
Economic and Social Commission for Asia and the Pacific
Committee on Statistics

Second session

Bangkok, 15-17 December 2010

Item 6(c) of the provisional agenda

Items for information: Report on the work of the secretariat on disability statistics

Report on the work of the secretariat on disability statistics

Note by the secretariat

Summary

The present note provides information on the secretariat's work and the results achieved on disability statistics as a subject area of strategic priority for the Asian and Pacific region. It describes the secretariat's initiative to improve the availability of data by developing international standards to measure disability. The note describes the secretariat's activities in the development of standard measurements for disability data collection through pilot studies and analyses, in-country advocacy workshops, training and advisory missions, and the promotion of country-to-country cooperation and knowledge sharing.

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I. Background

1. Disability statistics represent a crucial element for evidence-based policy-making and interventions aimed at improving the lives of persons with disabilities. In Asia and the Pacific, the Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-based Society for Persons with Disabilities¹ urges governments in the region to develop systems for disability data collection, using the same standard for defining and classifying disability, to allow inter-country comparison in the region (Strategy 8 and 9). Furthermore, the Convention on the Rights of Persons with Disabilities² mandates the collection of disability data to enable States to formulate and implement policies to give effect to the Convention (Article 31).

2. In support of these mandates, the main objective of the secretariat has been to promote and support international cooperation to develop international standards for disability measurement in close collaboration with the Washington Group on Disability Statistics and the World Health Organization (WHO). This partnership has contributed to the development of a short set of disability questions for censuses which was endorsed at the Sixth meeting of the Washington Group in Uganda in October 2006. The current undertaking of the secretariat and the Washington Group is the development of extended sets to measure disability through surveys. At the same time, the secretariat has been regularly involved in developing member States' capacity to collect internationally comparable data for the production of reliable disability statistics.

3. In response to the direct call of the BMF, the Convention on the Rights of Persons with Disabilities and the specific needs in the region, the secretariat and the WHO with support from the Government of the Republic of Korea, developed and implemented a project on disability measurement between 2004 and 2006. This project targeted a small group of interested countries with the objective of raising awareness of WHO's International Classification of Functioning, Disability and Health (ICF) contributing to developing standard data collection instruments for census and surveys through pilot testing; establishing regional forums for training and knowledge sharing; and producing a Training Manual on Disability Statistics for use in wider technical capacity building activities.

4. The 2004-06 project succeeded in creating interest and momentum among target countries to incorporate the ICF approach into any disability data collection. Field tests provided a valuable pool of empirical evidence based on which further tests and analyses have been framed to facilitate the formulation of regional recommendations and international standards. The Training Manual on Disability Statistics was produced (www.unescap.org/stat/disability/manual) and has since been regularly used in regional training courses offered by the secretariat and SIAP. Furthermore, as a result of this project, a number of countries decided to include disability questions in their Population and Housing Censuses.

¹ E/ESCAP/APDDP/4/Rev.1 (see also Commission resolution 59/3).

² General Assembly resolution 61/106, annex I.

II. Recent activities and major achievements

5. Building upon the achievement of the 2004-06 ESCAP/WHO disability project, a follow-up project entitled “Improvement of disability measurement and statistics in support of the Biwako Millennium Framework and the Regional Census Programme” has been implemented between 2008 and 2010. The main objective of this United Nations Development Account project was to further promote better disability data collection by developing measurement standards specifically for surveys, and improving national data collection capacity and expertise on disability. Key activities of the project included: regional advocacy workshops to encourage commitment among a wide range of stakeholders; targeted training of statistical experts to improve national technical expertise; cognitive and pilot testing of a question set for surveys; and country advisory services to support national data collection efforts.

A. Advocacy and technical assistance

6. In April 2008, the secretariat in collaboration with the Washington Group, WHO and the World Bank, organized the Regional Workshop on Promoting Disability Data Collection through the 2010 Population and Housing Censuses. The workshop aimed at bridging the mismatch between data users and producers by bringing together senior statisticians, health professionals and representatives of disabled people’s organizations (DPOs) from over 25 countries in the Asian and Pacific region. The meeting served the purpose of promoting the ICF-based approach towards disability data collection; provided practical training on the current global recommendations by advocating the adoption of the Washington Group’s short question set on disability; and observed the official launch of the Training Manual on Disability Statistics produced during the previous ESCAP/WHO project.

7. Project countries, namely Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka, actively participated in the 8th and 9th Washington Group meetings. During the 8th Washington Group meeting, held in the Philippines in October 2008, the draft question set for surveys was reviewed and discussed, leading to the development of a final questionnaire to be tested. The 9th Washington Group meeting, held in Tanzania in October 2009, served as a forum for presenting the preliminary results of the cognitive and pilot tests conducted in the Asia-Pacific region. During that meeting, countries from the African and Middle Eastern regions requested the Washington Group secretariat to recommend, in its report to the United Nations Statistical Commission,³ that the experience of Asia and the Pacific be replicated in their regions.

