

# Participants package

Disability Data Advocacy Workshop for Organisations  
of Persons with Disabilities



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# Programme Summary

## Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

By engaging in this workshop, participants will learn how to:

1. Identify sources of disability data and the best approaches for its collection and analysis
2. Review and research available local data
3. Advocate for data collection and investment in better data
4. Use data to support evidence-based advocacy

Session	Title of step	Summary of content by step
1	Introduction to the Disability Data Advocacy Workshop	<ol style="list-style-type: none"><li>1. Meet each other and set rules for engagement</li><li>2. Understand the objectives, scope, and components of the workshop, including how it fits with broader disability data advocacy</li><li>3. Gain general knowledge on the requirements for disability data in the CRPD and the 2030 Agenda and its Sustainable Development Goals</li></ol>
2	Leave no one behind': The critical role of data disaggregation	<ol style="list-style-type: none"><li>1. Understand data disaggregation by disability and its relationship to measuring equity and inclusion</li><li>2. Understand how disaggregation can help monitor the CRPD and SDGs</li><li>3. Be able to apply the knowledge on disaggregation to advocacy</li></ol>

Session	Title of step	Summary of content by step
3	Identifying the Population with Disabilities Using the Washington Group Questions	<ol style="list-style-type: none"> <li>1. Understand the Washington Group Short Set (WG-SS) of questions and why they are widely used, recommended and endorsed for disaggregation</li> <li>2. Be familiar with the WG-SS questions and response options and how these are used to identify the population with disabilities</li> <li>3. Begin applying the WG-SS to help shape advocacy messaging</li> </ol>
4	Beyond disaggregation	<ol style="list-style-type: none"> <li>1. Understand how the WG-SS can be used to inform disability issues, aside from disaggregation</li> <li>2. Be aware of the limitations of the WG-SS and possible ways to address these</li> <li>3. Understand additional information on functional status and barriers and enablers to inclusion that can supplement disaggregated data</li> </ol>
5	Disability data sources and quality	<ol style="list-style-type: none"> <li>1. Identify different sources of disability data and their advantages and disadvantages</li> <li>2. Critique how available data will meet their needs for specific advocacy objectives</li> <li>3. Demonstrate a basic knowledge of best practice for quality data collection and how to apply this when evaluating data used by policymakers, when advocating for improved data, and in collecting their own data</li> </ol>
6	How to advocate for better data	<ol style="list-style-type: none"> <li>1. Identify data needs and review available data for CRPD, SDGs and other global frameworks</li> <li>2. Explore how to meet data gaps, including through citizen generated data</li> <li>3. Begin developing a plan to advocate for better data</li> </ol>
7	OPDs role in advocacy using data	<ol style="list-style-type: none"> <li>1. Understand ways to use data for evidence-based advocacy</li> <li>2. Explore OPD roles in data collection and use</li> <li>3. Explore the use of data in local advocacy objectives</li> </ol>
8	Drafting an action plan and closing	<ol style="list-style-type: none"> <li>1. Begin drafting a collective action plan to help them take forward disability data advocacy in their country</li> <li>2. Demonstrate some key learnings from across the programme</li> </ol>

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# Session Summaries

Session 1    Session 5  
Session 2    Session 6  
Session 3    Session 7  
Session 4

# Summary: Introduction to the Disability Data Advocacy Workshop

## Session 1: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

### Overview

- Provide the framework for the rest of the workshop within the context of global disability data efforts.
- Participants are aware of global development and legal frameworks and the international experience of disability data collection.
- Participants understand key data needed for SDG and CPRD advocacy.
- Participants understand that the CRPD and the 2030 Agenda mandate countries to collect and disaggregate disability data, notably CRPD Articles 4 and 31, and in the 2030 Agenda: paragraphs 48 and 57, and Goal 17.18.
- It is key for OPDs to understand the real situation of persons with disabilities, to identify gaps that are not addressed through policies, and to provide examples of successes.
- It is also important for OPDs to understand how to analyse, use, and trust data to create advocacy messaging.

### Key concepts/terms

- This workshop is based on the Disability Data Advocacy Toolkit developed by the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, and CBM Global Disability Inclusion and launched in 2020.
  - This toolkit was created in response to increasing interest and requests from persons with disabilities and their representative organisations from all over the world.
  - 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 aspects of data: The first is **the need for data**, to understand the real situation of persons with disabilities, to identify gaps that are not addressed through policies, and to provide examples of successes; and the second is **use of data** once it exists. It is important to understand how to analyse, use, and verify data for advocacy.

- 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 Articles 3 and 31. Additionally, States Parties need to closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations under Article 4.3.
- In 2015, this is further strengthened by the political commitments of 193 countries to collect data on persons with disabilities and to disaggregate data by disability by adopting the 2030 Agenda for Sustainable Development and its Sustainable Development.
- In 2017, the global indicator framework was adopted, which provides a guide to measure SDG progress.
- There are 11 explicit references to persons with disabilities in the 2030 Agenda for Sustainable Development of which seven are in the SDGs. Refer to the session 1 handout for details.
- The global indicator framework has 231 global indicators from which 11 are disability inclusive, in addition to the call to disaggregate SDGs by disability. Refer to the session 1 handout for details.
- Data is being collected at the national level, but there are differences. Data is not being collected in all countries at the appropriate time intervals, at accepted standards of quality, or in a way that is internationally comparable to provide the information needed to monitor the implementation of the SDGs and the CRPD.
- To address lack of data on persons with disabilities, OPDs can advocate for data on disability to be increased and for it to be of good quality. OPDs can use available data to advocate for inclusive policies and programs and to measure progress on the implementation of the CRPD and SDGs.

## Resources

- [Disability Data Advocacy Toolkit](#) in various formats and languages.
- The [Convention on the Rights of Persons with Disabilities](#), specifically Articles 3, 31, and 4.3.
- The 2030 Agenda for Sustainable Development and its [Sustainable Development Goals](#), specifically paragraphs 48 and 57, and Goal 17.18.
- Read about the [Inter-agency and Expert Group on SDG Indicators](#), created by the UN Statistical Commission to develop and implement the SDG indicators.
- The [Stakeholder Group of Persons with Disabilities' disability data advocacy work in sustainable development](#).

# Summary: ‘Leave no one behind’: The critical role of data disaggregation

Session 2: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Overview

- Data disaggregation is a powerful tool to inform advocacy by identifying where full inclusion has not occurred.
- Disaggregation requires that the population with disability be identified.
- The indicator of interest is estimated for the population with and without disabilities and the estimates are compared to see if they are the same which would indicate that the CRPD and SDG objectives have been met for this indicator.
- The definition of disability is complex and varies over time and context. Given the complexity of the concept of disability and the need to identify a cut-off point on the disability/functioning continuum, there are different ways to identify the population which will produce different disaggregation.
- How the population with disabilities is defined will affect conclusions about whether the CRPD and SDG objectives have been met.
- Disaggregation requires that information that identifies the population with disabilities be collected on the same survey or census on which information on the indicators is collected.

