Measuring Child Disability in Low- and Middle Income Countries: the MICS Experience

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UNICEF’s support for data collection: the Multiple Indicator Cluster Surveys (MICS)
MICS: main characteristics

- Household surveys designed to collect data on children and women and to provide evidence base for improved policy formulation and programme planning
- Key data source for monitoring the MDGs, the World Fit for Children goals, and other major international commitments
- More than 100 indicators (nutrition, child health, mortality, child protection, education, HIV, etc.) with data available by background characteristics (sex, ethnicity, wealth, education, etc.)
- Harmonized with DHS
- Three rounds of MICS surveys conducted since 1995 (MICS1, MICS2 and MICS3)
- Current activities: MICS4 conducted in 2010-2011 in 59 countries
Multiple Indicator Cluster Surveys (MICS)
Since 1995, more than 100 countries and close to 230 surveys*

*As of October 2011
Countries with at least one MICS survey, including sub-national as well as ongoing MICS4 surveys
MICS methodology

Survey tools
Developed by UNICEF after consultations with relevant experts from various UN organizations as well as with interagency monitoring groups.

Implementation and capacity building
Surveys carried out by government organizations, with the support and assistance of UNICEF (HQ, RO and CO) and other partners.

Technical assistance and training provided through regional workshops (questionnaire content, sampling and survey implementation, data processing, data quality and data analysis, and report writing and dissemination)

Implementation, including sample size determination, sample-stratification variables vary across countries and decisions about which modules to include is done at the country level
Child disability in MICS2 and MICS3

• Second round of MICS (2000-2001), 22 countries collected data on child disability. Eight countries however used different questionnaires from the standard Ten Questions Screen. Among the 14 countries that used the Ten Questions Module, only 7 included the complete set of questions.

• Third round of MICS (2005-2006), 26 countries collected data on child disability, using the same standard set of questions (TQ)
  - module administered in 19 written languages

• Inclusion of the TQ Child Disability Module in UNICEF’s MICS3 has resulted in the first population-based comparable information from a broad range of LAMI countries
MICS 3 data on disability

Countries that participated in MICS3 and did not collect data on child disability
Countries that participated in MICS3 and collected data on child disability
The MICS Module on Child Disability: Rationale

- TQ developed by a team of scientists (M. S. Durkin et al.). Its validity has been tested in different epidemiological surveys involving screening and clinical assessments of more than 22,000 children, in Bangladesh, Pakistan and Jamaica.

- Looks specifically at activity limitations and participation restrictions (ICF framework).

- Ten questions addressed to parent or caregiver, yes/no format and some reverse worded questions.

- Focus on universal abilities, cross-culturally comparable.

- Reliance on caregiver assessment of child’s development & behavior relative to own cultural norms.

- 2-9 year age range.

- Shown not to be gender biased (equally valid for girls & boys).
Questionnaire

• Does the child:

(1) Have delay in sitting, standing or walking
(2) Have difficulty seeing, either in the daytime or at night
(3) Have difficulty hearing
(4) Have difficulty in understanding instructions
(5) Have difficulty walking or moving arms or has weakness or stiffness of limbs
(6) Have fits, becomes rigid, loses consciousness
(7) Not learn to do things like other children his/her age
(8) Not speak at all
(9) Speak differently from normal or cannot name at least one object
(10) Appear mentally backward, dull or slow
**DISABILITY**

To be administered to caretakers of all children 2 through 9 years old living in the household. For household members below age 2 or above age 9, leave rows blank.

I WOULD LIKE TO ASK YOU IF ANY CHILDREN IN THIS HOUSEHOLD AGED 2 THROUGH 9 HAS ANY OF THE HEALTH CONDITIONS I AM GOING TO MENTION TO YOU.

<table>
<thead>
<tr>
<th>DA1. Line no.</th>
<th>DA2. Child’s name</th>
<th>DA3. Compared with other children, does (name) appear to have any serious delay in sitting, standing, or walking?</th>
<th>DA4. Compared with other children, does (name) have difficulty seeing, either in the daytime or at night?</th>
<th>DA5. Does (name) appear to have difficulty hearing? (Uses hearing aid, hears with difficulty, completely deaf?)</th>
<th>DA6. When you tell (name) to do something, does he/she seem to understand what you are saying?</th>
<th>DA7. Does (name) have difficulty in walking or moving, his/her arms or legs?</th>
<th>DA8. Does (name) sometimes have fits, become rigid, or lose consciousness?</th>
<th>DA9. Does (name) have weakness and/or stiffness in the arms or legs?</th>
<th>DA10. Does (name) speak at all? (Can he/she make him or herself understood in words; can say any recognizable words?)</th>
<th>DA11. Does (name) speak at all? (Can he/she make him or herself understood in any way; different from normal, not clear enough to be understood by people other than the immediate family?)</th>
<th>DA12. (For 3-9 year olds): Can (name) name at least one object (for example, an animal, a toy, a cup, a spoon) in any way?</th>
<th>DA13. Compared with other children of the same age, does (name) appear in any way mentally backward, dull or slow?</th>
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</thead>
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<td>Name</td>
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</table>
Some considerations on the TQ

- The ‘Ten Questions’ is a screening tool; for those screening positive a professional diagnostic assessment is required.

