Stakeholder Group of **Persons with Disabilities** for Sustainable Development

2021 Virtual Meeting of the Washington Group on Disability Statistics

November 9, 2021

Session VIII: Brief Partner Presentation

Morning session: 11:00-11:15am EST, Dr. Elizabeth Lockwood, CBM Representative at the United Nations, CBM Global Disability Inclusion; also representing the Stakeholder Group of Persons with Disabilities

Afternoon session: 6:45-7:00pm EST, Dr. Mohammed Ali Loutfy, Chief Executive Officer of Disabled Peoples' International; also Co-Chair of the Stakeholder Group of Persons with Disabilities

Title: Innovative data partnerships to build capacity in and increase the quality of disability data

As we all know, we need available, high-quality, timely, reliable, statistics, data, and information on persons with disabilities. There is a significant lack of this and with no data, the situation of persons with disabilities is hidden and cannot be adequately addressed in programs and policies.

This invisibility has been particularly evident in the COVID-19 pandemic with dire consequences for many persons with disabilities around the world. Furthermore, out of the 231 global SDG indicators – out of which 213 have data as of October of this year – only **five** indicators can be disaggregated by disability. This, once again, glaringly demonstrates how data on persons with disabilities are not being collected, and thus excluding them. (It is projected that there will be four more indicators that can be disaggregated by disability by 2023, but it is still not enough.)

To ensure persons with disabilities are counted, the SGPwD and partners have been building key partnerships and capacity around data advocacy to provide a valuable space for dialogue and to address barriers to inclusion. A key component of these

partnerships is to ensure that organizations of persons with disabilities (OPDs) have a leading role at the table in all phases of data initiatives, because persons with disabilities and their representative organizations are the experts on issues affecting them.

One good example of a data partnership is the collaboration of the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, and CBM Global Disability Inclusion that launched a comprehensive disability data advocacy toolkit for OPDs in 2020. The impetus of this toolkit stemmed from feedback from OPDs from around the world that shared that they were looking for guidance on data advocacy: on both how to advocate for disability data and how to advocate using data.

The aim of the toolkit is to provide OPDs with basic knowledge on data collection, analysis, and use for evidenced-based advocacy to influence policy and decision makers. And, importantly, to support inclusion, with the toolkit available in English, French, Spanish, Easy Read, International Sign, and Arabic coming very soon.

Also included in the toolkit, are case studies of good practices of data advocacy efforts. One example is the Leave No One Behind Partnership that highlights the use of community-driven data to complement official data to measure the SDGs of the most marginalized groups, including persons with disabilities. Fortunately, we are witnessing a shift in attitude from authorities about community-driven data, and we hope this continues and grows into more partnerships.

Building on the toolkit, 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, is aimed to influence the 2030 Agenda for Sustainable Development and its Sustainable Development Goals.

As background, the Asia-Pacific region has seen varied engagement, investment, and approaches around disability data and related advocacy. To date there is no clear cross-regional analysis of the inclusion of disability data in census and large-scale household surveys.

A key way to address this is for representative organizations of persons with disabilities to play a meaningful role in data collection, analysis, and use. And, 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.

There are three overarching objectives of the project that include:

1: Data Mapping and Report: A regional report on the status of disability data in the Asia-Pacific region will be produced. Evidence is from:

- A review and analysis of recent disability data across the UNFPA Asia Pacific region, summarizing the availability and quality of data against key indicators, including the SDGs, and making recommendations for ways forward; and
- 2. Persons with disabilities and their representative organizations from the region will share experiences of disability data processes and outcomes through a narrative inquiry.
- 2: Disability data advocacy workshops for OPDs: An online, interactive disability data advocacy workshop with eight modules has been developed for OPDs to build capacity in understanding and using disability data and also how to advocate for disability data and better disability data at the national level. The workshop is being piloted in **Samoa** and **Nepal** later this month. The workshops are being facilitated by OPD representatives from the region who are also data experts.
- **3: Resources:** We will share project findings to advocate for the importance of disability data for all stakeholders. This includes producing content, including the training modules, as publicly available resources, prioritized by the regional disability movement and other key stakeholders.

We will share the findings 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.