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**EDUCATING CHILDREN WITH DISABILITIES  
IN DEVELOPING COUNTRIES:  
THE ROLE OF DATA SETS**

*Colin Robson, The University of Huddersfield  
with Peter Evans, The OECD Secretariat*



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# **Educating Children with Disabilities in Developing Countries: The Role of Data Sets**

*Colin Robson, The University of Huddersfield  
with Peter Evans, The OECD Secretariat*

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## **Introduction**

It appears highly likely that children with disabilities comprise one of the most socially excluded groups in all societies today. It has been estimated that 85 percent of the world's disabled children under 15 years of age live in developing countries (Helander, 1993). The brief provided by the World Bank for this study asserts that in developing countries, the "...vast majority of these children receive no education, are absent in school data sets, and invisible on the national policy agenda." In this situation the bringing about of change in nations' commitments to children with disabilities is critically dependent on the availability of data. This is the only route to the establishment of sound policies, strategic plans, and effective services and supports. Hence there is an urgent need to improve the quality and availability of international data related to the education of children with disabilities, in terms of coverage, reliability, and validity. Educational reform is crucially dependent on such data.

Given such initiatives and commitments on the part of developing countries there should be a corresponding commitment on the part of the World Bank and other funding bodies to providing the resources needed to realize such reforms.

In the absence of relevant data it will not be possible to ensure that children with disabilities are included in achieving the goals of two major global initiatives: Education for All (EFA), (see for example UNESCO, 2002) and the Millennium Development Goals (MDG), <http://www.developmentgoals.org>. The flow of international aid from multilateral and bilateral donors, regional banks, and other donor groups to the educational needs of children with disabilities is, in part, dependent upon having adequate, reliable, and valid data. Therefore, the main focus of this study must be on data sets which identify those children who have disabilities. Given good data on who and where they are, and on the nature of their disability, it becomes feasible to target educational and other services and programs. A secondary focus is on preschool and school data sets to establish the extent to which the children identified actually have access to education, permitting an assessment of the extent to which policy goals such as equitable treatment for boys and girls are being achieved.

## Defining Disability

A widely used term such as disability is likely to mean different things to different people. The international dimension of this study introduces the additional complexity of different languages. The translation of a term such as disability into other languages necessarily puts it into different linguistic and cultural contexts. Definitions do of course exist. A typical dictionary definition focuses on “want of power” linked with notions of weakness, incapacity, and disqualification. It is easy to stray from the purely descriptive to a pejorative usage, the avoidance of which, in part, explains the coining of alternative terms such as “differently abled.”

The United Nations, in providing recommendations for the conduct of national censuses defines a person with disability as:

*A person who is limited in the kind or amount of activities that he or she can do because of ongoing difficulties due to a long-term physical condition, mental condition or health problem (United Nations, 1998).*

The World Bank Disability Group’s Web site <http://wbln0018.worldbank.org> provides a section on Defining Disability:

*Defining what is meant by disability is sometimes a complex process, as disability is more than a description of a specific health issue; rather it is affected by people’s cultures, social institutions, and physical environments. The current international guide is the World Health Organization’s discussion and classification within ICF: International Classification of Functioning, Disability and Health. ICF presents a framework which encompasses the complex multifaceted interaction between health conditions and personal and environmental factors that determine the extent of disablement in any given situation.*

This does not in itself provide a definition, though it does provide a reference to the ICF framework discussed below. It provides, too, an important reminder that disability is not simply a health issue. In particular, there is a complex interaction between social institutions and health conditions that determine the extent to which a person is actually disabled, or not able to do something.

The ICF model views disability as “...the umbrella term for any or all of an impairment of body structure or function, a limitation of activities, or a restriction in participation” (AIHW, 2002; see also WHO, 2001:6). This approach has the advantage of including environmental factors, the lack of attention to which was strongly criticized in its predecessor classification, ICIDH: International Classification of Impairments, Disabilities and Handicaps (Bickenbach, et al., 1999 provide an account).

ICF essentially follows a top-down model. A group of experts, assisted by representative disability organizations, have produced a highly complex classificatory scheme with components of Body Functions and Structures, Activities and Participation, and Environmental Factors, each of which is comprised of various domains. This is used to provide a coding. Thus, as an example:

*The code recorded for a person experiencing moderate difficulty changing body position is d410.28, where:*

- *d denotes the component, in this case Activities and Participation.*
- *the first digit (4) denotes the chapter or domain, i.e., Mobility.*
- *the 2nd and 3rd digits (10) denote the 2nd level category, i.e., Changing basic body position.*
- *the first digit after the decimal point (2) denotes the uniform qualifier, indicating there is moderate difficulty with performance.*
- *the second digit after the decimal point (8) indicates that capacity is not specified.*

Notwithstanding its complexity if ICF were to be fully implemented, the tri-partite categorization of impairment (loss or malfunction at the level of organ or body part), activity limitation (work, school, self-care, or social interaction, and generally activities of daily living), and handicap (defined contextually in connection with survival roles), underlies much of the efforts to obtain national and international data sets in the disability field. Note, however, that there is much inconsistency in the use of these terms. In particular, the usefulness of making a distinction between disability and handicap is queried (e.g., Edwards, 1997) in that essentially external causes underlie both.

Zinkin and McConachie (1995) recommend the definitions agreed by disabled people's organizations:

*In essence, "impairment" is an individual limitation, whereas "disability" is restriction imposed by the current organization of society. "Impairment" is defined by WHO (1980a) as "any loss or abnormality of psychological, physiological, or anatomical structure or function." Making descriptions at the level of the impairment allows focus on the individual child and her/his needs as an individual. When the emphasis is on children with impairments as a social group (original emphasis) we have used the term "disabled children," defining disability as the disadvantage or restriction of activity caused by contemporary social organization which takes little or no account of people who have ... impairments and thus excludes them from participation in the mainstream of social activities (UPIAS 1976, Finkelstein 1993) (p. xi).*

Jonsson and Wiman (2001), in another World Bank publication on *Education, Poverty and Disability in Developing Countries*, point out that:



*The relevant terminology used in the education sector has changed dramatically during the last decades. The narrow disability based classifications and the resulting labelling of children are being replaced by wider definitions such as “disadvantaged children,” “children in especially difficult circumstances” or “children with special educational needs.” These broader terms include the whole range, from profound disabilities to minor difficulties in performing necessary functions (p. 3).*

The educational focus is valuable for the present study, but their approach runs the risk of conflating very different phenomena. The Organization for Economic Cooperation and Development (OECD) reported in a monograph (OECD, 2000a) and summarized in issues of the publication *Education at a Glance* (OECD, 1998; 2000b), separates out three cross-national categories currently referred to as disabilities, learning and behavior difficulties, and social disadvantages (OECD, 2003). These categories are derived from categories used in the collection of national educational statistics on children for whom additional resources are provided to enable them to access the regular school curriculum.

This type of resources definition is clearly wider than a more traditional medically based approach and is attractive as a means of operationalizing the broad educationally relevant definition advocated by Jonsson and Wiman (2001). However, it is based on data from the industrialized countries that constitute OECD, with the initial development of the instrument used in these studies incorporating pilot work in developing countries (OECD, 2000a; chapter 2).

This brief overview of some issues in defining disability for this study reinforces the stance taken by Fujira and Rutkowski-Kmitta (2001) in a detailed and insightful analysis of the issues involved in *Counting Disability*. Their chapter in the definitive *Handbook of Disability Studies* (Albrecht, et al., 2001) “challenges the validity or utility of a universally applicable or singular definition of disability” (p. 69). They reiterate the argument of Zola (1993) that “...how one chooses to define and thus count disability should largely be driven by the purposes of the count” (p. 78). Their approach that “focus is determined by function” recognizes that “counting disability is a ‘political arithmetic’ used to galvanize awareness of the relationship between society and disablement” (p. 93).

Several existing national systems for collecting data on disability have stated purposes similar to the purposes of the current study. For example, the Central Registry for Rehabilitation in Hong Kong aims “To facilitate provision of services and to assist in their reaching out to people with a disability” (Health and Welfare Bureau, 1995). In similar fashion, The National Intellectual Disability Database in Ireland is concerned “To provide information for decisionmaking in relation to the planning, funding, and management of services” (Health Research Board, 1997).

Given that the main purpose of this study is to foster the inclusion of children with disabilities in the educational systems of developing countries, the approach to disability adopted has to:

- Be appropriate for counting children;
- Have educational relevance
- And, above all, be feasible for use in developing countries.

Hence, rather than adopting a single explicit definition of disability, these considerations will be borne in mind throughout the report.

### **Types of Disability Data Sets**

The following account does not purport to provide a comprehensive review of all existing data sets in the general field of disability. It attempts to cover examples of data sets that appear to be of likely relevance to the purposes of this study.

Three main types of system for the collection of population level data on disability exist in the forms of national censuses, household surveys, and administrative registries.

#### *National Censuses*

Because of the great cost and substantial data demands of comprehensive national coverage in a census where the attempt is made to enumerate every person in a national population, the detail and depth of any questions about disability are severely limited. Nevertheless, there is a strong case for all national censuses to include a section on disability, and for this to cover childhood disability in order to help ensure that childhood disability becomes visible on the national policy agenda. The infrequency of national censuses limits their value as a tool for planning services and programs. Few of the censuses whose data are presented in the most recent version of the United Nations disability statistics database, which is itself still in preparation, DISTAT-2 (see Mbogoni and Me, 2002: Appendix 2), are less than 10 years old and several date from the 1980s or earlier.

Box 1 presents some of the advantages and disadvantages of using a national census to collect data on disability. An additional advantage of using a census is that it has the ability to examine the impact of different types of disability. The number of respondents is large enough to allow for this type of cross-comparison.

## *Box 1 Advantages and Disadvantages of Using a Census to Collect Data on Disability*

### **Advantages**

- 1. To provide small areas data.* The census is the only data collection activity nation-wide that can provide detailed data at the level of the smallest geographic area. Data collected through surveys can hardly be used to estimate disability prevalence even at the smallest level of geographical detail due to the limited sample size and the related sample errors. Data for program development and analysis at local level can only be collected through a census or a registration system, which is available only in a very limited number of countries.
- 2. To provide data to compare persons with disabilities and persons without disabilities.* Every census collects data on living arrangements, employment, and education and if these characteristics are tabulated for persons with and without disabilities, different levels of participation related for example to education and work and employment can be easily measured.
- 3. To allow for time-series analysis.* It is common in many countries that a census is undertaken on a regular basis, every five or ten years. If data on disability are collected in several censuses, time-series analysis can be performed in relation to disability prevalence rates and participation data.
- 4. To use as a sample-frame for a follow-up survey.* Several countries, e.g., Canada, France, and New Zealand, have used the census to establish a sample frame for follow-up specialized surveys. In countries where a specialized disability survey is planned, persons identified through the screening module included in the census can provide a frame to more effectively design a sample frame for a more detailed survey on disability.

