

# Strengthening Statistics on Children with Disabilities

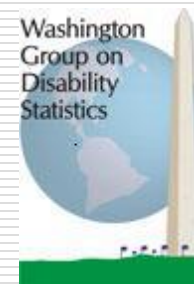
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UNICEF/WG work and planned activities

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# The Washington Group on Disability Statistics (WG)

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- June 2001: UN International Seminar on the Measurement of Disability
- WG established as a City Group under the aegis of the UN Statistical Commission to:
  - address the need for population based measures of disability
  - Foster international cooperation in the area of health and disability statistics
  - produce internationally tested measures to monitor status of persons with disability
  - Incorporate disability into national statistical systems

# The WG is Country driven

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- Countries have ownership
- The Secretariat for the WG is located at the National Center for Health Statistics
- A rotating Steering Committee oversees the work plan of the WG and preparations for the annual meetings
- Workgroups lead the development of specific tasks: currently child disability, the environment and participation, and analysis
- Emphasis on evidence and transparency – extensive testing of questions in multiple countries

# Membership of the Washington Group on Disability Statistics

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- Current representatives from national statistical authorities include 118 countries and territories
- Past and present representatives of international and national organizations representing persons with disabilities, and several national government and non-government organizations
- Other international organizations including among others: EUROSTAT, ILO, OECD, World Bank, WHO, UNICEF, UNESCAP, etc.

# WG Disability Measures:

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Short Set of Questions – six questions recommended for Censuses. (Recommended for use in all national censuses in the UN *Principles and Recommendations for Population and Housing Censuses*)

Extended questions set on functioning for national surveys. (Subset to be included on European Health Interview Survey)

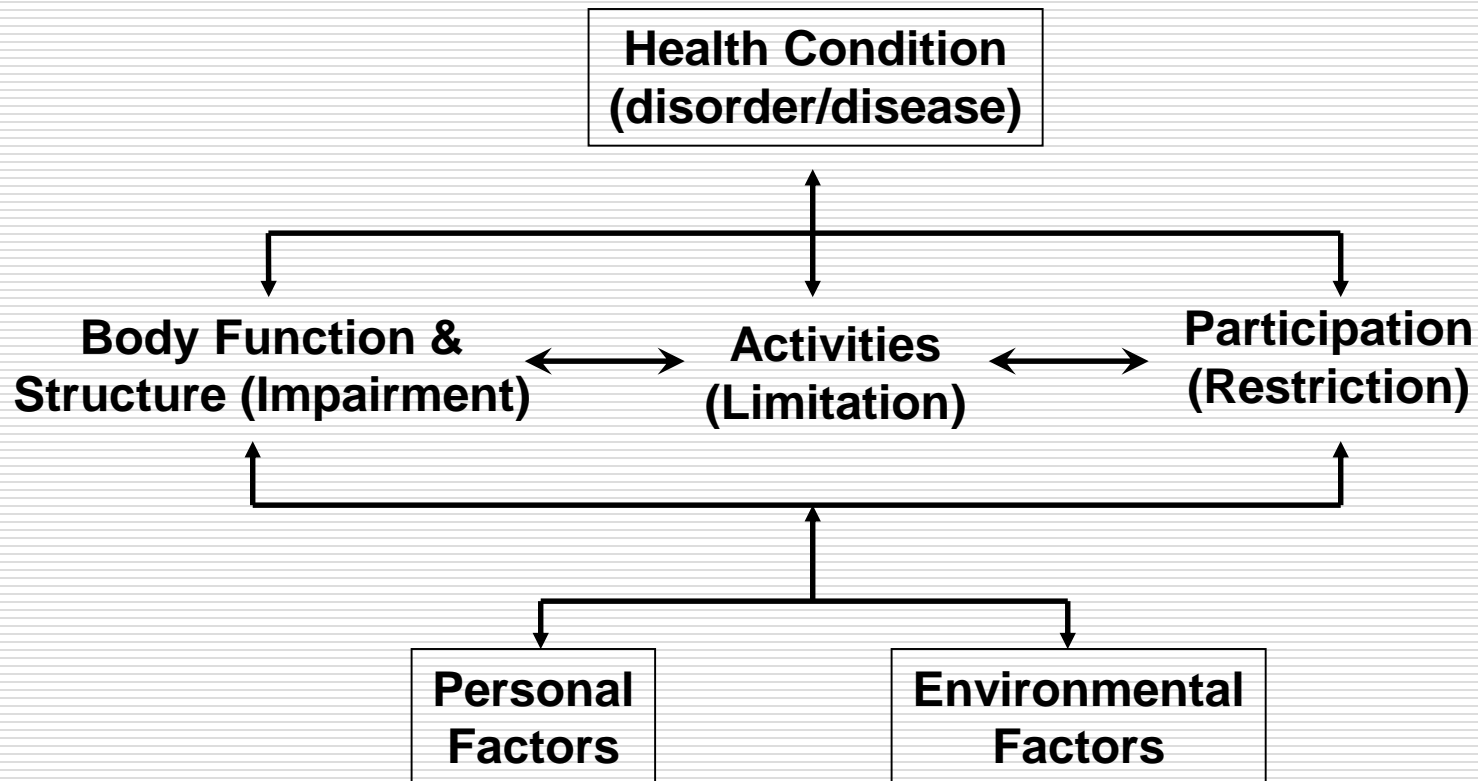
A module on Child Functioning and Disability is currently being tested.