## Key concepts/terms

- Both the CRPD and SDGs rely on data to evaluate whether their objectives of full inclusion have been achieved and identify **disaggregation** as the means to quantify the extent of inclusion.
- Disaggregated data is data that has been broken down by sub-groups, such as by age, ethnicity, or unemployment rate. Disaggregated data can indicate inequalities that may not be fully reflected in aggregated data.
- Disaggregated data by disability status is an important advocacy tool as it identifies areas where inclusion has not been achieved and the extent of the disparities between those with and without disabilities.
- The following terms are key to understanding disaggregation
  1. **Indicators:** Indicators are used to measure what is happening amongst a population

on a certain thing, such as around **unemployment**. Statistics are used to measure the indicator, e.g., by providing the **rate of unemployment**.

2. **Disability identifier:** A disability identifier is created from the question(s) in the survey or data collection tool that identifies whether that person has a disability.
- In most countries, the data needed to construct the SDG indicators are obtained from core data systems and targeted surveys (e.g., census, labour force surveys, living standard surveys, education surveys, health surveys, transportation surveys).
  - In addition to obtaining information on the indicator, it is necessary to identify the population with disabilities and the population without disabilities. This information is obtained from questions developed to identify the population with disabilities and must be included on the same data collection system as the indicators.
  - How the populations are identified is dependent on the questions used in the data collection. When using data to determine if full inclusion has occurred, it is critical to understand how the population with disabilities has been identified.
  - The term disability means different things to different people and in different contexts. In general use, it is an umbrella term that incorporates multiple components.
  - The term ‘functioning’ refers to an individual’s level of ability/difficulty in performing core functional domains and includes seeing, hearing, walking, cognition, communication, upper body function and psychosocial functioning.
  - Because of the complexity of the concept, the **language of disability is not specific** – the term means different things to different people including interviewers and, most important, to how the individual will report about themselves. If the term is not specific but means different things to different people, asking people if they have a disability will result in responses based on their different understanding of the term.
  - In addition, and very importantly, in some cultures, stigma is associated with disability. As a result, any questions that use the term disability or if respondents are told that the questions are about disability this will most likely result in the under-identification of those with functional characteristics of interest.
  - Functioning and disability exist on a continuum and are not inherently yes/no dimensions. This means that there is not one population with disabilities, but many, and that the characteristics of those populations will vary. It does mean that a place on the continuum needs to be identified (the cut point) that defines the groups with and without disabilities to monitor the CRPD.
  - Due to the complexity of the disability concept and the stigma attached to the term in some cultures, the question ‘Are you disabled?’ should not be used to identify the population with disabilities for monitoring inclusion.

## Resources

- Video: [Why is it important to identify the population with disabilities?](#) (with English captions and International Sign)
- Washington Group information: [Resources for Data Users](#)

# Summary: Identifying the population with disabilities using the Washington Group Questions

**Session 3: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities**

## Overview

- The questions included in a data collection (e.g., a census or survey) to identify the population with disabilities will affect what the data suggests about whether full inclusion has been achieved.
- The selection of the cut-off point on the continuum of functioning that defines the population with disabilities will affect:
- The percentage of the population identified (the prevalence).
- The characteristics of that population.
- Differences between those with and without disabilities on indicators of inclusion.
- There is no single estimate of the prevalence of disability.
- There are many estimates based on where the cut-off is chosen, and this choice should be based on the use of the data.
- Disaggregation is key to monitoring the CRPD, but other information is also needed to achieve the objectives of the CRPD. This will be discussed in Session 4.

## Key concepts/terms

- The Washington Group developed a set of questions to identify those who because of difficulties doing certain universal, basic actions are at greater risk for limitations of participation.
- The questions are used to disaggregate data by disability status to monitor the CRPD and SDGs.
- WG-SS has wide use. It has been used by over 80 countries national censuses or surveys. It has also been used by international aid donors and UN entities, such as United Kingdom and Australia Aid programmes, UN Statistics Division (UNSD) and the UN Economic Commission for Europe, the Incheon Strategy on Making the Right Real in Asia, and UN DESA's Disability Data Experts Group

- The WG-SS is the recommended set of disaggregation.
- The WG-SS six questions are:
  1. Do you have difficulty seeing even if wearing glasses?
  2. Do you have difficulty hearing even if using a hearing aid?
  3. Do you have difficulty walking or climbing steps?
  4. Do you have difficulty remembering or concentrating?
  5. Do you have difficulty with (self-care such as) washing all over or dressing?
  6. Using your usual language, do you have difficulty communicating (for example understanding or being understood by others)?
- The response categories are: No difficulty; Some difficulty; A lot of difficulty; Cannot do at all.
- ‘A lot of difficulty’ reported in at least one domain is the recommended definition to be used for international comparisons because it identifies the group of greatest policy relevance.
- It is important to assess the degree of difficulty in each domain, rather than simply asking a yes/no question about whether the person has a disability or difficulty in that functioning area:
  - Experience of disability is not as simple as ‘yes or no’ – most people experience difficulties with functioning to varying degrees, from some difficulty to great difficulty. Some people will also experience difficulties across multiple domains.
  - Because of the stigma around disability, if the question directly asks whether they have a disability, persons with disabilities may not be willing to openly identify. This would lead to an underrepresentation of disabilities.
- The definition of disability can differ depending on the ‘cut-off’ point used:
  - Disability may be defined as existing where the person has some difficulty in functioning in a domain area (such as seeing even when using glasses), or only where they have a lot of difficulty or cannot do at all.
  - People may have difficulties in functioning over multiple domains, e.g., difficulty remembering and difficulty communicating.
- When disability is defined more narrowly, or with a higher cut-off point – such as where someone cannot function at all in a domain:
  - Then the data for that indicator will pick up fewer persons as having disabilities and include only people with higher levels of difficulties functioning.
  - These people will likely face higher barriers (e.g., in obtaining employment).
  - The data will reflect a much greater difference between employment rates for persons with and without disabilities.
  - This will suggest we are further away from achieving equality and inclusion for that indicator.
- The relationship between prevalence and disaggregation:
  - The higher the percent with disability, the smaller the difference between those with and without disabilities.

