



Event: United Nations Virtual Expert Group Meeting in collaboration with UN Women and the UN Inter-Agency Support Group on CRPD: *Participation and Leadership of Persons with Disabilities in Building a Disability-Inclusive, Accessible and Sustainable Post-COVID-19 World*

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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 COVID-19 pandemic and to complement existing 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.

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

The initial 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. Data were gathered around thematic units related to the pandemic and the Sustainable Development Goals (SDGs). Methods to gather data included online interviews with disability movement leaders. 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 assess the situation in more depth in one region.

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.

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 in the re-opening 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. Additionally, 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.

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 gaps in government services. Many OPDs became sources of vital information, raised awareness with their members, and provided accessible materials in different formats. Moreover, in many countries, governments provided sign language interpretation and live captioning for news briefings, but not consistently. Often, these services were a direct result of advocacy efforts led by the Deaf community 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, communication barriers for deaf and hard of hearing people due to healthcare staff wearing personal protective equipment and lack of information in sign language, 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 hospitals and healthcare facilities, 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. Furthermore, some participants did not trust the accuracy of the COVID-19 data from the government, and there was limited available data about COVID-19 in institutions, because in some cases, governments withheld the data from the public. To address this lack of official government 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 COVID-19 information and data, and (4) lack of accessibility. Additionally, overlapping themes emerged, including: (1) new barriers due to changing roles in extended family situations, (2) increased competition to find employment with overall high unemployment in society, (3) lack of financial and technical resources to access information via phones and the internet, and (4) increased lack of security and safety.

The livelihoods of most participants and/or their family members who supported them were adversely affected due to lockdown measures and subsequent effects. The government rarely provided support in these situations, but rather OPDs and CSOs stepped in and filled the gaps by providing assistance and sharing vital information. Quite often, COVID-19 information was inaccessible to persons with disabilities due to inaccessible 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. Most participants believed that in an emergency, they would not be given life-saving procedures on an equal basis as persons without disabilities. Moreover, almost all interviewees indicated that access to regular medical treatments were negatively 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.

Below are some of the key recommendations taken from the national-level research.

Country-level 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;
- Review and revise social protection policies to be more inclusive to address future emergency crises;
- Develop an effective strategy that facilitates access to the vaccination for persons with disabilities, especially in rural areas;
- 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;
- Collect and share accurate national disability data to achieve disability inclusion in government COVID-19 response; and
- Strengthen inclusive education systems to ensure that persons with disabilities are included in 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.