

Data sources guidance:

Introduction



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The Convention on the Rights of Persons with Disabilities (CRPD), adopted by the United Nations 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 CRPD 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 CRPD is the only one with such a provision) calling for the collection and disaggregation of data (see [Foundations Guideline](#), section 3.5). In effect, the absence of data related to persons with disabilities has been a longstanding barrier to shaping laws and policies that improve development, access, 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 its fundamental role in shifting toward a sustainable and resilient path, the 2030 Agenda commits States to engage in systematic data collection and disaggregation to help achieve and measure its 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. The human rights-based approach to data identifies several key principles that are central to the collection of data. These principles focus on participation, data disaggregation, self-identification, transparency, privacy and accountability.

Human rights 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 [human rights indicators on the CRPD](#), 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 CRPD implementation. Since 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:

- Structural indicators track the State's commitment (e.g. ratification and adoption of laws, policies and institutional mechanisms for the promotion and protection of human rights).
- Process indicators track actions taken to achieve the fulfilment of those rights (e.g. training, awareness-raising, 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 CRPD indicators and OHCHR's human rights indicators methodology, see the [Frequently Asked Questions \(FAQs\)](#) on the CRPD indicators.

These three types of indicators, taken together, can provide a comprehensive country picture of the realization of the rights enshrined in the CRPD. By measuring against the CRPD indicators, it is possible to gauge CRPD implementation 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 CRPD Committee or other human rights mechanisms, including for a disability-specific perspective on progress toward the Sustainable Development Goals (SDGs). For more on reporting, see [FAQs 5 and 8](#) on the CRPD indicators.

Data sources

The production of outcome indicators in the OHCHR indicator framework requires the collection of data from a variety of sources. These sources include:

- Administrative data collected as part of the running of government programs.
- Census data obtained from population censuses, typically collected every 10 years.
- 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 to go into much more detail.
- Qualitative data from focus groups, structured interviews and other methods designed to get more detailed descriptions of the dynamics of life.

Administrative data tends to collect information on disability status only for programs where disability-related services are provided – as with disability pensions or special services in schools. As such, they are useful for indicators pertaining to particular programs but not for population-based indicators, because people not in a program 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.

Many censuses have collected data on disability 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 questions, recommended by the United Nations Statistical Division, has been growing significantly. Censuses, because they require large resources, are done at most every 10 years and often collect a limited amount of information on each person.

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 special 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 to collect data that takes a comprehensive look at the barriers and facilitators affecting participation. As these do not

change as rapidly as outcome indicators – such as income, poverty, or employment –, doing disability surveys less frequently, such as every five years, would be adequate for the indicators for which they are particularly well suited.

This guide 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 that may not target persons with disabilities specifically (epidemiological data). See below the example of the Disability Data Advocacy Toolkit. National statistical offices and policy-makers 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 to reflect on the principle of participation. See [Foundations Guideline](#), sections 2.4 and 4.

The International Disability Alliance, CBM and the Stakeholder Group of Persons with Disabilities for Sustainable Development developed the [Disability Data Advocacy Toolkit](#) which seeks to contribute to the growing global dialogue on the importance of data on persons with disabilities, providing basic knowledge on data collection, analysis, and use of data for evidenced-based advocacy. The toolkit includes examples of initiatives on generating community-driven data to monitor the progress of the SDGs.

Purpose and framework of the Data Sources Guidance

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

Examples of countries already producing an indicator are given or, when no country was found reporting on the indicator, it provides examples where modifications to existing data collection could be applied to produce it. The goal of this document 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 one of 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:

(a) can be produced with existing data but have not been reported on; or

(b) could 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 which are currently not in place.

An indicator is categorized as Level 1 if any example was found where the indicator is being produced and reported on. A brief description of this example is given, along with links to learn how it is being done in more detail. 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, can develop them into Level 1 indicators.

