups, are generally in agreement about calling for a universally inclusive and disability aware approach to pandemic mitigation across settings and sectors. The limited primary research on COVID-19 and disability is mostly focussed on high income settings and or populations with particular health concerns.

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Introduction

The purpose of this review is to provide a context for the survey research being undertaken, as part of research funded by the United Kingdom Research and Innovation Newton Fund, to gather the experiences of South Africans with disabilities during the COVID-19 pandemic in 2020-2021. It will give the research team background information to inform interpretation of the results and so deepen and support our analysis. It will also inform the recommendations made and the advocacy plan which will follow the survey analysis and the subsequent lobbying with the SA government to enhance the inclusivity of the existing framework, a need that has been identified.

The study and this review are underpinned by the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN 2007) which seeks to, “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UN 2007, 5).

The review identifies global, African and South African published and grey literature, including conceptual and empirical research on socio-economic (not clinical) impacts of the pandemic on people with disabilities, as well as advisory and advocacy material related to disability and COVID-19. It also reviews Inclusive Disaster Risk Reduction (IDRR) materials and South African policies, laws, regulations and other materials from relevant non-government agencies.

We draw on resources from a range of disciplines including international development, health, psychology, law, anthropology, economics and disability studies.

The main sections review:

- Global research on socio-economic impacts of COVID-19 on people with disabilities;
- Global grey literature and material predicting impacts and advising on mitigation and action for people with disabilities during pandemics
- The intersection of disability and COVID-19 in Africa
- Disability and inclusion in humanitarian relief and action in disasters and emergencies
- The intersection of South African policy and legislative environment on disability, disaster risk reduction and humanitarian action

The need to improve the South African framework for an inclusive approach in humanitarian action contexts to ensure that people with disabilities are not overlooked

Methodology used in the review

This is not a systematic review, but a broad scoping of published and grey literature in the different areas outlined above. A formal systematic review with very strict inclusion and exclusion criteria is unsuitable here, because of the very recent emergence of the pandemic and its sequelae, its current ongoing nature and because material from a vast array of formal and informal sources about it is constantly emerging. A huge amount of material is being produced, in different formats and for specialist and non-specialist audiences. Peer

reviewed material is being published but there is probably a larger volume of grey literature written by disability and development actors and agencies, including various representative and advocacy groups.

Of course, some material on South African disability policies and on the inclusiveness or lack thereof of humanitarian/disaster risk reduction guidelines and actions predates the pandemic, so some sources are older. However, we have chosen mainly not to include material from before the launch of the UNCRPD (UN 2007) as this is seen as the key global tipping point in relation to disability awareness and inclusive policies and practices.

At the time of writing (Nov 2021) many countries are still in a first, second or third wave of infection and some are expecting a further wave. Vaccinations are being rolled out in some countries but not all, and long-term impacts of the pandemic are not possible to understand clearly yet, either from the clinical or socio-economic perspective. Where the whole scenario is only about 18 months old, the first writings are bound to be suppositions about impacts on different sections of the population, and recommendations for action and mitigations based on these predictions from various interested parties.

Initial theoretical and conceptual discussions often emerge early and empirical evidence follows data has been collected. Thus, with time lags in publication and the initial need for resources to be directed toward the acute need to deal with the infection itself and mitigate its most severe effects, reflection and research on longer term impacts and especially effects on marginalised groups are often not prioritised. In the context of a pandemic where all populations are affected, research about and with people with disabilities is unlikely to be foregrounded, as they continue to be a forgotten group, even though they are one of the largest minority groups in all societies.

Our approach to this scoping review has been to use standard academic and other grey databases using key words: COVID-19, coronavirus, pandemic, disab, impairment, impacts, disaster risk reduction, policy, legislation, regulation, mitigation, global, Africa, South Africa. In each section a different combination of these was used as appropriate to the subtopic. In addition searches of key international and national agencies and organisations, snowballing and handsearching was used to identify further grey literature. Material was also sourced from multiple networks that team members are engaged with during the pandemic. We hope that our comprehensive and unrestricted search strategy will have identified most of the available and relevant materials but we do not claim that it is exhaustive. Additionally, as some is grey literature and as such has not peer reviewed, it is of varying quality and style. Nevertheless, at this stage it is deemed appropriate to use an extensive and all-encompassing approach to searching and review, rather than a selective one.

We have only reviewed material in English. Lastly, exceptions to our broad search strategy are that as the study is about understanding the socio-economic, wellbeing and human rights related experiences of people with disabilities during Covid-19 lockdown in South Africa, we have excluded pure clinical research about the coronavirus disease itself from our review. We have also chosen not to review in detail material about vaccine rollout, as this is

not directly relevant to the development of the South African disaster framework and is only being addressed lightly in the survey tool.

Global research on COVID-19 and disability

Research about the COVID-19 pandemic is being produced at a fast and accelerating rate as research groups globally chose to focus on a vast array of diverse and specific aspects, ranging from regional or national foci, clinical and or socio-economic and critical aspects, and also investigation of the impacts on particular demographic groups (e.g. women, children, elderly, refugees, different countries and regions) (UN Women 2020; WEI 2020; UNICEF 2020; UN OCHA 2020; PAHO 2020; Hillgrove and Pryor 2020; Jalali et al. 2020). This huge volume of publishing on diverse aspects of the pandemic echoes the flood of publishing around the HIV/AIDs pandemic during the 1980s to 2000s (although this was over a more protracted period), and more recently in relation to the Ebola outbreak in West Africa (WHO 2021).

It is being recognised that as with other pandemics the impacts of COVID-19 on populations globally are far-reaching and not equally spread (Rohwerder 2020). Often the poorest and most disadvantaged are disproportionately affected during these crisis situations, even though in some countries systems and structures are already progressive in trying to counteract such existing disadvantages.

The descriptions of COVID-19 as the “great equaliser” are not quite right, for the illness is hitting some people harder than others. The disease spreads faster in places where social distancing is an impossibility. Its collateral damage is hardest on those with low income. COVID-19 seems to be widening, not narrowing, racial and ethnic health disparities caused by longstanding systemic inequities (Choo 2020: 1333).

We could add to this quote that disparities for people with disabilities are similarly widening and disadvantage seems to be exacerbated for them as the pandemic unfolds.

Literature focussed on the risks, concerns and experiences of people with disabilities is rarer than for general populations, though it is increasing (Brennan et al. 2020; Rohwerder et al. 2021a; Wickenden et al. 2021b; Meaney-Davies et al. 2020; IDA 2020d). This smaller body of knowledge about disability compared with that on general populations, echoes the ongoing pattern of a persistent lack of research about the lives of people with disabilities in general or in particular circumstances. We see regularly that topics that are regarded as of major importance in relation to nondisabled or ‘mainstream’ populations are often not explored with people with disabilities (Kuper and Heydt 2019; Meaney-Davis et al. 2020; Scully 2020; Singh 2020). For example, the predicted increase in gender-based violence within all populations seems to be mirrored for women and girls with disabilities (Pearce 2020). However they are a group about whom data is often just missing (Goyal et al. 2020; Kuper et al. 2020; Kubenz and Kiwan 2021). We see this disproportionality in exploration of key development topics such as: poverty, work, nutrition and many other arenas. Some authors from within the disability movement, or their allies, propose that this lack of attention to people with disabilities’ lives and situations is indicative of historical and current devaluing of them and is rooted in still prevalent ‘medical models’ of disability which only pay

attention to impairment related aspects of people's lives (WEI 2020), rather than seeing this large minority as people with the same needs and rights as others as well as some specific ones (UN 2007). In some cases these omissions are likely to be through lack of awareness about the size of the disability population as a significant minority in any community. The WHO global ballpark figure is 15% of the population as having a disability, although this is now disputed, and the figure found in prevalence studies depends on measurement methodologies used. A more realistic figure may be about 10-12% in many countries (WHO 2011; Washington Group 2019). In South Africa, policy documents and studies indicated that the official prevalence of disability at around 7% (STATSSA 2014) was more likely to range from 12 to 20 percent (DSD 2016a; NDoH 2019), depending on willingness to report disability, limiting effects of disability and the understanding of the questions related to disability or impairment.

There is now emerging evidence about increased actual clinical risks of COVID-19 for people with impairments, for example for people with certain conditions (people with respiratory illness or who are immunocompromised, those with mental health conditions or intellectual impairments). Thus some individuals with disabilities have increased health related vulnerabilities. There is a growing body of research about the risks for and impacts on people with specific health conditions or impairment groups and on reported discrimination and deprioritisation of some people in relation to treatment and vaccination in various countries (Ahmad et al. 2020; Scully 2020; Turk and McDermott 2020; ONS 2020; Rotarou et al. 2021; Shakespeare et al. 2021).

Additionally, increased vulnerability, because of the continued poor access of people with disabilities to healthcare is now more recognised, irrespective of increased clinical need (Hashemi et al. 2020; Naami and Mfofo-M'Carthy 2020), although the concept of vulnerability remains a contested and shifting area (Ahmad et al. 2020). Evidence about reduced or unequal access to their usual health care and rehabilitation services during the pandemic is also noted in various countries and regions (Negroni et al. 2020; Hartman 2020).

There is evidence emerging about the social, emotional and financial impacts of the pandemic on people with disabilities in a variety of contexts. However, there is more focussing on high income settings such as the United States (US) and Europe and this is arguably of limited value when considering impacts in middle- or low-income settings such as Africa (Boyle et al. 2020; Kendall et al. 2020; Lund 2020). Data on the experiences of people with disabilities of COVID-19 in middle- and low-income countries is still mainly lacking, though beginning to emerge (Ahmed et al. 2020; Banks et al. 2021; COVID-19 DRM 2020; Christensen et al. 2020 a & b; Kubenz and Kiwan 2021; Rohwerder et al. 2021 a & b; Shaw et al. 2021; Thompson et al. 2021; Wickenden et al. 2021b).

Despite the majority of the studies focussing in the so-called 'Global North' (Rotarou et al. 2021), some findings may be of relevance, especially as South Africa is a middle-income country with a huge disparity of wealth and service provision, and a unique socio-political and economic history. It has some features of high-income countries and some of middle

and low-income contexts with a Human Development Index of 0.707 and is ranked 114 in the world (UNDP 2020).

It is perhaps inevitable that clinical research will emerge first and have greater prominence during a new disease outbreak and in response to the urgent need for better understanding of the illness itself and potential prevention and cure. However, calls for social science research and exploration of less obvious, longer term and more insidious impacts are emerging. Seeking out people's individual perspectives by asking people directly about their experience is thus important. The UNCRPD (UN 2007), articles 3 and 4.3, is explicit in setting out an obligation of state parties to facilitate the participation of people with disability in research, development programmes and policy making.

The following sections provide an overview of some emerging research on the impact of COVID-19 on disabled people. This is divided into quantitative and qualitative studies, although often there is an overlap between these methodologies. Some purely theoretical or commentary material is included.

Quantitative studies on COVID-19 and disability

Several predominantly quantitative studies focussing on people with disabilities' experiences of COVID-19 have been undertaken, aiming for global data from multiple countries or targeting particular regions or countries. Brennan et al's. (2020) study undertaken within the Disability Rights Monitoring programmes has testimonies from 134 countries. However the number of respondents in some countries is very low.

Other surveys look at specific aspects, for example accessibility of COVID-19 information. Fernandez-Diaz et al. (2020) show that the COVID-19 guidance on the WHO website is not sufficiently accessible for people with a range of impairments. Similarly Yap et al. (2020) looked at sign language interpretation (SLI) at press briefings on COVID in 123 low- and middle-income countries and found that only 65% provided SLI support. They also found that international organisations such as WHO were similarly lacking.

The World Blind Union (WBU 2020) conducted a global survey in collaboration with key stakeholders. 853 people from 75 countries participated. They identified barriers related to transportation and mobility, independence, autonomy & dignity, mental health & wellbeing, accessibility, health, physical distancing, attitudes, and inequitable policies and practices.

