

Rising to the challenge

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Rising to the challenge: disability organisations in the COVID-19 pandemic

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ABSTRACT

This paper examines the impact of COVID-19 on disabled people from the perspective of disability organisations located in the Global South. Drawing on the findings of an online survey, which received responses from 20 representatives of disability organisations located in 13 countries, this study builds on a growing body of recent research highlighting the disproportionate impact of COVID-19 on disabled people, many of whom have experienced greater levels of discrimination and deeper levels of isolation and poverty as the result of inadequate state responses to the pandemic. The study also highlights the crucial role played by many disability organisations in supporting disabled people during the crisis, often filling in the gaps in mainstream service provision, and argues that they should be enabled to play a much more prominent role in the long-term recovery process in order to ensure a more disability-inclusive post-pandemic world.

ARTICLE HISTORY

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COVID-19; disability; disability organisations; Global South; isolation; poverty

Points of interest

- This paper argues that:
- State responses to the pandemic have often failed to take account of the specific needs and priorities of disabled people.
- During the pandemic, many disabled people have been denied access to essential services, cut off from the support of their caregivers, excluded from education provision and exposed to severe economic hardship.
- Disability organisations have offered vital support to their members and beneficiaries, often helping to ensure that their basic needs are met.
- Policymakers and service providers should collaborate closely with disability organisations in order to ensure that disabled people are not left behind in the long-term recovery process.

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In 2020 COVID-19 spread rapidly across the globe, causing over four million deaths (World Health Organisation (WHO) 2021), stretching health resources to the limit, devastating economies and bringing unprecedented levels of disruption to everyday lives. The pandemic also highlighted the divisions in society, reinforcing pre-existing inequalities and impacting severely on some of the most vulnerable groups, especially elderly people. There is now a growing body of evidence to strongly suggest that disabled people have also been among those worst affected by COVID-19. They have been among those most at risk of catching the virus (WHO 2020) and have also been among the hardest hit in terms of fatalities (United Nations 2020a). Many have experienced increased levels of discrimination and a wide range of socioeconomic deprivations, reinforcing the already close relationship between disability and poverty. The 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), now ratified by the vast majority of nation states, places a clear obligation on governments around the world to 'take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk' (United Nations 2006, Article 11). As countries begin to emerge from the current crisis, however, it is becoming increasingly clear that ableist state responses to the pandemic have frequently disregarded the specific needs of disabled people and hence failed to afford them adequate protection (Mehrotra and Soldatic 2021).

Disability organisations, including both organisations *of* and organisations *for* disabled people (Oliver 1990), have taken part in various surveys that have been conducted since COVID-19 was declared a pandemic in March 2020, most notably an international survey conducted by the COVID-19 Disability Rights Monitor (COVID-19 Disability Rights Monitor (COVID-19 DRM) 2020). However, there have been few studies focusing exclusively on the experiences of disability organisations during the pandemic, despite the crucial role that they often play in supporting disabled people during times of crisis: ensuring that essential services are delivered, raising awareness of their rights and advocating on their behalf. This study is based on an international survey which aimed to address that gap by exploring how the pandemic had impacted on the work of disability organisations, as well as the lives of their members and beneficiaries. The survey targeted disabled people's organisations (DPOs), which are organisations that are predominantly governed by and comprised of disabled people themselves (Cobley 2018), disability or impairment-focused non-governmental organisations (NGOs), which are non-profit civil society organisations for which disabled people form the core beneficiary group, and governmental agencies with a main focus on disability issues. The survey gathered the views of disability organisation representatives from thirteen countries of the Global South, thus helping to counter the dominance of Global North perspectives in research that has been conducted around disability and COVID-19 so far (Mehrotra and Soldatic 2021).

The findings of this study are consistent with those of earlier studies, highlighting various ways in which official responses to the pandemic have failed to adequately support disabled people. The disability organisations that participated in the survey had been able to mitigate some of the worst effects of the pandemic for their members and beneficiaries, often providing vital support to families that were struggling to cope. As the world moves forward from COVID-19, this article argues that disability organisations should be empowered to play a more central role in the long-term recovery process, in order to ensure that disabled people are not left behind and that a new, more inclusive society emerges.

