

# THE INFORMAL NETWORK ON DISABILITY STATISTICS FOR INCLUSIVE DEVELOPMENT

Tuesday 4 March, 1.15-2.45 PM, UN Secretariat, Conference Room S-2727

Summary of the Meeting

**Ms. Akiko Ito**, Chief of the Secretariat for the Convention on the Rights of Persons with Disabilities (SCRPD/DSPD/DESA) provided opening remarks, in which she gave an overview of disability statistics and emphasized the need to harmonize and collaborate between different stakeholders.

**Ms. Jennifer Madans (Washington Group on Disability Statistics)** presented an overview of the developments and accomplishments of the Washington Group (WG) since its inception in 2001. A short set of six questions is ready for implementation and current work is being carried out to test extended sets of questions. Ms. Madans stressed the need to ensure that the set of six questions is incorporated into censuses and surveys in precisely the way they are phrased. When translating the set of questions, it is highly recommended to test the translated questions before incorporating them into censuses and surveys. <u>Link to presentation</u>

**Ms. Claudia Cappa (UNICEF)** provided an overview of joint activities of UNICEF and the Washington Group, consisting of the development of data collection tools to promote and harmonize disabilities statistics for children; manuals and guidelines for the implementation; and the organization of regional workshops around measurement of disabilities in seven regions. Ms. Cappa emphasized the need to ensure sustainability of all efforts so that compilation and analysis of disability data will be standardized. In this regard, Ms. Cappa stressed the importance of recognizing the work and accomplishments of the WG as a starting point to avoid duplication of efforts. Moreover, it is imperative to ensure strengthening national capacities to create a sustainable approach to disability data collection and analysis.

**Mr. Somnath Chatterji (WHO)** explained the background of the efforts of the WHO and World Bank in developing a Model Disability Survey (MDS) based on recommendations in the World Report on Disability. The MDS aims to collect comprehensive data on disability, going beyond prevalence. Disability is a complex experience, and as based on the CRPD definition of disability, the objective is to understand how disability plays out in connection to different real-life environments. WHO has consulted with other stakeholders including WG and the National Center for Health Statistics. Cognitive testing is currently taking place in a range of settings in low-, middle-, and high-income countries. WHO aims to have developed a pilot version instrument which incorporates the work that has been carried out so far but intends to go beyond that.

#### **Discussion points**

## **Translation of questions**

In response to a question of a representative of the Permanent Mission of Israel on where to find translations of the short set of six questions, Ms. Madans referred to <u>the website of the</u> <u>Washington Group</u>. When doubting if a question or set of questions will work after translation, or to test if questions should be translated, Ms. Madans recommended to do cognitive testing and emphasized that related costs are low.

### International comparability

Mr. Daniel Mont of the World Bank (WB) raised the issue of international comparability and stressed the importance of encouraging national surveys to include the short set of questions as developed by the Washington Group for gathering national data, in exact wording.

Mr. Mitch Loeb of the WG added important findings of a paper that is currently being finalized. When looking at countries that are using the short set of questions in surveys, the disparities in prevalence of disability between developing and developed countries that are usually found begin to narrow.

# Short set of questions of WG in MDS

Mr. Daniel Mont (WB) commended the WHO for the MDS in trying to capture the complexity of disability, but stressed the enhanced usefulness of the MDS when it is used in tandem with regular surveys, and inquired about the questions in the latest version of the MDS, that were inconsistent with the short set of questions as developed by the WG.

Mr. Somnath Chatterji (WHO) responded that this is a concern for WHO as well, but that the WHO is of the opinion that disability should not be put squarely in the health domain, as it is a continuum between individual and environment. He further pointed out that the MDS is a modular survey, with the aim of having a short version which can be included as a module in surveys or can be a stand-alone survey. Mr. Chatterji expressed the hope to be able to build on all the work that has been done so far.

Ms. Jennifer Madans (WG) reiterated the importance of the suggested six questions. Due to the fact that disability is a very sensitive issue, any alteration of the questions will tamper with the outcome of a survey. It will be even more useful and comparable if the six questions could become a core component of the MDS, which could still be improved.

# Sample size of surveys

The issue of sample sizes was discussed, especially with regard to the choice between a standalone disability survey as opposed to including the short set of six questions in existing surveys. Ms. Madans reassured that representative surveys ensure appropriate sample sizes. She also pointed to labour force participation surveys or health surveys as helpful tools to collect information about disability within a population.

#### Implementation

Since the WG's short set of questions has been endorsed by the UN Statistical Commission, a participant asked specifically about new efforts of the WG, partly in collaboration with UNICEF and moving towards an implementation phase. Ms. Madans stated that while the Washington Group initially began as collaboration between national offices, it has since grown and now includes an

overrepresentation of DPOs and NGOs. The WG constantly receives requests for information and assistance from non-statistical offices, indicating an increased interest in how to use the questions and what to proceed with collected data. In this regard, Mr. Daniel Mont of the World Bank referred to webinars on data collection that will be organized by UNICEF.

## **National Capacity Building**

Ms. Alexandra Heinsjo-Jackson from ESCWA pointed out some ongoing difficulties, including a lack of mandate, technical capacity, and resources. Therefore, ESCWA looks forward to technical cooperation with relevant offices.

Ms. Akiko Ito invited all participants to continue this interactive discussion beyond this meeting, and proposed three guiding questions:

- 1 A set of questions have been developed by the Washington Group and are used by a number of countries. How can we effectely implement this set of questions in the 2020 Census round and other instruments such as household surveys to generate globally comparable statistics of disability?
- 2 Once the questions are added, how can analysis of data be facilitated in a consistent way? What specifically would countries need to ensure viable analysis of raw data?
- 3 Data that is gathered and analyzed need to be reported to appropriate mechanisms for analysis, monitoring and evaluation. What are such mechanisms? How can we ensure data is utilized in a timely manner?

Ms. Ito concluded that the informal network should continue to exchange information and strategize about options to strengthen disability statistics for inclusive development. The coming months will be crucial to build on the momentum from the High-level Meeting on Disability and Development and to intensify efforts to promote the inclusion of persons with disabilities in all development efforts towards 2015 and beyond. In order to achieve this, cooperation with various focal points and other stakeholders is crucial in the post-2015 process for disability-inclusion.

There is a strong need for coordination and harmonization of data collection tools and new initiatives will need to focus on data gaps rather than on duplication of efforts. The UN Regional Commissions and their partners are well-positioned for collection of information about persons with disabilities and their analysis before the 2020 census round.

Integrating disability statistics into national censuses and surveys will take time, but it is of crucial importance to start planning now to assist countries to include questions on disability in a consistent manner in the 2020 census. In this regard, the Statistical Commission can play a pivotal role in ensuring consistency in collecting, analyzing and reporting of data through appropriate mechanisms.

Presentations and other supporting documents can be found on the <u>Enable Statistics for</u> <u>Inclusive Development section</u> on our website (<u>www.un.org/disabilities</u>)