

What's happening with disability data?

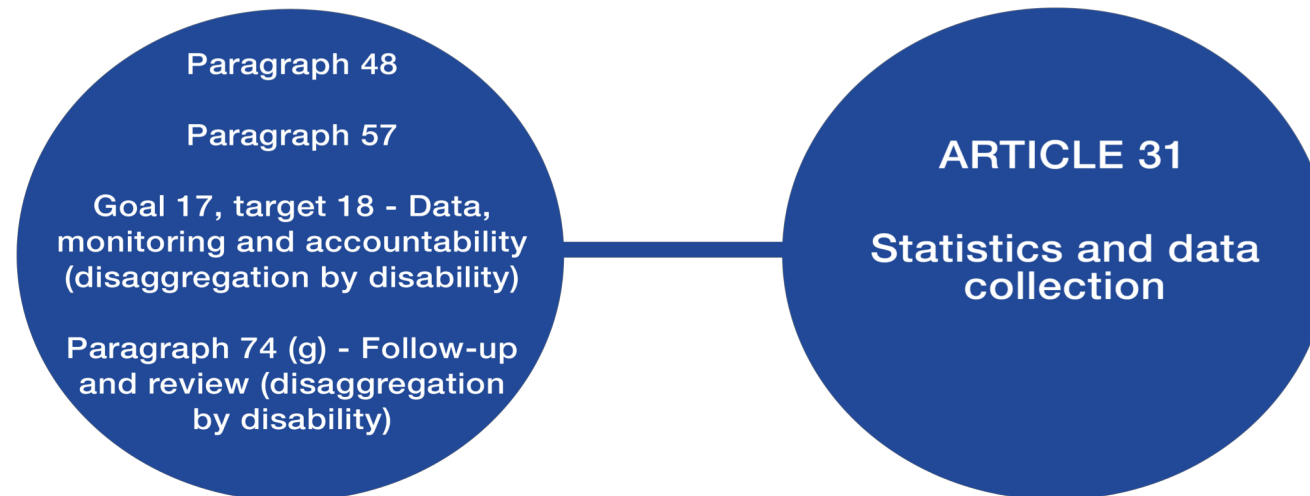
Together we will count and be counted!

A brief study and overview of DPO experiences
regarding disability data

The mandate

2030 AGENDA

CRPD



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) 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.

What's at stake?

If persons with disabilities are *not* counted, then they don't count.

- Globally, there is a lack of data on the situation of persons with disabilities.
- 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.”

What can be done?

Linking global and national data advocacy

- International and national aspirations must be linked.
- International-level commitments by policymakers on data collection must be translated into national priorities and realities.
- **In addition, advocacy at the global level on the collection and disaggregation of disability data is not enough.**
- Policymakers, DPOs, and allies need to understand and use disability data to combat the underlying challenges and gaps with evidence-based policy making.
- IDA and CBM, aiming to link global and national advocacy efforts on data, assessed and summarized what DPOs think about the availability of disability data.

Surveys

- IDA and CBM developed two surveys*: one for a data webinar (April 2018) and another for a data workshop (June 2018);
- Surveys were shared with 550 individuals;
- Questions asked about availability of disability data, knowledge on the 2030 Agenda, and the CRPD;
- A gap in this study is that the surveys were completed and sent back by individuals, but we have no way to verify the accuracy of the responses.

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

Survey 1 - disability data webinar (April 2018)

- A disability data and SDG capacity building webinar for DPOs took place.
 - 345+ people registered for the webinar;
 - 115 links (enabling groups of participants to attend) were used during the webinar (the maximum allowed); and
 - thus far the recording was watched 213 times post webinar.
- The webinar introduced the SDG global indicator framework, disability-inclusive indicators, and the use of the WG-SS for SDG indicator disaggregation.
- Participants engaged in an interactive dialogue.
- Additional information, including the recording, can be found here:
<http://www.internationaldisabilityalliance.org/webinar-disabilitydata>

Survey 2 – workshop (June 2018)

- A disability-measurement training for DPOs took place prior to the Conference of the States Parties to the CRPD.
- Over 110 applications were received and 35 DPO representatives and disability advocates attended the meeting.
- The objective was to connect technical and advocacy knowledge and encourage DPOs to translate these skills at the national level.
- The workshop discussed existing tools, how they can be used, what to do with collected data, and how to use data for advocacy purposes to address policy challenges and gaps.

