



# Facilitator package

Disability Data Advocacy Workshop for Organisations  
of Persons with Disabilities



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# Introduction

This manual supports facilitators to prepare for and deliver an online workshop on Disability Data Advocacy for Organisations of Persons with Disabilities (OPDs). It is part of a package of workshop materials to be used by the facilitator and presents the overall programme as well as guidance on preparation, delivery and follow up. Guidance on delivering specific sessions is provided separately.

The workshop materials were developed by CBM Global's Inclusion Advisory Group in partnership with UNFPA Asia Pacific, the Stakeholder Group of Persons with Disabilities for Sustainable Development, the International Disability Alliance, and various regional and national OPDs, including the Pacific Disability Forum. This partnership aims to build resources, awareness, and capacity on disability data with key stakeholders.

The workshop is designed for online remote delivery, using a digital platform. However, the materials have been tested for an in-person format and can be adapted easily for a face-to-face setting.

## 1.1 About this manual

This manual provides background materials, inclusive facilitation guidance, and supporting resources for the **overall workshop programme**. It is not a script and should be used in conjunction with the discrete session materials described in Section 3.2.

# Introductory briefing for facilitators

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## 2.1 Why is this workshop important?

The lack of data on persons with disabilities exacerbates inequalities and marginalisation. Data is key to identifying the inequalities and challenges experienced by persons with disabilities and to ensuring policies, programmes and investments are inclusive. OPDs have a key role in generating and using data for evidence-based advocacy as well as advocating for better disability data to inform policy, investment and accountability.

Drawing from the [Disability Data Advocacy Toolkit](#), the workshop aims to support persons with disabilities, and members of their representative organisations, to build skills and knowledge on disability data advocacy, which they can apply within their local context.

## 2.2 Preparatory reading and research

Facilitators should have some prior understanding of different types and sources of disability data as well as best practice on data collection, analysis and application. The following reading and tasks should be completed ahead of the workshop to update and reinforce this knowledge.

### 2.2.1 Required reading

- [Disability Data Advocacy Toolkit](#)

The toolkit provides an overview of disability data and disability data advocacy for OPDs. It is available in multiple languages and formats including Easy Read and International Sign. It is the foundation for the session materials developed for this workshop. It is also pre-reading for participants.

- [Producing Disability-Inclusive Data: Why it matters and what it takes](#)

This UNICEF publication presents key considerations for collecting and using different types of data that can be used to monitor inequalities.

- [An Introduction to the Washington Group \(WG\) on Disability Statistics Question Sets](#)

This is a primer on the tools developed by the [WG](#) on disability statistics with a focus on the WG Short Set. It highlights important criteria for the collection of disability data and introduces the social model of disability.

- [A brief explainer on the Washington Group Questions on Disability](#)

This offers a summary of the Washington Group questions ‘at a glance’ in a 3 page, ‘infographic style presentation.

- [Disability Disaggregation: Envisioning Inclusive Development](#)

This brief report by the WG discusses how the routine collection of disability data on development indicators supports monitoring of disability inclusion.

- [Videos by the Center for Inclusive Policy](#)

These short videos cover a range of topics, many of which relate to data. These are the most relevant:

[Why is it important to identify the population with disabilities?](#)

[What is the prevalence of disability?](#)

[Translation of the Washington Group Question Sets: Part 1](#)

[Translation of the Washington Group Question Sets: Part 2](#)

- Where are we?

[Questions to aid understanding of disability data and inform advocacy](#)

A ‘key questions at a glance’ resource for OPDs to aid in their use of and advocacy on disability data.

The materials for each session include links to further pre-reading for participants and facilitators.

### **2.2.2 Preparatory resources for the local context**

To make the workshop relevant to the local context it is important that facilitators are familiar with national disability data and data-related commitments relating to the advocacy priorities of the participating OPDs (e.g., employment, social protection, education). Here are some useful places to find this information:

- National Statistics Office (NSO)

Each country has an NSO which is responsible for producing reports with official statistics and analysis on demographic and social issues, including disability.

- [United Nations Statistics Division repository on disability statistics](#)

This UN entity compiles official statistics from national population and housing censuses, household surveys, and some administrative data. The repository includes statistics on the prevalence of disability in different countries and on the socio-economic characteristics and living conditions of persons with and without disabilities. This data is used to analyse equality of opportunities and inclusive development.

- [The Disability Data Portal](#)

This portal collates quantitative disability-disaggregated data from a large number of countries using key development indicators, mostly drawn from the Sustainable Development Goals (SDGs).

- [Regional statistics bodies](#)

There are some regional bodies which provide a platform for sharing disability data, for example, the [Pacific Community Statistics for Development Division](#).

- [Disability Data Initiative](#)

This initiative provides analysis of disability data to help advance the rights of persons with disabilities, including some country briefs with data on disability prevalence.

- [Global Disability Summit \(GDS\)](#)

At the 2018 GDS, governments, NGOs, and other organisations made 99 individual commitments relating to disaggregating data by disability. At the 2022 GDS, around a quarter were reported as achieved. Stakeholders made new data-related commitments which you can access on the [GDS Commitments Portal](#).

### **2.2.3 Other useful resources on disability data**

#### **Washington Group**

- Blog: '[Differences in reported disability prevalence rates: Is something wrong if I don't get 15%?](#)'

The World Disability Report estimates that 15 per cent of the population has a disability, but most surveys using the WGQs get a lower rate. This blog explores the reasons behind this difference and how this should be interpreted.

- Blog: '[How are the Washington Group Questions consistent with the social model of disability?](#)'

Explains how the social model informed the development of the WGQ.

- Guidance: '[The data collection tools developed by the Washington Group on Disability Statistics and their recommended use](#)'

An overview of all the Washington Group tools and advice for choosing the correct tool for different purposes. It includes guidance on using the WG tools for disaggregating outcome indicators (e.g., access to employment or education).

## **2.3 Facilitator responsibilities**

The role of the **facilitator** includes:

- Participation in briefing and preparatory work for the workshop.
- Presentation of key concepts and resources on disability data advocacy using the workshop materials provided.
- Facilitation of pre-prepared exercises to enable participants to apply and localise these key concepts.
- Ensuring an inclusive learning environment by following accessibility standards and providing reasonable accommodations.

# Overview of the training programme and materials

## 3.1 Objectives

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

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

## 3.2 Programme materials

### 3.2.1 Session specific materials

The programme contains eight individual sessions. The proposed methods follow principles of adult learning, such as promoting the sharing of knowledge between participants and incorporating a participatory planning process through presentations

Each session includes the following materials:



**Session facilitation guide:** step-by-step instructions including preparation, objectives, facilitation tips and additional resources.



**Handouts:** for participants to use in activities (e.g., worksheets, reading materials) or providing additional details, explanations, or reference materials on specific topics.



**PowerPoint presentation:** presented during the workshop or sent to participants in advance.



**Session summary:** key messages, concepts, and additional resources for participants.

The eight sessions are designed to be delivered in sequence to support the logical presentation and revision of ideas and information. Learning outcomes may be compromised if the order of sessions is changed.

### **3.2.2 Accessibility of materials**

The materials have been reviewed and tested for accessibility. Should facilitators decide to adapt the materials for the local context, they must take care to maintain the level of accessibility. Convenient tools to assist include the in-built [Microsoft Accessibility Checker](#) and screen reading software (e.g., Windows Narrator, MacOS Voiceover).

For more information on running accessible events and meetings, see pp. 79 of [Accessibility GO! A Guide to Action](#).

## **3.3 Programme overview**

### **3.3.1 Programme summary**

The eight sessions total approximately 12 hours of interactive content as outlined

Table I: Programme summary by session

<b>Session</b>	<b>Title</b>	<b>Objectives</b>
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>
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>

Session	Title	Objectives
5	Disability data sources and quality	<ol style="list-style-type: none"> <li>Identify different sources of disability data and their advantages and disadvantages</li> <li>Critique how available data will meet their needs for specific advocacy objectives</li> <li>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>Identify data needs and review available data for CRPD, SDGs and other global frameworks</li> <li>Explore how to meet data gaps, including through citizen generated data</li> <li>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>Understand ways to use data for evidence-based advocacy</li> <li>Explore OPD roles in data collection and use.</li> <li>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>Begin drafting a collective action plan to help them take forward disability data advocacy in their country</li> <li>Demonstrate some key learnings from across the programme</li> </ol>

### 3.3.2 Adapting the programme for the local context

#### 3.3.2.1 Format

The eight sessions should be run in order, over a minimum of two days. **The format to be decided by the facilitator and host organisation based on local conditions and needs.**

The sessions vary in length and complexity and can be delivered over different timeframes, such as:

- 2 sessions per day over 4 days (i.e., approx. 3 hrs per day)
- 3 sessions per day over 3 days (i.e., approx. 4.5 hrs per day)
- 4 sessions per day over 2 days (i.e., approx. 6 hrs per day)

Some sessions are more complex and facilitator-led. For example, Sessions 2-5 introduce information about disability data processes which may be new for many participants. The selected format must allow sufficient breaks between these sessions.

Sustained online participation can be challenging. Spreading the sessions over more days may improve participant engagement and learning. Inconsistent connectivity and scheduling conflicts can also affect participation.

The number of participants will depend on the experience of the facilitator and the reliability of internet connections. When facilitating the workshop for the first time, or if connections are unstable, it is advisable to limit the number of participants to no more than 12-15, to ensure high levels of engagement. The workshop can be run with as few as 3 or 4 participants by conducting all group activities in plenary. The materials are open access and the workshop can be repeated as many times as is necessary.

### **3.3.2.2 Mode of delivery – online, in person or hybrid?**

Online workshops are now a common and accepted format, enabling participation by individuals from a wide geographic area. However not everyone has easy access to video conferencing technology or a reliable internet connection.

While the workshop materials are designed for online use, they can be adapted locally for an in-person workshop or a ‘hybrid’ mix of online and in-person. Whichever format is chosen it is important to appoint a support person (or co-facilitator) to manage logistics before and during the workshop to allow the facilitator to focus on delivering the content and engaging participants.

#### **A note on hybrid meetings**

Hybrid meetings introduce new challenges. In addition to the guidance for online workshops here are some specific tips for preparing and delivering a hybrid workshop:

- Appoint two co-facilitators, one to support online facilitation and one to support in-person facilitation.
- Allow participants to express their communication preferences and establish clear ground-rules at the start of the workshop that meet all participation needs.
- Test the video conferencing technology in advance, including online platforms, microphones, and speakers, to ensure that all online and in-person participants can speak and hear one another.
- Adapt activities and prepare breakout groups in advance.
- Use tools that enable collaboration between online and in-person participants, such as an online interactive whiteboard.

More tips on hybrid facilitation are available online from [Slido.com](https://www.slido.com) and [Howspace.com](https://www.howspace.com)

### **3.4 Planning and preparing for an online workshop**

This section provides guidance on disability-inclusive workshop planning and preparation. It is advisable for the facilitator to have the support of another person to help with the administration and logistics.

### **3.4.1 Select and orient to an online platform**

There are many platforms for online meetings with varied cost and accessibility, including Zoom, Skype, Google Meet, Facetime, Microsoft Teams, WebEx, and others. Use this [checklist](#) to review the accessibility features of your preferred platforms. Also consider the following questions:

- Which platform is most familiar to your participants?
- Do you require a low connectivity option?
- Do you require additional facilitation functions (e.g., online whiteboard, automatic breakout groups)?
- Do you require accessibility functions (e.g., live captioning, transcripts, recording, ‘pinning’ interpreters’ video)?

If possible, provide an alternative method for participants to join the meeting, such as a dial-in phone number, as well as an internet link. Captioning and recording sessions also enable participants to catch up if they miss sessions due to poor connectivity.

### **3.4.2 Invitations and registrations**

The participant registration process is a good opportunity to collect information about accessibility requirements. A sample invitation and registration form are provided in the Guidance for Host Organisations.

Invitations and registration forms should be provided in accessible formats and sent out 12 weeks in advance to allow sufficient time to inform critical decisions about accessibility requirements and online platforms (e.g., booking interpreters).

The registration form should request the following information:

- Contact details
- Accessibility requirements
- Connectivity status
- Preferences for online platforms.

### **3.4.3 Sign language interpreters**

Consult with any individuals who require sign language interpretation to ensure that the selected services reflect their language preferences (e.g., local, national or International Sign). National sign language is advisable, particularly in sessions that introduce technical terms.

Brief interpreters on the content and context in advance of the workshop and provide them with the list of common acronyms and key terms from the package of workshop materials.

### **3.4.4 Participant preparation**

At least two weeks before the workshop, send the following information to the **registered participants**:

- Dates, location, sign-in details
- Programme outline
- Advice on testing the selected online platform
- Details of accessibility measures and individual accommodations
- Contact at host organisation for any questions
- Pre-reading material
- Brief biography of the facilitator.

### **3.4.5 Preparing to facilitate the sessions**

In addition to the preparation described in the session-specific guidance the facilitator should take the following steps before each session:

- Share materials for all activities with participants.
- Organise any breakout rooms, considering access requirements (e.g., allocation of interpreters or personal assistants).
- Brief any additional facilitators, ensuring they are clear on their role and have the relevant materials.
- Decide how to capture and share group discussions in plenary (e.g., online whiteboard, PowerPoint, verbal feedback by group notetaker).
- Prepare a short recap of previous sessions (e.g., in the form of a quiz or review of key messages).
- Allocate a co-facilitator who is responsible for logistics and managing any issues arising during the session (e.g., reallocating breakout rooms).
- Test your own connection and equipment (e.g., headset, microphone, speakers).

### **3.4.6 Contingency planning for online workshops**

Online workshops can be challenging. It is important to anticipate and take steps to mitigate any potential issues.

#### **Issue: Low internet connectivity that interrupts video and/or audio content**

*Mitigation strategies include:*

- Using the registration form to identify connectivity issues.
- Providing alternative ways to connect (e.g., mobile hotspot, phone credits, dial-in).
- Switching to an in-person workshop if connectivity problems cannot be solved.
- Scheduling the sessions at times of the day when internet connectivity may be better.

- Running the workshop with audio only and share the slides in advance.

**Issue: Interpretation and translation require additional time**

*Mitigation strategies include:*

- Building flexibility into your programme including a buffer in case sessions run over time.
- Sharing materials with participants and interpreters in advance to help them prepare.

**Issue: Informal learning and networking opportunities may be reduced**

*Mitigation strategies include:*

- Building extra ‘informal sharing’ and ‘break’ sessions into the programme, e.g., scheduling longer ‘break’ sessions where people re-join for informal, unmoderated discussions after time offline.
- Scheduling “chat” breaks between sessions into the program.

