



United Nations Statistics Division

ESCWA



**Central Agency for Public Mobilization and
Statistics (CAPMAS)**

**Meeting on Disability
Measurement for ESCWA
Countries**

**Cairo
1-5 June 2002**

Report

1. Introduction

The meeting on measurement of disability for ESCWA countries was held in Cairo from 1-5 June 2002. Census experts, representatives of national institutions involved in the implementation of disability programmes and representatives of persons with disabilities participated in the meeting. Other participants were experts from WHO, the U.S. Centers for Disease Control as well as staff of ESCWA and UNSD. A complete list of participants is attached as Annex 1.

The objectives of the meeting were:

- To agree on a regional common approach to collect data on disability on censuses
- To initiate a dialogue in the region between census managers and users of disability statistics on how best a census can be utilized to collect data on persons with disabilities
- To introduce countries to the International Classification of Functioning, Disability and Health (ICF) and discuss its use as a conceptual framework for collecting census data on disability
- To introduce the countries of the region to the work of the City Group on Disability Statistics

2. Content of the meeting

In accordance with the Agenda shown in Annex 2 the meeting was organized in plenary sessions, with a lead discussant introducing the topic, and working groups where the participants identified common approaches to define disability and designed questions to collect data on disability in censuses. The following background documents were distributed to the participants:

- The International Classification of Functioning, Disability, and Health (ICF) (English/extract in Arabic)
- Guidelines and Principles for the Development of Disability Statistics (Arabic/English)
- Manual for the Development of Statistical Information for Disability Programme and Policies (Arabic/English)
- Principles and Recommendations for Population and Housing Census, Revision 1 (Arabic/English)
- The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Arabic/English)
- Report of the First Meeting of the Washington Group on Disability Statistics (English)

The meeting started with an overview of the methods used to collect data on disability in the region (see Annex 5) that showed how countries extensively used the census to collect data on disability. Looking at the prevalence rates of persons with disabilities, it was noted that countries of the ESCWA region produced very low prevalence rates when compared with other regions such as Europe and North America. These differences were explained by the different methods and definitions used. Often ESCWA countries used sensitive questions¹ and focused only on the most severe and stereotyped types of impairments (the blind, deaf, paralyzed, ...). While countries in

¹For example: “*Is there in the household anyone who is disabled?*”. This type of question may affect the reporting of disability in society where disability is seen as a stigma.

Europe and North America have a broader view of disability. They look at activity limitations rather than impairments and used questions related to functioning rather than to a general idea of “being disabled”.

The Arab Organization of Disabled People (AODP) presented the plans for launching the *Arab Decade of Disabled People (2003-2012)* by the Arab League and the Council of Arab Ministers of Social Affairs. The objective of the initiative is to adopt an Arab convention and a programme of action on disability. The main areas that will be included in the programme of actions are: legislation for disabled people, poverty and disability, the condition of children with disability, the condition of women with disability, education and disability, accessibility and transport, recreation and sports, rehabilitation and employment, health, and information and community guidance.

Egypt and Palestine presented their experiences in collecting data on disability (see Annexes 7 and 8). Egypt reported its long history of collecting data on disability in censuses, which started in 1907. From 1947 to the latest census, prevalence of persons with disabilities ranged from 0.3-1.2. These rates were believed to be lower than expected² for reasons related to: (i) culture that tends to underreport disability (particularly for female), (ii) concepts and definitions that are not clear; and (iii) limited space available for questions on disability in census questionnaires. Suggestions were presented to improve the collection of disability statistics in the census that included the improvement of concepts, definitions, and training of enumerators. The use of the Post Enumeration Survey (PES) was suggested to evaluate the validity of the questions used in the census to develop a correction factor which could be used to adjust the data.

Palestine reported the results obtained in the 1997 census and 1996 Health survey. The definition of disability used was based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which is the earlier version of the International Classification of Functioning, Disability, and Health (ICF). The prevalence rates obtained were consistent in the census and the survey. Suggestions were made to collect data not only on the number of persons with disabilities but also on cause, duration, technical aids, medical care, and rehabilitation.

The participants were introduced to the International Classification of Functioning, Disability and Health (ICF) and to its use as a common framework for the collection of data on disability (See Annex 9). Copies of the classification were distributed in English and an extract in Arabic. In the discussions, the classification served as a unifying language and during the meeting the participants became more and more familiar with its structure and terminology.

In the process of discussing how to develop a common approach to the collection of data on disability in censuses, the following issues were discussed:

- How to identifying the needs of the data users (see Annex 10)
- How to design general questions to identify persons with disabilities in a census (see Annexes 11, 12, and 13)
- How to interview persons with disabilities (see Annex 14)

In identifying the needs of the data users, discussions focused on the relation between data and policy, the factors that affect policy priorities, and the role of the ICF in identifying priority areas. The United Nations Standard Rules on the Equalization of Opportunities were presented as a comprehensive framework to guide the development of disability programmes and identify priority

² Other sources produced higher rates for the region such as 7.5% from ESCWA (1992).

areas for data collection and policy intervention.

