



Participation and Leadership of Persons with Disabilities in Building a Disability-Inclusive, Accessible and Sustainable Post-COVID-19 World, 2021

Stakeholder Group of Persons with Disabilities COVID-19 Research Study

In response to the COVID-19 pandemic, the Stakeholder Group of Persons with Disabilities carried out two phases of qualitative research to gather information on the experiences of persons with disabilities in the context of the pandemic and to complement existing COVID-19 research studies. The [first phase of research took place in 2020](#) with disability movement leaders from around the world and the second phase followed in 2021 exploring three countries in depth: [Bangladesh](#), [Bolivia](#), and [Nigeria](#). The following provides a snapshot of findings and recommendations from both phases of research.

Phase I Research: The Experiences of Persons with Disabilities with COVID-19

The initial phase of research over the experiences of persons with disabilities with COVID-19 was carried out in May and June 2020 with 93 leaders from the disability movement. The data were gathered around thematic units related to the pandemic and the Sustainable Development Goals (SDGs). Methods to gather data included online interviews with leaders from the disability movement. These interviews were carried out via different methods depending on the context, internet access, and video quality. Additionally, focus group webinars took place to collect testimonials from different regional groups within the disability movement via online platforms. Also, online surveys were shared with organizations of persons with disabilities in Bolivia, Colombia, and Guatemala to explore one region in more depth. Interviews were conducted with 28 people with disabilities in six languages, including Arabic, English, Hungarian, International Sign, Russian, and Spanish. Four regional focus group discussions took place in English and Spanish via an online platform using live captioning and International Sign interpretation. Participants stemmed from all regions from more than 54 countries and represented all types of disabilities. Specifically, 65 people with disabilities participated from 13 countries in Africa, 16 countries in Asia and the Pacific, nine countries in Europe and North America, 12 countries in Latin America, and eight countries in the Middle East and North Africa.

Key findings

The findings indicated that most persons with disabilities around the world have been adversely affected by the pandemic with additional or new barriers, including barriers in the recovery phase. The most common barriers that emerged from the research included: (1) lack of access to COVID-19 information for all persons with disabilities; (2) barriers in receiving social protection measures and employment (formal and informal, losing employment first, and accessibility barriers in the virtual working environment); and (3) lack of disability inclusion in COVID-19 response and recovery efforts at all governmental levels, creating significant disconnections between national and local actions. In addition, three recurrent themes emerged from the research: (1) the role of organizations of persons with disabilities, (2) lack of access to healthcare facilities, and (3) lack of disability data, which are discussed below.

The role of organizations of persons with disabilities

To address lack of information and other gaps in government services, organizations of persons with disabilities (OPDs) stepped in and played a role to address these gaps. Many OPDs shared vital information otherwise inaccessible, raised awareness with their members, and provided accessible materials in different formats. Moreover, in many countries, governments began to provide national sign language interpretation and live captioning for news briefings. Often, the inclusion of these services was a direct result of advocacy efforts led by deaf communities and OPDs, and sometimes with support from international organizations.

Lack of access to healthcare facilities

In all regions, participants indicated barriers regarding access to healthcare facilities, including hospitals. Overall, many people believed that their life was considered less valuable than those without disabilities, and, in some grave cases persons with disabilities were denied access to hospitals and sent back home without support. Also, quite concerning, in some dire cases, the COVID-19 triage system excluded the appropriate treatment for persons with disabilities. The exclusion and denial of treatment were not on the basis of a medical condition, but rather because of discrimination. Other barriers in healthcare settings included, lack of disability awareness among staff and communication barriers for deaf and hard of hearing people due to healthcare staff wearing personal protective equipment and lack of information in sign language. Furthermore, there was lack of accessible transportation to and from healthcare facilities, and the inability for support persons and sign language interpreters to accompany persons with disabilities into healthcare settings, creating serious situations in some cases.

Lack of disability data

The findings indicated that by and large governments are not collecting COVID-19 data on persons with disabilities. Generally, there was disaggregation of COVID-19 data by age, gender, and sometimes location, but not disability. Moreover, some participants did not trust the accuracy of the COVID-19 data from the government, and there was limited data on COVID-19 in institutions, because in some cases, governments withheld the data from the public. To address this lack of official data, many OPDs, NGOs, and universities carried out surveys to collect information from persons with disabilities on their experiences. Data from this research and other studies can provide vital

information about the situation of persons with disabilities to adequately address inclusion in response and recovery policies, and to measure impacts, risk factors, changes, and trends of persons with disabilities over time.

