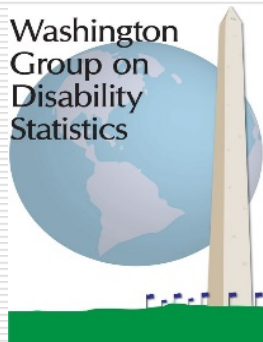


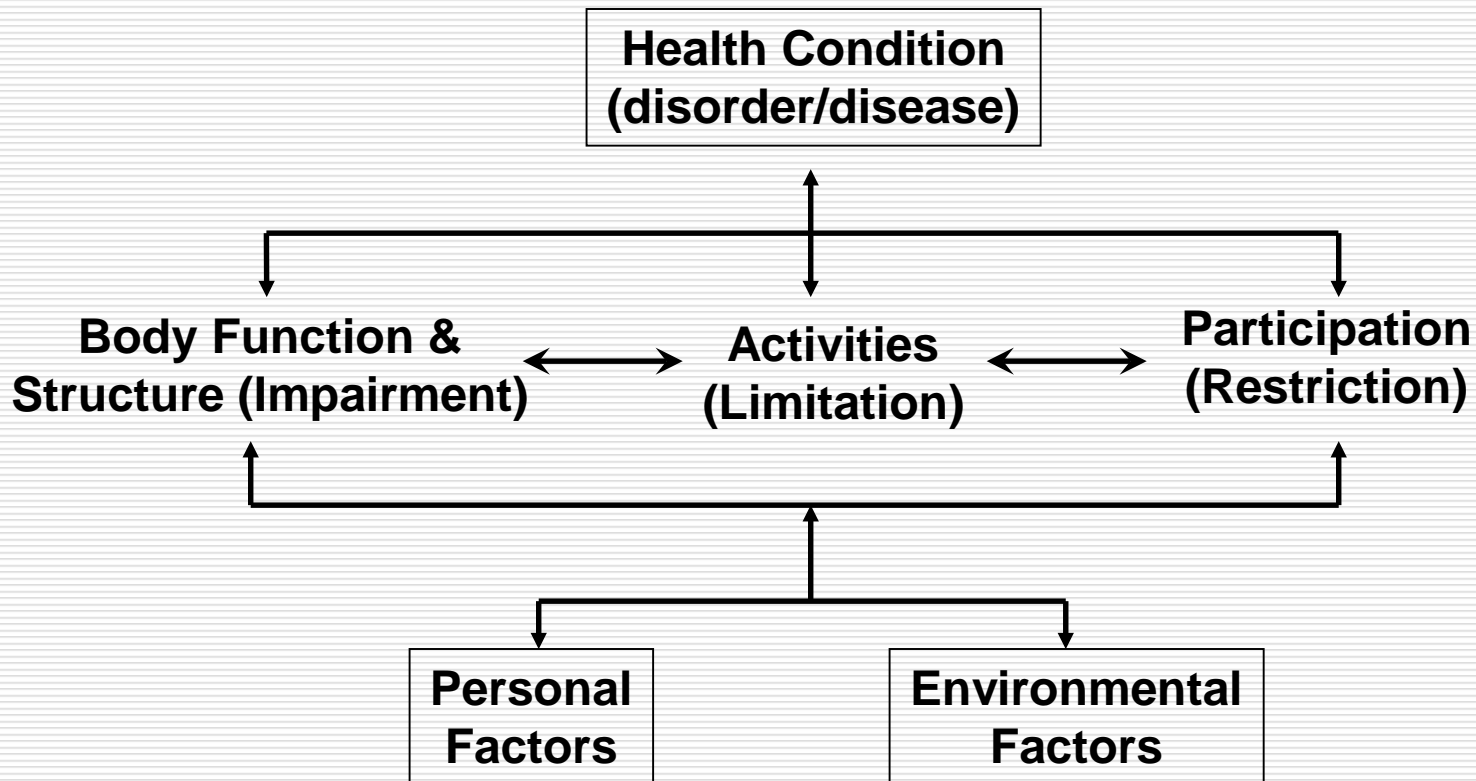
WG Child Functioning Workgroup



