Disability Data advocacy toolkit

Stakeholder Group of **Persons with Disabilities** for Sustainable Development

International Disability Alliance

cbm global disability inclusion

Acknowledgements

Contents

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Foreword

Dr. Vladimir Cuk, Executive Director, The International Disability Alliance

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.

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 (UNCRPD)[1] under Articles 4 and 31. This is further strengthened by the political commitments by 193 countries that committed to collect data on persons with disabilities and to disaggregate data by disability by adopting the 2030 Agenda for Sustainable Development and the global indicator framework that provides a guide on what data is needed to measure the implementation of the Sustainable Development Goals (SDGs). Yet, overall official disability data is not reaching the global level to measure the SDGs and this must be addressed.

Data is critical for the realization of the UNCRPD at the country level since the lack of data on persons with disabilities increases marginalization and fails to address the situation and discrimination encountered by persons with disabilities. As a result, planning and budgeting for reasonable accommodations with effective policymaking have suffered and persons with disabilities have largely fallen off the statistical "map."

Evidence-based data on persons with disabilities at the national and global levels are instrumental in identifying the gaps and challenges of persons with disabilities that can support policymakers to address gaps and amend existing policies and regulations.

In the past few years, there have been significant advocacy efforts carried out on data and persons with disabilities. Such efforts include the following achievements:

- In 2017, International Disability Alliance, the International Disability and Development Consortium, and the Stakeholder Group of Persons with Disabilities, in consultation with UN agencies, identified 32 critically important indicators that should be disaggregated by disability in order to gain data on the situation of persons with disabilities worldwide.

- In 2018, in response to a request from the UN Statistics Division, the Stakeholder Group of Persons with Disabilities identified key policy priority areas for persons with disabilities: poverty eradication, education, employment, health, and accessibility.

[1] The 2030 Agenda for Sustainable Development: paragraph 48, paragraph 57, and Goal 17.18; CRPD Article 31; and GA resolution A/RES/71/313

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- Emerging from the aforementioned efforts, in 2019, the Inter-agency and Expert Group on SDG Indicators (IAEG-SDGs) submitted a background document to the 50th session of the UN Statistical Commission on Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans. Disability data is strongly included in the document, including the availability of current and future indicators that disaggregate data by disability (15 additional indicators).

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

It is imperative to build on the aforementioned efforts to fill policy gaps related to the full inclusion of persons with disabilities in society. It is my hope that this toolkit is one way to do this by building the data capacity and knowledge of persons with disabilities and their representative organizations to benefit all persons with disabilities, particularly those underrepresented and in more impoverished regions of the world.

Introduction

This toolkit is designed to highlight the journey so far regarding data on disability and to also provide persons with disabilities and their representative organizations with some basic knowledge on data collection, analysis, and use of data for evidenced based advocacy. Organisations of persons with disabilities (OPDs) have many roles to play in both influencing for data generation, using data when it is available and contributing to the development of data.

ADVOCATING FOR BETTER DATA

1

OPDS

2

3

USING DATA IN ADVOCACY

CONTRIBUTING TO FILLING DATA GAPS
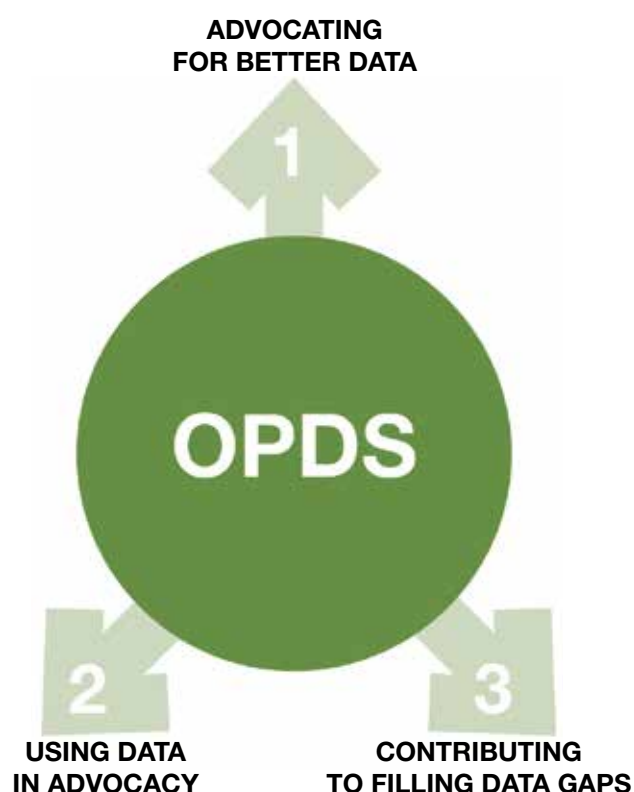
The journey starts with the need for data, so that it can be used for evidence-based advocacy and to get the data for evidence, advocacy needs to happen to ensure that those responsible for collecting and gathering data do so. This is where important advocacy work at national and international level needs to happen to influence those required to create data. This is beginning and is foundational to all other efforts.

The second aspect is once the data exists, it is vital to understand how to analyse, use and trust it for advocacy messaging. This is both to protect the integrity of advocates and to ensure that the change sought is based on an understanding of the reality of the situation and what works.

This toolkit looks at these aspects and aims to guide advocates, particularly those working at the grassroots level, to better understand the use of data in their advocacy. It provides an understanding of basic data literacy concepts, guidance on how to effectively turn data into compelling messages and shares some case studies using different types of data.

◀ Sarita, from Nepal, ©CBM

The toolkit has three sections and each section can be looked at independently. However, we would suggest you read all sections to be aware of the different aspects related to disability and data advocacy.

We need the data: Advocating for data. This section highlights why advocating for disability inclusive data is important as the first step to data creation.

Where do I find officially collected data and how I can check it is valid? What do I need to think about? This section highlights the different points that need to be considered when using official data.

When data doesn't exist or is limited what can we do? This section highlights examples of how unofficial data, qualitative data and storytelling can help when data gaps exist.

What this toolkit does not do:

• It does not go into an in-depth analysis of tools for data collection

• It does not provide a step by step guidance for example on the Washington Group Questions. If you are looking for specific information on WGQ, you can find them here (https://www.washingtongroup-disability.com)

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Advocating for better data on persons with disabilities

Lack of data can be a large obstacle in disability-inclusive policymaking and programming. Lack of data on disability also increases marginalization and failure to address the challenges and discrimination encountered by persons with disabilities. Without data, we cannot know where a country stands concerning the implementation of the rights of persons with disabilities. We are not able to show where progress has been made and, equally, we are not able to show where gaps exists. Without data, we cannot compare countries against other countries or different different districts with each other to see how they are making progress on implementing rights. If persons with disabilities are not counted, then they don't count. As a result, effective policymaking will suffer and persons with disabilities will fall off the statistical "map." Evidence-based data on persons with disabilities at the national and global levels is instrumental in identifying the policy gaps and challenges faced by persons with disabilities that can support policymakers to address these gaps and amend existing policies and regulations.

Accurate and appropriate national and international data collection on persons with disabilities:

- helps in identifying and addressing gaps, finding solutions and allows for evidence-based policies and development programmes, and

- helps with planning and budgeting for reasonable accommodations and effective policymaking that would ensure that persons with disabilities can participate in the society on an equal basis with others.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the 2030 Agenda have created a legal and policy push for better data on persons with disabilities.

What does the UNCRPD say about disability data

Once a State Party ratifies the Convention on the Rights of Persons with Disabilities (UNCRPD), it is obligated to collect data on persons with disabilities. Article 31 of the UNCRPD outlines the following obligations to collect data.

- It calls for all kinds of data to be gathered, from official data to research data. Also, it makes it very clear that data should be used to inform policymakers to support the implementation of the CPRD. Article 31 ask governments to use your national data to do research to better understand where your country needs to strengthen policies to implement the CRPD. A question for you to consider: is this what is happening in your country?

- It includes data collection principles. It describes the safeguards that States Parties must put in place for the collection of data and statistics. It specifies the requirement for legislation on data protection, confidentiality and respect for the privacy of persons with disabilities. It also requires the use of ethical principles and accepted norms to protect human rights and fundamental freedoms. This is particularly important for persons with disabilities as they face discrimination and stigma, and misusing data can have detrimental effects of their lives.

- It asks State Parties to identify, through data, the barriers that persons with disabilities face which impact on their participation in society on a basis equal to that of persons without disabilities. This means it asks State Parties to quantitatively compare the status of people with disabilities with the status of those without disabilities and take action to eliminate any disparities. A question for you to consider: Does your government provide comparative statistics on persons with disabilities and persons without disabilities?

- It calls on State Parties to ensure that data relevant to their situation is made available to persons with disabilities and their representative organisations. This means that if your country has ratified the UNCRPD and you as a person with disability or as a representative of an organisation of persons with disabilities can request data on the situation of persons with disabilities in your country, your National Statistical Office is obliged to provide you with that information.

Remember not every country has a National Statistics Office (NSO), to find out if your country has an NSO, the UN has developed a central repository of country profiles of statistical systems. The country profiles include, among others, a brief history of the country's statistical system, legal basis, the statistical programme and much more. To browse through all available country profiles in the database, please click here.

How do I find out what my actions my government is taking to collect data as obligated by the UNCRPD?

- Contact your National Statistics Office and ask for data on the situation of persons with disabilities. Inquire what type of data is collected or disaggregated on the situation of persons with disabilities in line with UNCRPD and the global SDG indicator framework.

- Check out government funded research institutions to see if they are publishing reports that include data on persons with disabilities

- Check out if the report your government makes to the UNCRPD committee includes data.

- Follow the UNCRPD committee discussions on your countries report and see if they include a recommendation for better data on disability.

- Recommendations by the Committee are found here. Use the recommendation for your formulating messaging for your data advocacy work.

Blessing from Uganda, ©CBM

How can UNCRPD committee recommendations be translated into advocacy for better data.

Some examples of UNCRPD recommendations on improving data collection

Australia: 'In response to the absence of national data disaggregated by disability at all stage of the 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.'

UNCRPD committee recommendation: 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 is important for understanding the population of persons with disabilities who are held in custody.

Kenya: 'The Committee is concerned about the multiple forms of discrimination faced by women with disabilities and the absence of measures to prevent and combat different forms of discrimination against them. It is also concerned about the lack of information on public policies and programmes on gender equality that include the rights of women and girls with disabilities.'

UNCRPD Committee recommends: Systematically collect data and statistics on the situation of women and girls with disabilities living in rural and urban areas, and belonging to ethnic minorities and pastoralist communities;

Advocacy message: We urge our government to ensure that the data and statistics on women with disabilities is collected so it can be used for the development of better programmes.

Spain: Freedom from exploitation, violence and abuse (art. 16)

The Committee is concerned about: 'The lack of concrete data, disaggregated by sex and age, on cases of violence and abuse committed in hospitals, particularly psychiatric hospitals, and places of detention; The lack of official records and data on the violence and discrimination to which persons with disabilities, particularly women, are exposed in both the public and private spheres, including in the workplace and in specialized mental health institutions.'

UNCRPD committee recommends: Collect data on and monitor the violence and discrimination to which persons with disabilities, particularly women, are exposed, both in the public and private spheres, including in the workplace and in mental health institutions.

Advocacy message: Disaggregated data on disability is important so that persons with disabilities can be protected from exploitation, violence and abuse. We ask our government to ensure disability data is collected and monitored to ensure persons with disabilities, particularly women with disabilities are included.

Disability Inclusive Data and the 2030 Agenda

The adoption of the 2030 Agenda for Sustainable Development in 2015 and the inclusion of persons with disabilities within the Agenda and its Sustainable Development Goals was a result of a successful advocacy campaign of the global disability movement, along with its allies. Once the 2030 Agenda was adopted, there were significant advocacy efforts by OPDs and allies to ensure that persons with disabilities were included in the global indicator framework with success. Annex 1 provides a detailed timeline of advocacy for global indicator framework highlighting the progress made on improving disability disggregated data.