Level 3 indicators are those for which no examples were found where countries were collecting data that could be easily employed to respond to these indicators. These will require more significant efforts and creativity. Guidance is given, however, on how to begin thinking about them. The naming of Level 3 indicators also serves to identify those areas where methodologies and systems of data collection are needed. As can be seen in the guide, they tend to be concentrated in particular articles where 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. This document is not meant to serve as an overview of countries' capacities or experiences on 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 thinking through 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 CRPD cuts across sectors and often those sectors are very interrelated. For example, under Article 7 on children with disabilities and Article 28 on the adequate standard of living, the same indicator on undernourishment is included. Where this occurs, they are cross-referenced.

In addition, sometimes indicators are more specific, or slightly different, than available data. In those instances, it is still recommended to report on the best available data that comes 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 CRPD, while efforts are made to improve the scope of data that can be reported.

It is important to note that the methodologies presented here are in no way meant to be prescriptive, but only suggestive of how these indicators can be produced. In a particular country or context, other statistical tools or administrative procedures may exist that are more appropriate. Further, this document 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 this document are aware of, or develop themselves good

examples of how to generate data responding to any particular indicator, we would welcome the sharing of those examples by sending information to disability@ohchr.org.

Leveraging Existing Resources

As set out and explained in the FAQs to the human rights indicators of the CRPD (see [FAQ 7](#)), a significant number of the indicators in this document are simply disaggregated versions of the Sustainable Development Goal (SDG) indicators. In those cases, the starting point is the metadata of the SDGs which can be found at <https://unstats.un.org/sdgs/metadata/>

Many agencies around the world are already compiling these indicators, but often they are not disaggregated by disability status. Sometimes, the national data sources already have information on disability status, in which case it would be very easy to do the disaggregation. If the data sources used for a variety of SDG indicators – such as labour force surveys, household income and expenditure surveys and demographic health surveys – include disability questions, then all of the indicators already being generated by those surveys could be disaggregated, as recommended by the SDG framework (SDG 17.18) and required for the CRPD indicator framework presented here. This would be the most efficient way of producing them. Agencies compiling SDG indicators from countries for their respective thematic areas should be encouraged to request that disaggregation when possible and recommend adding disability questions to existing data instruments so that this can be systematically done in the future.

This also increases 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 in the guidance, some indicators must be gathered through specialized surveys which 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?” on surveys will under-identify people with disabilities. Asking whether the person has a disability certification is also problematic. Obtaining such a certificate is dependent on many factors, such as whether people are aware of, or have the resources to go through, the certification process, whether it is accessible in their territories or support is provided to access them, and the nature of the eligibility requirements for disability programs.

The international standard for identifying people with disabilities for disaggregating the SDGs, and the one recommended for census-based prevalence estimates by the United Nations Statistical Division, is the [Washington Group \(WG\) Short Set on Disability](#). These questions ask about the level of difficulty doing core basic activities: 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 fully participate in society, due to barriers in the environment. This functionally-based approach is recommended for disability identification and the WG Short Set on Disability, which is already included in many data tools, is recommended for implementing it.

However, it should be mentioned that the WG Short Set on Disability 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 [WG developed a Child Functioning Module](#) that has been incorporated in [UNICEF’s Multiple Indicator Cluster Survey](#) and other tools. That is the recommended methodology for identifying children with disabilities in surveys.

The other significant limitation of the WG Short Set on Disability is that it under-identifies people with psychosocial disabilities. The WG has included additional questions for that functional domain in its [Extended Set](#) of questions and they have been adapted for use in the International Labour Organization’s (ILO) disability employment module. Even if the entire Extended Set – 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 WG Short Set on Disability when relevant. In some countries, other issues – such as albinism – might be of particular importance. Information and recommendations on these issues, and more, can be found at the WG website, at www.washingtongroup-disability.com. The key takeaway message, though, is that care should be taken in exactly how disability is defined in the construction of the indicator.

Despite these limitations, the WG Short Set on Disability has been endorsed widely by the CRPD Committee, the United Nations Special Rapporteur on the rights of persons with disabilities, OHCHR and other United Nations agencies, 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 SDG data disaggregation, which can be easily and cost-effectively inserted in all national data collection efforts.