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Disability statistics

Joint report of the Secretary-General, the Washington Group on Disability Statistics and international agencies on disability statistics

Summary

The present report, which was prepared in accordance with Economic and Social Council decision 2023/325 and past practices, describes ongoing and planned activities on disability statistics carried out by the Division for Inclusive Social Development of the Department of Economic and Social Affairs of the Secretariat, the Economic and Social Commission for Asia and the Pacific, the United Nations Children's Fund, the World Health Organization and the Washington Group on Disability Statistics. The Commission is invited to take note of the report.

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I. Introduction

- 1. In the 2030 Agenda for Sustainable Development, persons with disabilities are recognized as belonging to one of the marginalized groups whose members are disproportionately affected by poverty and exclusion. The 2030 Agenda, in its commitment to leaving no one behind in its implementation, emphasizes the need for accurate, timely and adequately disaggregated data for monitoring and assessing progress towards achieving disability-inclusive sustainable development. The present report highlights activities being undertaking by various agencies and organizations with the end objective of promoting a better life for persons with disabilities.
- 2. The report describes ongoing and planned activities on disability statistics that are carried out by the Division for Inclusive Social Development of the Department of Economic and Social Affairs of the Secretariat, the Economic and Social Commission for Asia and the Pacific (ESCAP), the United Nations Children's Fund (UNICEF), the World Health Organization (WHO) and the Washington Group on Disability Statistics, a city group under the aegis of the Statistical Commission.

II. Activities of United Nations organizations

A. Department of Economic and Social Affairs of the Secretariat

- 3. The Division for Inclusive Social Development is responsible for promoting the rights and advancement of persons with disabilities and monitoring the mainstreaming of disability in the development agenda, including in the Sustainable Development Goals. The Department of Economic and Social Affairs leads the preparation of the *Disability and Development Report*, a publication that reviews the situation of persons with disabilities vis-à-vis the Goals and the implementation of the Convention on the Rights of Persons with Disabilities. The *Disability and Development Report* is the only publication that addresses, at the global level, the nexus between disability and the Sustainable Development Goals.
- 4. In its resolution 75/154, the General Assembly tasked the Secretary-General to provide an update on the *Disability and Development Report* in 2023. Based on an unprecedented amount of data and information on legislation and policies from all countries, this most recent global report explores the socioeconomic circumstances of persons with disabilities worldwide and the challenges and barriers faced by them in their daily lives, including the exacerbated impacts of the coronavirus disease (COVID-19) pandemic. Against the backdrop of all the available evidence, the report identifies good practices and recommends urgent actions to be taken to realize the Sustainable Development Goals by, for and with persons with disabilities. The publication draws on the collective inputs of United Nations entities and a wide range of other contributors, such as country experts and civil society, including organizations of persons with disabilities.

B. Economic and Social Commission for Asia and the Pacific

5. ESCAP has worked to integrate disability statistics as a cross-cutting issue to implement disability-inclusive development within the framework of the 2030 Agenda for Sustainable Development and the Asian and Pacific Decade of Persons

¹ https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf.

with Disabilities, 2013-2022, which sets out disability-specific development goals for the region.

