



General Assembly

Distr.: General
28 December 2021

Original: English

Human Rights Council

Forty-ninth session

28 February–1 April 2022

Agenda items 2 and 3

Annual report of the United Nations High Commissioner for Human Rights and reports of the Office of the High Commissioner and the Secretary-General

Promotion and protection of all human rights, civil
political, economic, social and cultural rights,
including the right to development

Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities

Report of the Office of the United Nations High Commissioner for Human Rights

Summary

The present report, submitted pursuant to Human Rights Council resolution 43/23, contains an overview of State obligations under article 31 of the Convention on the Rights of Persons with Disabilities to collect and maintain data for the purpose of developing evidence-based policies aimed at realizing the rights set out in the Convention. The report contains guidance on a human rights-based approach to data, specifically for persons with disabilities, highlighting aspects connected to data collection and the rights to privacy and access to information.



Contents

	<i>Page</i>
I. Mandate and scope	3
II. Persons with disabilities, data collection and statistics	3
III. Measuring implementation of the human rights of persons with disabilities	5
IV. Right to privacy and data under the Convention	10
V. Right to access to information and data under the Convention	13
VI. Conclusions and recommendations	15

I. Mandate and scope

1. In its resolution 43/23, the Human Rights Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to prepare a study on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities, in consultation with States and other relevant stakeholders, including civil society organizations and organizations of persons with disabilities, and to make the study available to the Council prior to its forty-ninth session. The Council also requested that stakeholders' contributions and the present report be made available in an accessible format. Pursuant to the Council's request, OHCHR solicited contributions, which are available on the OHCHR website.¹

2. Pursuant to article 31 of the Convention, States parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention. Hence, in applying the provisions of the treaty, data must be used to support the realization of the rights contained therein. Data collection and administrative processes must comply with international privacy and other standards on ethical principles and the use of statistics. Moreover, data must be disaggregated by disability, as appropriate, to identify and address barriers faced by persons with disabilities in the exercise of their rights. Finally, States must disseminate accessible statistics for use by persons with disabilities and others.

II. Persons with disabilities, data collection and statistics

3. The States parties to the Convention have recognized that disability is an evolving concept and that it results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (preamble). The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (art. 1). States parties have undertaken to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention (art. 31 (1)). Consequently, data should be collected with the aim of fulfilling the purpose of the Convention and it should support both dimensions of disability, in other words the individual dimension (identifying persons with disabilities) and the social dimension (identifying the barriers that hinder the effective participation of persons with disabilities on an equal basis with others) (art. 31 (2)).

4. The Convention sets out the rights to be implemented. States parties to the Convention should identify strategic objectives under each right, develop policies to implement them and establish mechanisms to measure progress in implementation, including in such a way as to allow States to take remedial action.² The strategic objectives should guide the development of national and local action plans, which should include human rights indicators to define which data-collection efforts and statistics will be required to monitor implementation.³ The Convention and the Sustainable Development Goals should be viewed as complementary, the first framing human rights obligations and the second defining policy objectives.

5. Data should not be collected in a vacuum. Because of their complexity, strategic policy objectives need to be identified while achieving a balance between assessing the target population's priorities and the State's capacities. Data can support this process by identifying those groups of persons with disabilities that are most excluded, by type of impairment, type of barrier faced and any intersectionalities experienced. Doing so can help establish priorities and aid in the design of actionable policies. States should consider fulfilling the commitment

¹ See <http://ohchr.org/EN/Issues/Disability/Pages/StudiesReportsPapers.aspx>.

² See, for example, the National Action Plan for the Rights of Persons with Disabilities 2015–2030 of Paraguay (<https://acnudh.org/load/2019/07/047-Plan-de-Acci%C3%B3n-Nacional-DPcD.pdf>).

³ Human rights indicators for monitoring implementation of the Convention have been developed by OHCHR and are available at <http://ohchr.org/EN/Issues/Disability/Pages/SDG-CRPD-Resource.aspx>.

made in the context of the 2030 Agenda for Sustainable Development to leave no one behind by reaching the furthest behind first.

6. In the 2030 Agenda, States reaffirmed their commitment to implementing the Agenda in a manner consistent with the rights and obligations of States under international law,⁴ which includes those contained in the Convention. In addition, in target 17.18 of the Sustainable Development Goals, States committed to increasing significantly the availability of high-quality, timely and reliable data disaggregated by, among other criteria, disability.⁵ The Committee on the Rights of Persons with Disabilities has identified data gaps in multiple areas, such as on the rights to live independently in the community, the integrity of the person, health, habilitation and rehabilitation, freedom of expression and opinion, access to information, legal capacity, life, access to justice, freedom from exploitation, violence and abuse, education, liberty of movement and nationality, liberty and security of the person, international cooperation, accessibility, work and employment, an adequate standard of living and social protection, freedom from torture and cruel, inhuman or degrading treatment or punishment, participation in political and public life, equality and non-discrimination. It has also noted data gaps on gender-based violence against women and girls with disabilities, women with disabilities in situations of risk and humanitarian emergencies and children with disabilities.⁶ Having made these international commitments and entered into these obligations, States should make extensive efforts to address these gaps.