Survey Findings

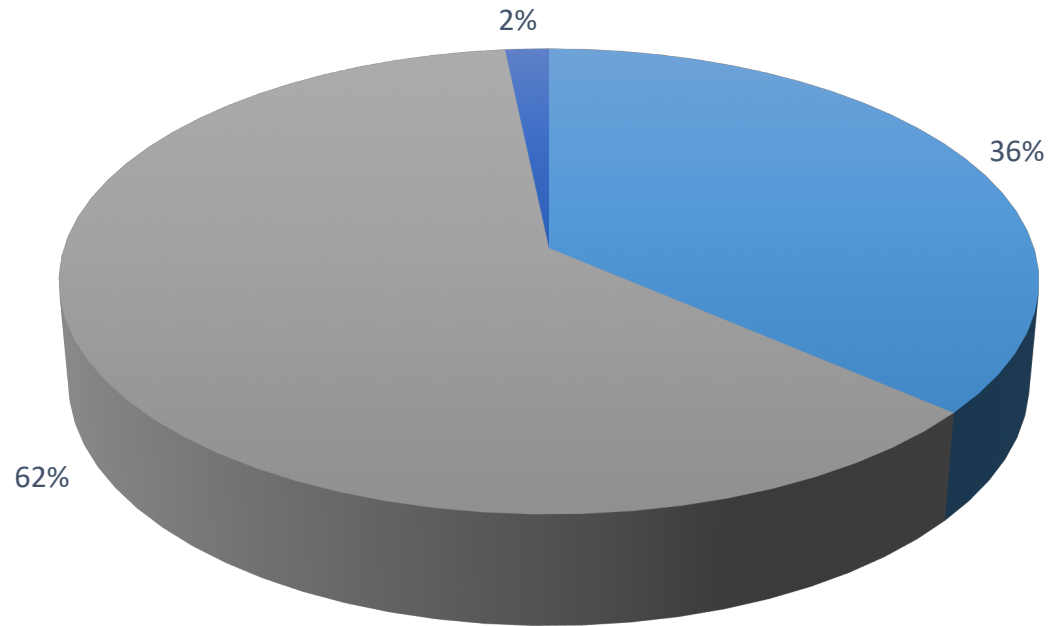
- 120 (out of 550) participants completed the surveys.
- Not all participants responded to all questions, and consequently the numbers vary in different sections.

Main finding: DPOs must play a key role

- DPOs need to be meaningfully included in data collection and analysis to change the situation of persons with disabilities.
- Statisticians, policymakers, DPOs, and allies need to learn from each other and 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.

