Data sources guidance:

Introduction

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Introduction

The Convention on the Rights of Persons with Disabilities, adopted by the General Assembly in December 2006, affirms and protects the human rights of persons with disabilities and their full equality under the law, free from discrimination.

As the first human rights treaty of the twenty-first century, the Convention put forward innovative provisions to facilitate the implementation and monitoring of human rights obligations, one of which is article 31. Article 31 is the first-ever stand-alone provision in a human rights treaty (and, to date, the Convention is the only one with such a provision) calling for the collection and disaggregation of data (see part II, section 1.5 of the Foundations guidance). In effect, the limited data related to persons with disabilities have been a long-standing barrier to shaping laws and policies that improve the development of, access to and exercise of their rights on an equal basis with the rest of society.

Identifying data sources, and their gaps, is key to ensuring that government action is informed to better reach out to those who are left behind. In recognition of the importance of data and their fundamental role in shifting towards a sustainable and resilient path, the 2030 Agenda for Sustainable Development commits States to engaging in systematic data collection and disaggregation to help achieve and measure the Sustainable Development Goals. This disaggregation takes place within the broader context of a human rights-based approach to data collection that brings together data relevant to stakeholders and develops communities of practice that improve the quality, relevance and use of data and statistics consistently with international human rights norms and principles. Through the human rights-based approach to data, several key principles are identified that are central to the collection of data. These principles are focused on participation, data disaggregation, self-identification, transparency, privacy and accountability.

Indicators on the Convention on the Rights of Persons with Disabilities

Against this background, the Office of the United Nations High Commissioner for Human Rights (OHCHR) developed indicators on the Convention to provide a comprehensive framework that covers the full breadth of human rights of persons with disabilities. These indicators serve to track and measure the progress of the implementation of the Convention. Because goals are accomplished over time, these indicators must capture the actions taken, as well as their subsequent effects. These are reflected in three types of indicators:

1. Structural indicators track a State's commitment (e.g. ratification and adoption of laws, policies and institutional mechanisms for the promotion and protection of human rights);

2. Process indicators track actions taken to achieve the fulfilment of those rights (e.g. training, awareness-raising and consultation);

Outcome indicators record the impact of actions and describe the extent to which the rights of persons with disabilities are being fulfilled. For more information on the indicators and

the human rights indicators methodology of OHCHR, see the Frequently Asked Questions (FAQs) on the indicators.

These three types of indicators, taken together, can provide a comprehensive country picture of the realization of the rights enshrined in the Convention. By measuring against the indicators on the Convention, it is possible to gauge implementation of the Convention at a given point in time and to then track progress over periods of time. As such, the information provided through the indicators can offer a strong foundation for monitoring reports to the Committee on the Rights of Persons with Disabilities or other human rights mechanisms, including for a disability-specific perspective on progress towards the achievement of the Sustainable Development Goals. For more information on reporting, see FAQs 6 and 9 on the indicators.

Data sources

The production of outcome indicators in the OHCHR indicator framework requires the collection of data from a variety of sources. The sources and the identified data-generating mechanisms should be suitable for assessing the compliance of States parties with international human rights treaties. Official data sources should be prioritized, such as United Nations agencies and national statistical offices and statistical systems. These sources include:

1. Administrative data collected primarily as part of the running of government programmes;

2. Census data obtained from population censuses, typically collected every 10 years;

3. Survey data, which can include both established surveys that are regularly fielded as part of a country's core national statistical infrastructure, but also special modules to gather information that is not regularly collected, and disability surveys, which have the space for gathering much more detail;

4. Qualitative data from focus groups, structured interviews and other methods designed to obtain more detailed descriptions of the dynamics of life.

Administrative data relating to disability status tend to be collected only for programmes where disability-related services are provided, such as disability pensions or special services in schools. As such, they are useful for indicators pertaining to particular programmes but not for population-based indicators, because people not in a programme are not included in the data. Some countries do, however, collect disability data more generally in some administrative data systems to monitor the participation of persons with disabilities.

Through many censuses, data on disability have been collected for quite some time. In the past, the questions used were often not optimal. However, in the last round or two of censuses, the number of countries using the Washington Group sets of questions, recommended by the Statistics Division of the United Nations, has been growing significantly. Because they require large resources, censuses are done at most every 10 years. Often, only a limited amount of information on each person is collected. In addition, an increasing number of countries collect census data, including data on persons with disabilities, from population registers,

that is, accounts of residents within a country. They are typically maintained through the legal requirement that both nationals and foreigners residing in the country must register with local authorities. Aggregation of these local accounts results in a record of the population and population movement at the national level.

