

Measuring disability in children



Claudia Cappa (ccappa@unicef.org)
Data and Analytics Section, UNICEF, NY

Major challenges

- UN General Assembly Special Session on Children (2002) highlighted the difficulty in gathering accurate data on the incidence of disability among children and referred to the fact that:
 - countries have used different definitions of both impairment and disability
 - the quality of statistical data varies widely
 - too little research has been done on the lives of disabled children

Plus: stigma and complexity linked to data collection

The case for children

- Children have been less visible in the data collection agenda
- General household surveys and censuses found to inadequately identify children with disabilities
- Children might be overlooked on surveys that do not ask specifically about them
- Children of low socioeconomic status and girls in general might be particularly under-enumerated

Review of available data

- Of the total 716 data sources identified, 375 are censuses
- Second most common type of data sources were household surveys
 - 139 household surveys with questions on disability (not part of international programs)
 - 2 of these surveys were exclusively about the child population
 - 20 of these surveys did not collect data on persons under the age of 15

2011 Montenegro Census

- Does the person have any disability that prevents him/her from performing everyday activities due to long lasting illness, invalidity or old age?
 - Question used for all household members

Specific measurement challenges for children (I)

- Disability in children is more difficult to assess:
 - Population is heterogeneous and includes infants, toddlers, middle-age children, adolescents - and their ability to perform activities is reflected in this developmental spectrum
 - Milestones of development can be reached with variation among children without necessarily being considered a developmental delay

Specific measurement challenges for children (II)

- Types of disability in children is different from adult disability
 - In adults the major problems are associated with mobility and sensory functioning, and personal care - especially in advancing years
 - In children the main disabilities are related to intellectual functioning, affect and behaviour
- Therefore, questions used for adults are not always appropriate for children
 - Questions addressed to adults are inappropriate or different in kind for children (e.g. falling over, stretching)
 - Questions addressed to children are sometimes inappropriate for adults (e.g. crawling, running)

Specific measurement challenges for children (III)

- Disability measurement often takes place through the filter of a parent or other adult
- Parental knowledge of norms and children's performance, as well as their expectations and variations by culture, may affect parental reporting



CHILD DISABILITY DATA WORK

Component 1:

Survey instruments

(UNICEF/WG module on child
functioning)

Component 2:

Guidelines for data collection

Component 3:

Workshops on the measurement
of child disability

Guidelines for the production of statistics on children with disabilities

- **Type of document:** Reference document/handbook
- **Purpose:** The purpose of this document is to provide guidance and recommendations for those interested in collecting data about disability in children and youth
- **Content:** The manual will discuss conceptual and theoretical issues related to measuring development and disability, and review methods previously used to assess disability in children. Considerations for designing, planning, and implementing a child disability data collection program will be presented.
- Drafted by UNICEF with inputs from the WG, several international experts, national statistical offices and representatives of Civil Society.
- **Audience(s):** Those commissioning or implementing data collection on children with disabilities, including National Statistical Offices, Academics, representatives of Civil Society and policy makers.

Table of contents

Chapter 1: Overview

Chapter 2: The importance of monitoring child development and disability

Chapter 3: Concepts and definitions

Chapter 4: Assessing factors of the environment and participation in child disability

Chapter 5: Key domains of child development and disability

Chapter 6: Review of methods and tools used to date to measure disability in children

Chapter 7: Key considerations in planning, designing, and implementing the collection of data on disability in children

Chapter 8: Data analysis and dissemination

Chapter 9: Translating knowledge into action

Chapter 10: Conclusions

Thank you



data.unicef.org