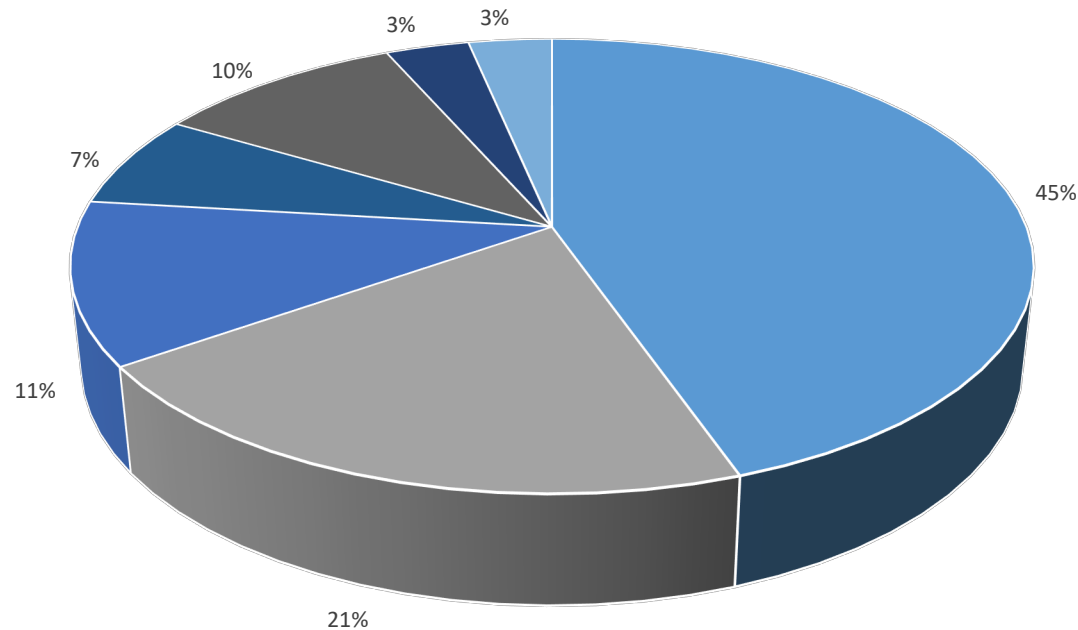
Together we will count and be counted!

Respondents' gender



- Female : **36 percent**
- Male : **62 percent**
- No answer : **2 percent**

Regional responses

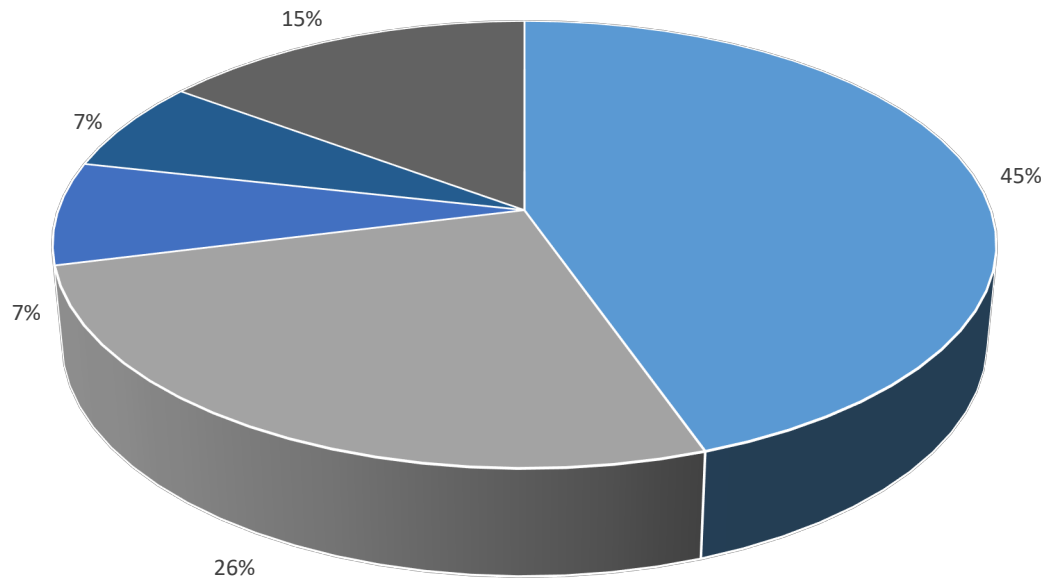


- Africa : **45 percent**
- Asia Pacific : **21 percent**
- Latin America : **11 percent**
- North America : **7 percent**
- Europe : **10 percent**
- MENA : **3 percent**
- No answer : **3 percent**

Analysis of regional responses

- There was widespread engagement from all regions.
- The African region was the most engaged, likely due to the MDGs.
- The Asia-Pacific region showed that it is very active in the SDGs, had different levels of development, and strong disability movements in some countries, but with some factions.
- The Latin American region had good representation despite the survey being only in English.
- The European and North American regions had adequate responses.
- The MENA region provided valuable responses since this region has particular challenges.