- Validity established only for relatively severe disabilities (intellectual, motor, seizure). Sensitivity is low for mild disabilities, and for vision and hearing disabilities generally.

- Positive predictive value of 20-25%.

- Not valid for establishing prevalence by type.


- Validity not established for behavioral disabilities such as autism and attention deficit disorders.
Ten Questions & 2-Phase Design

10 Questions Screen  
n=10,000

Screened Positive  
10 - 20%  
Clinical Evaluation

Disability  "true positive"  
No Disability  "false positive"

Screened Negative  
80 - 90%  
Clinical Evaluation  
10% random sample

Disability  "false negative"  
No Disability  "true positive"  
No Follow-Up  
70 - 80%
Monitoring Child Disability in Developing Countries
Results from the Multiple Indicator Cluster Surveys
Scope and methods

• Conducted in collaboration with the University of Wisconsin in 2008

• Results based on data from 20 of 53 countries participating in MICS3

• Completion rates for the disability module above 92% in all countries, with the exception of one country (79 percent)

• Question on understanding verbal direction produced some odd results in a few countries (Montenegro, Ghana, Serbia and Thailand)
<table>
<thead>
<tr>
<th>Country</th>
<th>Number Surveyed</th>
<th>Weighted</th>
<th>Language of Disability Module administration</th>
<th>% Urban</th>
<th>% Male</th>
<th>% school aged (6–9 years)</th>
<th>% Currently in School (ages 6–9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
<td>2,354</td>
<td>2,445</td>
<td>Albanian</td>
<td>37.8</td>
<td>53.3</td>
<td>56.5</td>
<td>94.9</td>
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<td>Bangladesh</td>
<td>58,441</td>
<td>58,592</td>
<td>Bangla</td>
<td>26.3</td>
<td>50.8</td>
<td>51.2</td>
<td>94.2</td>
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<td>Belize</td>
<td>1,537</td>
<td>1,505</td>
<td>English</td>
<td>43.9</td>
<td>48.0</td>
<td>53.0</td>
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<td>Bosnia and Herzegovina</td>
<td>3,589</td>
<td>1,639</td>
<td>Bosnian, Serbian, Croatian</td>
<td>33.6</td>
<td>49.5</td>
<td>51.6</td>
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<td>Cameroon</td>
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<td>10,368</td>
<td>French</td>
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<td>50.2</td>
<td>50.5</td>
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<td>Central African Republic</td>
<td>14,219</td>
<td>14,542</td>
<td>French</td>
<td>37.3</td>
<td>50.6</td>
<td>46.9</td>
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<td>Georgia</td>
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<td>3,922</td>
<td>Georgian</td>
<td>47.9</td>
<td>53.7</td>
<td>53.2</td>
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<td>Ghana</td>
<td>5,946</td>
<td>5,391</td>
<td>English</td>
<td>35.5</td>
<td>51.2</td>
<td>51.9</td>
<td>82.3</td>
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<td>Iraq</td>
<td>25,775</td>
<td>24,826</td>
<td>Arabic, Kurdish</td>
<td>58.3</td>
<td>51.3</td>
<td>48.7</td>
<td>82.1</td>
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<td>Jamaica</td>
<td>2,509</td>
<td>2,498</td>
<td>English</td>
<td>31.5</td>
<td>51.2</td>
<td>51.4</td>
<td>98.9</td>
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<td>Mauritania</td>
<td>15,193</td>
<td>15,429</td>
<td>Arabic, French</td>
<td>39.5</td>
<td>51.0</td>
<td>50.4</td>
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<td>Mongolia</td>
<td>4,921</td>
<td>4,910</td>
<td>Mongolian</td>
<td>49.6</td>
<td>52.0</td>
<td>44.1</td>
<td>86.0</td>
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<td>Montenegro</td>
<td>1,595</td>
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<td>Montenegrin, Albanian</td>
<td>62.8</td>
<td>51.7</td>
<td>49.9</td>
<td>92.0</td>
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<td>Sao Tome and Principe</td>
<td>5,353</td>
<td>5,040</td>
<td>Portuguese</td>
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<td>51.0</td>
<td>51.3</td>
<td>83.5</td>
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<td>Serbian, Albanian, Hungarian</td>
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<td>51.8</td>
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<td>95.1</td>
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<td>Sierra Leone</td>
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<td>76.6</td>
<td>50.1</td>
<td>50.5</td>
<td>89.7</td>
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<td>Suriname</td>
<td>3,896</td>
<td>3,831</td>
<td>Dutch</td>
<td>27.1</td>
<td>49.1</td>
<td>50.2</td>
<td>95.9</td>
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<tr>
<td>The Former Yugoslav Republic of Macedonia</td>
<td>5,921</td>
<td>2,887</td>
<td>Albanian, Macedonian</td>
<td>56.0</td>
<td>50.9</td>
<td>47.6</td>
<td>90.0</td>
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<td>Thailand</td>
<td>16,564</td>
<td>7,678,852†</td>
<td>Thai</td>
<td>64.1</td>
<td>50.9</td>
<td>51.9</td>
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<td>Uzbekistan</td>
<td>8,038</td>
<td>8,185</td>
<td>Uzbek, Russian</td>
<td>29.3</td>
<td>51.1</td>
<td>50.9</td>
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<td><strong>Total:</strong></td>
<td><strong>205,674</strong></td>
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</table>
Objectives

