

UNICEF's work and planned activities on the measurement of child disability



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Objectives

Update on UNICEF's current and future activities on child disability measurement:

- UNICEF's global database of child disability
- Data collection work

UNICEF's global database on child disability



Overview of UNICEF's global database on child disability

- Includes reported estimates, indicators, definitions, questionnaires, methodology used, and any other available supporting documentation
- More than 600 data sources found (household surveys or censuses)
- Data were identified for 187 countries with a population coverage of more than 90% (180 with data on children)
- 170 countries with data both for children and adults
- More than 400 data come from censuses
- Oldest data source found = 1830

Review of prevalence studies

- Reported prevalence rates vary from less than 1% to more than 50%
- Different classifications, definitions and questionnaires
- Outdated/offensive language and definitions
- No survey designed to cover the whole population of disabled children = same questionnaire used in most cases for both adults and children
- Data sources limited by age, and place of residence and other background characteristics

Dissemination

- Next issues of UNICEF's flagship publication, *The State of the World's Children (SOWC)*, will include a text box summarizing the main finding of this data compilation work
- Article for publication in a peer-reviewed journal

Some example of questions



Ireland

Population and Housing Census, 1901

Is he/she [all household members]:

- Deaf
- Dumb
- Blind
- Idiot
- Imbecile or lunatic

Bolivia

Demographic and Health Survey, 1997

Does [any child aged 6-17] have any of the following extreme physical impediments?

- Mentally retarded
- Deaf
- Mute
- Blind
- Paralyzed
- Crippled

Pakistan, Population and Housing Census, 1998

God forbid, is there any disabled person in the household? If so, state the nature of disability:

- Blind
- Deaf/Dumb
- Physical handicapped
- Mentally retarded
- Multiple disabled
- Insane
- Others