The ILO (2020b) have conducted 2 surveys on disability inclusion in response to COVID-19. They surveyed National Business and Disability Networks (BDNs) and companies who are members (159) across 22 countries. This showed varying levels of employer awareness and inclusive action in relation to their employees with disabilities and variation across regions. 31% of companies felt that their disability inclusion activities would be affected by COVID-19 and a further 31% didn't know. The report points out that often people with disabilities are the 'last in and first out' of employment so this is worrying, for them when contemplating finding or resuming work as things return to a 'new normal' post the pandemic. The risk is that gains in inclusivity that have been made before will be lost.

The question of how people with disabilities are identified or described (or self-identify) in surveys is important. The Washington Group suite of tools for determining risk of disability through measurement of types and severities of functional difficulties promotes the wide use of their tools during COVID-19 related data collection. This should enable disaggregation of data to show impacts on different subsets of the population and comparison with others (Washington Group 2020).

A US team have developed a 34-item 'COV-DIS' survey tool, developed by expert group consensus and so far it has been used just in the US (Bernard et al. 2020). It has a mainly public health perspective though it does ask questions about work, lifestyle etc. Whether this would be applicable in other cultural contexts is unclear.

Qualitative studies

Qualitative studies have been carried out on the impacts of COVID-19 in various geographical contexts and with diverse groups of people identifying as disabled, their organisations and allies. Again there is more research focussing on high income countries than low or medium, but some studies do look at these settings. Useful thematic overviews of the literature so far have been produced and these demonstrate that the volume of information on disability related issues is increasing (e.g. Kubenz and Kiwan 2021).

Empirical studies and more informal evidence collecting projects have used various qualitative methods and approaches to explore people's experiences. These vary from predominantly quantitative surveys with some free text opportunities, to structured, semi-structured or narrative interviews and case studies. Some have collected information on pre-set deductive categories or themes, whereas others have been more participant led and inductive. Sometimes the method of analysis is unclear.

The international disability alliance (IDA) carried out a short qualitative study in 2020, asking disability movement leaders globally for their perspectives and subsequently focussed on 3 countries: Bolivia, Bangladesh and Nigeria. This was around policy and programming across sectors and with links to the 2030 agenda for sustainable development (SDGs) (Stakeholder group of persons with disability for sustainable development, 2020). IDA has also been active in collecting stories and other data on people's experiences in multiple countries and has used this evidence in collaboration with others to lobby key organisations for a more inclusive approach to pandemic responses (WHO 2020 a & b).

The Institute of Development Studies (IDS) carried out a series of 135 online/phone narrative interviews in Nepal, Bangladesh, Uganda, Kenya and Nigeria, using a narrative approach asking the interviewees to prioritise what is most important to talk about while telling their story (Wickenden et al 2021a, Rohwerder et al. 2021a; Shaw et al. 2021; Thompson et al. 2021). Each person was interviewed twice with a 2-month interval to provide a picture of the progression of the situation for them over time. The choices the participants (gender balanced and with a range of impairments) made about what to report were surprisingly similar across the 5 countries. They emphasised the psychological impacts such as stress and shock, worries and fear about the future (e.g. about work and education), about safety, health and catching the virus, about financial security and family life, poor

access to information and support, and whether things would ever return to an old 'normal'. They consistently reported government responses not being disability inclusive enough, and their reliance on informal support and on INGO or OPD relief. Positive aspects were the gradual adaptation and resumption of education and work and in some cases new educational and employment initiatives and opportunities arising over time. Yet, many felt that as a person with disabilities their situation was worse than that of others and expected things to continue to be bad.

We can see here and elsewhere the impact of cumulative intersectional disadvantages, such as the combination of gender (being female), disability (including type and severity of impairment), rural location, socio-economic status, education level and other factors working together to worsen impacts for the already most excluded and marginalised individuals or families.

Some studies have focussed on particular impairment groups or sectors, for example Giebel et al. (2020) look at the impact of the closure of social support services on people with dementia and their carers in the United Kingdom.

Banks and Hameed (2021) explored through in-depth in-person interviews, the COVID-19 experiences of 60 people with disabilities and some key informants in 6 countries (Ghana, Zambia, Bangladesh, India, Zimbabwe and Syrian refugees in Turkey). They asked about health and economic other impacts and set out to evaluate levels of inclusivity in the various activities.

As well as doing research with people with disabilities themselves, there are examples of document research on policies and practices in particular contexts. For example Sakellariou et al. (2020) focused on the contexts of Argentina, Brazil, Chile, and Peru.

As well as talking to individuals with disabilities, there has also been exploration of the perspectives of organisations of people with disabilities (OPDs) and their involvement in relief and support for their local communities (Christensen et al. 2020 a & b; Ahmed et al. 2020). The International Disability and Development Consortium (IDDC) commissioned work exploring their members', (INGOs), experiences in responding to the needs of people with disabilities in their programmes (Bhakta 2021).

Qualitative studies focussing on specific countries rather than having a multiple country or global reach include Mathias et al. (2020: 232) in Northeast India, where they found

“people already disadvantaged by their social identity and structural exclusions are more likely to experience further social exclusion, greater health needs, reduced access to care and ultimately, worse outcomes in the COVID-19 crisis, which has acted as an inequality amplifier”.

These authors and others point to the need for an intersectional approach. The Indian government only collects data on age and state so cannot identify intersecting social disadvantages that might be revealed if other aspects such as disability status, caste, or religion were recorded. Shakespeare et al. (2021) make a similar point about 'triple

jeopardy' (the intersection of race, age, gender, or social class). Qualitative studies can play an important role in bringing out data that illustrates these complexities.

Smaller studies in the form of case studies are also interesting and illustrative of the increased difficulties brought to people's already precarious lives. Gahatraj (2020) provides a poignant example of the exacerbated disadvantage that COVID-19 has had for already excluded groups, in this case the Dalit community in Nepal. Some studies have focussed on particular issues such as health, financial or socio-economic impacts (HI 2020a; Meaney-Davis 2020) or even more specifically on the effects of social isolation (Castres and O'Reilly 2020).

Finally, it is important to recognise the contribution of more conceptual, theoretical work that is being done, which does not necessarily draw directly on new empirical data but explores difficult and controversial concepts that are pertinent to disability. For example, the language used (and hence the underlying assumptions revealed) when discussing prioritising people for treatment or vaccination. For example, how does the use of the words like 'normal' or, 'quality of life' or 'vulnerable' affect decisions that are made and services that are offered or declined for particular individuals (Scully 2020; Ahmadet al 2020)? People may be devalued or dehumanised by some of the vocabulary used, for example talking about people with 'underlying health conditions' (Abrams and Abbott 2020). There may be an implicit judgement made about the value of that person and their entitlement to use scarce resources. It is suggested that some deprioritising of people purely based on their disability contravenes their equal rights under international conventions and national antidiscrimination laws (Sabatello 2020).

Grey literature on predicted risks for people with disabilities - advice and mitigation actions

During the early months of the pandemic when the likelihood of it affecting all countries and communities began to be understood, many UN agencies, NGOs and others, produced predictive, guidance and mitigation documents for the general public and or various specific populations. Generic guidance, not focussed on disability, includes that from: WHO (2020a & b), OHCHR (2020), and ILO (2020a & b). More specific examples focus on children (UNICEF 2020) and women (UN Women 2020) or are targeted to particular services or sectors such as social protection (Banks et al. 2021) or water, sanitation and hygiene (WASH) (Nath and Gosling 2020; Water for Women et al. 2020). These of course overlap with each other, and some do address disability inclusion as part of this general advice.

Various advocacy groups for specific populations, including disability focussed INGOs and OPDs quickly produced documents underlining the likely increased risks for people with disabilities and also disseminated guidance on disability aware inclusive practice that should be implemented in different contexts (Pregel and Le Fanu 2020; IDA 2020; Inclusion International 2020; Hartley and Balakrishna 2020; ILO 2020a; UNCRPD committee 2020; UNPRPD 2020). Some documents are in nonprint formats, e.g. through videos and radio programmes (Light for the World 2020). All emphasise the rights-based arguments that people with disabilities have the same rights as others to protection, treatment, relief,

vaccines, etc. and may need adapted methods of information sharing, and services in order to access these (Castres and O'Reilly 2020). At the time of writing, these documents were mainly not based on empirical research as this was not available but were predictions and assumptions drawing on these organisations' previous knowledge and experience of disability related risks and the likelihood of COVID-19 compounding these.

Grey literature commentaries have also included particular critical or ethical, anthropological and epistemological stances such as feminist perspectives on the pandemic (GADN 2020; Bell 2021; Singh 2020) and ontological questions around the value of different people's lives (Goggin and Ellis 2020). These perspectives expose many ableist assumptions about what 'normal' means and how people with disabilities are often judged not to comply with such assumptions and how this may lead to discriminatory decisions about access to services and the value of people's lives.

People with disabilities themselves and their organisations have been active in lobbying for more information and increased awareness of the increased risks for and potential discrimination against them during a pandemic and for example in the UK are arguing for a specific inquiry into this (Webster 2020; Dror et al. 2020; Courtenay and Cooper 2021).

Advisory material which focuses on the extra risks and particular needs for people with disabilities have been produced by many different groups focussing either on disability generally (IDA 2020; IDA and IDDC 2020) or on specific impairment groups (e.g. psychosocial disabilities (WNUSP 2020), intellectual impairment (Inclusion International 2020; Courtenay 2020), children with disabilities (Leonard Cheshire 2020), and blind people (WBU 2020a). The focus has extended to particular situations such as those living in institutions (Ryan and El Ayad 2020). There are also regional resources, for example in Australia, Europe, Africa and Latin America (Madou 2020; CAN 2020; ECLAC 2020), which provide guidance based on those legislative and cultural contexts or in accessible formats. This material is sometimes targeted towards individuals and families' needs and sometimes to organisations of people with disabilities or service providers, such as community disability/rehabilitation workers (Hartley and Balakrishnan 2020) or to policymakers and implementers (Kavanagh 2020).

Some resources focus more on the need to ensure that short term, emergency actions and mitigations and acute responses are disability inclusive. Others also or separately address the need for longer term planning for accessibility and inclusivity as the after-effects of the pandemic evolve. Some additionally focus on planning for future possible crises, whether these are pandemics, natural disasters, or other crises. Advisory material about disaster risk reduction and disability is discussed later in this review.

As research is increasingly carried out with various populations and subpopulations globally on the impacts of the pandemic, it is anticipated that more data will be collected on the impacts on people with disabilities, in different contexts. So, the body of knowledge based on research will grow over time. The grey literature described here will then be more clearly informed by experiential and empirical data from sub-sections of the population.

Below is a compilation of some of the key points made in the advisory documents mentioned above about anticipated increased risks for people with disabilities and

suggested mitigations and actions. This is not an exhaustive list but gives a flavour of the types of risks and assumptions predicted and suggestions for types of actions proposed, depending of course on the particular impairment or other identity group producing the materials. There is a great deal of overlap and commonality between the various advisory documents from UN, INGO, disability/impairment related organisations and OPD bodies.

