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Stakeholder Group of Persons with Disabilities: The importance of collecting data on COVID and persons with disabilities and findings

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Collecting data on COVID and disability is essential because persons with disabilities have been one of the groups most adversely impacted by the pandemic and consequently even more left behind.

To better understand and address the dire situation of persons with disabilities around the globe, the Stakeholder Group of Persons with Disabilities (SGPwD) carried out [a qualitative research study](#) from May to June, 2020. The study aimed to complement existing COVID-19 efforts by gathering data from leaders from the disability movement. The data collected were gathered around thematic units related to the global pandemic and the Sustainable Development Goals (SDGs). These seven themes included living situation, safety concerns, home life and housing conditions, health care, social protection, employment and COVID-19 disability data.

How were data gathered?

Traditional methods for face-to-face data collection were not possible so data were by using virtual platforms with:

- **Online interviews** with 28 leaders in six languages (Arabic, English, Hungarian, International Sign, Russian, and Spanish) from the disability movement to collect information. These interviews were carried out via different methods depending on the context, internet access and video quality (e.g., necessary for interviews in International Sign). Platforms

utilized included Skype and video messages. It was very helpful to have individual interviews to gather in-depth knowledge, but the challenge was the investment of time to carry these out and then translate and analyze the responses.

- **Focus group webinars** to collect testimonials from different groups within the disability movement. Four focus groups were carried out in English and Spanish on GoToWebinar with captioning and IS interpretation. Participants were 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.). Carrying out regional focus groups was a good way to reach many people from different regions in a limited time frame, but challenging to gather so many compelling stories in only one session; and
- **Working with organizations of persons with disabilities** in Bolivia, Colombia and Guatemala to assess the situation in more depth in one region.

What were the key findings?

The report finds that most persons with disabilities around the world have been adversely affected by the pandemic in one way or another with additional or new barriers, including new barriers in the re-opening phase. The most common barriers that emerged include: (1) lack of access to COVID-19-related 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 efforts at all governmental levels, creating significant disconnections between national and local actions.

Some main themes that emerged from the research include the lack of access to information, the role of organizations of persons with disabilities (how they stepped in to replace lack of government support), lack of access to healthcare facilities, and lack of disability data.

In terms of **the lack of disability data**, none of the 93 participants indicated that their governments disaggregate COVID data by disability.

Generally, COVID-19 data updates were shared on government websites, in daily conferences and also via text blasting to update citizens via mobile phones. The government data typically included the number of infected, deaths (in hospitals and residential facilities) and recoveries. Disaggregation was available by age and gender, and in some cases location, but not by disability.

Some participants did not trust the accuracy of the COVID-19 data from the government. Also, there was limited available data about COVID in institutions, because in some cases, governments withheld the data from the public.

Some methods of collecting COVID disability data during the pandemic included door-to-door mobile data collection taking the temperature of household members and the use of telephone surveys.

To address the lack of official government data, many DPOs and NGOs carried out surveys to collect information from persons with disabilities. The following provides summary findings from two new reports.

[Experiences of people with disabilities in COVID-19: A summary of current evidence](#)

CBM Global Inclusion Advisory Group and Nossal Institute for Global Health carried out an analysis of 20 surveys from May to June, 2020 that focused on the health, economic and social impacts of COVID-19 on people with disabilities in low and middle-income countries in Asia and the Pacific. The analysis explored both (1) findings of recent surveys and (2) the implementation of data collection approaches.

The report found similar barriers to the SGPwD study, and that many of the barriers stemmed from trying to access government support. At the same time, there was a strong commitment by DPOs to use data to inform response and recovery policies.

The analysis also found that some important areas have limited available evidence, including experience of violence or abuse in institutions and residential care arrangements; accessibility of quarantine and COVID-19 treatment facilities; access to WASH infrastructure required for handwashing; and the experience of children with disabilities accessing remote learning.

Of the surveys examined, the sampling and recruitment approach varied. The survey design was mostly quantitative, often with additional qualitative questions. Most did not incorporate accepted question types, including Washington Group questions.

Consequently, this study reiterates the importance of being able to disaggregate data by disability, such as by using the WG questions in all population surveys on COVID response and in future emergencies, to allow for comparative analysis of the experiences of different population groups.

CBM Australia and Nossal Institute for Global Health will continue to track the experiences of people with disabilities in Asia and the Pacific as COVID-19 responses evolve and countries enter the recovery phase. The aim is to have an updated summary ready to disseminate in October with a focus on evidence gaps from Phase 1, which include analysis disaggregated for gender, impact of remote learning for children with disabilities, and evidence from the Pacific.

Amplifying Voices: Our Lives, Our Say

The World Blind Union report [“Amplifying Voices: Our Lives, Our Say”](#) is based on a global survey carried out from April to May, 2020 in English, French and Spanish to learn about challenges for blind and partially sighted people during the pandemic and their resilience strategies.

The report indicated that 853 people responded to the survey. The survey included Washington Group questions as well as qualitative research methods to gain details on how people’s lives were being impacted by the pandemic.

The findings show that the top challenges faced by blind and partially sighted people included transportation and mobility; independence, autonomy and dignity; mental health and well-being; and accessibility (in terms of the physical environment, transportation, information and communications, or facilities and services).

Some key strategies to address difficulties included:

- Connecting to personal support networks, such as family, friends, neighbors, and trusted guide dogs;
- Getting online – for those with access – to get information;
- Keeping physically and spiritually active and helping others to improve well-being;
- Using assistive technologies for independence; and
- Carrying out increased advocacy by DPOs and self-advocates (similar to the SGPwD research).

Key recommendations:

- Collect and disaggregate COVID data by disability to learn about barriers and to measure disability-inclusive response and recovery actions.
- Involve persons with disabilities and their representative organizations in planning, implementation and monitoring of COVID-19 response and recovery efforts and to ensure this is in line with the CRPD and SDGs.
- Invest in data for disability inclusive development and to build capacity in stakeholders, especially DPOs, to be better prepared to survey their communities in future emergencies.
- Continue to collaborate with survey participants to influence policymaking. For many who continue to face marginalization and exclusion, it can be tiresome to repeat personal experiences, and not hear back from data collectors and/or never see change.
- Support communities to gather citizen-generated data to complement traditional data sources and highlight information that cannot be captured in other ways.