

“We’re an afterthought”

Experiences of the deaf, blind, and deafblind in
sub-Saharan Africa during the COVID-19 pandemic



SEI discussion brief

June 2021

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We gratefully acknowledge the contributions of those who participated in the consultations that provided information for this brief. We thank the senior/executive representatives of the Cameroonian Association of Blind Women, the Deaf Federation of South Africa, the Rwanda Union of the Blind, and the Zimbabwe National League of the Blind.

Funding for this scoping study was received from the Swedish International Development Cooperation Agency (Sida), via SEI's core funding. We also gratefully acknowledge the generous comments on an earlier draft of this paper provided by Leilani Craig and Emma Calgare, both at University of Sydney.

IMAGE (ABOVE): Blind school child using Braille alphabet in a primary school, Tanzania, Africa © HUGH SITTON / GETTY

Key messages:

- Those who are deaf, blind, and deafblind living bear a disproportionate burden of the negative impacts of the pandemic, as shown by insights from four sub-Saharan African countries (Cameroon, Rwanda, South Africa, and Zimbabwe).
 - For people with these disabilities, the pandemic has exacerbated existing problems by elevating health risks, threatening livelihoods, and limiting access to key information. For example, wearing masks that are not transparent makes lip reading impossible, and social-distancing measures present difficulties for people with visual impairments who rely on guides.
 - The failure of governments to adequately respond to the needs of people with these disabilities in the pandemic and in other disaster situations underscores the important role played by organizations representing the deaf, blind, and deafblind in championing their rights.
 - Future research should strive to better understand the needs, perspectives, and priorities of the deaf, blind, and deafblind; and to gain better insights into ways to dismantle the political and cultural sources of discrimination in sub-Saharan Africa and elsewhere.
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Introduction

As the COVID-19 pandemic unfolded in early 2020, many observers stressed our shared human predicament in combatting the virus, and in the global recession it has triggered. But the impacts of the both the pandemic itself and government responses to it have been far from equal; this pandemic, like other disasters, has again exposed and compounded pre-existing societal weaknesses and high levels of inequality and injustice. Globally, the virus has caused more deaths among low-income and minority groups; societal lockdowns divert much-needed political attention and finances away from the most vulnerable (Human Rights Watch, 2020). In low-income countries, the pandemic and the associated austerity measures are also causing systemic setbacks for human development, pushing more poor people into food insecurity, heightening humanitarian aid dependency, and increasing the debt burden for poor nations (Sida, 2020).

As we argue in this brief, disproportionate effects are borne by those who are deaf, blind, and deafblind living in developing countries. Like other people with disabilities, deaf, blind and deafblind people face enduring environmental, physical, and social barriers that hinder their ability to cope and effectively respond to risk, particularly when

disasters arise (Calgaro et al., 2021). Moreover, a combination of their disabilities with other characteristics, such as gender, ethnicity, class and/or sexual orientation, can compound the problems they face (Craig et al., 2019).

The needs of deaf, blind, and deafblind in the context of the COVID-19 pandemic have received some international attention. For example, during the first half of 2020, it was pointed out that international organizations such as the World Health Organization and the World Bank lacked the provision of sign language interpreters at their press briefings, which prevented deaf people and their organizations from accessing vital information needed to safeguard their lives (Yap et al., 2020). Reports from South Africa also suggest that triage policies have negatively stereotyped and actively excluded disabled people from life-saving medical care (McKinney et al., 2020). Indeed, it is well known that a lack of access to equal health, education, social and mental health services is a key driver of disaster injustices that compound pre-existing levels of societal marginalization (White, 2006; Takayama, 2017).

In this brief, we discuss the impact of the COVID-19 pandemic on deaf, blind and deafblind people, and the inclusiveness of government responses, with a focus on sub-Saharan Africa. This brief is based on two sources of information: i) a desktop review of published research, government policy documents, and reports by development agencies and international organizations; and ii) consultations with four organizations representing deaf and blind people in Cameroon, Rwanda, South Africa, and Zimbabwe.

A research gap

Our review of the literature identified only three published studies with primary data about the impacts of the COVID-19 pandemic on deaf, deafblind, and/or blind people in sub-Saharan Africa:

- Swanwick et al. (2020) conducted interviews among deaf people in Ghana, showing how the combination of societal lockdown and an inaccessible language environment isolated people from peers and professional support, and excluded them from information about the pandemic.
- Tsiboe (2020) interviewed visually impaired elderly people in Ghana, finding that they lacked access to public health services, and that during lockdown, they lost access to informal caregiving, with many experiencing hunger and suicidal depression.
- Lazarus and Oluwole (2020) conducted an online survey in Nigeria to gauge knowledge about the pandemic among people with disabilities (some of whom are deafblind), showing that they lacked access to medical and economic support.

