

Increasing the availability of data (target 17.18)

This section will discuss the collection and availability of statistical data on persons with disabilities, including data disaggregated by disability, and reflect on the impact of the COVID-19 pandemic on the collection and availability of these data.

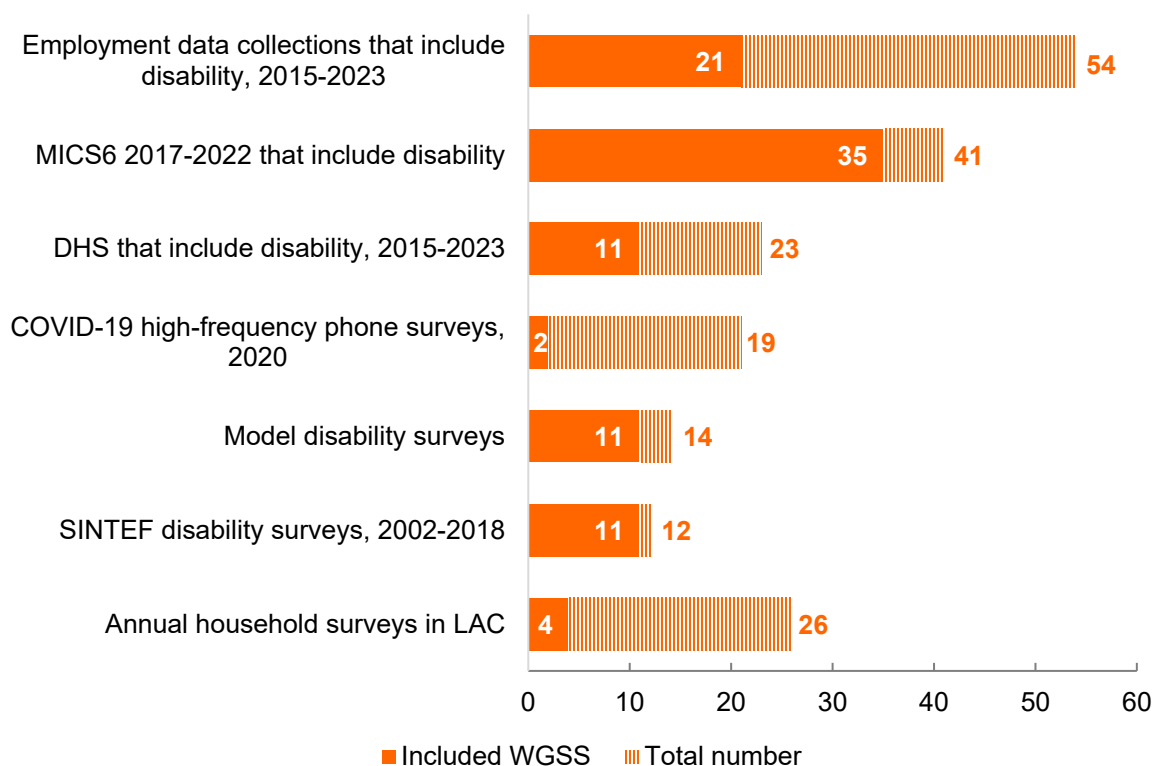
Target 17.18 calls for, by 2020, enhanced capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated, inter alia, by disability status. The Convention on the Rights of Persons with Disabilities (CRPD) calls on States Parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies related to the CRPD and to identify and address the barriers faced by persons with disabilities in exercising their rights (Article 31). States Parties are encouraged to disseminate the statistics and ensure their accessibility to persons with disabilities and others.

Since then, there have been further calls from the United Nations General Assembly and the World Health Assembly for countries to collect data on persons with disabilities and for United Nations entities and relevant international organizations to support countries in collecting, processing, analysing and disseminating data on disability.⁶¹⁹

Current situation and progress so far

Major international efforts to increase the availability of disability data date as far back as the 1980s, and these efforts were further intensified with the adoption of the CRPD in 2006 and the 2030 Agenda in 2015, promising to “leave no one behind”. An increasing number of countries have been including disability questions in their data collections in order to assess the gaps between persons with and without disabilities and to understand the enablers and the barriers persons with disabilities face in participation in society and in their daily lives. In 2015-2023, 54 compiled information on persons with disabilities in data collections on employment, 41 countries in multiple-indicator cluster surveys (MICS), 23 countries in demographic and health surveys (DHS) and 19 countries in COVID-19 high-frequency phone surveys (Figure 244). Model Disability Surveys have been conducted in 14 countries; and the SINTEF disability surveys have been conducted in 12 countries. Also, since 2005, many countries have included disability questions in their national censuses (Figure 245): 74 countries in 2005-2014 and 51 countries in 2015-2022.