Increased risks or challenges for people with disabilities

- Clinical vulnerabilities are linked to underlying health conditions (including some chronic respiratory, metabolic and or degenerative conditions and musculoskeletal conditions such as cerebral palsy, as well as more commonly mentioned risks such as diabetes, heart disease, autoimmune conditions and others) – increased risk of severe illness and complications if COVID-19 is contracted.
- Social vulnerability - Pre-existing marginalisation and discrimination which may be exacerbated due to lack of access to services during an emergency, including possible deprioritising of people with disabilities for services such as emergency healthcare, vaccination and relief (e.g. food, hygiene products, psychological support, physiotherapy, etc.).
- Pre-existing poor access to health and education.
- Pre-existing multidimensional poverty (exacerbated by loss of income and increased costs during crises, including direct disability costs).
- Intersectional disadvantage – such as gender, age and disability status and other factors compounding each other in negative ways.
- Difficulties with maintaining social distance because of need for support (e.g. for blind people), or because of lack of understanding of the need for distancing (some people with intellectual, communication and psychosocial impairments).
- Difficulties complying with additional hygiene measures such as increased handwashing, wearing a mask etc (due to physical difficulties, lack of facilities or lack of understanding of the need).
- Pre-existing lack of social support networks which could be called upon to help in a crisis.
- Increased financial pressure because of increased costs e.g. of food and transport.
- Loss of usual carer support (e.g. if carer has COVID and/or won't do normal support role because of concerns about infection—either becoming infected or infecting the cared for person).
- Rumour, misinformation and suspicion about people with disabilities being more infectious or more susceptible because disability is often seen as a weakness.
- Increased psychological stress and anxiety – can exacerbate pre-existing mental illness or increase additional emotional stress.
- Potential increase in conflict, violence and abuse both within the home and outside due to increased stress, financial worry, everyone being at home, lack of social support, increased discrimination and exclusion –possible exacerbation of the higher levels of abuse and violence generally experienced by women and girls with disabilities.

- Lack of consultation with people with disabilities or forward planning for inclusive responses to disasters and emergencies including pandemics. This can include lack of inclusion into appropriate post-COVID recovery plans.

Recommended ways to provide a disability inclusive response

- Ensure representation of and consultation with OPDs – e.g. involvement in all regional, national and local government COVID-19 response coordination meetings in emergency contexts and also in future planning forums.
- Public information to be provided in more than one sensory channel e.g. visual and audio and also in captioning, pictorial and easyread version for equitable access to all, with clear unambiguous and inclusive messaging.
- Use of universal design when producing communication materials.
- Ensure that essential services such as healthcare and rehabilitation are open and accessible to people with disabilities on an equitable basis.
- Specific recognition of additional social protection and relief needs for people with disabilities and their carers/families, making sure that access to these is inclusive.
- Recognition of the need for additional community support close to home and inclusion in all relief activities in accessible venues.
- Priority access to food and essential item shopping, etc. for people with disabilities
- Inclusive approaches to online provision of services /social support, education and work.

Examples of two specific advisory documents one from IDA and one from the World Network of Users and Survivors of Psychiatry are provided in the appendices.

There are various global, regional and national lobbying campaigns around disability and COVID-19 responses, which call for inclusive approaches to all activities related to managing and mitigating pandemics effects. For example, the International Disability and Development Consortium (IDDC) worked closely with WHO to ensure that their resolutions at the World Health Assembly in May 2021 were aligned to the UNCRPD and called for health systems strengthening to be disability aware when planning to ‘build back better’. UNESCO in collaboration with UNPRPD have produced a comprehensive resource to inform governments on policy responsiveness for inclusivity (UNESCO & UNPRPD 2021).

A short note on vaccination for people with disabilities

We will not discuss vaccination in detail in this review, as it is only briefly explored in the survey, however disability advocates and allies are lobbying to ensure that people with disabilities are not disadvantaged or deprioritised in receiving COVID-19 vaccines. There is evidence that this may have happened in some countries, or that only those with particular types of impairments or health conditions have been offered vaccines as a priority group. In the US, the Johns Hopkins Disability Health Research Center (JHDHRC) has created the COVID-19 Vaccine Prioritization Dashboard for People with Disabilities in collaboration with the Center for Dignity in Healthcare for People with Disabilities (CDHPD). This tool compiles COVID-19 vaccine prioritisation information across the states but may not be applicable in other contexts with different health care systems without adaptation (Epstein et al. 2021).

Globally, the IDA/IDDC campaign argues that people with disabilities should indeed be prioritized in a spirit of 'reaching the furthest behind first', developing a lobbying toolkit (IDDC statement for UNCRPD 25th session). WHO have also produced guidance on COVID vaccination and disability (UNICEF 2020a; WHO and UNICEF 2021).

African research on COVID and disability

Research about the impacts of COVID on people with disability in Africa has been relatively scant and is concentrated in a few countries. Where INGOs are actively working on disability, some have undertaken their own research (Christensen et al. 2020 a & b; i2i 2020). Universities with a speciality in disability have also undertaken both quantitative and qualitative work (McKinney et al. 2020; McKinney et al. 2021; Ned et al. 2020). Other data on Africa has been collected as part of larger global surveys (Brennan et al 2020)). The extent to which a disability aware perspective has been employed within broader COVID-19 research in Africa is difficult to determine to date.

Health services

For people with disabilities, access to health services and medicines during the pandemic was a challenge in many countries in Africa, due to a number of factors including increased cost of transport and other restrictions. A lack of accessible transport, remote rural living, and loss of personal assistance during the pandemic made access to services difficult. Evidence from South Africa suggests a shortage of medication and restrictions imposed on the number of items that could be purchased with no acknowledgement of the needs for certain categories of people also was a challenge for people with disabilities. In Zimbabwe, the cost of medicine was prohibitive and many pharmacies demanded to be paid in dollars (Brennan et al 2020). In Botswana, some people with disabilities were found to be more vulnerable to exposure to COVID-19 due to the need for ongoing support, rehabilitation therapy or regular healthcare treatment (UN Botswana 2020).

Similar lack of access to health and rehabilitation services and medication was found in Uganda, in part due to the lockdown and ban on public transport. Some caregivers also reported poor health and a lack of access to health care services themselves. Others were concerned about contracting COVID-19 in hospitals as they re-opened, so they avoided going (Mbazzi et al 2021). Also in Uganda, it was reported that people with albinism in particular faced challenges accessing the health care (e.g. skin care products) they required (IDA 2020 d). Others have highlighted difficulties with access to assistive technology during the pandemic across many countries (Smith et al. 2020)

In South Africa during pre-COVID-19 times people with disabilities often struggled to access healthcare in under-resourced areas. COVID-19 has increased the pressure on the health system, resulting in people with disabilities finding it even harder to access the medical care they need (Kathard, Padarath, Galvaan, and Lorenzo 2020). Where care is being offered virtually via the phone or internet, people with disabilities may not be able to access it due to a number of factors including a lack of awareness, language and communication barriers, cognitive and communicative impairments, dexterity challenges and technological challenges. Key disability-specific health services were not considered as essential services during the initial stages of lockdown, which had an impact on the health of people with

disabilities. De-prioritisation left some people with disabilities in South Africa without personal assistants and carers, assistive devices and technology services, rehabilitation services, therapeutic and developmental interventions, and without sign language interpretation services (Ned et al 2020). Other evidence from South Africa suggests that the government indicated that hospital triage should discriminate against COVID-19 patients with disabilities in the event of a shortage of hospital places (Brennan et al. 2020). A different policy analysis also came to the same conclusion - that current South African triage policies exclude many people with disabilities, especially those with physical disabilities (McKinney et al. 2020).

Thirty- nine percent of people with disabilities surveyed in Kenya reported experiencing disability discrimination, including exclusion from vital services. The sample was 312 people with disabilities but participants came from both Bangladesh and Kenya, so the actual number of people who experienced discrimination in accessing services in Kenya is not available (i2i 2020). Other evidence from Kenya indicates some services (such as psychiatric nurses) started to visit people with disabilities in their homes rather than in a hospital setting to avoid infection (Brennan et al. 2020). Hospitals are generally seen as places of potential infection.

People with disabilities were found to be more likely to be at risk from contracting COVID-19 in Lesotho (UNDP Lesotho 2020), Somalia, (HI 2020c) and South Africa (Maserame, Rumbold and Yah 2020). This increased risk was due to a number of factors including the need to access services, challenges associated with diagnosing people in care facilities, barriers to accessing health services and water sanitation and hygiene (WASH) facilities and a lack of accessible public health and COVID-19 communication.

Impact on mental health

There is increasing recognition of the impact of COVID-19 on people's mental health (Sale, Polyakov and Eaton 2020). A study involving 132 adults in Nigeria found that lockdown during COVID-19 was having a significant effect on anxiety levels. A significant and positive correlation was found between the pandemic and reported sleeplessness and anxiety. The lockdown is shown to have a negative impact on mental health in Nigeria (Afolabi 2020). Also in Nigeria negative impact of the pandemic on mental health was worse for women and girls (Joseph et al. 2021).

A Ugandan respondent to COVID-19 Disability Rights Monitor (Brennan et al. 2020) who is a representative of an organisation of persons with disabilities said:

“Due to isolation and social restrictions it has caused a lot of fear and psychological pain, anxiety, with uncertainty about what will happen next. This may culminate into an increase in mental breakdowns and increase in suicide cases.” (Brennan et al. 2020: 29).

Another Ugandan study found that the inability to access health care services caused parents with children with disabilities great distress as they noticed their child's health regress. Participants also reported emotional distress due to financial difficulties, home schooling, a lack of social support and not being able to attend funerals. Children with

disabilities also reported not being happy because they miss their friends and were unable to play (Mbazzi et al. 2021).

A representative of an OPD from South Africa expressed concern about the services available:

“Mental health services which are community based are not available, this put beneficiaries at risk of relapse” (Brennan et al. 2020: 5).

It is notable that this increased risk often comes from factors related to stigma and discrimination and a lack of accessibility and inclusivity in systems rather than because of increased clinical vulnerability, which is relevant for only a proportion of people identifying as disabled (Scully 2020). However, the interaction with poverty is important to remember, as we know that people with disabilities are disproportionately likely to be poor (Groce et al. 2011).

Public Information about COVID-19

Access to technologies including television, radio, or social media impacted how people with disabilities could receive information about the pandemic. Evidence from Ethiopia, Cape Verde, Malawi, Lesotho, Rwanda, and Zimbabwe suggests that information was inaccessible for persons with disabilities, particularly for those living in remote and rural areas, although respondent numbers were very small in these countries (Brennan et al. 2020; IDA 2020e; CAN 2020). There was concern expressed in South Africa that people with disabilities have little information on COVID-19, and the information that can be accessed does not result in people understanding the severity of the situation (reference). Fake news on social media has made the situation worse (IDA 2020c). In South Africa not all national televised broadcasts relating to COVID-19 had sub-titles, excluding people with hearing impairments (Hart, Msitshana and Bohler-Muller 2020; Ned et al. 2020). In Uganda, from a purposive sample of 40 OPD members, one in three reported not receiving the same COVID-19 information as people without disabilities (Christensen 2020a). Similar findings were reported in Botswana, where UN Botswana (2020) reported that people with disabilities may have unequal access to information on prevention and response measures as well as the services available. In Lesotho, limited access to information on prevention and assistance was reported to be a factor in increasing the risk of contracting COVID-19 for people with disabilities (UNDP Lesotho 2020).

However, some evidence suggests that information on COVID-19 was adequate and accessible. For example, in Uganda, a study involving 48 parents and their children with disabilities found that most were well informed about COVID-19 through various communication channels. Parents of children with hearing impairment and intellectual disabilities played an important role in translating or simplifying messages for their children (Mbazzi et al. 2021). Zambia provided sign language for all television updates from the Ministry of Health and the COVID-19 programmes. South Africa did the same but failed to provide captioning for the hearing-impaired non- Sign Language users (Hart, Msitshana and Bohler-Muller 2020). In Cote d’Ivoire, Ethiopia, Morocco and Namibia some information on COVID-19 is available in sign language. In Tanzania caregivers were educated about COVID-

19 to pass on the information to people with disabilities (CAN 2020). In Kenya, 89% of people with disabilities who were asked reported having access to general public information on COVID-19 (although the sample size is not clear) (i2i 2020). In Rwanda, sign language was used to improve accessibility of the information for deaf and hearing-impaired sign language users. The videos were shared using social media platforms and were designed to be as accessible as possible by using sign language and simplified formats (Brennan et al. 2020).