Most development indicators rely on household surveys that are done on a regular basis. Some, like labour force surveys, are done on an annual basis, while others are done anywhere from every two to five years. Adding disability questions to these surveys allows for all indicators generated by them to be disaggregated by disability status, as explained below. However, more specific or specialized indicators focusing on personal or environmental aspects particular to disability would require additional modules to be added to these surveys or the implementation of a specific disability survey. A disability survey is best suited for the collection of data to take a comprehensive look at the barriers and facilitators affecting participation. As development indicators do not change as rapidly as outcome indicators – such as those on income, poverty or employment – implementing disability surveys less frequently, such as every five years, would be adequate to determine the indicators for which they are particularly well suited.

The data sources guidance does not include examples of community-driven data from organizations of persons with disabilities or other civil society organizations. Data are commonly collected by these organizations and, although they may not have statistically significant information or a representative sample, they reflect the experiences of persons with disabilities. They can inform gaps in surveys that may not have targeted certain territories (such as slums or informal settlements) or persons with disabilities specifically (i.e. epidemiological data). See below the example of the Disability Data Advocacy Toolkit. National statistical offices and policymakers are encouraged to look at community-driven data as a resource for informing policy, in the spirit of recognizing the voices of persons with disabilities and reflecting the principle of participation. See part I, section 2.4, and part II, section 2 of the Foundations guidance.

The International Disability Alliance, CBM and the Stakeholder Group of Persons with Disabilities have produced a toolkit through which they seek to contribute to the growing global dialogue on the importance of data on persons with disabilities and to provide basic information on data collection and the analysis and use of data for evidenced-based advocacy. The toolkit includes examples of initiatives on generating community-driven data to monitor progress in the achievement of the Sustainable Development Goals.

In all cases, there is a need to combine different sources and data-generating mechanisms to encourage a more comprehensive and credible assessment of any human rights situation.

Purpose and framework of the data sources guidance

The data sources guidance provides guidance on how different sources of data can be used to respond to, and provide a measure for, the outcome indicators. For each article, the outcome indicators are listed, and information is given on examples of data sources for each indicator.

Examples of countries already producing an indicator are given or, when no country has been found to be reporting on the indicator, there are examples of where modifications to existing data collection could be applied to produce it, and links are provided to the data source, where available. The goal of the data sources guidance is to suggest appropriate methodologies that can build on existing data collection and fulfil reporting on these indicators as efficiently as possible. For some indicators, this is straightforward and requires few, if any, modifications to data collection. Other indicators are more challenging. For this reason, indicators have been categorized into three levels.

Data source classifications

Level 1. Indicators for which data are already being produced and reported on in at least some countries.

Level 2. Indicators that either:

1. Can be produced with existing data but have not been reported on; or
2. Can be produced with straightforward additions or modifications to existing data collection efforts.

Level 3. Indicators for which acquiring data is more complex or requires the development of data collection mechanisms that are not currently in place.

An indicator is categorized as **level 1** if any example has been found where the indicator was being produced and reported on. A brief description of this example is given, along with links to show in more detail how it is being done. The methodology for producing these indicators is clear and has been proven to work.

For **level 2** indicators, examples and sources are provided that, with some straightforward modifications or expansions, could be developed into level 1 indicators.

Level 3 indicators are those for which no examples have been found where countries were collecting data that could be easily employed to respond to these indicators. These will require significant efforts and creativity. Guidance is given, however, on how to begin to address this. The naming of level 3 indicators serves to identify those areas where methodologies and systems of data collection are needed. As can be seen in the guidance, these indicators tend to be on articles for which data collection has been less developed.

Clearly, data collection efforts and capabilities vary across countries. An indicator that is at level 1 in one country might be at level 2 in another. The data sources guidance is not meant to serve as an overview of countries' capacities or experiences in reporting on these indicators. It does not serve to grade countries, nor does it provide a representative overview of how various indicators are being generated globally. It merely provides examples of data collection efforts that can be useful for countries in determining the best way to generate these indicators in their own contexts.

Readers should be aware that, sometimes, the same indicator appears under multiple articles. The Convention cuts across sectors, and those sectors are often interrelated. For example, under article 7 on children with disabilities and article 28 on an adequate standard of living, the same indicator on undernourishment is included. Where this occurs, the indicators are cross-referenced.

In addition, sometimes the available data do not match the level of detail required to effectively use the indicator. In those instances, it is still recommended that countries report on the best available data that come closest to capturing the indicator. Some of the examples for the level 2 indicators do not exactly match the indicator as written, but they can still be useful in gauging progress towards fulfilling that aspect of the Convention, while efforts are made to improve the scope of data that can be reported.