### **Disadvantages**

- 1. Measuring the continuum.* Disability is not a phenomenon that can be easily described with a binary classification yes/no. It is rather an experience that needs to be measured in a continuum to consider several issues such as intensity, duration, and environment. It is important that the instruments used be able to capture as much as possible the different points on this continuum. In this context the design of the question(s) used as a screener to identify the target population with disability should be carefully studied to be sure they do not exclude part of that population. To measure the complexity of this continuum, multiple questions to set context, clarify terminology, and define multiple domains are required. This aspect is particularly difficult in a census where the number of questions asked is restricted.
- 2. Need for extensive training of enumerators.* The main focus of a census is the total counting of the population and their social and demographic characteristics. The collection of data on disability requires extensive training of enumerators on how to ask the questions, which may not be possible in a census.
- 3. Special Population Groups.* The use of a short question in a census tends to underestimate special population groups such as, children, elderly, persons with cognitive and psychological impairments. Specialized surveys where longer instruments can be used are more suitable to measure disability in these sub-population groups.
- 4. Use of proxy.* Censuses have an extensive use of proxy respondents.

Adapted from Mbogoni and Me (2001; Appendix 1),

In addition to the concerns discussed above about the impact of different approaches and terminology on prevalence rates, there are worries about the quality of census questions used to identify disability in terms of reliability and validity. Such testing as has been done in Australia (Davis and Gligora, 2001); Canada (Langlois, 2001) and the United States (McNeil, 1993) has not been encouraging. The Australian study, for example, led to a decision not to include any disability questions in the 2001 census as they did not reach criterion requirements for reliability and validity.

Although such studies provide valuable pointers toward improving validity and reliability, they are all in industrialized countries. Me and Mbogoni (2001) have analyzed the data available in DISTAT-2. They find that “person-level” questions (i.e., requesting information about individual household members) is associated with higher reporting of disability than “household-level” questions (i.e., is there anyone in this household who ...). Hess, et al., (2001), comparing the two types of question in a United States study, although replicating the finding, also reported that household-level questions produced more reliable data than the person-level approach, and in a shorter interview time. However, Mathiowetz and Lair (1994) find that household-level reports of functional limitations are higher than self-reports. Overall this is an area wherein the research base is weak and many of the factors likely to affect the reporting of disability are poorly understood,, particularly when the focus is on childhood disability in developing countries.

### *Household Surveys*

Household surveys involve the systematic sampling of households with the sample so constructed that it is possible to arrive at an estimate of the feature of interest. Such a survey could focus solely on disability issues, but it is more likely that these would be embedded within a more wide-ranging study, typically of general health issues. Examples include the National Health Interview Survey (NHIS) for the United States; an annual survey of health and health care (National Center for Health Statistics, 1998). Questions on activity limitations and the presence of acute or chronic health conditions permit some assessment of disability. A 1996 survey of the West Bank in Palestine is a similarly structured one-off example (Palestinian Central Bureau of Statistics, 1996).

Surveys of this type depend for their reliability and validity on the construction and implementation of well-designed, statistically representative, sampling frames, and high rates of response. They are resource intensive when the large scale samples needed to obtain accurate population estimates are employed, and the detail of disability related questions is likely to be severely limited. Box 2 lists some of the advantages and disadvantages of using a survey approach, but note that the issues covered here are not disability-specific. They typically apply regardless of the specific topic of the survey.

## Box 2 Advantages and Disadvantages of Questionnaire Based Surveys

### **Advantages**

#### General to all surveys using respondents

1. They provide a relatively simple and straightforward approach to the study of attitudes, values, beliefs and motives.
2. They may be adapted to collect generalizable information from almost any human population.
3. High amounts of data standardization.

#### Postal and other self-administered surveys

- 4 Often this is the only, or the easiest, way of retrieving information about the past history of a large set of people.
5. They can be extremely efficient at providing large amounts of data, at relatively low cost, in a short period of time.
6. They allow anonymity, which can encourage frankness when sensitive areas are involved.

#### Interview surveys

- 7 The interviewer can clarify questions.
- 8 The presence of the interviewer encourages participation and involvement (and the interviewer can judge the extent to which the exercise is treated seriously).

### **Disadvantages**

#### General to all surveys using respondents

- 1 Data are affected by the characteristics of the respondents (e.g., their memory; knowledge; experience; motivation; and personality).
- 2 Respondents won't necessarily report their beliefs, attitudes, etc. accurately (e.g., there is likely to be a social desirability response bias - people responding in a way that shows them in a good light).

#### Postal and other self-administered surveys

- 3 Typically have a low response rate. As you don't usually know the characteristics of nonrespondents, you don't know whether the sample is representative.
- 4 Ambiguities in, and misunderstandings of, the survey questions may not be detected. .
- 5 Respondents may not treat the exercise seriously, and you may not be able to detect this.

#### Interview surveys

- 6 Data may be affected by characteristics of the interviewers (e.g., their motivation; personality; skills; and experience). There may be interviewer bias, where the interviewer, probably unwittingly, influences the responses (e.g., through verbal or nonverbal cues indicating "correct" answers).
- 7 Data may be affected by interactions of interviewer/respondent characteristics (e.g., whether they are of the same or different class or ethnic background).
- 8 Respondents may feel their answers are not anonymous and be less forthcoming or open.

*Notes: Advantages 4 and 5 may be disadvantages if they seduce the researcher into using a survey when it may not be the most appropriate strategy to answer the research question(s).*

*The telephone survey is a variation of the interview survey which does not involve face-to-face interaction and has rather different advantages and disadvantages.*

Adapted from Robson (2002; pp. 233-4).

Surveys incorporating disability related questions can be on an annual or other regular basis, permitting the assessment of change or trend. An alternative is to have a regular general survey wherein more extensive disability related questions are included from time to time. The Health Survey for England (Department of Health, 1995) is an example of this approach.

There are disability-specific household surveys, though these are typically on a one-off basis or at relatively infrequent intervals. Examples include the five yearly National Survey of Disability, Ageing, and Carers in Australia (Australian Bureau of Health and Welfare, 1998), and the 1987 National Sampling Survey of Disability in China (Bureau of Statistics, 1990), which surveyed 1.6 million persons.

General health surveys in which disability questions form a minor part will be likely to present similar validity and reliability problems to those noted above in relation to censuses. Disability-specific household surveys can, in principle, avoid such problems, although question wording will require careful consideration and adequate pretesting. Durkin (2001), who has devised such an instrument (Durkin, et al., 1994, discussed below in Appendix 2), has carried out studies on validity, reliability, and sensitivity of survey questions in three developing countries in relation to child disability.

### *Service Registries*

This is an administrative record of the numbers of persons in receipt of a service or benefit. The most common forms are adult health and employment programs, and children's educational and social services. A large scale example is the Mexican Registration of Children with a Disability (*Instituto Nacional De Estadistica Geografia e Informatica*, 1998). Children of all education levels (2.7 million in 1995), from preschool upwards, are identified by type and number of disabilities together with basic demographic and socioeconomic indicators.

This type of record has the advantage that it is commonly collected routinely for administrative purposes. With current emphases on accountability, there is a strong argument for countries having good data on the recipients of services and benefits. It is, however, highly problematic for population level demographics, or for making cross-country comparisons (the number of children registered will be a complex function of the types of programs, the eligibility rules, and how positively the programs are perceived by the population). Even in industrialized countries, only a fraction of persons with a disability are typically in receipt of a service or benefit. Fujiura (1998) estimates, for example, that in the United States, only 11 percent of persons classified as "mentally retarded" are served by the long-term residential care system. This is, of course, not to assert that such persons should be in a residential care system, only that the numbers in the system do not provide a reliable population indicator. In developing countries it would be anticipated that discrepancies would be large. For example, in Mauritius, the 1990 census identified nearly 28,000 persons with a disability. Half of them were in receipt of disability pensions but only 400 received services from rehabilitation programs (United Nations, 1996:20).

The countries doing the most for children with disabilities inevitably appear to have the highest rates of disability. This may affect the willingness of government administrators to classify children as disabled.

Service records are, nevertheless, useful and important in providing information on who gains access to services and programs. The OECD study discussed above (OECD, 2000a; 2003) demonstrated, for example, that across a wide range of categories of not only disability, but also learning and behavior difficulties and social disadvantages, there is overrepresentation of male children in both special and regular school classrooms (typically a 60%/40% male/female split). This clearly raises important equity issues, discussed below.

### *Other Approaches*

Other methods of data collection have been employed. For example:

Key informant surveys, which involve asking key people in the community, such as community leaders, teachers, and midwives, to identify all disabled persons in their community. This approach is attractive as low cost and feasible in developing countries. However, the method has been shown to be inaccurate when tried in various countries with serious underestimation of less physically obvious conditions (e.g., Belmont, 1984; Thorburn, 1993).

Cohort studies include organized longitudinal studies which follow a birth cohort, typically of several thousand children (e.g., Davie, et al., 1972; Stewart-Brown and Haslum, 1988). They are heavily resource intensive and effectively ruled out because of this in developing countries.

### *Examples of Disability Data Systems and of the Results They Produce*

Table 1 provides a selection of disability data systems. They are classified by the type of data collection, and also by the concept of disability on which they are based (impairment, activity restriction, or handicap, as proposed in the ICF framework discussed above). This selection reflects the fact that most disability data systems are based on impairments and restricted activities. In the developing world, systems based on impairment predominate. Where comparisons are possible, the different types of definition produce relatively consistent differences in population estimates. For example, handicap type definitions typically produce lower estimates than activity restriction definitions. Impairment definitions are employed by countries reporting the lowest rates of disability.

This is reflected in United Nations figures for relatively recent censuses (1990 or later) reported in the United Nations Disability Statistics Database (DISTAT). A revised version (DISTAT-2) is currently being prepared, selections from which appear as Appendix 2 in Mbogoni and Me (2003). It is based on national censuses and surveys. Available data can be seen on-line together with a full list of the questions used to identify persons with disabilities (United Nations, 2003). It shows disability rates ranging from 0.35 percent in Thailand (1990) and 0.48 percent in Nigeria (1991), through 1.22 percent in Tunisia (1994), 5.55 percent in

Aruba (1991), 6.57 percent in Belize (1991), 7.56 percent in Bermuda (1991), to 12.15 percent in the United Kingdom (1991). It should be noted that the methodologies for obtaining these estimates differ considerably in method of data collection, type of definition, and date of the study.

