United Nations Guidelines and Principles for the Development of Disability Statistics

Margaret Mbogoni
UNSD Disability Statistics Programme
Methodological Guidelines

- Principles and Recommendations for Population and Housing Censuses (2015)
The Guidelines

- Provides technical guidance to producers of national data to assist them in responding to the growing demand for data on disability

- Addresses special issues related to planning, collecting, processing, tabulating and evaluating statistics on persons with disabilities in surveys and censuses (taking into account available national experiences)
The Guidelines

- Provides a broad starting point to the special methodological considerations required to collect and compile statistics on persons with disabilities
- Includes modules so that countries can choose and use only what they want depending on their capabilities, resources and interests
- Limited in treatment of key topics on operational aspects of data collection (e.g., operationalization of ICF)
Part One: Introduction

- International recommendations
  - The World Programme of Action
  - The Standard Rules

- ICIDH
  - ICIDH concepts (impairment, disability, handicap)
  - ICIDH-2 (currently ICF)
  - Application of the ICIDH in disability data collection

- Data sources – advantages/disadvantages
  - Surveys
  - Censuses
Part Two: General Issues in Planning and Organization in the Collection of Data on Disability

- **Preparatory activities**
  - Identifying study objectives (why?, who?, what?)
  - Consulting users and persons with disabilities and examining relevant existing data
  - Publicity (to destigmatize disability and encourage pwd to collaborate)
  - Defining the population with disability

- **Designing questions to identify PWD**
  - Choice of ICF concept embodied in questions
  - ICF as basis for concepts used in questions
  - Wording of questions and their comprehension and interpretation by respondents (clarity)
  - Cultural sensitivity and relevance of questions and need for pre-testing
  - Specific vs generic questions
  - Scope in terms of range of activities covered by questions
General Issues in Planning and Organization

General issues in design and operations

- Choice of respondent
- Issues of non-response
- Mode of data collection
- Translation of questionnaire
- Data processing - data entry, data editing, weighting, tabulation
- Planning outputs and dissemination of data
- Evaluating and improving the quality of the results – sampling and non-sampling errors (for proper use and interpretation)
  - Conceptual errors in designing and phrasing disability questions
  - Respondent errors
  - Interviewer errors
  - Non-response
Part Three: Modules

Detailed methodological information on:

- **Censuses**
  - General issues in use of census to collect data on disability
  - Questions for use in census
  - Use of a census to screen for a follow-up survey

- **Sample surveys**
  - Survey questionnaire design
  - Screening questions for general population, children, elderly
  - Screening for mental disability

- **Sampling for a disability survey**

- **Collecting disability data in institutions**
Part Four: Dissemination and Use of Disability Data

- Planned tabulations
- Reports and publications
- Other forms of dissemination
- Indicators
On the update...

- Many aspects of the Guidelines still relevant
- Guidelines recognized that treatment of some topics was inadequate due to limited available scientific information at the time
- Guidelines based on review and assessment of national studies - more up-to-date information on good national practices is available
- Other international frameworks (CRPD, SDGs)