**49th session of the Human Rights Council**

**Annual interactive debate on the rights of persons with disabilities

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

*Concept note (as of 10 March 2022)*

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| **Date and venue:** | **Monday, 14 March 2022, 4 to 6 p.m. Room XIX, Palais des Nations, Geneva and online platform (Zoom)** *(will be broadcast live and archived on* [*https://media.un.org/en/webtv*](https://media.un.org/en/webtv)*)* |
| **Objectives:** | This panel discussion will address the obligation under article 31 of the Convention on the Rights of Persons with Disabilities (hereinafter “Convention”) to collect appropriate information, including statistical and research data, to enable the formulation and implementation of policies to give effect to the Convention. The objectives are:* **To bring greater understanding** to the importance of data collection and disaggregation under article 31 of the Convention;
* **To provide guidance** on ensuring and enforcing confidentiality in data collection and data management and the right to privacy of persons with disabilities;
* **To discuss the role of data and information in measuring and monitoring human rights obligations and to strengthen accountability** by ensuring access by persons with disabilities to accessible data and information to participate in the design, implementation and monitoring of policies;
* **To share experiences, lessons learned and good practices** in the implementation of article 31 of the Convention, drawing on experiences from the global and national levels;
* **To propose** **strategies** to consolidate data collection and disaggregation efforts, as well as to ensure harmonization of disability data collection tools for increased consistency and use of data.
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| **Chair:**  | **H.E. Mr. Federico Villegas**,President of the Human Rights Council |
| **Opening statement:**  | **Ms. Ilze Brands Kehris**, Assistant Secretary-General for Human Rights *(Zoom)* |
| **Moderator:** | **Mr. Gerard Quinn**,Special Rapporteur on the rights of persons with disabilities |
| **Panellists and themes:** | * **Ms. María Cecilia Rodríguez Gauna**, representative of the Washington Group on Disability Statistics (*video message)*

*Gathering disaggregated data to address social equality, Washington Group Short Set questions** **Ms. Ana Brian Nougrères**, Special Rapporteur on the right to privacy

*Ensuring and enforcing confidentiality in data collection and data management and the right to privacy of persons with disabilities** **Ms. Laisa Vereti**,representative of the International Disability Alliance

