Reflection on disability data by organizations of persons with disabilities

Together we will count and be counted!

Based on a study and overview of international advocacy and national experiences

What is the status of statistics and data collection in 2018?

Overall official disability data are not reaching the global level to measure the SDGs.

- CRPD Article 31 requires States Parties (177 ratifications, countries) to collect data on persons with disabilities;

AND

- 193 countries committed to collect data on persons with disabilities and to disaggregate data by disability by adopting the 2030 Agenda and the global indicator framework;

Global advocacy aspirations - FACTS

- FACT: 232 global indicators from which 11 are inclusive of disability and there is the recommendaiton to disaggregate by disability

- **We heard numerous times that this poses a challenge!!! Moreover the SG's progress report only elaborates on social protection and unemployment data.**

In 2017 : SGPwD priority list of the 232 SDG indicators to be disaggregated
- IDA and IDDC, in consultation with UN agencies, identified 32 critically important indicators which should be disaggregated by disability in order to gain data on the situation of persons with disabilities worldwide.

*http://www.internationaldisabilityalliance.org/prioritylist-ofindicators

** https://unstats.un.org/sdgs/files/meetings/iaeg-sdgs-meeting-07/20180404_Update_Overview%20of%20standards%20after%20consultation%20mechanism.pdf
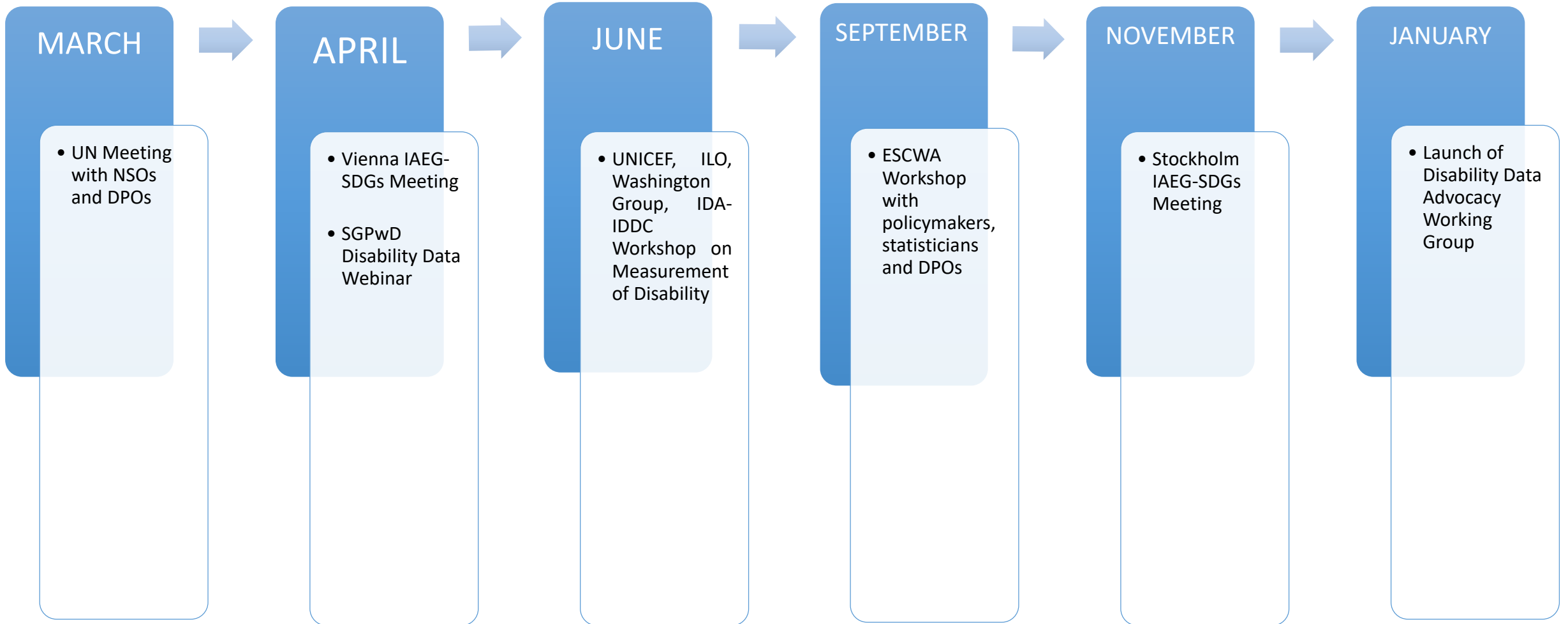
Critical areas to disaggregate