7. Data is commonly collected in the area of human rights to monitor and evaluate actual or potential discrimination; identify and remove systemic barriers; lessen or prevent disadvantage; and promote substantive equality for people identified as particularly excluded, such as persons with disabilities. Data can be collected through quantitative processes (e.g., censuses, surveys and administrative data collection efforts) or qualitative processes (e.g., structured interviews, focus groups and narrative inquiries). Both processes are recognized in the Convention. The means used to collect, administer and use data should follow international law and apply a human rights-based approach to ensure that data collection is performed lawfully while keeping a people-centred approach.⁷ Human rights indicators should guide data collection to meet development goals and human rights obligations under the Convention.⁸

Indicators and data collection

8. A global indicator framework for measuring progress towards the Sustainable Development Goals and targets has been developed.⁹ The indicators are currently categorized by tiers: indicators that can be readily produced since they have a clear methodology and are available are in tier I and those that have an established methodology but no regular data collection are in tier II. The indicators for target 17.18 referring to international standards on statistics and funding are classified as tier I indicators, while the indicator on statistical capacity is in tier II.¹⁰

9. OHCHR has developed human rights indicators for the Convention. In doing so, OHCHR identified core aspects within each article of the Convention and provided proxy indicators at three levels: structural, process and outcome.¹¹ Outcome indicators, which include indicators on the Sustainable Development Goals, can be used to measure progress in achieving certain goals and should be disaggregated to see if any gaps exist between persons with disabilities and the broader population. States can use all these indicators,

⁴ General Assembly resolution 70/1, para. 18.

⁵ *Ibid.*, p. 27.

⁶ See, for example, [CRPD/C/GRC/CO/1](#), para. 28; [CRPD/C/SLV/CO/2-3](#), para. 52; [CRPD/C/IND/CO/1](#), para. 34; and [CRPD/C/TUR/CO/1](#), para. 23.

⁷ OHCHR, “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development” (2018).

⁸ OHCHR, *Human Rights Indicators: A Guide to Measurement and Implementation* (HR/PUB/12/5).

⁹ General Assembly resolution 71/313, annex.

¹⁰ Tier III indicators were eliminated from the framework in 2021. See <http://unstats.un.org/sdgs/iaeg-sdgs/tier-classification/>.

¹¹ See <https://www.ohchr.org/EN/Issues/Disability/Pages/SDG-CRPDindicatorsFAQ.aspx>.

together with the policy guidelines connecting the Sustainable Development Goals and the Convention, in defining their policy objectives and focus their data-collection efforts so that they are in line with their human rights obligations and development commitments.¹²

III. Measuring implementation of the human rights of persons with disabilities

A. Disability identification is a requirement for data disaggregation

10. The Convention is both a human rights instrument and a development tool. States parties to the Convention have entered into binding legal obligations relating to participation, accountability, non-discrimination and empowerment, among other areas. As a development tool, the Convention guides policy implementation and frames the policy commitments made in the 2030 Agenda. Article 1 of the Convention sets out that persons with disabilities should participate in society on an equal basis with others and the Convention as a whole develops inclusive equality as a new model of equality.¹³ It also requires that persons with disabilities be treated without discrimination within the group and that recognition be given to the specific forms of discrimination persons with disabilities face based on their intersecting identities – as women, children, migrants, LGBTIQ+ persons or members of ethnic and cultural minorities, for example – and based on the diversity of the impairments they have – physical, psychosocial, intellectual or sensory, for example. Data must support all these comparisons.

11. Comparing outcome indicators across groups requires the proper identification of persons with disabilities in data tools in order to allow for disaggregation. Some methods have been shown to significantly under-identify persons with disabilities, particularly those that use a simple question such as “Do you have a disability?”¹⁴ because of the stigma attached to the term disability and a tendency to interpret the word as dealing only with the most severe impairments, as well as missing older persons who perceive themselves as simply old and not as having an impairment. Another approach, one which uses a list of medical conditions and impairments, also tends to under-identify, in part due to incomplete lists and lack of diagnoses.

12. There is a growing international consensus that a functional approach to identifying persons with disabilities should be adopted.¹⁵ In line with such an approach, people are identified as persons with disabilities if they have difficulties doing basic activities for reasons related to a health condition or impairment. Such persons risk exclusion if there are barriers in the environment, as there commonly are, and are thus those whose rights the Convention was designed to promote and protect. This functional approach to identifying persons with disabilities solves the problem of listing medical conditions and impairments, reducing the number of questions for disaggregation purposes.¹⁶

13. It is also the approach of the Washington Group on Disability Statistics, established by the Statistical Commission of the United Nations, in developing multiple sets of questions.¹⁷ These have been endorsed by many international statistics entities, including the

¹² OHCHR, “Policy guidelines for inclusive Sustainable Development Goals: foreword and introduction” (2020). Available from <https://www.ohchr.org/Documents/Issues/Disability/SDG-CRPD-Resource/policy-guideline-introduction.pdf>.

¹³ Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018), para. 11.

¹⁴ Daniel Mont, “Measuring disability prevalence”, Social Protection Discussion Paper No. 0706 (World Bank, 2007).

¹⁵ Nora E. Groce and Daniel Mont, “Counting disability: emerging consensus on the Washington Group questionnaire”, *The Lancet Global Health*, vol. 5, No. 7 (July 2017).

¹⁶ The functional approach to identifying persons with disabilities for the purpose of data disaggregation should not be confused with the use of similar terms in reference to, for example, the “functional approach to disability” or the “rehabilitation approach”.

¹⁷ Daniel Mont, “How are the Washington Group questions consistent with the social model of disability?”, *WG Blog* (14 August 2019).

Conference of European Statisticians¹⁸ and the Statistics Division of the United Nations,¹⁹ and is largely supported by international organizations working on disability rights.²⁰ The question sets are used in over 110 countries.²¹

14. The Washington Group short set of questions on functioning is the preferred tool to use in censuses and has been recommended by the Statistics Division. The questions have response categories that capture the range of functional difficulties a person may have in six domains: seeing, hearing, walking, cognition, communication and self-care. Persons are considered with disabilities if they have a lot of difficulty or are unable to do at least one of a list of activities.²² The six questions used in the Washington Group short set of questions on functioning thus make it possible to disaggregate within the group of persons with disabilities and have proven to provide high-quality, timely and reliable data, as required by target 17.18 of the Sustainable Development Goals.