The design of the question to identify persons with disabilities was discussed as a key aspect in the process of converting policy objectives into measurement instruments. It was stressed that questions should be carefully designed to identify the persons with disabilities according to the concepts expressed in the agreed definition³ (validity). Experiences of other countries in developing and testing census questions on disability were presented. It was shown that the wording of a question has a great effect on the ability of a question to accurately identify persons with disabilities particularly in societies with socio-cultural pressures to underreport disability⁴. It was also shown that questions based on activity limitations were able to capture a broader spectrum of disabilities producing more relevant data and higher prevalence rates of persons with disabilities. The choice of response categories was also discussed. Examples were reported where the use of scale response categories⁵ improved the reporting of disability.

The issue of improving the training of the interviewers was often mentioned as one of the most important aspects in improving the reporting of disability in censuses. Respondents are often reluctant to admit the presence of persons with disabilities in the household and interviewers tend to not ask about disability unless a person with a very severe kind of disability is seen during the interview. Some suggestions were presented on topics to be included in training of interviewers:

- Sensitivity to ask questions on disability
- Attitude in dealing with persons with disabilities, and not prejudiced
- Use of appropriate language
- Do not make assumptions about a person's disability

During the last day of the meeting, participants carried out interviews with persons with disabilities.

The participants were also introduced to the work of the Washington Group on Disability Statistics (see Annex 6). The role of the City Group in developing a comparable general disability measure to include in censuses and the need to have the ESCWA region represented in this endeavour were emphasized. A summary of the first meeting of the Group⁶ was presented where an agreement was reached to use an activity limitation approach to identify persons with disabilities and to develop a “matrix” to link disability measures with purposes.

3. Output of the Meeting

The meeting was successful in developing a common regional approach for the collection of data on disability in censuses. As shown in the Conclusions of the meeting (see Annex 3), there was a general agreement to use the ICF as a unifying framework to measure and define disability. It was agreed that a disability module in a census should include one question to identify the persons with

³ So for example if disability is defined as activity limitations, the wording of the question should refer to activities and not to a general concept of “being disabled”

⁴ It was discussed that the language used should be clear, unambiguous and simple and negative terms such as “disability” and “handicaps” should be avoided.

⁵ Such as *None/A little/A lot* and *Yes, sometimes/Yes, often/No*

⁶ This report was approved by the United Nations Statistical Commission at its 32nd Session on 5-8 March 2002.

disabilities, one on the types of disabilities/activities and one on the causes. The question to identify the persons with disabilities should be based on activity and participation and the wording of the question should relate to the Activities/Participation outcome.

The participants developed a model question to be used as a starting point in developing census questions in the region: ***Does ... have any difficulty that has lasted or is expected to last 6 months and more in performing usual activities? (such as seeing, hearing, walking, ...).*** Countries that are planning their census in the near future committed to use the question and some countries reported the interest to test it. It was agreed that UNSD will facilitate the exchange of experiences in using the agreed question/approach.

Other specific principles and recommendations agreed at the meeting are reported in Annex 3.

The meeting reached also the objective of initiating a dialogue between users and producers. Users and producers of disability statistics and representatives of persons with disabilities worked together bringing their different perspectives to develop a common approach to the collection of data on disability and produce a question that attempts to take into consideration the needs of all the participants.

At the end of the meeting, an evaluation survey was submitted to the participants. The results of the survey (see Annex 4) show that the participants agreed that the meeting was well organised and useful for clarifying problems, introduce new approaches and for future work. Almost 89% of the participants who responded to the questionnaire said that the presentations were excellent or very good.

4. Follow-up Actions

UNSD and ESCWA:

- to follow-up with the Arab Organization of Disabled People to highlight in the context of the *Arab Decade of Disabled People* the importance of collecting data on disability based on the ICF, and the need for statistics to monitor the goals of the *Decade*
- to facilitate the exchange of experiences and information among the countries
- to keep the countries informed about the activities of the City Group

Countries:

- to follow-up on the Conclusions of the meeting and consider the model question in the design of census questions on disability and perform qualitative and quantitative testing
- to actively participate in the work of the City Group on Disability Statistics

