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Economic and Social Commission for Western Asia

REPORT

WORKSHOP ON DISABILITY STATISTICS IN THE ESCWA REGION BEIRUT, 21-23 MARCH 2005

Summary

The Economic and Social Commission for Western Asia (ESCWA), in cooperation with the United Nations Statistics Division (UNSD) and the World Health Organization (WHO), held the Workshop on Disability Statistics in the ESCWA Region from 21 to 23 March 2005 at United Nations House in Beirut.

Discussions concentrated on the following subjects: (a) introducing the participants to the international standards and guidelines used in measuring disability, and promoting the use of the international classification of functioning, disability and health as a conceptual framework for the collection and classification of data on disability; (b) introducing the participants with methods of collecting disability data through population censuses, family surveys and administrative records; and (c) drafting a conceptual work plan for developing disability statistics in the ESCWA region. A draft regional project proposal to develop such statistics in cooperation with a number of regional and international organizations is being presented.

The Workshop concluded by encouraging the adoption of a number of recommendations to national Governments, central statistical offices and ESCWA. The recommendations concentrated on the following: (a) the importance of improving disability statistics through the collection, analysis and dissemination of data; (b) the importance of using the international classification of functioning, disability and health as a framework for measuring disability; (c) the organization of training courses and workshops on disability statistics; and (d) cooperation with United Nations agencies and, in particular, WHO, UNSD and the Washington Group on Disability Statistics.

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Introduction

1. The Economic and Social Commission for Western Asia (ESCWA), in cooperation with UNSD and WHO, organized the Workshop on Disability Statistics in the ESCWA Region, which was held at United Nations House in Beirut from 21 to 23 March 2005. The goals of the Workshop were to further familiarize statisticians and analysts with the Millennium Development Goals (MDGs), and to strengthen national capacities aimed at producing statistics and indicators for monitoring progress made towards meeting those Goals.

I. WORKSHOP RECOMMENDATIONS

2. The participants supported the adoption of various recommendations to the Governments of the member countries, central statistical offices and ESCWA.

A. RECOMMENDATIONS TO GOVERNMENTS

- 3. ESCWA member countries were encouraged to take the following actions:
- (a) Improve disability statistics at both the national and sub-national levels in terms of data accuracy, availability and comparability;
- (b) Allocate adequate budgetary resources for the collection, analysis and dissemination of disability data;
- (c) Use the international classification of functioning, disability and health as a framework for measuring disability, and provide a common framework for the national disability information system;
- (d) Establish mechanisms to coordinate the collection, analysis and dissemination of disability data in close consultation with ministries, Government agencies and organizations working in the disability field;
- (e) Set up forums at the national and sub-national levels to firmly establish an ongoing dialogue between producers and users of disability statistics.

B. RECOMMENDATIONS TO CENTRAL STATISTICAL OFFICES

- 4. Central statistical offices of member countries were encouraged to take the following actions:
- (a) Use the WHO international classification of functioning, disability and health as a framework for the collection, analysis and dissemination of disability statistics, in order to adopt standard definitions and neutral terminology and improve the comparability of data at the national and international levels;
- (b) Train statisticians on the concepts of the international classification of functioning, disability and health by sending them to training courses and workshops in the region;
- (c) Use the 2010 round of population censuses and national surveys to collect data on disability, using the international classification of functioning, disability and health system and concepts and, to the extent possible, apply United Nations recommendations in the formulation of questions on disability. Participate in reviewing and updating the Principles and Recommendations of Population and Housing Censuses in the light of the aforementioned classification; and ensure that disability-related censuses, surveys and registration systems are consistent with the principles and definitions of that classification, including the multidimensional and universal nature of disability, and the placing of disability on a continuum with health;
- (d) Involve stakeholders in the process of developing tools for the collection of data to measure disability and in various parts of the process of planning the collection, compilation and dissemination of disability data. Such groups should include Government institutions responsible for the formulation and

implementation of disability policies, data producers, disabled persons, non-governmental organizations (NGOs) working in the field of disability and researchers. Persons with disabilities should also be involved in the dialogue between data producers and users;

(e) Train interviewers on the disability-sensitive technique of eliciting information from respondents with disabilities.

