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Disability statistics

Report of the Secretary-General and the Washington Group

Summary

The present report, which was prepared in accordance with Economic and Social Council decision 2015/216 and past practices, provides a review of recent activities and developments on disability statistics by international stakeholders active in this area. The report introduces the new project that the Statistics Division of the Department of Economic and Social Affairs of the Secretariat launched in 2015 to strengthen disability statistics, with the financial support of the Department of Foreign Affairs and Trade of the Government of Australia. The report also provides a summary of the work of the Washington Group on Disability Statistics and, in particular, of ongoing tests of various modules for the measurement of disability and the Group's collaborative efforts with the United Nations Children's Fund, the Department of Foreign Affairs and Trade of the Government of Australia and the Department for International Development of the Government of the United Kingdom of Great Britain and Northern Ireland. The Commission is invited to take note of the report and the future work programmes contained therein.

* E/CN.3/2016/1.



I. Introduction

1. The present report describes the work of the Statistics Division of the Department of Economic and Social Affairs of the Secretariat and the Washington Group to advance disability statistics. It introduces the new project that the Division launched in May 2015 to strengthen disability statistics from an international perspective, with the financial support of the Department of Foreign Affairs and Trade of the Government of Australia. The report also describes the work of the Washington Group on Disability Statistics to improve the quality, availability and comparability of disability statistics. In particular, it describes the Group's work on developing and testing questions on disability for use in censuses and surveys and the joint work with the United Nations Children's Fund (UNICEF) on developing and testing question sets that focus on child functioning and disability.

II. Activities of the Statistics Division of the Department of Economic and Social Affairs of the Secretariat

2. At the international level, the Statistics Division is responsible for the development of statistical methodological standards, the compilation and dissemination of national data and the provision of technical assistance to countries. In the context of the 2030 Agenda for Sustainable Development and the 2020 World Population and Housing Census Programme, the Division, with funding from the Department of Foreign Affairs and Trade of the Government of Australia, has launched a project to enhance the capacity of national statistical offices to produce and disseminate good-quality and fit-for-purpose statistics on disability for all-inclusive development planning and monitoring, taking into account the situation of persons with disabilities. The project, which started in May 2015, runs through March 2019 and is being implemented by the Statistics Division.

3. The project has two expected accomplishments: (a) the development of international guidelines for the measurement of disability, taking into account existing measurement instruments, good national practices and country experiences; and (b) enhanced capacity of national statistical systems to collect and generate relevant, quality disability statistics based on international guidelines. To that end, the Division, through the project, will undertake a variety of activities: (a) collect, review, analyse and collate data and metadata on national practices in disability data collection and make that information available online and in print; (b) organize meetings of experts with a view to developing international guidelines for disability measurement based on a review of national practices as well as existing measures of disability; (c) conduct training workshops and provide technical assistance at the request of countries; (d) develop e-learning material on disability measurement; and (e) support South-South cooperation through study visits.

4. The project has several objectives, some at the national level and others at the international level, with each level having different stakeholders. Consequently, the Division will work in close collaboration with the United Nations regional commissions, the Washington Group, the World Health Organization (WHO), UNICEF, the World Bank, the Division for Social Policy and Development of the Department of Economic and Social Affairs of the Secretariat and other relevant stakeholders in disability policy and measurement for the benefit of countries to

enable them to have reliable and adequate statistics for inclusive development planning and monitoring.

5. The Statistics Division is currently undertaking the recruitment of project staff, with the main implementation of the project to commence in 2016. The Division is drafting a questionnaire to be sent to national statistical offices to collect data on disability, as well as supporting documents, such as questionnaires, from the 2010 census round or from recent sample surveys. These activities are built on the rich experience of the Division, which has led the World Population and Housing Census Programme for decades (see [E/CN.3/2016/19](#)). The collected information will form the basis for the analysis of national practices regarding disability measurement, upon which the development of international guidelines will partially be based, and for compilation and dissemination as data on the prevalence and characteristics of persons with disabilities.

6. The Statistics Division has contributed to the work of the Washington Group through its participation in the 15th meeting of the Group, which was held in Copenhagen in October 2015. The Division will also contribute by participating in three working groups of the Washington Group on work that will be reported at the next meeting of the Group.

III. Activities of the Washington Group on Disability Statistics

7. The Washington Group on Disability Statistics, a city group established under the Statistical Commission, was formed to address the urgent need for population-based measures of disability by promoting and coordinating international cooperation in the area of health statistics, focusing on disability data collection tools suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability that is comparable throughout the world. The following section of the report focuses on the work of the Washington Group since it last reported to the Commission in 2013.

