

**United Nations Statistics Division  
United Nations Children's Fund  
Statistical Office of the European Communities  
Centres for Disease Control and Prevention  
of the United States of America**

ESA/STAT/AC.81/7-1  
24 May 2001

**International Seminar on the  
Measurement of Disability**

**New York  
4-6 June 2001**

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*Maureen Durkin:  
Measurement of Childhood Disabilities in Population  
Studies*



## **Measurement of Childhood Disabilities in Population Studies**

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Prepared for  
International Seminar on the Measurement of Disability  
United Nations Statistics Division  
New York  
4-6 June 2001

## **Introduction**

The need for information on the frequency of childhood disabilities in populations, as well as the status and characteristics of children with disabilities, has been emphasized repeatedly (1-7). For example, information on the number and status of children with mental retardation, learning, vision, hearing and seizure disabilities, and behavioral disorders is needed to monitor on a population level the impacts of: improvements in survival; exposures to nutritional deficiencies, environmental toxins, serious diseases and trauma; and interventions designed to improved child health and development. In addition, population-based, epidemiologic studies of childhood disabilities are needed for identifying risk factors and causes, and for needs assessments to facilitate planning of services for children and families with special needs.

In countries with reasonably well-developed services for children with disabilities, administrative data and registries provide a useful source of population-based information on childhood disabilities (8-10). However, in most low income or developing countries, where services for children with disabilities are not universally available, administrative data, if available at all, provide an incomplete account. Census data provide an alternative source of population data on disability, but it is likely that these data under-identify disabilities in children and especially in girls and children of low socioeconomic status (11). A third approach is the so-called 'key informant' approach, which relies on interviews with teachers, health care providers and other key persons in a community to identify children in the population with disabilities. This approach, however, has been shown to miss disabilities that are least publicly evident, such as cognitive and hearing disabilities and to include children from outside the population of interest (12). A fourth approach consists of household surveys. However, information on the validity of single-phase survey data on disabilities in children is lacking, especially in developing countries. In addition, instruments that have been used to survey childhood disabilities in developed countries are unlikely to be cross-culturally valid in developing countries.

The above considerations led to the development of a two-phase methodology for surveying childhood disabilities in populations where professional resources are extremely limited. This paper describes the methodology, presents data on its reliability and validity across culture, discusses its uses and limitations, and identifies areas for future research.

## **Two-Phase Methodology for Population-Based Studies of Childhood Disability**

### Phase 1: The Ten Questions Screen (Table 1, References 13-19)

Universal abilities, cross-culturally comparable.

Parental judgements.

Low cost, rapid.

2-9 year age range.

Not gender biased (15).

Read questions verbatim for each child.

Identifies high risk group.

Sensitive for cognitive, motor, seizure disabilities, not for vision or hearing unless previously identified.

### Phase 2: Comprehensive Assessment

Determines what type(s) of disabilities are present (20, 21).

Information on severity, causes, impairment, disability, participation, rehabilitation needs (20).

Referral to services (22,23).

### **Comparative Results From Three Developing Countries (Bangladesh, Jamaica & Pakistan)**

Percentage screening positive ranges from 7% to 19% in general populations, higher in clinical or high risk populations (Table 2, Figure 1, References 24,25).

Reliability: Acceptable test-retest and internal consistency across cultures (Table 3, Reference 24).

Sensitivity: Greater than 80% for serious cognitive, motor and seizure disabilities, lower for vision and hearing disabilities not previously identified, lower for mild disabilities (Table 4, Reference 25).

Specificity: Greater than 85% for any serious disabilities (Table 5, Reference 25).

Positive Predictive Value: Less than 30%, indicating need for second phase to confirm presence of disability among children screening positive (Table 4, Reference 25).

Cannot infer specific disability from screening result, need second phase assessment (26).

Can estimate prevalence with confidence intervals and investigate risk factors, even if sensitivity is low, using two-phase survey design (25, 27-33).

Links to services.

### **Limitations of the Ten Questions Screen & Two-Phase Design**

Not sufficient as a single-phase survey tool, second phase assessment required (26).

Parent report not sensitive for vision and hearing unless previously identified (25).

Not sensitive for mild conditions (25).

Phase-two assessments are expensive and may not be feasible in settings with extremely limited professional resources (25).

Analysis of data from two-phase design is difficult, requires advanced computer programs and training.

### **Future Work**

Home-based vision and hearing screening methodology (34,35)

Behavioral questions

Low cost assessment tools

Links with new International Classification of Functioning, Disability and Health (ICF)  
(36)

### **Conclusion**

A low-cost, rapid and cross-culturally valid method of identifying disabilities in children has been tested in epidemiologic surveys involving screening (using the Ten Questions) and clinical assessments of more than 22,000 children, ages 2-9 years, in Bangladesh, Jamaica and Pakistan. These surveys have generated estimates of prevalence that range from 10 to 44 per 1000 children for severe disabilities and up to 20% for mild disabilities. The prevalence of childhood disabilities in these populations varies with geographic variations in causes, risk factors and survival patterns. In addition to providing locally relevant information on frequency and causes, the surveys have resulted in the establishment of community-based rehabilitation programs in several populations.

