IAEG-SDGs virtual meeting "Leaving no one behind: Data disaggregation for SDGs"

Date: 25 March, 8-10:15am EDT

**Dr. Mohammed Ali Loutfy, Representative of the Stakeholder Group of Persons with Disabilities**

*Disability Data Advocacy Toolkit*

I am presenting on the comprehensive disability data advocacy toolkit that was produced by the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, and CBM Global Disability Inclusion.

This toolkit responds to many pressing requests from persons with disabilities and their representative organizations from all over the world and building on the collaboration of the International Disability Alliance and the International Disability and Development Consortium.

In 2019 the Stakeholder Group of Persons with Disabilities established a Disability Data Advocacy Working Group to provide a global platform for information exchange, learning and dialogue, sharing of good practices, to support collaboration on disability data collection, disaggregation, and analysis. Through the Working Group, many organizations of persons with disabilities (OPDs) asked for guidance on how to advocate for and use disability data and as a result this toolkit was created.

The aim of this toolkit is to contribute to the growing global dialogue on the importance of data on persons with disabilities, specifically to provide some basic knowledge on data collection, analysis, and use of data for evidenced based advocacy to influence policy and decision makers.

The toolkit highlights two particular aspects of the journey on data, starting first with **the need for data**, so that we understand the real situation of persons with disabilities, to identify gaps that are not addressed through policies and / or to provide examples of successes. This is not only to support advocacy with data, but also to influence decision makers and convince them on the themes where the most urgent actions and steps must be taken at national, regional and global levels. This is the beginning and foundational to all other efforts.

The second aspect the toolkit touches upon is **once the data exist**. It is important to understand how to analyze, use and trust data for creating advocacy messaging. This is both to protect the integrity of advocates and to ensure that the change sought is based on an understanding of the reality of the situation and what works. The toolkit includes case studies in which OPDs have been involved in both of these aspects.

There is no excuse <u>not</u> to have data on persons with disabilities or to include OPDs in data collection and interpretation efforts. Persons with disabilities and their representative organizations are the experts on issues affecting them and are generating community-driven data to complement official statistics. With the guidance of the toolkit, persons with disabilities and their representative organizations can respond in a highly professional manner to data needs.

**The next steps**

We are very proud to share that we recently completed an abridged version of the toolkit in International Sign. Also, we are finalizing versions in Arabic, French, and Spanish with possible forthcoming versions in German and Easy Read.

As a next step, we would like to build on the toolkit to carry out trainings on disability data advocacy and disability awareness to OPDs, national statistical offices, and enumerators.

**The training would aim to:**

For OPDs:
- Build data knowledge to identify gaps that are not addressed through policies and / or to provide examples of successes.
- Learn how to analyze, use and trust data for creating advocacy messaging.
- Provide examples of community-driven data that can complement official data.

For NSOs and enumerators:
- To learn disability awareness, especially in terms of gathering data on persons with disabilities as this is a big gap in data collection.
- To have an exchange with OPDs to learn from each other and to influence policies.

We look forward to working with statisticians and together, we can count, collect and disaggregate disability data.

**Resources**

- Data Toolkit: https://cbm-global.org/wp-content/uploads/2020/11/DisabilityData_advocacytoolkit_accessible.pdf
- Information about the data toolkit: https://cbm-global.org/news/disability-data-toolkit/
- International Sign version of the data toolkit: https://youtu.be/HBXsTVOEqHA