A module on limitations to school participation is under development

Developed a comparable testing methodology

# The ICF Model - 2001

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# ...from *Concept* to *Operational Definition*

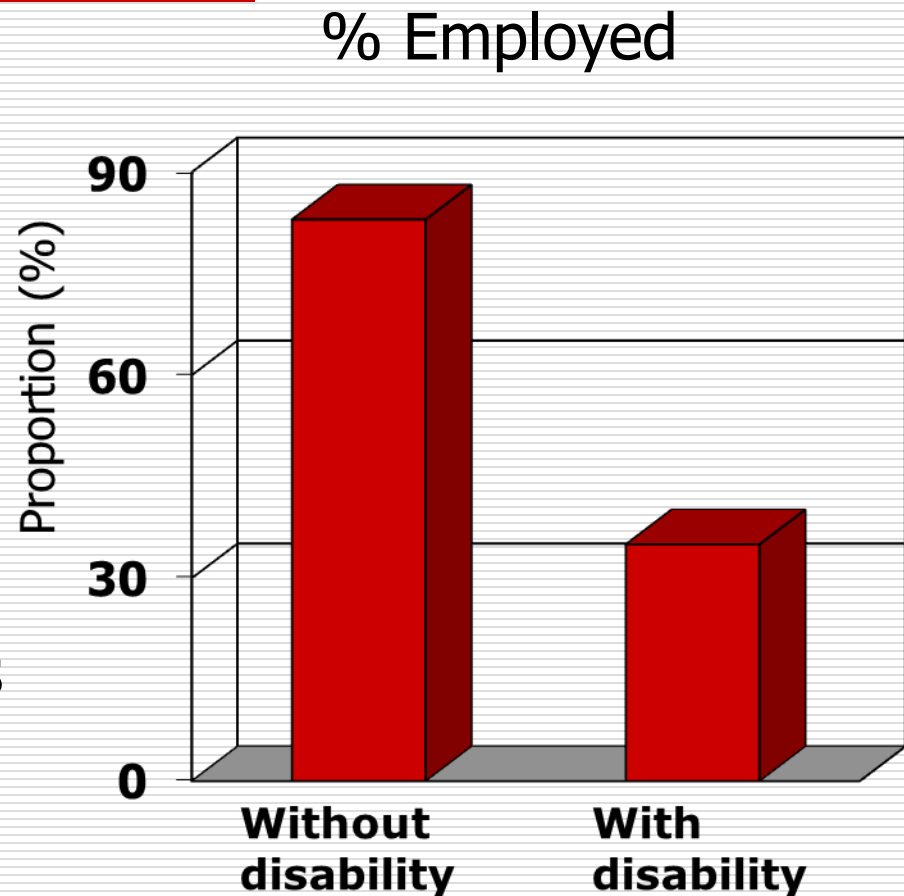
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## The Definitional Paradox

- There is no single **operational** definition of disability
- Different operational definitions lead to different estimates
- The question you are trying to answer (**the purpose**) will determine which definition to use
- Need to **understand the choices** that are being made when choosing a definition