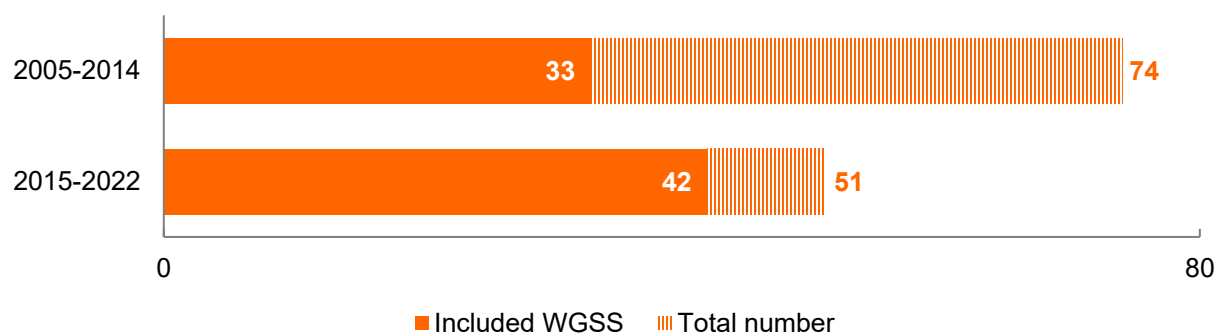
Figure 244. Number of countries with selected data collections and number of those that included the Washington Group short set of questions on functioning (WGSS).



Note: Employment data collections refer to the most recent data available in ILO records. LAC refers to Latin America and the Caribbean.

Source: DHS,⁶ DDI 2021,⁶²⁰ ILO, Inter-American Development Bank, IPUMS,⁸ SINTEF,⁹ UNDESA and WHO.

Figure 245. Number of countries that collected data on persons with disabilities in their censuses, and those that included the Washington Group short set of questions on functioning (WGSS), in 2005-2014 and in 2015-2022.



Source: DDI Collective (2024),⁶²¹ ECLAC,¹³ ESCWA, IPUMS,⁸ Mitra and Yap (2022)⁶²⁶ and UNDESA.

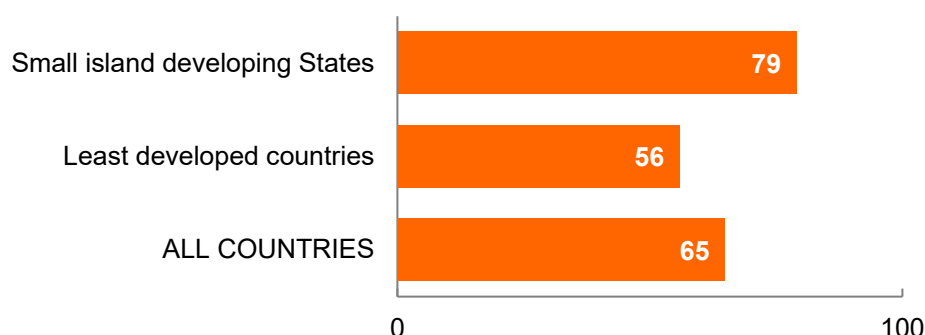
A variety of different methodologies is in place to collect data on persons with disabilities. Different questions are asked depending on the country. Within the same country, these questions may also differ across censuses, surveys and other data collection efforts. These differences prevent the comparison of data from country to country and within the same country.