- 6. In 2022, the High-level Intergovernmental Meeting on the Final Review of the Asian and Pacific Decade of Persons with Disabilities, 2013–2022, concluded the implementation of the Asian and Pacific Decade of Persons with Disabilities over the last decade. The final review process was based on a national survey among ESCAP member States which collected information and disability-disaggregated data to measure progress towards disability-inclusive development. The survey responses and data received from member States provided valuable sources for assessing the implementation of the Asian and Pacific Decade of Persons with Disabilities, 2013–2022 and contributed to the adoption of the Jakarta Declaration on the Asian and Pacific Decade of Persons with Disabilities, 2023–2032, which undergirds strategies, actions and priorities for disability inclusion over the course of the new decade.
- 7. The Jakarta Declaration underscores the importance of closing disability data gaps and strengthening statistical capacities as one of the six priority areas guiding the implementation of the Asian and Pacific Decade of Persons with Disabilities, 2023–2032. ESCAP is preparing an operational guide to provide policymakers and regional stakeholders with a set of recommendations for concrete actions and measures, with a view to accelerating the implementation of the Jakarta Declaration on the Asian and Pacific Decade of Persons with Disabilities, 2023–2032. The operational guide will encompass further guidance on improving disability data to ensure that data are considered in the context of national disability policies and strategies.
- 8. ESCAP has further utilized the data collected from member States to produce a publication entitled A Three-Decade Journey towards Inclusion: Assessing the State of Disability-Inclusive Development in Asia and the Pacific. The publication features a comprehensive regional analysis of disability-inclusive development which captures achievements, challenges and issues associated with advancing disability inclusion and disability rights. Disability-disaggregated data across employment, education, social protection, accessibility, disaster risk reduction and other dimensions that point to socioeconomic disparities concerning persons with disabilities are presented in the publication.
- 9. Capacity-building and technical assistance activities of ESCAP have continued to support ESCAP member countries and stakeholders in the region in tracking progress towards disability-inclusive development. ESCAP collaborated with the United Nations country team Indonesia in developing training modules on disability inclusion in United Nations monitoring and evaluation activities. Technical support was given for introducing internationally comparable data-collection methods and utilizing disability data within the United Nations monitoring and evaluation frameworks. Technical assistance was provided In India for enhancing disability data collection and analysis within the context of achieving the Sustainable Development Goals, as a part of training, in collaboration with the Government of India and the United Nations Office in India.
- 10. ESCAP is currently developing an online database that facilitates data comparison and analysis of the data collected from member States through the final review of the Asian and Pacific Decade of Persons with Disabilities, 2013–2022. ESCAP expects to continue to produce knowledge products to assist member States in closing the disability data gap and strengthening statistical capacities. A policy brief to advise policymakers and national statistical offices on disability data harmonization is expected to be published in 2024.

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C. United Nations Children's Fund

- 11. Over the course of 2023, UNICEF engaged in a range of activities to foster the availability, quality and use of data on children with disabilities, including:
- (a) Dedicated technical support and guidance on data collection and analysis. To support the uptake of the module on child functioning, developed by UNICEF and the Washington Group on Disability Statistics, in 2023, UNICEF provided direct technical support to more than 20 national statistical offices. This included substantive input on questionnaire design, data analyses and the resulting indicators. UNICEF led the preparation of Ukrainian and Slovak versions of the module to support the humanitarian response to the conflict in Ukraine. A Swahili version of the module was also issued. UNICEF published one guidance note in cooperation with the Washington Group on translating the module and a second guidance note on how to integrate the module in demographic and health surveys;
- (b) Testing of the teacher version of the module on child functioning. Following the integration of the module in household surveys, UNICEF and the Washington Group on Disability Statistics developed a teacher version of the module on child functioning which can be used in national education management information systems. The teacher version of the module takes advantage of teachers' knowledge of their pupils and their functioning among peers in a class setting. In 2023, activities for testing the teacher version continued. The module is expected to be released in 2024;
- (c) Testing of the inclusive education module. UNICEF and the Washington Group on Disability Statistics have been working on the inclusive education module (IEM). The module consists of five sets of questions related to school-age children which are meant to be used in surveys. The aim of those questions is to obtain information on various aspects of their access to education. The module includes questions that evaluate the accessibility of the physical space, the curriculum and other aspects of the school environment, as well as questions that are intended to capture school attendance determinants, including specific circumstances in the lives of children that could be impacting their school attendance. In 2023, activities for testing the module have continued. The module is expected to be released in 2024;
- (d) Production of data reports. UNICEF released a number of data-driven reports, including three regional reports on the well-being of children with disabilities in the Eastern and Southern Africa region, the Europe and Central Asia region and the Middle East and Northern Africa, and a thematic report entitled "Included, every step of the way: upholding the rights of migrant and displaced children with disabilities". For the first time, in 2023, The State of the World's Children, the flagship report of UNICEF, included a statistical table (No. 16) with data on children with disabilities. The table 16 presents a selection of indicators on child well-being across various domains: child protection, early childhood development, education, child nutrition, and social protection and equity, as well as on water, sanitation and hygiene. For each indicator, data are presented for children with and without disabilities;
- (e) Capacity-building workshops on collecting, analysing and using data on children with disabilities. UNICEF conducted two global and two country workshops on collecting, analysing and using data on children with disabilities, targeted at representatives of national statistical offices, organizations of persons with disabilities and other stakeholders working on data collection, analysis and dissemination. The four workshops were delivered to over 350 participants from 75 countries. During the training, learners engaged with eight modules covering an array of topics integral to strengthening capacity in collecting, analysing and using data on children with disabilities.