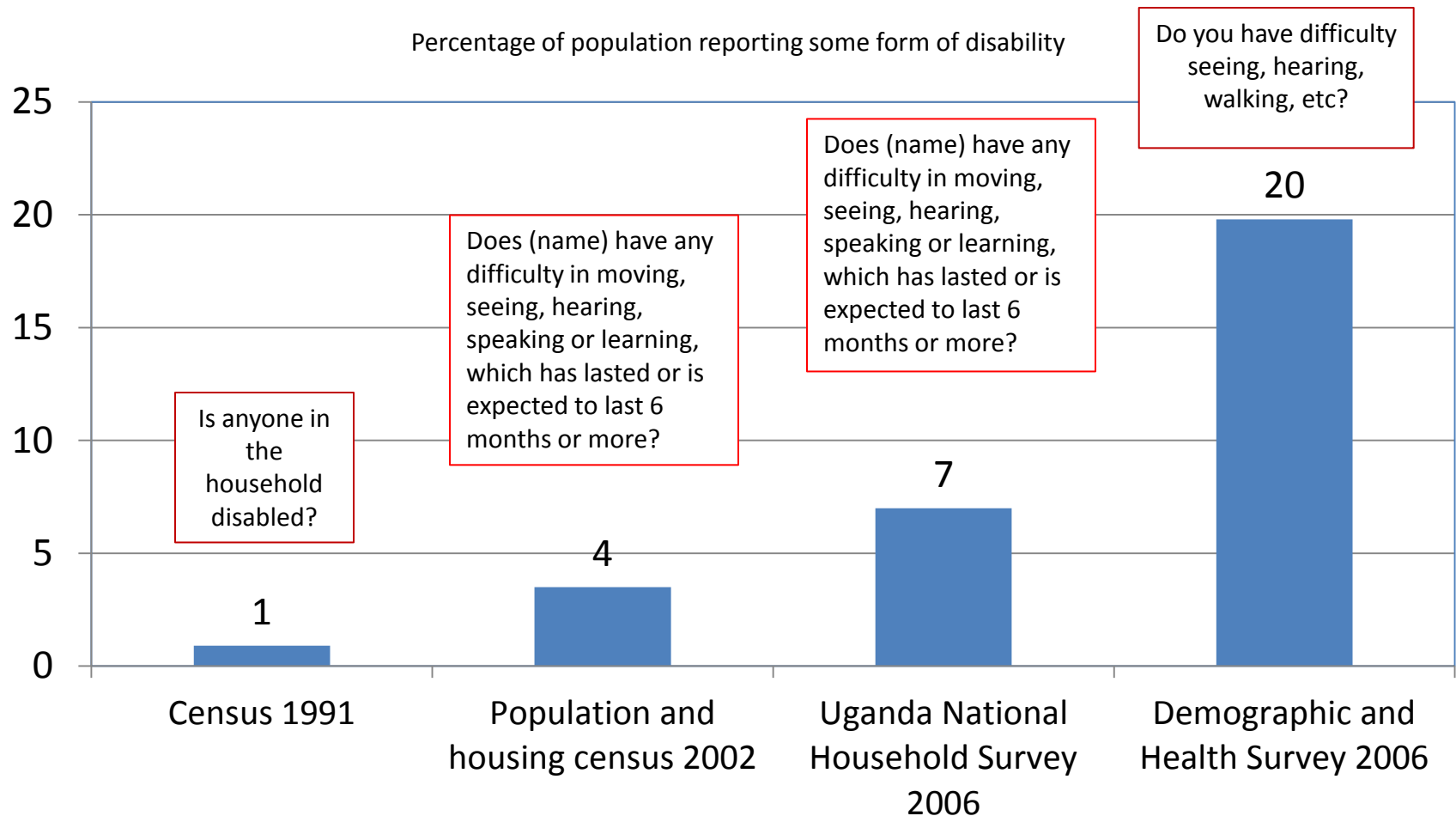
Tanzania

Population and Housing Census, 2002

Is he/she [all members of the household]:

- Not disabled
- Physically handicapped/leprosy
- Visually impaired
- Dumb
- Hearing/speech impaired
- Albino
- Mentally handicapped
- Multiple handicapped

How questions affected prevalence: The case of Uganda



UNICEF's work in the area of data collection



Rationale for measuring child disability

Information on the number and status of children with disabilities is needed to monitor on a population level the impacts of:

- Improvements in child survival and the potential that these are accompanied by increases in the prevalence of child disability
- Childhood exposures to nutritional deficiencies, environmental toxins, infectious diseases and trauma
- Facilitate planning/monitoring of services and interventions designed to improved child wellbeing
- Monitor and improve participation & quality of life

Equalization of opportunity for all children

UNICEF's contribution

Support LAMI countries to develop their own disability statistics program and strengthen countries' capacity to gather sound, relevant and comparable data on child disability

UNICEF's support for data collection: the Multiple Indicator Cluster Surveys (MICS)



MICS: main characteristics

- Household surveys designed to collect data on children and women and to provide evidence base for improved policy formulation and programme planning
- Key data source for monitoring the MDGs, the World Fit for Children goals, and other major international commitments
- More than 100 indicators (nutrition, child health, mortality, child protection, education, HIV, etc.)
- Data available by background characteristics (sex, ethnicity, wealth, education, etc.), and at the national and subnational level
- Harmonized with DHS
- With DHS, largest source of comparable data on children and their families in the developing world