Emerging evidence on the impact of COVID-19 on disabled people

With COVID-19 now into its second year, a number of studies have been conducted which show how disabled people around the world have been affected by the pandemic. One of the most significant of these was an international survey carried out by the COVID-19 DRM in the early stages of the pandemic. The survey gathered testimonies from 2,152 respondents, mostly disabled people themselves, across 134 countries, to produce ‘the largest internationally comparable data set on the experiences of persons with disabilities during the COVID-19 pandemic’ (COVID-19 DRM 2020, 19). These testimonies revealed numerous injustices and devastating socio-economic impacts, as well as the breakdown of essential services and informal support structures. Many respondents had felt trapped and abandoned within their own homes, often without access to essential supplies such as food, medicines and other basic necessities. Information from official sources was often confusing and inaccessible, with some respondents left with no access to information at all. Many respondents reported that they had been denied access to healthcare during the pandemic, even in relation to treatment for COVID-19 itself, due to discriminatory healthcare procedures and attitudes. The survey also highlighted the diverse needs and experiences of disabled people, with certain groups exposed to additional hardship and discrimination, including disabled women, children, homeless people, those from indigenous communities and those living in rural or remote areas. Many of the failures highlighted by the COVID-19 DRM survey had arisen because official responses have often focused on the perceived vulnerability of disabled people, rather than recognising their agency and engaging with them in a meaningful way to ensure that the most appropriate support was provided. Mladenov and Brennan (2021) go further, arguing that the survey findings show that policy responses have caused more harm to disabled people than the pandemic itself, often disregarding the disabling impact of society and reinvigorating the medicalisation of disability, thus undermining decades of progress in the promotion of disability rights on the international stage.

The findings of the COVID-19 DRM survey are supported by a number of country studies that have also been published since the start of the pandemic. One of the largest of these was a national survey conducted in India by the National Centre for Promotion of Employment for Disabled People (NCPEDP) (2020), which gathered online questionnaire responses from over 1,000 disabled people. 67 per cent of respondents reported that they had not been able to access government deliveries of essential supplies (in some cases because they had been unable to obtain disability certificates). The survey also revealed the breakdown of social and peer support networks, with many losing the support of the caregivers on whom they had relied for personal assistance. Many respondents were also facing a financial crisis, due to job losses, salary reductions and the loss of income-generating activities. A study in Kenya (Rohwerder et al. 2021), based on repeated interviews with a small group of disabled participants, reached similar conclusions. The majority of interviewees had experienced significant economic losses, usually due to the loss of their own jobs or those of family members that they were financially dependent on. Several also reported that they had not been able to access formal social protection, including cash payments, to which they should have been entitled, leading to family tensions and feelings of guilt and sadness arising from their increased levels of dependence on others. Another study revealing the harsh economic consequences of the pandemic was conducted in Nepal and Bangladesh (Wickenden et al. 2021), again based on repeated interviews with disabled people, in which participants revealed feelings of mental anguish arising from sudden job losses, business failures and resulting poverty during the pandemic. Research conducted in Algeria (Houari and Hadjoui 2021) also supports the findings of the COVID DRM survey, highlighting declining healthcare standards during the pandemic and increased levels of psychological pain among disabled people during periods of confinement.

Some studies have adopted an intersectional lens to explore how disability has combined with other social identities, such as gender and age, giving rise to additional discrimination and hardship during the pandemic. In Sri Lanka, for example, Kandasamy, Perera, and Soldatic (2021) draw on the narratives of two disabled women to explore how their exclusion and marginalisation, brought about through the combined effect of disability, gender, rurality, religion, age and ethnicity, had become further entrenched. In Afghanistan, Shajahan (2021) observes that the stigma and discrimination faced by disabled women in relation to their perceived failure to conform to traditional gendered expectations around motherhood, being a wife and performing household duties had greatly intensified. A study conducted in Nepal (Gurung 2021) notes the increased risk of gender-based violence to which disabled women and girls had been exposed, within families, communities and even public quarantine centres. This had impacted particularly

on disabled women from indigenous communities, who were situated right at the bottom of the social hierarchy and often denied access to medical and legal services. This finding should be viewed in the context of a more general rise in gender-based violence during COVID-19, with economic pressures often compounded by restrictions on movement and reduced access to support services. The United Nations (2020b) estimates a surge of over 25 per cent in reported cases in countries where reporting systems are in place, with case rates doubling in some countries.

There is strong evidence to suggest that disabled children have experienced greater inequality in terms of access to education, due to the shift to remote learning brought about by school closures during the pandemic. The World Bank (2020) reports that temporary school closures during lockdown periods have affected 85 per cent of the world's school children and caused '40 per cent of disadvantaged learners in low and middle-income countries to be left entirely unsupported in their education' (p. 7). The report goes on to note that disabled children have been among those most at risk of exclusion, with many remote learning packages not sufficiently accessible, especially for children with hearing and visual impairments. Furthermore, disabled children have also faced the risk of increased discrimination and isolation as schools have reopened, because new safety priorities have often meant that the extra learning support measures that many disabled children depend on could not be provided. These conclusions are supported by a large survey conducted in the Philippines, which collected 3,741 responses (Council for the Welfare of Children (CWC) 2020). The survey report revealed that 57 per cent of the respondents were concerned at the inability of disabled children to access education services during quarantine periods.