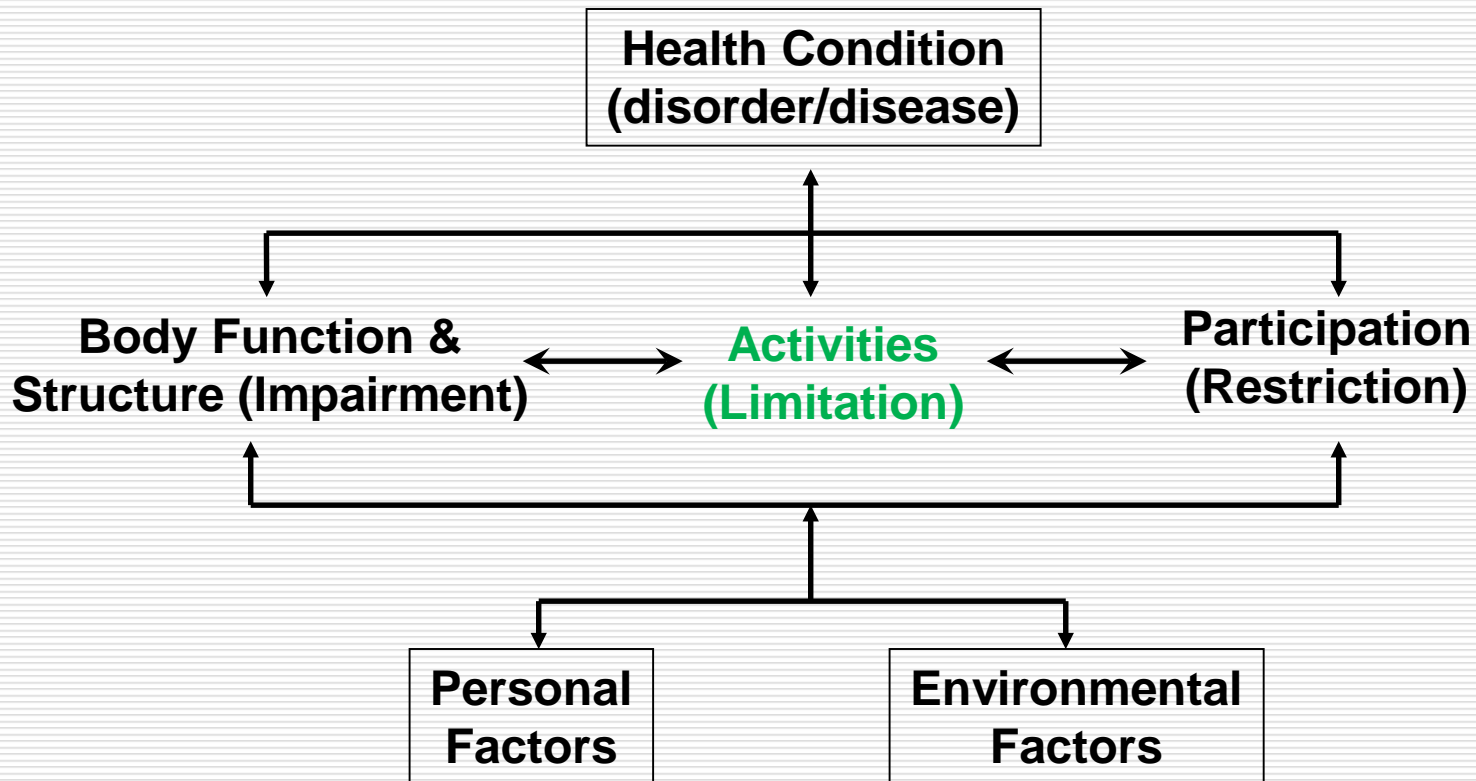
Mitchell Loeb

National Center for Health Statistics, USA and
Washington Group on Disability Statistics