Type of organizations

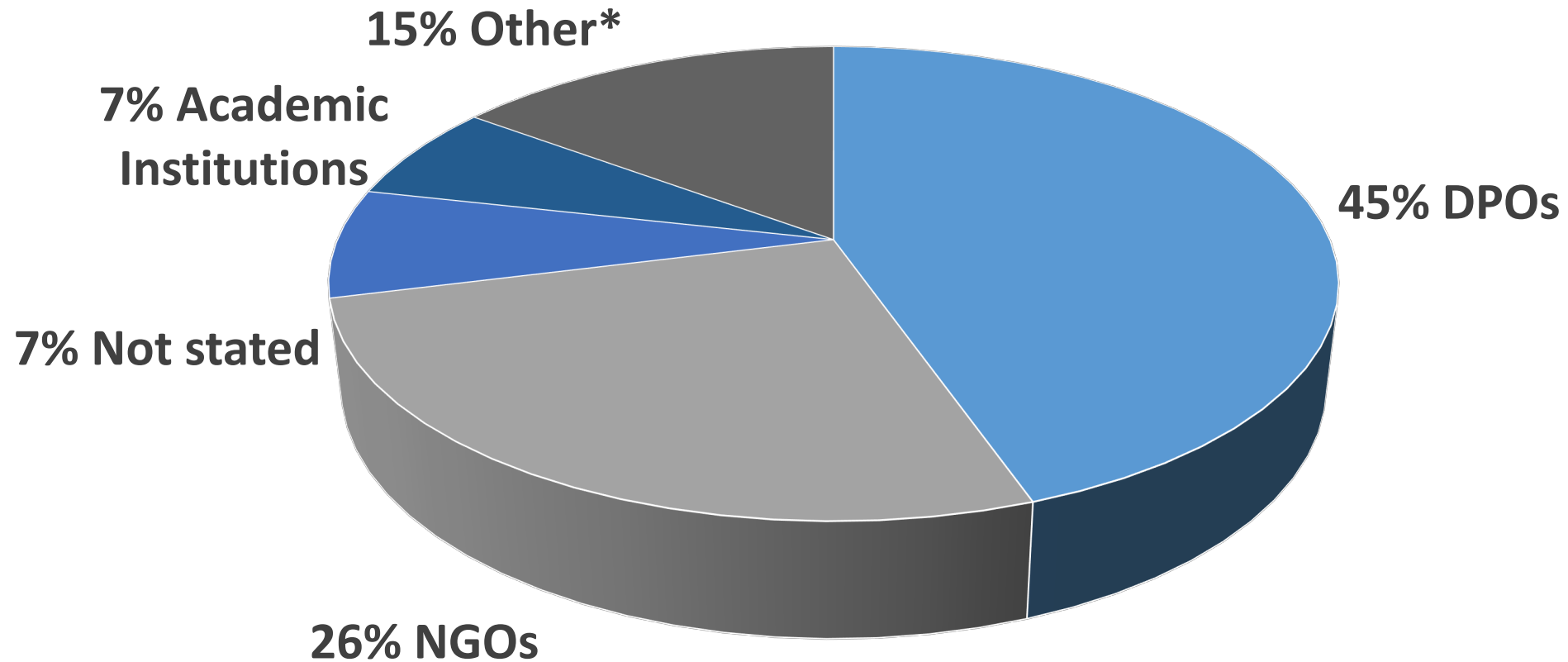


- DPOs: **45 percent**
- NGOs: **26 percent**
- Academic Institutions: **7 percent**
- Others: **15 percent**

(International Organizations, Private Sector, Development Agencies, Government, Community-Based Organizations, National Human Rights Institutions, an individual person, and a consulting firm)

- No answer: **7 percent**

Type of organizations continued



*International Organizations, Private Sector, Development Agencies, Government, Community-Based Organizations, National Human Rights Institutions, an individual person, and a consulting firm