COVID related relief and support for people with disabilities

In South Africa, the government provided a stimulus package, including food parcels and a social relief from distress grant (SRD), but many people with disabilities did not receive this support (Ned et al. 2020). In Uganda relief support was found to exclude people with disabilities, with 70% of people with disabilities asked reporting not receiving the support needed to meet survival needs. Distribution methods were found to be exclusive of people with disabilities (Christensen 2020a). This may not be because of deliberate exclusion but the result of a lack of a disability aware approach to organising relief. In Mali, some efforts were made to supply people with disabilities with provisions during COVID-19, but there was still unmet need. The cost of travelling to the point of collection was a barrier for some people with disabilities. Also, as the distribution process resulted in people being crammed together, there was an increased risk of infection (IDA 2020b).

The global report COVID-19 Disability Rights Monitor study reported that Uganda, Nigeria, Kenya, Côte d'Ivoire, Tanzania, and Rwanda were among the countries with the highest percentage of respondents who reported no access to food (Brennan et al. 2020). Evidence from Botswana indicated that restricted movements were found to hinder people with disabilities from accessing some basic needs including food parcels (UN Botswana 2020)

Personal protective equipment and hygiene supplies

People with disabilities in Uganda reported being discriminated against and not receiving the same protection support (such as face masks and soap) as others (Christensen 2020a). In Kenya, it was reported that government mechanisms to supply personal protective equipment to people with disabilities were ineffective. As some people with visual impairments have a greater reliance on touch than other people, they were acutely affected by the lack of soap. Also, in Kenya, the masks being used excluded the deaf community who use lip-reading as a means of communication (Gathu 2020). This finding was consistent with another study that reported that over a third of people with disabilities surveyed in Kenya reported not having access to all the necessary personal protective equipment (PPE) for themselves, their families or support workers (i2i 2020). No further details were provided as to whether PPE was generally in short supply, or whether publicly provided PPE was particularly in challenging to acquire.

The COVID-19 Disability Rights Monitor report included testimony from South Africa, among other countries, that suggested that the government had failed to provide PPE and adequate sanitation in institutions. The report also included some positive examples found in other African contexts, where governments had prioritised the health and safety of older

persons with disabilities. For example, the Sudanese government had made significant efforts to sanitise residential homes for older persons with disabilities (Brennan et al. 2020).

Financial impacts

Many poor people in Africa are self-employed in the informal sector, and their income has been badly affected by reduced demand for their work as a result of government responses to COVID-19. A rapid socio-economic impact assessment in Tanzania found that key sectors that employ the majority of the poor, the youth and people with disabilities are and will continue to be severely impacted by the pandemic (ESRF 2020). A study from Uganda reported that participants with disabilities reported losing 64% of their monthly household income since the crisis began (ADD International 2020). A socio-economic impact analysis of COVID-19 in Botswana found that restrictions on movements due to COVID-19 result in people with disabilities being most likely to be out of work and income, especially if they are involved in the agriculture and fishery sector and the informal economy, having potentially long-term consequences on their livelihoods. Also, as many of those affected are women, the impact of household food security is a major challenge (UN Botswana 2020). A study from Mali found that the finances of people with disabilities have been particularly negatively affected by COVID-19 (IDA 2020 b).

In South Africa it was reported that for people with disabilities, social grants to make up for the loss of income are very difficult to obtain (IDA 2020c). In Kenya, 68% of people with disabilities who participated in a study reported not being able to work, while 65% felt insecure in their current jobs (i2i 2020). In Uganda, all participants who took part in a study reported being affected economically by the lockdown as they could not work. Both the employed and self-employed were affected financially resulting in food insecurity. For many, the situation got worse over time (Mbazzi et al. 2021). IDA (2020 e) reported how in Zimbabwe people with disabilities had lost income during COVID-19 which had increased their food insecurity.

Risk of violence

There have been many anecdotal reports of the possibility of increased violence during the pandemic, although it is difficult to find clear empirical data on these incidents, probably because of the difficulties with collecting such data.

In Uganda people with disabilities were found to face an increased risk of violence during the COVID-19 crisis. Based on a sample of 40 OPD members, 77% of women and 80% of men reported an increase in economic, physical, psychological and/or sexual violence after Covid-19. In addition, one in three women respondents reported experiencing an increased risk of physical and/or sexual violence (ADD International 2020). The risk of violence experienced by people with disabilities in Uganda was also reported by IDA (2020d). Similar issues have also been highlighted in Kenya, with increased reports of domestic physical abuse towards women and girls with disabilities (Gathu 2020).

Risk of violence was found to increase for people with disabilities who lived in countries with strict curfews and strong police or military presence. Examples include those in Uganda experiencing violence because they were not aware of curfew times or because they had

deliberately broken the curfew to seek food, police brutality against women and girls with disabilities in Nigeria when collecting food relief, and parents in South Africa being fined or arrested for trying to buy essential supplies (including medication) for their children with disabilities (Brennan et al. 2020). While the government in South Africa is reported to be using disability rights-centred COVID-19 measures to support people with disabilities, abusive implementation from the South African Defence Force and the police remains a concern (Nwachukwu and Asuelime 2021).

Specific impact on children with disabilities

The impact of the pandemic on children with disabilities was significant in many countries in Africa. The education of children with disabilities were disproportionately affected by the move to remote schooling due to the lack of technology, electricity outages, and the lack of specialist teaching support in Nigeria (Samaila et al. 2020), Malawi (Brennan et al. 2020, UNDP Malawi 2020), Uganda (IDA 2020d; Mbazzi et al. 2021), South Africa (IDA 2020a), and Eritrea (UNDP Eritrea 2020). Gathu (2020) reported that in Kenya many children with disabilities did not have access to technology, but that for those that did, more time was needed to become oriented on how to engage with the virtual learning format. The education of children with hearing impairments or those with developmental disabilities was particularly disrupted due to the lack of sign language interpreters and the lack of professional teaching support (Gathu 2020). The lack of captioning may also be an issue.

Children with intellectual disabilities in the African context may be particularly affected by teaching moving online due to COVID-19 (Samboma 2021). In South Africa, there was particular concern about the education of children with autism, as some parents were found to be unable to meet their children's needs at home (IDA 2020a). However, evidence from Zimbabwe on the education of children with autism during the pandemic found that family members played an essential role during the crisis to overcome the challenges associated with the transition from school to home routines (Majoko and Dudu 2020).

IDA (2020a) also reported concern over food security as schools had played an important role in feeding children with disabilities in South Africa, and the temporary closure of schools prevented them and other learners getting at least one balanced meal a day. In Kenya, OPDs were found to have a significant role in overcoming some of the challenges posed by the pandemic to children with disabilities (see the section on OPDs below). There is also concern about children with disabilities being restricted to inaccessible and unsafe facilities, with testimonies about this from Uganda and Rwanda. There were particular concerns about the mental health of children with psycho-social disabilities who were homed in this way. Evidence from Uganda, Nigeria, and Tanzania among other countries suggests that governments took inadequate measures to protect children with disabilities who live on the streets. An OPD representative from Nigeria said:

“Children (with disabilities) and their parents are still in the street with no face masks, no social distancing. Their lives are in danger.” (Brennan et al. 2020: 38).

Role of OPDs in support and relief

In Uganda, OPDs were found to be supportive both in terms of communicating information and mobilising resources (ADD International 2020). Reflecting on the role of OPDs in helping children with disabilities, a representative of an OPD in Kenya said:

“It’s the [disability] organisations that are trying to help children [with disabilities] in this pandemic. The government has even refused some of our organisation[s] to help and deliver the medical care the people with disabilities may need in their communities” (Brennan et al. 2020: 36).

IDA (2020e) detailed how OPDs had supported people with disabilities during the pandemic in Zimbabwe. OPDs provided both food and information to people with disabilities.

Overall then, in Africa people with disabilities have been largely excluded from the pandemic mitigation measures, despite rare instances where governments have stepped-up to assist persons with disabilities in some but not most respects. Relief measures are focused on the general population and usually do not take into consideration the specific requirements of people with disabilities. The temporary closure of schools and the impact of loss of employment, or reductions in salaries have resulted directly or indirectly in people with disabilities becoming increasingly financially and food insecure. OPDs and other non-government organisations have had to supply essential services and address food insecurity, while also ensuring communications and updates about the virus are understood. Principles of non-discrimination, equal opportunities and accessibility seem to have been overlooked in Africa during the pandemic. Legislation, such as curfews have not accommodated or even acknowledged the challenges faced by people with disabilities and how COVID has exacerbated these. The literature and other reports indicate that governments in Africa are far from being disability inclusive, which has worsened the disadvantages experienced by this sector of the population directly and indirectly and seemingly worsened their marginal status.

Humanitarian Disaster Risk Reduction and Pandemics

Disaster risk reduction (DRR) is the concept and practice of reducing the risk of disaster through systematic efforts to analyse and manage causal factors. DRR strengthens capacities, including that of marginalised groups such as people with disabilities, to deal with shocks and stresses (Kunstmann et al. 2020). The 2015 Sendai Framework calls for a disability perspective to be integrated into disaster management. It was adopted at the Third UN World Conference on Disaster Risk Reduction in Sendai, Japan, in 2015. The framework sets out a broader and a more people-centred preventive approach to disaster risk than has previously been expressed, including how governments should engage with relevant stakeholders, including people with disabilities, when designing and implementing policies, plans and standards. Empowering people with disabilities to publicly lead and promote universally accessible response, recovery, rehabilitation and reconstruction approaches is described as key (UNDRR 2015).

As detailed by UNDRR (2016), the Bangkok Principles were agreed to guide the implementation of the health aspects of the Sendai Framework. These included the need to

strengthen the design and implementation of gender-responsive and inclusive disaster risk reduction policies and plans, with community involvement, to address the vulnerabilities of people with disabilities and other population at risk and protection needs before, during and after disasters. They also called for the incorporation of disaster-related mortality, morbidity and disability data into multi-hazards early warning system, health core indicators and national risk assessments, allowing for data to be disaggregated by disability and other factors in disaster loss databases (UNDRR 2016).

The World Health Organisation (2019) state that with regards to health, the needs and rights of people with disabilities (along with other marginalised groups) must be at the centre of work relating to emergency and disaster risk management.

Inclusive disaster risk reduction must deliver support to those most at risk (Gartrell et al. 2020). Evidence indicates that people with disabilities face particular risks during disasters that may increase the support they need (Yasukawa 2021). Women with disabilities have been found to be disproportionately impacted by disasters. They may be excluded due to social processes, which can cause heightened risk exposure and reduce resilience (Gartrell et al. 2020). Children with disabilities may be particularly at-risk during disasters, for many reasons given their age, but also due to the loss of parents and guardians. As such they must also be given the opportunity to contribute to the management of risks caused by disasters in any community (Ressa 2020).

The Paris Agreement - an international treaty on climate change that entered into force in 2016 - acknowledges that although climate change is a common concern of humankind, the rights of people with disabilities and other marginalised groups must be considered (UNFCCC 2015). The Sustainable Development Goals aim to leave no one behind. The interrelationship between disaster risk reduction and sustainable development is highlighted by a number of the Sustainable Development Goals, including SDG11 (cities) and SDG9 (building resilient infrastructure) (UN 2022). However, it could be argued that the SDGs relating to disaster risk reduction could be more explicitly inclusive of people with disabilities and their needs.

Another important development was the Charter on Inclusion of Persons with Disabilities in Humanitarian Action that was developed in 2016 ahead of the World Humanitarian Summit. The aim of the Charter was to make humanitarian action inclusive of persons with disabilities, by lifting barriers persons with disabilities are facing in accessing relief, protection and recovery support and ensuring their participation in the development, planning and implementation humanitarian programmes (Humanitarian Disability Charter 2022).