A. Washington Group short question set on functioning: monitoring and disaggregation

8. A major accomplishment of the Washington Group is the development, testing and endorsement of a short set of questions that can be used in censuses, sample-based national surveys or other data collection platforms for the primary purpose of informing policy on the full inclusion of persons with disability into civil society. The set includes questions, which were extensively tested in all regions of the world, on six core functional domains: seeing, hearing, walking, cognition, self-care and communication.

9. Recent international initiatives have focused on the applicability of the Washington Group short set of questions in monitoring the implementation of the Convention on the Rights of Persons with Disabilities and the post-2015 Sustainable Development Goals and, in particular, in the disaggregation of outcome indicators by disability status. The short set of questions has also been promoted by international aid programmes, the Department for International Development of the Government of the United Kingdom of Great Britain and Northern Ireland and the

Department of Foreign Affairs and Trade of the Government of Australia as the means of collecting disability data in all programmes and projects. The United States Agency for International Development has developed a disability module that will operationalize the Washington Group short set for its demographic and health surveys. Lastly, the Statistics Division and the Economic Commission for Europe have introduced the short set in their respective recommendations for the 2020 round of censuses.

B. Washington Group extended question set on functioning

10. The Washington Group has also developed an extended set of functioning questions, which builds on the short set, for use as components of population surveys, as supplements to surveys or as the core of a disability survey. The extended set includes domains that are not possible to address in a census but that can be addressed in surveys. In addition to the six domains of the short set, the extended set includes upper body functioning, affect, pain and fatigue. These domains can be used to create a more comprehensive continuum of functioning, building on the short set.

11. After extensive testing in multiple countries in collaboration with the Economic and Social Commission for Asia and the Pacific and the Budapest Initiative, the Washington Group extended set of questions was adopted in November 2010. The extended set of disability questions on functioning was added to the United States National Health Interview Survey beginning in 2010. During the past few years, analyses have been undertaken using data from 2010 and 2013 to develop algorithms for combining multiple domain questions into single domain indicators that describe a continuum of functioning in that domain and to identify standards for the determination of appropriate cut points for categorizing disability status for international comparisons. A small working group will finalize the analysis for the outstanding domains. All analyses will be compiled in a document describing the properties of individual domains of functioning. The document will also include examples of various cut points that can be used to estimate disability prevalence rates and provide a recommendation on the cut point to use for internationally comparable reporting.

C. United Nations Children's Fund/Washington Group module on child functioning

12. In 2009, the Washington Group began work on the development of a set of questions on child disability for use in surveys. This coincided with the plans of UNICEF to revise the existing data collection module used in the Multiple Indicator Cluster Survey programme (see http://www.unicef.org/statistics/index_24302.html). The UNICEF/Washington Group questionnaire on child functioning reflects the current thinking around child disability and can produce internationally comparable data. The questionnaire covers children between 2 and 17 years of age and assesses speech and language, hearing, vision, learning (cognition and intellectual development), mobility and motor skills, emotions and behaviours, as well as self-care, play and the development of relationships. The questionnaire has undergone cognitive testing in Mumbai, India; the United States of America, at the

National Center for Health Statistics; Belize, in association with UNICEF Belize, the Statistical Institute of Belize and CARE International; Oman, at the Central Statistical Office; and Montenegro. Field testing has been conducted in Cameroon, El Salvador, Haiti, India, Italy, Mexico and Samoa. Final field testing is scheduled for Serbia and it is expected that the module and the manual for its implementation will be finalized and launched in early 2016.

D. UNICEF/Washington Group survey module on inclusive education

13. UNICEF and the Washington Group have been working on the development of a survey module on the measurement of environmental barriers to school participation for children with and without disabilities. This module will complement the above-mentioned module on child functioning. The module begins to assess the outcome of the interaction between functional limitations and the environment with respect to school participation. The module covers three areas, namely, attitudes, accessibility and affordability. A separate section focuses on the reasons for which a child might be out of school. Cognitive testing began in the United States in 2015 and will continue in other international locations in 2016. Field testing will follow, and it is expected that the module will be finalized in late 2016 or early 2017.

E. Disability module for labour force surveys

14. In 2015, the Washington Group began collaborating with the International Labour Organization and University College of London on the development of a disability module intended for use in labour force surveys. A module has been drafted and will include sections on barriers to participation in the labour force, workplace accommodations, social attitudes and social protection. The Question Design Research Laboratory at the National Center for Health Statistics is scheduled to conduct cognitive testing of the module in the United States in 2016. Revisions will be made based on the cognitive test results, followed by cognitive and field testing in additional countries.

F. Mental health

15. The working group investigating the development of measures specific to mental health has prepared a plan for a systematic review of existing questions on activity limitations, participation restrictions and environmental barriers associated with common and severe mental disorders. The working group will also examine the existing Washington Group questions to determine the extent to which they address the measurement of activity limitations and participation restrictions commonly associated with severe and common mental disorders.