Annex 1

List of Participants

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Annex 2

Agenda

Meeting on Measurement of Disability in the ESCWA countries Cairo, 1-5 June 2002

Saturday, 1 June 2002

- 8:00 - 9:00 a.m. **Registration of participants**
- 9:00 - 9:30 a.m. **Opening: scope and purpose of the seminar**
Officials from Egypt
Hermann Habermann, UNSD
ESCWA
- 9:30 – 10:00 a.m. **Coffee Break**
- 10:00 a.m. – 12:00 p.m. **Disability statistics in the ESCWA region**
Discussion leader: Margaret Mbogoni, UNSD / Arab Organization of
Disabled Persons
- 12:00 – 12:30 a.m. **Coffee Break**
- 12:30 - 2:00 p.m. **Disability statistics in the ESCWA region: a country overview**
Discussion leader: CAPMAS, Egypt
Mr. Mahmoud Jaradat, Palestine

Sunday, 2 June 2002

Moderator: *Mr. Hermann Habermann*

- 8:00 – 9:45 a.m. **The International Classification of Functioning, Disability and Health (ICF) as a framework for disability measurement**
Discussion leader: Nenad Kostanjsek, WHO
- 9:45 – 10:30 a.m. **Identifying the needs of the data users**
Discussion leader: Don Lollar, Centers for Disease Control, U.S.A

- 10:30 - 11:00 a.m. **Coffee Break**
- 11:00 a.m. - 12:15 p.m. **Working Groups: identify the needs of the users**
Organizer: Nenad Kostanjsek, WHO / Don Lollar, Centers for Disease Control, U.S.A
- 12:15 - 12:45 p.m. **Coffee Break**
- 12:45 – 2:30 p.m. **Presentation by working groups**

Monday, 3 June 2002

Moderator: *Oman*

- 8:00 – 9:15 a.m. **The census as a tool to collect disability data: advantages and disadvantages**
Discussion leader: Angela Me, UNSD
- 9:15 – 10:30 a.m. **The design of a general question(s): general principles**
Discussion leader: Angela Me, UNSD
- 10:30 - 11:00 a.m. **Coffee Break**
- 11:00 a.m. - 12:15 p.m. **The design of a general question(s): examples from other regions**
Discussion leader: Angela Me, UNSD
- 12:15 - 12:45 p.m. **Coffee Break**
- 12:45 – 2:30 p.m. **Working groups: defining disability to be measured in a census**
Organizer: Nenad Kostanjsek, WHO / Don Lollar, Centers for Disease Control, U.S.A

Tuesday, 4 June 2002

Moderator: *ESCWA*

- 8:00 – 9:00 a.m. **Introduction to the work of the Washington Group on Disability Statistics**
Discussion leader: Don Lollar, Centers for Disease Control, U.S.A
- 9:00 – 10:30 a.m. **Working groups: development of disability questions to be included in a census**
Coordinator: Angela Me, UNSD
- 10:30 - 11:00 a.m. **Coffee Break**

- 11:00 a.m. - 12:15 p.m. **Presentation by working groups**
- 12:15 - 12:45 p.m. **Coffee Break**
- 12:45 – 2:30 p.m. **Presentation by working groups (continue)**

Wednesday, 5 June 2002
(Morning Session)

Moderator: *Egypt*

8:00 – 9:00 a.m. **Special issues in interviewing persons with disabilities**
Discussion leader: Margaret Mbogoni, UNSD

9:00 – 10:30 a.m. **Working groups: interviews**
Coordinator: Margaret Mbogoni, UNSD

10:30 - 11:00 a.m. **Coffee Break**

11:00 a.m. - 12:15 p.m. **Presentation by working groups**

12:15 - 12:45 p.m. **Coffee Break**

12:45 – 2:30 p.m. **Recommendations**
UNSD
ESCWA

Closing

Annex 3

Conclusions of the Meeting

- There is the need to improve the quality of the disability data collected in the region
- The census should be used to collect disability data:
 - To obtain prevalence rates and information on persons with disabilities in comparison with the persons without disabilities
 - As a framework for follow-up studies
- The ICF should be used as a unified framework to measure disability in the region
- Statisticians and data users including representatives of persons with disabilities should collaborate in the relevant aspects of the design, collection, dissemination, and analysis of data on disability
- Enumerators training should be improved to make sure enumerators do not make assumptions on the persons with disabilities and use a simple and clear language
- In the context of the *Arab Decade of Disabled People*, there is the need to highlight the importance of collecting data on disability based on the ICF, to monitor the goals of the *Decade*.
- It is important that countries of the region actively participate in the work of the Washington Group in order to bring into the discussion the experience of the region.
- The publicity campaign is an important tool to improve the participation of persons with disability in the census
- Within the region, exchange of experiences in the development and use of new census disability questions.
- UNSD and ESCWA should facilitate the exchange of experiences in the collection of disability data and the testing of new methods.
- Census questions should focus on Activities and Participation in the context of health
- The disability questions should be included in the main questionnaire and not only in the interviewer manual.
- General requirements:
 - One question to identify the persons with disabilities
 - One question on the “types” of limitations
 - One question on the causes

Question design

- The question should relate to each person and not to the household in general
- The question should include a reference to a duration (long-term disability)
- The wording of the question should relate to the Activities/Participation outcome
- The wording of the question should include simple language and should avoid the use of negative terms
- The term *disability* should be avoided in the formulation of the question and in the conversation between the interviewer and the respondent
- The “filter” question should be very simple and short
- Multiscale response categories can be considered in the filter question
- There is the need to carry out in the region the testing of census questions based on Activities/Participation to understand their appropriateness

Census Questions

Does ... have any difficulty that lasted or is expected to last 6 months and more in performing usual activities? (such as seeing, hearing, walking, ...)