Inclusive DRR best practice

The Inter-Agency Standing Committee's guidelines on the inclusion of persons with disabilities in humanitarian action set out essential actions that humanitarian actors must take in order to effectively identify and respond to the needs and rights of persons with disabilities who are most at risk of being left behind in humanitarian settings. They are

specific to persons with disabilities and to the context of humanitarian action and build on existing and more general standards and guidelines (IASC 2019)

While including people with disabilities in DRR planning will better ensure that the needs of people with disabilities are considered, for their meaningful inclusion, technical skills, knowledge and goodwill from all parties are needed (Rahmat and Pernanda 2021). To make pandemic planning and preparedness disability inclusive, people with disabilities must be involved as consultants and partners, not just as users. Emergency plans must be known and understood by all stakeholders who may need to use them (Mzini 2021).

The COVID-19 pandemic has highlighted the potential of digital tools for information sharing, contact tracing, and communication. However, barriers to access and adaptability for people with disabilities and other marginalised groups must be considered. There is however limited evidence about barriers to inclusivity of communication channels, so further research is needed (Chan et al. 2021). Mobile technologies have the potential to improve the inclusiveness of disaster responses, particularly for people with disabilities. However, to maximise effectiveness, DRR products should be co-developed with local stakeholders (including people with disabilities) through a user-centred design approach (Paul, Bee and Budimir 2021). There should also be some sort of national record keeping of people with disabilities across government departments. One may register for disability financial assistance with one department and neither this department nor any other will follow up in times of disaster as COVID-19 anecdotes portray. Departments do not communicate with one another neither does the private sector.

Statistical invisibility is important when considering DRR - if no information is available on people with disabilities, their level of need will not be recognised and understood, and they may then be excluded from public policy actions. Countries need updated and comparable information on people with disabilities, obtained in compliance with international recommendations, to facilitate rapid inclusive interventions in crisis and disaster situations (NU CEPAL 2021). Disaggregated data by impairment or type of need is essential to both understand the impact of the pandemic and monitor the inclusion of people with disabilities in the response and recovery (UN 2020). Effective implementation of any disability inclusive emergency plan requires monitoring and evaluating progress and success (Mzini 2021).

From a human rights perspective, both the UNCRPD and the 2030 SDG agenda emphasise the importance of including people with disabilities in planning and implementation of disaster response and recovery planning and is highly relevant to the COVID-19 crisis response and recovery (UN 2007; UN 2022). To ensure responses are inclusive, active involvement of people with disabilities is needed at all stages (from planning and design to implementation and monitoring) (UN 2020). Men, women, boys and girls with different types of impairment should be consulted in pandemic response planning. In particular they should be involved in discussions about the impact of public restrictions such as lockdowns, and recommendations to enhance safety and access to services (HI 2020a).

To ensure that the most marginalised people and groups are not left behind, pandemic response and recovery must reflect and respond to the multiple and intersecting forms of

discrimination that people with disabilities experience across sectors. It is particularly important to ensure that humanitarian assistance and disaster response through national and local coordination mechanisms and preparedness and response plans are disability inclusive. Planning must include considering access to WASH, health, and food and nutrition (UN 2020) as well as other essential services such as power/electrification.

DRR since COVID-19

When it became clear how serious the COVID-19 situation was, there were calls to ensure that disaster and recovery planning was disability inclusive (Djalante et al. 2020). The UN Global Humanitarian Response Plan for COVID-19 identified persons with disabilities as among the most affected population group in March 2020 (UN OCHA 2020).

Inclusive responses to the pandemic are needed to ensure the rights of people with disabilities are not overlooked or violated. This includes both during lockdown (access to supplies for life and health) and post-lockdown (access to quality inclusive education and inclusion in the labour market). The principles of non-discrimination, equal opportunities and accessibility must be included in the management of the health emergency itself, both during the pandemic and in the subsequent recovery phase, especially with regard to health services (NU CEPAL 2021). Equally important is an inclusive approach to the mitigation of post-acute phases of a pandemic where the psychosocial, educational and economic impacts can continue long after the acute health emergency has subsided.

Understandings of disability rights must be central to inclusive COVID-19 preparedness. In crises such as the COVID-19 pandemic standards of care and resource allocations must not be based on assumptions about people with disabilities' quality of life or value - stereotypes about disability must be avoided. People with disabilities should be included on triage protocol committees and disaster risk reduction working groups who work on response strategies (Singh 2020). Practical guidance includes engaging with people with disabilities and coordinating with OPDs to understand barriers, concerns and recommended actions that are needed during an emergency as well as monitoring the response from the government and other stakeholders. Where possible, the voices of people with disabilities should be amplified, to facilitate opportunities for them to share experiences, concerns and requests. It is essential that all official information and communications on a pandemic are disability inclusive (Armitage and Nellums 2020). Steps must be taken to strengthen disability-inclusive health systems. As well as regular health services, treatment protocols must not discriminate against people with disabilities (Pregel and Le Fanu 2020).

The COVID-19 pandemic has illustrated that governments need to think about the impact of disasters on mental health as well as physical health. Responses relating to mental health must be fast and provide early intervention. Media platforms can be used to provide accurate and reliable information. In addition, the government needs to expand its education and training of front-line staff, health officials, and policymakers to make appropriate responses to people's psychological and mental health needs during a pandemic (Bandares-Paulino and Tudy 2020).

The COVID-19 Disability Rights Monitor Survey highlighted a failure to include people with disabilities in collective responses to COVID-19 at both the national and global level. For many people with disabilities the only support they received was from OPDs and community-led initiatives. Many of the emergency measures taken by governments in response to the COVID-19 crisis were found to have exacerbated existing human rights abuses that affect people with disabilities and failed to prevent further human rights abuses. People with disabilities in institutions were particularly affected, with emergency measures resulting in the denial of access to healthcare, bans on visitors, and isolating residents. Many people with disabilities living in institutions were not informed about the state of emergency (Brennan et al. 2020).

Bhakta (2021) exploring the impact of the COVID-19 pandemic on the International Disability and Development Consortium (IDDC) members and their partners, found that the majority of pre-existing disability inclusion programmes have been adapted since the crisis to focus on direct responses to the pandemic and the needs of people with disabilities. It found that only 10 programmes were focused on Resilience/Disaster Risk Reduction (24% of responses). This is relatively low, compared to those involved in advocacy (90%). As the crisis developed, most programmes adopted an immediate risk mitigation and reduction response to the needs of people with disabilities. For example, a disaster risk reduction approach was needed for Cyclone Amphan, which struck parts of Bangladesh, Sri Lanka, India, and Bhutan as the pandemic developed. The report recommends that the implementation of all COVID-19 responses are evaluated for how inclusive they are, and that the results should feed into guidelines for future emergency action plans. Further it states:

The lack of preparedness to face a pandemic such as COVID-19 led to major disruptions in services, discrimination, human rights abuses and reversed hard won progress for people with disabilities. The pandemic has highlighted the need for disability inclusive DDR strategies to strengthen countries' preparedness to address future crises (Bhakta 2021: 7).

The report also highlighted the importance of taking into account the diverse and individual needs of people with disabilities, and in particular those experiencing intersectional identities (e.g. gender, age and disability) leading to discrimination and marginalisation (Bhakta 2021).

A survey from the Americas and the Caribbean of more than 230 participants found that 80% of the people who responded were not aware of any specific public actions, programs or initiatives in their country for people with disabilities to address the current pandemic. Of the 20% who responded that they were aware of such initiatives, 48% rated these measures as poor. Among the interventions that people knew about 59% were seen as public measures by national authorities and only 29% as those by local public authorities. It would seem likely that locally produced actions would be more fine-tuned to people's needs in the context. Slightly more than two-thirds (68%) of respondents stated that they do have access to information related to the pandemic in an accessible way (UNDRR 2020).

In India, mental health and psychosocial support (MHPSS) interventions as part of the COVID-19 response was found to be an issue, with greater attention on mental health needed in the disaster risk response process (Gray et al. 2021).

Research from Sierra Leone suggests that efforts to make emergency responses more inclusive that were developed during the Ebola crisis have been shown to be sustainable, as they have improved the responses to the COVID-19 pandemic. These interventions include decentralizing mental health services, working with organizations of people with disabilities to ensure the accessibility of public health messages, addressing barriers to accessing response services, as well as involving people with disabilities in planning and coordination, so that their needs and priorities were heard (Inter-Agency Standing Committee 2021).

In Australia, evidence suggests that the overall government COVID-19 response has been successful but that the pandemic has exposed and exacerbated social inequities, particularly for people with disabilities (Yates and Dickinson 2021). Similar findings relating to the impact of pre-existing forms of social injustice and discrimination faced by people with disabilities on experiences of COVID-19 have been reported elsewhere (Scully 2020; Sabatello 2020). Specifically relating to Australia, Yates and Dickinson (2021) argue that the governments lack attention to the intersection of disability and pandemic planning, resulting in people with disabilities feeling they are a low priority in public responses to crises.

The Ghanaian COVID-19 response strategy was found not to specifically address the needs of people with disabilities. For example, the government employed the services of the National Disaster Management Organisation and Faith-Based Organisations to distribute food and relief items, despite social welfare agencies being perhaps better placed to understand the needs of people with disabilities. In the future people with disabilities, including women, must form part of the crisis response teams (Naami and Mfoafo-M'Carthy 2020).

A review focused on gender-responsiveness and disability inclusion in DRR in the Pacific found only half of the 12 countries investigated are collecting and using sex-, age- and disability-disaggregated data to monitor the implementation of the Sendai Framework for DRR. Nine of the 12 countries committed to include people with disabilities in formulating DRR processes. However, people with disabilities were found to be commonly considered a homogenous group in national DRR plans, even though people with diverse types of impairments have different needs, which undermines inclusive DRR. In Asia, only six out of 14 countries investigated are collecting and using sex-, age- and disability-disaggregated data to monitor the implementation of the Sendai Framework for DRR. Of the 14 countries, 11 recognised the need to involve women in DRR formulation through consultation and participation, and seven countries are working towards including people with disabilities in these processes (UN Women 2020).

Evidence from Indonesia described how people with disabilities were involved in the emergency response with support from national organisations of persons with disabilities. Online meetings were held to gather information and collective action plans were

developed, including communications to raise awareness of the mental health implications of isolation (Brennan et al. 2020). In response to the predicted mental health challenges posed by lockdown, China offered psychological counselling by mental health professionals (Liu et al. 2020).

In Sierra Leone, responses including MHPSS that had been developed for previous disasters could be mobilised quickly during COVID-19 by utilizing many of the same coordination mechanisms (Gray et al. 2021).

Overall then, there have been moves in the last 20 years to make sure that disaster risk reduction strategies and guidance at global and national levels become more disability aware and inclusive. Progress has been patchy with many countries signing up to such pledges but not always implementing the practical actions needed. During the onset of an acute emergency, be it a natural or manmade physical disaster or a pandemic, approaches which would make interventions inclusive are often overlooked or forgotten and thus the exclusion or neglect of people with disabilities is easily exacerbated.

The South African policy and legislation environment on disability and humanitarian action

This section looks at the various directives in South Africa that directly or possibly relate to persons with disabilities. It begins by focusing on the Constitution and existing legislation relating to persons with disabilities and the protection of their rights, before examining the relevant directives issued so far during the pandemic.

The Legislative environment

The South African Constitution contains an equality clause with an anti-discrimination provision that explicitly lists disability among the prohibited grounds of discrimination (section 9(3)). The Bill of Rights further sets out the rights to dignity (section 10), to security of the person, which includes the right to freedom from all forms of violence (section 12), as well as the right to have access to adequate housing (section 26). Section 27 provides for all persons the right to have access to health care services, including reproductive health care, sufficient food and water; and social security, including, if they are unable to support themselves and their dependents, appropriate social assistance. Section 29 lays out that everyone has the right to a basic education, including adult basic education. All these provisions are underpinned by section 7(2), which enjoins the State to “respect, protect, promote and fulfil the rights in the Bill of Rights”. The Promotion of Equality and Prevention of Unfair Discrimination Act 4 (2000) gives effect to the implementation of section 9 of the Constitution and prohibits discrimination against people with disabilities.

