Measuring disability in children

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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

Adapted from Meltzer, 2010
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

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