The picture that emerges from this growing body of research is that the already high levels of discrimination and exclusion that many disabled people were experiencing, in areas such as community participation, access to health, education and employment, have become even higher since the start of the pandemic. This has largely been attributed to a failure of government responses to adequately take account of the specific needs and priorities of disabled people, as well as the particular risks that they are exposed to. Information provided about the pandemic and the control measures in place has often been unclear and not fully accessible. Economic measures have hit disabled people extremely hard, especially those working in the informal sector. The closures of schools have led to the further exclusion of disabled children, many of whom have been unable to access remote learning. Many disabled people have lost access to the support of caregivers and the essential services that they rely on. All of these themes are further explored, from the perspective of disability organisations, in this present study.

Methodology

This study is based on an online-survey, conducted during July 2021, which was sent out to disability organisations based in low and middle-income countries situated across five regions: South Asia, South-East Asia, the Middle East, North and East Africa, Southern Africa and the Caribbean. Three countries were chosen from each of these regions, selected on the basis of an initial internet search, using key words such as 'disability organisation', 'disabled people's organisation' and 'organisation of persons with disability', to identify the prevalence of relevant organisations (defined as organisations that aim to represent disabled people and/or provide services to them) with an online presence. With the help of a native French speaker, keywords were also translated into French, in order to widen the pool of potential participating organisations. The internet search led to the selection of the three countries in each region with the highest prevalence of relevant organisations. Five relevant organisations were then identified within each of the 18 countries selected (apart from two Caribbean countries for which only 4 organisations could be identified). 16 of these organisations were selected on the basis that they were known to the author through contacts or previous research while 12 others were selected on the basis that a named contact person was identifiable on their websites. These criteria were adopted as it was felt that these organisations would be most likely to respond. The remaining organisations were selected through a process of analysing the website information available to determine how cohesive and well-established the organisations appeared to be and whether they were engaged in activities that were likely to be affected by the pandemic. These judgements were made in an attempt to select the remaining organisations that would be most likely to be able to provide information relevant to the study. This selection process generated a total sample population of 88 organisations (these included 12 country offices of the international NGO Humanity and Inclusion (HI), which were treated as separate organisations for the purposes of the survey).

Survey responses were received from 20 representatives of disability organisations located in the following 13 countries: The Philippines, India, Bangladesh, Nepal, Kenya, Uganda, Tunisia, Zimbabwe, Madagascar, Palestine, Lebanon, Iraq and Jamaica. It should be noted that due to the relatively low survey response rate of around 23 per cent some countries were over-represented in the final sample while others were not represented at all. For example, three organisational responses were received from both Uganda and Bangladesh, while only a single response was received from the 13 organisations that were targeted in three Caribbean countries. This implies that caution should be exercised in terms of generalising from the survey findings, especially in relation to countries from which only single

responses were received. Furthermore, some of the respondents completed the survey in far more detail than others. Due to these final sample imbalances, certain countries feature more prominently than others in the survey analysis, especially Kenya, Uganda, Bangladesh and the Philippines. Although the final sample group included quite a small number of organisations, each participant had knowledge of disability issues and concerns far beyond their own personal experiences, through their roles as organisational representatives. Of the 20 responses, nine were received from DPOs (including one national umbrella body). A further seven were received from HI country offices, three were received from local disability-focused NGOs and one from a semi-autonomous government agency. The table below lists the participating organisations and the countries in which they were based.

The online survey questionnaire, developed using the Qualtrics software package and made available in both English and French, consisted of eleven open-ended questions exploring how the pandemic had impacted on the activities of the organisation and the lives of their members and/or beneficiaries. The areas covered included organisational impacts, isolation and loneliness, mental health impacts, impact on family carers, community participation, economic participation and hardship, health and rehabilitation services, access to education and access to COVID-19 testing and treatment. Although survey respondents were not involved in formulating the questionnaire, the open-ended wording of the questions allowed space for respondents to raise issues that they considered to be of most importance. The questionnaire also included a question on what more could have been done to support disability organisations during the pandemic and a final question providing an opportunity for participants to add any other information that they felt was relevant. Two responses were received in French, and these were translated by the native French speaker. The survey data was thematically analysed (Braun and Clarke 2012), which involved using manual colour coding to identify emerging patterns and themes which could be grouped together into broader categories. This inductive approach was based on the assumption that the data would reveal a certain commonality of experience (Patton 2014), despite the widely differing contexts within which participating organisations were operating.