*Table 1 Selected International Disability Data Systems by Disability Definition and Form of Data Collection*

<b>Form of Data Collection</b>			
<b>Disability Concept</b>	<b>Census</b>	<b>Household survey</b>	<b>Administrative registry</b>
Impairment	Population Census; 1981 (Bahrain) 1980 Census (Comoros, Kuwait, South Africa, Zambia) 1981 Census (Brazil, Hong Kong, Pakistan) 1982 Census of Disabled (Cyprus) Census of Population, 1992 (Cyprus) 1985 Census (Turkey) 1986 Census (Bangladesh, Qatar) 1987 Census (Mali) 1988 Census (Poland) 1990 Census of Population and Housing Taiwan-Fukien Area (Taiwan) 1990 Census (Panama) 1990 National Census of Population and Housing (Mauritius) 1991 Census (Aruba) 1992 Census (Paraguay) 1994 Census (Jordan) 1996 Census of Population and Dwellings' (New Zealand).	1983 Survey (Malawi) 1985 Survey (Singapore) 1989 Health Survey (Cyprus) 1994 living Condition Survey (Latvia) Accompanying Survey to the General Population and Housing Census of 1994 (Jordan) Household Survey, 1996-1997 (Mozambique) Ministry of Labor Survey (Japan) National Sampling Survey of Disability (CHN) (Thailand) j National Survey of Handicapped, 1981 (India) National Survey of Handicapped Adults (Japan) Survey of Disability (Northern Ireland)	1989 registry (Bulgaria) Benefits on Social Insurance Basis (Estonia) Registration system of disabled persons, 1991 (Germany) Registry of Children with a Disability (Mexico)
Activity restriction	Dicennial Census (United States) Health Survey 1989 (Cyprus) Population census, 1981 (Sri Lanka) Population census, 1975 (Turkey)	Survey of the Chronically III (Uruguay) 1996 Health Survey in West Bank and Gaza Strip (Palestine) 1996 Household Disability Survey (New Zealand) Health and Activity Limitation Survey (CAN) National Health Interview Survey (United States) National Health and Medical Survey, 1979.1981 (Egypt) National Survey, 1981 (Zimbabwe) Surveys of disability in Great Britain, 1985-1986 (England) Survey of Income and Program Participation (United States)	Disability Register of the State Social (Iceland) National Disability Unit (Barbados) RSA-11 (United States)
Handicap	1996 Census of Population and Housing (Australia)	1995 National Health Survey (Australia) National Disability Survey, 1988 (Australia) Survey of Disability, Ageing, and Carers, 1993, 1998 (Australia)	

From Fujiura and Rutkoski-Kmitta (1995; Table 2.2, p.76).



If comparison is restricted to national estimates of disability taken from impairment based national censuses, as shown in Table 2, the variability in estimation is substantially reduced. A similar convergence, but at much higher values, appears in major national surveys, mainly carried out in industrialized Western nations, which assess limitation prevalence. These are summarized in Table 3. Note that the number of “domains” (areas of activity) included varies from study to study.

*Asking Different Questions Produces Different Answers*

The above discussion makes it clear that there is a lack of uniformity in the questions used by countries to identify the population with disabilities and, linked to that, a lack of uniformity in the definition of disability employed. And that these differences are systematically related to the estimates of prevalence obtained. It is not only the type of question, but its exact wording, the context in which it is asked, and the order in which questions are asked that affect the answers received. All this is clearly a problem from the perspective of making valid international comparisons of prevalence rates in different countries. As discussed in the preceding section on defining disability, it is necessary to take note of the purpose to which a definition will be put in deciding its appropriateness. This issue is returned to in the final section of this report.

*Table 2 Disability Prevalence Estimates Based on Impairment Definitions*

<b>Region</b>	<b>Percentage Rate</b>
<b>Africa</b>	
South Africa (1980)	0.6
Zambia (1980)	1.6
Botswana (1991)	2.2
<b>Asia</b>	
Sri Lanka (1981)	0.5
Bangladesh (1986)	0.5
Hong Kong (1981)	0.8
<b>Central and South America</b>	
Panama (1990)	1.3
Brazil (1981)	1.7
<b>Middle East – Crescent</b>	
Qatar (1986)	0.2
Egypt (1976)	0.3
Kuwait (1980)	0.4
Pakistan (1981)	0.5
Iraq (1977)	0.9
Syria (1981)	1.0
Turkey (1985)	1.4
Bahrain (1981)	1.7

*Source:* DISTAT (United Nations, 1996); National censuses. (Definition classification after Fujiura and Rutkowski-Kmitta 2001; p. 81).

Table 3 Limitation Prevalence by Nation

Nation	Domains	Limitation Rate (percent)
Australia (1993) <sup>a</sup>	Self-care, mobility, verbal communication, school, employment	14.2
Canada (1986 HALS)	Mobility, agility, seeing, hearing, speaking	13.2
New Zealand (1996 HDS)	Walking, moving, carrying, standing, bending, reaching, dressing, getting in or out of bed, grasping, hearing, seeing, and cognitive impairments.	19.0
Spain (1986)	Seeing, hearing, speaking, personal care, walking, climbing, running, out of home, other activities of daily living, behavioral problems.	14.9
United Kingdom (1986 HSE)	Seeing, walking, bending, dressing, washing, eating, communication, hearing, personal care, climbing.	14.2
United States (1990-1991 SIPP) <sup>b</sup>	Seeing, hearing, speaking, walking, climbing, running, out of home, lifting and carrying.	17.5

a. Excludes canvas of impairments.

b. Functional limitations definition.

Source: Fujiura and Rutkoski-Kmitta (1995; table 2.8, p.83).

### Qualitative Studies on the Lives of Children in Developing Countries

Qualitative studies enable the experiences and feelings of people to be explored, permitting an understanding of their lives not accessible by means of quantitative surveys or other data collection techniques resulting in numerical information only. A wide variety of methods can be used, including the use of relatively unstructured interviews, focus groups or other group interviews, participant observation, and so on. Such studies are particularly important for marginalized groups such as children with disabilities in developing countries. In studying disabled childhood there is a tendency to rely on the views of parents, teachers, and other professionals, hence denying the voice of the child.

Shakespeare, et al., (2000) describe an ongoing qualitative study of life as a disabled child through the children's own experiences and perspectives. They focus on disabled children between 11 and 16 and include children with a wide range of physical, mental, and sensory impairments and who are from a range of backgrounds, in both inclusive and segregated settings. They aim to examine the role of structural factors, social settings, cultural contexts, and policy implementation by shedding light on all aspects of the lives of disabled children, their relationships with family, peer group and adults, their experiences at home, at school, and in leisure. Although their study is based in England and Scotland, the central features of their approach are applicable in all contexts, including developing countries.

The organization Save the Children (<http://www.savethechildren.org.uk>) has made outstanding efforts in this area and has practical manuals on carrying out such projects, for example Learning to Listen and Children and Participation. A booklet, *Children's Statements*, based on interviews with children involved in various Save the Children projects throughout the world, shows the profound sense of exclusion experienced by children who are disabled.

The United Nations Convention on the Rights of the Child (CRC) places great emphasis on the participation of children and the disabled in decisionmaking (Committee on the Rights of the Child, 1997). Regional meetings have been proposed "...to which disabled children and young people, and local disability organizations would be invited to present their experiences of respect or lack of respect for their rights, what they would like to see changed and their suggestions for further action" (Committee on the Rights of the Child, 1999; p. 50).

## **Data Sets and Classificatory Frameworks Produced by or Associated with International Organizations**

This section reviews and critiques the data that the World Bank and other international organizations are collecting regarding children with disabilities and their education. The main international organizations involved, apart from the World Bank, are the United Nations (particularly its Statistics Division), UNICEF, UNESCO, OECD, the European Community (particularly through its statistical arm, EUROSTAT, and WHO (primarily through the development of classificatory systems, including ICF).

Other potentially relevant organizations, briefly reviewed at the end of this section, include DHS (Demographic and Health Surveys), SIMPOC (an offshoot of the International Labor Organization, ILO, concerned with monitoring child labor), Development Banks (e.g., The Inter-American, African, and Asian Development Banks). There are also umbrella organizations such as the Washington Group on Disability Statistics and the PARIS21 Consortium (Partnership in Statistics for Development in the 21st Century), which bring together different organizations with interests in disability and development statistics respectively.

### *The World Bank*

The section on "Primary Data Documentation" in the World Bank publication on *World Development Indicators* (World Bank, 2002) makes it clear that:

*The World Bank is not a primary data collection agency for most areas other than living standards and debt. As a major user of socioeconomic data, however, the World Bank places particular emphasis on data documentation to inform users of data in economic analysis and policymaking. (p. 381)*

Relevant data and statistics to this study are available in the "EdStats" pages of the World Bank Web site <http://www.worldbank.org/data/>, which present country-specific and themed data, regional indicators, and links to other sources. It concentrates on making a variety of national and international data sources from the United Nations Institute for Statistics (UIS), and the OECD, available in one location.

There are extensive tables giving country profiles in respect of Education for All (EFA) and thematic data on progress in relation to the Millennium Development Goals (MDG) discussed below. Note, however, that these data sets do not include information about disability,

although it appears that there is existing disability information that could be included. For example a Lesotho national report includes a disability question, but data on this are excluded from the World Bank country profile (see <http://www1.worldbank.org/education/edstats/>, Education for All 2000 assessment, country specific data).

The link to “Children with disabilities” leads to United Nations and United States disability sites discussed below, and hence gives no new or additional information on children with disabilities and education. Similarly, a section on Vulnerable Children and Children with Disabilities, in material on Early Child Development (ECD) covers relevant reports from other organizations; for example “Early intervention and education for children and youth with disabilities into the twenty-first century: situation in the Asian and Pacific region” (UN Economic and Social Commission for Asia and the Pacific – ESCAP).

There is, however, recognition that the World Bank needs to be more proactive in this area. The call for the production of the present review results, presumably, from this. A recent meeting on Educating Children with Disabilities in Developing Nations (Scofield and Fineberg, 2002), to which Judith Heumann, recently appointed Disability and Development Advisor at the World Bank, and Robert Prouty, World Bank Lead Education Specialist, contributed, brought up lack of data as a key concern, regretting the fact that there are virtually no data on disability at the World Bank.

It should be stressed that there are of course other relevant World Bank activities apart from data collection. There is extensive material on Statistical Capacity Building, where technical assistance is offered to member countries on creating an adequate statistical base for the analysis of economic, financial, and social developments necessary to guide policy making. The World Bank also supports projects which serve persons with disabilities, and projects in this area are currently growing in number.

For example, in the education area, several projects have components that benefit persons with disabilities. They include:

- India Basic Education and District Primary Education Projects, which assists primary school teachers in the project districts in identifying and assessing children with disabilities and developing inclusive programs for their education.
- India Technician Education Project, which establishes two polytechnic institutions that are designed for students with disabilities.
- Nepal Second Basic and Primary Education Project, which supports inclusive education of children with nonsevere disabilities in primary schools.
- Yemen Vocational Training Project, which finances subprojects for vocational training and rehabilitation of persons with physical disabilities.
- Brazil Project on Education.

Various World Bank sponsored reports also are relevant. Metts (2000) contributed a lengthy report "...intended to provide the World Bank with the information and insights necessary for policy formulation and strategic planning in the area of disability" (p. ii). Although there are some data, the concern is primarily with policy formation. Lynch (1994) includes more data and is based on "...desk studies, documentary searches and 15 case studies of primary schooling for children with special educational needs in the Asia region" (p.1). "Special educational needs" is interpreted widely to include "impairments and other disadvantages." There are several papers on poverty and disability (e.g., Elwan, 1999) and a particularly useful one on "Education, Poverty and Disability in Developing Countries" (Jonsson and Wiman, 2001). It provides examples of the school enrollment rates of disabled children in some developing countries, reproduced below as Box 3.