Table 9. Tools developed to produce internationally comparable data on persons with disabilities, including data disaggregated by disability.

| Use | Tool | Developed by |
|--|---|---|
| Population-based household survey on persons with disabilities | Model Disability Survey | World Health Organization |
| | Surveys on the living conditions of persons with disabilities | SINTEF |
| To integrate into an existing survey/census to disaggregate data by disability | Short set of questions on functioning (WGSS) | Washington Group on Disability Statistics |
| | Functioning and Disability Disaggregation Tool (11 questions) | World Health Organization |
| | Short set on functioning – enhanced (12 questions) | Washington Group on Disability Statistics |
| | Extended set on functioning (37 questions) | Washington Group on Disability Statistics |
| In labour force surveys | Labour force survey module on disability | ILO in collaboration with the Washington Group on Disability Statistics |
| To compile information on children/youth with disabilities | Child Functioning Module | UNICEF and the Washington Group on Disability Statistics |
| To measure the impact on women of environmental challenges | Model questionnaire: measuring gender and the environment | UN Women |
| In demographic and health surveys | Disability module with the WGSS | DHS Program |

Since the early 2000s, a number of initiatives have delivered internationally comparable methods (that is, questions) to obtain disability data (Table 9). Among these methods, the Model Disability Survey has been conducted in 14 countries and the Washington Group short set of questions has been used in multiple countries and in various data collections (Figure 244 and Figure 245). For instance, these questions have been used in 33 countries for censuses in 2005-2014, 21 countries for employment data collections in 2015-2023, 35 countries for MICS, 11 countries for DHS, 11 countries for the SINTEF disability surveys, 4 countries for annual household surveys in Latin America and the Caribbean and 2 countries for the COVID-19 high-frequency phone surveys. In 2005-2014, 45 per cent of censuses that included disability questions used the WGSS. In more recent years, 82 per cent did so but the true percentage for the 2015-2024 census round remains unknown as this census round is not yet finalized (Figure 245). Since 2005, 79 per cent of small island developing States and 56 per cent of least developed countries have used the WGSS in their last census (Figure 246). Moreover, as of January 2023, 54 MICS surveys collected data on children and youth with disabilities using the child functioning model, which also provides internationally comparable data.⁶²²

Figure 246. Percentage of countries that used the Washington Group short set of questions on functioning, among countries that included disability in their last census, 2005-2022.



Source: UNDESA.

In addition to their use in censuses and surveys, the tools to produce internationally comparable data have been included in administrative systems, education contexts, program registration systems, disaster risk reduction and other humanitarian contexts, as well as in general program planning by civil society organizations.

From 2018 to 2022, several organizations have organized capacity-building activities on disability statistics, including the DHS Program, ILO, SINTEF, UNICEF, UNPRPD, the Washington Group and WHO. These activities include, among others, capacity building to governments. In particular, 59 per cent of the least developed countries and 45 per cent of small island developing States received this support.⁶²³

Many national online data portals are not accessible for all persons with disabilities because they lack accessibility features. This follows the trend of online governmental portals (see the chapter on Goal 16) – in 2020, only 37 per cent of countries had online governmental portals accessible for persons with disabilities according to W3C guidelines. Awareness of the need to make data accessible to all, including persons with disabilities, has been rising and online portals on internationally recommended methods to collect disability data have increasingly included disability features. For example, the WHO data webpage includes accessibility features, such as alternate text for graphic elements, use of plain language, logical heading structure and large links, buttons and controls. The website of the Washington Group on Disability Statistics, which includes guidelines on internationally comparable methods to collect data on persons with disabilities, includes various accessibility features, such as a colour scheme avoiding colours that do not offer enough contrast for common forms of colour blindness, the possibility of navigating the website by keyboard alone, and that the website can be used with common assistive technology – these accessibility features were developed in consultation with organizations of persons with disabilities.

Most data visualization guidelines still focus on persons without disabilities or blind and partially sighted persons, for which data visualisation descriptions are recommended, or persons who are colour blind, for whom the use of colour-independent patterns is recommended. Recently, new research has emerged on identifying accessible data visualizations for persons with intellectual and development disabilities, but this research remains scarce.⁶²⁴ In particular, more research on universal designs of data visualizations that are accessible to all, including persons with intellectual and developmental disabilities, is needed.