**Issue: Reduced participant engagement or concentration for long period online**

*Mitigation strategies include:*

- Spreading the sessions over a longer programme structure.
- Appointing ‘energiser’ leads for the different days and inviting them to introduce accessible activities or chat topics across the day (3-5 minute maximum).

### 3.5 During the workshop

The package of workshop materials provides specific guidance for each session. Here are some general tips which apply to all sessions:

*At the start:*

- Describe how to use the accessibility services and features.
- Provide directions to access captioning and chat functions.
- Introduce interpreters and ‘pin’ their videos in the main view window.
- Establish rules for participation including how to manage inputs (e.g., chat window, question breaks, and raise-hand function).
  - Please note that the raise-hand function is not always accessible for users of screen readers. An alternative approach is for those participants to say their name when they would like to speak and wait for the facilitator to acknowledge them.
- Ask participants/presenters for their permission to record the session.
- Check that all participants have received the session materials (e.g., slides, handouts, activity worksheets).
- Consider appointing an ‘accessibility captain’ for each session/day.
  - This role is responsible for monitoring accessibility and providing feedback to the facilitator. They can act as a feedback focal point for participants who do not feel comfortable raising concerns directly with the facilitator.

*During the sessions:*

- Keep close track of time; clearly communicate the time allowances for interventions and activities, and provide polite visual and verbal cues about the time remaining.
- Verbally describe any visual presentation. Provide captioning for any audio presentation.
- Always say your name before speaking to allow everybody to recognise your voice and name. Encourage all participants to do the same.
- Speak slowly and clearly, avoiding jargon or acronyms. This will give time for sign language interpreters and other interpreters to convey information in a clear way.
- Pace your session to allow for additional time required for interpretation. More time will be required for interpretation for persons with deafblindness.
- Monitor the chat function or appoint a co-facilitator to do so on your behalf – ensuring all questions are flagged and verbalised.
- Pause regularly to check whether participants have questions or requests relating to the content and pace etc.
- Plan frequent breaks; even short breaks can improve participant concentration.
- Share the notes or captioning transcripts with participants after each session to aid in reflection and learning. Clearly label the file with the corresponding programme session name.

# After the workshop

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The aim of the workshop is to **initiate** local learning and planning on disability data advocacy through enabling dialogue among members of the local disability movement. Therefore, follow up is essential.

It may not be the facilitators' responsibility to continue the discussion, however, you should remind participants to put into practice the actions identified in their individual daily reflection sheets.

During the final session, encourage participants to identify concrete next steps to develop, refine and seek peer feedback on their draft action plans. Share the notes in the concluding reflection session to encourage ongoing learning.

# Next steps

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After reading this Facilitators' Manual the next step is to read the materials specific to each of the eight sessions. Also check with the host organisation and support person(s) that the administrative and logistical arrangements are proceeding as expected.

Good luck with the workshop. We hope the discussions are productive and inspire plans for local, collective action on disability data advocacy.

# 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>Understand the Washington Group Short Set (WG-SS) of questions and why they are widely used, recommended and endorsed for disaggregation</li> <li>Be familiar with the WG-SS questions and response options and how these are used to identify the population with disabilities</li> <li>Begin applying the WG-SS to help shape advocacy messaging</li> </ol>
4	Beyond disaggregation	<ol style="list-style-type: none"> <li>Understand how the WG-SS can be used to inform disability issues, aside from disaggregation</li> <li>Be aware of the limitations of the WG-SS and possible ways to address these</li> <li>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>Identify different sources of disability data and their advantages and disadvantages</li> <li>Critique how available data will meet their needs for specific advocacy objectives</li> <li>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>Identify data needs and review available data for CRPD, SDGs and other global frameworks</li> <li>Explore how to meet data gaps, including through citizen generated data</li> <li>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>Understand ways to use data for evidence-based advocacy</li> <li>Explore OPD roles in data collection and use</li> <li>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>Begin drafting a collective action plan to help them take forward disability data advocacy in their country</li> <li>Demonstrate some key learnings from across the programme</li> </ol>

Session	Title of step	Summary of content by step
6	How to advocate for better data	<ul 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> </ul>
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8	Drafting an action plan and closing	<ul 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> </ul>

# Session

# 1

Facilitators guide  
Summary  
Handout  
Reflection sheet

# Introduction to the Disability Data Advocacy Workshop

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

- Meet each other and set rules for engagement.
- Understand the objectives, scope, and components of the workshop, including how it fits with broader disability data advocacy.
- Gain general knowledge on the requirements for disability data in the CRPD and the 2030 Agenda and its Sustainable Development Goals.

## Prerequisite learning/knowledge

[Disability Data Advocacy Toolkit](#). Available in various formats and languages.

## Key messages to be conveyed

- This introductory workshop aims to start or continue a local conversation around disability data advocacy, focused on persons with disabilities and their representative organisations (OPDs).
- The CRPD and the 2030 Agenda mandate countries to collect and disaggregate disability data.
- 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.

## Preparation

Facilitators need to be familiar with the main disability data processes and sources at national level, as well as the country's approach to disability data within SDG monitoring and reporting. Tips for helping explore this are provided in the pre-reading section of the Facilitators' Manual.

## Resources and handouts

- PowerPoint Session 1, Slides 1-16
- Handout of details around the CRPD and the 2030 Agenda and disability data

# Detailed plan and methodology

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## Step 1.1: Opening remarks

**Timing:** 5 minutes (depending on number of presenters)

**Objective:** Formally open the workshop and engage participants

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## Slide 2: Opening remarks (section title)

### Instructions

- Introduce the facilitators and hosts of the workshop.
  - Talk through key logistics, particularly around accessibility.
  - For tips see “During the workshop” section of the Facilitators’ Manual (e.g., use of chat functions, sign language interpreters, speaking pace, etc.)
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## Step 1.2: Introductions

**Timing:** 10 minutes (depending on number of participants and methods used)

**Objective:** Introduce participants to each other and set the scene for effective and interactive collaboration for the remainder of this workshop

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## Slide 3: Introductions (section title)

**Activity (optional):** Introductions (10 minutes)

In plenary, invite participants one by one to introduce themselves by telling the group:

1. Their name and the organisation/agency they represent.
2. How many people in this workshop they have met before.

Be sure to also introduce the facilitation team.

After all participants have introduced themselves, acknowledge the diverse levels of experience and expertise they are bringing to the session. Explain also to participants there will be plenty of opportunities for discussion and interaction through the session.

### Facilitation tips

**Variation:** If there is a large group of participants, introductions can be done in pairs or small groups. Each person in the small group can take notes about the person next to them and then introduce that person to the rest of the participants in plenary.

If you have other introductory activities you have used before that take a similar amount of time, feel free to substitute these.

## Step 1.3: Workshop overview

### Slide 4: Overview of the workshop (section title)

**Timing:** 20 minutes (activity)

#### Objectives:

- Participants understand the objectives, structure, and approach of the full workshop
- Participants set their expectations of what they hope to learn, share, and gain from the full workshop

#### Required materials:

- PowerPoint Slides 4-8
- Handout: Individual Reflection Worksheet
- Handout: Programme Outline for Participants

Remind participants that they should have received a copy of both handouts.

#### Activity: Setting expectations (10 minutes)

### Slide 5: Setting expectations

#### Instructions

Ask participants to reflect on the following questions:

- Expectations: What are you hoping to get from this workshop? What questions would you like to have answered?
- Contributions: What are you hoping to contribute or to share? What is your experience with disability data or data advocacy?

#### Facilitation tips

Ask each participant to write down their thoughts on these questions, and if they want to share them with the group, to write them in the chat box.

Document the participants' expectations and then refer back to them at the end of the workshop to see whether these have been addressed.

### Slide 6: Workshop objectives

#### Instructions

Read out the overall workshop objectives, which are to:

- **Be able to advocate** for data collection and investment in better data.
- **Be able to use data** to develop evidence in support of advocacy messaging.
- **Begin to apply** relevant knowledge and skills on disability data in the local context.
- **Have basic data advocacy knowledge** and suitable skills to engage in national and regional dialogues using data.

## Slide 7: Workshop sessions

### Instructions

Provide an overview of the full workshop. Read out the following session topics that will be covered in the workshop agenda.

- **Session 1:** Introduction to the Disability Data Advocacy Workshop
- **Session 2:** Leave no one behind: the critical role of data disaggregation
- **Session 3:** Identifying the population with disabilities using the Washington Group Questions
- **Session 4:** Beyond disaggregation
- **Session 5:** Disability data sources and quality
- **Session 6:** How to advocate for better data
- **Session 7:** OPDs role in advocacy using data
- **Session 8:** Building an action plan and closing

#### Facilitation tips

Remind participants about the format you have chosen locally (e.g., one session per day over eight weeks or two sessions a day over four days).

Note that presentation materials have been developed in PowerPoint, but it is not a requirement to be able to see these while the facilitator is speaking as the key content will be read out. They should be shared in advance to promote engagement and accessibility.

## Slide 8: Workshop format

### Instructions

Describe the format of the workshop sessions:

- Typically, 90-minutes long
- Include an OPD-led facilitation team
- Have a mix of presentation, discussion, and group activities
- Build on participants' knowledge and experience
- Welcome all questions
- Provide an inclusive workshop environment
- Offer reflection and feedback (introduce the reflection worksheets)

#### Facilitation tips

Ask participants to refer to their Individual Reflection Worksheets.

- **These worksheets help** to apply and reflect on what is learned in the local context.
- **Participants will use them as resources** in the final session to help develop their

their collective action plans.

- **Explain** that a worksheet needs to be completed at the end of each session.
- **They will not be shared with the facilitator** – they are memory prompts to support participants only.

The worksheets ask for some simple dot point reflections around the following questions:

- **What are two or more key learnings** that stand out from this session?
- **Reflecting** on what you know about your country:
  - a. How can these key learnings 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?

## Step 1.4: Introduction to disability data

**Timing:** 40 minutes

### **Objectives:**

- Participants are aware of global development and legal frameworks and the international experience of disability data collection.
- Participants have a basic understanding of key data needed for SDG and CRPD advocacy.

**Required materials:** Slides 9-15

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## Slide 9: Global frameworks and disability data (section title)

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## Slide 10: Data – definitions

### **Instructions**

**Explain to participants that this will be covered** in more depth in later sessions. This is just a basic introduction.

- **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.
- **Quantitative data** expresses a certain quantity, amount, or range recorded as numbers. It deals with measurable information and involves the calculation of statistics which summarise the data, such as the percentage of children with disabilities attending school.
- **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.
- Both quantitative and qualitative data are valuable in establishing evidence to support an argument or position, and they are often combined to provide a complete picture. Quantitative data provides scope and scale of the issue whereas qualitative

data provides a richness of detail of people's lives.

- **Citizen-generated or community-driven data** is produced by people or their organisations on issues affecting 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.

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## Slide 11: Why do we need disability data?

### Instructions

Discuss why disability data is needed to:

- **Understand** the real situation of persons with disabilities.
- **Identify** gaps in full inclusion of persons with disabilities that are not currently addressed through policies in your country or local area.
- **Provide** examples of successes.
- **Support** evidence-based advocacy for policies to address identified gaps and to influence decision makers at national, regional, and global levels.
- **Provide** a foundation for all advocacy efforts.

### Facilitation tips

Encourage participants to provide short examples from their own experience to illustrate these points.

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## Slide 12: Disability Data Advocacy Toolkit

### Instructions

Read out the information on the slide, emphasising that much of this workshop emerged from the **Disability Data Advocacy Toolkit**.

### Facilitation tips

**Ask participants** if they have read or used the toolkit before. Use this to get a sense of pre-existing knowledge in the room to guide facilitation needs in subsequent sessions.

- Remind participants it was recommended pre-reading and encourage them to use it as a reference source throughout.

Explain the background of the toolkit from the following key points:

- a. The Stakeholder Group of Persons with Disabilities, the International Disability Alliance, and CBM Global Disability Inclusion launched the very first comprehensive disability data advocacy toolkit in 2020.
- b. This toolkit was created in response to increasing interest and requests from

- c. 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:

1. **The need** to understand the situation of persons with disabilities, to identify gaps in policies, and to provide examples of successes.
2. **The importance** of understanding how to analyse, use and trust **existing data** to create advocacy messaging.

**The toolkit** is available in Arabic, Easy Read, English, French, Spanish, and an abridged version in International Sign. The link to the toolkit has already been shared.

## Slide 13: The CRPD and disability data

### Instructions

**Discuss** that the CRPD mandates State Parties to collect data on persons with disabilities. Highlight the key messages from below:

- 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 under Article 31.
- **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 CRPD** calls for all types of data to be gathered.
- **Calls for data** to inform policymakers to support CRPD implementation

### Facilitation tips

**Read Article 31 of the CRPD** on Statistics and data collection . This can be to refresh your memory for discussion and can also be read aloud to participants.

#### **“Article 31 on statistics and data collection, from the UN Convention on the Rights of Persons with Disabilities**

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.

**Emphasise Article 4.3** (shorter version on slide). 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.**

**Refer** to Session 1 handout that summarises these obligations and commitments.

**Refer** to page 10 of the [Disability Data Advocacy Toolkit](#) for more information.

## Slide 14: The 2030 Agenda and disability data

In 2015, this is further strengthened by the political commitment 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.

## Slide 15: Global SDG Indicator Framework

### Instructions

**Explain** the background of the global SDG indicator framework and the following points:

- **The framework** has 231 global indicators; 11 are disability inclusive.
- **In addition**, the framework calls to disaggregate – or to specifically collect disability data - SDGs by disability. Refer to Session 1 handout for details.
- **The 11 disability-inclusive indicators** are found in the areas of:
  - Poverty eradication
  - Education (two references)
  - Employment (two references)
  - Reducing inequalities
  - Sustainable and inclusive cities (three references)
  - Peaceful and inclusive societies (two references)

Data and information from existing national and international reporting mechanisms should be used where possible.

Overall official disability data is not internationally comparable which leaves a disability data gap to measure the SDGs.

Refer to pages 15-17 of the [Disability Data Advocacy Toolkit](#) for more information.

### Facilitation tips

**Share the Session 1 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.

## Slide 16: In order to advocate

### Instructions

**Discuss** the following questions to help frame what we need to know from disability data in order to advocate effectively. Highlight the questions on the slide:

1. **Who** makes up the population of persons with disabilities in your country (compared to other countries)?
  - a. What are the characteristics of the population with disabilities in your country in terms of their age, gender, residence, and disability type?
2. **Does the population** with disabilities participate in society to the same extent as those without disabilities?
  - a. For example, do they experience the same levels of employment, income, education, and civic engagement?
3. **What are the barriers** that limit full inclusion and equity?
  - a. Are current policies and services adequate to address the barriers?
  - b. Is data available to address the questions raised above?