What is the global indicator framework?

The global indicator framework was developed to monitor the implementation of the Sustainable Development Goals. The Inter-agency and Expert Group on SDG Indicators (IAEG-SDGs) was created with a mandate to develop the global indicator framework. The IAEG-SDGs has called on governments and all stakeholders to make available sufficiently disaggregated information and data for evidence-based planning and policy formulation that would ensure that persons with disabilities' needs are taken into account.

The global indicators were developed by Member States as well as statisticians working at the national level. These 231 indicators are designed to measure each target. Some targets have several indicators attached to them. The adoption of the global indicator framework meant that Member States agreed to integrate these indicators into their national statistical frameworks and will collect data and report the data back to global coordinating organizations. This agreement on global indicators is resulting in collection of data that is internationally comparable. As a result, it is possible to measure progress and to ensure that no one is left behind at the global level. The IAEG-SDGs remains responsible for guiding global monitoring and data disaggregation.

What does the global indictor framework mean for OPD advocacy?

The global indicator framework has two significant features that can help OPDs create advocacy messages:

- it requests that governments disaggregate any relevant SDG data by disability;

- it spells out 11 disability-inclusive indicators that measure the SDGs

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.

◀ Assan from Cameroon
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The 11 disability-inclusive indicators track progress on the following SDGs:

Goal 1: No Poverty:

Indicator 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: Quality Education:

Indicator 4.5.1 Equal access to all levels of education and vocational training including **persons with disabilities**

Indicator 4.a.1 Proportion of schools with the access to adapted infrastructure and materials for **students with disabilities**

Goal 8: Decent Work and Economic Growth
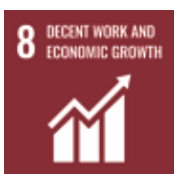
Indictor 8.5.1 Average hourly earnings of employees, by sex, age, occupation, and **persons with disabilities**

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

Goal 10: Reduced Inequalities

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

Goal 11: Sustainable Cities and Communities

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

Indicator 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**

Indicator 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: Peace, Justice and Strong Institutions

Indicator 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

Examples of OPD advocacy

Organisations of persons with disabilities (OPD) have an important role to play nationally, regionally and globally on advocating for the generation of data on the situation of persons with disabilities, whether that is to assess how the UNCRPD is being implemented or how the SDGs are including persons with disabilities. Some examples of this at the global and national levels are detailed below.

At the global level – promoting dialogue for better data

The Disability Data Advocacy Working Group: In 2019 the Stakeholder Group of Persons with Disabilities established a Disability Data Advocacy Working Group to provide a global platform for information exchange, learning and dialogue, sharing of good practices, and collaboration on disability data collection, disaggregation, and analysis. The Working Group was created after an assessment of disability data at the national level in 2018. The findings suggested that OPD engagement in data collection and disaggregation efforts is critical and missing. To address this gap, OPDs needed technical support, guidance on advocacy, and the opportunity for periodic information exchange and learning and as a result the Working Group was formed.

Action: Be part of the Disability Data Advocacy Working Group, seek inputs from technical experts, and learn from your peers.
Click here for more information on the Disability Data Advocacy Working Group and click here for information on how to join the listserv.

At the national level

Case study 1: Advocating for better data in the Pacific Region

The Pacific Disability Forum (PDF) is the regional focal point on disability issues in the Pacific, and supports various national OPDs, donor and development partners, as well as civil society and the private sector, in the quest to ensure that people with disabilities are able to participate in all facets of society across Pacific Island countries and territories. The organisation recognises the importance of data and evidence to influence policies and programs across the region[2], and has identified this area as a strategic priority in their work.

This commitment to strengthening disability data and evidence has been illustrated through an ongoing program of work related to strengthening the collection and use of disability data in the Pacific. **PDF has been working with national OPDs across a range of countries to advocate for inclusion of the Washington Group Short Set (WGSS) questions in national census and population surveys since 2015.** At the time the questions were new and had not been widely adopted in the region.

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[2] See PDF Strategy: http://www.pacificdisability.org/About-Us/What-we-do/KRA-3-Increased-Research,-Data-and-Inclusive-Pract.aspx

The first success was in 2015, when PDF worked closely with Kiribati DPOs to successfully advocate for inclusion of the questions in the upcoming national Census. However, they found that collecting disability data was only part of the story, and the risk was that the data would be collected but not analysed or shared. To address this issue, PDF met with the statistical commissioner to **advocate for disability-disaggregated data analysis and reporting** across a range out outcomes including health, education and WASH. It was soon realised that there was a lack of expertise and experience in undertaking this type of analysis. Recognising that this expertise and experience wasn't held within the national statistical offices, nor within the DPOs, PDF partnered with the UNICEF regional office, Secretariat of the Pacific Community (SPC) Statistics for Development Division, and the National Statistics Office (NSO) of Kiribati to undertake analysis and develop a the [Kiribati Disability Monograph](#), using funding the Australian Department of Foreign Affairs and Trade (DFAT). Since the production of the Kiribati monograph, detailed analysis has been undertaken for four countries: [Samoa](#), [Palau](#), [Tonga](#), with Fiji and Tuvalu (publication forthcoming).

One of the key aspects of the disability monograph work has been supporting governments to **undertake in-country analysis workshops** with national statistical offices as well as government agencies, to jointly interpret the disaggregated data and make recommendations. Each government agency then took responsibility for writing the chapter in their respective area (e.g. health, education, employment, Living Conditions, WASH) using the tables provided by the national statistical office. This means that when DPOs advocate for changes to happen, asks are based on the government's own recommendations rather than from an external agency.

Another important component in PDF's data advocacy work has been **supporting DPOs to develop their technical understanding of the WGQs**, in order to drive national-level advocacy and support local implementation. PDF realised early that in order for advocacy to be successful with government agencies, they first needed to develop their own technical capacity. PDF first sought training from the Washington Group directly, and subsequently offered training to national stakeholders (including DPOs, NGO partners, the national statistical offices and government reps) on technical aspects of WGQs; as well as a second focussed training for DPOs so they could participate in the census as enumerators; and using a training-of-trainer approach, train the rest of the enumerators in asking the WGQs in the national census.

PDF has many reflections and lessons from this work, including:

- Using the CRPD and SDG frameworks to drive advocacy messages on why disability disaggregated data is important;

- The importance joint analytical processes that strengthen commitment to disability inclusion from government stakeholders. This step requires additional resourcing but should be included where possible;

- The need to form good partnerships with the organisations will be undertaking the work, including through tripartite partnership arrangements;

- Having a long term view – in some settings, it's taken over 2 years of advocacy efforts to succeed in getting the WGSS included into national census;

- Continue advocating for the collection of other information in population surveys that's not provided by the WGSS, such as barriers to participation and support needed.

Data: Where can I find officially collected data?

This section focuses on quantitative data and the use of official data highlighting the different points that need to be considered when using data

Types of data

Data is/are pieces of information about members of group of people or things that when taken together and analysed describe the characteristics of that group.

- 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 summarize 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.

Frequently used terminology in quantitative data

- **Statistics** are often used to make sense of quantitative data and involve the practice of analysing and presenting numerical data. Individual statistics can be numbers that show information about something, e.g., the number of persons with disabilities in a country or that describe the relationship between entities, e.g., persons in one group are more likely to have disabilities than another. Statistics are used to make discoveries in research, decisions in policy making, and predictions about the future.

- An **indicator** is a measure that shows or suggests the condition or existence of something. Indicators are often used to track a situation, and in policy making, they are used to track progress against goals and targets. Indicators are sometimes expressed as statistics, e.g., the proportion of the population with disabilities receiving social protection can be an indicator of adherence to the SDG goal of eliminating poverty. This indicator may be combined with other indicators, such as the proportion of the population with disabilities living below the poverty line, to provide a more complete picture of the overarching goal. It is often necessary to have more than one indicator for a complex issue. Over time, indicators can be used to show if the situation has improved or not, providing valuable evidence for advocacy.

In order to track progress over time, it is best to start with a **baseline** or minimum starting point or scale with which other values can be compared. Baselines are often used at the start of programmes to establish a starting point and to draw conclusions on the progress of the programmes. Baselines may also be drawn artificially, e.g., based on a specific date or event, such as the year the country ratified the UNCRPD. OPDs can establish baselines where they do not exist in order to track progress on an issue over time.

Aggregate data is data combined over all members of a group of interest and, as a result, is usually a summary measure for the whole. The percent of the total population in a country that is living in poverty is an example of an indicator based on the aggregation of information representing all people in the country.

Disaggregated data is data divided into sub-categories of the total group. Disaggregation is very common – statistics are often reported for specific age groups or for men and women separately. An example of aggregated data would be the rate of primary school completion for all children, but these statistics may be disaggregated by various categories, such as gender, disability, ethnicity, school district, and more. Data disaggregated by disability allows for comparisons with persons without disabilities, which can help to establish the scope of a problem and reveal inequalities. The subcategories across which data are disaggregated can also be defined by more than one characteristic. For example, the rate of primary school completion can be disaggregated by disability and sex to compare girls with disabilities to boys with disabilities and to compare boys and girls with disabilities to boys and girts without disabilities. It is important to highlight that in disability data collection,

disaggregation, and analysis, categories of disability should follow guidelines identified by organizations of persons with disabilities.

Prevalence and incidence are often used in relation to disability and health conditions. **Prevalence** is how common something is in a defined population, and in statistics it is expressed as a proportion or percent of a population with a specific condition at a particular point in time. **Incidence** relates to the probability of occurrence and is therefore the number of new cases within a particular time. If the incidence rate is multiplied by the average duration of the disease, then this shows the prevalence. For example, the incidence of new cases of COVID-19 may be reported daily, and the prevalence is all existing cases of COVID-19 on a particular date. Prevalence and incidence can be reported for the total population or disaggregated by characteristics of interest.

Metadata is information that describes other data, including information about where and when data was collected, the group that collected the data, or details about the data, e.g., the currency used for questions on income levels. Metadata can be helpful in understanding the strengths and weakness of the data that was collected.

> **Prompt:** Think back to Section 1, Article 31 of the UNCRPD and its requirements for data disaggregated on disability and the global indictor framework are all examples of where this terminology can be found.

Where do I look for official data sources?

Data can come from a number of different sources including the government, private sector, UN agencies, civil society, academia, research institutes, and others. Data can be official and non-official. It is important to remember also that some data is more reliable than others. When using data for advocacy always provide a citation of the data source to demonstrate the credibility of the data. Annex 2 includes resources and portals that are helpful in finding data on disability.

Sources of government (or official) data

An official data source is another term for a government data source. The types of data you can find include:

National census – Typically compiled every 10 years to count the population and often includes basic information on education, housing, employment, occupation, income, gender, age, health, disability, marital status, language, family structure, migration, race/ethnicity, religion, and more. Information is basic and not frequently collected, but it is used as the basis for decision-making. A major advantage of census data is that it can be used to examine sub-groups of the population defined by more than one characteristic, such as employment information for women with disabilities, aged 25-44, living in rural areas.

Surveys – Surveys are questionnaires that use sampling, often randomly, to obtain information on a proportion of the population in order to draw conclusions about the entire population on a range of topics, e.g., labour surveys, household income surveys, etc. Surveys are cost-effective and may target a specific group or topic, but there can be problems with the selection of the sample and / or sample size, which can skew the results.   (For more information on sampling, see the section on Sampling).

Administrative data – Collected by national ministries or departments as well as local government for operational or regulatory purposes, e.g., births, deaths, marriages, divorces, social protection registries, finance records, etc. This data is already being collected, making it cost-effective, regularly updated, and easy to access, but it may not be representative if it is limited to those who use the service and may not be comparable if different methods are used across the country.[3]

Government reports – Government submissions to the CRPD Committee or High-Level Political Forum may contain data, usually from the above sources. It is best to use the original sources, but these reports may provide information on original sources of data.

