**Stakeholder Group of Persons with Disabilities HLPF Consultation Submission on Goal 17 – Data**

**17.18** By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts

**Data collection**

Data on persons with disabilities are needed so we understand the real situation of persons with disabilities, to identify gaps that are not addressed through policies and to provide examples of successes. This is not only beneficial for evidence-based advocacy, 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.

States are obligated to carry out their responsibility to collect and disaggregate data in line with the UN Convention on the Rights of Persons with Disabilities (CRPD) under Article 31. This is further strengthened by the political commitments by 193 countries that committed to collect data on persons with disabilities and to disaggregate data by disability by adopting the 2030 Agenda for Sustainable Development and the global indicator framework that provides a guide on what data are needed to measure the implementation of the SDGs.

Despite this, limited disability data are available at the global level and persons with disabilities remain invisible in data and statistics. As a result, existing and new barriers that persons with disabilities face are, once again, not addressed. This invisibility has been particularly evident during 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 – only **seven** indicators can be disaggregated by disability. Again, this glaringly demonstrates how data on persons with disabilities are not being collected and thus persons with disabilities are again excluded.

1. **What has changed since the last time this Goal was reviewed at the HLPF? Any deviations in progress from what was expected (including due to Covid-19)?**

The COVID-19 pandemic has adversely affected marginalized groups, including persons with disabilities in unprecedented ways. Yet, overall, governments do not have COVID data disaggregated by disability status. Often, disaggregation of COVID data was available by age and gender, and sometimes location, but not by disability. Clearly this presents a dire issue, because if no data are collected, the situation of persons with disabilities are unknown and cannot be adequately addressed in response and recovery policies. Also, it is not only important to collect disability data during a crisis, but also prior and afterward, to measure the impacts, risk factors, changes, and trends of persons with disabilities compared to those without disabilities in the same populations over time.

Collecting data on COVID-19 and disability is essential because persons with disabilities have been one of the groups most adversely impacted by the pandemic and consequently even more left behind. Countries are supposed to be collecting disability data to measure the SDGs, thus making visible a group most often left behind. Surveys and studies targeting persons with disabilities are essential to understand additional barriers faced in enjoying their human rights on an equal basis with others, and should be conducted using inclusive and accessible methods (including through accessible online survey tools).

1. **What are the main obstacles to implementation of this Goal, including interlinkages with other Goals and connections to related processes?**

The main challenge is that persons with disabilities are not a priority – for governments, international organizations, the private sector, and other sectors. To truly shift power and have data equity, there must be political will and action to effect change. There must be pre-conditions to inclusion, such as accessibility, meaningful participation, representation, and data collection, analysis, and use.

Significant barriers in data equity include:

* Data gained or produced by organizations of persons with disabilities (OPDs) and NGOs are usually not recognized by statistical authorities;
* Often there is a lack of cooperation between statistical offices and organizations (OPDs and NGOs) on exchange of statistical information and other data;
* It is difficult to find reliable sources of data with disaggregated levels that can be used in proposals, projects, and programs; and
* Persons with disabilities and their representative organizations often are excluded from data collection processes. This has become especially apparent with the shift to online work due to the pandemic and the exclusion of persons with disabilities due to inaccessible information and communication technologies.

To address this, national statistical offices need increased capacity, awareness training, and support to be proficient at collecting disability data, and ministries need to demand that disability data be collected across ministries in line with the CRPD and the 2030 Agenda.

1. **What are new/promising openings and opportunities to implement this goal, including interlinkages with other Goals and connections related processes?**

The Washington Group on Disability Statistics tools are important to use, especially the Washington Group short set of questions and the UNICEF/Washington Group Child Functioning Module (that supports identification of children with disabilities). This is especially important for measuring SDGs and to monitor the impact of COVID-19 on persons with disabilities.

Also, recognizing the usefulness of citizen-generated data to fill data gaps in measuring the SDGs for the most marginalized groups, which was recognized at the 53rd session of the UN Statistical Commission. UN Statistics Division is developing a toolkit on incorporating citizen-generated data into official statistics with best practices.

1. **Can you share an example of an innovative policy, programme, project or partnership related to this Goal that could be scaled up and support accelerated implementation?**
   1. UNFPA Asia Pacific 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. A regional report and additional documents [can be found here](https://asiapacific.unfpa.org/en/disability-data).
   2. The [Leave No One Behind Partnership](https://icscentre.org/our-work/leave-no-one-behind/) presents a good practice of the use of citizen-driven data to complement official statistics to measure the SDGs for the most marginalized groups.