• Present estimates of children screening positive to the TQ, i.e. child has symptom of disability on 1 or more questions

• Describe children screening positive by socio-demographic variables: gender, age, ethnicity, place of residence, wealth, parental education

• Nutrition variables: Height-for-age, Breastfeeding, Vitamin A supplementation, Salt Iodization

• Education variables: current school attendance (children over 5)

• Child protection variables: child discipline

• To provide recommendations on the measurement of Child Disability via household surveys
Some results

Percent Screening Positive to any of TQ (95% CI)
Differentials by region: Sierra Leone

- Northern Region: 18%
- Eastern Region: 24%
- Southern Region: 37%
- Western Region: 14%
Additional findings

- Overall, little difference is reported in percent of children screening positive by age and sex.

- No consistent relationship between maternal education and screening positive across countries.

- Consistent relationship between household wealth and screening positive across countries in 12 out of the 18 countries with data on wealth.

- Sufficient salt iodization is not correlated with percent of children screening positive.
**Additional findings**

- Important association between screening results and malnutrition (stunting and underweight) among children 2-4, vitamin A supplementation and breastfeeding.

- School attendance is slightly higher among children who screen negative (15 out of 20), but differences are quite small and only exceed 5% in 2 countries.

- Children screening positive are significantly more likely to receive several physical punishment in 7 of the 15 countries with data on discipline but differences are quite small in most countries.
Recommendations for data collection post-MICS3

• Screening children for increased risks of disability using the TQ module as part of large scale household surveys like MICS is feasible

• Need for medical follow-up to validate data
  - TQ alone misused/misinterpreted as if to produce disability prevalence estimates

• For the fourth round of MICS (MICS4, 2010-2011), it has been recommended that only countries that have the capacity, resources and commitment to conduct the medical assessment will include the Disability Module in their surveys
Current status of surveys

Bhutan, Macedonia, Mongolia, Belize and Moldova have decided to proceed with collecting data on child disability, including the second stage of the assessment

- Bhutan (data collection for phase 1 and 2 and data entry completed, analysis almost completed)
- Macedonia (data collection for phase 1 completed, data collection for phase 2 ongoing)
- Mongolia and Belize (data collection for phase 1 completed, waiting to implement data collection for phase 2)
- Moldova (planning stage)
Some considerations and challenges

• Different profiles of interviewers used in Bhutan and in Macedonia for the second stage (medical/non-medical personnel)

• Different assessment tools were used across countries

• Timing issue of the data collection and length of the assessment (overall and per each child)

• Logistics (house visits versus facility-based assessment)

• The clinical evaluation proved to be expensive, time-consuming and challenging
Some considerations and challenges

• Variation in terms of difference between first and second screening results

• High levels of participation from families

• Involvement of different key partners/actors at the country level

• Capacity-building element for local staff

• Need to support countries in the planning and implementation of the medical assessment and to develop a standardized methodology that can be adapted at the country level

• Importance of second stage for treatment and follow-up
Next steps

• The Statistics and Monitoring Section of UNICEF NYQH is currently working on the development of a methodology, including protocols, tools, instructions, training programme/materials and analysis plan for the second stage of disability screening

  – Including: minimum qualifications for the interviewers, the steps to undertake before, during and after the screening in order to ensure quality of collected data, ethical codes, procedures for follow-up in cases where a form of disability is detected, etc.

• The guidelines and tools to be tested and finalized in 2012

• Additional work on the questionnaire for the first stage (cognitive testing, changes in age group, inclusion of new domains and changes in wording)
Discrimination may increase vulnerability to abuse and neglect

One of the main recent priorities for UNICEF has been to improve protection of children from violence, abuse, exploitation and discrimination. Children with disabilities are particularly prone to discrimination from the very individuals and institutions with an obligation to protect them, including families, health and education services, and the state.

This discrimination often leads to reduced access to basic social services, especially education, as well as a lack of recognition of their equal humanity by their families, peers and communities. They are also especially vulnerable to abuse, exploitation and neglect, due to the same misperceptions which result in other forms of discrimination, and due to their increased vulnerability as a result of their specific physical or intellectual difference.

To allow children with disabilities to claim their rights, the discrimination which stands in their way must be addressed. This approach is very much in line with the
Thank you!

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