The importance of collecting data on COVID and persons with disabilities

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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. Data collection can help to understand who is being affected where and why, to understand the specific barriers persons with disabilities are facing, and what policies and programs are needed to mitigate those barriers to include persons with disabilities fully and equally into society.

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. Twenty-eight people with disabilities were individually interviewed in six languages, including International Sign. In addition, 65 people with disabilities from 54 countries participated in regional focus groups.

The data were framed around thematic Sustainable Development Goals (SDGs) relevant for persons with disabilities in the pandemic with findings synthesized to influence policies and SDG implementation.

The most critical findings indicated that myriad barriers exist for persons with disabilities as a result of the pandemic, including new and exacerbated barriers. The most common barriers that emerged from the findings 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 recovery and response efforts at all governmental levels, creating significant disconnections between national and local actions.

Main themes that emerged from the research include:

**Lack of access to information related to COVID-19**
including information in native sign languages, Braille, easy read and other alternative formats. (and in rural areas and in Indigenous languages)

**The role of organizations of persons with disabilities (DPOs)**
- Many DPOs became sources of information, were raising awareness with their members and providing accessible materials in different formats to address gaps in government services.

**Lack of access to healthcare facilities and hospitals**
- In all regions participants indicated barriers or limitations regarding access to healthcare facilities and hospitals due to discrimination.

**Lack of disability data**
None of the 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.

From additional research, we were able to find a few disability data sources, [including from the UK](#), and forthcoming sources from Ghana and UN Women from their regional surveys, but very little overall.

To address the lack of 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.

Amplifying Voices: Our Lives, Our Say

The World Blind Union is launching the report “Amplifying Voices: Our Lives, Our Say” on 4 September 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).

Summary recommendations for governments, statisticians, policymakers, DPOs, NGOs and others:

- Immediate action is required to ensure all persons with disabilities, including underrepresented groups, are not left further behind in all development efforts.
- 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.