One of the barriers to using disability data for policy guidance and for the assessment of progress towards the SDGs and the CRPD, is the lack of a centralized online portal with disability data from countries all over the world and for relevant indicators to monitor the SDGs and the CRPD. The lack of such a centralized portal has been recognized since the 1980s. Despite several initiatives, such a portal still does not exist. Four online portals focusing on disability data and with a global scope have been produced since the 1990s (Table 10), but they have remained limited in the indicator coverage and use only a small portion of the disability data available worldwide. All except one have been discontinued as of 2023, due to lack of regular and sustainable funding.

Since 2015, more United Nations entities and other stakeholders have started to compile disability data. As of early 2023, various actors held substantial global and regional disability data compilations, including ECLAC, ESCWA, ESCAP, Fordham University (United States), ILO, Leonard Cheshire (United Kingdom), SINTEF, UNDESA (including UNSD), UNESCO, UNICEF, WHO and the World Policy Analysis Center (United States). Many of these data are not publicly available online.

Progress has been made in the availability of data disaggregated by disability in the United Nations SDG Indicators Database. In 2024, this database contained seven indicators with country data disaggregated by disability, up from zero in 2018. Three of these indicators have data for more than three countries. This

progress however falls short of covering the 10 SDG indicators for which the 2030 Agenda explicitly requires disaggregation by disability (only two of these indicators have data for more than three countries).⁶²⁵ Moreover, this also falls short of the general call in the 2030 Agenda for SDG indicators to be disaggregated, where relevant, by sex and disability. Disaggregation by sex is more widely available than disaggregation by disability: 49 indicators have data disaggregated by sex but only 7 have data disaggregated by disability. Only three indicators in the database have data disaggregated by both sex and disability.

Table 10. Examples of disability data portals with global scope and that are publicly available online.

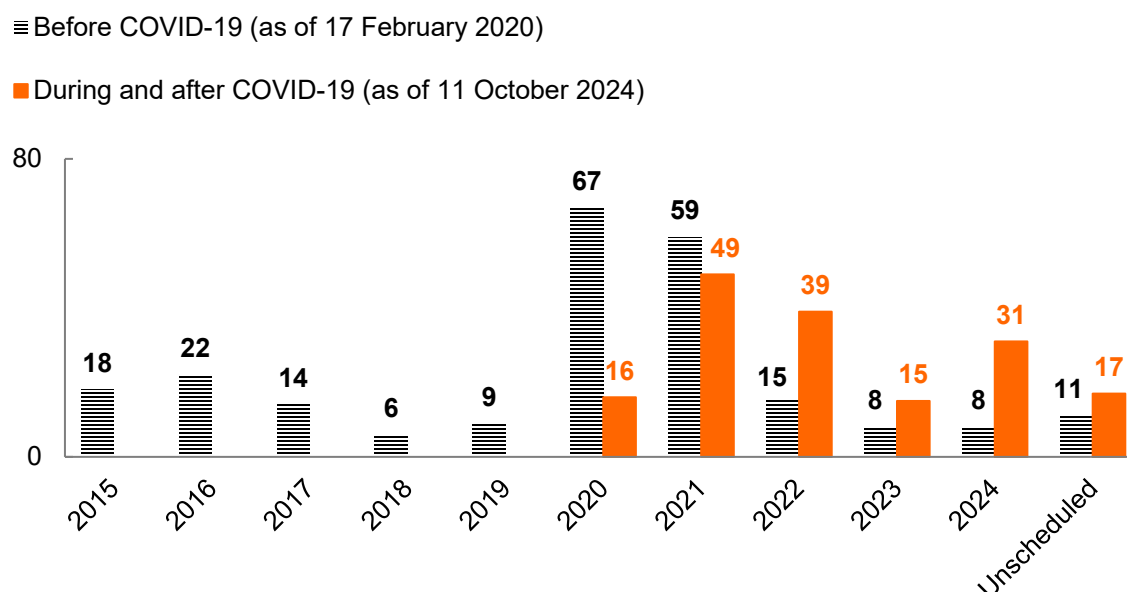
| Name of portal | Host | Scope | Period of regular updating |
|--|-----------------------------------|--|--|
| DISTAT | UN Statistics Division | Disability prevalence in various countries | 1990s |
| United Nations Disability Statistics Data Portal | UN Statistics Division | Disability prevalence in various countries | 2017-2019 |
| Disability Data Portal | Leonard Cheshire | Poverty, social protection, education, employment, empowerment of women and girls, violence – in various countries | 2018-2022, discontinued in December 2022 |
| Disability Data Initiative | Fordham University, United States | Poverty, health, education, standard of living – in various countries | Since 2021 and ongoing |