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Table 1. **THE TEN QUESTIONS SCREEN FOR CHILDHOOD DISABILITY (ages 2-9 years)**

	<u>Circle One Response For Each Question</u>	
1. Compared with other children, did the child have any serious delay in sitting, standing or walking?	NO	YES*
2. Compared with other children does the child have difficulty seeing, either in the daytime or at night?	NO	YES*
3. Does the child appear to have difficulty hearing?	NO	YES*
4. When you tell the child to do something, does he/she seem to understand what you are saying?	NO*	YES
5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?	NO	YES*
6. Does the child sometimes have fits, become rigid, or lose consciousness?	NO	YES*
7. Does the child learn to do things like other children his/her age?	NO*	YES
8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?	NO	YES*
9. <u>For 3 to 9 year-olds ask:</u> Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?	NO	YES*
<u>For 2 year-olds ask:</u> Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?	NO*	YES
10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow?	NO	YES*

\* Screening result is positive if any one or more of the responses with an asterisk (\*) is circled.

TABLE 2. Number of children (ages 2-9 years) screened, frequency of positive screening results, and number of children clinically evaluated in the three populations.

	Bangladesh	Jamaica	Pakistan
<u>Number of Children Screened</u>	10,299	5,461	6,365
Screened Positive (%)	845 (8.2)	852 (15.6)	936 (14.7)
Referred for Evaluation	1,916	1,215	1,576
Clinically Evaluated (% of those referred)	1,626 (84.9)	994 (81.9)	1,363 (86.4)

TABLE 3. Reliability of the Ten Questions Screen for Childhood Disability in Three Countries.

	Bangladesh	Jamaica	Pakistan
Test-Retest Reliability  (kappa coefficients)			
Internal Consistency Reliability  (Chronbach alpha coefficients)			

TABLE 4. Sensitivity (95% confidence intervals) of the Ten Questions for detecting serious disabilities among 2 to 9 year-old children, three populations.

	Bangladesh	Jamaica	Pakistan
Cognitive Total	.82 (.40-1.0)	.53 (.20-.86)	.84 (.55-1.0)
Cognitive + Other Disability <sup>h</sup>	.74 (.23-1.0)	1.0 (.33-1.0)	.89 (.55-1.0)
Cognitive Only (not Accompanied by other Disability)	1.0 (.35-1.0)	.41 (.09-1.0)	.70 (.14-1.0)
Cognitive-Severe	1.0 (.13-1.0)	1.0 (0-1.0)	1.0 (.53-1.0)
Cognitive-Moderate	.78 (.32-1.0)	.49 (.17-.83)	.76 (.41-1.0)
Motor Total	1.0 (.54-1.0)	1.0 (.13-1.0)	.84 (.55-1.0)
Seizure Total	1.0 (0-1.0)	1.0 (0-1.0)	1.0 (.48-1.0)
Vision Total	.57 (0-1.0)	1.0 (0-1.0)	.59 (.28-.89)
Hearing Total	.46 (.12-.80)	1.0 (.35-1.0)	.70 (.14-1.0)

<sup>h</sup> Other disabilities include mild or serious motor, seizure, vision or hearing disabilities

Table 5. Validity of the Ten Questions as a screen for serious non-sensory (cognitive, motor and/or seizure) disability in three populations: sensitivity, specificity, predictive values and prevalence (95% confidence intervals).

	Bangladesh	Jamaica	Pakistan
<b>Serious Non-Sensory Disability</b>			
Sensitivity	.87 (.52-1.0)	.56 (.23-.88)	.85 (.63-1.0)
Specificity	.93 (.92-.94)	.85 (.84-.87)	.88 (.87-.88)
Positive Predictive Value	.09 (.07-.11)	.07 (.05-.09)	.18 (.15-.21)
Negative Predictive Value	1.0	.99 (.98-1.0)	.99 (.98-1.0)
Prevalence (/1000)	8.10 (5.43-10.77)	19.79 (9.51-30.07)	30.97 (24.24-37.70)
<b>Serious Non-Sensory Disability-Restricted<sup>H</sup></b>			
Sensitivity	.83 (.42-1.0)	1.0 (.43-1.0)	.88 (.64-1.0)
Specificity	.92 (.92-.93)	.85 (.85-.85)	.87 (.87-.88)
Positive Predictive Value	.06 (.04-.08)	.03 (.02-.04)	.15 (.13-.18)
Negative Predictive Value	1.0	1.0	1.0
Prevalence (/1000)	6.15 (3.63-8.68)	5.08 (3.02-7.15)	25.81 (20.00-37.70)

\* Includes all cases with serious cognitive, motor or seizure disabilities.

<sup>H</sup> Includes all cases of serious motor or seizure disability, but includes cases of serious cognitive disability only if accompanied by at least one other disability (mild or serious).