



International Workshop on the Monitoring of the Sustainable Development Goals organized by the United Nations Statistics Division and the National Bureau of Statistics of China – January 13, 2022

Agenda 4 - Leaving no one behind and data disaggregation (12-15 minutes)

Title: Leaving no one behind and data disaggregation: Building data partnerships and capacity building for persons with disabilities

Presenter: José Viera, Advocacy Director, International Disability Alliance and Permanent Representative, Stakeholder Group of Persons with Disabilities

For persons with disabilities, data are important to understand who is being affected where and why, to understand the specific barriers persons with disabilities encounter, and what policies and programs are needed to mitigate those barriers to include persons with disabilities fully and equally into society. To change this, representative organizations of persons with disabilities (OPDs) must play a meaningful role in data collection, analysis, and use. And, with this, there is a need to strengthen the capacity of OPDs in understanding and using disability data to help develop and shape investments in evidence-based policies and programs.

As a result, the Stakeholder Group of Persons with Disabilities (SGPwD), the International Disability Alliance, and CBM Global Disability Inclusion developed a disability data advocacy toolkit for OPDs. The toolkit focuses on how to advocate for data, and better data, and how to advocate using data. It is available in Arabic, Easy Read, English, French, International Sign, and Spanish.

Emerging from the toolkit, in 2021, UNFPA and CBM Global Disability Inclusion, in close collaboration with the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, and national and regional organizations of persons with disabilities, including the Pacific Disability Forum and ASEAN Disability Forum, established an innovative partnership to build capacity in and increase the quality of disability data in the Asia-Pacific region. This, in turn, aimed to influence the 2030 Agenda for Sustainable Development and its Sustainable Development Goals.

As background, the UNFPA Asia-Pacific region has seen varied engagement, investment, and approaches around disability data and related advocacy. Up until now, there has been no clear cross-regional analysis of the inclusion of disability data in census and large-scale household surveys, so this partnership was particularly valuable.

The project finished at the end of 2021 and produced three key outcomes: a regional report on the status of disability data in the Asia-Pacific region, disability data advocacy trainings for OPDs, and publicly available resources. Now, I will share some key findings from the report and training.

**Report:** In 2021, a mapping was carried out on the national collection of disability data from censuses and large household surveys in the Asia-Pacific region (36 countries) through UNFPA Asia-Pacific Country Offices. Organizations of persons with disabilities also shared their experiences around disability data. Information was gathered from relevant sources such as National Statistical Offices and other government focal points responsible for monitoring the Incheon Strategy indicators and corresponding Sustainable Development Goal indicators. Twenty of the 36 countries responded.

Some key findings include that:

- The level of knowledge and ease of collecting disability data varied widely across respondents;
- Only 1 in 4 respondent countries in the Asia-Pacific region could monitor critical disability-inclusion indicators relating to healthcare access;
- Only 1 in 5 respondent countries in the Asia-Pacific region were using internationally recommended methods for identifying persons with disabilities in their national data systems;
- Only in 1 in 4 respondent countries in the Asia-Pacific region were systematically identifying and reporting on barriers and enablers for persons with disabilities to access education;
- Most of the respondent countries have significant gaps in their overall technical capacity to produce critical development indicators on persons with disabilities;
- Although many respondent countries can disaggregate the indicators they produce, very few are using questions framed around functioning to identify persons with disabilities, for example, the Washington Group questions. This raises questions on the quality, usefulness, and comparability of the data; and
- Many persons with disabilities are concerned about inadequate data and evidence around persons with disabilities, but do not feel they know enough to confidently use or advocate for better data.

**Trainings:** Two pilot disability data advocacy workshops for OPDs were carried out in November, 2021. The interactive workshop included eight modules and focused on OPDs to build capacity in understanding and using disability data and how to

advocate for disability data and better disability data at the national level. The workshops were carried out in person in Samoa with 15 persons with disabilities and online from Nepal with 28 persons with disabilities. Both workshops were facilitated by local OPD representatives who were also data experts.

Some workshop feedback includes that:

- It was particularly helpful to link the training materials to local languages and contexts, especially to understand where local data comes from and how to access local data;
- It was beneficial to focus on all data processes, including data use, collection, and analysis;
- There is a need to strengthen internal data collection mechanisms for OPDs to address barriers to participation and to reach out to include marginalized groups in OPDs;
- Having the training in person was more effective than online;
- It would be useful to set up a community of practice as a resource and to develop common concerns, assist with understanding disability data, and to interpret data tools, such as the Washington Group questions; and
- As a next step, it would be important to provide an advanced training on analyzing and using data in advocacy.

Overall, the findings from this project indicate that data are essential for government officials and policymakers to fulfill the rights of persons with disabilities. Understanding what, why, and how data are collected is important to inform future advocacy and investment in disability data. Also, it is imperative to involve persons with disabilities and their representative organizations to fully participate in all data processes. And, also key, is to invest in data for disability-inclusive development and to build capacity in stakeholders, including training for enumerators, and especially OPDs, to be better prepared to survey their communities.

We will share the final report, the training modules, and lessons learned from this partnership soon. Moreover, we hope to build on this current partnership and continue to engage in these and other partnerships, investment, and capacity building of disability data in the region and elsewhere.