MICS rounds

Three rounds of MICS surveys completed since 1995

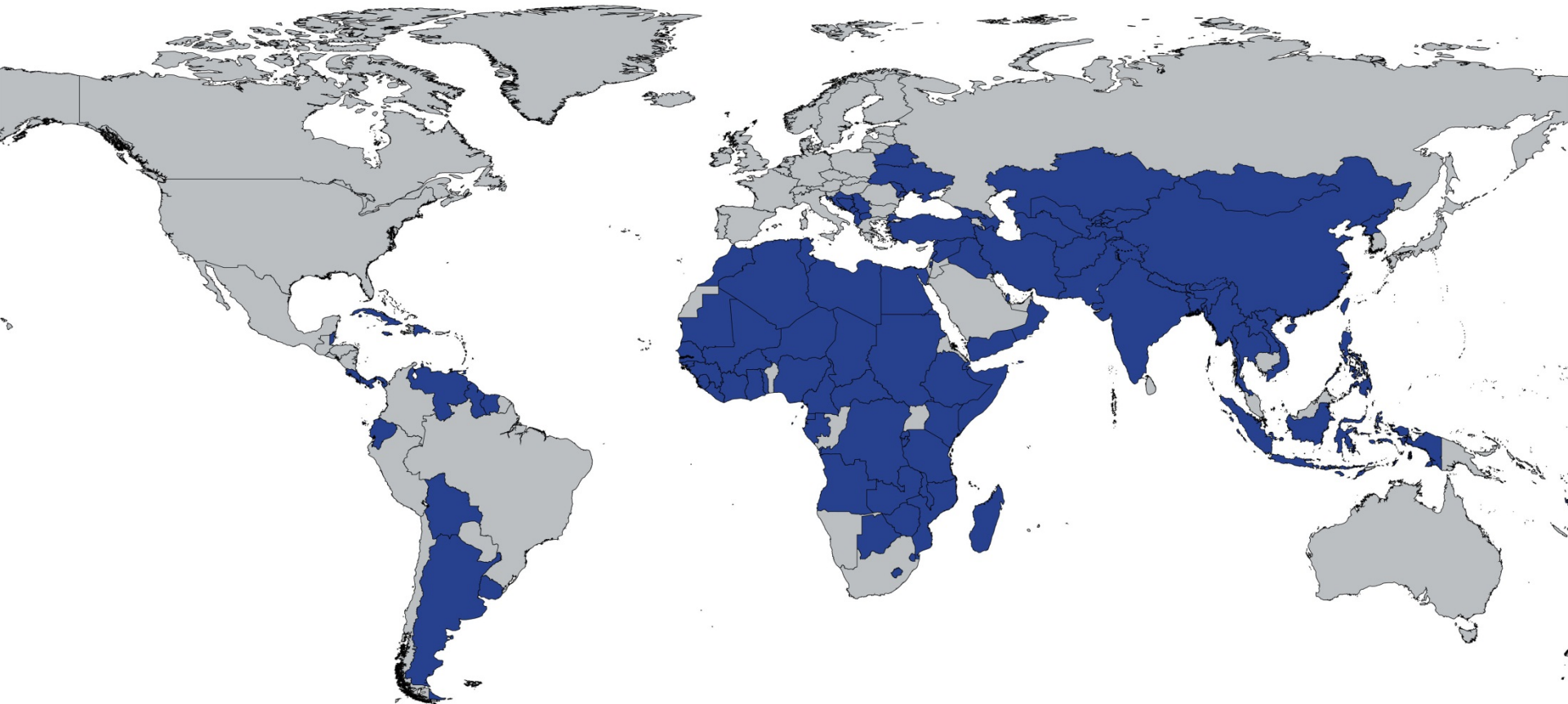
- MICS1 (1995-1996)
- MICS2 (2000-2001)
- MICS3 (2005-2006)

Current activities:

- MICS4 conducted mainly 2010-2012 in 64 surveys
- Planning phase for MICS5 (2013-2014)

Multiple Indicator Cluster Surveys (MICS)