### Activity: Your advocacy/change objectives (15 minutes)

1. Group discussion
2. Pose the question to the group: What are your advocacy objectives?

Take 10 minutes to discuss. Capture these ideas as they are raised on a whiteboard and/or ask participants to document these in their notes. These are draft ideas that they will revisit in later sessions.

Prompt the group to start to think about the questions posed immediately before this activity. And to continue to reflect on these throughout the workshop sessions as this is unpacked.

### Facilitation tips

Advocacy objectives can mean things you want to see changed or addressed. Give examples, e.g., about access to services, policy frameworks, legal options, etc.

**Close the session** and say when the next session will be held. If running multiple sessions in a row, give participants a 15-minute break between sessions.

Remind participants to **complete the Individual Reflection Worksheet** for this session.

## Background reading/additional resources for facilitators

- [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: 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 CRPD 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](#).



# 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



# 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?

Name	Date
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?	

<b>Question</b>	<b>Responses for session 2 – Role of data disaggregation</b>
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?	

<b>Question</b>	<b>Responses for session 3 – Identifying population using WGQ</b>
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?	

<b>Question</b>	<b>Responses for session 4 – beyond disaggregation</b>
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?	

<b>Question</b>	<b>Responses for session 5 – Disability data sources and quality</b>
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?	

<b>Question</b>	<b>Responses for session 6 – Advocating for better data</b>
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?	

<b>Question</b>	<b>Responses for session 7 – OPD role in advocacy using data</b>
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?	

# Session

# 2

Facilitators guide  
Summary  
Handout

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

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

- Understand data disaggregation by disability and its relationship to measuring equity and inclusion.
- Understand how disaggregation can help monitor the CRPD and SDGs.
- Be able to apply the knowledge on disaggregation to advocacy.

## Prerequisite learning/knowledge

Going into the session, participants should have general familiarity with:

- The data requirements of the CRPD and the SDGs
- Disability concepts
- How data is collected and used.

## Key messages to be conveyed

- Data disaggregation can identify where there has not been full inclusion of persons with disabilities. This makes it a powerful tool in advocacy work.
- Disaggregation involves identifying persons with disabilities within your focus population or group, e.g., all adults in your country.
- Indicators are used to measure what is happening among that population on a certain topic, e.g., unemployment. Statistics are used to measure the indicator, e.g., the rate of unemployment.
- By identifying the persons with disabilities within the population, disaggregated data allows you to separate out the statistics or rates under each indicator for persons with and without disabilities, e.g., rate of unemployment for persons with disabilities, rate of unemployment for persons without disabilities.
- If these rates are the same for both persons with and without disabilities, then there is equality. This means that CRPD and SDG objectives have been met for this indicator.
- Disability is complex and can change meaning in different times and contexts. As a result, there are different ways to identify the population with disabilities.
- Changes in disability definitions will affect data and the conclusions that can be drawn from the data.

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## Preparation

Review the slide set and the facilitator guide.

Review the data-related requirements of the CRPD and the SDGs:

- a. The [Convention on the Rights of Persons with Disabilities](#), specifically Articles 31 and 4.3
- b. The 2030 Agenda for Sustainable Development and its Sustainable Development Goals, specifically paragraphs 48 and 57, and Goal 17.18.

Review related information on the Washington Group website:

- The Washington Group Questions and The Disability Continuum
  - How Does The WG-SS Differ from Disability Eligibility Determination?
  - Washington Group Questions and The Sustainable Development Goals
- 

## Resources and handouts

- PowerPoint Session 2, Slides 1–20
- Handout – Definition of key statistical terms
- Handout – Summary for participants

# Detailed plan and methodology

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**Slide 1: (Title Slide) 'Leave no one behind': The critical role of data disaggregation**

**Slide 2: (Section title) Session overview**

**Slide 3: Overview of session**

## Instructions

- Introduce the topic and contents of the session as outlined on Slide 3.
  - Explain that the session will discuss the following:
    - a. What does data disaggregation mean, and what basic data is needed for it?
    - b. Why is disaggregation fundamental to measuring equity and inclusion?
    - c. What is the link between disaggregation and advocacy?
    - d. How can disaggregation help monitor whether CRPD and SDG requirements have been met?
  - Explain that this session builds on Session 1 and leads into Session 3, which will address how to identify the population with disabilities so that disaggregation can be successfully accomplished.
- 

## Step 2.1: Data disaggregation

**Timing:** 40 minutes

### Objective:

- Outline objectives of the session and desired outcomes.
- Explain what is meant by data disaggregation, how it can be used to monitor the CRPD and the SDGs, and the data needed to conduct disaggregation.

**Required materials:** PowerPoint Slides 2-12

## Slide 4: (Section title) Data disaggregation

## Slide 5: Useful definitions

**Introduce key terms outlined on Slide 5:**

- **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.
  - **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.
-

- **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 of persons without disabilities to see if the rates are equal. Data is also commonly disaggregated by age, sex, or 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.

**Note:** further useful definitions are provided in the Session 2 handout.

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## Slide 6: Data and the CRPD and the SDGs

Introduce key terms outlined on Slide 5:

Briefly introduce:

- The Convention on the Rights of Persons with Disabilities (CRPD) as the key international framework setting out rights which (signatory) national governments and other duty bearers must uphold.
- The Sustainable Development Goals (SDGs) are 17 interlinked global goals that seek to map the way to a better and more sustainable future – in economic, environmental, and social areas - for everyone. They were adopted in 2015 and are intended to be achieved by 2030.

Review the CRPD and SDGs' data requirements as described on the slide:

- As mentioned in Session 1, both the CRPD and the SDGs aim for full inclusion of persons with disabilities.
- They both rely on data to assess whether this aim is being achieved.
- They call for disaggregated data to measure this inclusion.

Outline why disaggregated data is so helpful to measure inclusion:

- By identifying the persons with disabilities within the population data set, disaggregated data then allows the separation of statistics under each indicator for persons with and without disabilities, e.g., rate of unemployment for persons with disabilities compared to persons without disabilities.
- If these rates are the same for both persons with and without disabilities, then there is equality. This means that CRPD and SDG objectives have been met for this indicator.

Summarise the importance of disability disaggregated data for advocacy because it:

1. Identifies the specific areas where inclusion has not been achieved for persons with disabilities.
2. Measures the difference between inclusion of persons with and without disabilities.

## Slide 7: An SDG example of disaggregation

### Instructions

**Explain** that we will now use an employment related example of the use of disaggregated data for advocacy. Note that this example will be revisited and built upon throughout the remainder of this session, as well as Sessions 3-4.

**Describe** the employment example as outlined on Slide 7:

- Advocacy objective: Persons with disabilities should experience the same levels of employment as those without disabilities.
- Associated CRPD Article 27: Right to work on equal basis with others.
- Associated SDG: Goal 8.5 regarding full, productive and decent work for all including persons with disabilities.
- ‘Full employment’: Comparing the percentage rate of persons with disabilities and persons without disabilities.
- ‘Leave no one behind’: Persons with disabilities need the same rate of employment as those without disabilities to achieve this goal and advocacy objective.

### Facilitation tips

**Reinforce** that the advocacy objective used is just an example. Other objectives and relevant SDGs could have been chosen (e.g., school attendance by children). When this example is used consider asking participants to suggest a different example and discuss how that example could be used to illustrate how disaggregation can help with advocacy objectives.

## Slide 8: Have we met the CRPD and SDG objectives around full equality and inclusion for persons with disabilities?

### Instructions

- **Explain** how disaggregated data can be used to tell whether CRPD and SDGs objectives around full equality and inclusion for persons with disabilities have been met.
- **Disaggregated data** allows us to split and compare the data between rates of employment for persons with disabilities versus persons without disabilities.
- **If the bars are equal height**, we have achieved the CRPD and SDG objectives. If they are not equal height, then more persons without disabilities are employed than persons with disabilities – therefore further advocacy work is required to achieve the CRPD and SDGs.
- **Explain** that we can only create this comparison if we are able to identify the population of those with disabilities within the total population captured in the data.
- **Introduce** the following activity.

### Activity (20 minutes)

**Objective:** Participants to think about and discuss indicators related to their advocacy objectives.

**Explain:** In this activity we will identify advocacy objectives in our local areas and think about which SDG or other indicators might be useful to show whether progress has been made for equality and inclusion of persons with disabilities.

**Depending on the size** of the group, this activity can either be a discussion among all participants or the participants can be split into groups. For this activity, participants from the same OPD or place can be in groups together. Groups can select their own facilitator and a spokesperson to take notes/report back to the plenary.

**Provide** the following instructions to participants:

1. Identify one or two advocacy objectives of interest/importance to them.
2. Identify indicators relevant to these objectives. These can be SDG indicators, from another source, or an indicator developed by a participant. Have the SDGs available for reference.
3. Discuss the following:
  - a. How disaggregating data would enable them to understand if their chosen objectives have been met; and
  - b. If it has not been met, how the disaggregated data might be used to inform others of the problem.

**Debrief** from the activity in plenary.

1. Ask spokespersons to summarise their group's discussion and ask all participants to comment on the material presented.
2. Reinforce the connection between the advocacy objective and chosen indicator and how disaggregation can inform the status of the advocacy objective. For example, if an indicator is not met, more advocacy on inclusive employment is needed.

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## Slide 9: Data needed to monitor indicators (such as the SDGs)

### Instructions

Discuss the data needed to monitor full inclusion and where to obtain it.

1. Explain that SDGs are a main set of indicators that are used to determine full inclusion, but there are also regional and country-specific indicators used to monitor inclusion (e.g., the Incheon Strategy indicators).
2. For most countries, 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).
3. To assess whether inclusion and equality has been achieved for persons with disabilities in accordance with the SDGs/CRPD, these surveys need to:
  - Collect information about the indicator (e.g., rate of employment), and
  - Identify populations with disabilities and without disabilities (so that the rates for each can be compared to determine whether there is equality).

4. This means the surveys collecting information for the indicators need to include questions to identify the populations with and without disabilities.

This information must be obtained from the **same data collection systems** that obtain information on the indicator—**this is a key point and should be emphasised**.

5. The framing of these questions can affect the data collected and therefore the conclusions drawn from the data about whether indicators are being achieved for persons with disabilities.
  6. When using data to determine if full inclusion has occurred, it is critical to understand how the population with disabilities has been identified.
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## **Slide 10: Defining disability - to identify the population with disabilities we need to define disability**

### **Instructions**

**Introduce** the notion that the term **disability** means different things to different people and in different contexts.

**Discuss that disability and functioning** are closely related concepts, particularly when related to data, but that disability also includes the human rights perspective.

- For the workshop we use the term functioning to refer to an individual's level of ability/ difficulty in performing core activities.
- These activities are referred to as core functional domains and include seeing, hearing, walking, cognition, communication, upper body function and psychosocial functioning.

Discuss the components that disability incorporates, as outlined on Slide 10:

- Limitations in body functions due to impairments or conditions (e.g., blindness)
- Limitations in doing core functional domains (e.g., difficulty walking)
- Restrictions in participation (e.g., exclusion from community events because of communication barriers)
- These components are often related and are greatly affected by personal characteristics and the environment:
  - For example, an accommodating environment will reduce barriers and thus increase participation.

### **Facilitation tips**

**A key message** from Slide 10 relates to the statement that the components are **potentially related**, however:

1. Conditions do not always lead to the same limitations in functioning.
2. Limitations in functioning do not always lead to the same restriction in participation.

**The environment** has a major effect on how these components are related. An accommodating environment will break the link between a functional condition and participation restriction – this is an underlying premise of the CRPD. Highlight this when discussing this slide.

### Activity (optional)

**Ask participants** for an example where an environmental accommodation addressed the impact on participation resulting from a limitation in functioning. Have an example you can use such as accessible buildings and sign language interpreters.

## Slide 11: What is disability?

### Instructions

- **The term disability** means different things to different people due to the varying ways in which environmental and personal characteristics interact with a person's condition, limiting functioning and restricting participation.
- **This is very important for data**, as the term 'disability' will mean different things to different people involved in data collection surveys – the interviewers and most importantly, how the respondents being interviewed will respond.
- **Stress this key point:** if the survey questions to identify persons with disabilities are understood differently by different individuals depending on their individual idea of disability, or how their region or country understands disability, then there will not be consistency with how people respond to the question across the populations. This means that the data collected will not be accurate or comparable.
- **In addition**, and very importantly, in some cultures, stigma associated with disability makes people hesitant to openly answer survey questions about disability. This leads to under-identification of persons with disabilities in the population surveyed.

## Slide 12: Risks of not identifying disability in data

### Instructions

**Discuss** some problems that could arise with survey respondents having different ideas of disabilities, or not being willing to discuss disability due to stigma.

1. Data that can't be compared between regions: If some regions have a broader understanding of what disability may involve, more survey respondents with disabilities will be identified – so the data will suggest that region has more persons with disabilities; whereas it may just be that more people understood that their difficulties in functioning should be classed as a 'disability', or more people were open to discussing this.

- 2. Data that conceals inequality experience by persons with disabilities:** If the survey's questions around disability are not specific enough, fewer persons with disabilities may answer in a way that identifies them in the data as having a disability. This will mean that persons with disabilities will be included in the 'persons without disabilities' group of data collected on specific indicators (e.g., employment rates). This may hide the additional barriers and inequalities that persons with disabilities are encountering in this area, and incorrectly suggest the indicator or goal is closer to being achieved.

## Step 2.2: Identifying the population with disabilities using statistical data

**Timing:** 40 minutes

**Objective:**

Discuss how the complexity of the concept of disability presents challenges for identifying the population with disabilities as required for disaggregation.

**Required materials:** Slides 13-20

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### Slide 13: (Section title) Identifying the population with disabilities using statistical data

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### Slide 14: Identifying the population with disabilities using statistical data (1)

**Instructions**

- **Introduce** the topic by reinforcing the need to define the population with disabilities to disaggregate data and monitor advocacy objectives.
- **Explain** that the data used to identify the population with disabilities is obtained from questions included in censuses and surveys and other data collection activities, including administrative data systems.
- **Remind** participants of the complexity of the concept of disability and that because of this it is not possible to write one question or a short set of survey questions that can adequately and accurately capture the full complexity of disability.
- **And yet**, survey questions must be short, clear, and precise.
- **As a result**, many problematic questions have been used:
  - Mostly based on the **medical model**
  - Using the word **disability** in the question even though there is stigma and different meanings associated with disability.

