

- (1) What is the current state of data on women and girls with disabilities and what efforts are being undertaken at global, regional and national levels to increase coverage?
 - (2) What is needed to foster better use of such data to inform policies?
 - (3) What are the current practices in terms of collaboration between national statistical offices and other actors, particularly civil society organizations and academia, and is there scope to increase such collaboration?
- Globally, a lack of data exists on the situation of persons with disabilities, in particular on women and girls with disabilities. The lack of data increases marginalization of women and girls with disabilities and leaves them behind.
 - The collection of comparable data is essential for evidence based policy-making and budgeting, as it can directly address the reduction of barriers that women and girls with disabilities face to achieve full participation in all aspects of their lives in society.
 - States are obligated to carry out their responsibility to collect and disaggregate data in line with the UN Convention on the Rights of Persons with Disabilities (CRPD) under Articles 4 and 31, which is further strengthened by the political commitment of the 2030 Agenda.
 - Yet, overall official disability data are not reaching the global level to measure the SDGs, creating gaps in SDG monitoring. As a consequence, we recommend that citizen-gathered disability data, including data on women with disabilities, can fill these gaps.
 - I'll now provide three examples of projects using **citizen-gathered data, with a focus on women with disabilities** and how this can complement official statistics and inform policies.

First, is the **LNOB Partnership** hosted by the International Civil Society Centre in which CBM is a member, on citizen-gathered data on the most marginalized communities, including persons and women with disabilities to create inclusive SDG implementation. The pilot project took place in Bangladesh, Kenya, India, Nepal, and Vietnam from January 2018 until March 2019.

From the findings, we recommend the following to address the gap in data collection of marginalized groups, including women with disabilities:

- Use a participatory approach involving people from communities in gathering data, in this case women with disabilities and their representative organizations;
- Have a dialogue with local authorities on policy change, informed through the use of community-driven data and feedback;
- Use national data whenever possible and then go further to complement the data to close data gaps;
- Improve reporting and accountability; and
- Advocate for budget allocation and government commitments to ensure disability inclusion.

Second, is the **SHOMOTA Project in Bangladesh** that is a World Vision project, funded by the Australian Government through the Water for Women Fund. The project incorporates water, sanitation and hygiene (WASH), empowerment of women and people with disabilities, and engagement with government and the private sector.

The project's primary goal is to improve gender and disability inclusive WASH in schools and communities.

The Project partners with disability-focused organizations and a national DPO representing women with disabilities in Bangladesh, with CBM Australia to support disability inclusion, and CARE Australia to support gender transformation.

Challenges:

- Backlash and potential of harm:
 - exploring the experiences of women and girls with disabilities can cause backlash in the home or community if the methodology is not sensitive to the context and the team has not been well trained, especially on how to respond to someone disclosing situations of violence
- Time:
 - There needs to be adequate time given to the development of data tools including consultation with all relevant stakeholders such as DPOs, especially those which represent women and girls with disabilities
 - Time needs to be given to translation and testing
 - Flexibility and time are needed to allow changes to be made to data tools if issues arise
- Participation of women and girls with disabilities:
 - Engagement of women and girls with disabilities and their representative organizations in the development of tools, data collection and analysis is key but can take advocacy and additional time
- Other areas of social inclusion:
 - The experiences of women and girls with disabilities is further influenced by other demographic and socio-economic factors. A focus on one element of social exclusion is important to ensure adequate data

collection, however, there should be additional attention given to how experiences of gender and disability can be further influenced by other factors e.g. age, ethnicity, religion, geography, sexuality, etc.

What works well:

- The local project team has both disability and gender awareness and understanding of the value of appropriate data collection tools;
- There has been good consultation with local stakeholders, including disability service providers and DPOs;
- There is input from technical advisors who can share learnings from other projects on how to integrate disability and gender; and
- Disability inclusion advisors are working closely with gender equality advisors including coordinating technical advice and integrating disability and gender for better understanding of intersectionality.

Third, through the SGPWD's Disability Data Advocacy Working Group (launched in January 2019)

- The Working Group aims to:
 - to provide a global platform for exchange, dialogue, and collaboration on disability data collection, disaggregation, and analysis; and
 - to strengthen DPO engagement in data collection and disaggregation efforts to influence policy change and create evidence-based policymaking.
- Through the working group's webinars and listserv, various examples of non-traditional data have been shared.
- One example is from the European Union of the Deaf that gathered information and challenges regarding the collection of data of deaf women in Europe from 31 National Associations of the Deaf.

Findings:

- Research on women with disabilities often are not accessible for deaf women and often there are lack of funds allocated for translation or interpretation into the national sign language.
- Due to lack of access to information in sign language and/or captions, critical information is not available, which can be dangerous. For example, some deaf women are not aware that violence from their husbands is forbidden and that they can report it and get help.
- Women and girls with disabilities encounter discrimination because of both disability *and* gender. This results in discrimination due to:
 - Lack of accessibility - in information, communication, built environment;

- Lack of access to health services and vital information about health care, and the lack of disability awareness and sensitivity by medical professionals;
- barriers to education; and linked to this
- barriers to employment.

As final recommendations:

- **Citizen-driven disability data needs to be recognized and utilized by NSOs to** fill data gaps in SDG monitoring for women and girls with disabilities. And local authorities need to be partners in the data collection process and informed by the data.
- Statisticians, policymakers, DPOs, and allies need to learn from each other and use available data to address challenges and gaps in policies to realize international commitments for women and girls with disabilities.
- The Washington Group short set of questions and UNICEF/Washington Group Child Functioning Module should be used to disaggregate disability and monitor progress in attaining the SDGs.
- **Build on disability data advocacy efforts led by the disability movement,** and widely share tools such as the disability data advocacy toolkit and training module for DPOs that will be released soon.