15. Other data instruments take this functional approach, including the model disability survey of the World Health Organization (WHO).²³ It contains many additional functional questions that can be used to create an index for describing the extent of a person's functional limitations. In addition to the full version of the model disability survey, a brief version has been developed by WHO that provides an abbreviated methodology for disaggregation purposes. The brief model disability survey is not a stand-alone survey but a module to be included in other surveys. The 12 questions in the brief version differ from those developed by the Washington Group on Disability Statistics. States should be aware of the methodological differences and ensure data harmonization to avoid creating inconsistencies in data comparability between censuses and surveys (see also paras. 30–31 below).

B. Censuses and general household surveys for disaggregation

16. Censuses are used to collect quantitative data on the entire population and are thus the broadest tool available for establishing a baseline from which to inform policy on areas such as employment, housing, education and other services. The strength of censuses is that, because of their size, they can provide information on small geographic regions and on small subpopulations, for example comparing men and women with different types of impairments in rural and urban areas. The two weaknesses of censuses are that they are carried out infrequently, typically every 10 years, and that they are expensive to run, which means that they often do not collect detailed information on each person.

17. Surveys can provide the detailed information on each household that censuses cannot provide. Most States regularly carry out household income and expenditure surveys, labour force surveys and demographic and health surveys, as well as a range of other sector-specific surveys. These surveys are the source of many of the indicators associated with the Sustainable Development Goals. If disability-related questions are included in these surveys, then the data on all those indicators can be disaggregated without the need for any additional surveys. In 2020, the World Bank produced a guidebook for designing household survey questionnaires²⁴ that provides substantive guidance on multiple tools currently available to disaggregate data by disability and information on their benefits and limitations.

¹⁸ In its Recommendations for the 2020 Censuses of Population and Housing.

¹⁹ In its Principles and Recommendations for Population and Housing Censuses.

²⁰ See the joint statement issued by Member States, United Nations agencies, organizations of persons with disabilities, civil society and independent experts available at <http://internationaldisabilityalliance.org/data-joint-statement-march2017>.

²¹ Based on information provided by the Washington Group on Disability Statistics secretariat, 111 countries have reported using the Washington Group short set of questions on functioning in censuses and surveys.

²² Functioning difficulties in the six domains are identified by asking persons whether and to what extent they experience difficulties in doing an activity according to the following response categories: no difficulty, some difficulty, a lot of difficulty or inability.

²³ Available at <https://apps.who.int/iris/bitstream/handle/10665/258513/9789241512862-eng.pdf>.

²⁴ Marco Tiberti and Valentina Costa, "Disability measurement in household surveys: a guidebook for designing household survey questionnaires" (Washington, D.C., World Bank, January 2020).

C. Disability-specific surveys: beyond disaggregation

18. Data disaggregation of standard indicators is important, but not sufficient, and must be complemented with the collection of disability-specific data and the identification of barriers. Disability-specific data include information on the need for and the provision of assistive technologies and support services, as well as information on the accessibility and effectiveness of certain services, such as disability benefits and rehabilitation, among others. It is also of prime importance to collect information about the attitudinal, physical, informational or institutional barriers that persons with disabilities face. For example, in Zimbabwe, a disability-specific survey captures information on barriers to access to transport, accessibility, information, health care, support at home and in education, among other areas.²⁵ The questions pertaining to these issues are too numerous for regular inclusion in standard household surveys. For this reason, it is essential to conduct disability-specific surveys.

19. A number of countries have undertaken disability-specific surveys.²⁶ Despite States' obligation to collect data on barriers, however, few do so. As part of their ongoing efforts to implement the Convention, States should do more to measure, in particular, environmental barriers. For example, the WHO model disability survey goes beyond data disaggregation and can contribute to identifying and tracking the impact of environmental barriers and provide valuable information for policy development.²⁷

D. Administrative data

20. Administrative data are another important source of information about persons with disabilities, as well as about barriers in the environment.²⁸ Administrative data are collected routinely by government agencies while implementing their programmes and policies. Although consisting of important ongoing and sustainable information, administrative data do not pertain to the entire population, only to individuals who come into contact with administrative systems. For example, children in school are included in educational management information systems, but children who are out of school are not. While many educational management information systems do not collect information on children with disabilities or on the inclusivity of the environment, more and more of them are starting to do so. In Fiji, for example, an educational management information system has been implemented to collect extensive data on both children with disabilities and the environment that is used to support learners.²⁹

21. An increasing number of countries are using population registers and administrative data for census.³⁰ Countries with robust administrative data systems may benefit from such a tool. Nevertheless, countries with lower recollection of administrative data may have only fragmented and incomplete data sets. Irrespective of how robust they are, administrative data collection systems carry certain risks, as they only feed on data on people currently in the system. For example, most persons with disabilities register in order to gain access to specific services; should they not need those services or should they have no access to registration systems, they would not be counted. States should collect data to manage policies (on social

²⁵ Zimbabwe, Ministry of Health and Child Care, and United Nations Children's Fund (UNICEF), *Zimbabwe, Living Conditions among Persons with Disability Survey: Key Findings Report* (2013).

²⁶ See, for example, Thailand (*The 2017 Disability Survey*) and Viet Nam (*Viet Nam National Survey on People with Disabilities 2016*).

²⁷ See, for example, Afghanistan (*Model Disability Survey of Afghanistan 2019*), Chile (*II Estudio Nacional de la Discapacidad 2015*), Costa Rica (*Encuesta Nacional sobre Discapacidad 2018*) and the Philippines (*National Disability Prevalence Survey 2016*).

²⁸ See <http://ohchr.org/EN/Issues/Disability/Pages/SDG-CRPD-Resource.aspx>.

²⁹ Fiji, Ministry of Education, and the Australian Agency for International Development, "Fiji education management information system (FEMIS): disability disaggregation package – guidelines and forms" (2017).