C. RECOMMENDATIONS TO ESCWA

- ESCWA was encouraged to consider taking the following actions:
- (a) Organize, in cooperation with WHO, training courses and workshops for data users and producers in order to introduce them to ways of using the international classification of functioning, disability and health as a framework for disability information, and to enhance statistical competency and comparability of disability statistics;
- (b) Collaborate with regional offices of the United Nations in promoting the mainstreaming of disability indicators into the MDG framework;
- (c) Collaborate with UNSD, WHO, the Washington Group on Disability Statistics and other related parties on the implementation of the international classification of functioning, disability and health framework in censuses, surveys and registration systems through the following methods:
 - (i) The formulation, piloting and implementation of a strategy and mechanism for the collection of data based on the international classification of functioning, disability and health in the ESCWA member countries;
 - (ii) The establishment of an electronic database to exchange information on progress achieved in questions related to disability statistics in the ESCWA region.

II. SUBJECTS DISCUSSED

6. Participants discussed a number of subjects. Set forth below is a brief overview of the most salient points raised and conclusions.

A. OBJECTIVES OF THE WORKSHOP AND IMPORTANCE OF DISABILITY STATISTICS FOR POLICY FORMULATION AND MONITORING

7. The Head of the Statistics Coordination Unit of ESCWA presented a paper on the goals of the Workshop, of which the most important was to introduce the participants to such international standards as the international classification of functioning, disability and health, and the guiding principles used in measuring disability and collecting related data. He referred to the importance of disability statistics in the formulation of development policies and programmes aimed at including disabled persons in society.

B. PRESENTATION OF NATIONAL REPORTS

- 8. Member country representatives presented the situation of disability statistics in their countries. They covered past experiences in the field of disability data collection, the definitions and questions used in collecting such data, sources of information, problems faced in the data collection process, national disability and inclusion policies, and the parties responsible for collecting disability data.
- 9. The following points were raised during the discussion:
- (a) There are shortcomings in the collection of data on disabled persons and in the accuracy of the available statistics;

- (b) There are differences between Arab and other countries with respect to the concept of disability;
- (c) A special census should be carried out on disabled persons separately from the population census;
- (d) It is important that administrative records on persons with special needs should be available;
- (e) It is important to develop data in order to enable changes to be monitored;
- (f) There is a need to create and/or agree on a standardized mechanism to measure disability, such as compliance with general statistical principles and the principles related to measuring disability adopted by the United Nations;
- (g) There is a need to make available the technical and financial resources for conducting surveys and censuses, to provide appropriate conditions and to remove obstacles to completion.
 - C. THE WHO FAMILY OF INTERNATIONAL CLASSIFICATIONS: MEMBERS AND NETWORK
- 10. A representative of UNSD gave a presentation on the WHO family of international classifications (WHO-FIC): members and network. The presentation included both original and new members. The speaker dealt with the WHO network at United Nations Headquarters, the Coordinating Offices, the Regional Offices and their respective committees, work plans and the annual meetings on disability statistics held by WHO.
- 11. The following points were raised during the discussion:
 - (a) It is important to determine the goal for the collection of disability data;
 - (b) Management systems should be clear and comprehensive;
 - (c) Disabled persons of all ages should be provided with disability cards.
 - D. THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH AS A FRAMEWORK FOR MEASURING DISABILITY
 - 1. Overview of the international classification
- 12. A WHO representative gave a general overview of the international classification of functioning, disability and health as a framework to measure disability. He noted the importance of disability statistics and stressed the value of using that classification to collect and classify accurate data on disability and establish its effect on society, in order to formulate policies and programmes to mainstream disabled people in society. He also noted the increase of disability and types of disabilities in the world, and explained that disability is not an individual responsibility but the responsibility of society as a whole. He remarked upon the lack of linkages between health and disability surveys, and referred to problems of comparability in international health statistics. He showed two documentary films on the importance of using the international classification to standardize concepts, diagnose the status of disabled persons, the effect of their disability on their daily activities and their inclusion in society.
- 13. The following points were raised during the discussion:
 - (a) The personal experience of disabled persons should not be ignored;
 - (b) The focus should be on the activities of disabled persons and their ability to participate in society;
- (c) The aim of collecting disability data is to understand the way disabled persons live, know what kinds of services they need and improve such services;
 - (d) It is difficult to determine the medical, social and economic cost of disability;
 - (e) The focus should be on obtaining comparable data in order to avoid potential basic problems;

- (f) The survey terminology adopted should not be demeaning and should encourage disabled persons to respond.
 - 2. Applications of the international classification of functioning, disability and health
- 14. A WHO representative presented an overview of the applications of the international classification of functioning, disability and health and, in particular, the process of applying that classification to the following six stages: (a) specify the purpose; (b) decide on measurement approach; (c) select ICF data set; (d) identify questions; (e) set thresholds; and (f) develop implementation strategy.
 - 3. Use of the international classification of disability, functioning and health as an organizing principle in surveys
- 15. The UNSD representative made a presentation on how to use the international classification of functioning, disability and health as an organizing principle in surveys. She dealt with different kinds of surveys, including, inter alia, population and housing censuses, population based surveys, health interview surveys and disability surveys. She then discussed the characteristics and problems of surveys, and gave examples of the use of the international classification of functioning, disability and health in surveys.
- 16. The following points were raised during the discussion:
- (a) Responses should be classified on the basis of a person's ability to carry out various activities rather than asking how many people are affected by one or more disabilities;
 - (b) Action should be taken to develop collective statistics for international comparison;
 - (c) Agreement should be reached on a standard term to be used for disabled persons;
 - (d) A distinction should be made between medical cases and disability;
- (e) It should be possible to change the way questions are asked to suit the concepts of the relevant country.