## **Slide 15: Identifying the population with disabilities using statistical data (2)**

### **Instructions**

Reinforce that the question ‘Are you disabled?’ should not be used to identify the population with disabilities to monitor inclusion due to:

- The complexity of the disability concept.
- The major differences in how the terms are understood within a community or country and across countries.
- The stigma attached to the term in some cultures.

If the single question ‘Are you disabled?’ cannot be used, how should the population be defined?

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## **Slide 16: Identifying the population with disabilities using statistical data (2)**

### **Instructions**

**Discuss** the answer to the question on the previous slide (Slide 15).

**For monitoring inclusion**, questions to identify the population with disabilities should obtain information on:

- limitations in functioning
- that affect one’s ability to participate in society
- if appropriate accommodations are not made

**This approach** is consistent with the CRPD.

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## **Slide 17: Review - Why do we need disaggregated data?**

### **Instructions**

**This slide is a quick reminder** that data disaggregation by disability is important because it allows us to determine if the CRPD objectives have been met.

Disaggregation can occur when a survey:

1. Identifies the groups with and without disabilities.
2. Obtains information on the indicators (in our example, about employment) from separate questions but the same data collection tool.
- 3. Both are analysed together.**

Disaggregation allows us to:

- Determine whether the CRPD objectives of equality and inclusion have been met.
- Inform national policy and budgeting initiatives.
- Monitor whether programmes and policies are effectively improving outcomes for persons with disabilities towards equality and inclusion, if done over time.

## Slide 18: Potential sources of data to disaggregate SDG 8.5.2?

### Instructions

Given the importance of disaggregation, discuss some key sources of data that can be used for this purpose, using our example of the SDG indicator on employment.

Data on the indicator is often obtained from:

- Censuses
- Labor Force Surveys
- Other surveys which can vary by country

If these sources also obtain information to identify the population with disabilities, SDG 8.5.2 can be disaggregated by disability status.

It is then possible to determine whether full inclusion on this indicator has been attained. In this hypothetical example, full inclusion has not been attained.

### Activity: (20 minutes)

**Objective:** Participants think about sources of data that can be used for disaggregation in their country.

**Explain:** in this activity we will identify potential sources of data that could be used to disaggregate the employment SDG that has been discussed. Note – this activity could be done using an advocacy objective and associated SDG provided by the participants.

**Depending on the size of the group** this activity can either be a discussion among all participants or the participants can be split into groups. For this activity participants from the same organisation of persons with disabilities or place can be in groups together. Groups can select their own facilitator and a spokesperson to take notes/report back to the plenary. Previously identified groups can be used.

**Provide** the following instructions to participants:

- Ask participants to list sources of data for the SDG indicator (or the indicator they propose) – potential sources are the census and labour force surveys.
- If participants do not have this information – have participants discuss where they might find it. Depending on the number of countries where the participants are from, the facilitator could have this information available.
- Ask participants if there are questions on the survey that allow the population with disabilities to be identified.
  - If not known, have participants discuss where to find this information.

**Debrief** from the activity in plenary.

- Ask group spokespersons to summarize the discussion in their groups and ask all participants to comment on the material presented in terms of their knowledge of available data.

## **Slide 19: Summary of key points**

### **Instructions**

**Review** the key summary points from the session.

- **Both the CRPD and the SDGs** require that data be collected to determine if their objectives around equality and inclusion have been met.
- **Data disaggregation** is used for this purpose.
- **Disaggregation** requires that the population with disabilities be identified.
- **Given the complexity** of the concept of disability, there are different ways to identify the population which will produce different disaggregation.

**To disaggregate indicators**, such as the SDGs, information that identifies the population with disabilities must be included in surveys that collect data.

- If this is not the case, **there is a strong need to advocate for collection of this data**.
  - If it is the case, the results of disaggregation can be used to advocate for policies or programmes that will address the inequalities observed.
- 

## **Slide 20: End of session slide**

### **Instructions**

**Ask participants** to fill out the individual reflection sheet.

**Participants are asked** to reflect 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 about your country:
  - 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 have learned?

## Background reading/additional resources for facilitators

- 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: ‘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](#)



# 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 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.



# Session

# 3

Facilitators guide  
Summary

# Identifying the population with disabilities using the Washington Group Questions

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

- Understand the Washington Group Short Set (WG-SS) of questions and why they are widely used, recommended and endorsed for disaggregation.
- Be familiar with the WG-SS questions and response options and how these are used to identify the population with disabilities.
- Begin applying the WG-SS to help shape advocacy messaging.

## Prerequisite learning/knowledge

- General familiarity with disability concepts and the importance of disaggregation as discussed in previous sessions.
- Understanding of the need to identify the population with disabilities in order to disaggregate data.

## Key messages to be conveyed

- 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).
  - 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, which will be discussed in the next session.

## **Preparation**

- Review and be familiar with all content in the slide set and the facilitator guide.
  - Review additional material, as needed regarding the key messages, as found on the Washington Group website, including:
    - Differences in Reported Disability Prevalence Rates: Is something wrong if I don't get 15%?
    - The Washington Group Questions And The Disability Continuum
    - How Does The WG-SS Differ From Disability Eligibility Determination?
    - Why The Washington Group Questions Ask About 'Difficulties' And Not 'Disabilities' - How A Single Word Can Make A Difference
- 

## **Resources and handouts**

- PowerPoint Session 3, Slides 1 to 18
- Handout - Summary

# Detailed plan and methodology

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**Slide 1: (title slide) Identifying the population with disabilities using the Washington Group Questions**

**Slide 2: (Section Title Slide) Session overview**

**Step 3.1: Recommended question set to be used to disaggregate data to monitor the CRPD and the SDGs**

**Timing:** 25 minutes

**Objective:**

- Outline objectives of the session and desired outcomes.
- Introduce participants to a recommended question set to increase understanding of disaggregated data for use in advocacy.

**Required materials:** Slides 4 to10

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**Slide 3: Overview of session**

**Instructions**

**Introduce** the topic and contents of the session.

**Refresh from previous session:**

1. To determine if the SDG and CRPD objectives of equality and inclusion are being achieved within a certain indicator (such as employment), we need to identify persons with disabilities within the population surveyed about this indicator.
2. This lets us then compare the progress against that indicator (e.g., rates of employment) for both persons with disabilities and persons without disabilities. This is called disaggregated data.
3. If there is a difference between these rates, then equality and inclusion has not been achieved and further advocacy work is required.

**Explain** the set of questions recommended to include in surveys to identify persons with disabilities within the population, for the purpose of disaggregation.

**Explain** how the questions can be used to identify different populations with disabilities, and explore how different definitions of disability can affect data findings on:

1. Prevalence of disability
  2. Disaggregation of indicators
- 

**Slide 4: (Section title slide) Recommended WG question set to disaggregate data to monitor the CRPD and the SDGs**

## **Slide 5: Washington Group Short Set (WG-SS)**

### **Instructions**

Introduce the objective of the Washington Group Short Set of questions as outlined on Slide 5:

The WG developed a set of questions to identify those who

- because of difficulties doing certain universal, basic actions
- are at greater risk than the general population
- for limitations in participation.

**Explain** that the questions are used to disaggregate data by disability status to monitor the CRPD and SDGs.

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## **Slide 6: What questions are included in WG-SS?**

### **Instructions**

**Read** the following six questions and the response categories.

The 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

**Explain** the questions further.

There are six questions in the question set – one for each of the six core functional domains:

Each question asks about difficulties in the domain.

Questions were designed to be short, clear and easy to administer so they could be used in a census.

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## **Slide 7: The WG-SS is the recommended question set for disability data disaggregation?**

### **Instructions**

**Emphasise** that the WG-SS is the recommended set for disability data disaggregation.

**Mention** the wide use of the questions as listed on the slide.

- Used in censuses or surveys in over 80 countries (at time of writing).

- Promoted as the means to collect disability data and disaggregate by disability status by:
  - International aid donors, e.g., DFID/UK and DFAT/Australia
  - UN Statistics Division (UNSD) and the UN Economic Commission for Europe
  - UN DESA's Disability Data Experts Group

## Slide 8: (Section Title Slide) How does the WG-SS measure difficulties?

### Slide 9: How do the WG-SS questions ask about degree of difficulty?

#### Instructions

**Explain** why 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.

Each WG question has four answer options to find out the degree of difficulty the person may experience in different domains of functioning (e.g., difficulty with walking).

Gathering data on the degrees of difficulty collects more information than a yes/no question. This is important because people's experience of disability is not as simple as 'yes or no'.

Most people experience difficulties with functioning to varying degrees, from experiencing some difficulty to experiencing great difficulty. This is described as the 'continuum' of functioning. The diagram on Slide 9 shows the different degrees of difficulty along the continuum.

Some people will also experience difficulties across multiple domains.

#### Facilitation tip

Ask participants to share examples of people with different disabilities and where they may be on the continuum of functioning – from no difficulty to some difficulty, to a lot of difficulty, to cannot do at all.

## Slide 10: Where on the continuum does a disability 'start'?

#### Instructions

Slide 10 shows that the definition of disability can differ depending on the 'cut-off' point used. Refer to the slide to explain that:

1. **Disability and functioning** exist along a continuum. There is a cut-off point on the continuum which establishes where disability starts. Below the cut-off point, disability does not exist; above the cut-off point, disability does exist. Definition is important.
2. If disability is defined as someone who has 'some difficulty or greater', we will count more persons as having disabilities than if we define disability as someone who has 'a lot of difficulty or cannot do at all'.

3. **It is important to remember** that people may have difficulties over more than one domain of functioning. A person could have ‘a lot of difficulty’ in seeing and ‘cannot do at all’ in walking.

More information on prevalence rates can be found at:

- [Differences in Reported Disability Prevalence Rates: Is something wrong if I don't get 15%?](#)
  - [The Washington Group Questions And The Disability Continuum](#)
- 

## Slide 11: What does the cut-off point mean?

### Instructions

**Slide 11 gives** some detail about the cut-off point. This is complicated and technical so it may help to share the video [What is the prevalence of disability?](#) (with International Sign translation and English captions). Note that:

**There is no standard definition** for deciding the cut-off point. It is particularly important to know the definition for the cut-off point when using disability disaggregated data in advocacy materials.

**The recommended definition** for international comparisons is that persons with disabilities are those who experience ‘a lot of difficulty’ in at least one domain (in red in the table on Slide 12).

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## Slide 12: The cut-off point is important when evaluating inclusion

### Instructions

Explain that the position of the cut-off point impacts the data and whether full inclusion is met. This is because:

The cut-off point affects the prevalence rate of disability (the number of persons with disabilities identified).

The number of persons with disabilities identified in the data affects the size or percentage difference between outcomes for persons with and without disabilities.

The table on Slide 12 shows this in relation to the SDG indicator regarding rate of employment.

## Step 3.2: The results of data disaggregation will be affected by how the population with disabilities is identified

**Timing:** 25 minutes

**Objective:** Illustrate how the identification of disability affects what disaggregated data tells us about whether equality and inclusion has been achieved for persons with disabilities.

**Required materials:** Slides 12 to 16

## **Slide 13: (Section title slide) Why the definition used for disability matters for advocacy**

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### **Slide 14: What happens when disability is defined more broadly?**

#### **Instructions**

**Highlight** how the definition of disability, if used broadly, will include more people who might have, for example, the need to use glasses. This can make the disability population look bigger. Then, using slide 14 and the following, discuss how a lower cut off point can have different implications for inclusion and advocacy related to employment.

When disability is defined more broadly, or with a lower cut-off point such as 'some difficulty' in one domain, then:

1. More persons with disabilities will be identified within the data for that indicator, including more people with lower 'difficulties' in functioning related to their disabilities. For example, using glasses to see distance.
  2. People with lower functioning 'difficulties' will be more likely to be employed than those with higher 'difficulties', so including people from lower difficulty categories will raise the level of employment across the whole group of persons identified as having a disability.
  3. The differences in employment rates for persons with and without disabilities will appear lower.
  4. This will suggest we are closer to achieving the CRPD and SDG objectives of equality and inclusion for that indicator.
- 

### **Slide 15: What happens when disability is defined more narrowly?**

#### **Instructions**

**Highlight** how the definition of disability, if used narrowly, includes less people. For example, the population of 'who cannot walk at all', is smaller than people who can walk with a cane.

**When disability is defined more narrowly**, or with a higher cut-off point (such as a cut-off point of 'cannot function at all' in one domain) then:

1. Data for that indicator will identify fewer persons with disabilities within the data set and include only people with higher levels of difficulty functioning.
2. Persons with disabilities will likely face more barriers obtaining employment than those with lower levels of difficulty functioning.
3. Data will reflect a much greater difference between employment rates for persons with and without disabilities.
4. This will suggest we are further away from achieving equality and inclusion for the employment indicator.

**This generally** applies to other indicators also, such as school enrolment for children, poverty levels, access to healthcare, and access to water, sanitation, and hygiene.

## Slide 16: Summary of key points

### Instructions

This slide summarises the key points from the session:

- **How many persons** with disabilities are identified within a data set will be determined by:
  1. The type of questions asked
  2. The cut-off point selected
- **These choices** will affect:
  1. The estimate of the population with disabilities
  2. The characteristics of the population
  3. The extent of differences between those with and without disabilities

This means that how the population is defined needs to be clearly reported within the data.

- **The recommended definition** (at least 'a lot' of difficulty in at least one domain) was chosen as the most suitable cut-off point in monitoring the SDGs.
- **If the questions used** are poorly designed or an inappropriate cut-off point is selected, the resulting data will give a misleading picture of the experience of those with disabilities and whether full inclusion has been achieved.

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## Slide 17: Applying identification of the population with disability to local SDG and CRPD monitoring

### Activity

1. **Introduce the activity:** the relationship between the identification of the population with disabilities and differences between those with and without disabilities in monitoring the CRPD and SDGs.

Explain that this activity will illustrate how different methods of identifying the population with disabilities can affect your advocacy work.
2. **Split participants** into groups of 5-8. Existing groups can be used. Groups can select their own facilitator and a spokesperson to take notes/report back if needed.
3. **Provide the following** instructions to participants in the group(s) as listed on Slide 17:
  - a. Identify an important advocacy issue in their work where disaggregated data would be used to support their advocacy (e.g., employment, school attendance, poverty indicators)
  - b. Discuss and recommend the data needed to determine any measurable differences between those with disabilities and those without.
4. **Debrief** from the activity in plenary.

## Slide 18: Close of session

### Instructions

Ask participants to fill out the individual reflection sheet.

