Measuring Disability in Children

LIMITATIONS AND EXAMPLES
Need For Disability Data For Children

- **UN Convention**
  - Article 7 “Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children
  - Requirement to collect appropriate information to monitor performance

- **Programs and policies**
  - Design and provision of services in clinical settings need base line information
  - Development of integrated educational opportunities for children with disabilities
  - Early intervention and appropriate treatment
Why is disability measurement different for children?

- Children are in the process of development.
  - The 6 domains are not applicable to young children

- Child development does not follow a fixed schedule.
  - Natural variation in the attainment of functional skills

- Disability measurement takes place through the filter of a parent or some other adult.
Scarcity of National Disability Surveys of Children

- Disability is more difficult to define for children.
  - The ICF CY was not published until 2007

- Disability is seen as relatively rare in children.

- National Statistical Agencies may think that children’s disability is being measured in other places.
  - Schools or health care settings

- Children may not fit into the mandate of ongoing disability surveys
National Surveys on Disability in Children

Examples of Methods of Measuring Disability
Unicef Multiple Indicator Cluster Surveys (MICS)

- Household survey programme developed by UNICEF to monitor the health of women and children
- Optional module on child disability
- Over half the participating countries in 2005-07 included the children’s module
- Uses the “Ten Questions”
Children were judged to screen positive if a parent reported an impairment in response to the following ten questions:

Compared with other children, did (name) have any serious delay in sitting, standing or walking?

Compared with other children does (name) have difficulty seeing, either in the daytime or at night?

Does (name) appear to have difficulty hearing?

When you tell (name) to do something, does he/she seem to understand what you are saying?

Does (name) have difficulty in walking or moving his/her arms or does he/she have weaknesses and/or stiffness in the arms or legs?
Does (name) sometimes have fits, become rigid or lose consciousness?

Does (name) learn to do things like other children his/her age?

Does (name) speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?

a. Ages 3-9: Is (name)’s speech in any way different from normal?  
b. Age 2: Can he/she name at least one object (animal, toy, cup or spoon)?

Compared with other children of his/her age, does (name) appear in any way mentally backward, dull or slow?
Canada: Participation and Activity Limitation Survey

- Disability estimates for children aged 0+

- Answers to Census filter questions provide a survey frame

*Does .... have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?*

1. Yes, sometimes  2. Yes, often  3. No

*Does a physical condition or mental condition or health problem reduce the amount or the kind of activity that ..... can do at home?*

    .... can do at work or at school?

    .... can do in other activities, for example, transportation or leisure?

1. Yes, sometimes  2. Yes, often  3. No
The 2006 Census in Ireland included two questions on disability. Answers to these Census questions were used to select a sample for a detailed follow-up survey – the National Disability Survey.

A total of 2377 children were sampled and questioned on limitations in seeing, hearing, speech, mobility and dexterity, remembering and concentrating, intellectual and learning difficulties, emotional, psychological and mental health problems, pain and breathing.

An overall disability rate of 3.5% was reported for children.
Ireland Census Disability Questions

Do you have any of the following long lasting conditions:

- Blindness, deafness or a severe vision or hearing impairment?
- A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying?
- A learning or intellectual disability?
- A psychological or emotional condition?
- Other including any chronic illness?

If yes to any of these questions, do you have any difficulty in doing any of the following activities:

- Learning, remembering or concentrating?
- Dressing, bathing or getting around inside the house?
- Going outside the home alone to shop or visit a doctor’s surgery?
- Working at a job or business or attending school or college?
- Participating in other activities, for example leisure or using transport?
United States – National Survey of Children’s Health

- 2003 telephone survey of over 100,000 children aged 2-17
- Survey of children’s health not disability
- Includes questions on different types of limitations
- Includes question on child’s development relative to other children of the same age
- No questions on participation limitations
NSCH Questions include:

- Has a doctor or health professional ever told you that {Sample child} has any of the following conditions?
  ...Asthma?
  ...Hearing problems or vision problems that cannot be corrected with glasses or contacts?
  ...Attention Deficit Disorder or Attention Deficit Hyperactive Disorder, that is ADD or ADHD?
  ...Depression or anxiety problems?
  ...Behavioral or conduct problems?
  ...Bone, joint, or muscle problems?
  ...Diabetes?
  ...Autism?
  ...Any developmental delay or physical impairment?
### Canada

#### Domains of Disability Measurement - PALS

<table>
<thead>
<tr>
<th>Aged 0 to 4</th>
<th>Aged 5 to 14</th>
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<tbody>
<tr>
<td>Hearing</td>
<td>Hearing</td>
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<tr>
<td>Seeing</td>
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<td>Chronic health</td>
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<td>conditions</td>
<td>Communications</td>
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<td>Delay</td>
<td>Mobility</td>
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<tr>
<td>Other</td>
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<td>Psychological</td>
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<td>Learning</td>
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<td>Domains of coverage</td>
<td>10 Questions</td>
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<tr>
<td>Vision</td>
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<tr>
<td>Hearing</td>
<td>All</td>
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<tr>
<td>Speech</td>
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## Domains of coverage

<table>
<thead>
<tr>
<th>10 Questions</th>
<th>Canada</th>
<th>Ireland</th>
<th>NCHS</th>
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<tbody>
<tr>
<td>Emotional</td>
<td>Over age 5</td>
<td>All</td>
<td>Over age 2</td>
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<tr>
<td>Developmental</td>
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<td>All</td>
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<td>Chronic conditions</td>
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<td>Allergies/Breathing</td>
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<td>All</td>
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<td>Learning</td>
<td>Over age 5</td>
<td>All</td>
<td>Over age 3</td>
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## Ireland – Threshold of Disability

<table>
<thead>
<tr>
<th>Domain</th>
<th>Just a little</th>
<th>A moderate level</th>
<th>A lot of difficulty</th>
<th>Cannot do at all</th>
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<tbody>
<tr>
<td>Seeing</td>
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<td>Mobility &amp; dexterity</td>
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<td>Remembering</td>
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<td>Intellectual &amp; learning</td>
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<td>Pain</td>
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<tr>
<td>Breathing</td>
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Moving Forward: