COSP16 Side Event: Zooming in on the rights of persons with disabilities: Launch of the 2023 Disability Data Initiative's report

Date: June 16, 2023

Time: 9:45-11am EDT on Zoom

Presenter: Rosario Galarza, International Disability Alliance

Talking Points

Data are important to understand the situation of persons with disabilities and as a result what policies and programs are needed to strengthen our full inclusion into society. Yet, there is a pervasive lack of disability data, which means it is difficult to create policy and programs inclusive of those most at risk of being left behind, including persons with disabilities who make up 16 percent of the world's population. There is a general lack of or out-of-date disability data at the national and sub-national levels, and especially in the Global South. There is even a greater lack of data on women and girls, children, older persons, and other underrepresented persons with disabilities, which pushes these groups even further behind. Moreover, there is little data on persons with disabilities in emergency situations, and on the experiences of migrants, refugees, and internally displaced persons with disabilities.

Despite this, it is good to remember that the CRPD and the 2030 Agenda mandate countries to collect and disaggregate disability data, notably CRPD Article 31, and in the 2030 Agenda: paragraphs 48 and 57, and SDG target 17.18.

I'll provide some reasons for the lack of national and sub-national disability data.
- Persons with disabilities and their representative organizations all too often are excluded from disability data decision-making processes, especially from the start, and thus their perspectives are not included or recognized.
- OPD data often are viewed as unreliable or out of date, especially if qualitative methods are used to collect data or sample sizes are small.
- Accessibility is an issue in collecting and accessing data. First, accessibility measures, such as sign language interpreters, are rarely provided in consultations with OPDs. Second, data tools and platforms are often inaccessible for screen reader users.
- The lack of disability training and awareness creates barriers, especially for enumerators. We have learned that if enumerators are trained on disability awareness, more persons with disabilities are captured in the data.

- The lack of surveys in local languages also is a challenge, including national sign languages which are needed to capture minority language users, including deaf sign language users.

Yet, we can strengthen inclusive data processes at the national and sub-national levels in the Global South and elsewhere by:

- First and foremost, consult and actively involve persons with disabilities and their representative organizations in the entire data value chain. This is essential since OPDs understand their communities and experiences better than anyone, can reach members easily, and have the trust and cultural awareness. Thus, this ensures a more accurate picture of the situation to create effective evidence-based policies and programs;
- Provide resources and support to OPDs in data capacity to ensure consistent and reliable data;
- Establish new and strengthen existing multi-stakeholder data partnerships that meaningfully include OPDs;
- Provide OPD-led training to national statistical authorities on disability awareness, especially using resources that we have developed, such as the [disability data advocacy toolkit](#) and the new [disability data advocacy workshop for OPDs](#);
- Train OPDs to become enumerators themselves to better survey their own communities;
- Strengthen and encourage the use of citizen-generated data in national statistical systems to fill data gaps; and
- Harmonize disability data to support the development of comprehensive, evidence-based policies and programs for persons with disabilities. One way to do this is to support official statistical bodies to collect and disaggregate data by disability using the Washington Group short set of questions and the Washington Group and UNICEF Child Functioning Module.

In closing, evidence-based data on persons with disabilities at the national and sub-national levels are instrumental in:
- identifying gaps and priorities in access to services, infrastructure, and support systems.
- Enabling policy makers, organizations and advocates to monitor the impact of national policies, laws and programs.

Highlighting intersectional issues such as gender identity, age, race, ethnicity, Indigeneity, sexual orientation, among others.