Participants are asked to reflect 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 about your country:
  - 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 have learned?

### Background reading/additional resources for facilitators

- Washington Group information: [Resources for Data Users](#)
- [Disability Data Advocacy Toolkit](#) in various formats and languages.
- Video: [What is the prevalence of disability?](#) (with International Sign translation and English captions).



# 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).



# Session

# 4

Facilitators guide  
Summary

# Beyond disaggregation

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

- Understand how the Washington Group Short Set of questions (WG-SS) can be used to inform other disability issues as well as disaggregation.
- Be aware of the limitations of the WG-SS and possible ways to address them.
- Understand additional information on functional status, barriers and enablers to inclusion that can supplement disaggregated data.

## Prerequisite learning/knowledge

- Familiarity with the material covered in Sessions 2 and 3.

## Key messages to be conveyed

- 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 will support evidence-based advocacy 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.

## Preparation

- Review the Session 4 slide set and facilitator guide and be familiar with all content.
- Review the [Disability Data Advocacy Toolkit](#), available in various formats and languages.
- Review [Resources for Data Users](#) from the Washington Group website.

## Resources and handouts

- PowerPoint Session 4 Slides 1–18
- Handout - Summary for participants

# Detailed plan and methodology

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## Slide 1: (Session title slide) Beyond disaggregation

### Step 4.1: Additional uses of the WG-SS

**Timing:** 35 minutes

**Objectives:**

1. Outline objectives of the session and desired outcomes.
2. Describe additional uses of the WG-SS other than the disaggregation and illustrate using the SDG example.

**Required materials:** Slides 2 to 10

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## Slide 2 (Section Title slide) Session overview

## Slide 3: Overview of session

**Instructions**

**Introduce** the topic and contents of the session, explaining as outlined on the slides, the session will:

1. Discuss additional uses of the WG-SS beyond disaggregation
  2. Review the limitations of the WG-SS and discuss possible ways to address them.
  3. Highlight the data collection tool for children with disabilities.
  4. Identify the information needed to go beyond disaggregation and build evidence for effective advocacy on how SDG targets are disability inclusive and how CRPD is being implemented.
- 

## Slide 4: (Section title slide) Additional uses of the WG-SS

### Facilitation tip

Before moving to the next slide, you can use this as an opportunity to check how much participants recall and understand about the WG-SS from the previous session. Ask “What do people remember about the WG-SS?”. Then check using the summary on slide 5.

## **Slide 5: What can the WG-SS tell us beyond identifying the population with disabilities?**

### **Instructions**

**Explain** that using WG-SS can tell us more than just identifying the population with disabilities for disaggregation. Since it obtains information **on functional status**, it can be used to provide more detail on this characteristic.

### **Refresh and remind participants about the WG-SS question set:**

1. Has six questions – one for each of the core functional domains or areas of functioning, e.g., walking, communication.
2. Reflects a continuum of functioning, as opposed to a yes/no question on disability or difficulties. For each question/domain, the respondent is asked whether they have difficulties (not at all, some of the time, most of the time, cannot do at all).

This approach focused on levels of difficulty functioning can also tell us about:

- the prevalence of persons with disabilities
- The level of support they might require that could be investigated (e.g., a person has some difficulty in walking may benefit from a mobility advice)
- People who may have difficulties across multiple domains.

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## **Slide 6: Why is it important to know more about the detail in the data?**

### **Instructions**

**Introductory comment:** It's important to know more than just numbers. The more detail, the better for policy, planning and even for OPDs to know more about their membership diversity and needs.

**Understanding the detail in the data** shows the different levels of difficulty faced by persons with disabilities and helps policy makers and others to understand the diverse needs of a population to aid in planning services.

**It can also help OPDs** in their advocacy efforts.

For example, the [World Blind Union research on the impact of COVID-19](#) on blind and partially sighted persons used the different levels of difficulty. It was able to differentiate the level of need among its members and found that:

- **In addition to having difficulty seeing**, 18 per cent of the respondents noted having at least one other significant level of difficulty from among the Washington Group questions asked.
- **Having this level of detail** about more than one domain, meant that the World Blind Union could better understand the needs of its members.

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## **Slide 7: How to assess if a data set is fit for use**

### **Instructions**

To determine 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 covered for the disability of interest? 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?

#### **Step 4.2: Limitations of the WG-SS**

**Timing:** 40 minutes

**Objective:** Describe the limitations of the WG-SS and ways to address the limitations.

**Required materials:** Slides 9 to 10

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### **Slide 8: (Section title slide) Limitations of the WG-SS**

#### **Slide 9: What are the general limitations of the WG-SS?**

##### **Instructions**

Explain that all questions have limitations; whether the limitations affect the quality of the data depends on the intended use of the data.

The WG-SS has limitations because of the requirements it had to meet to serve its purpose. The WG-SS was designed:

1. For use with the whole population.
2. To be able to be administered in a census, which meant:
  - i. Keeping the number of questions to a minimum.
  - ii. Questions could not be sensitive.

##### **Facilitation tip**

Before moving to the next slide, ask participants if they can think of any limitations of the WG-SS? Discuss and note those that will be covered in the following discussion.

### **Slide 10: Does the WG-SS include all persons with disabilities?**

##### **Instructions**

**Explain** that a limitation of the WG-SS is that it doesn't address all core functional domains.

To be brief and not too sensitive, the WG-SS does not identify:

1. Persons with psychosocial disabilities.
2. Persons with upper body limitations.

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

**To address these limitations**, the WG developed the WG-Extended Set and the WG-Enhanced Set of Questions, which:

- Include two questions each on upper body functioning, and anxiety and depression.
- Can be added to surveys such as those on labor force, living standards, health, and education.

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## **Slide 11: (Section title slide) Child Functioning Module (CFM) – a specific tool designed to gather data on children with disabilities**

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### **Slide 12: Disability in children**

#### **Instructions**

**Explain** that a 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. Is not appropriate for children under 5 years.
2. Misses some children with developmental issues aged between 5 and 18 years.

**To address these limitations**, the WG and UNICEF developed the Child Functioning Module (CFM). The CFM:

- Follows the basic design of the WG-SS but includes functional domains of importance to children.
- Has tested question sets 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.

#### **Introduce the activity**

##### **Facilitation tip**

This can be a short facilitator-led discussion or can be done in groups, if desired.

### **Activity: Data limitations**

**Ask participants** to think back to the advocacy objectives they discussed in Session 1 or think of another example of an area needing advocacy to achieve equality for persons with disabilities locally. Choose an area where disaggregated data will show that persons with disabilities are not equal to those without disabilities.

**Ask participants** to discuss what data may exist to show how persons with disabilities are experiencing inequality under this objective, and what information/data would be needed to advocate around this.

### **Step 4.3: Beyond disaggregation**

**Timing:** 40 minutes

**Objective:** Describe the data needed to meet advocacy objectives beyond disaggregation.

**Required materials:** Slides 14 to 17

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### **Slide 13: (Section title slide) Beyond disaggregation – using the data to build evidence for advocacy**

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### **Slide 14: Disaggregation tells us only one part of the story – what other data is needed?**

#### **Instructions**

**Explain** that the **The WG-SS does not tell us** that environmental factors act as barriers or enablers for better inclusion (such as assistive devices, supportive regulations, accessible buildings). They also do not address the difference assistive devices may make for persons with disabilities.

**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 enablers** are not addressed. To obtain this data, additional modules can be added to the existing data collection modules, or specific disability surveys exploring these factors can be conducted (or both).

**Read out the Irish case study below** for an example of further, supplementary data collection based on initial use of WG-SS.

### **Irish case study**

#### **Illustrating further data collection via a National Disability Survey**

##### **Ireland's National Disability Survey (NDS)**

Following Ireland's census in 2006, a national disability survey was administered to a smaller population section of persons with disabilities. The survey focused on persons who indicated in the 2006 census that they had a disability or a long-standing health condition. The purpose of the survey was to provide a comprehensive analysis of the situation of persons with disabilities and those indicating a long-standing health condition. It was a one-time survey to give a snapshot of the lives of persons with disabilities. The NDS questionnaire was based on the social model of disability which defines disability as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers they may face. The questionnaire was broadly divided into two parts. Section 1 collected a range of data on nine specific disability types including: level of severity, age of onset of disability, aids used or needed to assist with daily life, cause of the disability and in some cases frequency of occurrence. The rest of the questionnaire dealt with topics related to activity and participation such as education, employment, transport, and the built environment as well as collecting some basic demographic information. Collecting data on these areas gave a wider understanding of barriers faced by persons with disabilities.

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## **Slide 15: Advocating for inclusive employment –what other information is needed?**

### **Instructions**

Explain that discussion will continue using the example of employment discussed in earlier sessions, where disaggregated data showed the population with disabilities were accessing employment at a lower rate than the population without disabilities.

What other information could help inform policy, planning and advocacy?

**Data is needed on the barriers and enablers** of employment including:

- Accessibility of the physical environment, such as workplaces.
- Accessibility of transportation to, from and for work.
- Characteristics of working conditions, including flexibility.
- Legal and regulatory protections especially on workplace discrimination, or lack thereof.
- Attitudes of employers and other workers.

**Some of these characteristics** are included in the WG-ILO module on full employment that can be added to labor force surveys.

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## **Slide 16: What additional information would help assess barriers and differences experienced by persons with disabilities around employment?**

### **Instructions**

Explain that to better support employment of persons with disabilities, further information is needed on the availability, need and receipt of services such as:

- Assistive devices
- Personal assistance
- General and specialised health care
- Educational opportunities

This information can be obtained by adding the appropriate questions to surveys that also include questions to identify the population with disabilities.

It can also be obtained through interviewing persons with disabilities about their experiences in the workplace and the barriers they face.

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## **Slide 17: Summary of key points**

### **Facilitation tips**

As an (optional) way of checking participants understanding of checking the suitability of a data source, ask if they can come up with some questions, they could ask of a data set to see if it is fit for their intended use. Some sample questions could include:

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?

**Disaggregation** is critical to monitoring the CRPD and the SDGs, but disaggregation does not address other issues related to disability that are relevant for policy development and implementation.

**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.

**All data has limitations**, it is critical to understand the limitations and determine how they might affect the use of data for advocacy.

**If appropriate data is not available**, knowledge of the limitations of available data can be used to advocate for improved data.

## **Slide 18: (Section title slide) End of Session**

### **Instructions**

Ask participants to fill out the individual reflection sheet.

Participants are asked to reflect 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 about your country:
  - 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 have learned?

### **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: 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



# Session

# 5

Facilitators guide  
Summary  
Handouts

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

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

- 1) Identify different sources of disability data and their advantages and disadvantages.
- 2) Critique how available data will meet their needs for specific advocacy objectives.
- 3) Demonstrate a basic knowledge of best practice for quality data collection and how to apply this when:
  - a) evaluating data used by policymakers.
  - b) advocating for improved data.
  - c) collecting their own data.

## Prerequisite learning/knowledge

- General familiarity with disability concepts.
- General familiarity with data sources and characteristics of data of any type.
- Familiarity with the [Disability Data Advocacy Toolkit](#) (available in various formats and languages).

## Key messages to be conveyed

- 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.
- Knowledge of how to use disability data and the potential limitations of the data will support advocacy activities by ensuring that accurate evidence is used to support or contest policy and programme decisions.

## Preparation

- Review the content from Sessions 1, 2, 3 and 4.
  - Decide if the data sources in Step 5.1 will be explained in detail in plenary, or only in overview.
  - Prepare any required breakout groups in advance.
  - Prepare for the activity by reviewing the activity worksheet for Session 5. A generic example is provided but ideally you should prepare at least one local data source example to use instead. Document and circulate a local data collection example outlining any known information on how it was collected (e.g., Census, Labour Force Survey). This does not need to be a perfect example, as participants should learn from critiquing it in the activity. More than one example will allow break out groups to review different local data sources.
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## Resources and handouts

- PowerPoint Session 5 Slides 1 to 18
- Handout – Summary of data sources
- Handout – Activity: Reviewing data quality (optional generic review). Please prepare your own local example.
- Handout – Summary for participants
- Related materials from the Washington Group website:
  - [How Can Administrative Data Be Used for Collecting Data On Disability?](#)
  - [Training On How To Ask “Disability” Questions On Censuses And Surveys](#)
  - [Resources for Data Users](#)

# Detailed plan and methodology

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## Step 5.1: Data sources

### Objective:

- 1) Outline objectives of the session and desired outcomes.
- 2) Provide a basic understanding of the sources of disability data for use in advocacy.

**Required materials:** Slides 2 to 14

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## Slide 1( Session title slide) Disability data sources, quality and the role of OPDs

### Slide 2: (Section title slide) Session overview

#### Facilitation tip

**Aim to spend** 10-15 mins on the session overview and data sources plenary discussion below (Slides 2-11).

## Slide 3: Overview of session

### Instructions

Introduce the topic and contents of the session.

**Explain** that the session will:

- 1) Provide an overview of different disability data sources and their advantages and disadvantages.
- 2) Explore key tips for ensuring data quality for your advocacy work.
- 3) Understand how to use this data to inform your advocacy including:
  - a) Using accurate evidence to support or contest policy and programme decisions,
  - b) Identifying specific data needs to request in your data advocacy

## Slide 4: (Section title slide) Sources of data

#### Facilitation tip

To make this more interactive, before moving forward, ask participants to name any common sources of data on disability. Prompt for gaps with questions like: “More qualitative types of data? Government data? What sort of data is collected by people other than government, etc?” Then read out the ones listed on Slide 5 that they did not mention.

## Slide 5: Where can data be sourced?

### Instructions

**Describe** the most common sources of disability data often used in policy formation, research, civic engagement and advocacy. Wherever possible, ask participants to highlight local examples.

**Slide 5** reviews common sources of data on disability. Note that data from these sources can be obtained as microdata files or summarised in reports from:

- Censuses
- Surveys of people:
  - i. Multipurpose surveys
  - ii. Topic-specific surveys
  - iii. Health surveys
  - iv. Disability surveys
- Surveys , evaluations etc done by organisations
- Administrative systems:
  - i. Systems not focused on disability
  - ii. Systems focused on disability
- In-depth interviews
- Case studies

### Facilitation tips

**Add or brainstorm examples with the group** from your country to illustrate the key local sources that may exist

Ask participants can they think of any additional sources not listed on slide 5.

**Slides 6 to 10** has definitions for data sources and the advantages and disadvantages of the different sources, so users can match the best source for their data needs. These are also summarised in the **Session 5 Handout**.

