Identification of Child Disabilities in Low and Middle Income Countries

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Collaborators

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Overview

- Defining child disability
- Methods and strategies for monitoring child disability in populations
  - The Ten Questions (TQ) screen for child disability
- Results of the TQ in the Multiple Indicator Cluster Survey, round 3
- Conclusions and implications
Child disability in low- and middle-income (LAMI) countries

- Growing awareness of the society-wide impact of child development and disability
- Little known about frequency of children with disabilities in LAMI countries, their situation
- No established best practice for measuring child disability in LAMI countries
- Improvements in child survival may be accompanied by increased disability prevalence
Why monitor child disability?

- Stimulate awareness about disabilities
- Identify risk factors and prevention strategies
- Encourage development of services for children with disabilities and families
- Monitor and improve the quality of life of people with disabilities
UN Convention on the rights of persons with disabilities

- Defines disability as “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [a person’s] full and effective participation in society on an equal basis with others.”

- Article 7 addresses the need “to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.”

#UN Convention on rights of persons with disabilities 2008
Disability as an interaction between health conditions and contextual factors

Disability measured in 3 dimensions:
- Impairments
- Activity Limitations
- Participation Restriction

Towards a Common Language for Functioning, Disability and Health: ICF for Beginners, 2002
Strategies for monitoring child disability in populations

- Administrative Record Review
  - schools, medical facilities, social services
- Registries
- Birth Cohort studies
- Key Informant surveys or reports
Another strategy: the Ten Questions (TQ) screen & two-phase design for monitoring child disability in LAMI countries

1. Ten Questions screen
   - Identifies children at increased risk of disability

2. Clinical diagnostic evaluation
   - All children screening positive
   - Sample of those screening negative
Two-Phase design for identifying children with disabilities in LAMI countries

Screening of All Children

Screened +
- Clinical Assessment
  - Disability “True Positive”
  - No Disability “False Positive”

Screened –
- Clinical Assessment (10% of screened –)
  - Disability “False Negative”
- No Assessment (90% of screened –)
  - No Disability “True Negative”
The Ten Questions (TQ) screen for child disability

- 10 simple yes/no questions
- Respondents are primary caregivers of children 2-9 years
- Cross-culturally appropriate
  - universal abilities
  - parental reporting within given cultural context
- Low cost and rapid administration
- Most commonly used tool in this setting\(^1\)
- International studies support validity, reliability\(^2\)

\(^1\) Maulik and Darmstadt 2007; CeDR report 2009
\(^2\) Zaman et al. 1990; Durkin et al. 1992, 1994, & 1995; Mung’ala-Odera 2004
Some limitations of TQ

Reliable, feasible, and valid across cultures for detecting serious cognitive, motor and seizure disabilities in 2-9 year-old children, but...

- Low sensitivity for
  - previously undetected vision, hearing disabilities
  - mild disabilities
- Not designed to detect behavioral disabilities including autism
- Not diagnostic
Multiple Indicator Cluster Survey, round 3 (MICS3) General Methodology

- UNICEF supported household survey administered in 53 countries during 2005-2006 (cross-sectional)

- Collected data on multiple indicators of women and children’s health:
  - Education
  - Nutritional variables
  - Immunization coverage
  - Family material possessions
  - HIV/AIDS knowledge
Why include a measure of child disability in MICS3?

- Better understand the frequency and distribution of children screening positive/at risk for disability
- Raise awareness about child disability
- Investigate the relationship between children at risk for disability and...
  - Sociodemographic characteristics
  - Child healthy development experiences
  - Nutritional variables (ages 2-4 years only)
The TQ in MICS3

- *Optional* Child Disability module used in 20 countries
  - Other measures of disability used in 6 additional countries

- Two-phase design recommended
  - Screen alone used in participating countries (resource limitations)
Data Notes

- Only completed TQ screens included

- Some data weren’t collected in all countries
  - ex: Bangladesh anthropometric measurements

- Some countries were excluded from analyses:
  - Algeria used different disability questions
  - Bosnia & Herzegovina asked 9 of 10 questions
  - Djibouti following concerns about data quality
  - Sierra Leone from nutritional analyses due to high percentage of missing data
Monitoring Child Disability in Developing Countries
Results from the Multiple Indicator Cluster Surveys

This report is the result of a collaboration between the Statistics and Monitoring Section of UNICEF New York and the University of Wisconsin—Madison. Maureen Durkin, Carissa Gottlieb, and Matthew Maenner (Department of Population Health Sciences, University of Wisconsin School of Medicine and Public Health) were primarily responsible for the data analysis, interpretation, and writing of this document. Claudia Cappa and Edilberto Loaiza (Statistics and Monitoring Section, UNICEF NY) coordinated the study and contributed to the overall realization of the project.

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>Number Surveyed</th>
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<tr>
<td>Albania</td>
<td>2,354</td>
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<tr>
<td>Bangladesh</td>
<td>58,441</td>
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<td>Belize</td>
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<td>Bosnia and Herzegovina</td>
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<td>Cameroon</td>
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<td>Ghana</td>
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<td>Iraq</td>
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<td>Jamaica</td>
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<td>Montenegro</td>
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<td>Sao Tome and Principe</td>
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<td>Serbia</td>
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<td>Sierra Leone</td>
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<tr>
<td>Suriname</td>
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<tr>
<td>The Former Yugoslav Republic</td>
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<tr>
<td>of Macedonia†</td>
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<td>Thailand</td>
<td>16,564</td>
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<tr>
<td>Uzbekistan</td>
<td>8,038</td>
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<td><strong>Total:</strong></td>
<td><strong>205,674</strong></td>
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</table>

http://www.childinfo.org/publications.html
The median percent of children screening positive to the TQ is 24% (range 3% - 48%)
Early learning activities: children ages 2-4 years

In 8 of 18 countries, children who participated in more early learning activities screened positive to the TQ significantly less frequently than children who participated in fewer early learning activities.