12. In partnership with the Department of Psychology and Cognitive Science of the University of Trento, Italy, the UNICEF Centre of Excellence on Data for Children with Disabilities organized a four-day summer school course on data analysis in August 2023 for representatives of national statistical offices and line ministries. The training, which was attended by 23 participants from 13 countries, increased their knowledge on how to analyse and interpret data on children with disabilities and provided participants with the opportunity to use their own country's data set to conduct the analysis.

D. World Health Organization

- 13. Work of WHO on disability statistics relates to the global and national monitoring of needs, barriers and inequities faced by people with a disability. There is a long tradition in WHO of conceptualization and measurement of disability. An important milestone was achieved with the endorsement of the International Classification of Functioning, Disability and Health by all WHO member States at the fifty-fourth World Health Assembly in resolution 54.21 of 22 May 2001.
- 14. WHO launched the Global Report on Health Equity for Persons with Disabilities in December 2022. The report presents new evidence on the global and regional prevalence of persons with disabilities, updating the previous estimates included in the 2011 World Report on Disability. According to the global report, 1.3 billion people had significant disability as of 2021. This number has increased substantially in the last decade and is expected to rise, given the range of epidemiological and demographic changes in the population. The report provides detailed prevalence data by region, income group, sex and age.
- 15. In addition, the global report provides a synthesis of the latest global evidence on health inequities experienced by persons with disabilities (premature mortality, increased morbidity and functioning limitations) compared with persons without disabilities, as well as the contributing factors to health inequities for persons with disabilities.
- 16. WHO has been providing support to countries in the collection of disability and functioning data at population level using the model disability survey, a population-based household survey. Two versions of the survey are currently available: a standalone version for a dedicated survey on disability and a brief version, which could be used as a module and integrated into existing household surveys. WHO provides member States with technical support throughout the implementation process, with a strong focus on sustainable capacity-building strategies for national and regional statistical offices.
- 17. In 2022–2023, Georgia and Chile finalized the implementation of the survey at national level. For Chile, this was a follow-up assessment after the first implementation in 2015, allowing for comparisons between the two implementations. The report for Georgia is available at the WHO website.
- 18. WHO has developed a short instrument, the WHO Functioning and Disability Disaggregation Tool (FDD11), which can be integrated into existing surveys to allow for data disaggregation by disability. The instrument, which is derived from the model disability survey and contains 11 questions, is specifically designed to be used as a tool for disaggregation of other indicators by disability status.
- 19. In assessing the validity and reliability of the Functioning and Disability Disaggregation Tool (FDD11), WHO found that it showed excellent psychometric properties, making it feasible to integrate into existing surveys to allow for data

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disaggregation by disability status. The instrument will be included in the next round of implementation of the World Health Survey.