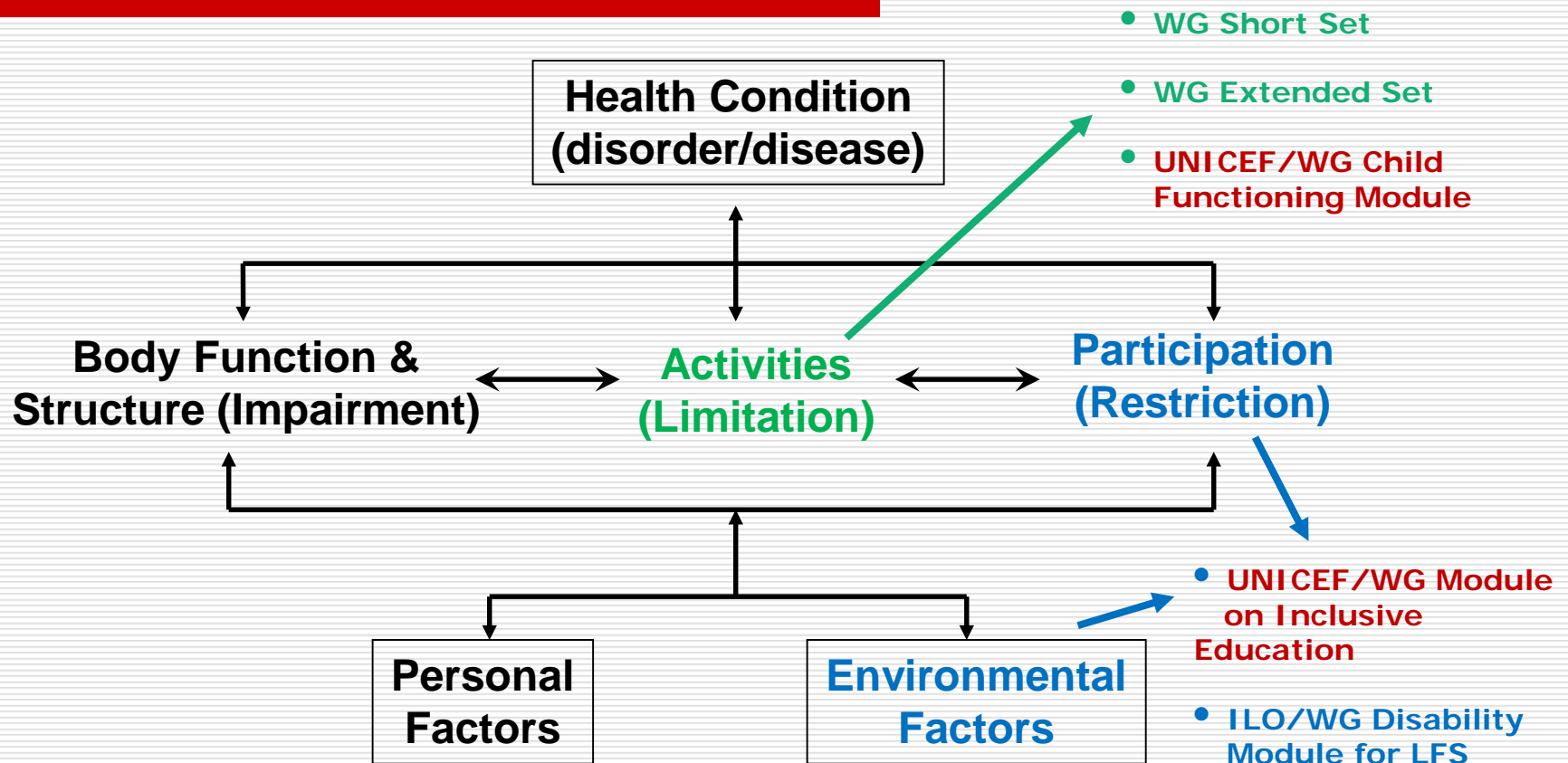
The ICF Model - 2001



The ICF Model - 2001



The ICF Model - 2001



WG/UNICEF Child Functioning Module (CFM)

Why do we need data on child disability? (1)

Raise awareness: to bring attention to this population by demonstrating the extent and impact of disability among children.

Advocate for the rights of Children with Disability: to provide support for advocacy efforts because it helps justify the need for change and for increase resources for appropriate interventions.

Quantify needs: to identify the number of children with disability as well as assess their unmet needs and thereby identify gaps in services that must be addressed.

Why do we need data on child disability? (2)

Prioritize interventions: to provide decision-makers with basic information that can be used to set priorities related to child with disabilities and their families.

Monitor progress: data collected over time can be used:

- ✓ to monitor outcomes on national policies and interventions in order to expand effective programs and modify/delete ineffective ones and
- ✓ to fulfill the requirements of the UN Conventions and the Sustainable Development Goals (SDGs).

Data on child disability varies widely across the world due to:

1. different priority given to *children* and/or to *disability* in the **political agenda** at national level
2. different level of **local resources** available for data collection at national level
3. **cultural factors** influence how child disabilities are reported in surveys
4. **lack of a standardized approach** to data collection: such as definition of disability, purpose of measurement, data collection method...