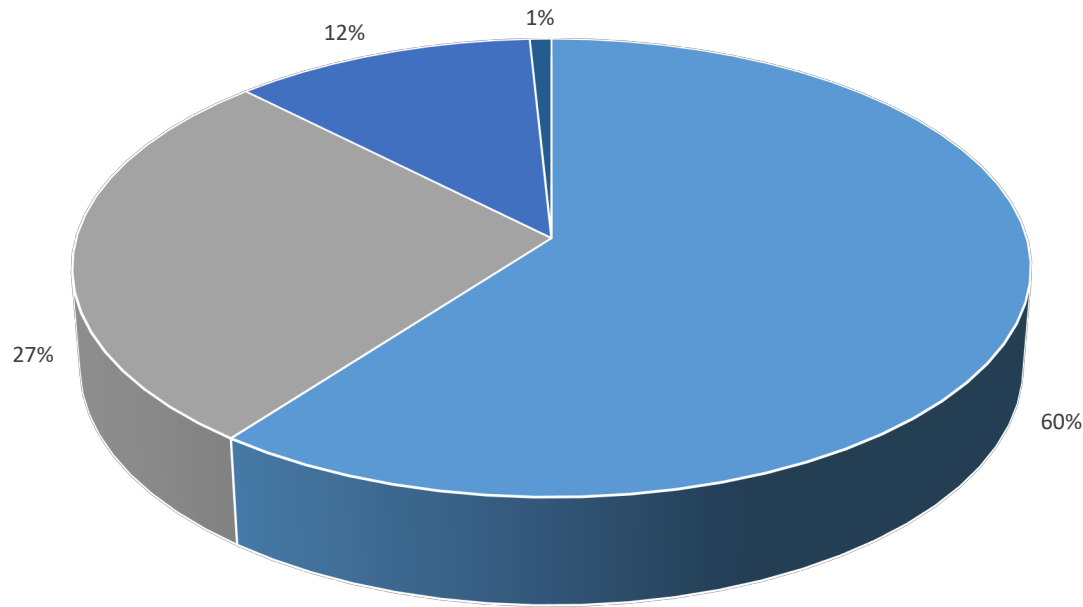
Analysis of organizations

- Type of organizations have a good balance. The majority (45 percent) of responses was from DPOs.
- The responses from NGOs were mostly from disability and development NGOs.
- Academic institutions were not strongly engaged and thus shows a need to reach out more to this sector.
- Foundations were missing and would be a good area to target.
- The “others” category needs additional analysis, but indicates an interest in leave-no-one-behind data.

Participant experience with disability data

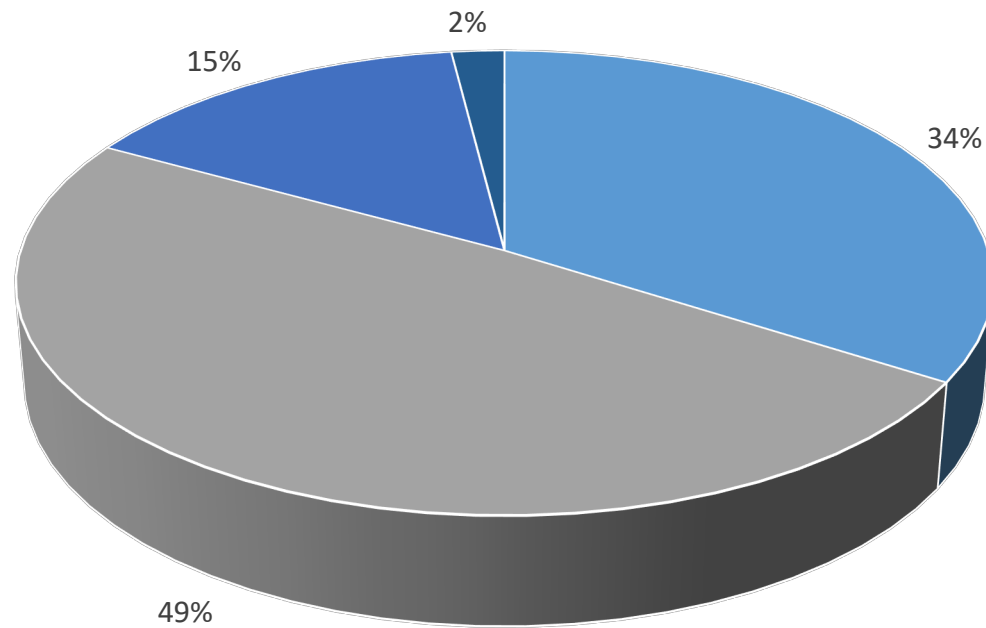
- The surveys focused on the availability of disability data and participants' experiences.
- This was important because advocacy for internationally comparable disability data is a key focus at the global level, but **in contrast** at the national level, we have limited knowledge of the availability and quality of disability data.
- Linking global and national advocacy is key, and the assessment of existing knowledge will help build future advocacy.