- 20. WHO proposes that countries collect and disaggregate disability data across all levels of their health information systems. Moreover, at input level, administrative sources such as financial tracking systems, databases and records on human resources, infrastructure and policies can be used to build an understanding of how financing for disability works and determine whether health facilities are accessible. At output level, facility assessments and facility reporting systems can measure availability of services and service readiness and quality. In terms of routine facility data collection, identifying persons with disabilities can be facilitated through collecting data on functioning. For example, WHO introduced a supplementary section on functioning assessment in the eleventh revision of the International Statistical Classification of Diseases and Related Health Problems. The section on functioning incorporates the WHO Disability Assessment Schedule 2.0 and the functioning module of the model disability survey. This is a major step forward in collecting data on disability within the health information system, since most countries use the International Statistical Classification for mortality and morbidity data and many use it also for reimbursement purposes.
- 21. At the outcome and impact levels, both facility and population-based data, including census data on disability, are fundamental sources for capturing information on health outcomes for persons with disabilities when disability status is identified. Very often, data on disability exist in many countries but are not used adequately. For example, while demographic and health surveys have a module on disability, the rest of the indicators (e.g., utilization of services, violence and knowledge about health services) are not disaggregated by disability. Such information can serve as a very good source of data for countries with regard to tracking progress on their health strategic plans and progress of Sustainable Development Goals for persons with disabilities.

III. Washington Group on Disability Statistics

- 22. The Washington Group on Disability Statistics was constituted as a city group in 2001 to improve the quality and international comparability of disability statistics. It currently has some 168 country members and partners, including multiple United Nations entities, non-governmental organizations, international non-governmental organizations and organizations of persons with disabilities. Twenty-three annual meetings have been held, 19 in person using a regional rotation system to facilitate attendance and the past 4, virtually. The most recent meeting, held from 30 October to 1 November 2023, hosted over 130 attendees representing national statistical offices of members and partner organizations. Topics of sessions at the meeting included cognitive testing and evaluation results for the teacher version of the module on child functioning, the inclusive education module and new questions designed to more fully capture psychosocial disability; guidance on the production of standard analytic country disability reports; a proposed new policy for making translations of Washington Group tools available to users; and reports from Washington Group regional disability groups. Over the years, the Washington Group has become a point of contact for those interested in disability statistics. The secretariat receives large numbers of questions and requests for assistance from a diverse range of partners and interested parties and responds to these requests, fostering connections among those with similar interests.
- 23. The Washington Group has developed multiple question sets addressing different aspects of disability statistics and incorporating the definition of disability presented in the Convention on the Rights of Persons with Disabilities. These include

the short set; the short set – enhanced; extended sets on functioning; the module on child functioning; and the labour force survey disability module. The sets have been developed collaboratively with partners and have been widely tested to ensure internationally comparable data relevant for policy and programme development and evaluation. They are extensively documented, including guidance for implementation and analysis. The Washington Group website is optimized for accessibility and contains all updated documents, frequently asked questions and topical blogs to assist data collectors and users.²

- 24. The Washington Group short set on functioning consists of six questions assessing difficulties in core domains of functioning to identify those at greater risk than the general population for participation restrictions in the absence of appropriate accommodations. The short set on functioning is therefore well suited for disaggregating data related to the Sustainable Development Goals. Disability status is determined on the basis of having "a lot of difficulty" or "cannot do" in at least one of six core domains of functioning. Adding the short set of questions to an existing survey allows for internationally comparable disaggregation of all indicators generated by that survey.
- 25. Adopted in 2006, the short set has been included in: (a) censuses or surveys in over 123 countries to date; (b) projects supported by international aid programmes; (c) the Principles and Recommendations for Population and Housing Censuses, Revision 3,3 the Conference of European Statisticians Recommendations for the 2020 Censuses of Population and Housing⁴ and a publication of the Economic Commission for Latin America and the Caribbean⁵ prepared for the 2020 censuses of population and housing; (d) demographic and health surveys; (e) some 70 World Bank-sponsored Living Standards Measurement Studies; (f) some 50 UNICEF-supported Multiple Indicator Cluster Surveys (see below); (g) data collections in humanitarian and crisis settings, including in the 2023 Global Survey Report on Persons with Disabilities and Disasters⁶ and the Office of the United Nations High Commissioner for Refugees (UNHCR) "Guidance: identification of persons with disabilities at registration and other data collection efforts"; (h) Recommendations on Ageing-related Statistics, prepared by the Task Force on Ageing-related Statistics of the Economic Commission for Europe⁸; and (i) the work of multiple United Nations entities, non-governmental organizations and academia.⁹
- 26. The Washington Group short set on functioning enhanced and the extended set on functioning include additional domains not included in the short set and obtain