# WG Purpose: Equalization of Opportunities

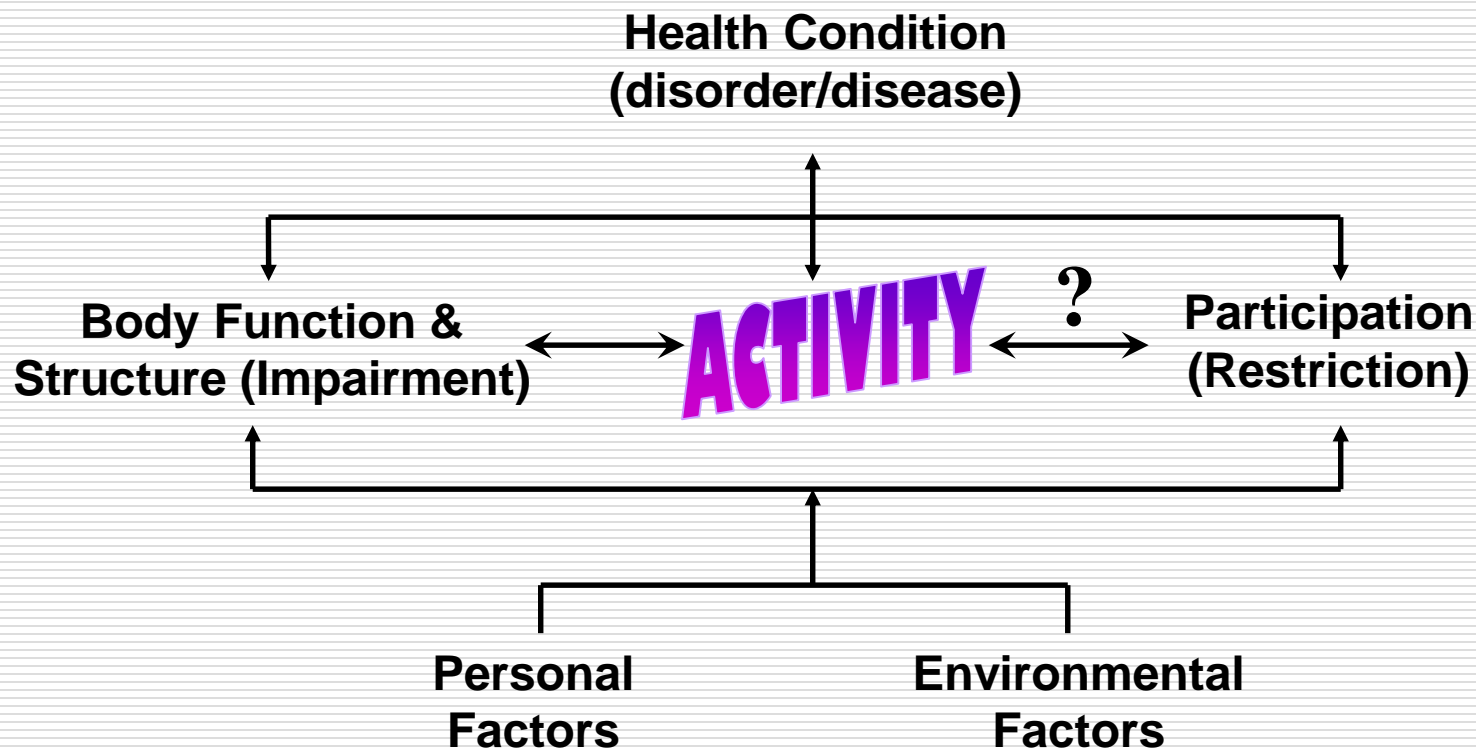
- Seeks to identify all those at greater risk than the general population for limitations in participation.
- Disability used as a demographic.





# Locating Risk in the ICF Model

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# Measuring Disability

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## **Because of a Health problem:**

- 1) Do you have difficulty **seeing** even if wearing glasses?
- 2) Do you have difficulty **hearing** even if using a hearing aid?
- 3) Do you have difficulty **walking** or **climbing** stairs?
- 4) Do you have difficulty **remembering** or **concentrating**?
- 5) Do you have difficulty with (**self-care** such as) washing all over or dressing?
- 6) Using your usual language, do you have difficulty **communicating** (for example understanding or being understood by others)?