³⁰ *Guidelines on the Use of Registers and Administrative Data for Population and Housing Censuses* (United Nations publication, Sales No. E.19.II.E.4), paras. 9–11.

protection, health, employment or education) and to guide transformational action to increase the inclusion of persons with disabilities beyond existing administrative systems.

22. National human rights institutions and monitoring mechanisms also collect administrative data on persons with disabilities through their monitoring functions. They have an enhanced capacity to properly assess the effectiveness of policies, identify any gaps and support remedial action. In Canada, Mexico and New Zealand,³¹ aggregated reports quantify claims by area, such as access to health, thereby giving an indication of the size of any policy gaps. National statistical offices and monitoring mechanisms should work together to focus data-collection efforts on areas of specific concern.

23. Similarly, administrative data collected through judicial processes can be used to assess policy implementation in areas under the exclusive competency of the judiciary. For example, data systems can assess the number of guardianships and the motivation behind them and guide an effective transition to a supported decision-making system, in accordance with article 12 of the Convention.

24. Disability-specific programmes also trigger administrative data collection. Gaining access to such programmes typically involves meeting eligibility criteria for what constitutes “disability” for the purpose of receiving benefits. While some benefits, such as free access to transport,³² can be granted to all persons with disabilities, other benefits, such as hearing aids, are for certain persons with disabilities who have been identified as requiring such assistive technology.

E. Disability determination and assessment

25. Disability determination is a procedure used to identify who can qualify for disability-related programmes. While it is undertaken by States by different means, it commonly includes the elements of assessment, determination and eligibility.³³ Some countries carry out assessments through medical examinations, others have different tools for different programmes and yet others have comprehensive tools that apply to most or all disability-specific programmes. The two most used comprehensive tools are the International Classification of Functioning, Disability and Health and the Disability Assessment Schedule 2.0, both developed by WHO. Under the Convention, States must not discriminate and people within a territory must enjoy equal rights, regardless where they live (art. 4 (5)). Nevertheless, States face significant challenges in implementing comprehensive tools throughout their territories, with different levels of access for making assessments in rural and urban settings. The complexity and cost of carrying out disability assessments is a limitation for States, particularly in low- and middle-income countries.³⁴ States should ensure that all people that require an assessment can gain access to one.

26. Disability assessment tools need to be fit for purpose and take into consideration human rights standards of accessibility, availability, acceptability and quality.³⁵ Some countries have established in law that assessments should be performed with certain tools,³⁶ which limits their ability to adjust their methods in accordance with their policy requirements, financial resources, assessment capacity, territorial networks, population distribution and geographic extension, among other factors. States should incorporate flexibility in definitions of which disability assessment tools they will use so that they can implement the tools that are most appropriate to reaching the target population.

³¹ Submissions by these countries’ national human rights institutions.

³² Argentina, Laws No. 22431, No. 24314 and No. 25635.

³³ OHCHR, *Policy Guidelines for Inclusive Sustainable Development Goals: Foundations* (2020), p. 24.

³⁴ Argentina, *Estudio Nacional sobre el Perfil de las Personas con Discapacidad: Resultados Definitivos 2018* (2018), p. 80.

³⁵ Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000), para. 12.

³⁶ See, for example, Uruguay, Law No. 18651, art. 38 (d).

27. The Committee on the Rights of Persons with Disabilities has raised concerns regarding the definition of disability adopted in laws, policies and administrative tools.³⁷ This has generated uncertainty among some policymakers in terms of human rights compliance of disability assessments. There must be a direct correlation between human rights, laws, policies and data for data-collection exercises to be considered lawful. Disability assessments that are directly derived from human rights obligations are lawful, even when limited to medical assessments. In such cases, States should justify that such medical assessments are the most appropriate tool for identifying eligibility criteria set in policy to ensure the enjoyment of the human right to the largest portion of the population possible.

28. When States define assessment tools that will allow them to implement policies to overcome environmental barriers, they are acting in compliance with the Convention. For example, gaining access to assistive technology is a right, according to the Convention. A law can recognize that deaf and hard-of-hearing persons have a right to hearing aids. To decide who will receive hearing aids, States should use an assessment tool. An audiometry test (the assessment tool) is used to identify who, according to the existing policy, has the right to that assistive technology (disability determination); persons deemed eligible by the administrative system (eligibility) would then be provided with the device (attribution). Such an assessment would be cost effective and could be implemented throughout the territory without discrimination, thereby ensuring enjoyment of a human right.

29. Data collected through disability assessments can greatly inform the development, implementation and evaluation of government policies and programmes. Systems for administering assessments and collecting the appropriate data should be designed to be as efficient and practical as possible in the local context and fulfil the purposes of delivering a service and collecting data. These data-collection processes are resource intensive and should, first of all, meet their primary objective of ensuring the development of policies that remove the barriers that persons with disabilities face every day. Disability assessments should not be used to limit or violate human rights, for example by institutionalizing some or segregating others in education.

F. Data harmonization

30. Consistency between the conceptual frameworks used in the tools for data collection is essential.³⁸ Different data sources can report very different prevalence rates of disability or different impacts of disability on people's lives, undermining the confidence and usefulness of the results. In turn, this can affect the monitoring, effectiveness and coverage of human rights-based policies, as well as the reliability of the data system itself.

31. South Africa has started to address this problem through a data harmonization project supported by the World Bank.³⁹ The goal is to have a common functionally based framework for data collection across all statistical and administrative systems. That way, different data sources can be compared and used together, increasing their usability.

G. Qualitative research

32. In addition to collecting quantitative data, States should promote qualitative research. Quantitative data provides evidence to support assessment of the scale and scope of a particular problem and to identify associated factors. It is less useful, however, in understanding the dynamics of daily life and how various complex factors interact with each other. Disability-based discrimination is the result of multiple interactions in daily life and includes a complex system of values and practices. Qualitative research, by including focus

³⁷ Lisa Waddington and Mark Priestley, "A human rights approach to disability assessment", *Journal of International and Comparative Social Policy*, vol. 37, No. 1 (2021), pp. 1–15.