Although sign language is not one of the eleven official languages, the constitution requires that sign language should be promoted and that conditions should be created for its development and use (section 6). Yet nothing is stated about open or closed captions on television or other video display devices for other hearing-impaired people who are not sign-language users.

The Constitution is far-reaching in its inclusion of provisions defining the relationship between international and national law. Although Section 231 requires an act of incorporation by parliament for an international agreement (such as the UNCRPD) to become law in the country, the Constitution also states that customary international law is law in South Africa unless it is inconsistent with the Constitution or national legislation (section 232). Importantly, Section 39(1)(b) of the Constitution requires a court to consider international law when interpreting the Bill of Rights. This may include both binding (i.e. treaties and conventions ratified by South Africa) and “non-binding” sources of international law, such as customary international law. In addition, section 233 of the Constitution states that every court, when interpreting legislation, must prefer any reasonable interpretation of such legislation that is consistent with international law.

South Africa does not at present have all-inclusive disability legislation. The implementation of disability rights is dealt with within “generic” anti-discrimination legislation for example

- Employment Equity Act 55 of 1998 and the Employment Equity Act No.55 of 1998 as amended in 2017
- Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000
- Skills Development Act (Act No. 97 of 1998)

Given a relatively progressive constitutional and legal framework, it is somewhat surprising that South Africa has not yielded more in the form of disability jurisprudence – apart from two cases arising from the field of employment law. Importantly, the Constitutional Court has not yet had been faced with the interpretation of the concept of ‘substantive equality’ in the context of disability.

Nevertheless, without a specific Act that protects the rights of persons with disabilities, South Africa does not have the necessary legislation or a sufficient framework to monitor, intervene and provide justice for persons with disabilities when necessary (Sibanda 2015). Maromoagae (2012: 345) notes that:

South African jurisprudence with regard to the reasonable accommodation of persons with disabilities in the workplace does not offer much guidance.

Thus, a more comprehensive Act than the EEA (and by implication the other Acts) is required to ensure that rights of employees and potential employees are safeguarded. The same applies generally to persons with disabilities in society with respect to PEPUA. Countries such as Kenya, Australia and the United Kingdom have specific legislation (Acts) explicitly for persons with disabilities.

South Africa is a party to the UNCRPD and in 2011, the then State President Jacob Zuma reported that a Disability Act was being drafted to deal with enforcement, non-compliance and implementation of the UNCRPD.

The UNCRPD covers matters such as accessibility, rehabilitation, participation in political life, equality and non-discrimination of people with disabilities. However, four years later nothing had materialised. Again in 2015, the Persons with Disabilities Rights Act was

promised in the 2015 White Paper of Persons with Disabilities. It is now long overdue, although it should be recognised that in mid-2019 the South African Law Reform Commission (SALRC) embarked on the process of research to inform draft legislation. In the absence of such legislation, persons with disabilities are largely left to rely on a “welfarist” approach – the kindness of government, non-governmental and private stakeholders, such as employers – for the protection of their interests and rights. In the absence of such formal and enforceable legal protection and an accompanying sea-change in attitudes within society, government policies can be deeply patronising and continue to foster dependence. Persons with disabilities are treated as little more than the object of health and welfarist interventions. These interventions are often well below the level of what is required for the multiple conditions, severity and diverse composition (age, gender, socioeconomic class, life stage and progressive disabilities) of people with disabilities. Although it is important to provide appropriate support to enable people to enjoy the same socio-economic and cultural opportunities as everyone else in South Africa, such an approach is no substitute for enshrining their rights in law.

COVID-19 regulations concerning People with Disabilities

This section discusses the Disaster Management Act 57 (2002) and how this responds to the COVID-19 pandemic and mentions, either implicitly or explicitly, ‘disability’ or related terms (GoSA nd). To date approximately 150 regulations have been promulgated since March 2020. However, very few of these have any direct focus on people with disabilities and their treatment. Similarly, regulations were withdrawn, repealed, replaced and at times reinstated as the country moved through different lockdown levels as infection rates and death toll rose.

In terms of the Disaster Management Act 57 of(2002), regulations can be promulgated that make provision for people with disabilities. Set out below is a brief description and discussion of the regulations that explicitly and implicitly relate to the 2020 Covid-19 pandemic. It is noteworthy that many of the regulations do not talk directly about people with disabilities or specific impairment related needs. In principle, the onus of identifying what kind of specific needs apply s in a particular situation falls on the regulator in question. In practice, however, the task of interpreting and applying relevant provisions falls on the implementers.

The International Air Services COVID-19 regulations restricting movement by air travel were among the first regulations to be promulgated.¹ They provided in broad terms that a passenger who is unable to wear a face mask or take a COVID-19 test due to a disability may be exempted.

Regulations setting out the criteria for self-quarantine and self-isolation for people inside the country,² don’t in fact deal with criteria for quarantine or self-isolation, but rather with

¹ Regulations issued and promulgated in Government Notice (‘GN’) 415 of 26 March 2020. Withdrawn by GN 63/2021.

² GN R868 in GG 43600 dated 7 August 2020, GN 1278 in GG 43954 dated 3 December 2020 and GN 240 in GG 44297 dated 19 March 2021.

the conditions under which quarantine or self-isolation must take place. These regulations do not expressly address the likely different needs of many people with disabilities.

The Minister of Home Affairs issued regulations about quarantining, where people need to travel abroad for medical services.³ When someone requires assistance, the person providing assistance must be screened and, where applicable, be subjected to mandatory quarantine. Care for people with disability is not mentioned explicitly but may, be encompassed within the definition.

The Minister of Social Development issued regulations that apply to all Department of Social Development (DSD), South African Social Security Agency (SASSA), and National Development Agency (NDA)-managed and mandated programmes and projects.⁴ These and other regulations promulgated on behalf of DSD pay relatively significant attention to people with disabilities.

These regulations have very broad application and require universal access for people with disabilities in a prescribed manner, to all service points, infrastructure and any other essential service and products that are related to COVID-19. For example, people with disabilities ‘must have access to personal assistance at all service points, hospitals, screening, testing facilities, supermarkets and any other available facilities which are appropriate and’, in a departure from general COVID-19 restrictions, ‘where it is deemed necessary, may be provided with regular care-giving services at their places of residence’.

The same set of lockdown regulations include provisions relating to old age homes and frail care facilities, and are relatively strict, given the greater vulnerabilities of residents and the elderly more generally to COVID-19. Thus, no clients may be released from these facilities; no visitation is allowed during the lockdown period; the family reunification and interaction programme is suspended; and no new admissions are allowed, except in the case of older persons ‘in distress’ and upon a social worker’s recommendation. Despite not elaborating or specifically referring to particular types of impairments, these regulations appear to apply to residents of these facilities who are both disabled and distressed.

These regulations also address residential facilities for people with disabilities, including respite care facilities that are centre- and community-based. The regulations provide that clients may be released from these facilities only upon the recommendation of a social worker or other relevant practitioner, taking into consideration the needs of persons with severe disability.

Care givers must be available to provide care in residential facilities and for required home-based care services during the lockdown period. This includes psychosocial support services, which must be provided to all those infected with or affected by COVID-19. Furthermore,

³ GN 416 on 26 March 2020.

⁴ The regulatory notice GN R430 dd 30 March 2020 has been amended by [GN R455](#) in Government Gazette (‘GG’) 43213 7 April 2020, [GN R517](#) GG 43300 dd 9 May 2020, [GN 727](#) GG 43494 dd 2 July 2020, [GN 853](#) GG 43588 dd 6 August 2020, [GN 1063](#) GG 43777 dd 7 October 2020, [BN 131](#) GG 43866 dd 2 November 2020 and [GN 111](#) GG 44174 dd 22 February 2021.

people with disabilities requiring psychosocial interventions must have access to all prescribed medications and counselling as a minimum requirement for crisis interventions.

When a person with disabilities is to be released from DSD-operated facilities, such as high care facilities in old age person (OAP) homes, as well as drug and alcohol rehabilitation centres, a social worker must be satisfied with regard to the state of readiness of the place that will accommodate that person.

In terms of these COVID-19 regulations, a monthly top-up amount of R250 became payable in addition to existing permanent and temporary disability grants. The same top-up amount applied to the following grants: Older Persons, War Veterans, Care Dependency Grant and Foster Child Grant, while the Child Support Grant (CSG) was topped up by R300 but only for the month of May 2020. From June 2020 until Oct 2020 a CSG Care Givers Allowance (CGA) of R500 per month was payable. It is unclear why a CGA was payable only for children and not also for example, at least adult persons with severe or extensive disabilities.

The COVID-19 regulations applicable to the South African Social Services Agency (SASSA), responsible for the administration and disbursement of all social grants, made special provision for temporary disability grants that would ordinarily lapse during the lockdown period. They were deemed to have not lapsed during this period and had to be continued until the end of October 2020, subsequently extended until the end of December 2020. The same was applicable to the COVID-19 additional form of Social Relief of Distress (SRD) grant. Similarly, the validity of medical reports required for disability grants in the period prior to the lockdown was extended from 3 months to 6 months. While not confirmed, it seems reasonable to anticipate that these extensions of validity of medical reports will be further extended in appropriate circumstances. Generally, these regulations reflect a recognition that especially stricter lockdown levels make it more difficult for certain people with disabilities to continue to follow the normal procedures during the various lockdown levels.

The regulations concerning various economic sectors⁵ provided that

‘Sector-specific health protocols may address matters such as...special measures affecting persons with greater vulnerabilities or similar measures, in order to achieve social distancing, protect employees or limit congestion in public transport and at the workplace’.

Although no specific mention was made of relevant categories of people with disabilities, the regulations were broadly phrased enough to include a requirement that health protocols must take account of the needs of persons with particular vulnerabilities, including people with disabilities.

Lockdown regulations also permitted continuation of private domestic live-in staff, and staff providing care to the sick, mentally ill, elderly, people with disabilities and children, recognising such staff as essential workers.

⁵ GN R480 issued on 29 April 2020, as amended. See Regulation 30(4) of the Regulations issued by the Minister for Cooperative Governance and Traditional Affairs.

Regulations issued by the Minister of Communications and Digital Technologies concerning electronic communications, postal and broadcasting services aimed to facilitate the broad public availability and use of digital and broadcast technologies to combat the spread of COVID-19, classifying them as essential services.⁶ Electronic communications and broadcast licensees were required to expand the provision of access to the education and health sectors, for example, to support remote learning; to

‘... support the health sector with programming and public announcements related to the COVID-19 disaster’; to zero-rate all COVID-19 sites as identified by the Department of Health and zero-rate all calls to the Department of Health’s national helpline number for COVID-19.⁷

Notably, the regulations require broadcasting service licensees ‘to receive and disseminate public information related to the national effort to combat the spread of COVID-19 in all local languages including sign language’.⁸

The regulations also enabled the home-delivery of medical products by pharmacies during various levels of lockdown.⁹ Although these regulations did not refer specifically to people with disabilities or their particular needs, they are clearly of benefit to them.

Regulations were issued by the Minister of Justice and Correctional Services to permit support persons for persons with disabilities in all courts, court precincts and justice service points.¹⁰ Regulations applicable in all correctional centres and remand detention facilities¹¹ outlined restrictions regarding placement, movement and release of inmates, parolees, and probationers during Alert Levels 3, 4 and 5. In addition, the referral of inmates to external health facilities was limited to medical emergencies only. The regulations also dealt with amenities, consultations and visits during alert levels 3, 4 and 5, suspending visits by external non-essential health care providers, such as specialists, dentists, psychiatrists, and physiotherapists, except for medical emergencies. The correctional services regulations have the potential to negatively impact people suffering with long-term physical and mental disabilities. If vulnerable individuals who may require these ‘non-essential’ treatments (which are undefined) are forced to wait for a ‘medical emergency’ to occur in order to receive treatment, this could arguably amount to neglect of such persons and the breach of their right of access to healthcare.