## **Response categories:**

No difficulty; Some difficulty; A lot of difficulty; Cannot do at all

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# 1<sup>st</sup> Extended Set on Functioning

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Having successfully developed and tested the short set of questions for censuses, the WG moved on to extended sets for national surveys.

First set of extended questions on functioning

- Expands the number of domains covered
- Provides more in-depth information on each domain
- Begins to construct the links between functioning in core domains without accommodation, functioning with accommodation, environment and participation

# WG/UNICEF Survey Module on Child Functioning and Disability

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# Background (1)

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- UN Convention on the Rights of the Child (1989)
- UN Convention on the Rights of Persons with Disabilities (2006)
- International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) (WHO, 2007)
- UN 66th General Assembly (2011)

set the international background for collecting data on childhood disability.

# Background (2)

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The strategic importance of the **synergy between policies and statistical information** has been fully recognized at the national and international level.

# Background (3)

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Nevertheless, **the quality and quantity of data available on child disability varies enormously** across the world due to:

1. the priority given to disability issues in the political agenda
2. the level of local resources available
3. cultural factors (such as differences in values and attitudes towards individuals with disabilities)
4. several aspects related to data collection

**...thus there is NO International comparability**

# Task:

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To develop and test a survey module specifically designed to capture child functioning and disability.



# Challenge:

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Several reasons why measuring disability for children is different than for adults:

- Children are in a process of development and transition – not all of the 6 domains in the WG Short set are applicable to young children
- Child development does not follow a fixed schedule – there is natural variation in the attainment of functional skills
- Disability measurement often takes place through the filter of a parent or other adult.

# Primary purpose of the module:

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to identify the sub-population of children and youth (aged 2-17 years) who are “at greater risk” than the children of the same age of experiencing limited social participation.

A major reason for this choice is the crucial importance of the issue of social participation and equal rights from a policy perspective as illustrated in the UN Convention on the Rights of Persons with Disabilities and in the UN Convention on Child.

# The aim of the module:

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- to provide cross-nationally comparable data.

The Module is intended to be used as a component of national population surveys or as supplement to surveys on specific topics of interest (health, education, etc.).

# A set of questions was drafted following these guidelines:

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- avoid a medical approach
- use the ICF bio-psycho-social model
- use, when appropriate, questions already tested and/or adopted by the WG;
- include the reference “Compared with children of the same age...” where appropriate
- consider age specificity when constructing questions
- response options to reflect disability continuum.

# Use of measures of child functioning and disability

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Describe the population at risk – to inform policy.

Classify the population to monitor disparities in participation by disability status (also provides a prevalence rate).

Identify a population for 2<sup>nd</sup> stage assessment. (Improve our understanding of population data.)

To provide services to children indentified.

# Domains of functioning:

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- seeing
- hearing
- mobility
- self-care
- communication
- learning
- emotions
- behaviour
- attention
- coping with change
- relationships
- playing

# Cognitive Training/Testing:

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- The first round of testing was conducted in the United States, India, Oman, Belize and Montenegro between September 2012 and July 2013.
- The second round of testing was conducted in the US in March/April 2014.
- The third round of testing was conducted in the US in August 2014.

## Analysis:

- Individual country reports
- Larger, unified analysis (N=258)

# Overview of Primary Findings

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- Child disability questions perform differently than adult disability questions
- Primarily in 2 ways:
  - Parental proxy
  - Parent's knowledge of "what is normal" - comparing to other children the same age



# Overview of Primary Findings

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- Parent proxy reports:
  - Parent expectations
  - Relationship between parent and child
  - Potential for False Positives
  - Domains most effected: those that generate parent frustration (Learning/remembering, communication, Attention/completing a task)

# Overview of Primary Findings

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- Comparing with children the same age
  - Respondents do not always make this comparison
  - Domains most effected: those that children do without other children; those that are isolated or internal activities (Self-care, Emotions, Attention)

# Field Testing:

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- Fall 2013: preparations for field testing begun, including development of a Manual for Implementation
- WG/UNICEF field testing begins in 2014 (Samoa testing June/July 2014)
- Independent field testing underway in Haiti, Cameroon, Italy

# Module to measure environmental factors and school participation:

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# Module to measure environmental factors and school participation:

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UNICEF and the WG have begun a similar process to identify facilitators and barriers to school participation for children with disability.