In relation to the initial sampling process, certain limitations that arose due to practical constraints should be acknowledged. Firstly, the sampling process was largely reliant on internet searching, which may have excluded many relevant organisations that do important work but not have a strong internet presence. Secondly, a wide range of terminology is used to refer to the various types of disability organisation that were the focus of the study, so my choice of keywords may have excluded some of these organisations. For example, DPOs are sometimes referred to as self-help groups or 'savings and lending groups' (Young, Reeve, and Grills 2016). Thirdly, some

organisations may have been excluded on the basis of language, especially in countries that were predominantly Arabic or Spanish speaking, due to a lack of translation resources. These limitations reduced the scope of the study, most likely leading to the exclusion of some organisations that would have been able to provide valuable insights into the impact of the pandemic within the disability sector, especially in countries where English or French is not widely spoken. The reliance on internet searching may also have reduced the extent to which the study was able to capture the perspectives of local grassroots disability organisations.

Survey findings

Five major themes emerged from the thematic analysis: organisational impact and response, isolation and loneliness, access to healthcare services, economic hardship, and educational inequalities. It should be noted that some of the areas covered by the eleven survey questions did not require a separate theme as responses were captured by one of more of these broader themes. For example, insights provided around the impact of COVID-19 on family carers were captured by both the 'isolation and loneliness' and 'economic hardship' themes, while responses to the question on community participation were captured by several of the major themes. Given the relatively small sample size, the thematic analysis was useful in terms of enabling a larger body of responses to be analysed in relation to each of the major themes than would have been the case if the interview questions themselves had been used as analytical categories. The findings in relation to each of the five major themes are presented in this section. In addition, responses to the question on how disability organisations could have been better supported are analysed separately. Where possible these findings are presented through the words of the organisational representatives themselves, in order to capture the voices of those with first-hand knowledge of the realities facing disabled people with whom they were in direct contact.

Organisational impact and response

Virtually all of the survey respondents reported that organisational activities had been severely disrupted during the pandemic. The imposition of lockdowns and curfews, together with travel restrictions, had led to the closure of offices and curtailment of activities involving face-to-face contact, such as home visits to provide therapies and counselling. In many cases funding had been reduced, from both donor and government sources, leaving some organisations facing a financial crisis. However, a pattern of resilience also emerged from the findings with organisations generally finding ways to adapt their services and continue to provide support to their members and

beneficiaries during lockdown periods. In Uganda, for example, the Masaka Association of Persons with Disabilities living with HIV/AIDS (MADIPHA) had mobilised a team of community peer monitors who maintained contact with members who were isolated in their homes and helped to ensure the delivery of essential supplies. In Bangladesh, a representative of the Bangladesh Disabled Development Trust (BDDT) reported that:

Home visits had to stop during the lockdown period so instead staff dropped off toys and education materials for families and provided counselling support for children over telephone and video.

In order to maintain some level of service delivery, 11 of the organisation representatives reported that they had established remote interventions. For example, the Centre for Disability and Development (CDD), also based in Bangladesh, had set up tele-counselling and tele-rehabilitation services, while the HI representative in Iraq reported that mental health and psychosocial support sessions were being delivered via telephone. Four respondents reported that remote modalities had been used to ensure that disabled people received reliable and accessible information about the state of the pandemic, the response measures in place and sources of support available to them. However, various challenges arose with the delivery of services via remote methods. For example, the HI representative based in Palestine, where there had been a recent escalation of conflict, reported that many beneficiaries were not able to access remote services due to 'chronic situations such as lack of electricity, internet and access to smart devices'.

Two respondents reported that their organisations had launched new awareness raising and advocacy initiatives, in order to highlight disability concerns during the pandemic. The Samarthanam Trust, based in India, had launched a special campaign to increase vaccination rates among disabled people, while HI in Madagascar had been working closely with local DPO partners to support them in sharing information with their members and raising awareness of issues such as gender-based violence.

Isolation and loneliness

The increased isolation and loneliness of disabled people was identified by 14 of the survey respondents as one of the major impacts of the pandemic. The HI representative in Madagascar reported that overprotection from families and general community perceptions associating disability with vulnerability had led to many disabled people isolating in their homes, even when they were not required to by law. In several countries disabled people had been cut off from their caregivers for a variety of reasons, including lockdown measures, transport restrictions and fears of infection through physical contact. In one particular case,

reported by the DPO representative in the Philippines, the consequences were tragic:

A colleague of ours died during the pandemic ... He was hospitalised and his personal assistant was not able to get back to the hospital after returning back home because of the lockdown measures. It resulted in further degradation of his health condition, probably adding to his sense of loneliness. In the end, he decided to remove life support. No one was there for him during the whole time.