Does the government publish official disability data?



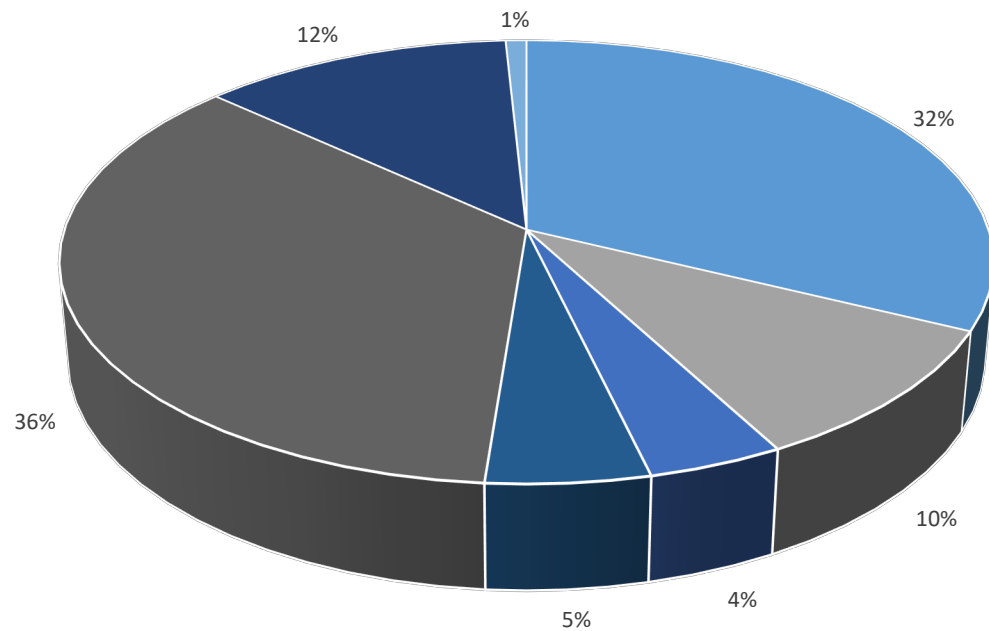
- Yes : **60 percent**
- No : **27 percent**
- I don't know : **12 percent**
- No answer given : **1 percent**

