# The WG-UNICEF Module on Child Functioning and disability:
review of the work

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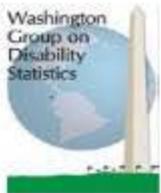
What do we know about *children with disabilities* at international level?

Not much, indeed, because…

… lack of data on children with disabilities…

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

1. different priority given to *children* and to *disability* in the political agenda at national level
2. different local resources available for data collection at national level
3. cultural factors (such as differences in values and attitudes towards individuals with disabilities) influence reporting child disability in the surveys
4. several aspects related to data collection (such as definition of disability, purpose of measurement, data collection method, different age-group bands….)

No international comparability
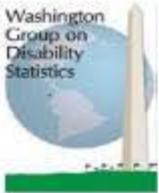
Why do we need data on child disability?

Understand the situation of children with disabilities: prevalence, social circumstances and geographic location, unmet needs and the quality of the support they are receiving.

Assess the role of environmental factors (including societal attitudes and physical barriers) in the experience of disability.

Advocate for the rights of children with disabilities.

Prioritize interventions: inform policies and programs, facilitate the planning of services, and improve participation and quality of life of children with disabilities and their families.

Monitor progress on the UN Convention on the Rights of People with Disabilities (CRPD) and Convention on the Rights of the Child (CRC).

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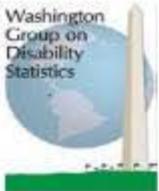
Specific measurement challenges for children

✓ Disability in children is far more difficult to define than in adult:

- children are in a constant developmental process that implies continuous changes in their ability to perform activities, especially in the early ages
- milestones of development can be reached with variation among children

✓ Type of disability in children is different from adult disability

✓ Disability measurement often takes place through the filter of a parent or other adult: parental knowledge of norms and children performances as well as their expectations and variations by culture may affect the parental reporting

Questions used for adult are not always appropriate for children
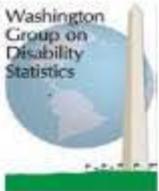
Objectives

At the end of 2009 the WG created a working group, that UNICEF has joined in *2011*, with the task to develop and test a survey module specially designed to capture child functioning and disability.

Purpose

To identify the sub-population of children and youth (aged 2-17 years) who are "*at greater risk*" than the child of the same age of experiencing limited social participation due to *functional limitations* .

Functional difficulties in basic actions are the focus of the measurement as these difficulties may place children at risk of experiencing limited participation in a non-accommodating environment.

Aim

To provide cross-nationally comparable data
To be used as part of national population surveys or in addition to specific surveys (e.g., health, education, etc.)
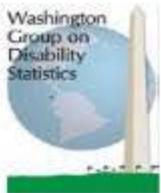
Main steps in developing the Child Module

1. Establish guiding principles

2. Select appropriate and feasible ICF domains

3. Draft and review the questionnaire

4. Validate the module and establish analytic properties of the module

5. Prepare a methodological manual
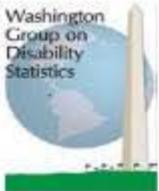
Principles for the development of the module

The working group, *composed by representatives of NSO and other "experts"*, took into account:

- WG work in the development of the short and the extended set of questions

- Studies already carried out on the development of child disability measures and national and international surveys

- Suggestions of the attendees, from across the world and with different expertise, of the WG meetings (10th-14th)

- Results from the experts consultation process (paediatricians, developmental psychologists, speech therapists etc.)- UNICEF meeting, June 2012

- Results from the cognitive testing and field tests

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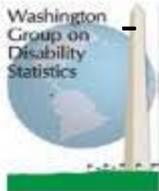
General principles for drafting the questions

- To use the ICF bio-psychosocial model

- To select basic actions and activities that can identify the main types of functional limitations in children

- To use, with appropriate changes, questions already tested and adopted by the WG or in other tools

- To design the questions in a way that enables to identify children with a similar type and level of functional difficulties regardless of nationality or culture

- To use as respondents parents or primary caregivers

- To standardize the expectations of the proxy-respondents, **where appropriate**, questions are prefaced with the clause "*Compared with children of the same age…*".

- To adopt response options that reflect the disability continuum: *no difficulty, some difficulty, a lot of difficulty, cannot do at all*

Three main challenges addressed

-Identifying appropriate and feasible ICF domains

-Selecting the age of the reference population

-Reducing the age-group disaggregation
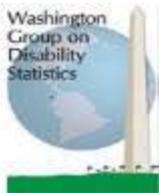
Identifying appropriate and feasible ICF domains

To accomplish this, questionnaires on children were collected and analyzed.

The questions used in population surveys to capture children with disabilities were mapped with the ICF-CY checklists specific to each age group.