In some cases the sense of isolation was reinforced through a lack of reliable information about the pandemic. In Uganda, for example, there was 'limited access to enough information on COVID-19 which intensified fears of infection and death'. Five respondents reported that their members or beneficiaries lacked access to modern technology, such as the Internet or even telephones. In Madagascar, for example, disabled people often had to 'rely on information shared by others, which are sometimes unverified rumours'.

In some countries it was reported that prolonged periods of confinement, withdrawal of essential support services and livelihood concerns had heightened insecurities and resulted in mental health issues for many disabled people. In Iraq, the HI representative reported a 'rise in psychosocial support needs among people with disabilities who had difficulty to accept being even more isolated than normal'. In Lebanon, a representative of the Lebanese Union for People with Physical Disabilities (LUPD) reported on a local COVID-19 survey which had garnered 583 responses from disabled people, 83 per cent of whom 'expressed an impact on psychological wellbeing including feeling more isolated'. A representative of the National Council for Persons with Disabilities (NCPWD) in Kenya elaborated further on this issue:

When persons with disabilities are unable to get personal assistants, or the required support from social workers due to the COVID-19 containment measures, they feel abandoned, alone and helpless. This in turn causes problems with their mental health. Also, some persons with disabilities, particularly those with cognitive challenges, may find it difficult to comprehend the containment measures of wearing masks and social distancing, hence may interpret the measures as an attempt by their caregivers to reject and isolate them. This can cause mental anguish.

An added burden on family caregivers, often coupled with a loss in household income, was noted by 17 of the 20 respondents. The widespread breakdown of support services had led to many family members taking on additional care responsibilities for disabled family members, often substituting for trained professionals. In Jamaica, the pandemic had impacted 'financially, emotionally and mentally' on family carers. In Kenya, Uganda, Madagascar, Bangladesh, Nepal and India it was reported that some caregivers had even been forced to give up work in order to provide the extra care needed. The HI representative in Kenya emphasised that 'at times disabled people had been neglected not through choice but because their carers needed to look for food'.

The survey findings suggest that the isolation and loneliness experienced by many disabled people during the pandemic persisted even with the easing of lockdown measures, partly due to fears of infection among disabled people themselves, but also due to the limited availability of accessible transport, lack of personal assistants and the reduced level of community activities. Some respondents also reported increased levels of discrimination within the community, due to restrictions on public gatherings, as well as fears that disabled people were carrying the virus. For example, the DPO representative in the Philippines reported that certain establishments within the community were denying entry to disabled people based on the assumption that they were more likely to be infected, while a DPO representative in Uganda explained how rules on the size of public gatherings impacted disproportionately on disabled people:

Only 20 people were allowed to gather. Usually people with disabilities are the last group to be thought of to participate in community events, so it was worse during this period of COVID-19.

Access to healthcare services

Respondents from all countries covered by the survey revealed that general healthcare services had been withdrawn or severely cut back, with hospitals and health centres saturated with cases of COVID-19. This had resulted in disabled people, many of whom have underlying health conditions, often being denied access to regular treatments and rehabilitation services. In Nepal, for example, it was reported that ‘most services were closed or providing limited emergency services only’, while in Kenya ‘hospitals became overwhelmed, hence almost inaccessible to persons with disabilities in need of regular therapy/rehabilitation services’. In India, disabled people had been deprived of regular health and rehabilitation services, medication supplies and assistive devices. In Uganda, both of the DPOs supporting disabled people with HIV/AIDS had received numerous calls from members who had run out of antiretroviral drugs as they could not reach the health centres. The healthcare crisis was sometimes exacerbated by a lack of accessible transport, as described by the HI representative based in Zimbabwe:

Some health facilities were closed, and mobility was compromised through the banning of inter-city transportation other than through quasi government transportation (which was not modified to suit the accessibility needs of persons with disabilities). There was also a loss of income to purchase essential medication and medical provisions.

Nine respondents reported that vaccination programmes had failed to prioritise disabled people, despite them often being among those most at risk of contracting the virus. In Nepal, for example, it was noted that disabled

people were often the last ones to get vaccinated. Failures on the part of government agencies to develop effective communication strategies around vaccination and testing programmes were also frequently reported, with disabled people often disadvantaged by a lack of accessible information. In Zimbabwe, for example, there was no effective education and communication strategy to promote vaccination take-up among disabled people, while in Jamaica deaf people were sometimes deterred from attending vaccination centres due to a lack of sign language interpreters.