E. COLLECTION AND DISSEMINATION OF DISABILITY STATISTICS BY UNSD

- 17. A UNSD representative made a presentation on the collection and dissemination of disability statistics by the Division. She began by introducing UNSD in general, and its work on disability statistics in particular. She discussed the activities of the Division, in collecting and disseminating disability statistics through studies, database and statistical books. She then presented the information that is required in order to collect data.
- 18. During the discussion, a point was raised on the importance of using questions in the Arab region that help to define who is disabled.

F. THE WASHINGTON GROUP ON DISABILITY STATISTICS

- 19. The UNSD representative made a presentation on the Washington Group on Disability Statistics. She introduced the purpose and objectives of the Group and discussed its activities and the meetings it organized in 2002, 2003 and 2004. She mentioned the international classification of functioning, disability and health as a tool for measuring disability both in terms of measuring methodology and the objectives of its use. Finally, she presented the Group's draft questions for measuring disability.
- 20. The following points were raised during the discussion:
 - (a) The draft questions presented were felt to be too general and not sufficiently accurate;

- (b) The questions did not ensure equality even though they were created as a concept to standardize questions on disability;
- (c) The way questions were asked should be modified to take into account the possibility that the person providing the data could be the head of the household;
- (d) The Washington Group should attempt to include the age group of five years and over when testing of the proposed questions;
 - (e) A question should be asked in order to establish the first instance of the disability;
- (f) If the symptoms of an impairment have continued for at least six months, it should be established whether there is a disability.

G. EXERCISES USED IN THE WORKSHOP

- 21. Five exercises were undertaken in the course of the Workshop, during which participants were divided into working groups to discuss various issues that were raised at the Workshop.
 - 1. Exercise 1: defining disability and the international classification of functioning, disability and health
- 22. In this exercise, the working groups discussed the definition of disability and the international classification of functioning, disability and health. They evaluated the various definitions proposed in terms of the extent to which they agreed with the international classification.
- 23. During exercise discussions, the importance of using the international classification of functioning, disability and health to define disability was stressed.
 - 2. Exercise 2: disability or health problem?
- 24. In this exercise, the working groups discussed the difference between disability and health problems. They were asked to define a number of cases as solely disability, solely health, or a combination of both.
 - 3. Exercise 3: Case study of a disabled person
- 25. In this exercise, the working groups discussed the issue of using the international classification of functioning, disability and health in disability statistics. They were asked to do the following:
 - (a) Give the appropriate code to a number of health cases;
- (b) Identify and analyse the case of a specific person, associated problems in their activities and areas of participation, and the facilities and impediments of their environment;
- (c) Discuss and evaluate the disability certificate in light of the specific definition of the international classification of functioning, disability and health and the concept of disability;
 - (d) Discuss and evaluate the decision of the authority responsible for health insurance;
- (e) Describe the importance of using the international classification of functioning, disability and health in that particular case and define the quality of disability statistics and possible comparisons between them.

4. Exercise 4: A disability survey in Gondoland

- For this exercise, the participants were divided into three groups and discussed a disability survey in Gondoland. They were asked to analyse and define the determinants required to evaluate the success of any disability support programme in three areas, through the collection of data about disability. They were also asked to evaluate the available data in order to produce determinants for the disability support programme in the three areas, and to identify basic target groups of the disability survey, with a view to obtaining the data necessary to define the determinants of a disability support programme.
- The following points were raised in the discussions during the fourth exercise: 27.
 - The data provided was not sufficiently complete, accurate or logical;
 - (b) The data did not include information on the participation of disabled persons in society;
 - (c) The questions in the questionnaire should be standardized in each of the three areas;
- (d) A plan to eradicate disability should be developed, commensurate with the prevalence of disability in the three areas.