³⁸ Sophie Mitra and Usha Sambamoorthi, "Disability prevalence among adults: estimates for 54 countries and progress toward a global estimate", *Disability and Rehabilitation*, vol. 36, No. 11 (2014), pp. 940–947.

³⁹ Kudakwashe A.K. Dube and Daniel Mont, "Harmonization and standardization of disability data and statistics in South Africa" (March 2021).

groups, structured interviews, video recordings and photographs, can shed light on these interactions and identify gaps in knowledge that could be filled by quantitative data. Qualitative data lack the ability to provide results that are representative of the entire population or produce population-based estimates. A mixed-methods research approach can be effective. Quantitative data can uncover problematic issues. Qualitative data can help explain, fill the gaps and complement the quantitative data results. By using the two methods, researchers can take advantage of the strengths of both.

33. Research is a powerful tool for evaluating existing policies, identifying policy gaps and guiding policy development.⁴⁰ States should support quantitative and qualitative research aimed at closing policy gaps by using emancipatory, participatory and inclusive research methodologies that meaningfully involve persons with disabilities as researchers and value their experiences as sources of knowledge.⁴¹

H. Participation and citizen-generated and community-based data collection

34. Participation is a principle of the human rights-based approach to data and an obligation under article 4 (3) of the Convention.⁴² States should involve persons with disabilities at all stages of data-collection processes, from strategic planning, identifying data needs and testing data-collection methodologies to collecting, storing, disseminating and interpreting data. Meaningful participation requires that persons with disabilities have the capacity to actively engage in data-collection processes.⁴³

35. Persons with disabilities are experts on the barriers they face. Citizen-generated data, including data produced by organizations of persons with disabilities and their networks, can contribute substantively to data-collection effort, and make it reflective of their experiences.⁴⁴ For example, during the coronavirus disease (COVID-19) pandemic, organizations collected data through online interviews and focus group webinars. The results of these data-collection processes provided crucial preliminary findings, not only for policymakers, but also for persons with disabilities, to plan, build resilience and actively seek support through informal networks. The impact of the disability data gap on pandemic responses is still being evaluated. In recovering from the pandemic and in preparing for the next waves and for new pandemics, substantial efforts will be required to avoid relying solely on citizen-driven data-collection exercises.⁴⁵

IV. Right to privacy and data under the Convention

36. Article 22 of the Convention protects persons with disabilities' right to privacy, including their right to have their personal, health and rehabilitation information respected on an equal basis with others. All people should enjoy the right to have their personal data protected,⁴⁶ but persons with disabilities are specifically exposed to higher risks of discrimination based on their impairments, which makes sensitive data on health and

⁴⁰ OHCHR, "Policy guidelines for inclusive Sustainable Development Goals: research and innovation" (2020).

⁴¹ Anna Arstein-Kerslake and others, "Introducing a human rights-based disability research methodology", *Human Rights Law Review*, vol. 20, No. 3 (September 2020), pp. 412–432. See also [CRPD/C/FRA/CO/1](#), para. 63; and [CRPD/C/EST/CO/1](#), para. 61 (c).

⁴² OHCHR, "A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development" (2018).

⁴³ Stakeholder Group of Persons with Disabilities for Sustainable Development, International Disability Alliance and CBM Global Disability Inclusion, *Disability Data Advocacy Toolkit* (2020).

⁴⁴ Transparency, Accountability and Participation Network, *SDG Accountability Handbook: A Practical Guide for Civil Society* (2019).

⁴⁵ Using the Washington Group Tools to Assess the Impact of COVID-19 on Persons with Disability, 2021.

⁴⁶ [A/HRC/39/29](#), paras. 5 and 27.

rehabilitation particularly relevant and in need of protection.⁴⁷ Article 31 (1) (a) of the Convention reinforces the right to privacy set out in article 22 and makes it applicable to data collection. In addition, article 31 (1) requires States parties to comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics, including the confidentiality of statistics.⁴⁸

A. Framework for data protection

37. The Convention provides a comprehensive framework for data protection, maintaining that the personal and statistical data of persons with disabilities should be protected on an equal basis with others in administrative, commercial, statistical and other data-collection processes. Data protection laws and policies should include persons with disabilities.

38. States should use data privacy and data protection principles when developing disability-related policies or other policies that may affect them, even if only indirectly. Given the specific impact on persons with disabilities of health-related data recognized by the Convention, States should give specific attention to this area.⁴⁹ States collecting data should ensure that persons with disabilities provide their consent in accordance with the standards set out in the Convention.⁵⁰ Adherence to data protection principles not only contributes to the enjoyment of the right to privacy; it also improves the efficacy and efficiency with which data is collected and used, as it supports defining human rights-based purposes and the provision of consent for data-collection processes.

39. Legislation on data protection varies substantially across countries, but a common set of principles does exist that should be followed: (a) data must be processed in a transparent, lawful and fair manner; (b) data must be collected for explicit, specific and legitimate purposes and must not be processed in a manner that is incompatible with the purposes for which they were originally collected; (c) data processing should be necessary and limited to the legitimate purpose pursued; (d) data must be adequate, relevant, accurate and up to date and it must be limited to and be fit for the purposes of the data processing that is to take place; (e) the integrity and confidentiality of data should be protected with appropriate measures that prevent unauthorized access, destruction, use, modification or disclosure; and (f) data processors, be they private or public, should be accountable for any breach of these principles.

40. Data subjects should be granted the right to receive information about the data being collected and stored, to rectify incorrect or outdated information and to request the deletion of data unlawfully stored. People and entities processing data should comply with key duties, such as having internal supervisory mechanisms, provide data breach notifications and perform privacy impact assessments, among other duties. States should establish independent data protection oversight bodies. Data protection laws should apply both to State authorities and to private parties.⁵¹ States implementing the above-mentioned principles, particularly those linking human rights obligations under the Convention to policy objectives, will benefit from a cohesive framework for collecting personal data.