*Box 3 Examples of Disabled Children's School Enrollment Rates*

**Philippines (1997)**

Department of Education enrollment records 1997-8 indicate that of 3.5 million disabled children of school-going age only 40,710 are actually enrolled in schools (1.16%). In the Asian Pacific Region the overall enrollment rate of disabled children is estimated to be less than 5 percent.

(V. Ilagen (2000) "Inclusive Education in the Asian Pacific Region: Are the Disabled Included?")

**Mozambique, Maputo Province (1997)**

Out of the total of 170,000 children attending regular schools, 1,167 were children with special educational needs (0.7%).

(E. Lehtomaki, L Chiluvane and I Viniche (2000) "Case Strengthening Social Networks in and around the School: Experiences in Maputo Province, Mozambique")

**Ethiopia (1999)**

The male/female ratio among students with disabilities enrolled in special settings was 140:1. The overall enrollment rate of children with disabilities enrolled in these settings was estimated to be less than 1 percent.

(M. Mengesha (2000) "Special Needs Education: Emerging in Ethiopia")

*Source:* Savolainen, et al., (2000).

Persuasive arguments are put forward in favor of an inclusive, mainstream education for children with disabilities, as against segregated residential provision, claiming that:

*Historically, the education of disabled persons, even those with mild disabilities (e.g., epilepsy) has been through institutions. These residential institutions were often run by charitable institutions and based on a medical model where the "patients" or "inmates" had to be diagnosed and, theoretically, cured. The model was then exported to developing countries by charitable NGOs and later by official development assistance (p. 9).*

The claim is made that few, if any, children who are disabled require segregated residential provision for educational or any other reasons. See also a World Bank report focusing on Eastern Europe and the former Soviet Union, which makes a similar case (Tobis, 2000).

*The United Nations Statistics Division*

The Statistics Division of the United Nations, which forms part of its Department of Economic and Social Affairs, produces extensive statistical databases. In the field of disability its central resource is the International Disability Statistics Data Base, DISTAT, the most up to date version of which is DISTAT-2, which is not yet fully available (Mbogoni and Me, 2002). The database is available on-line at <http://unstats.un.org/unsd/disability/>. Currently "...the only information we have on children with disabilities from DISTAT-2 are prevalence rates by age groups for those aged 0–14" (personal communication from Margaret Mbogoni, Statistician, United Nations Statistical Division to Jan Georgeson, researcher for the present study, 20 March 2003). Table 4 gives an example of the data available together with the questions used to identify persons with a disability. DISTAT (i.e., the original version of the database) included information on the socioeconomic characteristics of persons with disabilities, together with data on the educational attainment and school attendance of children (see the "Disability Statistics Compendium" United Nations, 1990). Unfortunately an update on these aspects is not yet available (Mbogoni, personal communication, as above).

*Table 4 Example of Results of Search of DISTAT*

<b>Percentage of persons with disability by age and sex</b>				
<b>Australia 1993 Survey</b>				
<b>All areas</b>	<b>Total</b>	<b>0-14</b>	<b>15-59</b>	<b>60 +</b>
Total	18.0	7.0	13.6	50.9
Male	18.4	8.3	14.1	53.8
Female	17.6	5.6	13.1	48.5

*Source:* Tables provided by country.

It is important to note that the database is a collection of census, survey, and administrative registration systems information as provided by countries, supplemented by information provided from correspondence with national statistical services. The questions used to collect information in individual countries are available on the database. Because of the methodology used in compiling the database, it carries the important warning "...due to differences in the concepts and methods used in collecting data on disability, prevalence rates should not be compared across countries."

Although there is little or no indication that this basic methodology will change, the Statistics Division is clearly committed to providing advice and support in the development of statistical systems for assessing disability in developing countries. This appears to have been stimulated by urging from the World Program of Action Concerning Disabled Persons ([www.un.org/esa/socdev/enable/diswpa00.htm](http://www.un.org/esa/socdev/enable/diswpa00.htm)) that the Statistics Division:

*Together with other units of the United Nations Secretariat, the specialized agencies and regional commissions, ... cooperate with developing countries in evolving a realistic and practical system of data collection based either on total enumeration or on representative samples, as may be appropriate, in regard to various disabilities, and in particular, ... prepare technical manuals/documents on how to use household surveys for the collection of such statistics (United Nations, 2001; p. iii).*

The resulting *Guidelines and Principles for the Development of Disability Statistics* (United Nations, 2001), although oriented to statisticians, is intended to be useful to managers of disability programs “as they are essential partners in developing objectives for a data collection activity and the use of the resulting data” (p. iii). Use of the ICIDH/ICF framework is advocated. It covers a wide range of issues that are central to planning and organization in collecting data on disability. There also are useful suggestions on sampling issues, and on the dissemination and use of disability data. It is intended to be applicable to both industrialized and developing world contexts. Box 4 provides details of the contents.

*Box 4 Contents of “Guidelines and Principles for the Development of Disability Statistics”*

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- A. International recommendations
- B. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH)
  - 1. The three ICIDH concepts of disablement
  - 2. The International Classification of Functioning, Disability and Health-ICF
  - 3. Application of the ICIDH in disability data collection
- C. Data sources on disability
  - 1. Surveys
  - 2. Population censuses
  - 3. Advantages and limitations of using censuses and surveys to collect disability data
  - 4. Administrative records and registers

GENERAL ISSUES IN PLANNING AND ORGANIZING THE COLLECTION OF DATA ON DISABILITY

- A. Preparatory activities
  - 1. Identifying the objectives of the study
  - 2. Consulting users and persons with disabilities, and examining relevant existing data
  - 3. Publicity
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- C. General issues in design and operations
  - 1. Choice of respondent
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2. Developing disability questions for a census
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### C. Sampling for a disability survey

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## **DISSEMINATION AND USE OF DISABILITY DATA**

### INTRODUCTION

#### A. Planned tabulations

1. Number of persons versus number of disabilities
2. The socioeconomic profile of the population with disabilities
3. Comparisons of persons with and without disabilities
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#### B. Reports and publications

#### C. Other forms of dissemination and use

1. Making unpublished data available
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3. Disseminating micro data on computer media
4. Providing on-line dissemination and computer access to the data

#### D. Indicators

1. Indicators that measure the presence of disability
2. Indicators that measure the equalization of opportunities
3. Disability-free life expectancy

*Source:* United Nations (2001; pp. v-vii).



### *Questions Used to Identify Persons with Disabilities*

1. Is there anyone in the household who has any loss of sight?
2. Can X see normally wearing glasses or contact lenses?
3. Does anyone have any loss of hearing?
4. Does anyone have anything wrong with their speech?
5. Is there anyone who has blackouts or fits, or loses consciousness?
6. Does anyone have any condition that makes them slow at learning or understanding things?
7. Does everyone have full use of their arms and fingers?
8. Does anyone have difficulty gripping or holding things such as a cup or pen?
9. Does everyone have full use of their feet and legs?
10. Is anyone receiving treatment for nerves or an emotional condition?
11. Does anyone have any condition that restricts them in physical activities, or in doing physical work?
12. Does anyone have any disfigurement or deformity?
13. Does anyone ever need to be helped or supervised in doing things because of any mental illness?

Appendixes provide more detailed information on ICF examples of questions for identifying disability among children, various instruments for identifying cognitive and psychological impairments, and national examples of survey questions relating to use of services and support. This document, and any revised versions that are published, represent key resources for all involved in the production and use of disability statistics in the developing world.

Other activities of the United Nations Statistics Division (UNSD), summarized in Mbogoni (2000) have included participation in the DISTAB project, organizing meetings in the field of disability statistics, and carrying out regional training workshops on disability statistics, using the *Guidelines and Principles for the Development of Disability Statistics* document as the main training tool. DISTAB (a United States National Center for Health Statistics initiative) seeks to examine the usability of ICIDH-2 (which became ICF) for coding disability and census data. Exercises have been undertaken to back-code existing survey data to ICIDH-2 codes. Attempts have been made to identify problems, and recommendations made to WHO on how to revise the classification. The group also has made recommendations on what countries need to make disability data more comparable, particularly in the area of questionnaire design. These recommendations fed into a meeting of the Washington City Group on Disability Statistics (set up by the United Nations), February 18–20, 2002, involving wide representation, including WHO and EUROSTAT as well as UNSD and the United States National Center for Health Statistics, as well as international organizations of people with disabilities. A central objective of

the meeting, fully accepted by the participants, was to guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world (p. 1).

This is an ongoing group, with a second meeting planned for 2003, followed by an estimated three further meetings (see their Web site for further developments, <http://www.cde.gov/nchs/citygroup.htm>). While it is currently a “work in progress” clearly such a development will be of considerable value in achieving the purposes of this study. UNSD representatives discussed some of the advantages and disadvantages of using the ICF framework and classification (Mbogoni and Me, 2002), which are considered below in the section on WHO. In relation to developing countries, Mbogoni (2000) points out the wide range of questions used in surveys and censuses to assess disability in the 1990 census round and shows that, although there is less variability in the 2000 round, only 5 of the 11 of the countries reviewed made use of the United Nations recommended list of disabilities, based upon the ICIDH, given below as Box 5. The “personal care” question was asked only in one of the 11 countries reviewed (Mauritius). Mbogoni also points out that use of the list did not mean that countries were asked the same kind of initial screener question; indeed each of the five employed quite different questions, as shown in Box 6.

*Box 5 UN Recommended List of Questions on Disability*

- a. Seeing difficulties (even with glasses, if worn)
- b. Hearing difficulties (even with hearing aid, if used)
- c. Speaking difficulties (talking)
- d. Moving/mobility difficulties (walking, climbing stairs, standing)
- e. Body movement difficulties (reaching, crouching, kneeling)
- f. Gripping/holding difficulties (using fingers to grip or handle objects)
- g. Learning difficulties (intellectual difficulties, retardation)
- h. Behavioral difficulties (psychological, emotional problems)
- i. Personal care difficulties (bathing, dressing, feeding)
- j. Others (specify)

*Note:* It is recommended that every respondent be asked each of the categories on the list.

*Box 6 Different “Screener” Questions Used by Those Countries Using the UN Recommended List*

1. Do you/Does ... have problems with any of the following?
2. Does the person experience any disability (i.e., any limitation to perform a daily-life activity in a manner considered normal for a person of his/her age) because of a long-term physical/mental condition or health problem?
3. Does ... suffer from any long-standing disability that prevents him/her from performing an activity?
4. Do you have any long-term illness or disability?
5. Which of the following basic activities are affected by any nonlasting condition that you may have?

The review points out the need for a standardized screener question, as well as a recommended list and guidance on its use.

*The World Health Organization (WHO)*

WHO, as its Web site makes clear, “...does not have any data on the number of people who have disabilities” (<http://www3.who.int/whosis/faq/>). What it does have, as already alluded to several times in this study, is the International Statistical Classification of Functioning, Disability, and Health (ICF), see <http://www.who.int/classification/icf>. It is a newly developed member of the WHO family of international classifications and seeks to describe how people live with their health condition. It is a classification of health and health-related domains that describe body functions and structures, activities, and participation. The domains are classified from body, individual, and societal perspectives, together with a list of environmental factors.