One might initially think that the scarcity of information is unsurprising, given the still-ongoing nature of the pandemic, and the fact that academic research and publishing takes time. However, it is instructive to contrast the paucity of studies of these groups with the wealth of other pandemic studies; a search of Google Scholar and the Web of Sciences in December 2020 found some 100 000 published research articles about the COVID-19 pandemic. Among these, some 15 000 studies focused on persons with disabilities other than deaf and deafblindness. Clearly, just because the research literature lacks attention to an issue does not mean there is no knowledge base. For example, civil society and international organizations may offer valuable insights (e.g. World Health Organization, 2020). Still, the paucity of attention to the subject is arguably indicative of a considerable knowledge gap about the vulnerabilities and

impacts on this group of people. This is also a measure of the limited attention their plight has received from both decision-makers and researchers.

Experiences of the deaf, blind and deafblind during the COVID-19 pandemic

In our consultations, representatives from four organizations supporting deaf, blind and deafblind people in sub-Saharan Africa told us about key issues, which we outline here. Throughout this section we draw on quotes from the consultations (in italicized text) to clarify the arguments made, and, where relevant, we indicate which country is concerned. Key issues are:

Heightened exposure to COVID-19, but limited access to health care

Overall, the deaf, blind and deafblind have been disproportionately exposed to contracting the virus. This is especially the case for people who are dependent on tactile contact for communication and navigation. For example, people with visual impairments often depend on assistance from others via physical contact. As one person stated, *“Keeping 1.5m distance is not possible, for a blind person who must be guided by the arm...”* Though special services may be available to enable access to medical care in principle, people have often been excluded from hospitals or health clinics in practice. Blind people have difficulty navigating in hospitals and medical clinics, and hence they may opt to stay at home, even when fatally ill. Such issues amplify pre-existing challenges with accessing medical assistance in sub-Saharan Africa, including the lack of trained medical staff (Armitage & Nellums, 2020; Senjam, 2020).

Exclusionary disaster communication

There has been a general lack of support to enable deaf and deafblind people to access information about health risks through measures, including but not limited to the use of sign language interpreters, subtitles, audio solutions, or text information via the Braille system of touch reading and writing. For deaf people who rely on lip-reading, the face masks worn by government staff or medical during press briefings impede communication. The deaf, blind and deafblind thus lacked vital health information, leaving them more exposed to the virus and without adequate understanding the risks, or how to protect themselves. *“Deaf people missed a lot of information,” one person stated in the consultation. “They believed that the COVID-19 mostly was like the common flu.”* Such insights echo findings from earlier disasters, globally, about the severity of pre-existing communication barriers, including, in particular for deaf people, disproportionately low literacy levels and shortages of qualified sign-language interpreters (Calgaro et al., 2021).

Increased burden on relatives, and isolation in families

Having difficulty accessing communication via media or government channels, deaf, blind and deafblind persons have often become even more dependent on their family members. They increasingly depend on family to convey health information and other disaster-related instructions, and to provide life-sustaining support, including access to food. As several of the contributors to this study noted, this is especially the case during lockdowns, when people have been cut off from social services, schools and workplaces. It is rare for family members to master sign language or otherwise know how to support their disabled relatives. This, in turn, increases isolation, particularly among older people with disabilities. Whereas young people may use social media to stay in touch with peers, many adults and especially the elderly, lack digital literacy or access to necessary technology.

Unemployment, livelihood loss, and food insecurity

Lockdowns have had tremendous impacts on the economies worldwide, but as the consultations highlighted, deaf, blind, and deafblind people appear to have been disproportionately affected, compounding already high rates of poverty and unemployment. This is oftentimes linked to culturally rooted stigmatization and discrimination, leading people to wrongly assume that individuals with physical impairments are also mentally impaired – and, shockingly, in some cases, even less human (see also Swanwick et al., 2020; Senjam & Singh, 2020). As one person stated in a consultation, *“People with disability are viewed as having less value...”* Before the pandemic, many blind people depended on singing on buses, or begging or selling sweets on the streets to survive. These meager livelihood options have typically been among the first to disappear with government restrictions. For example, a representative from Zimbabwe said in the consultation that prior to the pandemic, several poor deaf, blind, or deafblind Zimbabwean people had migrated to South Africa to pursue what they thought would be more and better opportunities to survive by begging or selling items on the street to make money. Pandemic-related restrictions have made it harder for these people to survive, he said.

