

# Measuring Environmental Factors and School Participation for Children with Disability

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## **Concept Note**

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## **Background**

The WG and UNICEF are currently working on the development of an extended set of questions on child disability that will focus on environmental factors and participation. The purpose of this set of questions is to provide information that can inform policy, to provide a statistical summary of environmental influences on participation in school, and to identify areas with key bottlenecks that can be followed-up on. The set of questions will be designed as a module that can be added to another survey and take approximately 10 minutes. The questions will focus on education through a formal mechanism and environmental factors that influence participation in that education. The questions will be designed to capture the interaction between the participant and the environment.

A brainstorming meeting was held at UNICEF Headquarters in NY in June 2013. The *UNICEF-WG Brainstorming meeting on facilitators and barriers to school participation for children with disability* aimed at understanding the different aspects related to the environment and disability within the context of school participation with the goal of identifying a conceptual framework that can guide the development of questions. Based on the discussion at the brainstorming meeting, a framework for the development of questions was drafted. Questions will be developed to assess four domains of barriers to school participation:

### **1. Attitudes**

This barrier includes parent's perceptions of disability, their perceptions of other's attitudes towards disability, societal and cultural norms, other children's attitudes towards disability, and school staff perceptions of disability.

### **2. Getting to school**

This barrier includes transportation - including the characteristics of all aspects of the system and the need for assistance-, environmental and social safety, and weather/seasonality.

### **3. Accessibility within the school**

This barrier includes physical accessibility (entryway, corridors, bathrooms, lunch room, classroom, common areas etc.), information accessibility, communication accessibility, programmatic accessibility/adaptability, and teacher and school attitudes towards disability.

#### **4. Affordability**

This barrier includes fees, costs, and competition for resources associated with attendance, the availability of types of assistance (financial, assistive devices, rehabilitation), and non-educational benefits (e.g., meals).

As a first step in the development of the extended set of questions, the WG and UNICEF identified the need to overview of tools which focus on environmental factors and participation of children with disabilities in school. The goal of the current project was to complete an in-depth review of survey tools looking at the effect of the environment on participation of children with disability in school with the goal of identifying and categorizing questions into the four domains. This includes studies conducted or commissioned by government, research institutions, international or regional organizations as well as NGOs in different parts of the world.

### **Measuring the Environment**

The International Classification of Functioning, Disability and Health (World Health Organization, 2001) and the social model of disability propose that the environment which those with physical, learning, or sensory impairments live will determine the extent of their participation. Environmental factors may act as barriers or facilitators to the participation of individuals. Disability then can be defined as a socially constructed experience explained by an absence or inadequate level of support provided by the external environment and the *UN Convention on the Rights of Persons with Disabilities* recognizes that environment factors are directly related to creation of disabilities (UN, 2006).

To understand problems encountered in school by students with disabilities, it is necessary to explore the interaction of the student and environmental factors involved in participation. The ICF provides a framework for defining set of participatory domains which are generally considered desirable and to which governmental resources might be directed. Five categories of environmental factors that influence participation are outlined in the International Classification of Functioning, Disability and Health: (1) Products and technology; (2) Natural environment and human-made changes to environment; (3) Support and relationships; (4) Attitudes; and (5) Services, systems and policies. The framework from the ICF are congruent with the four domains of environmental factors our working group has developed.

Measurement of the environment serves the purpose of gathering information about the environmental factors that facilitate or challenge participation. In the context of this project, measurement of the environment and participation can provide information that can inform policy, to provide a statistical summary of environmental influences on participation in school, and to identify areas with key bottlenecks that can be followed-up on.

### **Activities and Participation**

The ICF defines activity as the 'execution of a task' and participation as 'involvement in life situations' (WHO, 2001). The ICF does not use participation in the colloquial sense, referring to the participation with others or social involvement (McConachie et al., 2006). The ICF does not, however, include a well-defined distinction between the two, and lists domains of 'activities and participation' as one (Morris & Majnemer, 2012).

McConachie et al. (2006) list several important concepts which participation is not: (1) participation is not the environment; (2) participation is not quality of life; and (3) participation is not 'health utility'. While participation is certainly influenced by the environment- for example, a cafeteria which is inaccessible prevents a child from doing things within the cafeteria with other students- a measure of the environment alone will not capture whether the child is actually doing the same things as other children. Quality of life, is defined by the WHO, as the one's subjective perception of their life (1999). Third, participation is not health utility, which rates health on a scale and applies a social value (McConachie et al., 2006).