The precursor WHO classification, International Classification of Impairments, Disabilities, and Handicaps (ICIDH), was heavily criticized in relation to disability mainly because its conceptual basis was exclusively medical, leading to a medicalization of disability (e.g., Pfeiffer, 1998; though attempts were made to counter this criticism, e.g., Ustun, et al., 1998). The lack of involvement by persons with disability or their organizations also attracted criticism. ICF made attempts to counter this, with efforts to closely involve the organizations of people with disabilities and to remove “handicapism” language. ICF also recognizes that disability is a social construct.

There are three components of the classification: Body Functions and Body Structures, Activities and Participation, and Environmental Factors. Each component is composed of various domains. Table 5 gives examples.

*Table 5 Examples of ICF Components and Domains*

<b>Component</b>	<b>Domain</b>
Body function	Specific mental functions, e.g., memory function Sensory functions and pain, e.g., hearing function
Body structures	Structures of the nervous system, e.g., spinal cord Structures involved in voice and speech e.g., structure of mouth
Activities and Participation	Mobility, e.g., getting around inside or outside home Self-care, e.g., washing oneself, dressing
Environment - All Factors	Products and technology, e.g., for communication Support and relationships, e.g., immediate family, health professionals

There is classification within components. Domains consist of facets or blocks, within which are nested groups of up to four-level categories, as illustrated in Table 6.

*Table 6 Classification Within Components in the ICF*

Domain, e.g., Communication (within the Activities and Participation component)
Facet, e.g., Conversation and use of communication devices and techniques
Two-level category, e.g., Conversation
Three-level category, e.g., Sustaining a conversation
Four-level category, if needed

All domains are coded with a “generic” qualifier, recording the extent of the “problem” as none, mild, moderate, severe, or complete. There also are qualifiers for specific components. For example, a second qualifier for body structure measures the change in body structure and a third measures the localization of the impairment. There also are environmental factor qualifiers that measure the extent to which an environmental factor acts as a facilitator or barrier.

*The United Nations Educational, Scientific, and Cultural Organization (UNESCO)*

UNESCO has taken the lead role in worldwide organizations on matters concerning the education of children with disabilities and of special needs education more widely. As discussed earlier in this review the term “children with special needs,” although variously defined, is commonly taken to include those with a range of difficulties and sometimes disadvantages, as well as those with disabilities.

The organization has, for example, published reviews of the situation in special needs education (UNESCO, 1988:1995). The information in these reviews was collected by means of a questionnaire completed in the division or unit in the Ministry responsible for special education. In the 1995 exercise, 90 member states were contacted with 63 responses. Information was obtained on aspects such as:

- Number of countries using different forms of provision (e.g., boarding special schools);
- How pupils are recorded for official purpose (e.g., registered in disability groups);
- Presence or absence of policy of integration;
- Presence or absence of links between special and ordinary schools;
- Number of pupils in special schools as a percentage of school age population; and
- Preschool provision for children with special educational needs (e.g., available for less than 10 percent of children).

UNESCO has adopted a mission statement committing itself to the concept of “inclusive education” deriving from the Salamanca Statement and Framework for Action 1994 (see UNESCO, 1999). A typical project under this heading is “Steps towards inclusive education in Thailand and Lao PDR,” which promotes access and quality education for children with disabilities ([http://www.unescobkk.org/education/apeal/Bulletin81/part201a\\_special\\_needs.htm](http://www.unescobkk.org/education/apeal/Bulletin81/part201a_special_needs.htm)).

UNESCO also has been involved, together with EUROSTAT and OECD, in a special study on data collection between 1996 and 1999, focusing on the revision of the International Standard Classification of Education (ISCED) (UNESCO, 1997). As the title indicates, this is a classificatory system and has an analogous role in education to that of the ICF framework in the field of health. Box 7 shows the levels of the ISCED system. A central feature of the revised ISCED classification is that the prime criterion for assignment of an educational program to an ISCED level is the content of the program. Descriptions are given of the content expected for each level. The very different nature of educational systems in different countries, including different organization of the cycles of education (e.g., some but not all countries distinguish between lower and upper secondary education) complicate this exercise and make international comparisons difficult. The UOE (UNESCO, OECD, EUROSTAT) data collection exercise discussed below focuses on industrialized countries with OECD membership and makes use of the ISCED framework.

*Box 7 The ISCED Levels of Educational Programs*

Level 0 - Pre-primary
Level 1 - Primary Education – first cycle of basic education
Level 2 - Lower Secondary Education – second cycle of basic education
Level 3 - Upper Secondary Education
Level 4 - Non tertiary level programs serving students who have already completed the upper secondary level
Level 5 - Tertiary level programs not leading directly to an advanced research qualification
Level 6 - Tertiary level programs leading directly to an advanced research qualification

In the field of special educational needs the assignment of some programs to ISCED levels has proved contentious. For example, a program for older students with severe or profound learning difficulties may in content terms appear closest to primary basic education. However, it also could focus on life and self-help skills which share some of the aspirations of programs for students coming to the end of their school education.

UNESCO's role in relation to the Education for All (EFA) global initiative is discussed below.

*The Organization for Economic Cooperation and Development (OECD)*

OECD takes the lead role in the UOE data collection exercise referred to in the preceding section. This is used, among others, to produce the yearly *Education at a Glance* handbook (e.g., OECD, 2002). It is a substantial and influential book currently running to approximately 400 pages. Short "Highlights" are available and the data sets can be accessed via the Internet ([http://www.oecd.org/els/stats/els\\_stat.htm](http://www.oecd.org/els/stats/els_stat.htm)).

A wide range of indicators covers the context in which education systems work, the financial and human resources that OECD countries invest in education, access, participation, progression, and completion, the learning environment, outcomes, and student achievement. Although coverage is mainly of the industrialized OECD countries, recent editions have included some indicators for nonmember countries participating in the UNESCO/OECD World Education Indicators program funded by the World Bank. Coverage of children with disabilities was, until recent editions, limited to information about students educated in segregated special schools. However, recent editions have included new indicators on "Students Receiving Additional resources to Access the Curriculum" (disabilities, learning or behavior difficulties, and social disadvantages) (OECD, 2000:2001).

As the heading suggests, a "resource based" definition has been adopted. This approach was taken because of difficulties encountered in making meaningful international comparisons when different countries have very different national definitions of special educational needs. Some definitions are limited to purely organic physical and sensory disabilities although other countries include socially and economically disadvantaged students. However, it was accepted that many OECD countries made additional resources of various kinds available to students who had particular difficulties for a variety of reasons in accessing the regular curriculum, whether or not this came within a national definition of special educational needs. A further complication is that although a large proportion of countries had national categories of needs, the actual categories employed varied widely, ranging from 2 to 19. Hence, in addition to adopting a resource based definition, three cross-national categories have been developed corresponding to disabilities, learning or behavior difficulties, and social disadvantages). Through an iterative consensual process, national categories have been allocated to the three cross-national categories. Table 7 gives an example. Countries also provided definitions for the national categories, as the names of similar categories in different countries were commonly found to be different.

*Table 7 Examples of Allocation of National Categories to the Three Cross-national Categories*

	<b>Disabilities</b>	<b>Learning or behavior difficulties</b>	<b>Social disadvantages</b>
<u>Canada - Saskatchewan</u>	<ol style="list-style-type: none"> <li>1. Intellectual disabilities</li> <li>2. Visual impairments</li> <li>4. Orthopedic impairments</li> <li>5. Chronically ill</li> <li>7. Multiple disabilities</li> <li>8. Deaf or hard of hearing</li> <li>9. Autism</li> <li>10. Traumatic brain injury</li> </ol>	<ol style="list-style-type: none"> <li>3. Social, emotional or behavioral disorder</li> <li>6. Learning disabilities</li> </ol>	
<u>Czech Republic</u>	<ol style="list-style-type: none"> <li>1. Mentally retarded</li> <li>2. Hearing handicaps</li> <li>3. Sight handicaps</li> <li>4. Speech handicaps</li> <li>5. Physical handicaps</li> <li>6. Multiple handicaps</li> <li>9. Other handicaps</li> <li>10. With weakened health (Kindergarten only)</li> </ol>	<ol style="list-style-type: none"> <li>7. Students in hospitals</li> <li>8. Development, behavior and learning problems</li> </ol>	<ol style="list-style-type: none"> <li>11. Socially disadvantaged children, preparatory classes in regular schools</li> </ol>

*Source:* OECD (2003; Table 3.2).

The indicators developed (OECD, 2001) include the percentage of students receiving additional resources in primary and lower secondary education in different countries, both overall and within the cross-national categories; the location of their education in special schools, special classes, or regular classes; and the gender distribution in the different locations. A monograph giving further details and analyses of individual categories in relation to particular disabilities is available (OECD, 2000) and a further monograph is in preparation (OECD, 2003).

The general message obtained is of very wide country to country variability. In some countries virtually all children of whatever disability or difficulty are educated in integrated settings (e.g., Italy and the New Brunswick province of Canada). In others almost all students with disabilities are in special schools (e.g., Switzerland and the Czech Republic). However, there is a high degree of consistency in gender distributions, with a 60/40 male/female split for different categories and cross-national categories. It is not possible to state with any degree of confidence whether this represents an inequitable distribution. Further data collection is planned that should help elucidate this finding (OECD, 2003).

Data collection is based on responses to a questionnaire and the completion of data collection tables following the conventions of the main UOE data collection exercise (OECD, 2000; p. 105 and Appendix 3; p. 121). The collection relies on data that are either already collected nationally or regionally or which can be readily collected. The instrument has been tested in both paper and electronic versions and also has been piloted for data collection at school level.

Although this novel approach appears to hold considerable promise, it could not be adopted in developing countries without modification. For example, the particular version of “resources” definition adopted (resources made available) appears to be a useful

operationalization in the context of the industrialized countries of the ISCED-97 call for a definition in resource terms. In the developing countries context, a definition in terms of “additional resources needed” would appear to be both more realistic and to help pinpoint what is required to implement programs and services.

Through collaboration with UNESCO, initial pilot work was carried out in Sri Lanka and Zambia. The data collection instrument was further tested in Chile, Costa Rica, the Philippines, Uganda, and Zambia, with encouraging results. The instrument is currently forming the basis for further related data collection exercises in the countries of South America.

OECD also is responsible for PISA, the Program for International Student Assessment (OECD, 1999), a new regular survey of 15-year-olds assessing their preparedness for adult life. At present PISA does not appear to have fully taken on board what is needed to include students with disabilities (e.g., no accommodations of the test to make it accessible to blind or physically handicapped students are currently allowed). However, efforts are being made to remedy this situation.

OECD, through its Center for Research and Innovation in Education (CERI), has carried out studies on integrating students with special needs into mainstream schools. These studies have incorporated other exercises in comparative statistical data collections (e.g., Evans, et al., 1995).

PARIS21 (Partnership in Statistics for development in the 21st Century) is based at OECD. It was launched in 1999 “...to act as a catalyst for promoting a culture of evidence based policymaking and monitoring in all countries, and especially in developing countries” (PARIS21, 2002). It does not, to date, appear to have any disability focus.