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² All documents of the Washington Group, as well as detailed information on the group and the rationale, development, testing and use of all of its tools, are available at www.washingtongroup-disability.com.

³ United Nations, 2017.

⁴ United Nations, Economic Commission for Europe, 2015.

⁵ Aspectos conceptuales de los censos de población y vivienda: desafíos para la definición de contenidos incluyentes en la ronda 2020 (2019). Available at https://repositorio.cepal.org/bitstream/handle/11362/44944/1/S1900856 es.pdf.

⁶ Geneva, United Nations Office for Disaster Risk Reduction, 2023.

⁷ Available at www.unhcr.org/sites/default/files/2023-01/63a4504219.pdf.

September 2016. Available at https://unece.org/DAM/stats/documents/ece/ces/bur/2016/October/19Add1-Recommendations on Ageing-related Statistics.pdf.

⁹ The short set has been used by: (a) United Nations entities: the Statistics Division, the Office of the United Nations High Commissioner for Human Rights, UNICEF, ILO, the United Nations Population Fund, the United Nations Educational, Scientific and Cultural Organization, UNHCR, the United Nations Development Programme, the United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women), the United Nations Partnership on the Rights of Persons with Disabilities, the World Food Programme, WHO and the Special Rapporteur on the rights of persons with disabilities; and (b) international non-governmental organizations: CBM Global Disability Inclusion, Humanity and Inclusion, Save the Children and Sightsavers.

- more information on some domains, as well as information on the impact of mobility assistive devices on functioning. The short set enhanced includes the additional domains of affect and upper body functioning; the extended set includes pain, fatigue and upper body functioning. Both sets have scaled response categories similar to those used in the short set to describe the level of functioning in each domain. The extended set has been implemented in 35 countries through 2023.
- 27. The Washington Group/International Labour Organization (ILO) labour force survey disability module addresses the policy interest of ILO in establishing and monitoring the effectiveness and impact of national legislation and programmes and policies to promote equal employment opportunities for persons with disabilities. The module was endorsed at the 2019 annual meeting of the Group and has been integrated into the ILO model labour force survey questionnaire. ¹⁰ ILO recommends routine inclusion of the set in the labour force survey questionnaire and inclusion of the expanded module, including barriers to employment, every two to five years.
- 28. The Washington Group/UNICEF module on child functioning, which was adopted in 2016, addresses functioning among children aged 2–4 years over eight functional domains and among children aged 5–17 years over 12 domains. The module on child functioning and the Washington Group short set on functioning (for the population aged 18 or over) have been incorporated into 53 UNICEF-supported Multiple Indicator Cluster Surveys, with additional countries currently at various stages of implementation.
- 29. The Washington Group/UNICEF module on child functioning teacher version is designed to be administered to teachers in educational settings. In response to increased interest in using the teacher version in diverse contexts, including humanitarian emergencies, the Washington Group secretariat began convening regular meetings in 2021 to promote an exchange of knowledge among partners regarding their evaluation plans. The secretariat developed a best practices guide to conducting a module on child functioning teacher version evaluation. The module on child functioning teacher version has been tested in six countries, in over 80 school settings, by Washington Group partners. The module on child functioning teacher version, with supporting documentation, is expected to be finalized in 2024.
- 30. The Washington Group/UNICEF module on inclusive education includes questions in domains that affect school attendance and learning, including determinants of attendance, accessibility of the physical environment, transportation to and from school, information, communication and programmes and affordability and an out-of-school component. Cognitive testing has been completed in six countries and field testing in three. The module on inclusive education, with supporting documentation, is expected to be finalized in 2024.
- 31. Country reports on disability using Washington Group short set on functioning data are being developed by Washington Group member countries. The Washington Group supports the analysis and dissemination of disability data collected using Washington Group tools, especially at the country level. To this end, a standard template was developed to report on disability prevalence as well as on differences between populations with and without disabilities on selected outcome indicators. The report is short, to facilitate production, and guidance documents have been developed so that published results are as comparable as possible across countries. Countries are encouraged to expand on the core template and include topics of country interest. The regional disability groups, described below, are coordinating the production of reports in their respective regions. The Washington Group will be conducting webinars to provide technical assistance as needed.