Rao-Scott $\chi^2$ p-values: * $p < 0.05$, ‡ $p < 0.01$, † $p < 0.001$
Children ages 2-4 years who were breastfed screened positive less frequently than children who were not.
Children ages 2-4 years who received vitamin A supplements screened positive less frequently than children who did not.

Rao-Scott $\chi^2$ p-values:
- $*= p<.05$
- $**= p<.01$
- $***= p<.0001$

Children screening positive to TQ (%)

Graph showing the percentage of children screening positive to TQ in different countries, comparing those who received vitamin A supplements with those who did not.
Children ages 2-4 years who were stunted screened positive significantly more frequently than children who were not in 7 of 15 countries.

Rao-Scott χ² p-values:  *= p<.05,  **= p<.01 ,  ***= p<.0001
Underweight children ages 2-4 years screened positive significantly more frequently than children who were not in 8 of 15 countries.
Stimulation and nutrition status are associated with risk for disability

- Children who participated in more early learning activities screened positive to the TQ less frequently
- Children who have better nutritional status screened positive to the TQ less frequently
  - Nutritional deficiencies a risk factor for some disabilities?
  - Children with disabilities have reduced growth potential or access to food?
  - Both?
Children ages 6-9 years not currently in school screened positive to the TQ more frequently than children in school in 8 of 18 countries.

Rao-Scott χ² p-values: *= p<.05, **= p<.01, ***= p<.0001
Children living in the poorest 60% of families screen positive more frequently than children living in the wealthier 40% of households.

Rao-Scott $\chi^2$ p-values: * = p<.05, ** = p<.01, *** = p<.0001
Stimulation, education and development

- Children participating in more early learning activities screened positive to TQ less frequently
- Children attending school screened positive to TQ less frequently than children not in school
  - Stimulation related to development?
  - Discrimination against children not seen to be developing typically?
  - Both?
Limitations of this study

- Cross-sectional data
- Cross-country comparisons not straightforward
  - Cultural biases, translation, sample selection, survey respondent data
- Possible data management differences
- Follow-up information to confirm frequency of disability in children surveyed not obtained
- Questions do not address issues of stigma, inclusion, or discrimination
- Cannot generalize results to all LAMI countries
Child Disability and Poverty

- Living in poverty may increase risk for disability
- Discrimination against those with disabilities may lead to fewer educational and employment opportunities, resulting in poverty

- Achieving **MDG 1: to reduce poverty and hunger** should include targeting those at highest risk of negative impacts of poverty
- Child disability/development is one target area
Prevention vs. protection?

- **Prevention**: identifying and reducing exposure to risk factors
- **Protection**: ensuring equal rights and participation in all aspects of society

- Both: continue to obtain better information about children with disabilities to both prevent future cases and support services to address the needs of children with disabilities
Interventions to prevent child disability at many levels

**Primary Prevention**
- Prevent underlying impairment (e.g., vaccines to prevent brain infections, folic acid & iodine fortification)

**Secondary Prevention**
- Prevent activity limitations or disability following impairment (e.g., newborn screening & treatment, trauma care)

**Tertiary Prevention**
- Prevent participation restrictions, social isolation & stigma; enhance functioning, independence, participation, equal opportunity
Areas for intervention

- Improvement of services for children with disabilities and their families
  - Assessment: early detection, evaluation
  - Interventions: addressing impairments, activity limitations, and participation restrictions
  - Community-Based Rehabilitation is one method for interventions

- Addressing associated factors
  - Nutritional deficiencies
  - Stimulation/early learning activities
  - Education
Conclusions

- Internationally comparable data about the frequency and status of children with disabilities in several LAMI countries
- Associations between poor nutrition, early stimulation, education and risk for disability
- Early identification of children at risk for or with disabilities may improve their outcomes
  - Inclusion in education
  - Targeted services
  - Human/social development implications
Implications & strategy

- Move beyond administering surveys, disseminating results
- Need for development of public health, primary health care, & educational infrastructure
  - Improve monitoring & assessment
  - Increase capacity for support service provision
  - Enhance programs promoting equal rights and opportunities of children with disabilities
  - Support policies that improve outcomes for children with disabilities and their families
- Greater international attention to this topic may mobilize resources to achieve these goals
The Ten Questions (TQ) screen for child disability

1. Compared with other children, did (name) have any serious delay in sitting, standing, or walking?
2. Compared with other children does (name) have difficulty seeing, either in the daytime or at night?
3. Does (name) appear to have difficulty hearing?
4. When you tell (name) to do something, does he/she seem to understand what you are saying?
5. Does (name) have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?
6. Does (name) sometimes have fits, become rigid, or lose consciousness?
The Ten Questions (TQ) screen for child disability

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

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

9. 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, spoon)?

10. Compared with other children of his/her age, does (name) appear in any way mentally backward, dull or slow?