### Capacity, Performance, and Capability

The ICF classification qualifies participation and activities with the terms 'capacity' and 'performance'. Capacity refers to the best that a person can achieve in a standardized environment. Performance describes what a person does in their real life, influenced by environmental factors and personal factors (like choice). Environmental factors may also influence an individual's capability to participate. Capability refers to the opportunity, in contrast to whether the person can do (capacity), or does do (performance). Considering opportunity and choice is consistent with the intention that activities and participation are framed within a rights agenda alongside the UN conventions on the Rights of the Child (Morris & Majnemer, 2012) and should be incorporated in the measurement of activities and participation.

### Methods

We conducted a comprehensive literature search using PsycINFO and Google Scholar to identify measures with information about environmental factors that relating to children with disabilities participating in school in four domains: Attitudes, getting to school, accessibility within the school, and affordability. The following search terms were employed: environment, support, facilitator, barrier, attitudes, assessment, measurement, survey, self-report, participation, disability/ies. Searches were limited to documents in English.

Additionally, references lists from retrieved publications were reviewed to identify additional studies involving the development or use of environment measures. Experts in the field were contacted for feedback in identifying measures. We also reviewed the UNICEF database on disability data collection for questions regarding the environment as it relates to children with disabilities participating in school. This database includes censuses and population measures of disability used in large scale data collection in 137 countries. Finally, DHS surveys on school participation were reviewed for questions related to disability.

Only measures for which the entire instrument was available were retained. This search resulted in 31 measures which were obtained and retrieved for review. A list of measures reviewed can be found in Table 1. An inventory of questions was created in an Excel sheet; individual questions are organized by domain and listed by instrument under each domain. The question and response options are detailed. The full database is attached as "Annex 1" in the accompanying Excel Sheet.

### Results

The 32 measures were reviewed for relevant questions. Six-hundred sixty-eight questions were identified as related to environmental factors influencing children with disabilities participating in school. These questions

were grouped into the four themes: Attitudes, Getting to school, Accessibility within the school, and Affordability. Table 2 shows the frequency of questions for each instrument categorized under each theme.

## Basic Characteristics

Measures were primarily used in smaller scale research studies, and answered by a proxy respondent; typically the parent or primary caregiver. The year of publication ranged from 1986 to 2010. Surveys were administered in 20 different countries.

Many of the surveys used outdated definitions of disability, focusing on disability as a primary cause of lack of participation. For example, several household surveys included having a disability as a response option for why children were not attending school. Representative examples are included below:

Country	Time Period	Survey	Response options to the question: "Why is [child's name] not attending school?"
<b>Afghanistan</b>	2000	MICS2	<ol style="list-style-type: none"> <li>1. Schooling is too expensive</li> <li>2. School too far</li> <li>3. No adequate school</li> <li>4. Schooling not necessary</li> <li>5. No separate school for boys/girls</li> <li>6. Has to help in the household/home</li> <li>7. Has to support the household</li> <li>8. Child is sick/disabled</li> <li>9. Has sufficient schooling</li> <li>10. Other</li> </ol>
<b>Canada</b>	2001	Participation and Activity Limitation Survey, Canada	<ol style="list-style-type: none"> <li>1. Personal care such as feeding and toileting needed, but not available at school</li> <li>2. Teacher's aides or special education classes not available in regular school</li> <li>3. Special education school not available locally</li> <li>4. ( ....'s) condition or health problem prevented (him/her) from going to school</li> <li>5. ( .... ) is not ready or too young to attend school</li> <li>6. Other reason</li> </ol>
<b>Dominica</b>	2002	Survey of Living Conditions	<ol style="list-style-type: none"> <li>1. Illness/ disability</li> <li>2. Financial problems</li> <li>3. Failed exams</li> <li>4. Problems at school</li> <li>5. Other</li> </ol>
<b>Tanzania</b>	2008	Tanzania Disability Survey	<ol style="list-style-type: none"> <li>1. Disability</li> <li>2. Poverty situation of my family</li> <li>3. Environment of school conditions</li> <li>4. Transport allocation</li> <li>5. Distance to the school</li> <li>6. Lack of assistive devices</li> <li>7. Lack of Personal assistance/care</li> <li>8. Lack of disable school/class</li> </ol>

## Types of questions

Measures included questions from all four themes. Questions sampled a range of barriers within each theme. Sample questions from each theme are provided below.