### *The European Union*

The European Union through its statistical arm EUROSTAT and EURYDICE (the information network on education in Europe, which is part of SOCRATES, the communities’ program on education) provides extensive data on the education systems in Europe. In the field of interest to this review, much is published under the heading of special educational needs rather than disability.

There is a now somewhat dated compilation of provision for students with disabilities (EUROSTAT, 1991) largely based on national surveys and reports with different methodologies. The conclusion is that “information on the number of handicapped pupils in ordinary education is fairly rare, the only reliable data being for France” (p. 152). A handbook on *Disability and Social Participation in Europe* was published in 2001 (EUROSTAT, 2001). It is based on data from the European Community Household Panel (ECHP), which is a longitudinal multisubject survey. The ECHP contains several questions on health, including a general question on restrictions on everyday activities caused by a health problem. Unfortunately, from the perspective of this review the data are restricted to 16 years of age and above.



Eurybase is the EURYDICE database providing detailed information on European education systems. Central to this is *Key Data on Education in Europe* (European Commission, 2002), now in its 5th edition. It includes regional summary data on the number of children with special needs and country specific data on their education. Two indicators relevant to children with special needs are presented. The first provides a typology of organization models for their education (one-track, where nearly all pupils are integrated; two-track, where a significant proportion are in separate special education; and multitrack, where there is a multiplicity of approaches to their education). The situation in the different countries is displayed. The second indicator is the percentage of pupils recognized as having special needs and the percentage who are educated separately in special classes or special schools. The data are based on the definitions of special needs and the categories of need recognized in each country. As discussed in the context of the similar data produced by CERI/OECD, both definitions and categories vary considerably across countries.

#### *The United Nations Children's Fund (UNICEF)*

UNICEF is involved in helping countries assess progress for children at the end of the decade in relation to World Summit for Children goals (UNICEF, 1999, Appendix 1; 2001). Goal 6 (<http://www.childinfo.org/eddb/goals/goal6.htm>) is:

*Universal access to basic education, and achievement of primary education by at least 80 per cent of primary school-age children, through formal schooling or nonformal education of comparable learning standard, with emphasis on reducing the current disparity between boys and girls.*

Relevant indicators are the proportion of children entering first grade of primary school who eventually reach grade 5; the proportion of children of primary school age enrolled in primary school; and the proportion of children of primary school age attending primary school. Unfortunately no data on disability are presented. Relevant indicators have been proposed, as shown in Box 8:

#### *Box 8 Proposed Indicators for Children with Disabilities*

- a) Existence of legislation, policies and services responding to the needs of children with disabilities
- b) Proportion of children with disabilities receiving the services they need
- c) Adequate financial support given to the families of children with disabilities
- d) Proportion of children with disabilities who have access to mainstream education
- e) Number or proportion of children in institutions for those with disabilities

*(Note: It is not clear whether a high rate should be rated good or bad)*

*Source: UNICEF (1998).*

The data collection instrument known as MISC2 (Multiple Indicator Cluster Survey, second wave for end-of-decade assessment) did, however, include an optional module on child disability. This is based on the “Ten Questions” approach (discussed in Appendix 2). By accessing the national reports of individual countries (<http://www.childinfo.org/index2.htm>), it can be seen that some countries did make use of this module, although this information has not been included in the standard reports. For example, Lesotho provides data on responses to the Ten Questions by region, district and area, and mother’s education level, shown here as Table 8.

*Table 8 Percentage of Children 24 to 108 Months with Disability Problems*

Characteristic		Serious delay in sitting, standing or walking	Difficulty seeing compared with other children	Appears to have difficulty hearing	Seem to understand what you are saying	Difficulty with limbs?	Fits, become rigid, or lose consciousness	Learn to do things like other children his/her age	Does speak at all?	Speech different from normal	Can name at least one object	Appear in anyway mentally backward, dull, or slow?	No. of caretakers
Region	Lowland	7.5	2.2	2.0	46.9	1.4	1.8	49.1	44.8	7.7	12.3	4.9	2074
	Foothill	7.7	2.2	2.4	46.7	3.1	1.8	52.0	47.4	7.0	12.1	9.6	456
	Mountain	9.7	4.0	3.3	47.4	2.5	2.2	50.1	45.9	10.8	12.8	5.1	994
	Senqu Valley	13.3	5.2	5.7	51.9	3.8	3.8	56.2	51.9	10.5	16.2	7.1	210
District	Butha-Buthe	12.0	2.3	4.6	52.1	2.8	0.9	56.2	54.8	8.3	16.1	8.3	217
	Leribe	6.7	1.8	1.3	49.9	2.0	2.5	51.2	47.5	7.4	11.0	6.4	609
	Berea	5.1	0.9	2.4	48.8	1.1	0.9	48.8	45.0	8.6	12.4	7.3	453
	Maseru	6.1	2.4	2.0	44.9	2.7	2.0	48.7	44.1	6.5	11.5	5.1	750
	Mafeteng	10.8	2.7	2.0	51.5	0.2	2.0	53.9	46.3	8.3	14.0	2.0	408
	Mohale’s Hook	13.1	5.0	3.1	30.2	2.8	3.7	37.4	34.9	10.9	9.7	7.5	321
	Quthing	11.5	2.4	3.2	53.6	2.8	4.4	58.7	50.8	7.9	16.3	4.4	252
	Qacha’s Nek	15.3	5.3	4.7	50.0	2.7	2.0	57.3	52.0	14.0	12.7	8.7	150
	Mokhotlong	7.8	6.6	5.1	47.9	3.9	1.2	49.8	47.9	12.1	9.3	6.2	257
	Thaba-Tseka	6.3	3.2	2.2	47.3	0.6	0.9	47.3	43.5	9.1	17.4	3.5	317
Area	Urban	6.7	2.2	2.1	44.2	2.4	2.2	46.0	42.8	5.4	10.7	5.3	717
	Rural	8.8	3.0	2.7	48.0	2.0	2.0	51.1	46.5	9.3	13.1	5.7	3017
Mother’s education level	None	9.3	4.9	3.7	52.0	3.7	1.6	55.7	50.8	7.7	12.6	7.3	246
	Primary	8.8	2.8	3.1	48.3	2.0	2.3	51.0	47.1	9.6	13.1	6.2	2471
	Secondary	7.1	2.5	1.2	43.3	1.7	1.6	46.6	41.4	6.5	11.4	3.8	1018
<i>Total</i>		<i>8.4</i>	<i>2.8</i>	<i>2.6</i>	<i>47.2</i>	<i>2.0</i>	<i>2.0</i>	<i>50.1</i>	<i>45.8</i>	<i>8.6</i>	<i>12.6</i>	<i>5.6</i>	<i>3737</i>

*Source:* Lesotho, 2000.

The INNOCENTI Research Centre based in Florence is the main research arm of UNICEF. It publishes databases, for example, the TransMONEE database of socioeconomic indicators for Central and Eastern Europe. There is information about education (e.g., enrollment in different phases, pupil-teacher ratios, and public expenditure), but nothing on children and disability. Similarly, *A Comparison of Survey Instruments for Collecting Data on Child Labor* (Grimsrud, 2001) suggests ways of improving data collection in relation to education and health, but does not cover disability.

### *Other Data Sets and Data Sources*

There are, of course, many other sources of data, some of which are briefly considered below.

#### *Demographic and Health Surveys (DHS)*

DHS has available a wide range of data sets on a subscription basis. The data are collected by a commercial organization, ORC Macro. Data sets are available for 69 countries. These include DHS EdData household education surveys (implemented by a contract with USAID's Office of Education in the Bureau for Economic Growth, Agriculture and Trade—EGAT/ED, in collaboration with the Africa bureau Office of sustainable Development—AFR/SD and the Bureau for Global Health—GH). Topics include “the reasons for school age children never having attended school, having dropped out of school, and for overage first-time school enrollment” (<http://www.dhseddata.com/statistics.html>). Although it has the potential to provide information on disability, there are no relevant references on the Web sites listed.

#### *Statistical Information and Monitoring Program on Child Labor (SIMPOC)*

This is the statistics and monitoring unit of the International Program on the Elimination of Child Labor (IPEC). It is of interest in part because in addition to a standard quantitative survey it also has a Rapid Assessment Methodology (RA) which is a “... qualitative method specifically designed to extract in-depth information on the working and life circumstances of children that are not easily captured through more controlled methods” (<http://www.ilo.org/public/english/standards/ipecc/simpoc/about.htm>). However, child disability is not covered.

#### *Development Banks*

The Inter-American Development Bank provided a useful working paper on “Disability and Education: Toward an Inclusive Approach” (Porter, n.d.). It is mainly concerned with establishing the case for inclusive education and contains case studies from Jamaica and Brazil. Dudzik, et al., (n.d.) provide a useful review of disability policies, statistics, and strategies in Latin America and the Caribbean. Data on the prevalence of disability in the region, and an overview of disability types are provided, as well as general discussions on the issues involved.

The Asian Development Bank reported (personal communication Jan Georgeson, researcher for this study) that they do not collect data on disabilities in South Asia. However, they organized a Regional Workshop on Disability and Development last year (2–4 Oct 2002). Papers from India and Sri Lanka are available. The East and Central Asia division provided contact with a VSO, Susan Aird, who is working on a project in Mongolia on employment promotion for people with disabilities. Ms Aird provided helpful further information including details of a Save the Children (UK) initiative attempting to introduce inclusive education in Mongolia and presented responses from workers in the field which give an interesting, somewhat alarming, picture of the reality underlying prevalence statistics:

*A VSO colleague, Helene Cannesson, who is a Special Needs Teacher, has taught for the past three years in Choibalsan. For the past year she has been working with teachers to assist them with the integration of children with a disability in their classes. Of the 200 children who had been identified as 'disabled' she would only have classified 25 percent of them as disabled.*

*In a recent discussion with one of the program directors at the local Education Centre I learned that she, herself, is under the impression that any child who presents anything somewhat different is disabled. I found that there were no criteria or direction given to teachers.*

*I have been working in the area of integration of children with special needs in kindergarten and schools in Choibalsan, Dornod Province, for the last year. And, yes, I have been very surprised to find that children who wore glasses, had a very slight limp, or mispronounced two or three sounds were labeled 'disabled.' It was reported to me that at a recent workshop it was said that there were over 200 disabled children who were integrated. I know this is not true as I have almost completed my assessment and will provide a report to Save the Children. How is this data collected? Strictly by the teachers who attended one workshop in the Fall. From what I gather, they were asked to identify and give a list of children with disabilities in their classes.*

#### *Other Organizations*

Several other organizations have Web sites that bring together useful information. They include:

- *National Center for Education Statistics (NCES) (US). In particular their pages on "International Comparisons in Education" (<http://nces.ed.gov/surveys/international/>);*
- *International Center for Disability Information (ICDI) Wide range of disability tables (<http://www.icdi.wvu.edu/disability/tables.html>); and*
- *International Center for Disability Resources on the Internet (ICDRI) Similar coverage to above. (<http://www.icdri.org/Statistics/mainstats.htm>).*

### **Children with Disabilities and the Education for All (EFA) and Millennium Development Goals (MDG) Global Initiatives**

#### *Education for All (EFA)*

UNESCO has taken a lead role in the Education for All (EFA) global initiative. In 1990, the international community put education on the global agenda during the World Conference on Education for All which took place in Jomtien, Thailand. Ten years later, a World Education

Forum at Dakar, Senegal, examined the results over the decade, producing the *EFA 2000 Assessment* which took stock of the status of education in some 180 countries and evaluated the progress achieved during the 1990s. This assessment (UNESCO, 2000) pinpointed widespread shortcomings in many countries in achieving the goal of universal primary education. UNESCO was mandated to take the lead role in orchestrating global efforts to achieve EFA by 2015.