- The Stakeholder Group of Persons with Disabilities (SGPwD) shared the following key policy priority areas for persons with disabilities in response to a request from UNSD on December 5, 2018 for a disability data disaggregation policy priority consultation.

The key policy priority areas are

poverty eradication, education, employment, health, and accessibility.

- The Stakeholder Group of Persons with Disabilities highlights that the short set of questions developed by the Washington Group on Disability Statistics and the UNICEF/Washington Group Child Functioning Module (that supports identification of children with disabilities) are sustainable and suitable for disaggregating by disability status and monitoring progress in attaining the SDGs on an ongoing basis. These modules are internationally comparable, well tested, efficient, low cost, and easy to incorporate into ongoing data collection of national statistical systems.

Timeline of relevant activities

MARCH →

- UN Meeting with NSOs and DPOs

APRIL →

- Vienna IAEG-SDGs Meeting
- SGPwD Disability Data Webinar

JUNE →

- UNICEF, ILO, Washington Group, IDA-IDDC Workshop on Measurement of Disability

SEPTEMBER →

- ESCWA Workshop with policymakers, statisticians and DPOs

NOVEMBER →

- Stockholm IAEG-SDGs Meeting

JANUARY

- Launch of Disability Data Advocacy Working Group

What is happening at the national level?

- The lack of data on persons with disabilities increases marginalization and fails to address the situation and discrimination encountered by persons with disabilities.

- As a result, planning and budgeting for reasonable accommodations with effective policymaking have suffered and persons with disabilities have largely fallen off the statistical "map." Evidence-based data on persons with disabilities at the national and global levels are instrumental in identifying the gaps and challenges of persons with disabilities that can support policymakers to address gaps and amend existing policies and regulations.

DPOs have a key role to play

- If we want to change the situation of persons with disabilities, we need DPOs and the disability movement to be meaningfully included in data collection and analysis.

- Statisticians, policy makers, DPOs, and allies need to learn from each other, use available data to address challenges and gaps in policies to realize international commitments and obligations by using existing tools and solutions for evidence-based policy making.

Together we will count and be counted!

Surveys

- IDA and CBM developed surveys for both the data webinar (April) and the data workshop (June) that were shared with a total of 550 individuals.

- These surveys had questions on the availability of disability data, knowledge on the 2030 Agenda and the CRPD.

- A gap in this study is that the survey was completed by individuals who provided respective answers, but we have no way to verify these responses.

- Survey findings and outcomes are summarized next.

*Please note that this analysis was not conducted by statisticians.