Impact of the COVID-19 pandemic

The COVID-19 pandemic has disproportionately affected persons with disabilities (see the chapter on Goal 3) and yet, few countries collected data on persons with disabilities or disaggregated data by disability at the national level since the start of the pandemic. For example, only two countries have disaggregated the national COVID-19 mortality data by disability – the United Kingdom and the Republic of Korea. To monitor the impact of the COVID-19 pandemic, COVID-19 high-frequency phone surveys were conducted in 55 countries, but questions to identify persons with disabilities were only included in 19 of those countries.⁶²⁶

Furthermore, the pandemic also impacted the availability of statistics on disability collected through population and housing censuses, which are a principal source for producing statistics on persons with disabilities in most countries. Countries usually conduct their censuses every ten years. The onset of the COVID-19 pandemic in the middle of the 2020 census round⁶²⁷ (that is, the period from 2015 to 2024) had a significant and adverse impact on its implementation. National statistical offices or census agencies were challenged to produce timely, accurate and reliable statistics during the pandemic. The pandemic circumstances, with social distancing measures, impacted on the implementation of censuses, particularly in countries conducting their censuses fully or partly with the traditional method, whereby every household in the country is approached with a request for information.

Figure 247. Number of countries by the year their census was scheduled, before and during/after the COVID-19 pandemic.



Source: United Nations Statistics Division.

Consequently, the collection and dissemination of data, including on persons with disabilities, were affected, resulting in at least one- or two-year delays (Figure 247). Before the pandemic, 67 countries were planning to conduct the census in 2020 but only 16 of them were able to conduct the census as scheduled. The others had to postpone to later years. As a result, while before the pandemic only 15 countries had planned to conduct their census in 2022, this number increased to 39 countries after the pandemic. Another 15 countries delayed their census to 2023; and 31 countries to 2024.

Census operations also took longer than usual during the pandemic, resulting in further delays. Among the countries that managed to conduct their census in 2020 in the middle of the pandemic and social

distancing restrictions, a few of them had to extend the enumeration period for more than six months to increase response rates and ensure completeness.

Conducting the 2020 round of censuses under the pressure of the COVID-19 pandemic has also raised concerns about the quality of census results. Many people moved to different addresses when schools and workplaces were closed or changed their place of residence to join another household. All these circumstances have created difficulties in counting people in their place of usual residence. In addition, due to constraints on time and resources, some countries had to shorten their census questionnaires, which may have affected disability-related questions and resulted in the loss of time series data and intertemporal comparability.

Compared to previous census rounds, the availability of detailed statistics on persons with disabilities coming from censuses is delayed, and in some countries not yet available at all. As a positive development, the pandemic has been a catalyst for more innovative and agile ways of data collection, like remote or online data collection, with the potential for increasing both the quality and availability of data on persons with disabilities.

Summary of findings and the way forward

In the context of the 2030 Agenda and the promise to “leave no one behind,” substantial efforts have been made to generate data and information to monitor the situation of persons with disabilities. An increasing number of countries is collecting data on persons with disabilities, and using established internationally comparable methods to do so, ensuring progress towards the achievement of target 17.18. Since 2015, 42 countries have used the Washington Group questions out of 51 countries collecting disability data in censuses and 14 countries have conducted Model Disability Surveys. However, capacity to use internationally recommended methods is still lacking in many countries, particularly in least developed countries. To achieve target 17.18, it is crucial to direct more capacity-building efforts towards countries that need them the most.

The onset of the COVID-19 pandemic resulted in less data on disability being available than expected, due to disrupted data collections, particularly censuses and surveys. Moreover, although rapid emergency data collections were conducted in some countries during the pandemic to understand its impact and guide policy formulation, those data collections rarely compiled data disaggregated by disability status.

Only a minority of developing countries have comparable data across time that would allow for the tracking of progress towards the realization of the SDGs for persons with disabilities. The lack of standardized methods along time prevents measuring this progress for many topics covered by the SDGs.

