



---

# 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)
  - Manual for the Development of Statistical Information for Disability Programmes and Policies (1996)
  - Guidelines and Principles for the Development of Disability Statistics (2001)
-



## 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)
-