Regulations were issued by the Minister of Trade, Industry and Competition regarding e-commerce sales during alert level 4 of the COVID-19 national state of disaster. They provided for ‘Identification of vulnerable workers and special measures for their protection,

⁶ GN 417 in GG 43164 dd 26 March 2020, and amended by [GN 451](#) GG 43209 dd 6 April 2020 and [GN 516](#) in GG 43299 dd 8 May 2020.

⁷ Ibid. paras 10.1 and 10.2.

⁸ Ibid. para 5.1.

⁹ GN 484 dd 3 May 2020 as amended (not materially) by [GN 590](#) GG 43351 dd 26 May 2020 [GN 671](#) GG 43439 dd 12 June 2020 and [GN 594](#) GG 44814 dd 7 July 2021.

¹⁰ GN R489 dd 4 May 2020, amended by GN 6232 dd June 2020.

¹¹ GN 698 dd 22 June 2020, repealed and replaced by GN 54 in GG 44111 dd 28 January 2021.

including protection against unfair discrimination or victimisation'.¹² While not aimed solely at people with disabilities, these regulations can be interpreted and applied in a way that ensures that their particular needs are respected.

Paragraph 8 of the Regulations by the National and Provincial Departments of Basic Education regarding the re-opening of schools while preventing and combating the spread of COVID-19 set out a plan for the phased return of learners to schools.¹³ The following categories of schools, referring specifically to learners' disabilities, are mentioned individually as part of the breakdown of grades/ages for phased school return: 'Schools for Learners with Severe Intellectual Disabilities (SID); schools with Learners with Severe and Profound Intellectual Disabilities (LSPID) and schools with autistic learners'.

The Regulations include detailed provisions for 'learners with special educational needs' and are fairly comprehensive, covering a wide range of disabilities, including learning difficulties and visual impairment. In addition to the guidelines developed for schools with specific categories of learners with disabilities, all schools with learners with special educational needs, as contemplated in the South African Schools Act, must comply with all directions and circulars regarding the re-opening of schools. In addition, schools must comply with the *Guidelines for Schools for Autistic Learners* and with the DBE's guidelines applicable to learners who are blind, partially sighted or deaf.

These back-to-school regulations also provided that education officials who are unable to practise social distancing from learners with special education needs must be provided by each provincial education department with appropriate personal protective equipment (PPE), including protective clothing, where necessary. The regulations require that officials who carry out symptom screening in schools for deaf learners must be able to communicate using South African Sign Language. Where this is not possible, a sign language interpreter must be available to ensure proper communication with the learners. Furthermore, provision must be made for written communication for blind learners, as well as those who are both deaf and blind, through Braille.

Each provincial education department must, at a minimum, provide the following PPE to learners with visual and hearing impairments: face shields must be provided to blind learners; cloth face masks must be provided to low vision learners, teachers and support staff; and face shields must be provided to teachers, support staff and learners in schools for the deaf. Where a learner with disabilities does not return to school for any relevant reason, the Head of Department must make all reasonable efforts to ensure that the learner is provided with appropriate learning and teaching support material, assistive devices and therapeutic support.

¹² GN R535 dd 14 May 2020.

¹³ GN 343 dd 23 June 2020, as amended by GN 42 in GG 44154 dd 12 February 2021 and by [Gen N 145](#) in GG 44339 dd 27 March 2021, [Gen N 224](#) in GG 44486 dd 23 April 2021, [GN 451](#) in GG 44633 dd 28 May 2021, [GN 393](#) in GG 44779 dd 29 June 2021, [Gen N 422](#) in GG 44858 dd 15 July 2021 and [GN 442](#) in GG 44922 dd 1 August 2021.

The Regulations creating the COVID-19 temporary employee/employer relief scheme (C19 TERS) define 'vulnerable employee' as an individual 'with known or disclosed health issues or comorbidities or .. any employee at ... higher risk of complications or death than other employees if infected with COVID-19'. While this definition could be applicable to certain categories of people with disabilities, it could also apply to those over 60 years old who are recognised by medical experts as being more vulnerable. No explicit or clear mention is made in the regulations of additional or special consideration of any needs of people with disabilities.

Consolidated regulations on occupational health and safety measures in certain workplaces deal with risk assessments and plans for protective measures and require employers to 'identify vulnerable employees'. Employers must require employees to disclose whether they have any of the health issues, comorbidities or conditions contemplated in the definition of vulnerable employees (does not necessarily include persons with disabilities) and thereafter take special measures to mitigate the risk of COVID-19 for those employees in accordance with the Department of Health's Guidelines to facilitate their safe return to work or their working from home. Employers with 50+ employees must report to the National Institute for Occupational Health each employee's vulnerability status for serious outcomes of a COVID-19 infection. However, it is not clear what vulnerabilities must be disclosed and by law persons with disabilities need not disclose their disability or where relevant any related comorbidities of health vulnerabilities.

Regulations issued by the Minister of Social Development dealing with early childhood development (ECD) centres, include 'partial care facilities'.¹⁴ The definition of 'partial care facilities' in these regulations extends to all partial care facilities that provide an 'after school service'. However, the regulations also provide for controlled access to and COVID safety protocols in old age homes ('older persons' residential facilities') and frail care facilities (neither of which are defined in these regulations), as well as 'community nutrition and development centres' (CNDs). The impression given is that insufficient care and attention is given to ensuring that regulations and directives are properly named or labelled so that individuals, groups or organisations affected are given adequate notice of changes to the law that may affect them.

Overall then, no regulations are dedicated *solely* to including or expressly taking into account the needs of particular categories or groups of people with various types of impairment. Those few regulations that did include some measures aiming to assist people with disabilities, largely emerged from the DSD and the DBE. Most regulations aimed at people with disabilities focused on those resident in care facilities, places of safety, attending court, prisoners and parolees. Where certain provisions or measures are expressly stated, they are included in regulations that have a broader focus than only people with disabilities. Even when measures are included that expressly address the needs of people with disabilities, those measures are usually limited in scope and are phrased in broad terms that treat all impairment groups in the same way. The only explicit exceptions relate to the provision of educational materials in Braille for partly or wholly unsighted learners, and the

¹⁴ GN 993 in GG 43710 dd 11 September 2020.

provision of SA sign language for people who are hearing impaired or deaf. Although few regulations and directives explicitly or obviously detract from normal activities by persons with disabilities. Their failure to explicitly take into account their uneven impact on people with and without disabilities renders them discriminatory or at least insensitive. The regulations seem to have an institutional bias in most respects and focus on people within institutions or attending law courts and accessing social grants, public health services and education facilities.

Some regulations have very broad application and require universal access for persons with disabilities in a prescribed manner, to all service points, infrastructure and any other essential service and products that are related to COVID-19. For example, a DSD directive, noted above, indicated that people with disabilities

‘must have access to personal assistance at all service points, hospitals, screening, testing facilities, supermarkets and any other available facilities which are appropriate and’, in a departure from general COVID-19 restrictions,

‘where it is deemed necessary, may be provided with regular care-giving services at their places of residence’.

As can be seen, however, a strong element of discretion is built into these provisions through phrases such as ‘which are appropriate’ and ‘where it is deemed necessary’. It is evident that many regulations appear to have implicitly acknowledged the limited capacity of the state to proactively reach out to meet the diverse needs of people with disabilities, therefore resorting to reactively providing or requiring the provision by others of ‘personal assistance’ at service points that could be reached by people with disabilities. Similarly, many of these regulations implicitly anticipate the extensive reliance, both of people with disabilities and of the state, on existing networks of established or repurposed organisations to meet the range of needs of people with disabilities during the pandemic. One example to illustrate the ‘blind spot’ is that the regulations provide for physical distancing and other hygiene protocols at nutrition centres but made no mention of ensuring that nutrition support was taken to people with disabilities who might be in isolation under lockdown and not living in a residential institution of some kind.

A final point is that most disaster regulations, including those pertaining to disability, focus on controlling the spread of the virus rather than addressing particular needs of a diverse marginalised group in society in daily life.. In some cases, the regulations have had far reaching undesirable social, economic and human rights consequences and need mitigation in light of these consequences.

The need for an inclusive framework on humanitarian action in South Africa

Under the auspices of the UNPRPD, UNESCO has produced 2 documents which aim to guide governments in disability inclusive pandemic responses and recovery. These might well be useful documents to inform the framework.

- Policy responsiveness for Inclusion of Persons with disabilities in the context of the COVID-19 Pandemic (2021)
- Disability Inclusive Covid-19 response best practices

The 1996 Constitution and acts of parliament, such as the Promotion of Equality and Prevention of Unfair Discrimination Act 4 (2000) and White Paper on the Rights of Persons with Disabilities (DSD 2016a), enshrine their rights. During COVID-19, emerging evidence suggests that they face exacerbated inequities and greater exclusion regarding healthcare and other essential services (Brennan et al. 2020; Ned et al. 2020). Furthermore, despite some rights protection, the Disaster Management Act 57 (2002), which guides state intervention during the pandemic, makes no mention of inclusive approaches or accommodating people with disabilities who are never specifically mentioned. Some government regulations make limited reference to people with disabilities, but nothing about urgent care or support for essential services. The National Coronavirus Command Council (NCCC) that approves COVID-19 mitigation strategies indicated in December 2020 that its workstreams include a disability focus (SA News 2020) but nothing tangible or encompassing is evident.

While the South African government heeds many of the recommendations of WHO, particularly those related to safety and prevention put forward by the Strategic Advisory Group of Experts on Immunisation (WHO SAGE) during the pandemic, they fail to distinguish the specific needs of people with disabilities. The National Disaster Management Centre (DMC), responsible for disaster management and mitigation, simply argues that the Disaster Management Act and the National Disaster Management Framework of 2005 provide for the protection of vulnerable households and communities and that this definition implies people with disabilities and argues that it is still work in progress (DMC nd). The DMC ignores specific circumstances and makes no distinction between persons with disabilities and other vulnerable groups in the country, a trend seemingly adopted by the NCCC. In April 2021, the WHO argued that disabled status must be factored into COVID-19 vaccination plans because:

persons with disabilities may be at greater risk of severe disease and death if they become infected with COVID-19 due to health conditions that underlie their disability and barriers to accessing appropriate and timely health care (WHO and UNICEF 2021).

They warned that difficulties with communication, inaccessibility to transport, health facilities and support services, and potential discriminatory triage practices may impair access to vital healthcare services, including vaccinations (WHO SAGE 2020). However, the government paid little heed to these warnings or the increased vulnerability of this group or the need to prioritise them as Stage II priority cases as recommended by WHO SAGE in October 2020 (ibid.) and continued to rollout the vaccination process according to age cohorts. As late as 28 July 2021, the NDoH (2021) acknowledged growing concerns about vaccinating persons with disabilities and the need to schedule home visits, emphasising nothing was done when the pandemic started to ensure the inclusion of people with disabilities. Possibly because the DMC still sees their activities in this regard as work in

progress¹⁶ and there is little national buy-in of Section 3.5 of the Implementation Matrix 2015-2030 of the White Paper on the Rights of Persons with Disabilities (DSD 2016b) by them, other departments or the NCCC. Section 3.5.1 of the Matrix deals with compiling disability-inclusive risk-management documentation. Sections 3.5.2 and 3.5.3 deal with providing “accessible disaster relief services” and “accessible emergency services”. However, Section 3.5.1. has not been completed and perhaps nothing has been done, given that few COVID-19 disaster regulations include the diverse needs and circumstances of people with disabilities but rather focus on specific instances such as education, travel and incarceration.