Difficulties in swaying government and accessing international support

In these efforts, organizations supporting the blind, deaf or deafblind report tremendous challenges with convincing governments to take their views seriously. One example concerns the use of Braille. Whereas blind persons would considerably benefit from Braille-based information, this has rarely been accommodated. *“The government thinks it is cheaper and faster to produce information in audio format than to generate text in Braille.”* In Rwanda and Zimbabwe, government agencies rejected calls for investments in Braille from organizations representing the blind; instead, the government took the advice from those outside the blind community who advocated for purely audio-based communication to reduce costs. Arguably, such attitudes ignore the fact that what constitutes appropriate forms of communication depends entirely on the group concerned. For instance, audio solutions do not address the needs of the deaf or deafblind, for whom the governments adopted no special communications methods, such as Braille. Offering several different communication techniques would increase accessibility and inclusion.

Self-organized actions and mobilization

National organizations supporting the blind, deaf and deafblind have worked hard to raise awareness of the issues, and to prompt their respective governments to take action. This has often been in collaboration with regional or international organizations, such as the African Union for the Blind, the World Blind Union, the World Federation of the Deaf, and the World Federation of the Deafblind. In several cases, organizations have filed complaints in court, as means to put on pressure for change. As one participant noted in the consultation, *“Governments are not aware... [and] ignore the blind people.”* Professionals across sectors have also embarked on collaborations to address needs. For example, teacher communities in South Africa are making special efforts to support deaf students isolated at home. As one participant in the consultations said, *“They are trying to spread ‘happiness’ to deaf children [in] home quarantine... to keep their mood [up].”*

Ways forward: urgent development and research needs

The COVID-19 pandemic presents the global community with an opportunity to address these issues. Ways forward could emerge through international agreements already in place, such as the Convention on the Rights of Persons with Disabilities (through, for example, articles 9 and 11) and the Sendai Framework for Disaster Risk Reduction (2015-2030). These measures recognize that the inclusion of persons with disabilities in disaster preparedness and responses is a human right. These agreements recognize the need to shift from a charity model of disability in disaster responses, wherein people are viewed as “either victims or needy recipients” (Calgaro et al., 2021), to a model that treats people as self-determining cultural groups and individuals with distinct human rights and agency (Craig et al., 2019; Swanwick et al., 2020).

Despite such efforts, the COVID-19 disaster response in sub-Saharan Africa appear to have adopted conventional, top-down and exclusionary approaches that perpetuate outdated views. Rwanda, Zimbabwe and South Africa have signed and ratified the Convention on the Rights of Persons with Disabilities. (Cameroon has signed but not yet ratified it.) Yet, our scoping study suggests that their responses to the pandemic have largely failed in moving towards the rights-based approach that underpins the convention. Instead, governments appear to have perpetuated the charity model, often ignoring the rights and agency of deaf, blind and deafblind people. In light of the observed failures in government responses in this regard, a central insight emerging from this study is the crucial importance of self-initiated actions by organizations representing the deaf, blind, and deafblind themselves.

Arguably, such failure of governments may partly be explained by lack of resources and capacities needed for implementation. Nevertheless, our findings indicate that deeper and more significant issues are at play. Just as has been documented by previous research from other disasters globally, key causes appear to be rooted in cultural and political structures of discrimination against these groups (e.g. Calgaro et al., 2020). There is still a great lack of knowledge about these groups and their needs, which are the necessary starting points for taking steps to address their concerns and to more fully include this marginalized group of people into society.

We therefore stress the urgent need for national governments, development NGOs, and international development organizations to pay much-needed attention to and deliver on the needs of the deaf, blind and deafblind. More importantly, the focus must recognize their perspectives and competences. Partnerships with the key individuals and organizations have the potential to lead the way. These people and groups can champion a shift in perspectives and offer information to lead governments to take more informed actions that can help these communities. To this end, a relevant place to start would be to review past and current development programmes to shed light on the answers to key questions: What support has been provided so far? What is needed to generate more appropriate programming? What financing is needed? And how can organizations representing the deaf, blind and deafblind can be more involved in such decisions?

This brief shows the urgent need to probe deeper into the needs, perspectives and priorities of the deaf, blind and deafblind in sub-Saharan Africa – and, indeed, in other areas of the world that are facing similar issues. There is a need to examine the political and cultural structures of discrimination, and to understand how they can be dismantled. To date, little is known, either in the context of the COVID-19 pandemic, or other environmental or health-related disasters. It is our hope that this scoping study contributes to setting out and furthering this important research agenda.



Published by

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DOI: 10.51414/sei2021.017

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