Open data – Open data refers to publicly available data through online tools that does not have restrictions, such as copyright. While open data can come from private or non-governmental sources, many governments, such as the UK, Brazil, and Kenya[4], have set up open data portals.

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[3]For more information on how administrative data can be used for collecting data on disability, see the article on the Washington Group for Disability Statistics' website: http://www.washingtongroup-disability.com/can-administrative-data-used-collecting-data-disability/

[4]A list of open data portals can be found at https://dataportals.org/.

Once data is found, what's next?

Consider the scope and limitations of the data. There are some limitations to take into consideration once data has been sourced, including the quality of the data and whether it is appropriate (i.e., the right kind of data). The sections below provide insight on the scope and limitations of data. To get started, consider the following questions:

- What population does the data describe, and is it the population of interest

- Is the data disaggregated by disability and other factors?

- How is disability (or another important term, such as unemployment) defined?

- When was the data collected?

- Who collected the data, and how did they interpret responses?

- What information is available about how the data was collected and the quality of the data including the response rate (for surveys)?

- How big was the sample size (for surveys)?

- Is there more data on the same topic?

Each of these questions are detailed below.

Population of interest

The population of interest is the group or population from which a researcher draws conclusions and may be a subset of the general population. It is important to define the population of interest before searching for data. This may be a larger group e.g., persons with disabilities in Uganda, or a very specific group, e.g., girls with disabilities in Wakiso District, depending on the advocacy objective.

It is important to use data that pertains to the population of interest. For disability advocacy the population of interest is the population with disabilities so that this population can be compared with the population without disabilities (i.e., disaggregation). An example to highlight this is maternal mortality rates that are not disaggregated by disability do not give an accurate picture of how many women with disabilities die in childbirth and do not demonstrate how women with disabilities are affected, even if the rate is high in the country.

Disaggregation

Disaggregated data is data that is divided into sub-categories, such as gender, age, disability, ethnicity, geographic region, etc. It is essential for advocacy because it enables OPDs to make comparisons between persons with disabilities and persons without disabilities, and thus identify inequalities.

For data that is disaggregated by disability, further disaggregation by other characteristics, e.g., age, gender, geographic region, etc., may also help to explain how different groups of persons with disabilities are affected by an issue. For example, women with disabilities may

be affected by unemployment more than men with disabilities, and youth with disabilities may be affected more than persons with disabilities who are middle age. Data that is disaggregated by multiple identifiers provides a better picture of how different groups are affected by an issue and should be taken into consideration.

Disaggregation requires that the population with disabilities be identified. The Washington Group Questions (WGQ) provide a consistent way to define the population and disaggregate data by disability, but even the WGQs can be interpreted in different ways, depending on which set was used, e.g., the Short Set of six questions, Enhanced Set of 12 questions, or Extended Set of up to 39 questions. Similarly, different cut-off points, e.g., some difficulty, a lot of difficulty, or cannot do at all, for counting respondents as persons with disabilities may vary. The WG has a way to use the WG tools to define the population with disabilities in a consistent was for international comparisons. With increasing use of the Washington Group Questions, it will be possible to expand analyses to address the experiences of persons with mild or moderate disabilities versus persons with severe disabilities, based on the cut-off points. It will also be possible to examine how different types of functional difficulties are affected by an issue. To learn more about the different ways to analyse the WGQs, review the analytic guidelines on the website of the Washington Group on Disability Statistics. Most important is to select the definition that reflects the question of interest and to be clear in how the group with disabilities is defined.

Definitions

As noted above, disability can be defined in different ways and different data sources will use different defintions. Check to see how the definition of disability was developed for the data. If data was collected through a survey where respondents were asked if they have a disability through a yes/no question, then there will likely be underreporting of disability. If the Washington Group Questions were used in a survey, then it may be more accurate, but it is important to check if the questions were altered or translated into another language, as this can affect the results. If the disability was defined by whether people have a disability identity card or whether they receive disability benefits, then this may also underreport the number of persons with a disability, or the data may omit specific types of persons with disabilities who do not have an identity card or who do not participate in benefit programmes.

Other terms relating to the data may also be defined narrowly, which may affect the results of the data. For example, employment is often defined as regular, waged employment, often leaving out irregular (or occasional) employment, employment through the informal economy (e.g., street vendors), and/or unpaid work (e.g., voluntary work or care work).

Data that use definitions that are not ideal may still be useable but require some explanation so that the limitations of the data are understood.

Frequency and timeliness

Data that is very old may be out of date and therefore may not be useful. One of the challenges of using data from a national census is that the data is usually collected every ten years or longer. It important to take note of when data was collected, which may also differ from when it was analysed or published, e.g., if raw data from a survey was collected and subsequently used in a report published several

years later. In some cases, the only available data may be data that is ten or more years old. There are no rules on the cut-off date for using and publishing data as evidence; however, it is recommended that census data is collected every ten years. Therefore, it is not advisable to use data beyond 10 years, but this may depend on the type of data and the overall availability of data in the country. Older data is used in conjunction with more recent data to look at trends over time – an important advocacy tool for determining if necessary changes have been made.

Tips for frequency and timeliness

- Check the date that the data was collected, which may be different from the date it was published

- If it has been a long time, check to see if additional data has been collected, e.g., if survey data was collected in between censuses or larger surveys to fill gaps

- Consider how much time has passed and how much the context has changed, e.g., changes to the population / demographics, economy, political situation, etc. If there have been drastic changes, this could make the data less useful, e.g., if a conflict has broken out in the country

- Decide whether to use the data or not. If data is old and is collected periodically, it may be better to wait for the forthcoming data

- If older data is going to be used, consider how it will be interpreted and communicated so that decision-makers understand that the data is illustrative and not up to date.

Data collectors

Data is often collected by enumerators or interviewers. If the enumerators are not adequately trained, it may affect how the data is collected, e.g., if they do not feel comfortable asking questions about disability or functioning. Some other ways that enumerators may affect the data include:

- Selecting a head of household as the respondent who is unable to speak for everyone, selecting the wrong respondent, or excluding respondents, e.g., due to a disability or lack of accommodations, such as a Sign Language interpreter

- Not asking the questions and answer categories as written and/ or using technical language or any language not in the questions that respondents do not understand

- Changing or skipping questions or asking leading questions to generate a particular response

- Acting negatively to responses or respondents with disabilities

- Using inappropriate terms or discriminatory language, which may affect the respondent's participation.

Ask questions about the data collection process to assess the reliability and impartiality of the data. The lead agency may have more information on this, or they may publish notes on the methodologies. Additionally, OPDs from the locations where the data was collected may have information from respondents with disabilities about the methods used.

Sampling methods, sample sizes and response

Surveys use sampling usually through simple random sampling or more complex methods to obtain information on a proportion of the population and then draw conclusions about the entire population on a range of topics. Non-random methods can be used but the resulting data may not be generalizable to the target population of interest. It is important to examine the universe from which the sample is drawn, the methods for drawing the sample and reasons for using those methods in order to determine the usability of the survey results. If there is bias in the definition of the universe of the selection of the sample, e.g., persons with disabilities are excluded in a survey because of their disability, then the results will most likely be impacted. It is important to determine whether the sampling methods used affect how the results are interpreted for advocacy. The method of sampling depends on the information being collected, the target population and a variety of logistic and resource issues.

If the survey intends to collect information from the general population but to disaggregate the data by population characteristics, then the sample size needs to be large to generate statistics on the subgroups of interest and should not exclude groups. In addition, some surveys may target specific populations, such as people who use disability services.

It is common for surveys to have sampling errors, which is often explained in the footnotes of survey results, e.g., +/- 2%. Recognise that survey results usually carry some degree of error which can affect the conclusions that can be drawn from the sample. For example, if the sampling error is large due to small sample it may not be possible to identify differences among groups with and without disabilities even if they exist. For surveys, it is also important to evaluate the response rate which is the percent of the sample selected that participated in the survey. In general, when response rates are high the sample will represent the target population from which it was drawn but when rates are low the sample might give biased results if those not responding are different from those who do respond. Methods exist to determine if bias due to non-response exists and to describe the impact of that bias on how the data can be interpreted. Data producers should provide information on the quality of the data so it is not necessary to have technical skills to evaluate data quality. However, if there are concerns about the accuracy of data and the sampling, it may be useful to talk to experts, e.g., staff at NSOs, university researchers, or consultants, to answer questions about data quality.

Data appropriateness

Data disaggregated by disability is not commonly available. It is, therefore, important to check if the sourced data is the right kind of data for the intended purpose. For example, school completion rates disaggregated by disability will not reveal how many children with disabilities are out of school. However, if there is corresponding data on school enrolment rates disaggregated by disability, it may be possible to calculate the dropout rate for children with disabilities, which is a portion of the children with disabilities out of school. Think about what the data is saying and what it is not saying. If the data does not provide the right kind of information, check to see if there is other data on the same broad topic that may be usable or combined to conduct additional analysis.

Analyzing Data

Organisations of persons with disabilities do not need to have technical skills, rather having a basic understanding of data and how and why it is used is a good start.

Comparisons and trends

Once the data has been sourced, the quality has been assessed, and the appropriateness has been considered, the data needs to be analysed in order to draw conclusions. Data analysis involves conducting calculations and / or synthesising information to make estimates and to show trends and patterns, which help to draw conclusions. Comparisons help to identify areas where differences that need to be addressed exist. To analyse data and draw conclusions, check if the selected data:

- Is available on persons with disabilities and persons without disabilities, which establishes a comparison and can demonstrate the impact of barriers due to disability

- Can be analysed using additional disaggregation, such as age, gender, etc., which demonstrates how different groups of persons with disabilities are affected and shows the added value of intersectional solutions

- Is available across different years, e.g., if the data was collected annually, which enables comparisons over time and can demonstrate the rate of progression or if backward steps have taken place

- Can be broken down by geographic location, which enables comparisons by region and can reveal gaps in the distribution of resources or the way services were delivered in one region versus another. Comparisons may also be made between countries, which can compel governments to take action

- Are there concerns about data quality that will impact the conclusions drawn from the data.

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Triangulation

It's good practice to check your data sources with additional data sources, which is called triangulation. Triangulation involves drawing on different data sources on the same topic to provide a clearer picture of the situation and overcome weaknesses of a single-data source. If the data is of poor quality, missing, or does not reflect the target population, consider combining data sources if appropriate. For example, to establish disability prevalence rates, a combination of old census data and data registry figures may help to provide a more complete picture. The figures may not be fully accurate, but by adding an additional data source, new information can be used to improve understanding on prevalence. Remember that combining two sources of poor quality data will not improve the overall quality unless one source can correct for the deficiencies of another. It is important to clearly describe how data are combined and what effect that has on data quality. In the example above, if the registry omits some groups with disabilities the combined data will also omit these groups but the combined data may be a better description of the target group than either data set alone.

Low rates

One of the challenges of using quantitative data to highlight the situation of persons with disabilities is in dealing with relatively low prevalence rates, such as with persons with deafblindness or persons with albinism. A low rate can make it difficult to persuade decision-makers about the urgency to allocate resources or to take action. To address this problem, consider different ways the data may be expressed. For example, use estimates of the total number of people affected, rather than using rates or percentages, since the overall figure is a larger number than the percentage and appears more significant. For example, 1.5% of the population sounds small, but if the population is 18 million, that comes to 270,000 people, which is a significant number of people. Combined with qualitative data, case studies, and stories, this quantitative data can be compelling. Think about a time when government took action on similar figures to demonstrate a pattern of practice, e.g., if the measles cases annually did not exceed 270,000, and the government took many steps to address measles, this can provide evidence of the government's practice of taking action, even when the percentage of the population affected is low.