Phase II Research: Case Studies in Bangladesh, Bolivia, and Nigeria

The second phase of research was carried out by local and regional researchers in Bangladesh, Bolivia, and Nigeria from February to April 2021. Data were gathered around thematic units related to the pandemic and the SDGs, particularly in the areas of health, social protection, employment and livelihood, accessibility, data, and access to vaccines. Methods to gather data included document analysis and key informant interviews with underrepresented persons with disabilities from different locations to gain in-depth views at the local level. The interviews were carried out in the local languages, including the national sign languages and via different methods and depending on the country's pandemic rules, internet access, video quality, and ability to travel.

Key Findings

All three studies indicated that the most significant barriers were: (1) lack of employment and social protection, (2) inaccessible healthcare facilities, (3) lack of access to information and data, and (4) lack of accessibility. Additionally, there were overlapping themes, including: (1) new barriers in the changing roles in extended family situations, (2) increased competition to find employment with overall high unemployment in society, (3) lack of resources to access information via phones and the internet increasing the digital divide, and (4) increased lack of security and safety.

Bangladesh

In Bangladesh, the research was carried out through semi-structured, in-depth interviews online and over the phone with individual persons with disabilities in open-ended queries and document analysis. The study interviewed 24 persons with disabilities considering a balance of gender, age, disability type, and geographical representation. The interviews consisted of 12 women with disabilities and 12 men with disabilities. Participants included 10 people with physical disabilities, seven blind people and one partially sighted person, two deaf people, one person with an intellectual disability, one person with a speech disability, one person with cerebral palsy, and one person with multiple disabilities. Participants' ages ranged from 22 to 55 years old. Participants came from eight divisions from Dhaka, Chattogram, Sylhet, Barisal, Rajshahi, Mymensing, Khulna, and Rangpur. Among those, 12 lived in cities, 11 lived in villages, and three in peri-urban areas. The findings show that existing barriers have increased and new challenges have emerged as a result of the COVID-19 pandemic. The main barriers that emerged include: (1) lack of inclusion in healthcare facilities, (2) lack of employment and social protection, and (3) lack of information and accessibility.

Findings indicated that healthcare facilities are not prepared for persons with disabilities, especially for persons with significant disabilities. The government has not given persons with disabilities priority access to get the vaccine. In most cases, the respondents believed that if they contracted COVID-19, they would be less likely to get proper treatment compared to persons without disabilities. Moreover, interviewees were concerned about their family members getting vaccinated because many had become

full-time caretakers, especially for persons with significant disabilities. The lack of transportation and accessibility barriers also thwarted access to treatment facilities.

Employment and livelihood have been hampered due to the impacts of COVID-19. A large number of people in the country have lost their jobs increasing the overall competition in the job market. Consequently, for many persons with disabilities, it will be more challenging to get new employment. The lack of new jobs circulating, a prolonged educational life, and the discontinuation of entrepreneurship have led many persons with disabilities into depression and increased anxiety. Unemployed persons with disabilities have not received any assistance or support, including any cash support from the government. The government has left out persons with disabilities from food and cash programs because of their enrollment in regular social protection programs. As a result, persons with disabilities have been deprived of emergency support that highlights discrimination between social protection mechanisms and emergency support policies.

As a result, OPDs came forward to support persons with disabilities with food and cash. Communities, community-based organizations, CSOs, and corporate entities supported persons with disabilities through OPDs. This has strengthened the relationship between OPDs and other organizations, and thus, collaboration among OPDs has significantly improved, which will benefit the disability movement.

Persons with disabilities overall lacked awareness about COVID-19 with most respondents indicating that they were not properly receiving information. TV and social media were the most useful tool in sharing information in an accessible way, and persons with disabilities active on social media were a bit ahead in receiving information. However, due to poor internet connections, and those living outside of Dhaka, many did not receive essential information. Deaf people were the most adversely affected by this since neither healthcare settings nor updates on COVID-19 information provided information in national sign language. In addition, blind and partially sighted persons also faced accessibility barriers in accessing information. Lack of information and accessibility regarding COVID-19 in the areas of health care, employment and livelihood, social protection, and education have exacerbated the current situation for many persons with disabilities.

Recommendations

- Ensure that international NGOs, bilateral donors, and UN agencies have an effective role to include representative organizations of persons with disabilities in government planning, implementation, monitoring and evaluation of COVID-19 response and set a separate indicator for persons with disabilities in data collection;
- Establish a specific mechanism to resolve healthcare, employment, entrepreneurial, accessibility and social protection barriers for persons with disabilities; and
- Review and revise social protection policies to be more inclusive for future emergencies.