The “DAKAR” objectives were:

1. Expand and improve comprehensive early childhood care and education, especially the most vulnerable and disadvantaged children.
2. Ensure that by 2015 all children, particularly girls, children in different circumstances, and those belonging to ethnic minorities, have access to, and are able to complete education that is free, compulsory and of good quality.
3. Ensure that the learning needs of all young people and adults are met through equitable access to appropriate learning and life-skills programs.
4. Achieve a 50 per cent improvement in levels of adult literacy by 2015, especially women, and equitable access to basic and continuing education for all adults.
5. Eliminating gender disparities in primary and secondary education by 2005, and achieving gender equality in education by 2015, with a focus on ensuring girls' full and equal access to, and achievement in, basic education of good quality.
6. Improving all aspects of the quality of education and ensuring excellence of all so that recognized and measurable learning outcomes are achieved by all, especially literacy, numeracy and essential life skills.

With the exception of objectives 4 (which is solely concerned with adults) and 3 (where the intention appears to be to target those aged 15 and above), the objectives have clear relevance to children with disabilities. This is explicit in objective 1, but in the other objectives it is indisputable that “all” includes children with disabilities. There is, for example, considerable concern about drop-outs and repeaters. It appears likely that children with disabilities are over-represented in these groups, and one might expect relevant data and analyses.

Given this, it is surprising that the EFA 2000 assessment appears to be silent on the education of children with disabilities. In particular, none of the 18 indicators used to assess the extent to which the objectives are being met include any mention of disability. Worryingly, a declaration in the DAKAR final report stating explicitly that additional indicators, including ones for people with disabilities (World Education Forum, 2000; p. 47), should be developed does not appear to have been taken on board at a later meeting on proposals for the future development on EFA indicators (UNESCO Institute for Statistics, 2001: Table 2). Neither in their proposals for short term, nor for medium term improvements in the existing indicators, is there any indication

that attention is to be given to children with disabilities. It is therefore unsurprising that the most recent monitoring report on progress toward EFA (UNESCO, 2002) is similarly silent.

However, there are other UNESCO related activities that appear to be attempting to stimulate attention to disability issues. One of the 12 thematic studies for the World Education Forum conference on the EFA 2000 assessment ([http://ww2.unesco.org/wef/en-leadup/findings\\_excluded%20summary.shtm](http://ww2.unesco.org/wef/en-leadup/findings_excluded%20summary.shtm)) covering “Education for All and Children Who Are Excluded” considers under the heading of “Protecting the Most Vulnerable” the position of children with disabilities. However, this is primarily a discussion of the philosophy of inclusive education with case study illustrations, rather than an attempt to provide linkage to indicators.

UNESCO clearly recognizes the need to link EDA and disabilities and has established what they term a “flagship” program the purpose of which is to focus extra attention on disability issues as key to achieving the overall goals of EFA (Mindes, 2001). The main aim of this program appears to be to bring organizations from the disability community into the EFA dialogue. The Flagship has as one of its main strategies the gathering of data on children with disabilities in order to help this group of children be fully included in EFA.

The current work program of the United Nations Institute for Statistics (<http://portal.unesco.org/uis/ev.php>) includes the EFA Observatory. This is the international monitoring body that examines progress toward the objectives of Education for All. They have data on school entrance and duration, but none on disability in relation to their monitoring of EFA. Note however that the Institute’s Web site covering the 2002 EFA Global Monitoring Report in a table listing EFA Flagship Programs includes one on “EFA and the Rights of Persons with Disabilities Towards Inclusion” (EFA Monitoring Team, 2001; Table 5.11, p. 185). This project, under the joint auspices of 15 organizations, including those representing people with different disabilities, seeks amongst other activities to “Support research to produce the data needed to inform governments and international financial institutions.” However, this program still appears to be at the planning stage. There also is an appreciation at the Institute that data on disability would be “good to collect” (personal communication from Simon Ellis, [s.ellis@unesco.org](mailto:s.ellis@unesco.org), to Jan Georgeson, researcher for this review 12 Mar 2003).

### *Millennium Development Goals (MDG)*

The Millennium Development Goals have grown out of agreements and resolutions of world conferences organized by the United Nations in the last decade of the 20th century. They have been commonly accepted as a framework for measuring development progress.

The World Bank has taken a lead role in relation to MDG and the statistics associated with the achievement of these goals. They are:

1. Eradicate extreme poverty and hunger.
2. Achieve universal primary education.

3. Promote gender equality and empower women.
4. Reduce child mortality.
5. Improve maternal health.
6. Combat HIV/AIDS, malaria, and other diseases.
7. Ensure environmental sustainability.
8. Develop a global partnership for development.

The goals are operationalized with specific targets. The target for goal 2, for example, is to “...ensure that by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling.”

The second goal has clear relevance to children with disabilities. It is indisputable that “universal” includes children with disabilities.

Each goal has a number of indicators. For goal 2 these are:

- Net enrollment ratio in primary education;
- Proportion of pupils starting grade 1 who reach grade 5; and
- Literacy rate of 15- to 24-year-olds.

Extensive data tables are provided for over 200 countries (<http://www.developmentgoals.org.htm>). However, they do not appear to include anything relating to disability.

The assessment is therefore straightforward. At present children with disabilities are not explicitly incorporated into the Education for All (EFA) and Millennium Development Goals (MDG) global initiatives. They should be. This could be achieved by developing indicators for EFA objectives 1, 2, 5, and 6, and MDG goal 2 which give explicit mention of children with disabilities.

### **Information From World Bank Regions**

Efforts to obtain information from the World Bank regions have met with little success. The researcher working for this study contacted by e-mail each of the regional officers whose details had been supplied, explaining the nature of the study and asking for information about any relevant regional developments. No response was received.

A similar effort was made by the author of the report. A short questionnaire, reproduced as Appendix 1, was used asking for details of any current data efforts and future needs in the

field of child disability. More specific questions enquired about any experiences in the use of the ICF framework, or of the Ten Questions Screen.

A response was received from the East Asia and Pacific Region that they were proposing to undertake a study during May and June to provide a statistical overview of people with disabilities in the East Asia and Pacific Region. A follow up obtained the information that this was in the planning stage. The consultant to the project (Mr. Yutaka Takamine) indicated that he “may use ICF in my study to clarify the definitions of disability.” He did not know about the Ten Questions Screen and requested information. This has been provided.

No response has been received from the other regions. This lack of response is surprising as it is understood from a peer reviewer of this paper that new regional groups on disability are currently underway.

## **Conclusions and Recommendations**

It is clear from the above review that, although there has been much time and effort put into collecting and disseminating data on children with disabilities, a substantial amount of which focuses on developing countries, good data sets do not currently exist. Existing data sets are fragmentary and inconsistent in their definitions of disability. They provide little basis for meaningful international comparisons and, with some exceptions, are of unknown reliability and validity. This depressing conclusion applies both to data on the prevalence of developmental disabilities and to data on the education of children with disabilities in developing countries.

A particularly disturbing feature is that the major global initiatives Education for All (EFA) and the Millennium Development Goals (MDG) are essentially silent on the topic of disability as far as data are concerned. This is unsurprising as the indicators adopted to assess the success of these initiatives do not currently give explicit mention to disability, nor is there any indication that this situation is likely to change in the short to medium term.

This absence is, however, extremely surprising given that both EFA and MDG have espoused a rhetoric acknowledging the importance of including children with disabilities within these initiatives. Indeed, in the case of EFA, UNESCO has actually established a so-called “flagship” program, the purpose of which is to focus attention on disability issues as key to achieving the goals of EFA. And their statistics arm, the EFA Observatory has clearly seized this issue.

There are other instances of children with disabilities being excluded from large international initiatives purporting to be for all. The Program for International Student Assessment (PISA), insisted that there should be no testing accommodations for students with disabilities, effectively excluding many students with visual, auditory, and physical handicaps.

The impression is gained that those responsible for the design and collection of statistical data in such large international initiatives are primarily concerned with ensuring that their



programs are technically and psychometrically defensible. The collection of data on “difficult” minority groups such as children with disabilities complicates an already very complex task and is hence not prioritized. The disappointing lack of response from World Bank regional representatives (to a request emanating from a study sponsored by the World Bank!) also gives the impression of a low priority being accorded to children with disabilities.

We are faced here with a classic “chicken and egg” situation. Until there are good data sets on children with disabilities in developing countries this is taken as justification in excluding them. When they are excluded the need for acquiring good data is not seen as a priority. Problems of poor attendance, repeaters, dropouts, and poor performance are already being influenced by the fact that they are ignoring children with disabilities. Without inclusion, these documented problems can not be adequately addressed. This is not a side issue, but is integral to EFA and the MDG. The pressing requirement is for initiatives to encourage the widespread collection of prevalence data.

*Recommendation 1:* That the proposals of UNSD for standardizing the questions on disability in national censuses and surveys are adopted, together with their “Guidelines and Principles for the Development of Disability Statistics.” The Washington City Group, supported by UNSD, is also presently trying to construct a set of questions that could be used transnationally. These proposals may be a preferable alternative.

*Note:* The available DISTAT statistics carry the warning that differences in definition and methodology render international comparisons virtually meaningless. DISTAT-2 is only partially available currently and it appears that less than half the countries analyzed have followed the UNSD proposals. This recommendation refers to the next DISTAT exercise, presumably based on the 2010 census round. Following this approach links the data collection to the ICF framework. It also avoids extensive semantic discussions about the definition of disability through the listing of a set of “difficulties.”

*Recommendation 2:* That all developing countries are encouraged to include a section on children with disabilities in national censuses and surveys

*Note:* By linking answers to the disability questions to demographic and socioeconomic answers it is of course feasible to obtain data on possible gender differences, poverty, and so on.

*Recommendation 3:* That the above proposals are operationalized through the adoption of the Ten Questions Screen (see additional note below).

*Note:* This instrument stands out as one that is closely linked to the purposes of this study. It is appropriate for the assessment of developmental disabilities, is simple, has been extensively trialed in developing countries, and is well validated. It also has been advocated by UNSD. Further details are presented in Appendix 2.

*Recommendation 4:* That developing countries are encouraged to use the Ten Questions Screen in other data collection exercises (e.g., in disability-specific household surveys). These

could be stand-alone exercises or linked into a development project or scheme (see additional note below).

*Note:* The instrument could be used by itself, or actually as a “screen” for subsequent follow up by more detailed or specialized instruments.

The secondary focus of this study is on school (and preschool) data sets to establish the extent to which the children identified actually have access to education, permitting an assessment of the extent to which policy goals (e.g., of equitable treatment for boys and girls) are being achieved.