This allowed a review of the domains already covered in at least one population survey and has provided, together with disability childhood literature review, the base for selecting a parsimonious set of ICF domains that reliably describes the most common types of disability in children.
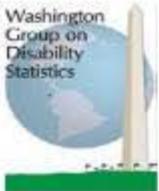
Selected domains for the Module

The following domains are included in the survey disability measure for children and youth for international comparison:

Seeing	Behavior
Hearing	Attention
Walking	Self-care
Communication	Emotions
Learning	Coping with change
Playing	Dexterity
Relationships	

Not all domains are covered in both age bands identified (children aged 2-4 and 5-17), taking into account accuracy/reliability of the data that could be collected due to the level of development in children and other cultural factors.

Selecting the age of the reference population

Early detection of disability in children and thus early intensive intervention can have a profound impact on the quality of life for children at risk and their families.

However, children are constantly developing and this complicate the task of assessing function, distinguishing significant limitations from variations in normal developmental process.
Furthermore, the development of infants and toddlers is very variable, subjective and culturally influenced and a developmental delay at this age is not necessarily a sign of functional limitation.

Despite the recognized importance of early detection of functional difficulties, it is extremely difficult to capture children disability among those less than 2 years of age through population surveys.

The population reference ages for the module is 2-17 years.
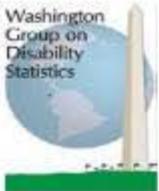
Selecting the age-group disaggregation

Considering the continuous changes of children in their ability to perform actions and activities, to obtain accurate information on their functional difficulties requires to include questions on specific activities that apply to very limited age ranges.

The first draft of questions based on this approach led to a questionnaire that proved to be very complicated to administer accurately, requiring numerous skip patterns.

To balance simplicity and accuracy of the measurement, questions appropriate for larger age ranges were designed.

The module is composited by two questionnaires:
- one for children 2-4 aged
- another for children/youth 5-17 aged
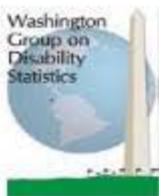
Domains and number of questions by age class

| DOMAINS	AGE CLASS	
	2-4 years	5-17 years
Vision	2	2
Hearing	2	2
Walking	2-3	2-7
Communication/Comprehension	2	2
Learning	1	1
Behaviour	1	1
Playing	1	-
Dexterity/Fine motor	1	-
Remembering	-	1
Attention	-	1
Relationships	-	1
Self-care	-	1
Emotions	-	2
Coping with change	-	1

Question wording

The purpose of each question is to identify children who have difficulties that affect their ability to undertake **age appropriate activities**

PREAMBLE *(interviewer read):* **The next questions ask about difficulties your child may have in doing certain activities…**

Would you say… [*Read response categories*]

Response categories are:
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Validation process

From September 2012 cognitive tests and fields test have been carried out.

Cognitive testing determines if respondents understand the question as intended:

> Do individual respondents understand the survey question differently?
> Does the question mean the same in all the languages, cultures and socio-economic groups that it is asked?

India, Belize, Oman, Montenegro and by several rounds in USA

Field testing provides evidence to better understand the extent to which patterns of interpretations exist in a population.

At different stage of the development of the Module:

> Independent field testing in Haiti, India, Cameroon, Italy, Samoa, Myanmar, El Salvador, Zambia, South Africa and Mexico
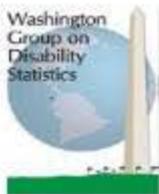
Cognitive testing

The results from cognitive test led to:

- simplifying wordings

- eliminate examples or specification in some questions

- avoid using the preface "compared with children of the same age...", when not necessary

- select the best wording when alternative questions have been used

- reduce the number of questions used for the same domain, when the same population was identified by more questions

- add questions for the some domains when necessary.

Future steps

✓Final Field Test in Serbia by the end of this year

✓Finalization of module and release in Spring 2016

✓Finalization of a methodological manual user of Module in Spring 2016.
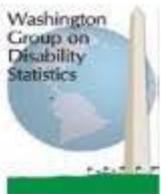
Thank you

"How do you know I have a learning disability?
— Maybe you have a *teaching* disability!"

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Dexterity / Self-care

2-4 years	5-17 years
Compared with children of the same age, does [name] have difficulty **picking up small objects with his/her hand**? Would you say… [*Read response categories*]	Does [name] have difficulty with **self-care such as feeding or dressing** [him/herself]? Would you say… [Read response categories]

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

Communication/Comprehension

2-4 years	5-17 years
Does [name] have difficulty **understanding you**? Would you say… [*Read response categories*]	When [name] speaks, does he/she have difficulty being understood by **people inside of this household**? Would you say… [*Read response categories*]
When [name] speaks, does he/she have difficulty **being understood by you**? Would you say… [*Read response categories*]	When [name] speaks, does he/she have difficulty being understood by **people outside of this household**? Would you say… [*Read response categories*]

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

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