<p><b>1. Attitudes</b></p> <p><b>In general, how do society’s standards of “appearance” influence your participation in activities?<sup>1</sup></b></p> <ol style="list-style-type: none"> <li><b>1. Help a lot</b></li> <li><b>2. Help some</b></li> <li><b>3. Have no effect</b></li> <li><b>4. Limit some</b></li> <li><b>5. Limit a lot</b></li> </ol>
<p><b>2. Getting to school</b></p> <p><b>Does your child normally need help in getting in and out of the house?<sup>2</sup></b></p>
<p><b>3. Accessibility within the school</b></p> <p><b>Because of your condition, DID you require adapted or modified building features to attend school?<sup>3</sup></b></p>
<p><b>4. Affordability</b></p> <p><b>Do you (ADULT CARE GIVER) receive any assistance in cash or kind to help you with your child?<sup>4</sup></b></p> <ol style="list-style-type: none"> <li><b>1. Yes, cash</b></li> <li><b>2. Yes, in kind</b></li> <li><b>3. Yes, cash and in kind</b></li> <li><b>4. No</b></li> <li><b>5. Don’t know</b></li> </ol>

Measures included both open-ended and closed-ended questions. Closed-ended questions took the form of rating scales, yes/no questions, and multiple choice questions. Representative examples for each are provided:

### 1. Open-ended

<sup>1</sup> Gray, D. B., Hollingsworth, H. H., Stark, S., & Morgan, K. A. (2008). A subjective measure of environmental facilitators and barriers to participation for people with mobility limitations. *Disability & Rehabilitation*, 30(6), 434-457.

<sup>2</sup> Mackie, P. C., Jessen, E. C., & Jarvis, S. N. (1998). The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child: care, health and development*, 24(6), 473-486.

<sup>3</sup> Statistics Canada (2012) Canadian Survey on Disability, 2012. Ottawa, Ontario: Statistics Canada.

<sup>4</sup> United Republic of Tanzania (2008). 2008 Tanzania Disability Survey. Dar es Salaam, Tanzania: Ministry of Health and Social Welfare.

**Examples:**

**Can you describe the barriers or constraints you deal with at school?<sup>5</sup>**

**What makes it EASIER to participate (perform) including products, technology (includes AT), person support, attitudes, natural environment, services, systems and policies?<sup>6</sup>**

**2. Closed-ended**

**a. Rating Scales**

**Examples:**

**I wouldn't mind if a handicapped child sits next to me<sup>7</sup>**

- 1. Agree**
- 2. Neutral**
- 3. Disagree**

**In the past year, to what extent do the people who work with your child help you feel competent as a parent?<sup>8</sup>**

- 1. To a Very Great Extent**
- 2. To a Great Extent**
- 3. To a Fairly Great Extent**
- 4. To a Moderate Extent**
- 5. To a Small Extent**
- 6. To a Very Small Extent**

**b. Multiple Choice**

**Examples:**

**I would now like you to consider all the places you need to go to, by car or other transport.**

**Which statement best describes your overall transport situation?<sup>9</sup>**

- 1. Can easily get to the places needed**
- 2. Sometimes have difficulty getting to the places needed**
- 3. Often have difficulty getting to the places needed**
- 4. Can't get to the places needed**
- 5. Never go out / housebound**

**How does the child with disability attend school or kindergarten?<sup>10</sup>**

- 1. On his or her own**
- 2. With a parent, by foot**
- 3. By transport provided by the government or an NGO**
- 4. By transport, at his or her expense**
- 5. Other**

**c. Yes/No**

<sup>5</sup> Pivik, J., McComas, J., & Laflamme, M. (2002). Barriers and facilitators to inclusive education. *Exceptional Children*, 69(1), 97-107.

<sup>6</sup> Eide, A., Nhiwaitiwa, S., Muderedzi, J., & Loeb, M.E. (2003). Living conditions among people with activity limitations in Zimbabwe: a representative regional survey. *Oslo: SINTEF Health Research*

<sup>7</sup> Olaleye, A., Ogundele, O., Deji, S., Ajayi, O., Olaleye, O., & Adeyanju, T. (2012). Attitudes of Students towards Peers with Disability in an Inclusive School in Nigeria. *Disability, CBR & Inclusive Development*, 23(3), 65-75.

<sup>8</sup> King, S., Rosenbaum, P. & King, G. (1995). *The Measure of Processes of Care MPOC*. Neurodevelopmental Clinical Research Unit, McMaster University and Chedoke-McMaster Hospitals, Hamilton, Ontario, Canada.