# Background reading/additional resources for facilitators

- Washington Group information: [Resources for Data Users](#)
- [Disability Data Advocacy Toolkit](#) in various formats and languages.
- [Differences in Reported Disability Prevalence Rates: Is something wrong if don't get 15%?](#)
- [The Washington Group Questions and The Disability Continuum](#)
- Video: [What is the prevalence of disability?](#) (with International Sign translation and English captions).

## Summary: Beyond disaggregation

### Session 4: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Overview

- All data has limitations.
- Even if imperfect, data can be successfully used for advocacy if the nature of the limitations is known and the data is determined to be fit for purpose.
- Knowledge of how to use disability data and its potential limitations will support advocacy activities by assuring that accurate evidence is used to support or contest policy and programme decisions.
- While disaggregation is key to monitoring the CRPD, the SDGs and advocacy objectives, other types of data on functioning and participation barriers and facilitators is also needed.

## Key concepts/terms

- The WG-SS provides extensive information on disability beyond identifying the population with disabilities for disaggregation.
  - The six questions can be used to describe functioning in each of the domains individually, such as difficulty in seeing. Data on two or more domains can be combined to obtain information on difficulty in functioning on all the domains.
- All questions have limitations but whether the limitations will affect the quality of the data depends on the intended use of the data.
- Some of these limitations of the WG-SS reflect the design requirements for their intended purpose, which included:
  - 1) Use with the whole population.
  - 2) For administration in a census where, the number of questions must be kept to a minimum, and they cannot be sensitive in nature.
- A limitation of the WG-SS is that not all core functional domains are addressed. As a result of the question requirements, the WG-SS does not identify:
  1. Persons with psychosocial disabilities that do not affect other domains such as communication, cognition, or self-care.

## 2. Persons with upper body limitations.

Note: unless these affect other domains such as self-care or communication.

- To address these limitations, the WG developed the WG-Extended Set and the WG-Enhanced Set of Questions, which:
  - Includes two questions each on upper body functioning, and anxiety and depression.
  - Can be added to surveys such as labor force surveys, living standards surveys, health surveys, education surveys, etc.
- Another limitation of the WG-SS is that it does not address the full range of information needed to understand disability. For example the WG-SS does not capture:
  1. Age of onset: which can inform the degree to which national contexts are meeting their obligations under the CRPD and commitments in the SDGs to persons with disabilities from different age groups, importantly, including older persons who may acquire disabilities later in life.  
Causes of disability: the WG question tools use a functional approach to define disability, focusing on difficulty in doing a core set of activities, rather than the cause of that difficulty, or diagnosis of disability. This is because the level of functioning is what affects persons with disabilities' participation in society, rather than the cause of the functioning difficulty.
- Another limitation of the WG-SS is that it is not as effective in identifying the population of children with disabilities as it is in identifying the population of adults with disabilities. As a result of the design requirements, the WG-SS:
  1. It is not appropriate for children under 5 years.
  2. Misses some children with developmental issues aged between 5-18 years.
- To address these limitations, the WG and UNICEF developed the Child Functioning Module (CFM). The module follows the basic design of the WG-SS but includes functional domains of importance to children. The question sets have been tested and divided into two age groupings:
  1. The question set for children aged 2 to 4 years contains 8 domains.
  2. The question set for children aged 5 to 17 years contains 13 domains.
- The CFM is included in UNICEF's Multiple Indicator Cluster Survey Programme; a programme coordinated by UNICEF that obtains core information on various aspects of children's wellbeing.
- Disaggregation (and the WG-SS) does not:
  1. Directly capture environmental barriers and facilitators such as assistive devices, supportive regulations, accessible buildings.
  2. Address functioning with and without assistive devices.
- To address the latter limitation, the WG-Enhanced Set includes questions on the use of mobility assistive devices and functioning with the use of these devices. However, other barriers and facilitators are not addressed. Other data is needed to obtain this information, either by adding additional modules to the ongoing data collections or conducting a disability survey, or both.

- Additional information that is needed to address the disparity in the inclusion of persons with disabilities (e.g., in employment) could include:
  - Accessibility of the physical environment, such as workplaces or transportation.
  - Legal and regulatory requirements or lack thereof.
  - Attitudes
  - Accessibility of information and communications
- Additional information would help understand and address the disparity in inclusion between persons with and without disabilities. This includes what persons with disabilities need, have access to, and use in terms of supports and services, including:
  1. Assistive devices
  2. Personal assistance
  3. General and specialised health care
  4. Educational opportunities
- This information can be obtained by adding the appropriate questions to surveys that also include questions to identify the population with disabilities. Some of the needed information is obtained in surveys run by the government. Administrative data systems can also provide needed information.

To assess whether a data set is fit for your intended use, you can ask the following questions:

1. Are all functional domains of interest included? If not, which ones are omitted and how will this affect your use of the data?
2. Are the aspects of disability of interest covered? If not, which ones are omitted and how will that affect your use of the data?
3. Do the questions adequately address the age range of interest? If not, where are the omissions and how will that affect your use of the data?
4. What other sources of data could be considered and how does this inform your advocacy?

## Background reading/additional resources for facilitators

- Washington Group information: [Resources for Data Users](#)
- [Disability Data Advocacy Toolkit](#) in various formats and languages.
- [WG-ILO module on full employment](#)
- [The Washington Group/UNICEF Module on Child Functioning](#)
- The [World Blind Union research on the impact of COVID-19](#) on blind and partially sighted persons

# Summary: Disability data sources, quality, and the role of OPDs

**Session 5: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities**

## Overview

- There are multiple sources of data on disability – all have advantages and disadvantages.
- Data used for advocacy should meet basic quality standards.
- The data source and type of data should be appropriate for the respective uses.
- Well developed and tested questions are necessary, but not a sufficient requirement for good data – appropriate training and administrative procedures must be in place.
- Knowledge of how to use disability data and the potential limitations of the data will support advocacy activities by assuring that accurate evidence is used to support or contest policy and programme decisions.