Type of organizations
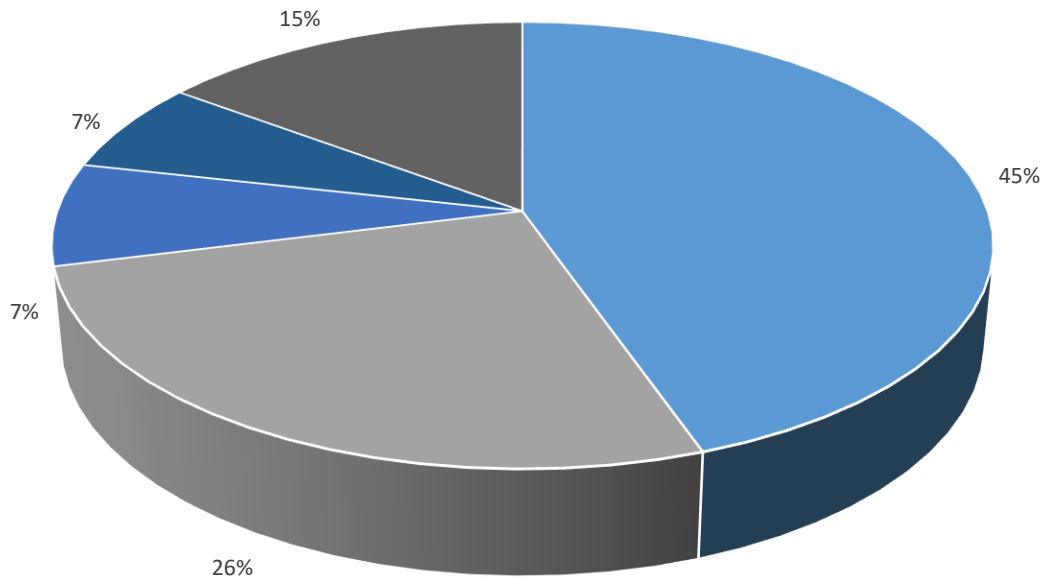
- o DPOs: **45 percent**
- o NGOs: **26 percent**
- o Academic Institutions: **7 percent**
- o Others: **15 percent**

(International Organizations, Private Sector, Development Agencies, Government, Community-Based Organizations, National Human Rights Institutions, an individual person, and a consulting firm)
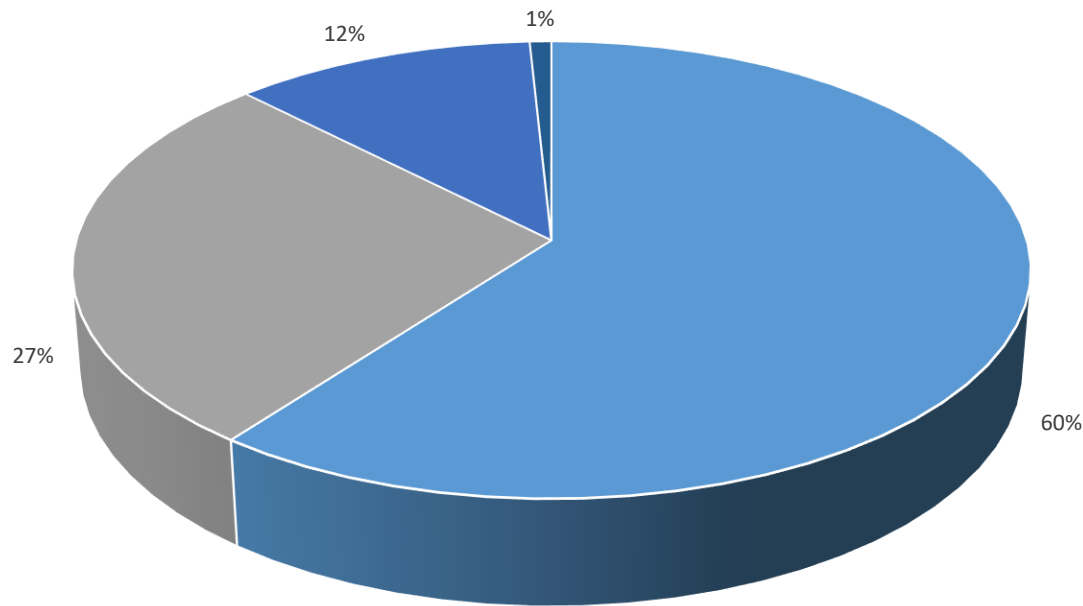
- o No answer: **7 percent**

Participant experience with disability data

- The surveys focused on the availability of disability data and participants' experiences.

- This was important because advocacy for internationally comparable disability data is a key focus at the global level, but **in contrast** at the national level, we have limited knowledge of the availability and quality of disability data.