Economic hardship

The survey revealed numerous stories of economic hardship, brought about through the loss of regular income. Nine respondents noted that their members and beneficiaries often relied on informal work activities, which had either ceased during lockdown periods or been badly affected by a loss of market. The HI representative in Iraq observed that disabled entrepreneurs had limited market share in normal times, with the situation becoming ‘really critical’ since the onset of the pandemic, while a DPO representative in India reported that the majority of members had lost their livelihoods. A DPO representative from Uganda elaborated further on how members’ livelihood activities had been affected:

Many persons with disabilities were stopped from their work because they don’t fall into the categories of essential workers. They engage in casual types of work—street and market vendors, tailors, shoe repairs, salon operators—which are always affected by the lockdown. In general people with disabilities have been badly treated by COVID, they have lost their income generating activities/businesses apart from the few engaging in small scale or subsistence farming.

Widespread job losses were reported in all of the countries surveyed, as a result of the pandemic, but disabled people had often been disproportionately affected in this regard. As the HI representative based in Nepal explained, when unemployment is on the rise ‘persons with disabilities are the first to lose their jobs, and when there are some opportunities they are the last ones to get it’. In Lebanon, similarly, the LUPD representative reported that disabled people had been the first to lose their jobs during the pandemic. Respondents based in the Philippines and Tunisia noted that for those working in formal sector jobs a general shift towards home working had provided a lifeline, enabling some disabled people to continue to earn a living. However, as the DPO representative from the Philippines explained ‘working from home may also be challenging. One must have a computer or smartphone and a good Internet. Internet is not reliable in many places’. In Tunisia, similarly, the HI representative reported that disabled people could not always participate under alternative working arrangements due to ‘inaccessible and limited digital access’.

The devastating economic impact of the pandemic had led to severe impoverishment among disabled people and their families, according to 11 of the survey respondents. Many families were facing a food crisis, as well as being unable to access medication and other essential supplies. A DPO representative in India revealed that some members were ‘suffering from hunger and starvation’, while a DPO representative in Bangladesh also revealed the extent of economic hardship among members:

There is no limit to the suffering for disabled people ... The situation is that now there is no food, no matches to light fire, no cooking medium, no shops no transport. Disabled people are soliciting food.

Educational inequalities

There was a general consensus among survey respondents that school closures during lockdown periods had reinforced educational inequalities, with the shift to remote teaching often disadvantaging disabled children. It was frequently reported that many families with disabled children were not able to access online lessons, either because they could not connect to the Internet or because the online lessons were not fully accessible. Even where teaching was delivered via television or radio, some children were excluded due to inaccessible content and electricity shortages.

Four respondents noted that children with hearing and visual impairments were most likely to be excluded from remote teaching. A representative of the Jamaica Association for the Deaf (JAD) reported that many deaf children did not have access to devices and those that did often relied on parental support to participate in online lessons, which was not always available. In Uganda, the challenges faced by deaf children during periods of school closure had led to them underperforming in examinations, as explained by a DPO representative:

All schools were closed by the Government. They provided reading materials in inaccessible formats to children with disabilities in primary and secondary levels, then there were teaching sessions or programs on local radio and television without consideration of reasonable accommodation for deaf, blind children, or slow learners. Later classes opened in phases one month before examinations took place. When the results of the primary leaving examinations for 2020 were released by the Uganda Examination Board all deaf children who sat the exams were ungraded (failed). Most of these children come from poor families that cannot afford high internet costs or monthly television subscriptions.

Three respondents commented on the social costs arising from the school closures, which often occurred with very little notice. As the HI representative in Nepal observed, disabled children were cut off from their peers and denied access to recreational space. While these experiences were common to most children during the pandemic, many disabled children were particularly

affected by the sudden change in routine, as explained by a representative of the Centre for Services and Information on Disability (CSID) in Bangladesh:

For children with autism and neurodiversity the sudden closure of schools was traumatic, representing a huge change in their daily routines which has been difficult to get used to. Children with disabilities always enjoy going outside, especially to school, which is one of their recreational places that reduces their frustration. But because of the pandemic situation the school are closed and they are not allowed to go outside. Some of them don't even know what the crisis is about.

How disability organisations could have been better supported

Various suggestions were put forward by respondents as to what more could have been done to support disability organisations and their members during the pandemic. Seven respondents commented on the need for more effective communication strategies, in order to ensure that information was accessible to all disabled people and could be accessed in a timely manner. Five respondents called for disabled people to be compensated for the loss of household income and/or the extra costs that they had often incurred in order to protect themselves from the virus. Four respondents expressed the view that vaccination and testing programmes should prioritise disabled people, due their increased levels of vulnerability to infection. Other suggestions included the provision of basic necessities to households with disabled members and the targeted provision of psycho-social support. However, the strongest response to emerge on this question was the need for disability organisations to be more involved in the planning and implementing of official pandemic responses. Of the fourteen representatives who answered this question, thirteen of them expressed the view that disability organisations should be at least consulted, with six of them arguing that their organisations should have been fully involved in planning the response from the outset.