⁴⁷ Mark C. Weber, "Protection for privacy under the United Nations Convention on the Rights of Persons with Disabilities", *Laws*, vol. 6, No. 10 (2017).

⁴⁸ See also *United Nations Fundamental Principles of Official Statistics: Implementation Guidelines* (2015).

⁴⁹ [A/74/277](#).

⁵⁰ Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014).

⁵¹ [A/HRC/39/29](#), paras. 29–33.

B. Big data and disability assessments

41. The principles set out in paragraph 39 above can also reduce the data management risks related to big data.⁵² Big data has the potential to significantly benefit policy development and implementation, addressing the barriers that persons with disabilities face. Big data can support a better description of how persons with disabilities engage in their communities or gain access to sector-specific policies. It can improve budget management and, in connection with artificial intelligence, can contribute to the predictability of assistive technology use, increasing the localization of services and the efficiency of resource allocation. Furthermore, it can increase the accuracy of needs assessments, the use of accessible itineraries and facilitate micro-area interventions to promote community-based networks.⁵³

42. Nevertheless, there continue to be warnings about the possible human rights violations stemming from the misuse of big data. Preliminary research has shown the disproportionately high risks to persons with disabilities arising from biased data sets and discriminatory algorithms that restrict persons with disabilities' access to and affordability of services in social protection and health, as well as their access to opportunities in employment and education.⁵⁴ States should require greater transparency and accountability in respect of algorithms used in disability-related services, and adopt a human rights-based approach to big data, including on persons with disabilities and their human rights.⁵⁵

C. Privacy and data collection

43. Privacy should not be used as an argument to not collect disability-related data but as a framework to improve data collection in line with human rights purposes. Recommendations from the Special Rapporteur on the right to privacy regarding persons with disabilities can substantively guide data-collection efforts, even beyond the scope of the recommendations the Special Rapporteur has already made on health-related data. Particular attention should be paid to the recommendations on non-discrimination, prohibition of mandatory disclosure of impairments and health conditions, sufficiency of disability assessments for gaining access to benefits or entitlements, and accessibility to personal data.⁵⁶

44. The Committee on the Rights of Persons with Disabilities has raised concerns on the right to privacy in multiple areas, on the right to health, statistics and data collection, home and the family, children, protection of the integrity of the person, liberty and security of the person and in the banking sector.⁵⁷ States should address these areas of concern so that persons with disabilities, including those in social care, psychiatric or other institutions, enjoy their right to privacy on an equal basis with others.

45. Beyond personal data protection, persons with disabilities should feel and actually be able to safely contribute to data-collection processes aimed at improving policy design and implementation. States should implement regulations that allow for personal data to be used only for statistical purposes and to be aggregated in a way that does not allow for the identification of individuals. In line with statistical confidentiality principles, personal data collected for statistical purposes cannot be used for non-statistical purposes, ensuring that the

⁵² The term "big data" has been described as "a popular phrase used to describe a massive volume of both structured and unstructured data that is so large that it's difficult to process with traditional database and software techniques. The characteristics which broadly distinguish Big Data are sometimes called the '3 V's': more volume, more variety and higher rates of velocity." See Global Pulse, "Big data for development: challenges and opportunities" (May 2012), p. 13.

⁵³ Sriganesh Lokanathan, Dwayne Carruthers and Rivandra Royono, "Disaggregated data can help provide more inclusive transport services" (6 July 2021).

⁵⁴ [A/73/438](#) and [A/HRC/49/52](#).

⁵⁵ [A/HRC/48/31](#).

⁵⁶ [A/74/277](#), annex, chap. XX.

⁵⁷ See, for example, [CRPD/C/TUR/CO/1](#), paras. 50–51; [CRPD/C/RUS/CO/1](#), para. 63; [CRPD/C/GBR/CO/1](#), paras. 48–49; [CRPD/C/CYP/CO/1](#), paras. 41–42; [CRPD/C/DEU/CO/1](#), paras. 29–30; [CRPD/C/UGA/CO/1](#), paras. 44–45; and [CRPD/C/ARM/CO/1](#), paras. 37–38.

data do not allow for the identification of persons with disabilities.⁵⁸ States and other data users should ensure that they are following international standards on statistical confidentiality and microdata access.⁵⁹

V. Right to gain access to information and data under the Convention

46. The Convention recognizes the right to information (art. 21), including to statistical data (art. 31). Specifically, States parties to the Convention should assume responsibility for the dissemination of statistics and ensure their accessibility to persons with disabilities and others. States parties also recognize that having the freedom to seek, receive and impart information is an integral part of the right to freedom of expression (art. 21).⁶⁰ Freedom of expression is, in addition, a precondition for the right to participation, which is also recognized in the Convention (art. 4 (3)). States should, as part of the human rights-based approach, uphold the principle of transparency in respect of data to ensure accountability in policy implementation and to enhance the capacity of persons with disabilities to engage in policy design and implementation.

47. The Convention requires inclusive equality. To achieve it, States should seek systemic transformation while ensuring good management and governance of existing policies. Access to data, be it statistical, administrative, citizen-generated or community-based, is fundamental to assessing the outcomes of existing policies and whether they further human rights objectives or not. Data analysis is key to designing transformative agendas that support the innovation proposed by the Convention, to ensure the enjoyment of human rights and to meet development goals. Despite persistent challenges and gaps in disability-related data, progress has been made in recent years. States should continue to increase and improve their efforts on data collection and use to capitalize on such progress.