It is important to note that the methodologies presented in the guidance are in no way meant to be prescriptive; they are only suggestive of how the indicators can be produced. In a particular country or context, other statistical tools or administrative procedures may exist that are more appropriate. Furthermore, the present guidance is meant to be a living document; as better examples are found – or new methodologies or data gathering tools are developed – the guidance herein will be updated. To that end, if users of the present guidance are aware of, or develop, good examples of how to generate data responding to any particular indicator, the sharing of those examples would be welcomed. Such information can be sent to disability@ohchr.org.

Leveraging existing resources

As set out and explained in the FAQs on the indicators on the Convention (see in particular FAQ 8), a significant number of the indicators referred to in the data sources guidance are simply disaggregated versions of the Sustainable Development Goal indicators. In those cases, the starting point is the metadata of the Goals, which can be found in the metadata repository.

Globally, many agencies are already compiling data on these indicators, but they are not often disaggregated by disability status. Sometimes, national data sources already contain information on disability status, in which case it would be straightforward to do the disaggregation. If the data sources used for a variety of Sustainable Development Goal indicators – such as labour force surveys, Household Income and Expenditure Surveys, and Demographic and Health Surveys – include disability questions, then all of the indicators already being generated through those surveys could be disaggregated, as recommended in the global indicator framework for the Sustainable Development Goals and targets of the 2030 Agenda for Sustainable Development (target 17.18) and as required for the Convention indicator framework presented in the present guidance. This would be the most efficient way of populating the indicators with data. Within countries, agencies compiling data for the indicators on the Goals in their respective thematic areas should be encouraged to request disaggregation when possible and to recommend adding disability questions to existing data instruments so that disaggregation can be done systematically in the future.

Systematic disaggregation would increase the sustainability and continuity of indicator generation. When possible, it is preferable to generate indicators using ongoing surveys that are done regularly, not more intermittent or one-off surveys from which no time trend can be established. As mentioned above, however, some indicators must be generated through specialized surveys that are carried out on a less frequent basis because of the resources needed for their collection.

Disability identification

Many of the indicators require the identification of persons with disabilities, and how this is done will affect the results. For example, studies have shown that simply asking "Do you have a disability?" in surveys will underidentify persons with disabilities. Asking whether the person has a disability certification is also problematic. Obtaining such a certificate is dependent upon many factors, such as whether a person is aware of, or has the resources to go through, the certification process, whether the certification process is accessible in the territory or if support is provided to access it, and the nature of the eligibility requirements for disability programmes.

The international standard for identifying persons with disabilities in order to disaggregate data for the Sustainable Development Goals, and the one recommended by the Statistical Division of the United Nations for census-based prevalence estimates, is the Washington Group short set of questions on functioning. These questions are focused on measuring the level of difficulty in doing basic activities such as seeing, hearing, walking, remembering/concentrating, communicating and self-care. The idea is that people who have difficulty or who are unable to engage in those activities on their own are at risk of not being able to participate fully in society due to barriers in the environment. This function-based approach is recommended for disability identification, and the Washington Group short set of questions, which is already included in many data tools, is recommended for implementing the function-based approach.

However, it should be noted that the Washington Group short set has limitations. For example, it is known to miss many children with developmental disabilities. It is for that reason that the United Nations Children's Fund (UNICEF) and the Washington Group developed the Child Functioning Module, which has been incorporated into the Multiple Indicator Cluster Survey and other tools. It is the recommended methodology for identifying children with disabilities in surveys.

The other significant limitation of the Washington Group short set is that it underidentifies people with psychosocial disabilities. The Washington Group has included additional questions for that functional domain in its Extended Set of questions, and they have been adapted for use in the Labour Force Survey Disability Module, which was developed together with the International Labour Organization. Even if the entire Washington Group extended set of questions – which is quite lengthy and mainly suitable for specific disability modules or surveys – is not used, the four questions on psychosocial issues can be added to the Washington Group short set where relevant. In some countries, other issues or specific populations – such as

persons with albinism – might be of particular importance. Information and recommendations on these issues, and more, can be found on the website of the Washington Group on Disability Statistics. The key takeaway message is that care should be taken in exactly how disability is defined in the construction of the indicator.

Despite these limitations, the Washington Group short set of questions has been widely endorsed by the Committee on the Rights of Persons with Disabilities, the Special Rapporteur on the rights of persons with disabilities, OHCHR and other United Nations entities, the World Bank, civil society (including the International Disability Alliance and the International Disability and Development Consortium) and many States. It is currently recognized as the instrument best placed to disaggregate data by disability for the purposes of the Sustainable Development Goals, and it can be easily and cost-effectively inserted into all national data collection efforts.

OHCHR has developed examples of survey questions to facilitate data disaggregation by relevant characteristics, including disability. See "Guidance note for implementation of survey module on SDG indicator 16.b.1 & 10.3.1 (discrimination)", annex.