## Key concepts/terms

- There are many potential sources of data on disability in the form of microdata files or summarised in reports often used in policy formation, research, civic engagement and advocacy. Common sources are:
  1. Censuses
  2. Surveys of people
    - i. Multipurpose surveys
    - ii. Topic specific surveys
    - iii. Health surveys
    - iv. Disability surveys
  3. Surveys of organisations and establishments
  4. Administrative systems
    - i. Systems not focused on disability
    - ii. Systems focused on disability
  5. In-depth interviews
  6. Case studies

- Refer to ‘Handout: Summary of common sources of data’ for more details.
- All sources have advantages and disadvantages, and users need to match the best source to their data needs.
- Evaluating data quality can be complex, however, asking key questions about the data can provide a good understanding of whether the data meets advocacy objectives. If data is of poor quality, understanding the quality issues is important to inform how we advocate for better data.
- Standard interviewing best practices apply to questions related to disability. Interviewers should ask the questions as they are written and not improvise or assume they know the response from observation. They should not use the term ‘disability’ at any point during the data collection unless it is explicitly written as part of the question. Interviewers need to be aware that the questions are not sensitive, they concern universal basic activities that all people, regardless of nationality or culture, should understand.
- Training that addresses interviewing persons with disabilities should be part of standard interviewer training as they apply to all data collections and all questions asked, not just those related to disability.
- Data collection procedures should be accessible so persons with disabilities can participate – this is a necessary practice in all data collection.

## Background reading/additional resources for facilitators

- [Resources for Data Users](#)

# Summary: How to advocate for better data

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Overview

- The CRPD and the 2030 Agenda mandate countries to collect and disaggregate disability data, yet disability significant data gaps remain that prevent achieving full CRPD and SDG implementation.
- The lack of data on persons with disabilities increases marginalisation and governments then fail to address the barriers and discrimination encountered by persons with disabilities.
- Citizen-generated data is increasingly being recognised as a complement to official statistics to measure progress of those most left behind in the SDGs.

## Key concepts/terms

- **Recap:** The CRPD and the 2030 Agenda require countries to collect and disaggregate disability data.
  - **CRPD requirements:**
    - CRPD Article 31 requires States Parties to collect data on persons with disabilities.
    - CRPD Article 3 General Principles
    - CRPD Article 4.3 requires that States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.
  - **The 2030 Agenda and its SDGs requirements:**
    - The SDGs include 231 global indicators, of which 11 are specifically disability inclusive.
    - The SDGs also include a general recommendation for countries to disaggregate by disability: see 2030 Agenda paragraphs 48 and 57, and Goal 17.18.
- Disaggregation enables us to separate the rate for those with and without disabilities, to determine whether the indicator is being achieved **equally** between these groups.

- Gaps in disaggregation of formal disability data arise from a range of sources:
- It is a combination of lack of disability training and awareness in National Statistics Offices (NSOs) and, the lack of political will. Often persons with disabilities are not a priority for governments and as a result get left behind.
- Sometimes disability data is held to a higher standard and at times NSOs face challenges on how to identify disability in data collection.
- Disability data can get lost in ministries since it is spread across areas, such as employment, education, and health. But unlike age and gender, disability data has not been adopted by all ministries, which leaves a serious gap in the collection of disability data.

### To assess CRPD implementation and data collection:

- **Ask the NSO** for data about persons with disabilities.
- **Inquire what type of data** is collected or disaggregated about persons with disabilities in line with CRPD and the global SDG indicator framework.
- **Inquire how data files** are disseminated and what reports are produced as part of a series or as special reports.
- **Review government-funded research institutions** to see if they are publishing reports that include data on persons with disabilities.

### Data and CRPD reports:

- **Check if data** is included in the government report to the CRPD committee as well as shadow reports done by OPDs.
- **Follow CRPD committee** discussions on your country's report and if recommendations are included around disability data.
- **Use recommendations** from the CRPD Committee to formulate advocacy messages.
- **The 2030 Agenda** mandates countries to collect and disaggregate disability data, yet overall, there is a lack of internationally comparable disability data to measure the SDGs. Many countries are not collecting data:
  - at the appropriate time intervals,
  - at accepted standards of quality, or
  - that provides adequate information needed to monitor the implementation of the SDGs and the CRPD.
- **As a result**, the lack of data on persons with disabilities increases marginalisation and the government fails to address barriers and discrimination encountered by persons with disabilities.
- **Citizen-generated data:** This is increasingly being recognised as a complement to official statistics to measure progress of those most left behind in the SDGs.
  - Citizen-generated or community-driven data is data that people, or their organisations, produce on issues that affect them (e.g., measuring the SDGs). It is generated in several ways, including surveys, texts, phone calls, emails, reports, storytelling, and social media. It can be quantitative or qualitative, structured or

unstructured, open or closed. The data is used to directly monitor, demand or drive change. Citizen-generated data is a useful complement to institutional data, not a replacement for it.

- The Leave No One Behind (LNOB) Partnership highlights how civil society organisations are working to promote the recognition of community-driven data in monitoring and influencing for positive change. For more information on citizen-generated data, see the example from the LNOB Partnership.

## Resources

- [Disability Data Advocacy Toolkit](#) in various formats and languages.
- The [global indicator framework](#) and [availability of current and future indicators that disaggregate data by disability](#).
- Review the [identified 32 critically important SDG indicators](#) to be disaggregated by disability.
- The Stakeholder Group of Persons with Disabilities' disability data advocacy work in sustainable development. Read [here for more information on this advocacy](#) and join [the disability data listserv](#) to engage in a platform of exchange.
- Washington Group: [Disaggregation by Disability Status: A Report on Selected Sustainable Development Goal \(SDG\) Indicators](#).
- The Leave No One Behind ([LNOB](#)) Partnership highlights how civil society is working to promote the recognition of community-driven data in monitoring and influencing for positive change. Read the LNOB Partnership case study on pages 29 to 31 of the [Disability Data Advocacy Toolkit](#).
- As an example of OPD-led advocacy for better data, read the Pacific Disability Forum case study on pages 18 to 19 of the [Disability Data Advocacy Toolkit](#).

# Summary: How to advocate for better data

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Overview

- OPDs can incorporate data into their CRPD and SDG monitoring and reporting processes and use the CRPD and SDGs to drive advocacy messages on why disability disaggregated data is important.
- OPDs can build evidence-based advocacy messages for more effective advocacy outcomes, using both qualitative and quantitative data in advocacy messaging.
- OPDs should be leading discussions and advocacy activities around disability data and should be meaningfully included in all stages of the process (planning, implementation, monitoring).
- OPDs should advise government agencies on what they should be collecting and how to interpret the data.
- Key advocacy strategies in the local context can include collaboration with other OPDs and other stakeholders, development of joint advocacy actions, use of social networks and media to promote advocacy messages, and coalition building.
- Data must be inclusive, accessible, and consistent for OPDs to effectively advocate using data.

## Key concepts/terms

- Data is used to build advocacy messages by:
  - Showing patterns or where change is needed.
  - Highlighting a key point, often a shocking situation.
  - Overcoming stigma and discrimination.
  - Demonstrating the effectiveness of interventions.
  - Sharing stories and highlighting experiences.
- OPDs should use official data in advocacy:
  - OPDs can encourage governments to base policy and budget decisions on data, which is more effective and creates more meaningful change.