Some factors affecting the international comparability of survey data

- **Questions designed** specifically to target children vs applying questions designed for adults to child population
- **Questions that ask** about “disability” or “impairment” vs questions on “difficulties in functioning”
- **Age range** of target population
- **Reporting prevalence** on different age ranges
- **Answer categories**: dichotomous vs graded responses

The result is: **No international comparability**

A trajectory of development

Defining disability in children is more difficult than in adults:

- Children are in a constant developmental process that implies continuous changes in their ability to perform actions and activities, especially in the early ages
- Child development does not follow a fixed schedule: milestones of development can be reached by children at different ages

0

17

65

Challenges in developing questions:

The WG and UNICEF wanted to build a question set for children based on experience from the WG-SS, but

- not all of the 6 WG short set domains are applicable to young children
- nor do they cover the full range of domains of particular interest in child development
- Disability measurement often takes place through the filter of a parent or another adult

Determination of disability status

The WG defined an approach to measuring disability based on identifying those who:

- because of **difficulties** doing certain **universal, basic actions**,
- are at greater **risk** than the general population
- for **limitations in participation**
- in an **unaccommodating environment**.

This approach minimizes stigma, reduces respondent burden, maximizes the consistency of the response process.

Guiding principles for drafting the questions (1)

- to avoid a medical approach and use the ICF bio-psycho-social model of disability
- to measure “difficulties in functioning”
- to select basic actions and activities that can identify the main types of functional limitations in children
- to propose age-specific questions
- to formulate questions that are culturally relevant and able to collect comparable data cross-nationally

Guiding principles for drafting the questions (2)

- to adopt, where applicable, questions already tested including those of the WG short and extended sets
- to use answer categories able to get the severity of the activities limitation in order to reflect the disability continuum
- to include, when appropriate, the reference “Compared with children of the same age...”
- to ask questions to parents or primary caregivers.

UNICEF/WG Child Functioning Module (CFM)

WG/UNICEF CFM adopted 2016

- module for 2-4 years of age is comprised of **max 16** questions covering 8 core domains of functioning
- module for 5-17 years of age is comprised of **max 24** questions covering 12 core domains of functioning
- Domains were selected based on their universality and commonality across cultures and countries at various stages of economic development.

Selected domains

1. Seeing*
2. Hearing*
3. Mobility**
4. Self-care (5-17)*
5. Dexterity (2-4)
6. Communication*
7. Learning
8. Remembering (5-17)*
9. Emotions (5-17)**
10. Behaviour
11. Attention (5-17)
12. Coping with change (5-17)
13. Relationships (5-17)
14. Playing (2-4)

There is no single disability prevalence

- Disability in a population is best described as a continuum of functioning, and the determination of the prevalence of disability will depend on where a cut-off is determined along that continuum.
- There is more than one possible cut-off.
- It becomes important therefore when describing disability in text or tables to clearly define which cut-off was chosen and reasons for making that choice.

Disability Identifiers - CFM

Three levels of difficulty defined:

WG
cut-off



	Children age 2-4	Children age 5-17
Level 1: Mild to severe	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except Controlling behavior: coded more or a lot more 	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except Anxiety and Depression: coded weekly or daily
Level 2: Moderate to severe	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Anxiety and Depression: coded daily
Level 3: Severe	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Anxiety and Depression: coded daily

Child Functioning Module Updates...

- CFM translations: English, French, Spanish, Vietnamese, Russian, Chinese, Arabic, Portuguese (standard and Brazilian), Khmer
- CFM Manual for Interviewers (available in English, French & Spanish)
- Guidelines on the Measurement of Child Disability (under review)
- Resource Document based on FAQs arising from a Workshop on the Measurement of Disability targeted to DPOs (under review)

SPSS and Stata code available

Tabulation plans, narrative and analytic syntax in SPSS and Stata are all available here:

<https://data.unicef.org/resources/module-child-functioning-tabulation-plan-narrative/>

Official translations of the module are available here:

<https://data.unicef.org/resources/module-child-functioning/>

Videos on Disability Measurement

- 1. Disability statistics/Understanding data needs:** the importance of disability statistics in the context of the CRPD and the SDGs
- 2. Current status of disability data:** data availability and measurement challenges
- 3. How to measure disability:** data sources and how these affect measurement
- 4. The UNICEF/WG Module on Child Functioning:** the use of the instrument and its use as an advocacy tool
- 5. The WG Short Set Module:** the use of the instrument and its potential use as an advocacy tool
- 6. Disability statistics/Translating knowledge into action:** how to analyze and interpret disability statistics to identify disparities and promote action

UNICEF MICS 6

Includes:

CFM: 2-4 years of age

CFM: 5-17 years of age

WG-SS: adult sample women

WG-SS: adult sample men

UNICEF MICS 6

Rolled out and in different stages in 68 countries/
regions:

- East Asia and the Pacific - 10
- Eastern and Southern Africa - 5
- Europe and Central Asia - 17
- Latin America and Caribbean - 12
- Middle East and North Africa - 7
- South Asia – 7 (including 5 regions in Pakistan)
- West and Central Africa - 10

Discussion