Accessibility features are still lacking in many data disseminations. And the lack of a centralized, accessible, publicly available and global online platform for data on persons with disabilities causes

barriers to a sustainable and regular monitoring of progress for persons with disabilities towards the SDGs and the realization of the CRPD.

The availability of data disaggregated by disability in the United Nations SDG Indicators Database has increased since 2018, but progress has been too slow. With current trends less than half of the indicators for which the 2030 Agenda explicitly requires disability disaggregation will have data by 2030. The rates of progress will need to be four times faster in order to achieve, by 2030, availability of data disaggregated by disability for these 10 indicators. To achieve a level comparable to the current availability of gender disaggregated data, rates of progress will need to increase six-fold.

To increase the availability of relevant and high-quality data on persons with disabilities, the following actions are recommended:

1. Integrate and harmonize disability data collections in all relevant national information systems.

Integration of disability in the national information systems implies collecting and disaggregating population data by disability as well as collecting data on persons with disabilities in relevant national information systems – for instance, for national health information systems, to collect health facilities-based data disaggregated by disability; similarly for education information systems, collect data on disability across educational facilities.

2. Encourage the use of internationally comparable methods. The most effective way of understanding disability is to use valid and reliable tools assessing functioning difficulties in undertaking specific activities like walking, seeing, or hearing as well as barriers in the environment that may contribute to those limitations. The selection of a specific tool will depend on the resources that countries have, their objectives and specific contexts. Statistical methods to harmonize data from different functioning tools already exist for comparability and countries should be encouraged to use them, including the newest revision of the United Nations Principles and Recommendations for Population and Housing Censuses.

3. Establish regular and standardized data collections across time. Data collected with the same methods in different time periods are essential to measure progress. While many countries currently have only one point-in-time data on persons with disabilities, population data systems that continuously produce such data are key to effectively inform policy and decision-making. Countries may consider establishing a register of persons with disabilities to produce timely, frequent and accurate data; as well as enhancing the frequency and the quality of disability-related data by using various data collection methods.

4. Invest in collecting and disseminating data on women and girls with disabilities. More investments in data collection on women and girls with disabilities are needed. Data disaggregation and collection of individual-level data must be prioritized to ensure that everyone is included in policy formulation and programme design. When such compelling evidence is available, policymakers cannot turn a blind eye. Ignoring such data will leave women and girls with disabilities behind.

5. Make all data, in online websites and printed formats, accessible for persons with disabilities.

Many websites lack accessibility features, like audio versions, captioning of data charts and alternatives to mouse use. Data is an important tool for participation and all persons with disabilities should have access to data in accessible formats.

6. Build capacity of developing countries, particularly least developed countries and small island developing States.

The use of standardized and internationally comparable methodologies to collect disability data remains particularly low in least developed countries.

7. Promote partnerships to coordinate for the production of a centralized global, online, publicly available and accessible repository for data on persons with disabilities.

Previous efforts have been hampered by lack of regular and sustainable funding and lacked coordination among relevant stakeholders. Many actors are involved in the production of data on persons with disabilities covering the scope of the CRPD and the SDGs, and they should all be engaged in this effort.

8. Involve persons with disabilities and their representative organizations in all stages of data production, from planning to dissemination, and data utilization, especially in census planning and operations.

It is key to involve a diversity of persons with disabilities, including persons with various types of disabilities and gender, and their representative organizations to ensure that data are fit for purpose and accessible to all.

9. Increase the number of indicators with data disaggregated by disability in the United Nations SDG indicator database.

Data disaggregated by disability has increased substantially in the past five years, but this has only partially been reflected in the SDG Indicator database. Making these data available in the SDG indicators database will provide a solid evidence base to inform on the progress towards the SDGs for persons with disabilities.

10. Invest in research to identify the best visualizations for data accessibility for persons with disabilities, including for persons with intellectual and developmental disabilities, focusing on universal design visualizations accessible to all.

With the proliferation of data-driven reasoning and decision-making increasing across all aspects of life, making data accessible to all is crucial. Without data accessibility, many persons with disabilities will need to rely on others to relay relevant information and to make decisions using that data and not be able to access and use the data independently.