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



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

Familiarity with tools to collect data on persons with disabilities



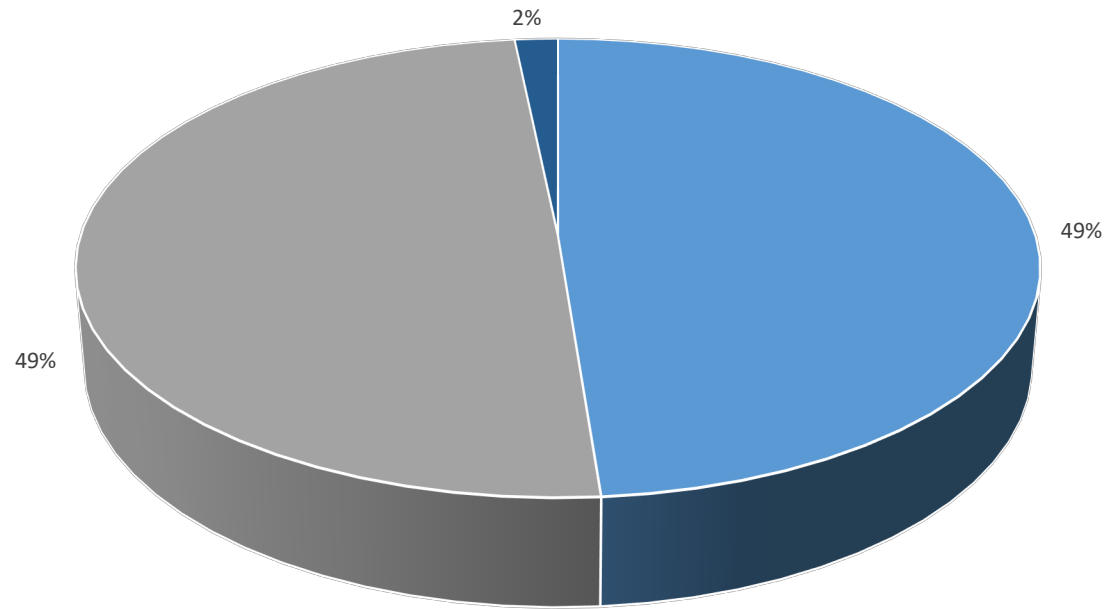
- Yes, the Washington Group Short Set of questions: **32 percent**
- Yes the Washington Group Extended Set of questions: **10 percent**
- Yes, a modified version of it: **4 percent**
- Yes, the UNICEF/ Washington Group Child Functioning Module: **5 percent**
- No: **36 percent**
- I don't know: **12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

Additional information on disability data

In addition to the aforementioned graphs, we received the following responses:

- 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.

Does your organization routinely generate disability data?



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

Organizations and 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.

Disability data – thematic areas

The following thematic areas were considered important in collecting data for advocacy efforts:

- Education:
 - admission and drop-out rates;
 - number of children in school,
 - the availability, accessibility, and quality of services provided,
 - number of children benefiting from inclusive services;
- numbers of registered voters with disabilities;
- employment and entrepreneurship;
- disaggregation by disability type;
- Special Olympics programs and sports.

Gaps and challenges

- 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 continued

- There is 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 policymakers

- Carry out capacity building on disability data to develop evidence-based policies and programs;
- Carry out data analysis of comparing the general population between persons with and without disabilities;
- Collect data to support inclusive budgeting and to attract international funding from development and donor agencies.

Recommendations for donors

- 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;
- Allocate budget for inclusion of persons with disabilities, including data on inclusion - to measure inclusion - and leave no one behind;
- Bring the concern of lack of disability data to the global level at the High-level Political Forum to the attention of countries reporting on SDG implementation (VNRs) and call on these countries to report along the lines of global indicators;
- Use and report on the OECD DAC disability policy marker frequently, consistently, and systematically;
- Disseminate and champion the OECD DAC disability policy marker to monitor its implementation.

Recommendations for statisticians

- Carry out capacity building for enumerators by DPOs to learn how to use the right language and right approach to use programs inclusive of disability data;
- Carry out capacity building for NSOs to encourage them to work with DPOs on data collection;
- 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).

Recommendations for DPOs

- Advocate for a meaningful role in data collection to understand and use data to assist in the realization of the CRPD and 2030 Agenda;
- Build partnerships between DPOs and NGOs, especially mainstream NGOs at all levels;
- Carry out capacity building for DPOs with a strategic action plan for advocacy and toolkit to effectively engage NSOs, statisticians, and policymakers;
- Increase efforts to learn and exchange information at national and regional levels.

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!

Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
DPO	Organization of Persons with Disabilities
IDA	International Disability Alliance
MDGs	Millennium Development Goals
MENA	Middle East and North Africa
MoU	Memorandum of Understanding
NGO	Non-Governmental Organization
NSO	National Statistics Office

Abbreviations continued

SDGs	Sustainable Development Goals
UNICEF	United Nations International Children's Emergency Fund
VNR	Voluntary National Review
WG	Washington Group
WG-SS	Washington Group Short Set of Questions