A. Global actions

48. At the first Global Disability Summit, held in London in 2018,⁶¹ a number of stakeholders, including States, civil society organizations and United Nations entities, made commitments to disaggregate data by disability. In a report on the implementation of 82 of the 117 data-related commitments made at the Summit it was found that for 49 per cent of those commitments implementation was under way, for 37 per cent implementation had been completed, for 11 per cent implementation had been delayed and for 3 per cent implementation had not yet started. While acknowledging the increasing commitment to and use of the Washington Group on Disability Statistics questions, gaps were identified with respect to the level of analysis and research on barriers, limiting the translation of disability disaggregated data into programming.⁶² Overall, and acting in compliance with their obligations under the Convention, many countries have included or upgraded the disability questions in their 2020 census for the purpose of prevalence estimates and disaggregation.⁶³

⁵⁸ Pursuant to regulation (EC) No. 223/2209 of the European Parliament and of the Council of 11 March 2009, art. 2 (1) (e), “statistical confidentiality” means “the protection of confidential data related to single statistical units which are obtained directly for statistical purposes or indirectly from administrative or other sources and implying the prohibition of use for non-statistical purposes of the data obtained and of their unlawful disclosure.”

⁵⁹ *Managing Statistical Confidentiality and Microdata Access: Principles and Guidelines of Good Practice* (United Nations publication, Sales No. E.07.II.E.7), paras. 25–26.

⁶⁰ See also International Covenant on Civil and Political Rights, art. 19.

⁶¹ See <https://gov.uk/government/collections/global-disability-summit-commitments>.

⁶² United Kingdom of Great Britain and Northern Ireland Foreign, Commonwealth and Development Office and the International Disability Alliance, “Global Disability Summit +2 years: progress on implementation of commitments” (2021), pp. 38–39.

⁶³ According to the Washington Group on Disability Statistics secretariat, recent progress in the adoption and use of the Washington Group short set of questions on functioning have been made by Guatemala (2018), Kenya (2019), Mali (2021), Mexico (2020), Myanmar (2019) and Singapore (2020).

Progress has also been noted by the Committee on the Rights of Persons with Disabilities.⁶⁴ Nevertheless, organizations of persons with disabilities continue to report that collected data are not used and analysed in developing policies.

49. Since the World Humanitarian Summit was held in 2016, progress has been made in the collection and use of data on persons with disabilities in humanitarian action. For example, the templates for producing the humanitarian needs overviews and humanitarian response plans of the Office for the Coordination of Humanitarian Affairs now allow for data to be disaggregated by disability and there has been an increase in the presentation of data on persons with disabilities in these documents, including in persons-in-need figures, in descriptions of needs and in monitoring frameworks. In another example, multisectoral needs assessment processes are increasingly integrating the Washington Group short set of questions on functioning to disaggregate data. Aside from humanitarian coordination processes, individual humanitarian entities are also increasingly integrating disability into their data-collection tools and processes. The United Nations Children's Fund (UNICEF) regularly reports on the children with disabilities it has reached in its annual humanitarian action results report.⁶⁵ The Office of the United Nations High Commissioner for Refugees has integrated the Washington Group short set of questions into its refugee registration system in order to improve the identification of persons with disabilities.⁶⁶ And, going beyond data disaggregation, the International Organization for Migration and others have developed the Displacement Tracking Matrix Field Companion for Disability Inclusion to identify barriers to inclusion.

50. In 2018, the Organisation for Economic Co-operation and Development (OECD) adopted a voluntary marker on disability and, in 2020, issued a handbook.⁶⁷ While no evaluation of the marker's implementation is yet available,⁶⁸ research shows that funding on disability is low.⁶⁹ Disaggregating funding data can give more visibility to the funding gap and motivate further mainstreaming.

B. Next steps

51. To improve data systems, the first step to be taken is to review what data is currently being collected and to assess existing methodologies. Even when data has not been reported, States should not assume it does not exist. Important work has been done in recent years to map existing data that can inform human rights indicators. For example, the disability data initiative at Fordham University in the United States of America reviewed data sets from 180 countries and found that 136 included disability questions of some kind, 84 of which used a functional approach.⁷⁰ Similarly, OHCHR undertook a data sources analysis in 2020 based on the human rights indicators that had been developed for the Convention to show what data sources were available and what data gaps remained.⁷¹ Civil society organizations too have worked in this area. For example, Leonard Cheshire has created the Disability Data Portal, which displays information on data sources in 40 countries.⁷² The International Civil Society Centre has created a coalition of organizations to support community-driven data collection on members of the most marginalized groups in certain countries and to monitor implementation of the Sustainable Development Goals, also involving organizations of

⁶⁴ See [CRPD/C/OMN/CO/1](#), para. 55.

⁶⁵ UNICEF, *Humanitarian Action: Global Annual Results Report 2020* (2020), pp. 51–55.

⁶⁶ Submission by the Office of the United Nations High Commissioner for Refugees.

⁶⁷ See [https://one.oecd.org/document/DCD/DAC/STAT\(2020\)48/en/pdf](https://one.oecd.org/document/DCD/DAC/STAT(2020)48/en/pdf).

⁶⁸ See

[https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DCD/DAC/STAT\(2020\)27&docLanguage=En](https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DCD/DAC/STAT(2020)27&docLanguage=En), para. 36.

⁶⁹ Lorraine Wapling, Arlene Wilson-Grant and Aapurv Jain, "Reversing the trend: the time is now to fund disability rights" (Human Rights Funders Network, 3 November 2021).

⁷⁰ Sophie Mitra and Jaelyn Yap, *The Disability Data Report 2021* (New York, 2021).

⁷¹ OHCHR, *Data Sources Guidance: Introduction*, United Nations, 2020.