Discussion

The organisations that participated in this study were all based in the Global South, which is largely comprised of countries that share a history of colonial exploitation and control that has left a legacy of poverty and inequality (Meekosha 2011). However, the country settings also spanned three continents and varied significantly in terms of social and cultural norms, governance structures, security issues and economic context. Despite these very different contextual settings, the picture that emerges from these findings is strikingly consistent and sadly all too familiar. When disasters strike they tend to exert a disproportionate impact on disabled people, who are often at a disadvantage due to pre-existing structural inequalities arising through

disability-related stigma, discriminatory procedures and practices, inaccessible infrastructure, inadequate data on disability and a lack of participation in disaster planning and management processes (King et al. 2019; Smith, Jolley, and Schmidt 2012; International Federation of Red Cross and Red Crescent Societies (IFRC) 2007). In the aftermath of disasters, these pre-existing inequalities deepen and poverty becomes more firmly entrenched. Following the 2015 earthquake in Nepal, for example, disabled people experienced even greater levels of vulnerability and exclusion than before, largely due to their lowly position within the social hierarchy and a wide range of disabling barriers (Lord et al. 2016). COVID-19 is a very different kind of disaster on a much greater scale but these study findings suggest that, for disabled people linked to the organisations that responded to the survey, history has repeated itself once again. This very much reinforces the messages arising from the studies reviewed earlier in this article, especially the COVID-19 DRM survey.

The findings suggest that many disabled people in the countries surveyed had experienced increased levels of isolation due to being labelled as vulnerable, sometimes purely on the basis of being disabled, and hence experiencing even stricter restrictions on freedom of movement than the general population. In line with some of the studies reviewed earlier (National Centre for Promotion of Employment for Disabled People (NCPEDP) 2020; Rohwerder et al. 2021; Wickenden et al. 2021; COVID-19 DRM 2020), this increased sense of isolation had been reinforced by job losses, business failures and a breakdown of support services, often having a detrimental impact on mental health. Disabled children, in particular, had experienced increased levels of social isolation during school closures due to being cut off from their peers. This is consistent with the findings of a survey in Australia on the educational impact of COVID-19, conducted by the national representative organisation Children and Young People with Disability Australia (CYDA), which collected 700 responses from its membership base (Dickinson et al. 2021). In this Australian survey 72 per cent of respondents agreed with the statement that 'students felt more socially isolated from their peers' during periods of remote learning. One of the respondents did acknowledge that this was a general problem for society as a whole, but also suggested that the situation was worse for disabled learners because many already had mental health issues due to the discrimination within mainstream society that they typically experience.

Another clear example of the pandemic reinforcing inequality relates to the digital divide, which refers to the gap between those who are able to benefit from access to digital technology and those who are excluded from it (Feather 2018). Various international surveys conducted over the past decade have shown that disabled people consistently have less access to the Internet than non-disabled people (a gap of up to 30 per cent in some countries), and that households with disabled members are similarly

disadvantaged (United Nations Department for Economic and Social Affairs (UNDESA) 2018). The digital divide is further reinforced for many disabled people through digital illiteracy, often as a result of missed schooling, or where digital technology is not fully accessible. The findings of this study suggest that increased reliance on digital technology during the pandemic, particularly in the fields of education and employment, had reinforced the inequalities arising from the digital divide. Disabled children had fallen further behind in their education and disabled employees had been disadvantaged due to issues around digital accessibility while working from home.

The findings also provide evidence of deepening inequalities in terms of access to healthcare. Disabled people typically have less access to healthcare than the general population, across all age groups, and thus have greater levels of unmet health needs (WHO and World Bank 2011). With the pandemic placing extreme pressures on healthcare systems around the world, movement restrictions in place and transport options reduced, the survey revealed that many disabled people had been denied access to regular treatments, therapies and even medication. This had been particularly harmful for those with underlying health conditions, such as the members of the two Uganda-based DPOs supporting disabled people living with HIV/AIDS.

Disabled people are similarly disadvantaged in terms of employment, with the employment gap between men and women estimated to be 24 per cent globally (UNDESA 2018). Most of the survey respondents reported significant job losses among disabled people, who were often the first to lose their jobs during the crisis, while other respondents noted the huge impact on informal sector activities, on which many disabled people and their families depend. The findings suggest that either governments had failed to implement measures to protect the livelihoods of disabled people during the pandemic, particularly those dependent on the informal sector, or that many disabled people had been unable to access the support available. Either way, inequalities in terms of economic participation had deepened, especially during lockdown periods.