### Facilitation tip

You can choose to skip or move quickly through the information on Slides 6 to 10 on formal data sources and go to the activity. Participants can use the Session 5 handout (and/or slides) which summarises this content on the data sources to help complete the activity.

## Slide 6: Census

### Instructions

**Ask participants** to give share some experiences or thoughts they may have about a census, including any advantages and disadvantages. Do they know when the last

census was in their country? What (if any questions) were there on disability?

**Definition:** 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. 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.

**Advantages:**

- When a census does include data on persons with disabilities, they can be a good source of data for disaggregating indicators (e.g., SDG indicator on persons with disabilities in employment).

**Limitations:**

- The number of questions that can be included is limited.
  - Limited control over enumerators due to full coverage of the population, can compromise data collection.
- 

## Slide 7: Surveys gathering data on specific themes

**Instructions**

**Facilitator and/or participants** share any knowledge they have about surveys in that country

**Explain** or read the below information on surveys, which reflects the contents of the slide.

**Definition:** Surveys obtain information about people or organisations by 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.

While surveys on some topics are done as part of national statistical systems, such as surveys on labor force participation, there is considerable variation in the surveys done on other topics.

**Advantages:**

- Good source of data for disaggregating indicators by disability status – when questions to identify the population with disabilities are included.
- Can add additional questions especially on barriers and facilitators to full participation on a periodic basis.

**Limitations:**

- The number of questions that can be included.
  - Sample sizes may limit the stability of estimates for any subgroup but can increase the quality of data collection.
-

## **Slide 8: Surveys that are disability specific**

### **Instructions**

**Share with or ask participants** if and when a disability specific survey has been done in their country

**Explain** that the definition is the same as for other surveys, but these focus specifically on collecting data on disability. This is the most comprehensive source of data on functioning and disability.

### **Advantages:**

- Best opportunity to add additional questions on barriers and facilitators to full participation.

### **Limitations:**

- Sample size may limit the stability of estimates for any subgroup but can increase quality of data collection.
  - Generally, not done on a set schedule and there are usually long gaps.
  - Changes in design and questions asked make it a poor source of data for tracing progress on SDG inclusion.
  - Sample needs to be large enough to provide stable estimates for the population with disabilities, which presents design challenges.
- 

## **Slide 9: General administrative data systems**

### **Instructions**

Read the definition listed below that reflect the content of the slide. Be prepared to share some examples that might exist, such education information management systems

**Definition:** 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 data is data derived from an administrative 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.

### **Advantages:**

- Available source of information for disaggregation if items identifying the population with disabilities are included in the data system.

### **Limitations:**

- Provides information on all persons served by the programme for which the administrative data is kept.
  - Only includes those who meet eligibility criteria and, for many systems, choose to obtain services through the programme.
  - The disability indicator used (if any) by the programme may not produce high-quality data or address the aspects of interest.
  - Data quality can be an issue for all items but especially for data items not needed to administer the programme.
-

## Slide 10: Disability-related administrative data systems

### Instructions

**Definition:** 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. There are administrative systems for programmes that provide services and benefits specifically to persons with disabilities.

### Advantages:

- Source of information on disability services or benefits provided by the programme.

### Limitations:

- Provides information on all persons served by the programme the administrative data system is designed for.
- Only includes those who meet eligibility criteria and, for many systems, choose to obtain services through the programme.
- Eligibility criteria for those included in the programme might not match the population of interest.
- Data quality can be an issue, especially for data items not needed to administer the programme.

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## Step 5.2: Data quality

### Slide 11: (Sections title slide) Key tips for checking data quality

#### Facilitation tips

Make sure you have your Session 5 activity worksheet prepared in advance as outlined in the preparation for the activity at the end of this section. Share the local data collection example you have prepared (if relevant).

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## Slide 12: Checking data quality

### Instructions

**Highlight how important it is to check the quality of data**, as data can go out of date quickly or be incomplete. There is also an abundance of data available, so decisions need to be made on what to use and why. Always check data for the following:

- Accuracy: the data is reliably true and correct.
- Relevancy: the data should meet the requirements for the intended use.
- Completeness: the data should not have missing values or missing data records.
- Timeliness: the data should be up to date.
- Consistency: the data should have the data format as expected and can be cross referenced with other sources to produce the same results.

If the data you use for advocacy purposes deviates from the above points, it can be used to help refine your advocacy on how to improve data for policy and programming. If the data is strong, then this helps strengthen the evidence for your advocacy case.

## **Activity to review data sources and quality (20 mins)**

### **Instructions**

#### **1) Prepare the groups:**

- Depending on the number of participants, break people into smaller groups of 5-6 to discuss the activity.
- Use the activity worksheet and summary of data sources handouts provided. Where relevant, use the local example of data provided to guide the activity and discussion.
- Appoint a note taker and lead for any break-out groups.

#### **2) Using the data source provided participants should:**

1. Review the data collection in terms of the population covered and the content.
  - a. Who is covered (or not) by the data collection?
  - b. 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?

## **Slide 13: (Section title slide) Data collection and OPDs**

## **Slide 14: The CRPD and the involvement of persons with disabilities and OPDs in data**

### **Instructions**

**Highlight** the legal and policy framework underpinning the inclusion of persons with disabilities and OPDs in data, particularly the CRPD, noting that:

- The CRPD ensures a role for persons with disabilities in providing input into policies and decisions in all areas of life, this also includes data collection by governments.
- Governments that have ratified the CRPD, which is most countries, have an obligation to collect data to assist with policy formulation.
- OPDs have a role in advocating for this as well as for better data.
- Persons with disabilities can be trained as enumerators and OPDs can be involved in data collection.

## **Slide 15: Interviewer training for OPDs**

### **Instructions**

**Ask** if any participants have previously worked as an interviewer in data collection or been interviewed for data collection purposes. Ask how was that experience? Was it consistent? Accessible? Inclusive?

### **Facilitation tips**

If anyone has been involved in data collection – invite the participant to briefly share/reflect on their experience and then use this example to illustrate the key points below about the training experience and its importance.

**Explain** that standard interviewing best practices apply to questions related to disability and are on Slide 15 (and listed below).

- Interviewers should ask the questions as they are written. They should not improvise.
- Interviewers should not use the term ‘disability’ at any point during data collection unless it is explicitly written as part of the question.
- Interviews should make sure the respondent answers each question and not assume a response from observation.
- If the interviewer is uncomfortable, the respondent will be too – so interviewers need to be familiar with the material and be relaxed.
- Training in interviewing persons with disabilities should be part of standard interviewer training for all data collections (not just those related to disability).

## **Slide 16: Data collection with persons with disabilities**

### **Facilitation tip**

**Invite a person** to briefly share/reflect on their experience as a person with a disability when data was collected about them, and use this story to prompt and reflect on the points below around data collection with persons with disabilities.

### **Instructions**

**Remind** participants that a component on how to interview/include persons with disabilities should be part of all interview training, regardless of whether the person has a disability or the type of data set.

**Data collection procedures** should be accessible so persons with disabilities can participate themselves – this is good practice in all data collection.

**There are a variety of reasons** for using a proxy rather than the individual as the respondent to a data collection. Examples of proxies are someone in the household, such as the household head, who is responding for all persons in the household, or a mother responding for her children.

**Obtaining information** from the individual should be done where possible. If not possible and a proxy is used, an explanation should be provided by the interviewer.

## Slide 17: Summary of key points

### Instructions

Review the major points of the session, which include:

- There are multiple sources of data on disability – all have advantages and disadvantages.
- The data source should be appropriate for the intended use and the data should meet basic quality standards.
- Well developed and tested questions are necessary, but not a sufficient requirement for good data – appropriate training and administrative procedures must be in place.

Some countries have little, none or poor-quality formal sources:

- i. Need to advocate for these.
- ii. Understand how these can be supplemented with other sources for good advocacy – acknowledging the limitations.

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## Slide 18: End of session

### Instructions

**Remind participants** to fill out the individual reflection sheet.

**Participants are asked** to reflect 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 about your country:
  - 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 have learned?

### Background reading/additional resources for facilitators

- [Resources for Data Users](#)



# 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](#)



# 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.</p> <p>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.</p> <p>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>



# Session

# 6

Facilitators guide  
Summary  
Handout

# How to advocate for better data

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

1. Identify data needs and review available data for CRPD, SDGs and other frameworks.
2. Explore how to meet data gaps, including through citizen-generated data.
3. Begin developing a plan to advocate for better data.

## Prerequisite learning/knowledge

- Sessions 1 to 5
- The CRPD and 2030 Agenda for Sustainable Development

## Key messages to be conveyed

- The CRPD and the 2030 Agenda mandate countries to collect and disaggregate disability data, yet significant data gaps remain that prevent achieving full CRPD and SDG implementation.
- The lack of data on persons with disabilities increases marginalisation and fails to address the situations 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.

## Preparation

- Review the Session 6 PowerPoint slide set, summary, and guide.
- Review an example of citizen-generated data from the [LNOB Partnership](#).
- Read the Pacific Disability Forum case study on pages 18 to 19 of the [Disability Data Advocacy Toolkit](#).
- Review the handout from Session 1 on disability data references in the 2030 Agenda.

## Resources and handouts

- Session 6 Slides 1 to 17
- Handout – Session 6 Summary for participants
- Recommended reading:
  - Share information about the Stakeholder Group of Persons with Disabilities' [Disability Data Advocacy Working Group](#).
  - Adapt as relevant and share relevant data resources from the national context.

# Detailed plan and methodology

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## Slide 1: (Session title slide) How to advocate for better data

## Slide 2: (Section title slide) Session overview

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### Step 6.1: How to advocate for better data

**Timing:** 30 minutes

**Objectives:**

- Review data in the context of the CRPD and 2030 Agenda.
- Learn ways to determine what data are missing.

Required materials: Slides 1 to 15

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## Slide 3: Overview of session

**Instructions**

**Introduce** the topic and contents of the session.

**Explain** that this session will:

- Provide information on how to advocate for better data.
  - Examine what data is required to monitor global frameworks and to determine when this data is missing.
  - Build on all previous sessions and prepare for building an action plan in Session 8.
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## Slide 4: (Section title slide) How to advocate for better data

## Slide 5: Data collection requirements

**Instructions**

**Remind participants, as noted in the Session 1**, the CRPD and the 2030 Agenda (SDGs) require countries to collect and disaggregate disability data. These requirements are summarised on Slide 5 and below.

**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.
- **Discuss whether the participants' country has ratified the CRPD and the national laws that exist post-CRPD ratification.**

## **2030 Agenda (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.
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## **Slide 6: Disaggregation helps us determine whether we are meeting the CRPD and SDG objectives equally**

### **Instructions**

**Remind** participants of the definition of **disaggregation**: Identifying persons with disabilities **within** the data collected to measure whether an indicator (such as rate of employment, or education) is being met.

Disaggregation enables us to separate the rate for those with and without disabilities, to determine whether the indicator is achieved **equally** between these groups. If the bars, or rates, are not equal, then the CRPD and SDG objectives of equality and inclusion are not being achieved in relation to that indicator, and further advocacy work is required to secure the policies and programmes to improve this.

Slide 6 repeats an earlier slide indicating how disaggregation can help determine if the CRPD and SDG objectives are being met equally, using employment as an example. The bar graph indicates that those without disabilities are employed around 50% more than those with disabilities by around 50%.

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## **Slide 7: Why are there disability data gaps**

### **Instructions**

**Explain** that despite the importance of and requirements for disaggregated disability data, it is still often not collected.

1. Why have governments not prioritised disaggregated data on persons with disabilities?
2. Why do we still have serious gaps in this area?

**Explain** why there are disability data gaps. These are listed below and summarised on Slide 7.

- It is a combination of lack of disability training and awareness in National Statistics Offices (NSOs) and, most importantly, lack of political will. Often persons with disabilities are not a priority for governments and as a result get left behind.
- There is a lack of disability awareness and attitudinal barriers from officials at all levels.
- Sometimes disability data is held to a higher standard and at times NSOs face challenges on how to identify disability in data collection.
- Also, disability data can get lost in ministries since disability data 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 its collection.

**Explain** what needs to be done to close disability data gaps. Solutions (as listed on the slide) include:

- NSOs need increased capacity, awareness training, and support to be proficient at collecting disability data.
  - There are resources to support this such as the ones developed by the Washington Group on Disability Statistics.
  - Ministries need to demand that disability data be collected across ministries in line with the CRPD and the SDGs.
  - **The CRPD and SDGs can be useful frameworks for advocating for better data collection.** Explain that we will now focus on these in turn.
- 

## Slide 8: CRPD implementation and data collection

### Instructions

**Ask** participants to discuss what their government is doing to collect data as obligated by the CRPD?

**Use the suggestions** summarized on the slide and listed below to identify ways they can find out about data in their country:

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

## Slide 9: CRPD reports and data

### Instructions

**Advise** participants that following on from the previous suggestions, you should also check the different CRPD reports and discussions in relation to your country around data.

**Some suggestions** focusing on **CRPD reports** include:

- 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 there are recommendations included on disability data.
  - Formulate advocacy messages from the CRPD Committee's recommendations on data and other related areas.
-

## Slide 10: Example of CRPD recommendation to improve data collection - Australia

### Instructions

Inform participants that we will now apply the suggestions regarding CRPD reporting, using an Australian example:

**In Australia's CRPD report:** There is the “absence of national data disaggregated by disability at all stages of the criminal justice system, including data on the number of persons ‘unfit to plead’ who are committed to custody in prison and other facilities.”

**CRPD committee recommendation** to address this gap: Collect data disaggregated by disability, age, gender, location, and ethnicity at all stages of the criminal justice system, including on the number of persons unfit to plead who are committed to custody in prison and other facilities.

**Advocacy message:** Disaggregated data on disability, age, gender, location, and ethnicity are important for understanding the population of persons with disabilities held in custody.

#### Facilitation tip

**Ask participants for examples from the local context.** Are they aware of any data recommendations from CRPD reports (government or shadow)? How can these be shaped into advocacy messages for improved data?

## Slide 11: Data and SDG Implementation

### Instructions

**Remind the group** that the 2030 Agenda mandates countries to collect and disaggregate disability data. As noted on the slide

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 and the lack of harmonisation of data on persons with disabilities increases marginalisation and subsequent failure by governments to address the barriers and discrimination encountered by persons with disabilities.

**Also note that, often the** data collected does not include barriers faced by persons with disabilities.

**Remind participants** that if questions to identify the population with disabilities are included in all core data systems it will be possible to disaggregate all the indicators collected by this system – not just those related to poverty and employment (which are currently covered). Advocating for the inclusion of questions to identify the population with disabilities will provide much needed data to address marginalisation.