Bolivia

In Bolivia a semi-structured questionnaire was developed that addressed 10 study dimensions to investigate during the interviews. Virtual meetings were conducted for the

more complex interviews, and for the other cases, an online form was used. Nine individuals were interviewed: four men and five women with disabilities. Interviewees were from Cochabamba, Sucre, and Riberalta. The average age of the participants was 36 years of age, ranging from 21 to 55 years old. The interviewees included one deaf person, three persons with psychosocial disabilities, two autistic people, three persons with physical disabilities, and one blind person. The most significant barriers included: (1) inaccessible healthcare facilities, (2) lack of social protection and unemployment, and (3) lack of information and data.

In terms of health care, in general, most interviewees were concerned about contagion, because adequate protocols of care for persons with disabilities do not exist or are not respected. Most general medical services have been suspended and information from the authorities was insufficient, which further complicated the already difficult situation persons with disabilities experienced prior to the pandemic. Persons with disabilities have little social protection due to lack of information from individual cases. Many persons with disabilities have lost their jobs and now face a more difficult situation with increased employment competition with persons without disabilities who are also seeking employment. This causes a new and complicated scenario. Lack of information and data continues to be a barrier. Most of the interviewees stated that there is not enough available information on persons with disabilities in the context of COVID-19.

Recommendations

- Develop an effective strategy that facilitates access to vaccines for persons with disabilities, especially in rural areas;
- Invest to ensure the disability rights movement can work together ensuring full engagement in government policies and programs;
- Include the most marginalized groups including persons with disabilities in government programs and policies, including in emergency plans; and
- Collect data on the situation of persons with disabilities to address barriers and for evidence-based policymaking.

Nigeria

In Nigeria, a qualitative exploratory study was carried out with key informant interviews, observation, and document analysis to generate data. Information was gathered through in-depth semi-structured interviews and life histories of 58 participants with disabilities from underrepresented groups across five out of six of Nigeria's geographical regions. The median age of participants was 37 ranging from 17 to 79 years old. The participants included 18 persons with physical disabilities, 10 blind and partially sighted persons, 10 deaf and hard of hearing people, 12 persons with intellectual disabilities, and eight persons with psychosocial disabilities. Sixty-two percent of the respondents had more than one disability. The most significant barriers for persons with disabilities include: (1) lack of access to social protection, (2) lack of access to vital information, and (3) inaccessible healthcare systems.

The livelihoods of most participants and their family members who supported them were adversely affected due to the lockdown and subsequent effects. Despite this, no participants received COVID-19-related cash benefits from the government. Additionally, very few – and only in urban settings – received food donations from other sources.

Often, COVID-19 information was inaccessible to persons with disabilities due to lack of accessible formats, but also the inability to access the information. Barriers that compounded this lack of access, included lack of finances to access technology and the internet, and lack of ICT skills to use technology. While a good number of participants were aware of the vaccine, none had information on how to access the vaccine, and it was difficult to find information on how to obtain personal protective equipment. Most participants believed that in an emergency they would not be given life-saving procedures on an equal basis to persons without disabilities. Moreover, almost all interviewees indicated that access to regular medical treatments were adversely impacted during the pandemic. Not the majority, but some participants experienced a new kind of violence and/or lack of security during the lockdown, which is important to note. These situations arose from extended family members, security agents, and strangers, and at home and in the community. The interviewees shared that they were targeted because of their disability.

Recommendations

- Provide awareness campaigns to familiarize governments and their agencies about disability-inclusive protocols;
- Share COVID-19 information in accessible formats for all persons with disabilities, and use all appropriate channels to disseminate the information to reach the widest audience;
- Support more research to identify barriers on the inclusion of persons with disabilities in COVID-19 response and recovery efforts in the Global South;
- Collect and share accurate national disability data to achieve disability inclusion in government COVID-19 response;
- Provide a disability COVID-19 liaison in all regions in official government COVID-19 websites; and
- Strengthen inclusive education systems to help ensure that persons with disabilities are not excluded from virtual learning environments.

In closing, findings from this research can be used to highlight gaps and barriers, and to remind governments, the UN system, and other stakeholders that persons with disabilities and their representative organizations are being left behind more than ever and must have active roles in all phases of COVID-19 response and recovery efforts.