Despite some legislation and policies, such as the *White Paper on the Rights of Persons with Disabilities* (DSD 2016a), there seems to be little adherence to these or even adoption disability inclusive disaster regulations during the pandemic.

Conclusions

Many agencies predicted that the COVID-19 would have especially negative effects on people with disabilities, with high risks of exacerbating their already disadvantaged position, both in relation to access to services such as health, education, social protection and relief, their status in the community and levels of support they receive, increased poverty and difficulties with securing work as well as lack of accessible and inclusive information and considerable emotional distress. Rates of infection and deaths were expected to be higher for this population even though not all people with disabilities have increased clinical vulnerability.

The conclusions from the report on the Disability Rights Monitor survey were that the impact of COVID-19 have indeed been catastrophic. They suggest that:

‘This impact can be mitigated if appropriate actions and protective measures are taken by key stakeholders ‘Has advice different actors – e.g. people with disabilities, governments, healthcare providers, disability service providers in the community, institutional settings, the community’ (Brennan et al. 2020).

Other emerging studies are supporting these findings, both quantitatively and qualitatively in a range of regions, countries and particular situations.

However many international development agencies, UN bodies and INGOs have galvanised to produce clear and fairly consensual guidance about what needs to be done to mitigate these impacts and ensure that they are not repeated during future crises.

The situation in South Africa is very particular because of its unique social and political history. It shows many of the same negative impacts on people with disabilities as we see in other countries, but also has no specific legislation for persons with disabilities, such as a specific Act as found in Australia, United Kingdom and Kenya. This is despite a strong rights-based approach to disability since the late 1990s, as promulgated in various sections of the 1996 Constitution. Moreover, this has been emphasised with the introduction of the *White Paper on the Rights of Persons with Disabilities* in 2016. However, the DMA and the National Disaster Management Framework of 2005 still lack a disability inclusive focus. Rather this is

still work in progress. This appears to have had some impact on the type of regulations promulgated and their lack of focus on specific needs of diverse people with disabilities including the type of disability. Government argues that the framework is all encompassing and provides for the protection of vulnerable households and communities and that this definition implies people with disabilities alongside others. There is no distinction made to support or even identify the diversity of people and their range of needs. As with other countries there is no monitoring or tracing system in place to address the specific needs of persons with disabilities.

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Appendices – 2 Examples of recommendations made by Organisations of people with disabilities

1)

COVID-19 and persons with psychosocial disabilities Pan African Network of Persons with Psychosocial Disabilities

Redesfera Latinoamericana de la Diversidad Psicosocial

TCI Asia Pacific (Transforming communities for Inclusion of persons with psychosocial disabilities, Asia Pacific)

European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP)

Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP)

World Network of Users and Survivors of Psychiatry (WNUSP)

26 March 2020

We, persons with psychosocial disabilities from regional and international organizations across the world, are concerned about the vulnerability of persons with psychosocial disabilities to COVID-19 infection and deaths. 'Persons with psychosocial disabilities' refers to a historically discriminated and marginalised group that includes users and ex-users of psychiatry, victims-survivors of psychiatric violence, mad people, voice-hearers, and people with psychosocial diversity.

People with psychosocial disabilities may be at increased risk of contracting coronavirus as a result of:

- their being placed and/or deprived of their liberty in psychiatric units and institutions, social care institutions, vagrancy homes, unregulated and informal 'shelters', jails, prisons, and correctional facilities, where they are unable to exercise social distancing as per their will and preferences.
- the inherent risk of infection in these environments, exacerbated by their being overcrowded and unsanitary, and places where ill-treatment tends to occur.
- barriers in accessing health information, including lack of information in plain language and communication support.
- barriers in implementing preventive hygiene measures due to poverty, unequal access to resources within households and homelessness.
- mistreatment and abuse.
- lack of social support networks and inclusive communities; and
- the systemic discrimination against persons with psychosocial disabilities, especially of women, children, older persons, LGBTQIA+ persons, indigenous persons, persons of diverse race, colour, descent, caste, national or ethnic origin, persons of different religious affiliations, persons with other disabilities, and other groups otherwise facing multiple and intersectional discrimination.

People with psychosocial disabilities may also be at increased risk of developing more severe symptoms and dying due to:

- poor nutrition, healthcare and sanitary conditions in psychiatric units and institutions, social care institutions, group homes and prisons.
- weakened immune systems due to poor nutrition, neglect, institutionalization and homelessness, including in children and older persons with psychosocial disabilities.
- long-term consequences of physical, psychological and sexual violence and abuse, particularly against women with psychosocial disabilities.

- reluctance to access the health system due to experiences of discrimination, dismissiveness, neglect, violence and traumatization in that system.
- underlying health conditions such as diabetes and hypertension caused or exacerbated by psychiatric drugs, often administered against people's will or under coerced consent; and
- barriers in accessing healthcare and lack of health insurance coverage.

States have the responsibility under international law to respect and ensure the human rights of people with psychosocial disabilities on an equal basis with others. This responsibility is heightened during a national and global emergency, such as the COVID-19 pandemic. The vulnerabilities highlighted during the pandemic as a result of structural discrimination, discriminatory legislation, and practices of exclusion and violence both in communities and in medical and social care settings, must be taken into account and remedied both during the emergency and afterwards.

We remind states that the Convention on the Rights of Persons with Disabilities requires states to abolish involuntary admissions and treatment in mental health settings and to release those detained and treated against their will under such regimes. This obligation is not suspended during the COVID-19 pandemic, as discriminatory detention is never justified, nor is the administration of mind-altering treatments against a person's will.

We call on national and local governments to implement the following measures:

Institutional settings

- Drastically reduce the number of people in psychiatric units and institutions, and institute a moratorium on involuntary admissions. Ensure that no one is compelled to remain in such settings against their will, where they are at greater risk of infection, more severe illness, and death.
- Urgently implement sanitary and preventive measures to avoid infections in psychiatric units and institutions, social care institutions and group homes, including environmental cleaning and disinfection, air circulation, regular hand hygiene and free access to sanitary supplies such as soap, hand sanitizer, toilet paper, and paper towels. People should not have to go to a centralised place to get sanitary supplies. Staff must be required to comply with all sanitary and preventive measures.
- Stop the use of seclusion, restraints, non-consensual medication, and any restriction on using the lavatories in psychiatric units and institutions. In addition to being contrary to people's dignity and integrity, these practices inevitably generate unsanitary conditions and cause severe stress and physical deterioration, resulting in weakened immunity.
- Provide people in psychiatric units, institutions and group homes with access to the latest information about COVID-19 and enable them to keep in touch with their friends and family. People should not be banned from leaving their rooms or having contact with the outside world as a way to prevent infections. While preventive measures to avoid infections from visitors are needed, blanket policies barring visitors are disproportional and can expose people to further abuse and neglect. Alternative means of keeping in contact, such as telephone and Internet, must be allowed without restriction.
- Drastically reduce the population in jails, prisons and correctional facilities, including by releasing those who are in pre-trial, imprisoned for non-violent offences, or scheduled to be released soon, including persons with psychosocial disabilities on an equal basis as others.
- Ensure in each and every case that people deprived of their liberty and those in congregate settings are tested in a timely manner, given their differential vulnerability, and that all such settings implement proper sanitary and preventive measures. When an outbreak occurs in an institutional setting, those affected must be moved to competent healthcare facilities, and the rest should be removed from the infectious environment. Any quarantine efforts must not result in persons being put into more restrictive environments, such as solitary confinement.

Non-discrimination

- Ensure that persons with psychosocial disabilities have equal access to testing, healthcare and public information related to COVID-19. Quality healthcare should be provided to those infected without discrimination of any kind, and regardless of health insurance coverage. Persons with psychosocial disabilities should not be diverted from mainstream hospitals to psychiatric units and institutions for treatment, where healthcare for COVID-19 is often of a lower standard.
- Public restrictions based on public health, and actions of law enforcement and security personnel, must not discriminate in any way against persons with psychosocial disabilities. Psychiatric coercive measures must not be used as any part of the response to COVID-19. Human rights standards and mechanisms offering protection to persons deprived of their liberty and those in congregate settings, including those in psychiatric units and institutions, must remain in effect and not be reduced as part of emergency measures.
- No one should be compelled to take psychiatric drugs or other treatments that inflict suffering and that compromise their health or immune systems. Compulsory treatment orders must be lifted, and no new ones introduced, as required by international law
- Ensure persons with psychosocial disabilities are not discriminated against in accessing the temporary measures implemented by governments to ensure the continuity of services during the COVID-19 outbreak, including education and social protection programs.

Community support

- Ensure continued access to support for people experiencing distress or unusual states of consciousness during the COVID-19 outbreak, including through call-in and online psychosocial support and peer support, based on respect for individual will and preferences.
- Step up efforts to develop a wide range of community-based services that respond to the needs of persons with psychosocial disabilities and respect people's autonomy, choices, dignity and privacy, including peer support and other alternatives to conventional mental health services.
- Guarantee voluntary access to psychiatric drugs during the COVID-19 outbreak for those who want them and offer support to anyone who wants to come off their medication or experience home-based withdrawal.
- Prepare and encourage communities to be supportive of one another in an inclusive way, including of persons with psychosocial disabilities, during the COVID-19 outbreak. This is especially important since mandatory quarantine, home confinement and information overload may result in heightened states of distress
- Provide practical support, such as support with obtaining food and supplies, for people with psychosocial disabilities who may be unable to leave their homes due to quarantine or experience difficulty with leaving home during this period of heightened concerns about contamination.
- Consider flexible mechanisms to authorize people with psychosocial disabilities to be able to leave their homes during mandatory quarantines, for short periods and in a safe way, when they experience particular difficulty with home confinement.
- Adopt additional financial measures to support people with psychosocial disabilities who may need to self-isolate during the COVID-19 outbreak, particularly those who live in poverty, or are unemployed or self-employed.
- Encourage media to report responsibly and accurately about the COVID-19 outbreak and the general population to exercise critical thinking and judgment when reading and sharing information on social media platforms.

Vulnerable groups

- Provide access to domestic violence information and services to support people, including children, experiencing abuse and violence at home. People with psychosocial disabilities, of any

age, may experience increased risk of abuse and violence during home quarantine or home isolation.

- Conduct community outreach activities to identify and rescue persons with psychosocial disabilities deprived of their liberty or ill-treated at home or within communities, including by shackling and pasung, and provide adequate support to them in a manner that respects their human rights.
 - Ensure access by homeless people, including those with psychosocial disabilities, to preventive measures against COVID-19 infection, such as access to well-supplied and clean sanitation facilities, as well as testing and treatment, without discrimination, and in a manner that respects their human rights. Governments must ensure that people with psychosocial disabilities who are homeless during the period of social isolation are not mistreated by authorities, and provided with water, food and shelter on equal basis with others.
 - Guarantee the continued provision of harm reduction services, such as needle and syringe programs and opioid substitution therapy, to prevent the spread of COVID-19 among drug users.
- Participation
- Consult and actively involve persons with psychosocial disabilities and their representative organizations in the state response to the COVID-19 outbreak.
 - Involve persons with disabilities and their representative organizations in the independent monitoring of institutional settings.

2.

International Disability Alliance Key Recommendations

- Persons with disabilities must receive information about infection mitigating tips, public restriction plans, and the services offered, in a diversity of accessible formats with use of accessible technologies
- Additional protective measures must be taken for people with certain types of impairment
- All preparedness and response plans must be inclusive of and accessible to women with disabilities
- No disability-based institutionalization and abandonment is acceptable
- During quarantine, support services, personal assistance, physical and communication accessibility must be ensured
- Measures of public restrictions must consider persons with disabilities on an equal basis with others
- Persons with disabilities in need of health services due to COVID19 cannot be deprioritized on the ground of their disability
- OPDs can and should play a key role in raising awareness of persons

with disabilities and their families

- OPDs can and should play a key role in advocating for disability inclusive response to the COVID19 crisis