## Slide 12: Citizen-generated data

### Instructions

**Remind** participants that citizen-generated data was briefly introduced in Session 1.

Explain that one solution to addressing disability data gaps is **citizen-generated data**. Citizen generated data is:

- Increasingly recognised as a complement to official statistics to measure progress of those most left behind in the SDGs.
- Defined as data that people, or their organisations, produce on issues that affect them (e.g., measuring the SDGs).
- Generated in several ways, including surveys, texts, phone calls, emails, reports, storytelling, and social media.
- Found in different forms including quantitative or qualitative, structured or unstructured, openly available or collected or closed.
- Used to directly monitor, demand or drive change.
- A useful complement to institutional data, not a replacement for it.

**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. For more information, read the LNOB Partnership and refer to the LNOB Partnership case study on pages 29-31 of the Disability Data Advocacy Toolkit.

#### Facilitation tip

Ask participants about their involvement in SDG monitoring locally or any examples of citizen generated data they may have been involved in. Prompts can include things like OPD membership surveys, case studies of the experiences of children in schools, etc.

## Slide 13: Advocating for better data in the Pacific

### Instructions

**Explain** that it is helpful to learn from the experience of others, so we will turn now to an example from the Pacific Disability Forum (PDF). For additional information read the Pacific Disability Forum case study on pages 18-19 if the Disability Data Advocacy Toolkit.

The Pacific Disability Forum learned the following lessons around Disability Data Advocacy, which are summarised on Slide 13.

- Use the CRPD and SDGs to drive advocacy messages on why disability disaggregated data is important.
- Ensure joint analytical processes that strengthen commitment to disability inclusion from government stakeholders. This step requires additional resources but should be included where possible.
- Form good partnerships with the organisations undertaking the work, including through tripartite partnership arrangements.

- Have a long-term view – in some settings, it has taken over two years of advocacy efforts to get the WG-SS included in the national census.
- Continue advocating for the collection of other information not provided by the WG-SS in population surveys, such as barriers to participation and support needed.

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## Slide 14: (Section title slide) How to advocate for better data using the CRPD and the SDGs

### Step 6.2: Activity on advocating for better data

**Timing:** 45 minutes (5 minutes introduction, 25 minutes for work, 15 minutes for plenary discussion and closing)

**Objectives:** Participants will develop a plan to advocate for better data.

**Required materials:** Slides 14 to 15

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## Slide 15: Activity

### Instructions

**Share** the activity handout with participants.

**Emphasise** that this is a brainstorming exercise to start developing data advocacy objectives and action plans. Today's activity is **based on what they now know**, acknowledging that further research would need to be done in many instances for more refined objectives. It is not meant to be completed at this time, rather starting to practice what has been learned. We are starting to get some ideas down in this session and will revisit this in the final session.

**Decide** to do the exercise in plenary or small groups. If plenary is greater than 10 people, break into smaller groups of 5-8 people each. Ensure each group has a timekeeper, notetaker, rapporteur, and facilitator.

**Provide** the following instructions to participants (also included in the handout):

#### 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 toward 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 the 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 (prompt questions below):**
1. Who do you need to influence?
  2. What changes to data would you like to see?
  3. Who might you work with?

#### **Facilitation tip**

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.

**Debrief** the activity in plenary.

**Facilitate discussion**, trying to draw out the following key points:

- Who are the key people, ministries, or offices to influence (e.g., NSO)?
- What specific actions, collaborators, and key messages would you include?
- What steps would you take to engage?
- Why is this data important?

#### **Facilitation tip**

**Notes should be shared** by the facilitator at the end of the session as a resource for the final session of the workshop.

## **Slide 16: Summary of key points**

### **Instructions**

End the session with a recap of the following key summary points:

- The CRPD and the 2030 Agenda mandate countries to collect and disaggregate disability data, yet significant data gaps remain that affect achieving full CRPD and SDG implementation.
- Lack of data on persons with disabilities increases marginalisation and the government then fails to address the barriers and discrimination encountered by persons with disabilities.
- Citizen-generated data is increasingly being recognised as a complement to official statistics.

## Slide 17: End of session

**Ask participants** to fill out the individual reflection sheet.

**Participants are asked** to reflect 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 about your country:
  - 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 have learned? •

### Background reading/additional resources for facilitators

- Share information about the Stakeholder Group of Persons with Disabilities' [Disability Data Advocacy Working Group](#). Join [the disability data listserv](#) to engage in a platform of exchange.
- 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 case study on the LNOB Partnership in the [disability data advocacy toolkit](#) on pages 29-31.
- As an example of OPD-led advocacy for better data, read the Pacific Disability Forum case study in the [disability data advocacy toolkit](#) on pages 18-19.



# 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 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](#).



# 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.

# Session

# 7

Facilitators guide  
Summary  
Handout

# OPDs role in advocacy using data

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

1. Understand ways to use data for evidence-based advocacy.
2. Explore OPD roles in data collection and use.
3. Explore the use of data in local advocacy objectives.

## Prerequisite learning/knowledge

- Sessions 1 to 6

## Key messages to be conveyed

- 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, and 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.

## Preparation

- Facilitators should review Sessions 1to6 prior to this workshop, especially Session 2 on disaggregation.
- Review 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.
- If the country has submitted a state report and shadow report to the CRPD committee, review this and see how data was used (or not) on either report or how this could be strengthened to aid discussion.
- Review the [Disability Data Advocacy Toolkit](#) (available in various formats and languages).
- Read the blog with an example of OPD-led data advocacy by UDPK (Kenya): [Persons with disabilities and data inclusion](#).
- Look at the [Voluntary National Review Toolkit for OPDs](#) that has examples of advocacy actions for OPDs at the national, regional, and global levels.

## Resources and handouts

- Session 7 Slides 1- to 22
- Recommended reading:
  - Review the [identified 32 critically important SDG indicators](#) to be disaggregated by disability.
  - Review the [Disability Data Advocacy Toolkit](#) in various formats and languages.
  - Read the blog with an example of OPD-led data advocacy by UDPK (Kenya): [Persons with disabilities and data inclusion](#).

# Detailed plan and methodology

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**Slide 1: (Session title slide) OPDs role in advocacy using data**

**Slide 2: (Section title slide) Session overview**

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**Slide 3: Overview of session**

## Instructions

Introduce and explain that, as outlined on Slide 3, the session will:

- Provide information on how to advocate using data.
- Review approaches for supporting advocacy messages with strong data-based evidence with a focus on official data.
- Understand how to create and present advocacy objectives with data.
- Provide lessons learned and examples of data advocacy steps that can be taken.

## Step 7.1: How we can advocate using data

**Timing:** 20 minutes

**Objective:** Participants will review approaches for supporting advocacy messages with strong data-based evidence with a focus on official data.

**Required materials:** Slides 4 to 9

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**Slide 4: (Section title slide) How we can advocate using data**

**Slide 5: Building advocacy messages**

## Instructions

**Explain** how data is used to build advocacy messages, as summarised on the slide and outlined below. Data is commonly used in advocacy messages to:

- Showing patterns or where change is needed.
  - Highlighting a key point, often a shocking situation.
  - Overcome stigma and discrimination.
  - Demonstrate the effectiveness of interventions.
  - Shareg stories and highlighting experiences.
-

## **Slide 6: Disaggregation helps us determine whether we are meeting the CRPD and SDG objectives equally**

### **Instructions**

**Outline** the following reasons why organisations of persons with disabilities should use data in advocacy, as summarised on the slide. Provide examples from local context where relevant.

**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 linked with the CRPD and the 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 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.

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## **Slide 7: How can OPDs use data to monitor the CRPD?**

### **Instructions**

**Review the CRPD reporting processes, introduce the role OPDs can play in using data to monitor the CRPD:** The CRPD Committee requires States to report periodically on their progress in implementing the CRPD. Civil society organisations, including OPDs, can submit a shadow report to highlight gaps in the State report or to flag concerns to the CRPD Committee. OPDs should monitor the use of data reported by their government to the CRPD Committee and should use data in their shadow reports to hold their government to account.

**Outline** the actions OPDs can take below in their CRPD shadow reporting processes as summarised on the slides and below, drawing on examples wherever possible from the local context to illustrate.

**Review** the [Reporting Guidelines](#) 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. The government should make a draft of the State report available to OPDs before submitting it to the CRPD Committee.

- a. 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.
- b. 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.

- a. 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.
- b. It can be data not requested by the Reporting Guidelines, such as the number and percentage of schools with accessible WASH facilities.
- c. 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.

#### **Facilitation tip**

Ask participants if anyone has been involved in CRPD shadow reporting mechanism before. Ask how they were involved in analysis of gaps, identifying other data sources, etc, and invite them to share any lessons from their experience.

## **Slide 8: What do the SDG indicators mean for OPD advocacy?**

### **Instructions**

**Explain** that the global SDG indicator framework has two significant features that can help OPDs create advocacy messages, which are outlined on the slide. The SDG Indicator Frameowrk:

1. **Requests** that governments disaggregate any relevant SDG data by disability.
2. **Specifies** 11 disability-inclusive indicators that measure the SDGs.

Remind participants that The global indicator framework clearly states that "...SDG 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".

**Share an example** of an SDG indicator that can be disaggregated by disability without disability being explicitly included. An example from [Disaggregation by Disability Status: A Report on Selected Sustainable Development Goal \(SDG\) Indicators](#) is provided below.

- SDG 7.1.1: "Proportion of population with access to electricity" can be disaggregated by disability.
  - An example of this is: "Access to electricity disaggregated by disability status and sex for population 15 years and older."

## **Slide 9: How can OPDs use data to monitor the SDGs?**

### **Instructions**

**Explain as outlined on the slide, OPDs can take the following steps** to use data to monitor if and 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 11 disability-inclusive indicators, the call for disaggregation of data by disability, and [availability of current and future indicators that disaggregate data by disability](#). This continues to be updated.
- Review the [identified 32 critically important indicators](#) that are recommended by OPDs and allies to be disaggregated by disability.
- 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. OPDs have an important role to play in highlighting persons with disabilities as a group that has been left behind.
- Engage in national SDG Forums, regional SDG forums and the global High-level Political Forum to continue to push for improvements to disability disaggregated data and to fill disability data gaps in achieving the SDGs.

#### **Facilitation tip**

Ask participants if anyone has been involved in using or reviewing Agenda 2030 reporting as it relates to disability. Ask what they did and invite them to share any lessons from their experience.

### **Step 7.2: Building evidence-based advocacy**

**Timing:** 10 minutes

**Objective:** Understand how to create and present advocacy objectives with data.

**Required materials:** Slides 10 to 13

### **Slide 10: (Section title slide) Building evidence-based advocacy**

### **Slide 11: Possible steps for using official data for advocacy**

#### **Instructions**

**Explain** that the following steps outline the ways OPDs can use data to inform their advocacy, and are summarised on the slide:

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.

## Slide 12: Disaggregated data in advocacy – an example

### Facilitation tip

Use this as an opportunity to check understanding of disaggregation, but asking first what they remember about disaggregation. Then read through the example below and on the slide allowing space for discussion as you believe is needed to ensure common understanding.

### Instructions

Explain this slide gives a quick refresh on why disaggregated data is useful to advocacy, using the employment example from Session 2.

- SDG 8 aims for full employment for all. SDG 8.5.2 disaggregates by disability, by examining “Unemployment rate, by sex, age and persons with disabilities.”
- Looking at the difference in employment rates between persons with and without disabilities helps us identify whether the SDG and CRPD objectives of equality and inclusion are being achieved, and if not, by how much.
- Recall Sessions 2–3 where we discussed that in order to make this comparison the group of persons with disabilities needs to be:
  - a. Identified within the entire population measured.
  - b. Clearly defined, so that we are correctly identifying persons with disabilities.
    - This is important, as changes to the prevalence rate/size of the group of persons with disabilities within the general population will affect **employment rates** associated with that group from the data, and therefore the size of the inequality that the data identifies between those groups.
- **It is also important** to address all aspects of inclusion for persons with disabilities to ensure the outcomes. For example, inclusion of persons with disabilities in employment.
- **Once the gap is demonstrated** it needs to be monitored, and if the gap does not close over time, advocacy is needed.

## Slide 13: Building advocacy messages with data

### Facilitation tip

To be more interactive and draw on participants experience, ask them what they think are the characteristics of good evidence-based advocacy messages before showing Slide 13.

### Instructions

**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 is defined and compare with your data supporting your advocacy messages.

### **Step 7.3: OPDs and their role in the collection and use of data**

**Timing:** 15 minutes

**Objectives:**

- Participants will begin to apply relevant knowledge and skills on disability data in their local context.
- Participants will learn about data advocacy challenges and solutions from other OPDs.

**Required materials:** Slides 14 to 17

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### **Slide 14: (Section title slide) OPDs and their role in the collection and use of data**

#### **Slide 15: OPDs and data collection and use**

**Explain** that this is a reminder that OPDs should be leading discussions and advocacy activities around disability data and should be meaningfully included in all stages of the process (planning, implementation, and monitoring).

**OPDs should also advise** government agencies on what they should be collecting and how to interpret the data.

**The following slides** present some lessons learned from OPDs around using data in advocacy.

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### **Slide 16: OPDs and data collaboration**

#### **Instructions**

**Highlight** the importance of collaborative data efforts, as outlined below and summarised on the slide.

- Data collaboration with other stakeholders can encourage the generation and use of citizen-generated data, which can complement official statistics to measure progress for persons with disabilities in the CRPD and SDGs.

- You can collaborate with other OPDs, governments, subnational and regional bodies, development partners, local communities, other civil society organisations, national human rights institutes, national SDG forums, universities, researchers, the media, and the private sector, which all have a role in the development of strong data ecosystems.
- OPDs that are meaningfully included in these collaborations can ensure that the data ecosystems are inclusive and representative.
- Data partnerships strongly benefit from an atmosphere of co-creation and co-ownership, in which partners jointly design their goals and apply methodologies together at the peer level.
  - Data co-creation is when civil society organisations (or other stakeholders) and 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 ensures 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.

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## Slide 17: Data advocacy challenges and solutions in Kenya

### Instructions

Explain we will now talk through an example of how disability data challenges in Kenya were addressed through data advocacy. This is also summarised on the slide.

These challenges and solutions regarding disability data were identified by an umbrella OPD from Kenya, United Disabled Persons of Kenya (UDPK).

**Lack of disaggregated data:** It has not been possible for the OPD to access data needed for advocacy from the KNBS (statistics bureau).

– **Solution:** The OPD engaged and collaborated with other partners to collect disability data. Link this to the points from the previous slide.