5. Exercise 5: Action plan for Gondoland

- The participants were divided into groups to discuss the drafting of a work plan for Gondoland, with the aim of offering an overall shared framework for developing the data system and ensuring the production of the necessary data in line with international standards.
- Each country then presented their work plan for Gondoland, based on the following elements: 29.
- (a) Formulation of a strategy to raise awareness and promote the use of the international classification of functioning, disability and health, and the possibility of drafting a special agenda for national or regional disability policy by the parties concerned;
- (b) Development and testing of a standard set of disability question according to the requirements of the survey and/or census;
- (c) Designing a plan and a strategy to implement the international classification of functioning, disability and health, to the greatest extent possible;
- (d) Adopting training tools for producers of disability data on the international classification of functioning, disability and health for national use.
- During the presentations made in the context of this exercise, the following points were raised: 30.
 - (a) The questions should be tested;
 - (b) The data did not include information on the participation of disabled persons in society;
 - (c) The questionnaire's questions in the three areas should be standardized;
 - (d) A plan should be developed to prevent disability, based on its prevalence in the three areas.

H. PROJECT PROPOSAL FOR THE DEVELOPMENT OF DISABILITY STATISTICS IN THE ESCWA REGION

The Head of the Statistics Coordination Unit at ESCWA presented a paper on a proposal for a threeyear project aimed at developing disability statistics in the ESCWA region. The paper discussed the quality of disability statistics already available and reasons for the importance of disability statistics, in addition to project objectives, activities, outputs and results, beneficiaries, partners, cost and potential funders.

III. PARTICIPANTS AND ORGANIZATION OF WORK

A. VENUE AND DATE OF WORKSHOP

32. The Workshop on Disability Statistics in the ESCWA Region was held at United Nations House in Beirut from 21 to 23 March 2005.

B. OPENING

- 33. Two statements were made at the opening session of the Workshop, one by the Chief of the Social Development Division (SDD) of ESCWA and one by the WHO representative.
- 34. The Chief of SDD welcomed participants and thanked UNSD, WHO and the Washington Group on Disability Statistics for participating in organizing the Workshop. He stressed the importance of using international standards and classifications in producing disability statistics, and the need to produce comprehensive, accurate and well-documented statistics on disabled persons in order to make it possible to formulate development policies and programmes aimed at including those persons in society.
- 35. The WHO representative then thanked ESCWA for inviting his organization to participate in the Workshop and affirmed that cooperation between ESCWA and WHO would continue through a range of activities and projects. He encouraged countries to consolidate their cooperation with ESCWA in particular and with United Nations organizations in general.
- 36. The Head of the ESCWA Statistics Coordination Unit welcomed participants and thanked UNSD, WHO and the Washington Group on Disability Statistics for their cooperation in the organization of the Workshop.

C. PARTICIPANTS

37. The Workshop was attended by representatives of 12 of the ESCWA member countries. Two experts from a United Nations organization and a specialist agency also attended, together with representatives of other governmental and non-governmental organizations. Annex I comprises the list of participants.

D. AGENDA

- 38. The Workshop agenda is set out below:
 - "1. Opening of the Workshop;
 - 2. Objectives of the Workshop and the importance of disability statistics for policy formulation and monitoring;
 - 3. Presentation of national reports;
 - 4. The international classification of functioning, disability and health as a framework to measure disability;
 - 5. Exercise 1: defining disability and the international classification of functioning, disability and health;
 - 6. Exercise 2: disability and health problems;
 - 7. Exercise 3: case study;
 - 8. Applications of the international classification of functioning, disability and health (WHO);

- 9. Exercise 4: A disability survey in Gondoland;
- 10. The WHO family of international classifications: members and the network;
- 11. The use of the international classification of functioning, disability and health as an organizing principle in surveys;
- 12. The Washington Group on Disability Statistics;
- 13. Collection and dissemination of disability statistics by UNSD;
- 14. Exercise 5: A work plan for Gondoland;
- 15. Project document for the development of disability statistics in the ESCWA region;
- 16. Workshop recommendations and closing."

E. DOCUMENTS

39. Annex II of this report comprises a list of the documents submitted during the Workshop and basic related documents.

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Annex II

LIST OF DOCUMENTS

Symbol	Title		
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E/CN.3/2005/11	تعدادات السكان والمساكن – تقرير الأمين العام (عربي/إنكليزي)		
ESA/STAT/AC.97/L4	Report of the United Nations Symposium on Population and Housing Censuses		
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	نرير فريق واشنطن المعني بإحصاءات الإعاقة (عربي/إنكليزي)		
E/CN.3/2005/14	Manual on International Classification of Functioning Disability and Health (English-Arabic)		
	Washington Group on Disability Statistics		
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	UNSD collection and dissemination of disability statistics		
	Use of ICF as an organization principle for surveys		
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