Limited data, or data gaps - what can be done?

There are many reasons why data can be limited or why data gaps exist, some of these reasons can be:

- Structural and technical such as limited resources for data collection and low capacity at government or national level to collect, anaylse and interpret data.

- Lack of visibility as a policy issue; often unless your issue is already a policy issue and has data collected on it, data will not be forthcoming.

- Times of crisis and disruption; in situations of a national or even a global crisis such as the 2020 pandemic create the need for immediate data which can often leave out in its early stages of data collection, data on persons with disabilities and other groups.

- Emerging areas the UNCRPD and the SDGs look for data across a range of areas in life, and also look for data that can highlight for example intersecting inequalities

This section highlights case studies with some positive examples of how international non-governmental organisations (INGOs) and OPDs can generate data where data limitations and gaps exist.

Citizen generated data – what is it?

Citizens generated data, is data individuals, communities or their organizations produce to directly monitor, demand or drive change on issues that affect them — for example to support the effective tracking of progress on the SDGs. The Leave No One Behind case study highlights how INGOs are working to promote the recognition of community-driven data in monitoring and influencing for positive change.

Case Study 2: Leave No One Behind partnership

The Leave No One Behind partnership was launched in late 2017 as a partnership of 12 international civil society organisations, including CBM. In 2018, the partnership set up national coalitions in five pilot countries bringing together national NGOs and civic platforms, as well as community-based organisations.

The partnership's main goal is to make SDG implementation more inclusive and accountable towards those who are furthest behind in society. Specifically, the objective is to gain recognition of community-driven data in SDG monitoring in national and international policy decision-making and to influence national policies, particularly for marginalized groups, including persons with disabilities, older persons, youth, women and girls, ethnic minorities, transgender people, street dwellers, and other marginalised groups.

The pilot project ran from 2018 until March 2019 in five countries Bangladesh, India, and Kenya, Nepal, and Vietnam.

The project aimed to:

- have **more inclusive SDG implementation** that addresses the needs of marginalized groups effectively;

- use a **participatory approach** that involves people from communities in data generation and retrieving direct feedback; and

- have **dialogue with authorities** on policy change, informed through the use of community-driven data and feedback.

Each country identified data gaps and collected data on the most marginalized groups. Data on the situation of persons with disabilities was collected in each country, and for example, in India, organisations of persons with disabilities (OPDs) led and collected the collection of disability data. CBM in Vietnam with OPD partners were active in the coalition in Vietnam. One compelling outcome is that most data comes from national averages (from surveys) and the project addresses this gap by gathering data from marginalised groups that are often left out.

Civil society organisations (CSOs) play an important role in data collection, including:

- Fill knowledge gaps in SDG monitoring through the use of community-driven data as complementary (local) source of information and the voices of the people most left behind;

- Community-driven data can inform policies to ensure that the most marginalised groups, including persons with disabilities, ethnic minorities, young people, older persons, and other are included and everyone is counted and thereby fostering inclusive national SDG implementation.

Methodology:

- Across five countries, different community-driven monitoring tools were used, including a mixture of scorecards, key informant interviews, household surveys, focus groups, social audits, and regular surveys.

- It is important to note that the key informant interviews were with target groups (marginalised groups) as well as local service providers and decision makers.

- Existing indicators from the government were used whenever possible and then the community-driven data went in more depth to complement the available official national data, which were scarce in terms of the groups in focus.

Sample size:

- More than 2,000 representatives of marginalised communities (in all five countries) were directly engaged in the data generation carried out across different provinces, counties, and urban neighbourhoods.

- The mobile app that was used in India can be scaled up and gather large amounts of data.

- It is important to highlight that this was a pilot project – on the side lines of the other work of organisations - with no funding.

Various policy recommendations emerged from the outcomes that were discussed with authorities and public service providers at the national and local levels. Looking into these local project results, partners at the global level derived the following overall advocacy claims:

- Foster collaborative research to close data gaps;

- Strengthening inclusive decision making;

- Improve reporting and accountability; and

- Advocate for budget allocation and government commitments to ensure inclusive SDG implementation and monitoring.

LNOB Data Platform:

- In September 2020, the LNOB Partnership's data platform was launched.

- IISD and Development Initiatives will contribute to this work.

- The platform will set up a series of data platforms for six months in three countries.

- Since every country has different data collection, the platform aims to make the data being collected more comparable.

- The goal also is to increase recognition of civil society data in official processes and for official use.

- Ultimately one platform will be set up for all the data.

- The platform will be accessible for persons with disabilities.

Next steps:

The results from the pilot will be used to scale up the approach internationally with the aim of implementing the project in 10 countries by 2022. Phase II will begin in 2021 with the possibility of adding Canada, Denmark, Malawi and the Philippines as action countries. Funding was secured from the Robert Bosch Foundation mid-2020, and follow-up funding from Swedish International Development Cooperation Agency is expected for 2021. This will allow the project to scale up, aiming to reach 100,000 representatives of marginalised groups by the end of 2022.

At the global level, the partnership has entered into a strategic collaboration with Partners for Review and the Danish Institute of Human Rights. A joint project will be launched at the end of 2020 with National SDG Coordination Units, Statistics Agencies, National Human Rights Institutes and civil society platforms from six countries to map out possible pathways toward cross-sector SDG data partnerships. UN Statistics Division will support this global exchange and learning project, aiming to build trust between "data users" and "producers" from across the sectors.

The new project phase aims to scale up the active use and recognition of civil society data in a growing number of countries and will use the name "Making Voices Heard and Count." To find out more about the partnership and to enquire possibilities for engagement, please contact the global partnership lead Peter Koblowsky at pkoblowsky@icscentre.org.

Whether collected by governments or citizen generated it is good practice to provide the necessary information so that users understand how the data was collected and the quality of the data. This adds to the credibility of the conclusions drawn from the data and used for advocacy.

OPDs gathering data for evidence-based advocacy on COVID-19

The COVID-19 pandemic took hold of the world in early 2020 and continues to disrupt and create chaos across many of the world's countries particularly their health systems and economies. Accessing up-to-date data in its earliest stages focused on health information from official systems but as the pandemic continued to evolve, gathering data on the impact of COVID-19 on different groups in society began to emerge as an issue, particularly for persons living at increased risk and on the margins of society. This includes persons with disabilities and many organisations of persons with disabilities reached out to their members to gather data on the impact of COVID-19.

Case study 3 and 4 describe examples of how OPDs engaged in collecting data from their networks and members.

Case study 3: Stakeholder Group of Persons with Disabilities (SGPwD) – a global call for evidence-based data.

Introduction

When COVID-19 was declared a pandemic in March 2020, OPDs worldwide knew that the impact would be dire for persons with disabilities. Immediately, the International Disability Alliance (IDA) responded by sharing key recommendations toward a disability-inclusive COVID-19 response and setting up a COVID-19 portal and working groups with the International Disability and Development Consortium (IDDC). Disseminating advocacy messages on the discrimination and inequality that persons with disabilities faced was critical to ensure persons with disabilities were included in the response to COVID-19.

To complement this work of IDA and IDDC, the Stakeholder Group of Persons with Disabilities (SGPwD) carried out a qualitative research study to gather additional and new information on the impact that the COVID-19 pandemic has had on persons with disabilities around the world. The data collected were gathered around thematic units related to the global pandemic and the Sustainable Development Goals (SDGs). These seven themes included living situation, safety concerns, home life and housing conditions, health care, social protection, employment and COVID-19 disability data. All names, nationalities, and identifying characteristics of research participants were changed for their protection and confidentiality.

How was the data for the report gathered?

Traditional methods for face-to-face data collection were not possible – COVID19 had restricted travel, being in close contact with people and also timeframes for gathering data needed to be quick. Thus, the SGPwD gathered data by using virtual platforms with:

- **Online interviews** with leaders from the disability movement to collect information. These interviews were carried out via different methods depending on the context, internet access and video quality (e.g., necessary for interviews in International Sign). Platforms utilized included Skype and video messages. It was very helpful to have individual interviews to gather in-depth knowledge, but the challenge was the investment of time to carry these out and then translate and analyze the responses.

- **Focus group webinars**, to collect testimonials from different groups within the disability movement. Focus groups were carried out on GoToWebinar. Regional focus groups was a good way to reach many people from different regions in a limited time frame, but challenging to gather so many compelling stories in only one session; and

- **Working with organizations of persons with disabilities** in Bolivia, Colombia and Guatemala to assess the situation in more depth in one region.

Doing it this way this meant more people with disabilities could be reached across different regions of the world.

Interviews were conducted with 28 people with disabilities in six languages, including Arabic, English, Hungarian, International Sign, Russian, and Spanish. Four regional focus group discussions were carried out in English and Spanish via an online platform using real-time captioning and International Sign interpretation. Participants were from all regions from more than 54 countries and represented all types of disabilities. Specifically, 65 people with disabilities participated from 13 countries in Africa, 16 countries in Asia and the Pacific, nine countries in Europe and North America, 12 countries in Latin America and eight countries in the Middle East and North Africa. There was a balanced participation between men and women in all regions.

When was the data collected? Why was this timing important?

The data was collected during May 2020 and the report was ready by June 2020, so it was a very quick turnaround. The data collection methods included empirical data collection using a semi-structured interview format with open-ended queries with persons with disabilities, empirical data collection from focus group discussions with persons with disabilities and document analysis. Qualitative data reduction techniques were applied to synthesize and organize raw data from interviews, focus groups and public documents using content analysis.

What were the lessons learnt?

The research confirmed that persons with disabilities were particularly impacted by the pandemic and that new barriers had emerged exacerbating existing barriers. More research is needed to understand the situation of persons with disabilities in more depth and to provide solutions and a way to support persons with disabilities. Additionally, there is a need to look at the barriers in the response and recovery phases.

Limitations existed in this research due to a short time frame to gather and analyze data and synthesize findings, as well as the inability to have in-person interviews. Due to the pandemic, online platforms have improved at a rapid pace, including accessibility features. This makes future online work easier and more feasible. The Washington Group on Disability Statistics has shared helpful suggestions on Using the Washington Group Short Set in a Telephone Survey and Using the Washington Group Tools to Assess the Impact of COVID-19 on Persons with Disability.

Furthermore, this study was done without additional resources with lack of human capacity. For future planning during emergencies workplans need to be diverted to carry out urgent actions, such as collecting data.

What were the key findings?

The findings were framed around relevant Sustainable Development Goals, targets and indicators to address the situation of persons with disabilities via a COVID-19 pandemic lens.

The report finds that most persons with disabilities around the world have been adversely affected by the pandemic in one way or another with additional or new barriers, including new barriers in the re-opening phase. The most common barriers that emerged include: (1) lack of access to COVID-19-related information for all persons with disabilities, (2) barriers in receiving social protection measures and employment (formal and informal, losing employment first, and accessibility barriers in the virtual working environment) and (3) lack of disability inclusion in COVID-19 response efforts at all governmental levels, creating significant disconnections between national and local actions.

Some main themes that emerged from the research include the lack of access to information, the role of organizations of persons with disabilities, lack of access to healthcare facilities, and lack of disability data.

Lack of access to information

Overwhelmingly, there was lack of access to information for persons with disabilities related to COVID-19. This included lack of information in native sign languages, Braille, easy read and other alternative formats. In some places, information did not reach communities in rural and remote settings, which impacted indigenous peoples, refugees, and persons in institutions, impacting older persons and persons with disabilities in these communities.

The role of organizations of persons with disabilities

To address lack of information and other gaps in government services, organizations of persons with disabilities (DPOs) stepped in and played a role to address gaps in government services. Many DPOs became sources of information, were raising awareness with their members and providing accessible materials in different formats.