**Inaccessibility of key government officials:** Initially it was a challenge to set up a call with needed officials in the government.

– **Solution:** The OPD found and engaged with key people in different departments and built their relationships from there.

**Data-driven advocacy:** The key advocacy issues were not initially guided by data.

– Solution: The OPD formulated data-driven advocacy strategies for more effective advocacy outcomes.

**Resources/environment:** There were not enough resources to hold advocacy activities and engagements.

– **Solution:** The OPD focused on specific issues for a fixed amount of time, then sought out more partners, and diversified approaches for advocacy.

**Information unavailable:** Some information needed to formulate advocacy strategies were not readily available.

– **Solution:** The OPD engaged in data mining and research.

## Step 7.4: Possible advocacy actions

**Timing:** 10 minutes

**Objectives:**

- Participants will gain ideas on possible advocacy actions to take.

**Required materials:** Slides 18 to 19

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### Slide 18: (Section title slide) Possible advocacy actions

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#### Slide 19: Possible advocacy to NSOs

**Instructions**

**Explain** that participants will learn some advocacy ideas and reflect on applying these in the local context, which will be taken further in the following activity. This will be built into a draft action plan that will be the focus of Session 8.

**Read** the advocacy ideas for engaging with NSOs as outlined on slide 19 to improve your country's disability data:

**Collaborate with other OPDs**, including the national OPD umbrella:

- Establish a collaborative plan toward developing a data advocacy strategy.
- Include allies working on disability rights and disability-inclusive development to create synergy and to avoid duplication.

**Develop a joint advocacy paper:**

- Share action-oriented recommendations on what your government should achieve for persons with disabilities.
- Link the recommendations with CRPD Articles and the SDGs.
- Produce a brief and long version: the long version should contain critical issues and the brief version should prioritise the three main issues for persons with disabilities.

**Use social networks and media** to promote advocacy messages.

**Collaborate and partner with other stakeholders:**

- Data collaboration** helps fill data gaps by encouraging the generation and use of alternative data like citizen-generated data or human rights data, which can complement official statistics.
- Explain that OPDs can collaborate with other OPDs (as mentioned above), governments, subnational and regional bodies, development partners, citizens and local communities, other civil society organisations, national human rights institutes, national SDG forums, universities, researchers, the media, and the private sector, to partner for inclusive data.
- For example, it may be helpful to work in **partnership with national human rights** institutes that may have data on violence, discrimination or barriers to inclusion. From a political point of view, it gives political support to strengthen an OPD's role in advocacy using data. For example, in Indonesia the national commission on women's anti violation may have data on violence against women with disabilities.

## **Build coalitions**

- Connect with other stakeholders (refer to above), such as national civil society organisations to build coalitions with unified messages, and provide strategic opportunities to engage, learn, and exchange information.
- Connect with the UN at the country level. This is helpful around the SDGs since the UN is mandated to support SDG implementation.
- The UN can serve as a bridge to connect government and civil society in data collection on CRPD and SDG implementation and other areas.

## **Meet with the NSO**

- Present advocacy recommendations and share knowledge on the availability of international standards for collecting data on persons with disabilities.
- Follow up to ensure your requests are addressed.
- Offer disability awareness training to NSOs and enumerators.
- Carry out capacity building workshops on effective data collection with NSO technical staff.

## **Step 7.5: Activity on data advocacy actions**

**Timing:** 30mins (25 minutes for work, 5 mins for feedback in plenary if required)

### **Objectives:**

- Participants will brainstorm on possible data advocacy actions that can be carried out locally.

**Required materials:** Slides 20 to 21

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### **Slide 20: (Section title slide) Data advocacy actions**

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### **Slide 21: Activity – identify opportunities and challenges for the advocacy objectives of your OPD**

#### **Instructions**

**Ensure** participants have a copy of the Session 7 Activity handout.

**Explain** that this activity will help you begin to reflect on what data is required to support progress toward the advocacy objectives you identified in Session 1, and what actions your OPD could begin to take around this.

**Split participants** into groups of 5 to 8 people. Each group needs to have a timekeeper, notetaker, rapporteur, and facilitator.

**Provide the following instructions** to participants (also included in Slide 21). They should take 20-25 mins for this activity.

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?

**Debrief** from the activity in plenary for 5 minutes

- Facilitate discussion, trying to draw out participants' understanding of their advocacy objectives, how data can be used to support this, and where they may need to advocate for better data to do so.
- Each group reports back. Focused on 2 key points at most as per instructions in their activity handout. There is a main notetaker taking down the points and consolidating similar themes amongst all groups.

### Facilitation tip

Ensure the groups stay on time and start to put together steps and actions that can be formulated into an action plan in Session 8.

## Slide 22: End of session

### Instructions

- **Ask participants** to fill out the individual reflection sheet.
- **Participants are asked** to reflect 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 about your country:
    - 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 have learned?

### Background reading/additional resources for facilitators

- Washington Group: [Disaggregation by Disability Status: A Report on Selected Sustainable Development Goal \(SDG\) Indicators](#)



# 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.



# 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.

# Session

# 8

Facilitators guide  
Handout

# Drafting an action plan and closing

Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

## Session objectives

In this session, participants will:

1. Begin drafting a collective action plan to help them advance disability data advocacy in their country.
2. Demonstrate some key learnings from across the programme.

## Prerequisite learning/knowledge

- Sessions 1 to 7.
- Draft advocacy and data advocacy objectives developed and refined in earlier sessions.
- Individual reflection worksheets.

## Key messages to be conveyed

- OPDs can and should advocate for and help improve the available data.
- OPDs can use data to influence for change (policy, investment etc.) in their country, by providing evidence of:
  - Whether persons with disabilities are included.
  - If persons with disabilities experience progress in realising their rights in line with others.
  - The barriers to inclusion and progress for persons with disabilities.
- Initial discussions and planning today are part of an ongoing dialogue and opportunity to link to other allies.
- Participant's feedback will help refine the package for use by other OPDs – so honest and constructive feedback is appreciated.

## Preparation

- Note there are no slides for this session.
- Make sure participants have the relevant templates and resources sent to them in advance of the session.
- Prepare any breakout groups in advance and brief small group facilitators. Make sure they are clear on their role as outlined in the Draft Action Plan Template worksheet.

## Resources and handouts

- Worksheet – Draft Action Plan template and instructions
- Completed worksheets – Individual Reflection
- Please note there are no slides or summary handouts for the closing session

# Detailed plan and methodology

## Step 8.1: Context and next steps

**Timing:** 5 minutes

**Objective:** Participants recognise the positioning of today's draft action plan within the ongoing dialogue around disability data advocacy.

**Required materials:**

- Draft Action Plan template and instruction worksheet

**Instructions**

**Outline that in today's session** we will begin drafting an action plan to advance some of the learning from the workshop locally.

**Refer to the Draft Action Plan template worksheet.**

- Ask participants to locate the Action plan template and their completed Individual Reflection worksheets.
- **Point out** that the instructions for the next activity and the template to use are on that Draft Action Plan template worksheet.
- Highlight that this template is just a resource **to start discussions** about applying what they have learned through an action plan, there is no expectation to complete every column today. The focus will largely be on the objectives, actions and timelines.
- Aim to **agree on next steps** by the end of the session to keep the conversation going.

## Step 8.2: Activity – Beginning to draft an action plan

**Timing:** 60 minutes

**Objective:**

- Begin drafting a collective action plan to help them advance disability data advocacy in their country.
- Participants will propose next steps for revising the action plan.

**Required materials:**

- Worksheet – Draft Action Plan template and instructions
- Completed worksheets – Individual Reflection
- Draft responses from activities in earlier sessions (especially Sessions 1, 5, and 7)

**Instructions**

**Highlight the resources they have available** including their Individual Reflection worksheets, their preliminary thinking on advocacy objectives and resources from earlier sessions, and a Draft Action Plan template to aid them in their collective discussions.

**This activity can be done** in plenary or small break-out groups, depending on the number in a plenary session. To ensure everyone gets a chance to include their thoughts, aim for working groups of a maximum of 6-8 people.

**Appoint/confirm** a notetaker/chair (for each group) to record discussions and fill out the Draft Action Plan template. If more than one group is required, all groups will work on the same activity.

**Provide the instructions** to participants (listed below and included in the Draft Action Plan):

1. Choose a notetaker and facilitator if one has not already been nominated.

2. Complete the Draft Action Plan template.

3. Each participant should refer to their Individual Reflection worksheets from previous sessions to help prompt contributions and discussion.

**1. Begin with the objectives/change areas and the strategies that might be used to achieve these (10 minutes):**

- a) Review and discuss the draft advocacy objectives and strategies you developed in previous sessions.
- b) Consider any new high-level objectives specifically about improving the data, e.g., ideas that might have emerged in Session 5.
- c) List these change objectives and strategies at the top of the table. Don't worry about trying to get the perfect wording.

**2. Move to the action component of the table. This is about starting a 'to-do' list of things arising from this workshop that you need to do to help refine and action an evidence-based advocacy strategy (40 minutes):**

- a) Invite individual participants in turn to share actions that they think could be taken to use data to help meet these local advocacy objectives.
- b) The answers from Question 2 on the Individual Reflection worksheets may help, as will content from earlier workshop sessions. Note any actions that need to be taken to have stronger evidence-based advocacy objectives and related strategies. Some of the actions could be about things you need to learn or find out to address current knowledge gaps (e.g., find out what non-census data exists, or if persons with disabilities are part of data collection processes).
- c) Invite discussion and feedback on the suggestions within the group to ensure common understanding and some agreement.
- d) Try to ensure each group member has a chance to provide input.
- e) Write answers in the table, completing as many columns as possible – allocating timelines, persons responsible, etc. It's okay if there are blank spaces, at least get some actions down.

**3. As a wider plenary group**, spend 15 minutes discussing next steps. If small groups were used, invite people in plenary to share their objectives and two key actions as instructed and facilitate a discussion, i.e., How do others feel about this action? Did others have this? Does it make sense? Does it seem a priority action to others? Who do we think should do it?

### **Facilitation tip**

It's a good idea to brief a notetaker/facilitator ahead of the session, or you can facilitate this yourself if you decide to do this in a plenary format.

If more than one group is required, reduce the time you spend working on the action plan to 40 minutes to allow more time for discussion.

Discuss next steps with participants. The aim is to keep momentum on actioning the learnings locally after the workshop.

- Ask the notetakers to clean up their notes and share with the facilitators so all draft action plans can then be shared with the wider group.
- Work together to start trying to consolidate and refine these into a collective action plan.
- Set meeting dates for next steps:
  - Meet to refine plan and work on some key actions.
  - Meet to discuss priorities and actions with local key stakeholders and other allies.

## **Step 8.3: Reflection activity and closing**

**Timing:** 25 minutes

**Objectives:**

- Participants can demonstrate some key learnings from across the programme.
- Participants give feedback to refine the workshop programme.

**Required materials:**

- Individual Reflection worksheets.
- (Optional - see facilitation tip): Use Menti or another online whiteboard or word cloud option. Make sure this is accessible for all participants.

**Instructions**

**For the reflection activity, invite each participant** to share with the group three key learnings/takeaways and one personal action they commit to taking forward as an outcome of this workshop. Participants can use their Individual Reflection worksheets as reminders/prompts.

- Participants can share these in chat or in person.
- Briefly discuss and use these reflections to reinforce and clarify key learnings with the wider group.
- If desired, write them down on a whiteboard to share with participants.

### **Facilitation tip**

If you have access to or are familiar with more interactive and accessible options for different online platforms (e.g., Menti or word cloud generators), then set these up in advance of the session using the same questions.

Close the session by thanking people for the participation, sign language interpreters, captioners, hosts, and so forth.

- Acknowledge that the content and online participation can be a challenge and give thanks for their engagement.
- Reinforce the need to apply the learning and that this is the start of the conversation.
- Consider a final activity to closes the session on a positive note (e.g., each person says thank you, something they learned, and one thing they are grateful for).

### **Background reading/additional resources for facilitators**

- [Disability Data Advocacy Toolkit](#) in various formats and languages



# Activity: Draft Action Plan

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

### Instructions

1. Choose a notetaker and facilitator if one has not already been nominated.
2. This activity involves completing the Draft Action Plan template below.
3. Each participant should refer to their Individual Reflection worksheets from previous sessions to help prompt contributions and discussion.

**1. Begin with the objectives/change areas of your OPD and the strategies that might be used to achieve these (10 minutes):**

- a. Review and discuss draft advocacy objectives and strategies you developed in previous sessions.
- b. Consider any new high-level objectives specifically about improving the data. For example, ideas that might have emerged in Session 5.
- c. List these change objectives and strategies at the top of the table. Don't worry about trying to get the perfect wording. The general concept is fine for now.

**2. Move to the action component of the table. This is about starting a 'to-do' list of things arising from this workshop that you need to do to help refine and action an evidence-based advocacy strategy (40 minutes):**

- a. Invite individual participants in turn to share actions that they think could be taken to use data to help meet these local advocacy objectives.
- b. The answers from Question 2 on Individual Reflection worksheets may help, as will content from earlier workshop sessions. Note any actions that need to be taken to have stronger evidence-based advocacy objectives and related strategies. Some of those actions can be about to fill gaps in your knowledge, like things you need to learn about or investigate (e.g., find out what non-census data exists, or if persons with disabilities are part of data collection processes).
- c. Invite discussion and feedback on the suggestions within the group to ensure common understanding and some agreement.
- d. Try to ensure each group member has a chance to provide input.
- e. Write answers in the table, completing as many columns as possible – allocating timelines, persons responsible, etc. It's okay if there are blank spaces, at least get some actions down.

- f. Try to prioritise a few key actions as you go through for report back to the wider group.

**3. As a wider plenary group, spend 15 minutes discussing next steps as guided by the facilitator.**

- a. You should come prepared to identify your high-level objectives and two actions you will prioritise to address these.

**Group members names:** \_\_\_\_\_ **Date** \_\_\_\_\_

## Action Plan:

### High-level advocacy/change objectives:

1. List high-level objective
    - a. List some strategies to bring these about (e.g., lobbying X minister, CRPD shadow report, investigate x data source further for quality, etc.)
  2. List high-level objective
    - a. Strategies
  3. List high-level objective
    - a. Strategies
  4. List high-level objective
    - a. Strategies

### **Proposed next steps to refine and pitch the action plan:**

Suggest a date and any additional participants that may be needed to help combine and refine the action plan.

## **Activity: Draft Action Plan**

Session 8: Disability Data Advocacy Workshop for Organisations of Persons with Disabilities