Yes, often Yes, sometimes No

*In which area does ... have this difficulty?
(all that apply)*

*Seeing
Hearing*

*Speaking
Learning
Moving around
Self-care
Other ...*

What is the main cause of difficulty?

*Congenital/prenatal
Diseases/illness
Other*

*Ageing
Injury/accidents/trauma*

Annex 4

Evaluation Survey

IN GENERAL, HOW WOULD YOU RATE THE ...

| | | | | |
|---|--------------------------|----------|----------|-----------|
| A | Duration of the workshop | Too long | Adequate | Too short |
| | | 10.5% | 84% | 5.5% |

| | | | | | | |
|---|---|---------------|-----------|----------|-------|-----------|
| B | Organizational arrangements | Excellent | Very good | Adequate | Poor | Very poor |
| | | 42% | 31.5% | 21% | 5.5% | |
| C | Translation English-Arabic | 55% | 30% | 15% | | |
| D | Usefulness of documents and other materials distributed to the participants | | | | | |
| | | 1. Up-to-date | 46.5% | 40% | 13.5% | |
| | | 2. Clarity | 53.5% | 40% | 6.5% | |
| E | Presentations | 61% | 27.5% | 11.5% | | |

| | | | | | |
|---|----------------|-------------|--------|-------------|-------------|
| F | Working Groups | Very useful | Useful | Indifferent | Not helpful |
| | | 55% | 35% | 5% | 5% |

PLEASE RATE THE WORKSHOP IN TERMS OF ...

| | | | | | |
|---|---|-------------|--------|-------------|------------|
| G | Clarification of problems related to measurement of disability | Very useful | Useful | Some extent | Inadequate |
| | | 65% | 35% | | |
| H | Introduction of new approaches | 60% | 35% | | 5% |
| I | Long-term usefulness to your professional work | 53% | 42% | 5% | |
| J | Exchange of ideas, experiences and views between the participants | | | | |

IS THERE ANY OTHER TOPIC THAT SHOULD HAVE BEEN INCLUDED, WHERE?

DO YOU HAVE ANY FURTHER COMMENTS OR SUGGESTIONS?

HOW WOULD YOU RATE THE FOLLOWING SESSIONS?

| | The presentation was: | | | The topic of this session was: | | | | Will you use the information for future work? | | |
|--|-----------------------|-------|-----------|--------------------------------|--------|---------------|------------|---|---------|----|
| | Very clear | Clear | Not clear | Very useful | Useful | Fairly useful | Not useful | Yes | Perhaps | No |
| Disability Statistics in the ESCWA region (Margaret Mbogoni) | 69% | 26% | 5% | 45% | 50% | 5% | | 89% | 11% | |
| Disability Statistics in the ESCWA region (Arab Organization of Disabled Persons) | 56% | 39% | 5% | 53% | 35% | 12% | | 82% | 18% | |
| Disability Statistics in the ESCWA region (CAPMAS) | 61% | 39% | | 50% | 37.5% | 12.5% | | 76% | 24% | |
| Disability Statistics in the ESCWA region (Mahamoud Jaradat, Palestine) | 56% | 44% | | 46% | 46% | 8% | | 75% | 25% | |
| ICF as a framework for disability measurement (Nenad Kostanjsek) | 50% | 50% | | 50% | 38% | 12% | | 88% | 12% | |
| Identifying the needs of the users (Don Lollar) | 78% | 22% | | 56% | 32% | 12% | | 88% | 12% | |
| The census as a tool to collect disability data: advantages and disadvantages (Angela Me) | 80% | 15% | 5% | 53% | 41% | 6% | | 94% | 6% | |
| The design of general question(s): general principles (Angela Me) | 80% | 20% | | 59% | 35% | 6% | | 83% | 17% | |
| The design of general question(s): examples from other regions (Angela Me) | 83% | 11% | 6% | 63% | 31% | 6% | | 94% | 6% | |
| Introduction to the work of the Washington Group on Disability Statistics (Don Lollar) | 68% | 32% | | 65% | 29% | 6% | | 82% | 18% | |
| Special issues in interviewing persons with disabilities (Margaret Mbogoni) | 72% | 28% | | 69% | 25% | 6% | | 82% | 18% | |