- Linking global and national advocacy is key, and the assessment of existing knowledge will help build future advocacy.
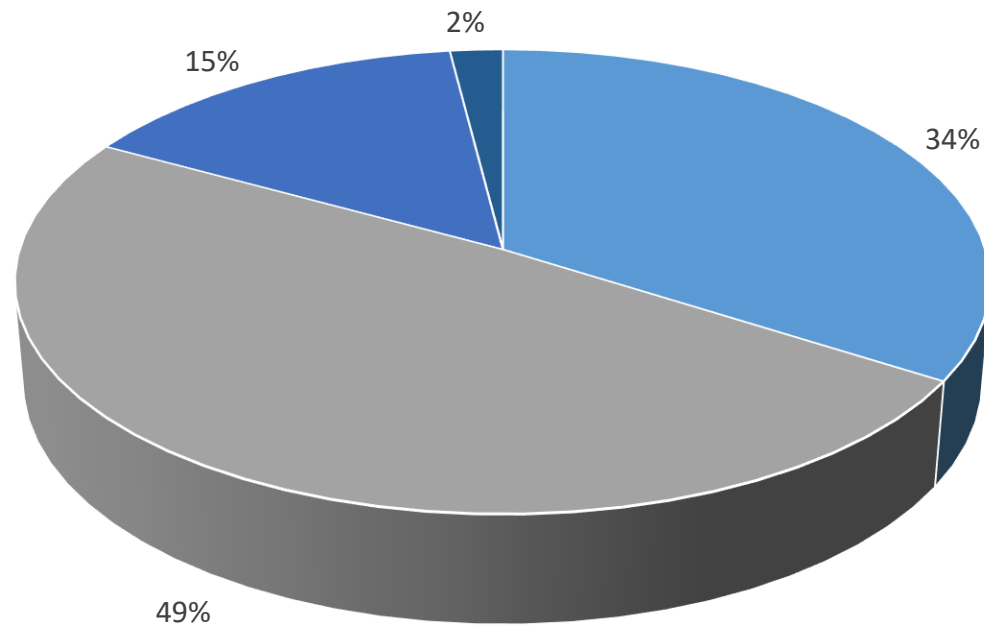
Participant experience with disability data

- Therefore, in the surveys the first question asked participants of their **knowledge on official disability data in their country and if this had been collected in the last 10 years or less**.

- The next question asked about **disability-specific data being collected**, followed by if participants are familiar with tools to collect and disaggregate disability data.

- Finally, participants were asked **if they (or their organizations) were interested in collecting data.**

- The responses to the questions on participants' **"experience with disability data"** will be discussed next.

# Is there official disability data published by the government?

o Yes : **60 percent**

o No : **27 percent**

o I don't know : **12 percent**

o No answer given : **1 percent**

Has your country done a disability-specific national survey in the last 10 years?


2%

15%

34%

49%

- o Yes : **34 percent**
- o No : **49 percent**
- o I don't know : **15 percent**
- o No answer : **2 percent**

Familiarity with tools to collect data on persons with disabilities
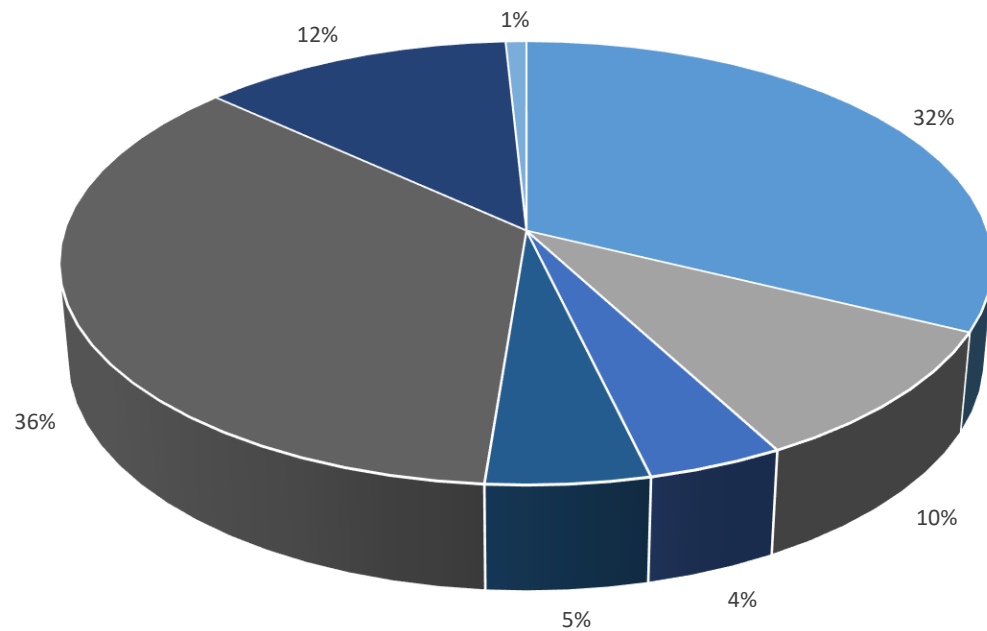
- Yes, the Washington Group Short Set of questions: **32 percent**
- Yes the Washington Group Extended Set of questions: **10 percent**
- Yes, a modified version of it: **4 percent**
- Yes, the UNICEF/ Washington Group Child Functioning Module: **5 percent**
- No: **36 percent**
- I don't know: **12 percent**
- No answer given: **1 percent**