- Using official data strengthens the evidence base to compel governments to act. Official data from National Statistics Offices (NSOs) is checked for accuracy so it is reliable to use.
- The implementation of the CRPD and SDGs are monitored through data, and OPDs can monitor the progress of the CRPD, SDGs, and government programmes through data.
- Data is increasingly available, especially keeping in line with the CRPD and 2030 Agenda.
- OPDs are increasingly able to compare data internationally due to the growing use of the Washington Group Questions (WGQs) and can use data to identify patterns and trends or to highlight key points.
- Data introduces objectivity and establishes credibility, if used accurately and effectively, the reputation and influence of the OPD can be strengthened.
- Organisations of persons with disabilities can incorporate the following into their CRPD shadow reporting processes:
  - Review the [Reporting Guidelines](#), contained in several documents, to map out and become aware of the data being requested by the CRPD Committee for the State report.
  - Examine the draft State report to see how the government reported on the requested data outlined in the Reporting Guidelines.
  - Look for inaccurate data or gaps in their reporting and advise the government to fill in the data gaps before submitting to the CRPD Committee.
  - Also review how the data is being interpreted in terms of the CRPD requirements and identify any ways that data is being inappropriately interpreted to show progress in meeting goals.
  - Examine the final State report and highlight any inaccuracies and gaps reported in the data as well as any incorrect interpretations to the CRPD Committee in the shadow report.
- Use data in the shadow report to the CRPD Committee.
  - This can be data that the government did not put into the State report based on the Reporting Guidelines, such as the number and percentage of students with disabilities in early-stage education.
  - It can be data not requested by the Reporting Guidelines, such as the number and percentage of schools with accessible WASH facilities.
  - If there is reliable data available to demonstrate gaps in achieving the CRPD, it should be reported to the CRPD Committee and used to create improved governmental targets.
- The global SDG indicator framework has two significant features that can help OPDs create advocacy messages:
  1. it requests that governments disaggregate any relevant SDG data by disability, and
  2. it has 11 disability-inclusive indicators that measure the SDGs.

- OPDs can take the following steps to use data to monitor if/how persons with disabilities are being left behind in their country's progress under the SDGs:
  - Review the [global indicator framework](#) and be aware of the disability-inclusive indicators, call for disaggregation of data by disability, and [availability of current and future indicators that disaggregate data by disability](#).
  - Review the [identified 32 critically important indicators](#) which should be disaggregated by disability in order to gather data on the situation of persons with disabilities worldwide.
  - Participate in the national-level consultations and provide a good account of the gaps in the inclusion of persons with disabilities, including causes behind the challenges and suggestions for overcoming these challenges.
  - Engage in regional forums and the High-level Political Forum and continue to push for improvements to disability disaggregated data and gaps in achieving the SDGs.
- OPDs can use data to inform their advocacy:
  1. Identify the advocacy objective; sometimes available data can inform the advocacy message.
  2. Search for available data, both quantitative and qualitative, to gain more information about the situation to strengthen the advocacy message.
  3. Consider the limitations of the data.
  4. If relevant data is sourced, analyse it and draw conclusions.
  5. Build advocacy messages and incorporate the data findings.
- Outline the following tips for building evidence-based advocacy messages:
  - Advocacy messages should define the problem, compel the decision-maker or influencer to act, and clearly state what is being asked.
  - Messages should be simple and clear, reference the data sources and provide explanations of the data, where needed.
  - If there is a lot of data to communicate, it may be best to use tables and highlight a few key figures.
  - Visuals should be clear, simple, and easy to read and understand.
  - Present the key messages in different ways and adjust to local contexts and resources.
  - Messages should also be adapted for different people and communications platforms. For example:
    - Decision-makers responsible for delivering change, e.g., government ministers, senior civil servants, and
    - The people who can influence them, e.g., other government officials, civil society organisations, the media, community leaders
- If there is different data related to the advocacy messages, assess how the population with disabilities and outcomes are defined and compare with your data supporting your advocacy messages.

- Advocacy ideas for engaging with National Statistics Offices (NSOs) to improve your country's disability data:
  - Collaborate with other OPDs and allies.
  - Develop a joint advocacy paper.
  - Use social networks and media to promote advocacy messages.
  - Collaborate and partner with other stakeholders.
  - Engage in coalition building.
  - Meet with the NSO.
  - Carry out capacity building workshops on effective data collection with NSO technical staff.

## Resources

- A short blog with an example of OPD-led data advocacy by UDPK (Kenya): [Persons with disabilities and data inclusion](#).
- [The Voluntary National Review Toolkit for OPDs](#) that has examples of advocacy actions for OPDs at the national, regional, and global levels.

# Session Handouts

Session 1  
Session 2

Session 5  
Session 6  
Session 7

# **Handout: Summary of relevant articles in Convention on the Rights of Persons with Disabilities and Disability Inclusive Goals and Indicators in the 2030 Agenda for Sustainable Development**

**Session 1: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities**

## **The Convention on the Rights of Persons with Disabilities and Data**

### **Article 31 - Statistics and data collection**

1. **States Parties** undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
  - a. Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities.
  - b. Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

### **Article 4.3 for consultation and engagement**

**In the development** and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

# The 2030 Agenda for Sustainable Development

There are 11 explicit references to persons with disabilities in the 2030 Agenda for Sustainable Development of which seven are in the SDGs. Persons with disabilities are referenced in three paragraphs in the declaration section:

- human rights (paragraph 19),
- vulnerable groups (paragraph 23), and
- education (Paragraph 25).

Additionally, there is one reference in the follow-up and review section on data disaggregation by disability (paragraph 74, g).

## Sustainable Development Goals (SDGs)

**There are seven explicit references** to persons with disabilities in SDG targets:

Goal 4: education (2 References),

Goal 8: employment (1 Reference),

Goal 10: reducing inequalities (1 Reference),

Goal 11: sustainable and inclusive cities (2 References), and

Goal 17: means of implementation, data (1 Reference).

## Global Indicator Framework

**In the global indicator framework**, there are 11 disability-inclusive SDG indicators in the areas of:

- poverty eradication,
- education (two references),
- employment (two references),
- reducing inequalities,
- sustainable and inclusive cities (three references), and
- peaceful and inclusive societies (two references).

Also, the chapeau on disaggregation includes a reference to disability: “Sustainable Development Goal indicators should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, **disability** and geographic location, or other characteristics, in accordance with the Fundamental Principles of Official Statistics” (A/Res/71/313).