*Experience of civil society organizations working with national governments towards disability data collection and disaggregation efforts* |
| **Outcome:** | The debate seeks to bring greater understanding on the importance of data collection and disaggregation and its role in upholding the rights of persons with disabilities, namely by: exposing the barriers to, and the disparity in the enjoyment of rights experienced by persons with disabilities compared with the broader population; driving informed policies and programming; and strengthening accountability toward persons with disabilities. The debate will explore the obligation to collect data as set out in the Convention and identify practical approaches to implementation of article 31 through the expansion of sources (including community-based data collection), harmonization across data instruments, and the use of indicators. In addition, the discussion will address the right to privacy and confidentiality of persons with disabilities and access to information to promote transparency and participation. An informal summary of the interactive debate will be prepared by the Office of the United Nations High Commissioner for Human Rights (OHCHR) and posted on the OHCHR website. |
| **Mandate:**  | In its resolution [43/23](https://undocs.org/A/HRC/RES/43/23), the Human Rights Council decided that the annual interactive debate on the rights of persons with disabilities to be held at its forty-ninth session would focus on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities, and would have international sign interpretation and captioning. The Council requested the OHCHR to prepare the annual study on the rights of persons with disabilities for its forty-ninth session on statistics and data collection, in consultation with States and other relevant stakeholders, regional organizations, the Special Rapporteur on the rights of persons with disabilities, civil society organizations, including organizations of persons with disabilities, and national human rights institutions, requiring contributions to be submitted in an accessible format, and requested that such stakeholder contributions, the study and an easy-to-read-version of it, be made available on the website of the Office, in an accessible format, prior to the session. To this end, OHCHR invited States and all the aforementioned stakeholders to provide responses to a set of questions concerning existing legislation, policies and practices on statistics and data collection relating to persons with disabilities. OHCHR received 30 responses from States, 4 from intergovernmental organizations and 12 responses from civil society organizations.[[1]](#footnote-1) These responses informed the report of OHCHR on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities (document A/HRC/49/60). |
| **Format:**  | The annual debate will be limited to two hours. The opening statement and initial presentations by the panellists will be followed by an interactive discussion divided into two segments. A maximum of one hour will be set aside for the podium, including the opening statement, panellists’ presentations and their responses to questions and concluding remarks. The remaining hour will be reserved for two segments of interventions from the floor, with each segment consisting of interventions from 12 States or observers, 1 national human rights institution and two non-governmental organizations. The list of speakers for the discussion will be established through the online inscription system and, as per practice, statements by high-level dignitaries and groups of States will be moved to the beginning of the list. Each speaker will have two minutes to raise issues and to ask panellists questions. Delegates who have not been able to take the floor due to time constraints will be able to upload their statements on the online system to be posted on the HRC Extranet. |
| **Accessibility:** | In an effort to render the Human Rights Council more accessible to persons with disabilities and to promote their full participation in the work of the Council on an equal basis with others, the interactive debate will be webcast and made accessible. International sign interpretation and real-time captioning in English will be provided. During the event itself, participants can access live English captioning on the StreamText web page (<https://www.streamtext.net/player?event=CFI-UNOG>). Hearing loops are available for collection from the Secretariat desk. Oral statements may be embossed in Braille from any of the six official languages of the United Nations, upon request and following the procedure described in *The accessibility guide to the Human Rights Council for persons with disabilities* (<https://www.ohchr.org/EN/HRBodies/HRC/Pages/Accessibility.aspx>). |
| **Background:** | Under article 31 of the treaty, States commit to “undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.”[[2]](#footnote-2) Hence, data collection should aim at fulfilling the purpose of the treaty and measurement should address both dimensions of disability, the individual dimension, identifying persons with disabilities and, the social dimension, the barriers that hinder their effective participation on an equal basis with others.Across the globe, persons with disabilities continue to be left behind and overlooked in policy reform and development due to the absence of information and data about them. Efforts to collect data, such as censuses and household surveys, often fail to systematically disaggregate by disability, thereby losing important opportunities to establish a baseline to know, compare and advance the situation of persons with disabilities in relation with the broader population. Where disaggregation and/or disability assessments are undertaken, they may not always serve their purpose and data collection and analysis do not commonly link human rights obligations, development commitments and concrete actions to advance policy implementation in line with the Convention. Disability-specific surveys are also difficult to implement due to extensive costs involved and their infrequent practice propagates data gaps. The lack of consistency and harmonization of data across different instruments hinders reliable data collection and usage. Furthermore, there is a need to strengthen privacy of data concerning persons with disabilities and to better monitor disclosure of disability-related data, particularly given the risks associated with big data. Persons with disabilities also have the right to information on an equal basis with others, yet often face barriers due to inaccessible data and information and are denied participation to contribute to policy implementation through data analysis and use.In order to implement article 31 of the Convention, systematic disaggregation by disability in censuses and household surveys is essential and should be guided by the Washington Group Short Set questions. In addition, it is important to conduct regular disability-specific surveys, systematize administrative data collection processes and take steps to harmonize disability data collection across diverse data tools. Human rights indicators can also help States to measure and monitor action to implement national plans and programmes related to persons with disabilities, as well as the Convention and policy commitments enshrined in the 2030 Agenda for Sustainable Development. Disability assessment tools should be fit for purpose to ensure that all eligible persons with disabilities can access services and support to exercise their rights on an equal basis with others. Furthermore, it is key that data protection laws are inclusive of persons with disabilities with respect to statistical confidentiality, and promote access to accessible information to enable persons with disabilities to participate in the design, implementation and monitoring of data-related policies and, more broadly, the Convention.  |
| **Background documents:** | * [Human Rights Council resolution 43/23](https://undocs.org/A/HRC/RES/43/23) of 22 June 2020 on awareness-raising on the rights of persons with disabilities and habilitation and rehabilitation
* Report of OHCHR on statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities ([A/HRC/49/60](https://undocs.org/A/HRC/49/60))
	+ [Easy to read version](https://www.ohchr.org/Documents/Issues/Disability/A-HRC-49-60-ETR.docx) of the report in English
* [Human Rights Council resolution 7/9](http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/RES/7/9) of 27 March 2008 on human rights of persons with disabilities
* OHCHR web page with [studies, reports and papers on the rights of persons with disabilities](http://www.ohchr.org/EN/Issues/Disability/Pages/StudiesReportsPapers.aspx)
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1. See <https://www.ohchr.org/EN/Issues/Disability/Pages/CFI-statistics-data-collection.aspx> [↑](#footnote-ref-1)
2. Convention on the Rights of Persons with Disabilities, article 31(1). [↑](#footnote-ref-2)