⁷² Submission by Leonard Cheshire. See also <https://www.disabilitydataportal.com/>.

persons with disabilities, and published summary reports on action taken at the country level, including data analysis.⁷³

52. States and the United Nations should increase support for the collection, analysis and use of data by persons with disabilities and their representative organizations. A human rights-based approach to data calls for a redoubling of efforts to ensure that data are processed and provided to persons with disabilities in a way that they can immediately use to conduct independent analyses. The use of indicators, be they disability-specific or disaggregated by disability, can contribute to linking human rights obligations, development commitments and outcomes and, subsequently, focus future data-collection efforts to fill gaps in understanding.

53. Bringing in a wide range of actors is critical for improving data collection and analysis. The involvement of national statistical offices, persons with disabilities, national human rights institutions and policymakers is key for developing data systems that aim at improving data collection and analysis. Several participatory initiatives are under way to develop data collection and use. For example, the Economic and Social Commission for Western Asia has developed multiple data-collection and analysis tools, promoting collaboration between persons with disabilities and Governments, including national statistical offices.⁷⁴

54. Under articles 9, 21 and 31 of the Convention, States are obliged to ensure access to information in accessible formats that provide for the diversity of means of communication of persons with disabilities. Particular attention should be paid to information and communications technology, as data are mainly available through websites. Administrative data should also be made accessible to and used by persons with all types of impairments.

55. In humanitarian contexts, it is important to build on gains and consolidate learning to ensure a system-wide approach to the collection and use of data on persons with disabilities. The Washington Group short set of questions on functioning should be consistently applied as a disaggregation tool and increased attention should be paid to the collection of qualitative information on how persons with disabilities are affected by humanitarian emergencies and on the barriers to assistance faced by persons with disabilities. Furthermore, data on needs and priorities need to be better translated into response plans. This requires building the capacity of humanitarian actors and improving the availability of technical support to apply data-collection tools to challenging humanitarian contexts and to analyse data for use in response planning. Organizations of persons with disabilities have an important role to play in supporting these actions.

VI. Conclusions and recommendations

56. **Collecting data on persons with disabilities and on the barriers they face is a human rights obligation under article 31 of the Convention. The Convention expands the recognition of existing human rights as applicable to persons with disabilities, providing both human rights obligations and policy guidance. The innovative aspects contained in the Convention may not be completely captured by policies designed for the broader population and, consequently, may not be reflected in general areas of data collection included in censuses or sector-specific surveys.**

57. **To ensure sustainable and comprehensive data collection regarding persons with disabilities, States should uphold the principles of the human rights-based approach to data. In other words, they should: (a) include in their censuses and all household surveys questions identifying persons with disabilities; (b) ensure that those questions incorporate a functional approach, such as that adopted in the Washington Group short set of questions on functioning questions; (c) disaggregate by disability all individual- and household-level indicators already being reported; (d) conduct regular disability-specific surveys to collect more detailed information, including qualitative information, on persons with disabilities and the environment; and (e) systematize their administrative data collection processes to collect data on disability and identify gaps**

⁷³ See <http://icscentre.org/our-work/leave-no-one-behind/#resources>.

⁷⁴ See <https://archive.unescwa.org/our-work/disability-statistics>.

in policy implementation that prevent the enjoyment of human rights enshrined in the Convention and international human rights law. Moreover, efforts should be taken to harmonize disability-related data collection so that data from different data tools can be consistent and used in conjunction with each other.

58. Analyses should incorporate the intersecting identities of persons with disabilities and possible related forms of discrimination to compare the impact of policies with the broader population, with persons with different types of impairments, with women, children, older persons and LGBTQ+ persons and with members of certain ethnicities, among others.

59. Collecting data on persons with disabilities and the barriers they face is at an early stage, although progress is being made. While data systems continue to be strengthened, citizen-driven and community-based data-collection processes and analyses led by or involving persons with disabilities are valuable sources of data. States should encourage, value and support these data-collection sources, particularly when they provide practical information to address policy gaps and to design a transformational agenda that goes beyond the management of existing policies that may not be in line with the Convention.

60. Data-collection efforts and analyses do not commonly link human rights obligations, development commitments and concrete actions to advance policy implementation in line with the Convention. States should devise indicators for national development and disability-specific action plans that give effect to human rights objectives and policy commitments enshrined in the 2030 Agenda, as well as measure progress and enhance accountability for outcomes.

61. Disability-inclusive policies trigger disability assessments of persons with disabilities to determine their eligibility for benefits and entitlements, but assessments are not generally available to all persons with disabilities who meet the criteria for benefiting from such policies. States should select disability assessment tools that ensure that all eligible persons with disabilities, regardless of their place of residence, can gain access to policies that provide for the enjoyment of their rights. Particular attention should be paid to indigenous peoples with disabilities and persons with disabilities in institutions or prisons, who may have less access to disability assessment processes.

62. Persons with disabilities should enjoy the right to privacy on an equal basis with others and be able to contribute safely to data-collection processes that aim at improving the implementation of policies that benefit them. States should adopt or amend existing data protection laws to include persons with disabilities and ensure that statistical confidentiality is enforced in data collection and data management for statistical purposes. Particular attention should be paid to health-related and rehabilitation data that may lead to the unauthorized disclosure of impairments, increasing the risk of discrimination on the basis of disability.

63. Persons with disabilities should enjoy the right to access information, in accessible formats, and participate in the design, implementation and monitoring of data-related policies. They should also be in a position to analyse and use the data to contribute to policy implementation. States should ensure that data on persons with disabilities and the barriers they face are accessible to persons with disabilities and that the data are relevant for measuring and monitoring compliance with the human rights obligations under international human rights law, including the Convention.

64. The COVID-19 pandemic has revealed data gaps in multiple areas, including in tracking disability funding. In building back better, international cooperation should track and address funding gaps, including through the implementation and use of the policy marker on the inclusion and empowerment of persons with disabilities of the OECD Development Assistance Committee. International cooperation should also shift from being characterized primarily by North-South cooperation to global and South-South strategies.