8. Advocacy and training efforts also included advisory missions to specific member States. A mission to Vientiane took place in January 2009 to support the meeting “Drafting Disability Action Plans in Lao PDR” organized by the Lao Disabled People’s Association in collaboration with several line ministries. Another advisory mission to Hanoi took place in March 2010 to revise the questions of a disability survey to be conducted in the city of Da Nang by Vietnam Assistance for the Handicapped. The

³ E/CN.3/2010/20, submitted to the Statistical Commission at its forty-first session, held in New York from 23 to 26 February 2010. For the related report of the Commission, see *Official Records of the Economic and Social Council, 2010, Supplement No. 4* (E/CN.3/2010/34).

secretariat shared the results of the project with the Budapest Initiative⁴ as part of European efforts to improve their Eurostat Health Interview Survey to be conducted in 2010/2011.

B. Cognitive and field testing

9. An extended question set was developed by the Washington Group in close collaboration with the secretariat and project countries, with the intention of testing the validity of the questions and to understand how these perform in different settings and cultures. Intended for population surveys, this question set expanded on the number of disability domains contained in the Washington Group's short question set for censuses.

10. A task force involving all project countries was established during the 8th Washington Group meeting, and several discussions on the question set for surveys were held among the group countries between October 2008 and January 2009. A training workshop on cognitive and field testing procedures was held in February 2009 in anticipation of the cognitive test, which was undertaken between March and April 2009. Project countries regarded this exercise as a useful tool not only for the development of questions addressing disability, but also for the improvement and design of any type of questionnaire.

11. Based on the results of the cognitive test, the secretariat together with the Washington Group, compiled a final question set to be pilot tested. The corresponding field tests were conducted in project countries as follows: Sri Lanka, 29 June-3 July 2009; Maldives, 6-10 July 2009; Mongolia, 6-10 July 2009; Cambodia, 3-7 August 2009; Philippines, 10-14 August 2009; Kazakhstan, 31 August-4 September 2009. Ahead of each field test, in-country trainings provided for by the secretariat contributed to strengthening the capacity of national statistical offices (NSOs) in collecting data on disability. These workshops were also used as an opportunity to inform and link the project work with that of local DPOs.

12. With the objective of sharing the main results of the cognitive and pilot tests, the secretariat held the regional workshop entitled "Count us in: towards better disability measurement and statistics in Asia and the Pacific" in December 2009. The meeting, attended by over 20 NSOs from Asia and the Pacific, focused on the implementation of cognitive and field tests and questionnaire design, and further advocated WHO's ICF-based approach for disability data collection through training on census and survey data collection. The workshop was welcomed by countries, and several member States expressed an interest in measuring disability through surveys in the near future.

13. A final workshop for project participating countries was organized in July 2010 to train senior statisticians on the skills required to analyse the results of the cognitive and pilot test, and to share countries' experiences on these rounds of testing. A final report of the outcomes of this project together with a handbook on how to conduct disability-specific data collection have been made available as part of the project at its website www.unescap.org/stat/disability.

⁴ The Budapest Initiative is a collaborative effort involving European national statistical offices and international organizations, working on developing internationally comparable measures of health states.

III. Challenges in the field of disability statistics

14. Despite progress made by countries and international organizations, disability statistics in most countries in Asia and the Pacific remains underdeveloped. A small number of countries give priority to the collection of data on disability for which no information is made available regularly through censuses or surveys. There is also a wide variance of definitions, standards, and methodologies applied in data collection. Furthermore, the limited data that currently exists often refers only to the most visible and severe forms of physical and mental impairments, grossly underestimating the prevalence of persons with disabilities.

15. In many countries, technical capacity to collect, disseminate and analyse disability statistics is limited. There is a need to streamline global work among development partners on defining international standards as to assure quality of data, especially with regard to consistency, comparability, level of disaggregation, and reliability. There is also a need for countries to become more familiar with WHO's ICF based approach to data collection, moving from a medical approach focusing solely on physical or mental impairments, to a more comprehensive social model aimed towards an inclusive and barrier-free society for persons with disabilities.

16. In order to increase the availability of disability statistics at both the national and international levels, it is important to continue advocating for the collection of data on disability and persist in the work on developing internationally comparable measurement tools. In sum, it is imperative to fully develop and adopt a unifying international approach for data collection through censuses and surveys, and to increase national political commitment and technical capacity to collect and disseminate better disability statistics.