Does your organization routinely generate disability data?

2%

49%

49%
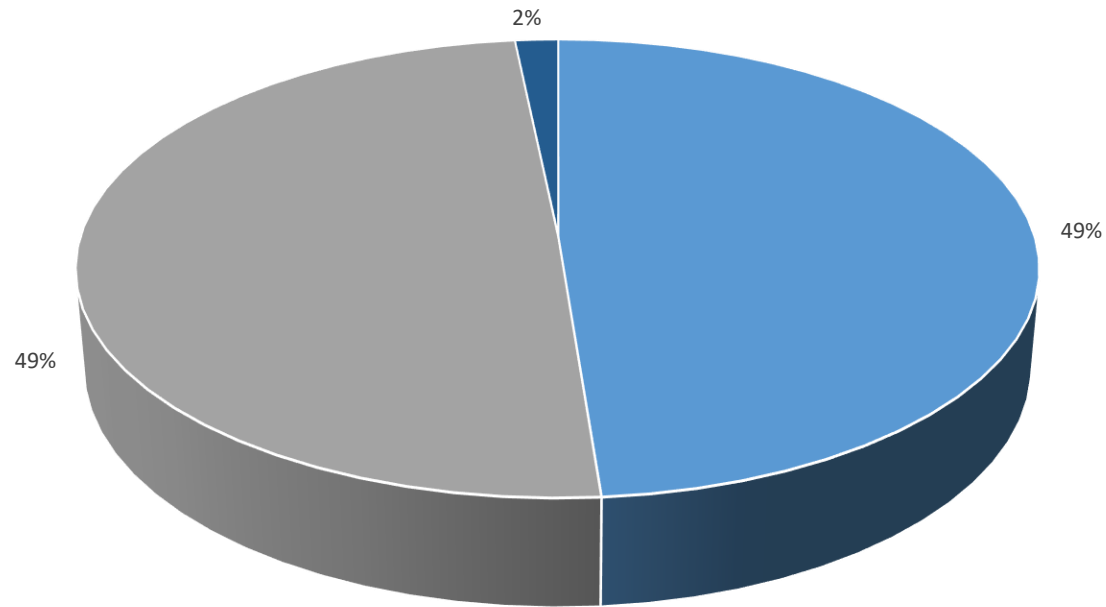
- Yes : **49 percent**
- No : **49 percent**
- I don't know: **0 percent**
- No answer given: **2 percent**

Lobby asks regarding data at national level?

- There is significant lobbying efforts toward institutions (government, government agencies, NSOs, Eurostat, Parliament, and local governments) with the purpose to:
  - include the Washington Group Short Set of Questions (mostly) in surveys, censuses, and housing;
  - ask for disaggregation of available data by disability;
  - develop integrated system for disability data collection and national register;
  - put surveys in an easy-read version for people with intellectual disabilities;
  - push for accessible material, including in Braille.