# SDG targets and related indicators with disability references

## Goal 1. End poverty in all its forms everywhere

1.3 Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable

1.3.1 Proportion of population covered by social protection floors/systems, by sex, distinguishing children, unemployed persons, older persons, **persons with disabilities**, pregnant women, newborns, work-injury victims and the poor and the vulnerable

## Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all

4.5 By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with **disabilities**, indigenous peoples and children in vulnerable situations

4.5.1 Parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as **disability** status, indigenous peoples and conflict-affected, as data become available) for all education indicators on this list that can be disaggregated

4.a Build and upgrade education facilities that are child, **disability** and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all

4.a.1 Proportion of schools offering basic services, by type of service [Proportion of schools with access to (a) electricity; (b) the Internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) **adapted infrastructure and materials for students with disabilities**; (e) basic drinking water; (f) single-sex basic sanitation facilities; (g) basic handwashing facilities (as per the WASH indicator definitions)]

## Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all

8.5 By 2030, achieve full and productive employment and decent work for all women and men, including for young people and **persons with disabilities**, and equal pay for work of equal value

8.5.1 Average hourly earnings of employees, by sex, age, occupation, and **persons with disabilities**

8.5.2 Unemployment rate, by sex, age and **persons with disabilities**

## Goal 10. Reduce inequality within and among countries

10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, **disability**, race, ethnicity, origin, religion or economic or other status

10.2.1 Proportion of people living below 50 per cent of median income, by sex, age and **persons with disabilities**

## Goal 11. Make cities and human settlements inclusive, safe, resilient and sustainable

11.2 By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, **persons with disabilities** and older persons

11.2.1 Proportion of population that has convenient access to public transport, by sex, age and **persons with disabilities**

11.7 By 2030, provide universal access to safe, inclusive, and accessible, green and public spaces, in particular for women and children, older persons, and **persons with disabilities**

11.7.1 Average share of the built-up area of cities that is open space for public use for all, by sex, age, and **persons with disabilities**

11.7.2 Proportion of persons victim of physical or sexual harassment, by sex, age, **disability status** and place of occurrence, in the previous 12 months

## Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable, and inclusive institutions at all levels

16.7 Ensure responsive, inclusive, participatory and representative decision-making at all levels

16.7.1 Proportions of positions in national and local institutions, including (a) the legislatures; (b) the public service; and (c) the judiciary, compared to national distributions, by sex, age, **persons with disabilities** and population groups

16.7.2 Proportion of population who believe decision-making is inclusive and responsive, by sex, age, **disability** and population group

## Goal 17. Strengthen the means of implementation and revitalize the Global Partnership for Sustainable Development

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

# Handout: Definitions of key statistical terms

## Session 2: 'Leave no one behind': The critical role of data disaggregation

**Administrative data:** Administrative data is data derived from an administrative system and produced as part of the operation of that system. The source of data is the participant's administrative records rather than direct contact with the participant although information included in administrative records can be obtained directly from participants.

**Administrative data systems:** Administrative data systems are data collections that are held by institutions belonging to the governmental sector, and that are collected and used for administrative purposes such as taxes, benefits, or services. Many administrative systems do not target persons with disabilities (e.g., education management information system, social protection registries, registration of births, deaths) but there are administrative systems for programs that provide services and benefits to persons with disabilities.

**Aggregate data:** Aggregate data is quantitative data combined over all members of a group of interest and, as a result, is a summary measure for the group.

**Baseline:** The baseline is the first measurement value which other values can be compared to, in order to describe change over time. It is the first measure of the indicator and is compared to estimates of the indicator based on data collected at future time periods.

**Census:** A census is an official count of all members of a group. Population censuses determine the total number of people in a country or part of a country and collect information on their characteristics such as age, sex, or where they lived at the time of data collection. Information is usually collected using questionnaires with data collected at set intervals of time (e.g., every 5 or 10 years). Not every census includes questions on disability.

**Citizen-generated data:** Citizen-generated or community-driven data is data that people or their organisations produce on issues that affect them. It is generated in several ways, including surveys, texts, phone calls, emails, reports, storytelling, and social media. It can be quantitative or qualitative, structured, or unstructured, and open or closed. The data is used to directly monitor, demand, or drive change. Citizen-generated data is a useful complement to institutional data, not a replacement for it.

**Co-creation:** Data co-creation is when civil society organisations (or other stakeholders) and National Statistics Offices (NSOs) collect data together and each has a central role from the beginning of the data collection process. This is ideal as the participation of the NSO in the data collection assures that the data will have the appropriate quality standards. Less ideal is data **co-production** when civil society organisations or other stakeholders bring finished data to NSOs. Since the NSO was not involved in the data collection it can be difficult for the NSO to verify that the data meets the NSO's quality requirements.

**Data:** Data is pieces of information about individual members of groups, whether people or things, that when combined and analysed describe the characteristics of that group.

**Data disaggregated by disability:** Data disaggregated by disability refers to describing and comparing the characteristics of persons with disabilities and persons without disabilities to determine if the two groups are similar on the characteristics of interest. For example, employment rates disaggregated by disability compare the employment rate of persons with disabilities to the rate for persons without disabilities to see if the rates are equal. Data is also commonly disaggregated by age, by sex, or by where people live.

**Disability identifier:** A disability identifier is created from the question(s) in the survey or data collection tool that identifies whether that person has a disability.

**Disaggregated data:** Disaggregated data is data that has been broken down by sub-groups, such as by age, ethnicity, or unemployment rate. Disaggregated data can indicate inequalities that may not be fully reflected in aggregated data.

**Functional domains:** Functional domains include a set of basic actions that individuals perform, such as seeing, hearing, walking, cognition, communication, upper body and psychosocial.

**Functioning:** Functioning refers to an individual's level of ability/difficulty in performing core activities. These activities are referred to as **core functional domains**.

**Indicators:** Indicators are used to measure what is happening amongst a population on a certain thing, such as around **unemployment**. Statistics are used to measure the indicator e.g., by providing the **rate of unemployment**.

**Qualitative data:** Qualitative data expresses qualities or characteristics, usually through descriptive narratives, such as the experiences of children with disabilities in attending school. Qualitative data is non-numerical and is often collected through observations, interviews, focus groups, or other similar methods.

**Quantitative data:** Quantitative data expresses a certain quantity, amount, or range recorded as numbers. Quantitative data deals with measurable information and involves the calculation of statistics which summarise the data, such as the percentage of children with disabilities attending school.

**Metadata:** Metadata describes information about the data collected. Metadata can clarify the strengths and weakness of the data that was collected.

**National Statistics Office:** The National Statistics Office (NSO) is the leading statistical agency within a national statistical system. The NSO is responsible for collecting, compiling, classifying, producing, publishing, and disseminating general-purpose, official statistics.