<sup>9</sup> Australian Bureau of Statistics (2006). General Social Survey, 2006: Questionnaire. Canberra: ABS

<sup>10</sup> UNICEF (2012). It's about Inclusion: Access to Education, Health and Social Protection Services for Children with Disabilities in Armenia. Yerevan, Armenia: Ministry of Labour and Social Issues of the Republic of Armenia

**Examples:**

***Can you use your transportation independently?<sup>11</sup>***

***Did you hide your child from around when you understood that your child was different?<sup>12</sup>***

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<sup>11</sup> Whiteneck, G. G., Charlifue, S. W., Gerhart, K. A., Overholser, J. D., & Richardson, G. N. (1992). Guide for use of the CHART: Craig handicap assessment and reporting technique. Englewood, CO: Craig Hospital.

<sup>12</sup> Baskanligi, O. I. (2002). Turkey disability survey. Ankara: Basbakanlik Yayinlari.

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Table 1. Measures included for review.

Assessment of Life Habits (LIFE-H)
Canadian Community Health Survey (CCHS)
Canadian Survey on Disability (CSD)
Chedoke-McMaster Attitudes Towards Children with Handicaps
Child and Adolescent Scale of Participation (CASP)
Child and Family Follow-Up Survey (CFFS)
Children Participation Questionnaire (CPQ)
Classroom Participation Questionnaire
Facilitators and Barriers Survey - Mobility (FABS/M)
Family Quality of Life Survey (FQOLS)
General Social Survey - Australia
Health and Activity Limitation Survey (HALS)
Healthy Kids Survey
Lifestyle Assessment Questionnaire (LAQ-CP and LAQ-G)
Living Conditions among People with Activity Limitations in Zimbabwe: A Representative Regional Survey
Measure of the Quality of the Environment (MQE)
Measures of Process of Care (MPOC-56)
National Disability Survey - Afghanistan
National Disability Survey - Ireland
National Household Education Survey (NHES)
Participation and Environment Measure for Children and Youth (PEM-CY)
Participation Survey - Mobility (PARTS)
School Setting Interview (SSI)
Service Obstacles Scale (SOS)
The Craig Handicap Assessment Reporting Technique (CHART)
The Craig Hospital Inventory of Environmental Factors (CHIEF)
The Participation and Activity Limitation Survey (PALS)
Tonga
Turkey Disability Survey
UNICEF 'It's about Inclusion Access to Education, Health, and Social Protection Services for Children with Disabilities in Armenia'
United Republic of Tanzania - Tanzania Disability Survey

Table 2.

Instrument (in alphabetical order)	Attitudes	Getting to School	Accessibility Within the School	Affordability
Assessment of Life Habits (LIFE-H)	0	7	9	0
Canadian Community Health Survey (CCHS)	13	0	0	0
Canadian Survey on Disability (CSD)	2	8	6	20
Chedoke-McMaster Attitudes Towards Children with Handicaps	36	0	0	0
Child and Adolescent Scale of Participation (CASP)	0	2	9	0
Child and Family Follow-Up Survey (CFFS)	4	2	6	3
Children Participation Questionnaire (CPQ)	0	0	12	0
Classroom Participation Questionnaire	0	0	28	0
DHS EdData Survey	8	3	5	24
Facilitators and Barriers Survey - Mobility (FABS/M)	11	7	16	0
Family Quality of Life Survey (FQOLS)	7	0	0	4
UNICEF for Children with Disabilities in Armenia	17	3	16	32
General Social Survey - Australia	6	6	0	2
Health and Activity Limitation Survey (HALS)	2	20	2	26
Healthy Kids Survey	0	0	20	0
Lifestyle Assessment Questionnaire (LAQ-CP and LAQ-G)	12	7	2	12
Living Conditions among People with Activity Limitations in Zimbabwe: A Representative Regional Survey	0	0	2	0
Measure of the Quality of the Environment (MQE)	0	3	10	0
Measures of Process of Care (MPOC-56)	15	0	15	0
National Disability Survey - Afghanistan	44	0	0	0
National Disability Survey - Ireland	<b>1</b>	<b>17</b>	<b>5</b>	<b>15</b>
National Household Education Survey (NHES)	0	0	5	0
Participation and Environment Measure for Children and Youth (PEM-CY)	0	0	0	0
Participation Survey - Mobility (PARTS)	0	7	0	0
School Setting Interview (SSI)	0	0	0	0
Service Obstacles Scale (SOS)	0	1	0	4
The Craig Handicap Assessment Reporting Technique (CHART)	7	7	0	5
The Craig Hospital Inventory of Environmental Factors (CHIEF)	0	2	0	3
The Participation and Activity Limitation Survey (PALS)	0	2	0	0
Tonga	0	0	0	2
Turkey Disability Survey	15	10	0	10
United Republic of Tanzania - Tanzania Disability Survey	13	7	0	8