Participant experience with disability data

Respondents shared that:

- some organizations collected data and conducted baseline studies that are used to:
  - maintain a members registry and disaggregate by type of disability, sex, and age, but are unsure how to use the data further;
  - serve as a benchmark for developing projects.
- they attended a few data conferences, workshops and meetings
- Researchers used data to support their findings using qualitative methods, particularly participant observation.

Gaps and challenges

- The size of a national budget should not influence the prevalence of persons with disabilities in societies: In some countries the national percentage of persons with disabilities is decreasing and/or does not reflect reality (in particular in countries where the prevalence of persons with disabilities entitled for benefits is kept low due to the lack of or limited funding.)
- Disability data can be insufficient, inconsistent, biased, and unreliable;
- Enumerators are not trained and thus relevant data is rarely collected;
- Available data (not disability related) are not systematically aggregated due to lack of awareness among state officials who are unaware of disability disaggregation tools;
- Data gained or produced by organizations are not recognized and are disregarded by statistical authorities.

Gaps and challenges

- There is a lack of cooperation between statistical offices and organizations 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;
- Often psychosocial disabilities and intellectual disabilities are classified as mental health conditions without any distinction, which is inaccurate.

Recommendations for policy makers

Data are needed to address policy gaps related to the inclusion of persons with disabilities in most societies. Data are based on government budgets and not on population groups such as persons with disabilities, which is important to remember.

- Capacity building on the importance of requesting and analyzing disability data to use for developing evidence-based policies and programs;

- The "dichotomy" approach: Data analysis should focus on comparing the population with and without disabilities

- Data collection to support inclusive budgeting and to attract international funding from development and donor agencies;

Recommendations

- Development of small scare projects between NSOs and DPOs to secure funding from donors for disability data collection projects linked to evidence based policy changes that shall be measured, including to carry out smaller sample surveys in larger countries to really test and analyze availability of disability data and its influence on policymakers;

- Foster partnerships between statisticians, policymakers and DPOs to ensure the inclusion and engagement of DPOs in data-related work at national and sub-regional levels;

Recommendations for Statisticians

- Partnership between policymakers, statisticians and DPOs to address gaps in policies and to use data for evidence-based policymaking;

- Training on analysing and understanding data

- Carry out capacity building / training for enumerators by DPOs to learn how to use the right language and right approach;

- Provide technical support to DPOs to undertake data collection that can be used or leveraged by NSOs (e.g., establish an MoU between NSOs and DPOs).

Disability Data Advocacy Working Group

- In January 2019, the Stakeholder Group of Persons with Disabilities launched its Disability Data Advocacy Working Group, with the objective to provide a platform for information sharing, learning, dialogue, good practices and collaboration on disability data collection, disaggregation and analysis.

- The Working Group was created after an assessment of disability data at the national level in 2018. The findings suggested that DPO engagement in data collection and disaggregation efforts is critical and missing. To address this gap, DPOs need technical support, advocacy guidance, and the opportunity for periodical information exchange and learning. Consequently, the Disability Data Advocacy Working Group was established.

- The Working Group has its own listserv where there is information shared on disability data webinars organized by the SGPwD, online learning opportunities, and periodical newsletters with data information. Members of the listserv are encouraged to raise any issues, make suggestions, and to communicate with one another.

cbm
together we can do more

International Disability Alliance

Disability Data Advocacy Working Group Activities

- Since the launch of the Disability Data Advocacy Working Group, the following has been accomplished:

  - Two disability data webinars have been hosted by the Stakeholder Group of Persons with Disabilities, one in January and one in February. Both webinars had a high number of registration and attendance.

  - Two newsletters have been issued, one in January and one in February, to provide new and relevant information on disability data and to serve as a practical resource. The newsletters contain the following sections:
    - Information on the disability data webinar series
    - A main article related to disability data
    - Blogs
    - Updates and news
    - Resources
    - Marketplace

  - The Working Group also has its own listserv where there is active communication about disability data.

Disability Data Newsletters

The 'nothing about us without us' or 'together we will count and be counted' must be guiding principles in the data processes at all levels.

Thank you!