**Proxy measure:** A proxy measure is a measure that is similar enough to the desired measure that can be used instead of the desired measure when it is not possible to obtain the desired measure.

**Proxy respondent:** A proxy respondent is someone who provides information about the subject when the information cannot be obtained from the subject. Examples of a proxy include someone in a household responding for all household members or a mother responding for her children. The quality of information provided by a proxy respondent depends on the nature of the data collection and the reasons for not obtaining information directly from the subject.

**Statistics:** Statistics summarise quantitative data in numerical form. Statistics are used to draw conclusions in research, decisions when developing policies, and predictions about the future.

**Survey:** Surveys obtain information about people or organisations using questionnaires and other data collection tools. They are one of the most important sources of social and demographic statistics. Surveys can obtain information on multiple topics or can focus on one topic such as labor force surveys, living standards surveys, health surveys, education surveys, transportation surveys, and so forth. Surveys can obtain information on households and the people living in them, on establishments such as hospitals and the services they provide, or on individuals based on one or more characteristics, such as occupation.

## Activity: Reviewing data quality and sources

### Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

This handout outlines the activity in Session 5 on data quality. Participants will have an opportunity to evaluate data using one data collection as an example. You can either use the data collection example provided below, or one provided by the facilitator from the local context. The questions for the activity are the same regardless. You should also use the Session 5 Handout summarising data sources as a resource to help complete this activity.

You have 20 minutes for this activity.

#### Sample data collection for use if a local example is not used

- Data needs: Data of employment (to be disaggregated by disability status) in Country A.
- **Data Collection Source:** Yearly Labour Force Survey (LFS) collected by the Ministry of Labour.
- **Details:** The National Statistical Office (NSO) in Country A conducts a Labour Force Survey every year. The sample is based on a list of households maintained by the NSO which covers all addresses in the country but is known to be incomplete in rural areas. The head of the household responds for all persons in the household; the list of household members is obtained from a household respondent. Standard information on whether persons are employed, sector of employment (public, private, etc), hours worked, occupation and industry are collected. It is known that the questions do not effectively capture unpaid work in family enterprises. The survey includes the Washington Group-Short Set (WG-SS) of questions but no information on barriers or facilitators to employment.

#### Questions to apply to the activity:

1. Review the data collection in terms of the population covered and the content:
  - Who is covered (or not) by the data collection?
  - What data is collected?
2. What kinds of advocacy issues/change objectives could the data inform?
3. What changes could reasonably be made to the data collections to improve their usefulness? i.e., What would you ask for in future data collection?
4. In plenary, discuss what was learned.

# Handout: Summary of common sources of data

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

Sources of data	Description	Advantages	Limitations
<b>Censuses and multi-purpose general surveys</b>	Both censuses and multi-purpose general surveys address multiple topics as opposed to being focused on only one topic.	<ul style="list-style-type: none"> <li>• Good source of data for disaggregating indicators (e.g., SDGs) by disability status.</li> <li>• Censuses provide data for smaller geographic areas.</li> </ul>	<ul style="list-style-type: none"> <li>• The number of questions that can be included is more limited.</li> <li>• Censuses – limited control over enumerators due to logistics needed for full coverage of the population can compromise quality of data collection.</li> <li>• Surveys – sample size may limit the stability of estimates for any subgroup.</li> </ul>
<b>Topic-specific survey</b>	Surveys that focus on a specific topic such as labour force surveys, living standards surveys, education surveys, and transportation surveys.	<ul style="list-style-type: none"> <li>• Core sources of data on these topics resulting in more detail obtained on the topic than in multi-purpose surveys.</li> <li>• Good sources of data for disaggregating indicators related to the topic of the survey by disability status.</li> <li>• Provides opportunities to add additional questions especially on barriers and facilitators to full participation in the area covered by the survey</li> <li>• Core surveys are done on an ongoing or periodic basis making it possible to track trends.</li> </ul>	<ul style="list-style-type: none"> <li>• The number of questions that can be included can be more limited</li> <li>• Sample sizes may limit the stability of estimates for any subgroup (e.g., Women with disabilities in full time employment in X district)</li> </ul>

Sources of data	Description	Advantages	Limitations
<b>Health survey</b>	Health surveys are topic-specific surveys but are addressed separately here since they provide greater opportunity to obtain information about persons with disabilities, even when disability is clearly defined as a functional issue.	<ul style="list-style-type: none"> <li>• Good source of data for disaggregating indicators related to health by disability status.</li> <li>• Functioning is associated with health so there are usually more opportunities to add questions related to functioning and disability such as age of onset of functional difficulties, cause of difficulty, associated body function and structure characteristics, health conditions and health care, making this a good source of more comprehensive data on functioning and disability.</li> <li>• Opportunity to add additional questions on barriers and facilitators to full participation.</li> </ul>	<ul style="list-style-type: none"> <li>• Sample size may limit the stability of estimates for any subgroup</li> <li>• Distrust of health systems, particularly for persons with disabilities who have experienced abuse within those systems, may impact results if the data collection is associated with the healthcare system.</li> </ul>
<b>Disability survey</b>	Targeted disability surveys provide the best opportunity to obtain comprehensive and detailed information on persons with disabilities but are usually limited in terms of frequency due to cost and complexity.	<ul style="list-style-type: none"> <li>• Source of most comprehensive data on functioning and different types and degrees of disabilities.</li> <li>• Best opportunity to add additional questions on barriers and facilitators to full participation, services received, unmet need for services, and experience of stigma.</li> </ul>	<ul style="list-style-type: none"> <li>• Sample size may limit the stability of estimates for any subgroup</li> <li>• Can have insufficient control over field operations which compromises quality of data collection.</li> <li>• Generally, not done on a set schedule and there are usually long lags between administration.</li> <li>• Changes in design and questions used, make it a poor source of data for tracing progress on inclusion in the SDGs.</li> </ul>

Sources of data	Description	Advantages	Limitations
<b>General Administrative data systems (not disability related)</b>	<p>Administrative data systems are data collections held by institutions belonging to the governmental sector that are collected and used for administrative purposes such as taxes, benefits or services. Administrative systems that are not disability related or targeted can be a source of information. To use such systems, it is necessary for a disability indicator to be included in the system. Examples include education management information systems or data used to implement an unemployment benefits system.</p> <p>When using data from these systems, it is critical to be aware of: (1) the population included, (2) the source and content of the data, and (3) how the data was processed.</p>	<ul style="list-style-type: none"> <li>• Available source of information for disaggregating items included in the data system.</li> <li>• Provides a relatively cost-effective source of information on all persons served by the programme</li> </ul>	<ul style="list-style-type: none"> <li>• The disability indicator used by the programme may not produce high-quality data or address specific disability aspects.</li> <li>• Data quality can be an issue for all items but especially for data items not needed to administer the programme.</li> <li>• Only includes those who meet eligibility criteria and, for many systems, those who choose to obtain services through the programme limiting the generalisability of the results.</li> </ul>