# Rationale

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The WG and UNICEF have started working on an **extended set** of questions on child disability that will focus on environmental factors and participation

- to provide information that can inform policy
- to provide a statistical summary of environmental influences on participation in school
- to identify areas with key bottlenecks

# Basic principles

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This set of questions will:

- Be a module that can be added to another survey
- To be used in conjunction with the module on child functioning and disability
- Take approximately 10 minutes
- Focus on *formal* education and environmental factors that influence participation
- Be designed to capture the *interaction* between the participant and the environment

# Conceptual Framework

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## **Attitudes**

- parents' perceptions
- their perceptions of others' attitudes, including school staff
- societal and cultural norms
- the attitudes of other children



# Conceptual Framework

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## **School Environment**

### **a) getting to school**

- transportation (characteristics of all aspects of the system and the need for assistance)
- environmental and social safety

# Conceptual Framework

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## **School Environment**

### **b) accessibility within the school**

- physical accessibility (entryway, corridors, bathrooms, lunch room, classroom, common areas etc.)
- information accessibility
- communication accessibility
- programmatic accessibility/adaptability
- teacher and school attitudes towards disability

# Conceptual Framework

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## **School Environment**

### **c) affordability**

- fees, costs, and competition for resources associated with attendance
- the availability of types of assistance (financial, assistive devices, rehabilitation)
- non-educational benefits (e.g., meals)

# Conceptual Framework

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## **Out of school**

- Reasons for not attending school

# Completed tasks and next steps

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- Review of existing questions finalized (32 measures and 668 questions related to environmental factors reviewed)
- Preparation of a draft module ongoing
- Meetings with key stakeholders to finalize a module for testing : December 2014
- Cognitive and field testing will follow
- Module to be finalized by end of 2015

# Development of Guidelines and Manual for data collection

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# Guidelines for producing statistics on children with disabilities

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- Objective: Provide guidance for those considering collecting data on children with disabilities
- Discusses conceptual and theoretical issues related to measuring disability
- Includes considerations for designing, planning, and implementing the collection of data on children with disabilities
- Expected to be ready in late 2014/early 2015

# Table of contents

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**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



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**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

# Manual/User's Guide for the UNICEF/ WG module on functioning & disability

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- Objective: This manual provides background information on the development of the module, as well as technical information that will be useful for countries intending to implement it.
- The manual should be used in conjunction with the general Multiple Indicator Cluster Survey (MICS) manual which discusses the overall survey methodology in detail.
- Expected to be ready in late 2014/early 2015

# Table of contents

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**1: The Importance of Disability Statistics for Children:** discusses the need for reliable data that is comparable across countries; the complexities in collecting such data and findings from previous data collection efforts.

**2: Background:** presents the International Classification of Functioning, Disability and Health (ICF) as the conceptual framework for the child functioning and disability module and describes the steps that UNICEF and the WG used to design, test and validate the instrument.

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**3: How to Use the Module:** presents options for using the questionnaire as a module in an ongoing household survey such as the MICS or the Demographic & Health Survey (DHS), as a screening tool for a 2-stage data collection process or as a stand-alone module in a health or disability survey.

**4: Content of the Module:** describes the rationale behind each question and how the module differs from questionnaires designed to measure disability among adults.

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**5: Implementing the Module:** provides special instructions about translation, pretesting, sample requirements, identification of respondents and eligible children and guidelines for customization

**6: Data processing:** provides guidance and for entering the data and syntaxes for data processing.

**7: Data analysis and dissemination:** provides guidance for analysing and interpreting the findings, calculating indicators, and tabulating and reporting the data.

# Capacity Building

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# Workshops on the measurement of child disability

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**Purpose:** To build/strengthen local capacity for data collection, interpretation, and use.

**Content:** Concepts, models and measures of disability, survey design, data processing, data analysis, data dissemination and data use.

**Audience(s):** National Statistics Offices, other Government staff, local researchers, DPOs, etc.

# Workshops on the measurement of child disability

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**When:** The workshops are expected to take place in 2015/2016.

**Where:** All 7 UNICEF regions (Latin America and the Caribbean, West and Central Africa, East and Southern Africa, Middle East and North Africa, CEE/CIS, East Asia and the Pacific, and South Asia).



# THANK YOU!

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