In many countries, governments provided sign language interpretation and captioning for COVID news briefings, but not always consistently. Often these services were put in place as a result of Deaf community and DPO-led advocacy and in sometimes with support from international organizations.

Lack of access to healthcare facilities

In all regions, participants indicated barriers or limitations regarding access to healthcare facilities, including hospitals. Overall, many people said they felt that their life was considered less valuable than those without disabilities, and, in some grave cases persons with disabilities were denied access to hospitals and sent back home without support. Also quite concerning, in some dire cases, the COVID-19 triage system excluded the appropriate treatment for persons with disabilities. The exclusion and denial of treatment were not on the basis of a medical condition, but because of discrimination.

Other barriers included, lack of disability awareness among staff, communication barriers for deaf and hard of hearing people from healthcare staff wearing personal protective equipment and lack of access to information in sign language, lack of accessible transportation to and from health facilities, and support persons and sign language interpreters were unable to accompany persons with disabilities into hospitals and healthcare facilities, creating serious situations in some cases.

Lack of disability data

In terms of data, we asked participants to share any resources on national-level data on COVID-19 and persons with disabilities. Overwhelmingly, participants had access to basic government data sources on the daily number of infected cases, deaths and recoveries. In some cases, they had sources of data disaggregated by gender, age, pre-existing health conditions, location, but not disability. Overall, participants indicated that governments are not disaggregating by disability, or if they are, are not sharing the data.

To address this gap, many surveys are being carried out by OPDs and other organizations around the world to collect information from persons with disabilities. We learned about surveys in the Philippines and the Dominican Republic, as well as from various international OPDs and organizations.

These findings were presented at the 2020 High-level Political Forum and in other data-related events.

How did the finding help shape recommendations?

Building on the excellent efforts of the International Disability Alliance and the International Disability and Development Consortium, the following key actions were recommended:

- Periodically visit the IDA website and follow the key disability inclusive COVID-19 recommendations.

- Refer to key resources and tools for action to include persons with disabilities.

- Ensure all virtual meetings, events and activities are inclusive for all persons with disabilities and refer to these periodically updated accessibility guides.

- Increase awareness by sharing stories about people with disabilities during the COVID-19 outbreak.

- Publish and disseminate information about persons with disabilities in mainstream journals and periodicals to gain widespread attention about disability inclusion.

- Develop a disability inclusion guide based on lessons learned from the pandemic for governments and local authorities. This can save lives and ensure persons with disabilities receive the vaccine first.

- Launch a campaign on kindness as an integral part of non-discrimination and equality in order to remind people about the importance and value of kindness in society.

How were the findings used for advocacy?

The research findings were timely and integral in providing stories and evidence on the situation of persons with disabilities during the pandemic (May and June, 2020). The findings have been used in a variety of ways. The findings with recommendations have been:

- Presented to organizations of persons with disabilities and other stakeholders to share, learn and gather testimonies on the situation around the world;

- Shared in high-level meetings, such as the High-level Political Forum, to government, UN entities, civil society, academia and other stakeholders;

- Presented to statisticians and policymakers to fill a gap on the experience of persons with disabilities during the pandemic and also in response and recovery efforts; and

- Published in various formats in Spanish and English to reach a wide audience.

Conclusion

The data gathered and related findings are important to identify new barriers for persons with disabilities in the global pandemic. Results from this study can be used in advocacy efforts to influence governments and bilateral and multilateral agencies to urgently measure the situation of persons with disabilities worldwide in the context of COVID-19. This can support the realization of disability-inclusive policies and programs to build back better, safer, resilient and more inclusive communities worldwide.

Case study 4: A Global OPD engages with its members through data collection

The World Blind Union (WBU), a global OPD made a decision in March 2020 to reach out to its membership (approximately 250 national members of organisations of blind persons or organisations working on behalf of blind persons) to find out what they can do as organisations promoting the right of people with disabilities, in order to assure that their community is fully included in the context of Covid-19. This case study highlights the steps WBU took in carrying out their data collection and building their advocacy messages.

Step 1: Coming up with the questions to ask

WBU wanted to find out two things, firstly, how blind and partially sighted people were facing and experiencing lockdown. Secondly, what WBU members, the organisations of the blind, were trying to do to support individuals. One of the first steps WBU took to unpack these two questions was that they realised they first of all needed to know what the population was, what the demographic data that we had to collect in order to come up with a report which was evidence-based report – we need to disaggregate our data. Without that, it would have been impossible for us to identify what we wanted in terms of advocacy strategies and the accommodations and to action etc. So, the first work stream was deciding the best tool to understand who we were going to listen to and at the same time who we were going to give responses to. The second element was we really need to know what our individuals

and organisations actually were doing around Covid-19. We wanted to make a clear distinction between organisations and individuals because the report that it was our product, of course, a report that contains a letter for advocacy strategies for organisations. But at the same time, in order to make that report something useful, something that it was legitimate coming from the individuals we needed to hear what the individuals wanted to say and that included how rights of persons were being impacted from challenges around mobility and personal safety to access to technology, switching to online platforms etc.

Step 2: Planning what disaggregated data you wish to collect

In the survey questions, WBU wanted to ensure that they had a good understanding of the demographic profile of our respondents to the survey. They asked a number of basic demographic questions: what your gender is, where do you live (rural or urban), what country are you in; what age range are you? Having these questions answered, gave us how many men and women responded, how many lived in urban or rural places, what age they were and also what country they were in. They knew that their respondents would be blind or partially sighted people, but also understood that that one of the biggest concerns was, what happened with those who have a visual impairment and also another type of disability, for example, mental health and well-being. Using the WGQ questions it gave us the opportunity to find out different combinations.

Step 3: Rolling out an accessible and inclusive survey

- **Plan for Accessibility:**

  In terms of the sample, WBU tried its best to make it as inclusive and as simple as possible and that's why WBU had to spend a lot of time in selecting the most accessible platform to collect data. WBU ended up having to use two platforms, google form and survey monkey. When WBU talks about accessibility, they often leave out usability and how friendly those platforms are. And the biggest challenge WBU is still facing is the captcha when you need to enter to prove you are not a robot. it remains quite difficult when you have to listen to mp3 file, or where you have to try to understand where you have to enter the words, the letters or whatever. The captcha is still something that WBU is really concerned about, in terms of accessibility. WBU wishes those platforms could provide a direct voice assistance service when completing those surveys. So perhaps instead of typing or selecting the choice of text or numbers, a system that would allow people to do it via speaking to the system or something like that.

- **Consider the Digital literacy of respondents**

  Second WBU needed to consider the digital literacy of respondents which is another big element when defining the tools that you are going to use to collect the data. The type of survey platform used put all the responsibility to provide data on the respondents, because it was assumed that the respondent has a device that they can use. WBU saw the evidence of this in the survey respondents, you could clearly see from the demographics that people who actually under this pandemic were listed as one of the main risk groups, meaning people over 60, their response rate was lower. Unless you have other methods to support respondents give their data, this can be a limitation of the survey and the data you collect. In more general terms then, digital literacy is definitely something that we should invest more and more in this type of pandemic. Because apparently now in this kind of pandemic, where we all have quickly shifted into a more online world, WBU assumed that people with disabilities were able to shift into this more online world, which is not the case.

- **Think about availability of internet connectivity**

  Not everyone has access to the internet in their home or on their devices to answer the survey. WBU members who generally need more assistance/or who do not have internet connectivity would usually come to partners or institutions where WBU works at a national level. Due to persons with disabilities being one of the risk groups, and due to many institutions being closed because of the pandemic, this meant the usual support, and access to computers and internet connections were not a possibility for completing the survey. Again this is a limitation for collecting data.

- **Increase your data collection by having survey in different languages**

  As a global organisation, WBU membership is across a wide range of countries and regions. Doing only the survey in English limited the number of responses, so WBU also included French and Spanish. This was still quite limiting, but increased the number of potential responses.

- **Reaching those furthest behind with the survey**

  WBU provided some support to national members and their local chapters in reaching out to people through phone or by whatsapp. WBU created some whatsapp groups to support individuals who were trying to respond to questions. It is important to highlight how can you go from top to bottom to reach people because the local chapters of national members facilitated the process through various forms of platforms, like whatsapp groups for individuals to respond to our survey.

Step 4: Analysing the data and building our advocacy messaging

WBU drafted the first questionnaire the second week of March 2020 and published the final report in the first week of September. In total it took five months and this included support from national members supporting the survey roll-out and WBU had to contract in technical expertise for data analysis and for shaping the report. Part of the technical expertise included knowledge transfer to two members of WBU on the process but definitely more capacity building is needed for organisations of persons with disabilities and persons with disabilities from the movement to do this type of work.

Advocacy messaging is mainly orientated to identify actions at national level because that's where WBU believes the change needs to happen. So, for WBU the idea is how we can equip our national members with concrete tools and practical guidelines for advocacy efforts during the pandemic. The key findings of the survey, were actually to try and identify what members should do, or what members could do in supporting their individual affiliates.

Concluding remarks: The role of OPDs in unofficial data collection, some take-away messages

- **Evidence and data drives strong advocacy**

  WBU really wanted to use the data collection work, the whole data piece as a way to better engage national members. Because when the data work has some strategic direction that WBU national members can use, they recognise that data driven advocacy is something that will not come from bottom to top, but rather should come from top to bottom. Because it is at the global level where it is a bit easier to get resources to access to these types of knowledge. WBU believes that as they deal with many other things like the CRPD and the 2030 Agenda, a top to bottom driven advocacy vastly changes national members in getting at least part of the work done at the global level.

- **Need for clarity on roles of OPD in unofficial data collection**

  WBU believes that it is not clear for the OPDs what the different possible roles that they can play in the field of data collection. On one hand it can be from pure advocacy work, that means going to national governments to ask for data collection and data disaggregation (as required by the CRPD and SDGs). But at the same time, they can play roles in collecting very specific data that no governmental agency will collect around persons with disabilities, particularly in such a period like the pandemic.

- **Donor support is needed for OPD data collection**

  One of the main questions that the donor should try to address when defining their funding strategy is capacity building, roles to be played by OPDs, and actually, what kind of partnerships WBU wants with possible donors. Would that exclusively be just financial support and/or would it be a combination of financial support, with technical resources? Especially for those donors who have national offices in different countries, perhaps those national offices could also help OPDs in collecting that data and provide training to data collection processes at a national level. Finally, another consideration would be around how OPDs are going to use the data that is collected. Donors could use the WBU report for some guidance in finding future funding work streams of possible donors. For example, digital literacy is definitely something that should be invested in more in this type of pandemic so that persons with disabilities are fully included in the current growth of online opportunities.

Annex 1: Detailed timeline of advocacy at the UN for SDG implementation

Timeline of Disability Data Advocacy at the United Nations

Purpose of document: This annex was compiled to provide a documented history of disability data advocacy, including advocacy briefs, participation, and outcomes at the United Nations since 2014.

Inter-agency and Expert Group on SDG Indicators (**IAEG-SDGs) Summary of Advocacy**

On 6 March 2015, at its forty-sixth session, the United Nations Statistical Commission created the Inter-agency and Expert Group on SDG Indicators (IAEG-SDGs), composed of Member States and including regional and international agencies as observers. The IAEG-SDGs was tasked to develop and implement the global indicator framework for the Goals and targets of the 2030 Agenda. The global indicator framework was developed by the IAEG-SDGs and agreed upon, including refinements on several indicators, at the 48th session of the United Nations Statistical Commission held in March 2017. The global indicator framework was subsequently adopted by the General Assembly on 6 July 2017 and is contained in the Resolution adopted by the General Assembly on Work of the Statistical Commission pertaining to the 2030 Agenda for Sustainable Development (A/RES/71/313).

CBM in partnership with the International Disability Alliance (IDA), and as a member of the International Disability and Development Consortium (IDDC), and later as a member of the Stakeholder Group of Persons with Disabilities has been advocating for the inclusion of disability data since 2014.

