Disability Data

Towards improved measures of disability for development indicators
Overview of the State of Disability Data

• In the past, disability data was of poor quality and varied dramatically
• Recent international efforts have improved our ability to collect reliable, meaningful disability data
• The population of people with disabilities is very heterogeneous, and this must be accounted for in data analysis
What is disability?
CRPD Definition of Disability

“...those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”
International Classification of Functioning

Health Condition

- Body functions & structure
- Activity
- Participation

Factors:
- Environmental factors
- Personal factors
Previous Survey Questions Greatly Undercount People with Disabilities

- “Do you have a disability?”
  - Stigma
  - Only severe conditions
  - Can miss elderly

- “Do you have (medical condition)?”
  - Incomplete list of conditions
  - Only those with education and access to doctors know diagnosis
  - Great variance among people with same diagnosis
  - Completely divorced from the environment
Functional Approach

- We want to ask questions that get at the difficulty people have doing various activities
  - e.g., Do you have difficulty walking?
- Want to ask across a range of activities, and want to get the level of difficulty
- We are concerned with what people can do, not what people “have”.
  - Of course for some public health initiatives we want to know about diagnoses
Census-based Disability Prevalence by Type of Question

<table>
<thead>
<tr>
<th>Do you have a disability</th>
<th>List of conditions</th>
<th>Functional approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nigeria</td>
<td>.05</td>
<td>Colombia</td>
</tr>
<tr>
<td>Jordan</td>
<td>1.2</td>
<td>Chile</td>
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<tr>
<td>Philippines</td>
<td>1.3</td>
<td>Uganda</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>3.8</td>
<td>Hungary</td>
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</table>
Where do we draw the line?

- The distribution of human functioning is not binary
- As the environment becomes more inclusive, the line where people face participation restrictions will shift to the right
- Where we draw the line can differ based on our purpose for identifying people
Recent Efforts in Improving Disability Data by Washington Group

- **UN Washington Group (WG) on Disability**
  - Short set of disability questions
  - Extended Set

- **WG/UNICEF**
  - Child questions
  - School Environment

- **WG/ILO**
  - Disability questions for Labor Force Surveys
WG Short Set

- Ask about difficulties in six core basic activities
  - Seeing, hearing, walking, communicating, cognition, and self-care
  - Initially designed for censuses

- Scaled responses
  - For UNSD measure of disability prevalence use “a lot or unable” but possible to look at wider range

- Identify people at risk of social exclusion
  - To be used to disaggregate indicators by disability status
WG Short Set of Disability Questions

- Do you have difficulty seeing even if wearing glasses?
- Do you have difficulty hearing even if using hearing aid/s or are you deaf?
- Do you have difficulty walking or climbing stairs?
- Do you have difficulty remembering or concentrating?
- Do you have difficulty (with self-care such as) washing all over or dressing?
- Do you have difficulty communicating (for example, understanding or being understood by others)?

Question response categories: No, Some, A lot, and Unable.

Source: http://www.cdc.gov/nchs/ctyggroup.htm
Advantages

- Functional approach
  - Tested successfully in many countries
- Widely adopted
  - by UNSD for use in censuses
  - By UN Disability Data Experts Group for SDG disaggregation
  - By DFID and DFAT for evaluating their programs
  - Used in growing number of censuses and surveys around the world
- Designed to be internationally comparable
- Identifies most people with disabilities
- Can easily be added to existing censuses and surveys or to project based data.
  - About 1.25 minutes to administer
Shortcomings

- Not appropriate for children under age 5, and misses some children with developmental issues
- Misses those with psychosocial issues that do not affect communication or self-care
- Does not capture age of onset
- Does not capture environmental barriers
Actions to fill the gaps

- WG Extended Set includes questions:
  - to get at psychosocial issues
  - to get at the use of assistive devices
  - that are widely tested
- UNICEF/WG Children questions
  - appropriate for children age 2-17
  - get at full range of childhood disability
  - undergoing final field test
- Environment
  - UNICEF/WG educational environmental module (being tested)
  - ILO/WG employment – basic questions being tested, more extended set under development
- WG working group on mental health (early stages)
Analytical Issues

- Age of Onset
- Heterogeneity
  - Type of disability
  - Degree of disability
- Capacity (“in the skin”) vs. Performance (“in the environment”)
- Interaction with environment
Example: Disability and Poverty

- Impacted by age of onset
  - Accumulated wealth, skills, and experience
  - Children to rely on
- Environmental barriers (and policies) can differ by type of disability
- Extra costs of living, so standard consumption measures of poverty inadequate
- Poor people w/ disabilities may have higher mortality rates and so “disappear” from data
- As countries get richer, people live longer, and age is correlated with disability
- In fact, disability more correlated with multi-dimensional measures of poverty than with consumption measures
  - Varies by country context
Take Home Messages

- Well tested questions for disability exist and are growing in use around the world
  - More detailed ones are on the way
- Care should be taken to use high quality disability questions because poor questions can create misleading information
- Disability is complex and very heterogeneous and analysis should take that into account
THANK YOU