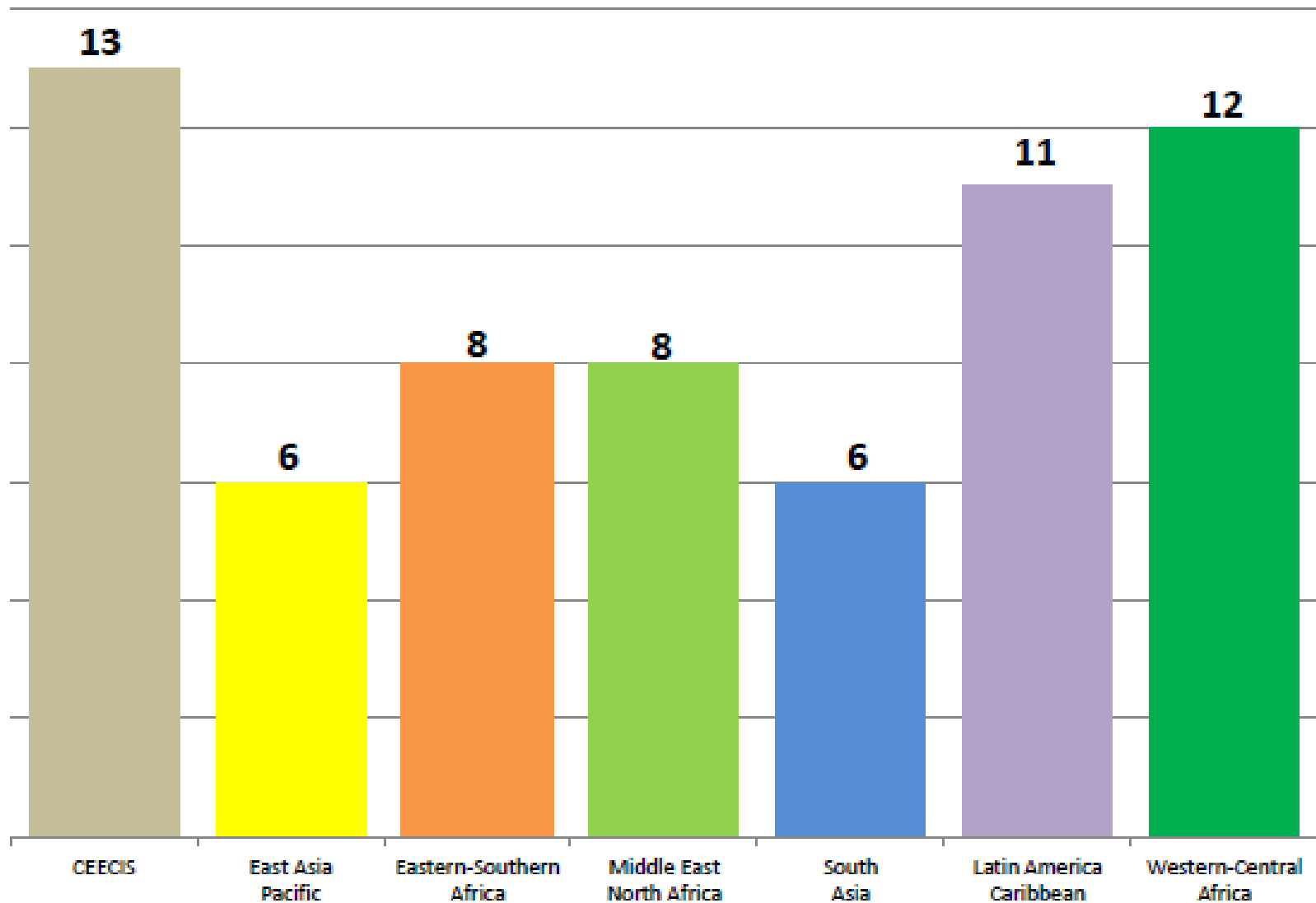
Since 1995, more than 100 countries and more than 230 surveys*



Average sample size: around 10,000 households (994 – 102,000)

*Countries with at least one MICS survey, including sub-national as well as ongoing surveys as of January 2012

MICS4 Surveys by Region



MICS methodology

Survey tools

Developed by UNICEF after consultations with relevant experts from various UN organizations as well as with interagency monitoring groups.

Implementation and capacity building

Surveys carried out by government organizations (with involvement of different ministries), with the support and assistance of UNICEF (HQ, RO and CO) and other partners

Technical assistance and training provided through regional workshops (questionnaire content, sampling and survey implementation, data processing, data quality and data analysis, and report writing and dissemination)

Implementation, including sample size determination, sample-stratification variables vary across countries and decisions about which modules to include is done at the country level

Child Disability in MICS



Child disability in MICS

- MICS 2 (2000-2001), 22 countries collected data on child disability.
- MICS 3 (2005-2006), 26 countries collected data on child disability, using the same standard set of questions (TQ)
 - module administered in 19 written languages
- MICS 4 (2010-2012), 6 countries (completed) as of October 2012
- MICS 5 = Planning stage with methodological revisions being introduced

Methodological innovations - Part 1

- New draft questionnaire developed in partnership with the ***Washington Group on Disability Statistics***
- The primary *purpose* of the questionnaire is to identify the sub-population of children that are *at greater risk* than the children of the same age of experiencing limited *social participation* due to *functional limitations*
- Questionnaire can be included in any data collection effort as individual module

Rationale for revising the first-stage screening

Need to:

- Avoid a medical approach
- Use the ICF bio-psycho-social model
- Strengthen the focus on activity limitations
- Expand the age group
- Consider age specificity when constructing questions
- Include additional functional domains
- Introduce changes in wording and terminology
- Introduce changes in response categories to reflect the *continuum of disability*

Selected Domains

- Seeing
- Hearing
- Mobility
- Self-care
- Communication
- Learning
- Emotions, behaviour, attention
- Coping with change
- Relationships
- Playing

Methodological innovations – Part 2

Development of a standardized methodology/guidelines for follow-up assessments, based on existing best practice approaches for the evaluation of disability in children in developing countries

Objective: to validate data and collect additional information on the child, and his/her environment (including additional questions on participation, access to services, family life etc)

Methodology can be part of a stand alone survey or be used as second stage follow-up after a screening tool

Objectives of the second stage assessment

- Assessment for specific domains of interest:
 - Mobility / motor, vision, hearing, communication, developmental / behaviour and learning
- Functional limitations in broader environment
 - Physical, social, political, financial environments
 - Help with daily activities
 - Unmet needs
- Follow-up and treatment for children in need

Content of the guidelines

Methodological package to include:

- assessment tools
- instructions
- training program/materials
- analysis plan and reporting template
- minimum qualifications for the field team
- ethical codes
- protocols
- procedures for follow-up

Processes and partnerships

- Team of experts mobilized, including :
 - UNICEF Team in NY (1 survey coordinator, 2 survey specialists, 2 data processing experts, 2 data analysis experts, Disability Unit)
 - MICS coordinators in the regional and country offices
 - Washington Group on Disability Statistics
 - External partners (selected academics, NGOs and international organizations)
- Some 30 international experts as contributors to the guidelines and 50 reviewers
- Two international consultations (June 2012, June 2013)
- Guidelines, tools and training materials to be tested and finalized in 2013



Child Disability

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Last update:
January 2008



Ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities and children with special needs, ensure the recognition of their dignity, promote their self-reliance, and facilitate their active participation in the community.

Discrimination may increase vulnerability to abuse and neglect

One of the main recent priorities for UNICEF has been to improve protection of children from violence, abuse, exploitation and discrimination. Children with disabilities are particularly prone to discrimination from the very individuals and institutions with an obligation to protect them, including families, health and education services, and the state.

This discrimination often leads to reduced access to basic social services, especially education, as well as a lack of recognition of their equal humanity by their families, peers and communities. They are also especially vulnerable to abuse, exploitation and neglect, due to the same misperceptions which result in other forms of discrimination, and due to their increased vulnerability as a result of their specific physical or intellectual difference.

To allow children with disabilities to claim their rights, the discrimination which stands in their way must be addressed. This approach is very much in line with the



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Thank you!

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