Disability advocates (at this time this was coordinated efforts of the International Disability Alliance and the International Disability and Development Consortium) advocated for the inclusion of persons with disabilities as part of the post-2015 negotiations in which we influenced the development of the SDG indicator framework. We advocated for civil society to have an active, rather than an observer status with the group that would become the IAEG-SDGs.

For details and a timeline on disability data advocacy at the UN at the global level, continue reading.

Prior to the IAEG-SDGs

Prior to the establishment of the IAEG-SDGs, regular negotiations were taking place to create what would become the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs). The International Disability Alliance (IDA), the International Disability and Development Consortium (IDDC) and other disability stakeholders collaboratively advocated for the inclusion of persons with disabilities in the UN post-2015 development processes.

The focus of our IDA-IDDC advocacy was to ensure the SDGs included persons with disabilities since the previous MDGs had not with dire consequences. Throughout these negotiations, discussions on an indicator framework emerged and we engaged in these closely to ensure disability was included in what would become the global indicator framework. A snapshot of these early data advocacy moments is listed below.

2014

On **6 November, 2014** the Secretary-General's Independent Expert Advisory Group on a Data Revolution for Sustainable Development (IEAG) released a report "A World That Counts: Mobilising the Data Revolution for Sustainable Development" that included four references to persons with disabilities. The references were related to the overall lack of disability data, lack of data of children with disabilities in school, lack of data on persons with disabilities in households and in the labor force, and a call for disaggregation of data by disability and other dimensions. The report fed into the post-2015 intergovernmental processes.

December 2014

The UN Sustainable Development Solutions Network (SDSN) working draft on SDG indicators "Indicators and a monitoring framework for Sustainable Development Goals: Launching a data revolution for the SDGs" included 10 references to persons with disabilities (and one footnote). The references were linked to disaggregation of data by disability.

Our participation and advocacy: As IDA and IDDC, we made strong contributions to this draft document.

January 2015

On **16 January, 2015** persons with disabilities had a strong presence at the UN Stakeholder Preparatory Forum for the Post-2015 Development Agenda Negotiations. This session was especially important because both civil society and Member States were in attendance in preparation for the first round of intergovernmental negotiations to be held on 19-21 January. These negotiations were extremely important because they paved the way for the final post-2015 outcomes in September 2015 that eventually led to the adoption of the 2030 Agenda for Sustainable Development and the inclusion of 11 explicit disability references.

25-26 February, 2015 Expert Group Meeting on the indicator framework for the post-2015 development agenda – STAT 441/2/58A

Our participation and advocacy:

We attended this meeting to gather information and influence. More specifically, during this period, IDA and IDDC advocated for civil society to have an active rather than an observer status role with this group (what would become the IAEG-SDGs – Read more here on the establishment of the IAEG-SDGs).

3-6 March, 2015 46th session of the UN Statistical Commission

The Inter-agency Expert Group on SDG Indicators (IAEG-SDGs) was established by the Statistical Commission at its 46th session (3-6 March, 2015) to develop an indicator framework for the monitoring of the goals and targets of the 2030 Agenda for sustainable development at the global level, and to support its implementation.

Our participation and advocacy:

Advocacy Brief: IDA-IDDC Global Indicators Advocacy Brief

Outcome: Assistant Secretary-General included persons with disabilities in his presentation in the Statistical Commission.

6 March, 2015 UN expert meeting: One UN approach to disability statistics

Our participation and advocacy:

• IDA and IDDC participated and presented at this meeting during the special session.

• An outcome was that civil society would be the group to push for disaggregation for data by disability.

May 2015: Intergovernmental negotiations on the post-2015 development agenda

The intergovernmental negotiations on the post-2015 development agenda were held at the UN in New York on 18-22 May, 2015 with a focus on follow-up and review of the agenda, including an update on the indicator framework.

First meeting of the IAEG-SDGs **from 1-2 June, 2015 in New York at the UN Headquarters**

Our participation and advocacy:

Participants: Elizabeth Lockwood, CBM; Orsolya Bartha, IDA

Advocacy Briefs:

• IDA-IDDC: Sustainable Development Goals and Indicators

• IDA and IDDC disseminated our joint IDA-IDDC policy paper on disability-inclusive indicators with the following recommendations:

1. Inclusion of persons with disabilities within the work of the IAEG-SDGs;

2. Disaggregation of data to include persons with disabilities is a priority; and

3. Specific indicators are included to track key issues affecting persons with disabilities.

On **7 July, 2015** the UN Statistics Division released a document with a tentative timeline, work plan and organization of work of the IAEG-SDGs. Click here for details and the new list of indicators (dated 7 July, 2015).

September 2015

The Republic of Korea generously hosted a side event focused on disability indicators on **September 22, 2015**. The event was timely in order to influence the inclusion of persons with disabilities in the second IAEG-SDGs meeting in Bangkok (26-28 October) that aimed to discuss the indicator framework for the monitoring of the Goals and targets of the 2030 Agenda for Sustainable Development at the global level, and to support its implementation. The event was collaborative with support and organization from the International Disability Alliance (IDA), the International Disability and Development Consortium (IDDC), UN organizations and many UN Missions.

September 25, 2015

The UN General Assembly adopted the 2030 Agenda for Sustainable Development at the UN Headquarters on 25 September 2015, but the road map of global follow-up and review continued to be developed. In particular, the development of the global SDG indicators was an on-going process.

Second meeting of the IAEG-SDGs **from 26-28 October, 2015 in Bangkok, Thailand hosted by UNESCAP**

At this meeting, the chapeau (introduction) of the final IAEG-SDGs report was shared with a statement on disaggregation of data, including disability.

Our participation:

Participants: Elizabeth Lockwood, CBM; Orsolya Bartha, IDA; and Mosharraf Hossain, ADD International

Advocacy actions and outcomes: IDA and IDDC composed and disseminated an advocacy brief and letter to advocate for inclusion in the global indicator framework. During the meeting, stakeholders provided brief statements to the IAEG and persons with disabilities were included in the statements on education and health (twice), poverty eradication, employment, and in an overall principles paper (details below).

Advocacy Briefs:

- IDA-IDDC advocacy brief
- IDA-IDDC letter

Stakeholder statements that include persons with disabilities:

- Opening statement
- Global indicators under Goals 1 and 2
- Global indicators under Goals 3 and 4
- Global indicators under Goals 8 and 10
- Global indicators under Goal 16
- Global indicators under Goal 17
- Theme 7: Protect the planet (Goal 7, 12, 13,14 and 15)

December 2015

The theme for the 2015 International Day of Persons with Disabilities on **December 3rd** was **"inclusion matters: access and empowerment for people of all abilities"** with one sub-theme on "improving disability data and statistics." As a result the UN Headquarters hosted discussions on improving and disseminating rigorous disability data collection, identifying key challenges, and mapping out strategies to involve persons with disabilities and their representative organizations in these important processes.

January 2016

On 6 January, 2016 the UN Statistics Division released the Report of the Inter-agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs). The report contains 9 global indicators with explicit reference to persons with disabilities and additionally declared disaggregation of data by disability as a core principle. Read the following blog for details: Global indicators and inclusion of persons with disabilities

Advocacy response:

On **26 January, 2016** IDA, IDDC, World Vision, Together 2030 and ChildFund Alliance co-sponsored a side event on 26 January, 2016 at the UN in New York titled "Civil Society perspectives on the development of the SDGs global indicators framework: Briefing and exchange with Member States." A joint brief from CSOs and stakeholders was presented on the global indicators in reaction to the second IAEG-SDGs report on global indicators that was released on 6 January and Vladimir Cuk from IDA was a panelist

On **28 January, 2016** the President of the General Assembly held an informal meeting on the global SDG indicators to Member States and stakeholders. The focus was on SDG implementation, data disaggregation and the way forward. The IAEG-SDGs indicated that it is committed to include an overarching principle of data disaggregation to ensure that indicators cover specific population groups and other disaggregation elements specified in the targets. The implementation of Global SDG indicator framework will be carried out by: (1) The UN Secretary-General's mandate to produce an annual SDG progress report to support follow-up and review at the High-Level Political Forum; (2) national ownership – data will be produced by national statistical systems and information will be aggregated at the sub-regional, regional and global levels; and (3) statistical capacity building that is essential for national statistical systems to meet the demands of the 2030 Agenda. For details, read the following blog: UN Sustainable Development Goals Global Indicator Framework.

February 2016

The revised IAEG-SDG global indicators report was released with a revised and "Final list of proposed Sustainable Development Goal indicators" (Annex IV). In the updated version, two more explicit references to persons with disabilities were included (11.7.2 and 16.7.2) with a total of 11 explicit references to persons with disabilities in the proposed global Sustainable Development Goal (SDG) indicators.

For additional information, read the blog: The proposed sustainable development goal indicators and the inclusion of persons with disabilities. For additional information, read the blog: The proposed sustainable development goal indicators and the inclusion of persons with disabilities.

The 47th session of the Statistical Commission, 8-11 March, 2016 at UN HQ

The 47th Session of the United Nations Statistical Commission took place on 8-11 March at the United Nations in New York where the Statistical Commission agreed that the global SDG indicator framework would be a practical starting point for global follow-up and review of the 2030 Agenda for Sustainable Development subject to future technical refinement. This was a "decision," not an "adoption" of the resolution to accompany the Report of the Inter-Agency and Expert Group on Sustainable Development Goal Indicators. Read this blog for details.

Third meeting of the IAEG-SDGs **from 30 March to 1 April, 2016 in Mexico City, Mexico hosted by the Ministry of Foreign Affairs of Mexico.**

The IAEG-SDGs meeting in Mexico defined which indicators could be measured, on the basis of availability of data and methodology. At this meeting, as next steps, it was decided that the IAEG-SDGs would set up the work stream on data disaggregation, as well as three working groups on statistical data and metadata exchange, geospatial information, and interlinkages.

Our participation and advocacy:

Participants: Vladimir Cuk, International Disability Alliance; Madezha Cepeda, Musas Inspiradoras de Cambios (Representative of an organization of persons with disabilities from Peru)

Advocacy Briefs:
- Advocacy suggestions
- Advocacy suggestions Español

Outcome: Vladimir Cuk, IDA was nominated by the CSOs to deliver the closing statement.

Stakeholder statements that include persons with disabilities:

- Closing statement

- Statement on disaggregation of data

- Statement on indicators on Goals 1, 2 and 10 (includes reference to the Washington Group)

- Statement on indicators on Goals 11 and 17 (includes reference to the Washington Group)

- Statement on indicators on Goal 16

Fourth meeting of the IAEG-SDGs **from 15-18 November, 2016 in Geneva, Switzerland hosted by the *United Nations Economic Commission for Europe*** (Re-scheduled from original meeting that was scheduled to be in Addis Ababa, Ethiopia and canceled due to security issues.)

This is when the format changed with a closed **meeting** with only IAEG-SDGs members during the first two days and a **plenary session** during the last two days for all countries, international and regional agencies and entities, and other stakeholders. (We advocated to change the format at the sixth meeting, and it was changed at the seventh meeting and onward).

Our participation and advocacy:

Participants:

Catalina Devandas, UN Special Rapporteur on the Rights of Persons with Disabilities; Facundo Chavez, OHCHR; Alarcos Cieza, WHO; Alex Cote, International Disability Alliance; Stefan Tromel, ILO; and Mosharraf Hossain, ADD International

Advocacy Briefs:

- Inputs prior to the meeting: IDA and IDDC Inputs into the Consultation on Possible Refinements of Indicators Identified by the Inter-agency and Expert Group on Sustainable Development Goal Indicators (19-28 September, 2016)

- At the meeting: Disability Data Disaggregation Joint Statement by the Disability Sector

Stakeholder statements that include persons with disabilities:

- Civil society statement on Thursday 17 November morning #1

- Civil society statement on Thursday 17 November morning #2

- Statement on disaggregation by civil society on Friday 18 November (references the Washington Group on Disability Statistics):

First UN World Data Forum 15-18 January, 2017, Cape Town, South Africa, hosted by the Government of South Africa and Statistics South Africa

The first UN World Data Forum took place in Cape Town, South Africa, from 15-18 January 2017, hosted by the Government of South Africa and Statistics South Africa. The Forum brought together key experts from governments, businesses, civil society and the scientific and academic communities to discuss opportunities and challenges and showcase the latest innovations to improve data and statistics for the 2030 Agenda for Sustainable Development.