¹⁰ Available at https://ilo.org/LFSresources.

Technical assistance and capacity-building

- 32. The Washington Group is developing regional and national capacity in disability measurement and data analysis and dissemination, as well as strengthening capacity among civil society organizations. The Washington Group has conducted in-person workshops and webinars to support these efforts but travel restrictions have resulted in substitution of webinars and individualized virtual consultations with partners. In 2022–2023, the Group has provided direct technical assistance to national statistical offices and other national public entities in multiple countries and has responded to requests for information and translations of the tools presented at conferences and seminars and contributed comments and inputs to partner consultations and documents. A summary of these activities is provided in the background document.
- 33. The Washington Group is supporting the work of regional disability groups. Those groups focus on region-specific needs and work with the Group secretariat to coordinate disability activities and strengthen capacity to collect and disseminate high-quality disability data. To date, there are six active groups, 11 with two based in Africa, currently being supported by an agreement with the Federal Ministry for Economic Cooperation and Development of Germany. The groups have developed terms of reference and workplans which include supporting comparable data collection and consistent application of methodologies for reporting. The groups are involved in the production of the individual country disability reports and there is the potential for creating regional reports.

Planned activities for 2024

- 34. The Washington Group will continue efforts to support the regional disability statistics groups to advance work among countries that share a common language or culture and common disability data challenges.
- 35. The following next steps were identified at the twenty-third annual meeting: (a) further testing of psychosocial functioning questions; (b) finalizing the policy for making translations available to users; (c) assisting partners in combining results from the testing of the module on child Functioning teacher version and collaborating on the development of implementation guidelines; (d) finalizing the module on inclusive education with UNICEF; (e) advancing the work of the regional disability statistics groups; (f) convening a set of subject-specific webinars to further the work in these areas; (g) exploring additional avenues of communication between members; and (h) continuing to act as a central clearing house for a wide range of partners and interested parties on disability statistics through responding to questions and requests for assistance.
- 36. The Washington Group disseminates its work products through its website (www.washingtongroup-disability.com) and scientific publications.

IV. Summary and conclusions

37. The present report provides information on ongoing and planned activities of the various entities regarding disability measurement and statistics. Those activities, which are carried out in the context of the 2030 Agenda for Sustainable Development, are intended to help countries generate good-quality data on disability for policy

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Washington Group regional disability statistics groups: Brazzaville group (French-speaking countries of Africa), Buenos Aires group (countries of Latin America), Casablanca group (Arabic-speaking countries of the Middle East and Northern Africa), Kathmandu group (South Asian countries), Pacific group (island States of the Pacific) and South and East Africa group.

formation and monitoring aimed at ensuring that persons with disabilities are not left behind.

V. Action to be taken by the Statistical Commission

38. The Commission is invited to take note of the present report.