Measuring Disability: Considerations and Challenges

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Objectives

- Review key conceptual information related to measuring disability
- Highlight challenges with studying/surveying people with disabilities
- Share promising practices needed to improve surveillance for people with disabilities
Health outcomes for people with disabilities

- **Mortality** (premature and disproportionate mortality among people with severe to profound intellectual disabilities)
- **Morbidity** (associated conditions, co-morbidities, secondary conditions)
- **Quality of life** (independence, inclusion in programs, poverty, employment)
Public health surveillance: purpose

- Determine health status of PWDs
- Identify priorities for intervention
- Identify patterns of comorbidity
- Plan for program and policy intervention
- Evaluate programs and policies for effectiveness
- Extend knowledge base through research
## Prevalence of disability

<table>
<thead>
<tr>
<th>Data System</th>
<th>Year</th>
<th>Age</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>BRFSS</td>
<td>2008</td>
<td>18+ years</td>
<td>≈ 22%</td>
</tr>
<tr>
<td>NHIS</td>
<td>2008</td>
<td>17+ years</td>
<td>33.3%</td>
</tr>
<tr>
<td>SIPP</td>
<td>2005</td>
<td>All ages</td>
<td>18.7%</td>
</tr>
<tr>
<td>ACS</td>
<td>2008</td>
<td>All ages</td>
<td>12.1%</td>
</tr>
</tbody>
</table>

BRFSS: Behavioral Risk Factor Surveillance System  
NHIS: National Health Interview Survey  
SIPP: Survey of Income and Program Participation  
ACS: American Community Survey
Overarching factors impacting disability measures

- Varying definition of disability
- Varying perspective on the concept of disability
  - Models and paradigms
- Varying methods and methodologies used for data collection
  - Homogeneity of PWDs
Connecting disability to public health surveillance

Disability Measure

Disability Perspective

Public Health Surveillance
What is surveillance?

“Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of data essential to the planning, implementation, and evaluation of public health practice…..dissemination of these data to those responsible for prevention and control.”

(Institute of Medicine, 2003)
What is disability?

“Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).”

(WHO, 2001)
Disability models and paradigms

<table>
<thead>
<tr>
<th>Medical Model</th>
<th>Social Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability is an individual condition</td>
<td>Disability seen as a societal problem</td>
</tr>
<tr>
<td>Disability due to individual impairment</td>
<td>Disability is a product of the environment</td>
</tr>
<tr>
<td>Perceived to be less inclusive</td>
<td>Perceived to be more inclusive</td>
</tr>
<tr>
<td>Fix the person</td>
<td>Fix the environment</td>
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</tbody>
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- Medical Model:
  - Disability is an individual condition
  - Disability due to individual impairment
  - Perceived to be less inclusive
  - Fix the person

- Social Model:
  - Disability seen as a societal problem
  - Disability is a product of the environment
  - Perceived to be more inclusive
  - Fix the environment
International Classification of Functioning, Disability and Health (ICF Model)

Health Conditions (disorder or disease)

Body Functions & Structures

Activities

Participation

Environmental Factors

Personal Factors

(World Health Organization, 2001)
Methodological issues related to studying and measuring PWDs

- Cognitive abilities
- Proxies
- Sampling bias
- Response bias
- Non-response
- Interviewer training
- Under-representation in clinical trials
Evaluating the quality of research & surveillance

(Illustration adapted from Trochim, 2006)
Validity of disability measures in public health surveillance/research

<table>
<thead>
<tr>
<th>Sampling (External validity)</th>
<th>Measurement (Construct validity)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Representativeness</td>
<td>• Instrumentation</td>
</tr>
<tr>
<td>• Types of disability</td>
<td>• Self vs. Proxy</td>
</tr>
<tr>
<td>• Institutional/Non-institutional</td>
<td>• Cognitive/Stamina</td>
</tr>
<tr>
<td></td>
<td>• Questionnaire/Interviewer training</td>
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Applying **sampling** methods in disability surveillance/research

<table>
<thead>
<tr>
<th>Probability sampling</th>
<th>Non-probability sampling</th>
</tr>
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<tbody>
<tr>
<td>▪ Random sampling (simple, stratified, systematic)</td>
<td>▪ Convenience/Accidental sampling</td>
</tr>
<tr>
<td>▪ Cluster sampling</td>
<td>▪ Purposive sampling</td>
</tr>
<tr>
<td>▪ Multi-stage sampling</td>
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</table>
Using *proxies* in disability surveillance/research activities

- Useful for increasing response rate
- May also be subjective rather than objective
- May be ineffective for data on psychological functioning/status
- More than 30% of respondents in NHIS and SIPP use proxies
Cognitive abilities

- Cognitive barriers:
  - People with profound intellectual disabilities have limited ability to respond to interviews

- Communication challenges:
  - Recall bias is likely to be higher for people severe or profound disabilities

- Stamina
  - The endurance of those with severe disabilities may affect participation

- Consent
Recommendations
- Sampling -

- Proactively engage survey designers from the beginning
- Pay attention to subgroups with a high propensity for non-response
- Deploy devices to increase response rate (advance letters, incentives, etc)
Recommendations
- measurement -

- Use decomposition techniques in questionnaire design
  - Spatial cues
  - Temporal cues
- Interviewer training