Disability inclusion at the Forum

Persons with disabilities had a strong presence at the Forum. This included the **International Disability Alliance** (IDA) and the International Disability and Development Consortium (IDDC) disability-focused event, having various panelists throughout the Forum highlight disability (e.g., World Bank, DFID, **and WHO**), and with many organizations of persons with disabilities (DPO) representatives and allies as participants and panelists. Also, there is a disability reference in the **Cape Town Global Action Plan for Sustainable Development Data** (GAP) that was launched at the World Data Forum.

Blogs:

- IDA and IDDC joint blog for the UN World Data Forum in International Sign
- World Data Forum Article on persons with disabilities
- Blog: Disability inclusion at the UN World Data Forum

Fifth meeting of the IAEG-SDGs **from 28-31 March, 2017 in Ottawa, Canada hosted by Statistics Canada**

Our participation and advocacy:

Participants: Glenn Martin, International Federation of Hard of Hearing People; Penny Hartin, World Blind Union

There were many references to disability disaggregation during the meetings. The statement on the use of the Washington Group Short Set of Questions was put into a joint statement on disaggregation. In addition, the IAEG member from Mexico supported the Washington Group Short Set of Questions and the joint statement on disaggregation was distributed to all Member States and UN agencies at the meeting.

Advocacy briefs:

- Disability Data Disaggregation Joint Statement by the Disability Sector

Stakeholder statements that include persons with disabilities:

- Civil society statement on data disaggregation

Group Statement by New Zealand at the 10th session of the Conference of States Parties to the CRPD, 13-15 June, 2017 to recommend the Washington Group Short Set of Questions to be used as a tool to disaggregate data by disability. Countries included: Antigua and Barbuda, Argentina, Australia, Austria, Brazil, Bulgaria, Canada, Costa Rica, Dominican Republic, Finland, Iceland, Jamaica, Jordan, Mexico, Morocco, New Zealand, Norway, Panama, Poland, Spain, Tunisia, Turkey, United Kingdom, United States and Zambia.

Sixth meeting of the IAEG-SDGs **from 11-14 November, 2017 in Manama, Kingdom of Bahrain hosted by** *The Bahrain Center for Strategic, International and Energy Studies (DERASAT)*

Our participation and advocacy:

Participants: Elizabeth Lockwood, CBM; Orsolya Bartha, IDA

IDA and IDDC advocated for disaggregation of data by disability during the plenary as well as with the co-chairs of the disaggregation work stream. The disaggregation work stream released its first document on disaggregation entitled "Overview of standards for data disaggregation." You can read more here.

As part of the larger stakeholder group, we had the excellent opportunity to meet with the IAEG-SDGs co-chairs (Mexico and Tanzania) to propose our recommendations to make the process more inclusive. Our feedback was received well overall and to open the space for civil society to engage more meaningfully in the indicator process. One of the requests was to ensure that all stakeholders could attend all IAEG-SDGs meetings.

Outcome: Our advocacy was successful and the following IAEG-SDG meeting (7th) was open to all stakeholders for the entire time, including UN agencies and civil society.

Read here for additional information and the blog: Data collection and persons with disabilities.

Advocacy Briefs:

- Advocacy Brief: Disaggregation by Disability (short version)
- Advocacy Brief: Disaggregation by Disability (long version)

Stakeholder statements that include persons with disabilities:

- Stakeholder Statement on Agenda item 10: data disaggregation (presented by Orsolya Bartha and statement coordinated by Elizabeth Lockwood)
- Presentation by Stakeholders over Agenda item 8: SDG implementation and reporting at national regional, global and thematic levels; Open Data Watch - Gender Data and the SDGs
- Presentation by Stakeholders over Agenda item 8: SDG implementation and reporting at national regional, global and thematic levels; Women's Major Group SDG Implementation

Expert meeting on disability disaggregated statistics for monitoring of the SDGs, March 26-27 2018 at the Church Center, NYC, organized by UNICEF, IDA, Washington Group. IDA-IDDC presented jointly in the meeting.

Seventh meeting of the IAEG-SDGs **9-12 April, 2018 in Vienna, Austria at UNIDO**

Our Participation and Advocacy:

Participants: Elizabeth Lockwood, CBM; Orsolya Bartha, IDA; Sarah Meschenmoser, CBM Germany, Andrew Griffiths, Sightsavers

The meeting focused on several topics. The most pertinent for persons with disabilities and our advocacy were the (1) discussion on progress made on the work stream on data disaggregation and (2) experiences on implementing monitoring of the SDGs. Also, new and updated documents were shared. Relevant for persons with disabilities, we are quite pleased that the Working Document "Overview of standards for data disaggregation" included all the inputs from the Stakeholder Group of Persons with Disabilities, which includes the Priority List of Indicators that should be Disaggregated by Disability.

Advocacy Briefs:

The Stakeholder Group of Persons with Disabilities' Priority List of Indicators that should be Disaggregated by Disability.

Outcomes:

Stakeholder briefing with co-chairs (Mexico and Tanzania): We met with the IAEG co-chairs and had a very good and inclusive meeting. The session on data disaggregation was quite inclusive of persons with disabilities. OHCHR presented during the session and included disaggregation by disability and also referenced CRPD Article 31 on statistics and data collection. Click here for the full presentation. In addition, UN Women mentioned that the Washington Group was a good tool for data collection. Most impressive was that UNICEF presented specifically on disability disaggregation focusing much on the recent disability data disaggregation meeting in New York with UN Agencies, IDDC, IDA, and others. You can see some of the presentation slides here. The priority list of SDG indicators, again, was included. Click here for the full presentation. Later in the meeting, disability data was mentioned again by UN Women and also by the National Statistical Office (NSO) from Egypt on SDG data that they are collecting.

Workshop on the Measurement of Disability for DPOs, June 10, 2018 – Organized by IDA, IDDC, UNICEF, and Washington Group on the margins of COSP. UNICEF funded the event and IDA and IDDC coordinated DPO selection and logistics. This was held at the Church Center in New York. We presented as IDA and IDDC, and supported the DPO and NGO representatives, many were IDA and IDDC members.

Second UN World Data Forum, 22-24 October 2018, Dubai, United Arab Emirates

Advocacy:

IDA and IDDC hosted a side event on disability data and the Global Action on Disability (GLAD) Network Joint Statement on data disaggregated by disability was shared.

Outcome:

The Dubai Declaration Supporting the Implementation of the Cape Town Global Action Plan for Sustainable Development Data was announced at the UN World Data Forum. It was prepared by the HLG-PCCB (and endorsed at the 50th Session of the UN Statistical Commission in March 2019). It includes a disability reference to "ensure that quality, relevant, timely, open and disaggregated data by income, sex, age, race, ethnicity, migration status, **disability** and geographic location and other characteristics relevant in national contexts are made available and accessible to all users" (para 13).

Eighth Meeting of the IAEG-SDGs **5 to 8 November, 2018 in Stockholm, Sweden at SIDA**

This was the first time that persons with disabilities were part of an official panel at an IAEG meeting, which was presented by Vladimir Cuk, Executive Director of the International Disability Alliance on behalf of the Stakeholder Group of Persons with Disabilities.

Our Participation and Advocacy:

Participants: Elizabeth Lockwood, CBM; Orsolya Bartha, IDA; Vladimir Cuk, IDA

Presentations:

- Agenda Item 8: SDG Implementation and monitoring - data disaggregation case studies and best practices

- Additional Information

Outcomes:

Overall, the meeting was positive and inclusive. In addition to having an official speaking role, another positive outcome of the IAEG meeting was that three disability-inclusive indicators were reviewed and declared measurable. There was an official panel on disaggregation in which there was strong support for disability data:

Disaggregation meeting (following the IAEG-SDGs meeting)

This was the first time the Stakeholder Group of Persons with Disabilities was invited to a disaggregation meeting. Quite positively, data disaggregation by disability was discussed throughout the meeting.

Outcome: From discussions at the disaggregation meeting, a paper on policy priorities of disaggregated data for underrepresented groups was included as an official background document at the 50th session of the Statistical Commission Paper: Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans. Refer to the section on the 50th session of the UN Statistical Commission for details.

The Stakeholder Group of Persons with Disabilities' Disability Data Advocacy Working Group, established in January 2019

The Stakeholder Group of Persons with Disabilities established a Disability Data Advocacy Working Group **on January 7, 2019** to provide a global platform for information exchange, learning and dialogue, sharing of good practices, and collaboration on disability data collection, disaggregation, research and analysis. Click here for more information. The HLPF Secretariat coordinates the logistics of the webinars and newsletters.

The 50th Statistical Commission, 5-8 March, 2019 at UN HQ

This event was particularly relevant as it marked the 50th session of the Statistical Commission.

Outcome: As a fruitful outcome from long-term advocacy, an official background document was shared at the Statistical Commission over Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans. Disability data are strongly included in the document, such as the availability of current and future indicators that disaggregate data by disability (15 additional indicators), You can read more here for details.

Side Event: Making disability visible in statistics, 6 March, 2019

For the first time the Statistical Commission held a side event co-sponsored by the Stakeholder Group of Persons with Disabilities, IDA, CBM, the Washington Group, and the Department of International Development (DFID). The event focused on bridging the gap between policymakers, civil society and statisticians. Click here for more information about the side event.

Ninth meeting of the IAEG-SDGs **25-28 March, 2019 in Beirut, Lebanon at UNESCWA**

Our Participation and Advocacy:

Participants: Elizabeth Lockwood, CBM; Orsolya Bartha, IDA

During the meeting, IDA and CBM conveyed key advocacy messages, including the importance of using the Washington Group short set of questions and WG/UNICEF Child Functioning Module, and the importance of bringing civil society, statisticians, and policymakers together for evidence-based policymaking. The latter message was reinforced several times by many actors at the meeting (e.g., UNSD, Ghana, ILO, UK, and Cambodia). IDA and CBM gave two official presentations: (1) on the disability data advocacy working group (that we co-facilitate with IDA) and (2) perspectives of a data user. A number of countries and UN Agencies included disaggregation by disability in their interventions, as well as the importance of using the WG-SS, but also indicated the challenges of collecting data. For details read the blog: Disability-inclusive policy change through data.

Outcomes:

• A number of countries and UN Agencies included disaggregation by disability in their interventions (e.g., UN Women), as well as the importance of using the Washington Group short set of questions.

• UN Statistics Division highlighted persons with disabilities as one of two good examples of policy priorities of disaggregated data included in an official background document at the 50th session of the Statistical Commission: Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans.

• All additional relevant tiers for persons with disabilities (16.6.2, 16.7.1b, 16.7.1c, 16.7.2, 4.2.1*) were reclassified from tier III to II as measurable.

Presentation:

• Presentation of the Disability Data Advocacy Working Group

IAEG-SDGs 2020 Comprehensive Review of Global Indicators, 3 June, 2019

The Stakeholder Group of Persons with Disabilities (SGPwD) hosted an open call with Major Groups and other Stakeholders on 3 June on the IAEG-SDGs 2020 Comprehensive Review. Following the call, the SGPwD submitted feedback into the open consultation of the 2020 comprehensive review in August, 2019 and shared an advocacy paper with UN Statistics Division and WHO.

The 12th session of the Conference of States Parties to the CRPD, 11-13 June, 2019

At the Conference of States Parties to the CRPD, we organized and participated in data events.

On 10 June, 2019 the Stakeholder Group of Persons with Disabilities, in collaboration with the Permanent Missions of Italy, Australia and the Republic of Zambia to the United Nations, the International Disability Alliance, Disabled Peoples' International, World Blind Union, CBM, UN Statistics Division and the Washington Group on Disability Statistics, organized its first side event at the Conference of States Parties to the CRPD titled "Including the furthest left behind: Disability Data Advocacy Working Group." Details can be found here: Including the furthest left behind: Disability Data Advocacy Working Group"

On 11 June, the League of Arab States along with the Stakeholder Group of Persons with Disabilities, International Disability Alliance, CBM, Leonard Cheshire, and the Washington Group on Disability Statistics organized a panel discussion that contributed to the dialogue on improving data collection and disaggregation for persons with disabilities by sharing experiences of current activities mandated by the global SDG indicator framework. More information can be found here: Making Disability Visible in Disability Statistics.

Workshop on the Measurement of Disability for DPOs – organized by UNICEF, Stakeholder Group of Persons with Disabilities, and CBM, 14 June, 2019

On 14 June, 2019 UNICEF, in collaboration with the Washington Group on Disability Statistics, Stakeholder Group of Persons with Disabilities, International Disability Alliance and CBM (funded fully by CBM), organized a full-day disability data training on the margins of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities. You can read more about the workshop here.

VNR Lab: Bridging the policy-statistics gap: Strengthening the use of data for evidence-based VNRs, 17 July, 2019, at UN HQ, organized by UN Statistics Division during the 2019 HLPF

Elizabeth Lockwood presented as CBM on behalf of the International Civil Society Centre to present at the UNSD organized VNR Lab Bridging the policy-statistics gap: Strengthening the use of data for evidence-based VNRs with NSOs, OECD, and Open Data Watch.

Tenth meeting of the IAEG-SDGs 21-24 October, 2019 in Addis Ababa, Ethiopia at UNECA

This meeting was critical since at the meeting the IAEG-SDGs discussed proposals containing possible indicator deletions, replacements, adjustments and additions with custodian agencies and other experts in preparation for the final proposal for the 2020 review. This final proposal was finalized by the end of November, 2019 in order to be submitted to the Commission for consideration at the 51st session of the UNSC in March 2020. We engaged extensively in this process. Read the blog for details: Measuring the implementation of the Sustainable Development Goals

Our Participation and Advocacy:

Participants: Elizabeth Lockwood, CBM; Mohammed Loutfy, DPI and Stakeholder Group of Persons with Disabilities

Presentations:

As CBM and the Stakeholder Group of Persons with Disabilities, we were very active and presented a total of four times (two were as official panelists), including:

- In the Stakeholder Briefing on behalf of stakeholders calling for a stakeholder side event at the 51st session of the Statistical Commission;

- At the data disaggregation side event on two best practices, including the Washington Group review on which data on SDG indicators currently available can be disaggregated by disability status and the CBM and Fundación Vision, Paraguay project on disability disaggregated data collection in an eye hospital in Paraguay;

- As an official panelist on the disability data advocacy working group's advances in producing data disaggregated by disability; and

- As an official panelist as CBM on the International Civil Society Centre's Leave No One Behind Partnership on inclusive SDG implementation that addresses the needs of marginalized groups effectively, including persons with disabilities.

UN Women and UN Statistics Division organized a global conference "Counted & Visible" 26-27 February, 2020

UN Women and UN Statistics Division organized a global conference "Counted & Visible" on the measurement of gender and intersecting inequalities from 26-27 February, 2020 at the UN Headquarters. The event took place on the margins of the 51st session of the UN Statistical Commission, but with a particular focus on intersectionality that is increasingly important in global processes, as well as in data collection. Disability was highlighted throughout the event as a key area in which to focus, truly indicating how far we've come to increase the visibility of disability data at the global level. One session was specifically dedicated to data and women and girls with disabilities with presentations from Chile, Senegal, UN ESCWA, UNICEF, and CBM and the Stakeholder Group of Persons with Disabilities. Elizabeth Lockwood presented from the civil society perspective, particularly looking at citizen-generated disability data with three examples from the local level. Read more about the event here.

51st Session of the UN Statistical Commission, 3-6 March, 2020

From 3-6 March the 51st session of the UN Statistical Commission took place at the UN in New York. A Joint report of the Secretary-General, the Washington Group on Disability Statistics and international agencies was shared as an official document. The report contains a good compilation of disability data work being carried out by different international agencies: ESCAP, ILO, UNESCO, UNESCWA, UNICEF, World Bank, and the Washington Group on Disability Statistics. In addition, UN Women also works on disability data, but is not included in the report, yet they included disability data in their intervention. It is very positive to see civil society included in this report as key partners in this work, including CBM. The Washington Group made an official statement on 6 March, 2020 in response to the report that also highlighted civil society's role in disability data work. UN Women and Kenya also highlighted disability data in their interventions during the meeting.

COVID disability data work under the SGPwD, May to June, 2020

The SGPwD published a report on The experience of persons with disabilities with COVID-19 // En Español. CBM Global Disability Inclusion co-wrote and co-coordinated with IDA the SGPwD report on persons with disabilities and their experiences with COVID-19. There is an important chapter on COVID and disability data gathered from participants.

UN Statistics Division Open Virtual Meeting of the IAEG-SDGs, 2 June, 2020

Elizabeth Lockwood presented on behalf of CBM Global and the SGPwD in the IAEG-SDGs online webinar "Covid-19 impacts and responses on data collection and SDG monitoring for persons with disabilities." For a summary, read the blog here and the full presentation here.

Washington Group on Disability Statistics first webinar, 25 August, 2020

The SGPwD presented in the Washington Group on Disability Statistics first webinar on "Using the Washington Group Tools to Assess the Impact of COVID-19 on Persons with Disabilities." The SGPwD presented on the importance of collecting data on COVID and persons with disabilities. You can read the full presentation here.

Annual virtual meeting of the Washington Group on Disability Statistics, 22-24 September, 2020

The Stakeholder Group of Persons with Disabilities was invited to present twice on the importance of collecting data on COVID and persons with disabilities. Click here to read the full presentation.

A Virtual UN World Data Forum, 19–21 October 2020

An event on "Persons with disabilities and COVID-19 data collection and disaggregation efforts" is being organized by the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, World Blind Union and CBM.

Annex 2: Disability Data Sources

Name of resource	Link	Description
The United Nations Statistics Division Disability Statistics Portal	https://unstats.un.org/unsd/demographic-social/sconcerns/disability/statistics/#/countries	has maintained a comprehensive repository on disability statistics since 1988. It contains data and metadata on disability from official statistics compiled from national population and household censuses, household surveys and some administrative data. The data mainly shows prevalence of disability in some countries and aims to illustrate socio-economic characteristics and living conditions of persons with disabilities compared with persons without disabilities.
Disability Data Portal run by Leonard Cheshire	https://www.disabilitydataportal.com/	A UK NGO focused on disability. This portal is funded by the UK Department for International Development (DFID). The Disability Data Portal has statistics for countries on five major topics: disability incidence, inclusion in education, economic empowerment, technology and innovation, and stigma and discrimination.
International Household Survey Networks	http://www.ihsn.org/	
SDG Data Hub	http://www.sdg.org/	can download data for all of the SDG indicators
Sustainable Development Goals Report	https://www.un.org/sustainabledevelopment/progress-report/	Annually reviews progress on the SDGs implementation of the SDGs and the accompanying statistical mapping. While it is a well-designed interactive website there doesn't seem to be much on disability, and it seems to lack a search facility.

Name of resource	Link	Description
the UN Statistics Division	h<u>ttps://unstats.un.org/sdgs/</u>	However, on the website of the UN Statistics Division[5] all the progress reports from 2016-2019 are available and accompanied by a statistical annex that provides information on indicators for which data are available. There is global data available for social protection and employment, but the data is presented by subregions and not by country. Country level data can be found on the website of the custodian agency, which is the International Labour Organization (ILO).
SDG Tracker	<u>https://sdg-tracker.org/</u>	while the site contains an option to search indicator by indicator it seems to be hard to access data that is disaggregated by disability. For instance, it is possible to find goal 4.5, "Ensure the proportion of schools by 100% with access to adopted infrastructure and materials for the child/students with disability" but when we click on "view" it just takes us back to the beginning ("All goals").
Economic and Social Commission for Asia and the Pacific (ESCAP) Statistical Division Data Portal	<u>http://data.unescap.org/escap_ stat/#home</u>	
the United Nations Economic Commission for Africa (ECA) Statistical Division Data Portal	<u>https://ecastats.uneca.org/ data/</u>	

[5] <u>https://unstats.un.org/sdgs/</u>

Name of resource	Link	Description
UN Women data portal	https://data.unwomen.org/data-portal	The UN Women data site has information on the following broad topics for many countries: poverty, hunger, health, education, gender equality, work and economic group, peace and justice. Specific statistics of interest for disability are the proportion of the population with severe disabilities receiving disability cash benefit (by sex) and the proportion of the vulnerable population receiving social assistance cash benefit (by sex.)
UNICEF data portal	https://data.unicef.org/	The UNICEF data portal has many statistics on the status of children and families around the world, including Bangladesh and Kenya. However, there is no data directly relevant to disability.
ILO Stats portal	https://ilostat.ilo.org/data/	the main source of the ILO's data on social protection is the Social Security Inquiry, which is ILO's "periodic collection of administrative data from national ministries of labour, social security, welfare, finance, and others."
National Voluntary Reviews	https://sustainabledevelopment.un.org/vnrs/	

The ILO Stats portal[6]

According to metadata on the SDGs found on the UN's Department of Economic and Social Affairs Statistics Division website,[7] the main source of the ILO's data on social protection is the Social Security Inquiry, which is ILO's "periodic collection of administrative data from national ministries of labour, social security, welfare, finance, and others."

Non-governmental data sources

Non-governmental data sources can be important. Typically, governments and international organizations have the most resources to gather data on large groups of people, but non-governmental data can fill gaps. Typical sources of non-governmental data are foundations, NGOs, research institutions, as well as academics writing alone or in small groups. Following is a list of some non-governmental sources of data on disability in tabular format.

Data Source	Site Address	Notes
UN World Data Forum	https://unstats.un.org/unsd/undataforum/index.html	An international conference of data experts.
Disability Data Collection	https://reliefweb.int/report/world/disability-data-collection-summary-review-use-washington-group-questions-development	A summary review of the use of the Washington Group Questions by development and humanitarian actors
International Centre for Evidence in Disability (ICED)	https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability	Mainly a clearinghouse for research articles.
Country Diagnostics	https://www.countrydiagnostics.com	Country-focused analysis from development groups readily accessible to decision-makers, researchers and civil society. Leading development finance institutions have launched a new joint website that provides in-depth economic analysis of the countries they support and helps them address key challenges.
ICSC Leave no one behind project	https://icscentre.org/our-work/leave-no-one-behind/	Mainly a clearinghouse for research articles.
Washington Group on Disability Data	http://www.washingtongroup-disability.com/	The Washington Group's Report of 30 October 2018, Selected SDG Indicators Disaggregated by Disability Status, has data for 39 countries.

[6] https://ilostat.ilo.org/data/
[7] https://unstats.un.org/sdgs/metadata/

▼ Balukhali, Bangladesh - 2018-08-01 - An inclusive group activity in the Centre for Disability in Development (CDD)/ CBM inclusive child friendly space (CFS) led by Mohi Uddun, inclusive education facilitator, in the Rohingya refugee camps in Balukhali, Cox's Bazar district, Bangladesh on August 1, 2018.

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