Sources of data	Description	Advantages	Limitations
<b>Administrative systems that focus on disability programmes</b>	<p>Administrative systems that focus on disability programmes provide a source of information on disability services or benefits provided by a programme.</p> <p>When using data from these systems, it is critical to be aware of: (1) the population included, (2) the source and content of the data, and (3) how the data was processed.</p>	<ul style="list-style-type: none"> <li>• Provides a relative cost-effective source of data on aspects of disability addressed by the programme to which the administrative data system is tied.</li> <li>• Provides information on the disability services or benefits provided by the programme.</li> <li>• Provides information on all persons served by the programme to which the administrative data system is designed for.</li> </ul>	<ul style="list-style-type: none"> <li>• Only those who meet eligibility criteria and/or who choose to obtain services through the programme tied to the administrative system will be included limiting the generalisability of the results</li> <li>• Data quality can be an issue for all items but especially for data items not needed to administer the programme.</li> </ul>

## Activity: Advocating for better data

### Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

This handout supports the Session 6 activity on how to advocate for better data. This is a brainstorming exercise to **start** developing data advocacy objectives and action plans **based on what you now know**. Further research would need to be done in many instances for more refined advocacy objectives.

You have 20 minutes for this discussion before wider group discussion with the facilitator.

1. What key gaps in disability data exist in your country?
  - Draw on learning from previous sessions as well as this one, and consider:
    1. Formal data and other sources like citizen generated data
    2. If the population of persons with disabilities can be identified
    3. If persons with disabilities are being equally included in efforts towards the SDGs (e.g., equal employment or education rates)?
    4. If not, is there any information or data pointing to **how** persons with disabilities are being left behind, or the barriers causing this?
    5. What is the quality and sources of data?
    6. What questions do data sources use to identify persons with disabilities, and are there any limitations to these questions?
    7. What can be and is disaggregated?
    8. How does this relate to the primary concerns and priorities of your OPD members (e.g., employment)?
  
2. Start to think of some actions you might need to take to address these gaps:
  1. Who do you need to influence?
  2. What changes to data would you like to see?
  3. Who might you work with?
  
3. If done in smaller groups, come back to the group prepared to share **three key points** from your discussion. This can be a gap, something you want to change, an action you will take, and/or someone you need to influence.

# Activity: identify opportunities and challenges for the advocacy objectives of your OPD

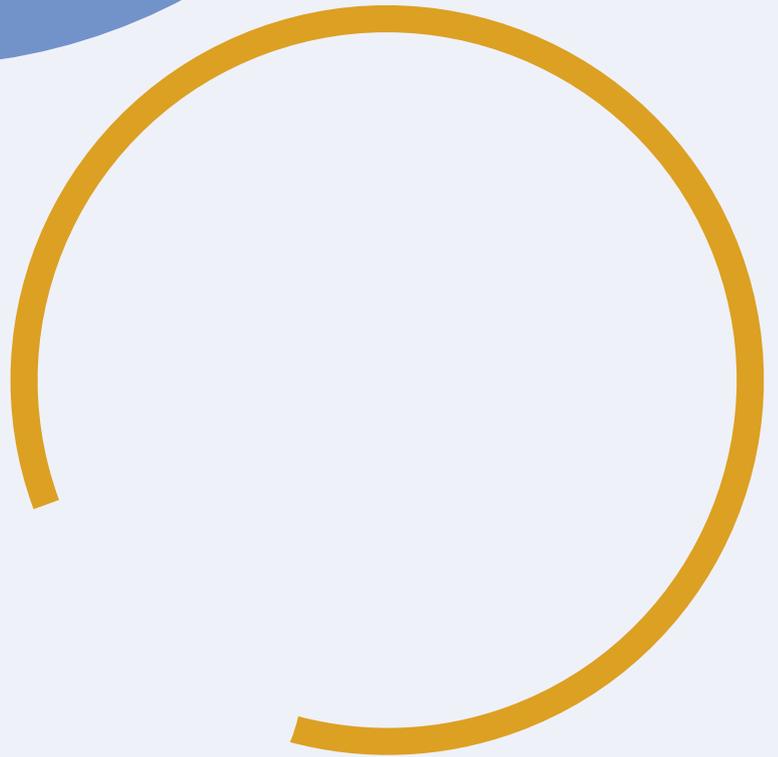
## Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

This activity handout supports the activity in Session 7 exploring OPD data advocacy actions. The discussion begins here, leading into a draft action plan in Session 8.

You have 25 minutes for this discussion before wider group discussion with the facilitator.

1. Recall the advocacy objectives you identified in Session 1. Do these remain the same? Have you identified other advocacy objectives to focus on first?
2. Reflecting on all you have learned about advocacy and data, and particularly the lessons from the OPDs covered today, identify:
  - a) What are some challenges in using data to progress these advocacy objectives in your context? What are some possible solutions to these challenges?
  - b) What are some key opportunities or strengths your OPD has in relation to data that you could use to progress your advocacy objective? e.g., relationships with NSOs or access to data?
3. If done in smaller groups, come back to the group prepared to share **two key points** from your discussion.

# Individual Reflection sheet



# Session-Specific Individual Reflection Sheet

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

**Instructions:**

This worksheet is to be completed by each individual participant following each session/group of sessions. The aim is to begin applying and reflecting on what is learned in a session, in the local context. These worksheets will be resources for participants to use in the final sessions to help develop their collective action plans.

Participants are asked to reflect at the end of each session on the following questions:

1. What are two or more key “takeaways” (learnings, messages) that stand out for you from this session?
2. Reflecting on what you know (or do not) about your country/context:
  - a. How can this already be applied/actioned to help you in your advocacy objectives?
  - b. What more do you need to find out to understand or use what you learned?

<b>Name</b>	<b>Date</b>
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Question	Responses for session 1 - Introduction
1. List two or more key takeaways	1.  2.  3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 2 – Role of data disaggregation
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 3 – Identifying population using WGQ
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 4 – beyond disaggregation
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 5 – Disability data sources and quality
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 6 – Advocating for better data
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 7 – OPD role in advocacy using data
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	

Question	Responses for session 8 – action plan drafting and closing
1. List two or more key takeaways	1. 2. 3.
2a. How to action now in your country?	
2b. What more do you need to find out?	