G. Environmental factors and participation

16. Ongoing work on the development of questions on environmental factors and participation was discussed at the 2015 meeting of the Washington Group, held in Copenhagen. Two approaches to capturing information about the environment were

presented by the working group: directly, by measuring the environment independently of the person; and indirectly, by measuring the environment through the person's participation in selected activities. The working group was asked to develop, over the following year, a more specific proposal using the approach of measuring the environment indirectly through the person's participation in selected activities and to draft a set of questions for one domain to illustrate the proposed approach.

H. UNICEF/Washington Group regional capacity-building workshops and technical assistance on the measurement of child disability

17. UNICEF and the Washington Group have begun to develop training materials and have conducted the first of a planned series of workshops on the measurement of child disability. The training material is intended to be used in technical workshops as well as for technical assistance. The workshops are meant to take place in all seven UNICEF regions. The purpose of the workshops will be to build and strengthen local capacity for data collection. Training will be provided to national statistics offices, other government staff and local researchers on concepts, models and measures of disability, survey design, data processing, data analysis, data dissemination and data use. A national workshop was held in Tunisia in February 2015 and a regional workshop was held in Geneva, Switzerland in July 2015 for the Central and Eastern European/Commonwealth of Independent States region.

I. Washington Group meetings and capacity-building and training activities

18. The Washington Group has held 15 meetings since its inception: 2002: Washington, D.C.; 2003: Ottawa; 2004: Brussels; 2004: Bangkok; 2005: Rio de Janeiro, Brazil; 2006: Kampala; 2007: Dublin; 2008: Manila; 2009: Dar es Salaam, United Republic of Tanzania; 2010: Luxembourg; 2011: Southampton, Bermuda; 2012: Bangkok; 2013: Amman; 2014: Buenos Aires; and 2015: Copenhagen. Annual meetings are rotated through major geographic regions to facilitate participation, especially that of the developing countries.

19. The Washington Group has sought to foster international collaboration and, in particular, to ensure that the efforts of the Group are broad-based and inclusive of voices from developing countries from every region of the world. Thus, representatives of national statistical authorities, disabled people's organizations and other international organizations participate in the Washington Group. Since its inception, representatives of national statistical offices in 133 countries have participated in at least one annual meeting of the Washington Group. In addition to national statistical offices, the Group also includes representatives from seven international organizations, six organizations that represent persons with disabilities, the Statistics Division and other United Nations affiliates.

20. Between 2008 and 2015, the Washington Group participated in or facilitated training workshops that introduced Washington Group products (Washington Group short set of questions, Washington Group extended set of questions, UNICEF/Washington Group module on child functioning) for the purpose of building

capacity locally and nationally in disability data collection in censuses and surveys (see http://www.cdc.gov/nchs/washington_group.htm).

J. Washington Group support

21. The Department of Foreign Affairs and Trade of the Government of Australia has provided funding to the Washington Group to improve the collection and analysis of disability statistics globally by strengthening the Washington Group's capacity to broadly disseminate and provide technical assistance to support the consistent implementation of the Washington Group's existing data collection tools and to engage in new work on measures of participation and functional limitations related to mental health.

K. Washington Group publication

22. The work of the Washington Group over the past 15 years will be the topic of a new book, to be entitled "International Measurement of Disability: Purpose, Method and Application". The four sections of the book cover the origin of the Washington Group and issues in disability data collection; the purpose, process and testing of questions designed for census formats; extended sets of questions and methodological advances; and outcomes and the role of the Washington Group measures in international data collections. It is expected that the book will be published in early 2016.

L. Workplan of the Washington Group for 2016

23. The workplan of the Washington Group for 2016 is set out below.

- Develop final guidance for the analysis and presentation of data from the extended question set on functioning
- Finalize the UNICEF/Washington Group module on child functioning
- Analyse field-test data
- Adopt final question set
- Develop an implementation manual
- Continue development of the module on inclusive education
- Complete draft module
- Analyse cognitive test data and propose revisions based on the test results
- Continue the development of the disability module for use in labour force surveys
- Continue the development of measures specific to mental health
- Continue the development of the Washington Group extended set of questions on environmental factors and participation

- Conduct a series of regional workshops to facilitate the incorporation of the Washington Group short set of questions into censuses and surveys for use in monitoring the implementation of the Convention on the Rights of Persons with Disabilities and the post-2015 Sustainable Development Goals
- Collaborate with partners on projects of mutual interest

The Washington Group disseminates its work products globally through the worldwide web (http://www.cdc.gov/nchs/washington_group.htm) and scientific publications.

IV. Summary and conclusions

24. The present report provides a review of activities undertaken and planned by the Statistics Division and the Washington Group in the area of disability statistics. The Commission is invited to take note of the report.