As the world continues to adjust to the impact of COVID-19, new societal norms will be established. These norms need to accommodate the full scope of human diversity, rather than penalising those who cannot easily conform to new patterns of living. If working from home is going to become standard practice, for example, then companies need to ensure that reasonable adjustments are applied not only to communal workplaces but to the homes of disabled employees. The era of COVID-19 has seen a rapid growth in digital opportunities, such as on-line shopping, social media platforms and video conferencing platforms which have the potential to transform the lives of disabled people, enabling them to connect with others in ways that would have been unimaginable only a few years ago. It is vital to ensure that disabled people, including those living in the poorest communities around

the world, are able to take advantage of these opportunities. For example, if schools are going to switch to online learning when there is an outbreak of a new virus, or a new variant of an existing virus, then measures must be implemented to ensure that disabled children can access remote learning on an equal basis with other children. All children have the right to an education, whether that education takes place in school or at home.

As several of the survey respondents suggested, the starting point is to engage in a meaningful way with disabled people and the organisations that represent them, so that disability-inclusive responses are developed from the outset, rather than as an afterthought. The importance of recognising the potential of disabled people and their representative organisations to play a crucial role as active contributors to disaster planning and management processes is clearly spelt out in the Sendai Framework (United Nations 2015a), the current international blueprint for disaster planning and management which was adopted at the 2015 World Conference on Disaster Risk Reduction in Japan:

Persons with disabilities and their organisations are critical in the assessment of disaster risk and in designing and implementing plans tailored to specific requirements. (Paragraph 36(iii))

The adoption of the Sendai Framework marked a significant commitment, on the part of governments and humanitarian agencies around the world, to prioritise the mainstreaming of disability and active involvement of disabled people themselves in disaster management processes, rather than simply viewing them as a vulnerable group. The vast majority of nation states have also ratified the CRPD, which upholds the participation rights of disabled people, and signed up to the 2030 Agenda for Sustainable Development (United Nations 2015b), which promises to leave no one behind. The evidence that has emerged since the onset of the COVID-19 pandemic, very much supported by these study findings, is that these commitments have carried little weight in terms of ensuring disability-inclusive responses to the pandemic that draw on the knowledge and experience of disabled people and the organisations that represent them.

Conclusion

This study was based on a small and geographically uneven sample of organisation representatives. It is important therefore to stress that the views expressed and experiences revealed do not necessarily represent those of the wider community of disabled people in any of the 13 countries that were represented in the sample. However, the insights provided were consistent with those arising from the growing body of literature on the experiences of disabled people during the COVID-19 pandemic. The clear and consistent

messages arising from this literature should serve as a wake-up call to policymakers and service providers around the world. Official responses to the pandemic have failed to provide adequate support and protection to disabled people, many of whom have been left isolated from their support networks, cut off from essential services, excluded from education and living in deeper poverty than before. The pandemic has also created new opportunities and new ways of living which could signal a brighter future. Shakespeare, Ndagire, and Seketi (2021) point out that disabled people do not want a return to the pre-pandemic world, in which they face barriers to virtually every aspect of societal inclusion. As this study has shown, disability organisations have provided vital support to their members and beneficiaries during the pandemic, checking on their welfare, listening to their concerns and often filling in the gaps in mainstream service provision as they try to ensure that essential needs are met. As the world continues to emerge from the pandemic, such organisations need to be empowered to play a much more prominent role in the long-term recovery process. If a more inclusive, just and resilient society is to arise from the ashes of COVID-19 then policymakers and service providers need to collaborate with disabled people and their representative organisations to deliver disability-inclusive solutions to the challenges that they are faced with, rather than adopting a ‘one size fits all’ mentality.

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Table 1. Participating organisations.

Organisation	Type	Location
Humanity and Inclusion (HI) (seven responses received from country offices)	International NGO	Nepal, Philippines, Madagascar, Kenya, Tunisia, Palestine, Iraq.
Life Haven	DPO	Philippines
Bangladesh Disabled Development Trust (BDDT) (two responses received)	DPO	Bangladesh
Centre for Services and Information on Disability (CSID)	DPO	Bangladesh
Centre for Disability and Development (CDD)	NGO	Bangladesh
Samarthanam Trust	NGO	India
Lebanese Union for People with Physical Disabilities (LUPD)	DPO	Lebanon
Jamaica Association for the Deaf (JAD)	NGO	Jamaica
National Council for Persons with Disabilities (NCPWD)	Semi-autonomous government agency	Kenya
National Association of Societies for the Care of the Handicapped (NASCOH)	National DPO umbrella body	Zimbabwe
Masaka Association of Persons with Disabilities living with HIV/AIDS (MADIPHA)	DPO	Uganda
Rakai Association of Persons with Disabilities living with HIV/AIDS (RADIPHA)	DPO	Uganda
Uganda National Association of Cerebral Palsy (UNACP)	DPO	Uganda

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