*Recommendation 5:* That use of the OECD DDD “resources based definition” questionnaire is encouraged to obtain data on the education (including preschool education) of children with disabilities, including its location (segregated or integrated settings) and possible gender differences.

*Note:* This questionnaire links to the widely used UOE data collection exercise and hence to ISCED. If implemented, it would provide data relevant to UNICEF’s “proposed indicators for children with disabilities.” Although, as an OECD initiative, it is primarily focused on the industrialized countries, UNESCO involvement has led to its piloting in several developing countries and there is ongoing use of this approach in Central and South America. A definition in terms of “resources needed” in relation to the child’s disabilities is advocated for use in developing countries. The instrument makes use of existing national or other categories of disability, where available. Alternatively, it can employ categories derived from the UNSD Ten Questions Screen approach. There are mechanisms for establishing meaningful, international comparisons. Variants of the questionnaire also may be used at regional, local, or school levels.

*Recommendation 6:* That any future World Bank development projects carry a requirement that the Ten Questions Screen and OECD DDD questionnaire are used whenever relevant (see additional note below).

Disability does not currently feature in the EFA Monitoring Reports. This is in part explained by the absence of any indicators for achieving the EFA objectives that mention disabilities. The situation in relation to the MDG education goal is the same. Again, this can be seen as linked to the current absence of usable data sets on children with disabilities.

*Recommendation 7:* That strenuous efforts are made to have explicit disability related indicators incorporated into EFA and MDG.

*Note:* This will call for lobbying of meetings on the future development of EFA Indicators. The case for this will be strengthened if it proves feasible to take on board the previous recommendations.

In advance of action on these recommendations it appears premature to attempt a synthesis of data that might be included in the EFA Monitoring Report. However, it would be valuable for the report to acknowledge its deficiency in this area.

*Recommendation 8:* That the next EFA Monitoring Report acknowledge that Education for All includes education for children with disabilities. That this aspect has not been monitored to date also should be acknowledged, and strenuous efforts should be made to remedy this.

Qualitative data collection can provide invaluable insights into the lives of disabled children and throw light on the quantitative data generated by censuses and surveys. Quantitative data can establish the size and to some extent the nature of the need, but is of limited assistance in designing programs and services that meet the needs of those targeted. Qualitative studies can provide the perspective not only of families and teachers and other professionals, but also of the children themselves.

*Recommendation 9:* That the particular expertise of Save the Children be drawn upon to set up qualitative projects on the lives of children with disabilities in developing countries, and to provide a watching brief that any qualitative projects on the lives of children in developing countries explicitly includes children with disabilities.

*Note:* An ongoing project “About Young Lives,” under the auspices of Save the Children conducts both qualitative and quantitative data primarily focused on childhood poverty in developing countries. It does not currently collect data on disability, but appears to have great potential to provide information on childhood experiences (<http://www.younglives.org.uk>).

*Additional note on the recommendations advocating the Ten Questions Screen:*

The Ten Questions Screen has been advocated as currently the “best game in town.” To reiterate, it exists, has been thoroughly researched particularly in respect of its reliability and validity, has been widely used, is advocated by UNSD, and is feasible for use with children with disabilities in developing countries. It is not perfect for all purposes. Something as simple and short as this could not possibly be. It may be that UNSD or the Washington City Group will come up with a better instrument. However, such an instrument does not yet exist in a validated form. Awaiting its development could, realistically, hold back progress by several years.

## **A Warning Note**

The collection of disability statistics is legitimately viewed by the World Bank as a necessary precursor to development activities in this field. There is a danger, particularly in special surveys on disability issues, but not so much in the addition of disability questions to national censuses, that the collection of such data comes to be viewed as an end in itself and that an inordinate amount of effort is devoted to devising complex, intellectually satisfying, collection instruments. There also is the danger that the data collection itself can raise expectations that may not be fulfilled. As Ingstad (2001) stresses:

*Clearly, a disabled person or family visited for the purpose of a survey will easily come to expect that something will be done to help them. However, only rarely will a rehabilitation program be able to help all those who are surveyed. A survey often exhausts most of the available donor money so that once the figures are completed, there is little more that can be done. For this reason, voices have been raised, especially from the organizations of people with disabilities themselves, to limit (or drop) the surveys and start to give help, on a small scale, to those in need and to expand help as needs arise (p. 774).*

The moral is that the data collection instrument should be simple and that data collection should be directly linked to the provision of services or involvement in programs. The first aspiration is not difficult, providing that the purpose of collecting the data is kept firmly in mind. The second may be thought utopian and outside the remit of those collecting data. However, without such linkage their activity is, in the last analysis, pointless.

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## Appendix 1

### Questionnaire Sent to Representatives of World Bank Regions

1. What current efforts, if any, are there in your region to obtain Data on Children with Disabilities?
2. Have any of them made use of the ICF (the International Classification of Functioning, Disability and Health - from WHO)?
3. Do you have any comments on the use of ICF?
4. Have any of them made use of the Ten Questions Screen for childhood disability (developed by Durkin and colleagues)?
5. Do you have any comments on the use of the Ten Questions Screen?
6. What do you see as future needs in this field?

## Appendix 2

This instrument (Durkin, et al., 1994) has been developed "...with the primary objective of developing a low-cost and rapid method of screening children with serious disabilities by community workers in populations where professional resources are scarce. A secondary objective was to ascertain the prevalence and distribution of various disabilities for the sake of prioritizing limited resources into rehabilitation work" (Khan and Durkin, 1995; pp 3-4). The questions are listed in Box 1.

### *Box 1 The Ten Questions Screen*

1. Compared with other children, did the child have any serious delay in sitting, standing, or walking?
2. Compared with other children does the child have difficulty seeing, either in the daytime or at night?
3. Does the child appear to have difficulty hearing?
4. When you tell the child to do something, does he/she seem to understand what you are saying?
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?
6. Does the child sometimes have fits, become rigid, or lose consciousness?
7. Does the child learn to do things like other children his/her age?
8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words?)
9. *For 3- to 9-year-olds ask:*  
  
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?)  
  
*For 2-year-olds ask:*  
  
Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?
10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull, or slow?

*Source:* Durkin, et al., (1994).

The questionnaire is designed to identify children in any culture who may have developmental disabilities, including seizures and cognitive, motor, vision and hearing disabilities. It provides a simple screening procedure making use of resources available in the community. It is intended to be administered by community workers who can read and write and

who have participated in a brief interviewer training program. The questions are presented as a personal interview with a parent or other adult who knows the child being screened.

It has been used as the basis for studies in Bangladesh, Jamaica, and Pakistan (Durkin, et al., 1994). The results of the Bangladesh study are summarized here (Khan and Durkin, 1995 provide details). A total of 10,299 children were screened and about half lived in urban and half in rural communities. A child was regarded as screening positive if one or more problems were reported in answers to the 10 questions. With essentially identical percentages in rural and urban settings, about 8.2 percent screened positive.

All children who screened positive, and a random sample of about 10 percent of those who screened negative were referred for medical and psychological assessments. These assessments provided a basis for determining whether or not a child was disabled, hence providing a check on the screening result. Assessments were made blind (i.e., made without knowledge of the screening results). Standard assessment procedures and criteria were used with a structured form based, where possible, on codes derived from the ICIDH framework (WHO, 1980b). The questions, with minor caveats (Chamie, 1994), have held up under these strict conditions for testing validity and reliability.

Khan and Durkin (1995) provide estimated prevalence rates for their Bangladesh study, reproduced here as Tables 1 and 2. Overall, the estimate is that just under 7 percent of 2 to 9 year old children in Bangladesh have developmental disabilities. Some of the specific differences, such as the greater overall prevalence of disabilities in girls than in boys, may reflect cultural patterns (where priority is given to male children); others may be linked to specific medical conditions (e.g., hearing disabilities being more common in older children linked to otitis media common where children are in and out of water frequently, though this might be a reflection of early underidentification of a covert impairment such as hearing disability). However, although the main focus should be on prevention so that fewer children need treatment and rehabilitation, the type of information provided here is invaluable for educational planning and the tailoring of services and programs to demonstrated needs.

Box 2 discusses the advantages and disadvantages of the Ten Questions Screen from the perspective of the purposes of this study.

*Table 1 Estimated Prevalence Per 1,000 of Disabilities Among 2- to 9-Year-Old Children in Bangladesh*

<b>Type of disability</b>	<b>Total (N=10,299)</b>	<b>Urban (N=5,103)</b>	<b>Rural (N=5,196)</b>
Any disability			
Serious	15.68	19.90	11.75
Mild	52.84	45.26	59.98
Cognitive			
Serious	5.93	6.05	5.84
Mild	14.84	15.80	13.18
Motor			
Serious	3.79	3.58	4.01
Mild	2.17	2.02	2.32
Vision			
Serious	2.46	3.74	1.27
Mild	13.33	22.04	5.14
Hearing			
Serious	5.87	9.66	2.32
Mild	23.06	6.37	38.77
Seizures			
Serious	0.33	0.45	0.21
Mild	4.57	3.52	5.57

*Source:* Khan and Durkin (1995: Table 1.2).

*Table 2 Estimated Prevalence Per 1,000 of Serious Disabilities Among 2- to 9-Year-Old Children in Bangladesh, by Age and Gender*

<b>Type of serious disability</b>	<b>2-5 yrs (N=4,947)</b>	<b>6-9 yrs (N=5,532)</b>	<b>All boys (N=5,413)</b>	<b>All girls (N=4,886)</b>
Any	12.27	18.68	13.66	18.05
Cognitive	5.12	6.62	5.08	6.94
Motor	6.46	1.26	3.66	3.95
Vision	2.91	2.10	3.17	1.63
Hearing	1.34	9.96	3.98	8.08
Seizures	0.45	0.21	0.61	0.00

*Source:* Khan and Durkin (1995: Table 1.3).

## *Box 2 Advantages and Disadvantages of the Ten Questions Screen*

### **Advantages in its use for the purposes of the study:**

- **Simplicity.** It is undoubtedly simple to administer. This gives it an undoubted edge over more complex instruments particularly in developing countries.
- **Specifically designed for use in the conditions encountered in developing countries.** The tool's simplicity, reliance on available personnel with minimal training requirements, and prior field testing in several developing world contexts is notable.
- **But also usable in industrialized countries.** The approach of asking the basic functional questions used in the Ten Questions Screen could without difficulty be adopted in surveys in industrialized countries. Chamie (1994) provides examples where such questions have been effectively tried for screening in industrialized countries (though the examples are limited to adult populations where the adults were interviewed directly, rather than being identified through interviews with caretakers. In industrialized countries where educational provision is largely universal in coverage, children with disabilities can be identified through school, or other centre, attendance records. The ten basic questions could then be compared with information about receipt of educational provision as a form of cross-validation.
- **Designed for use in identifying children.** Instruments which are more generally focused, or targeted at adults, can cause problems when dealing with children. For example the commonly used 'activities of daily living' approach to assessing disability, typically includes questions about using the toilet, preparing food, getting dressed, etc. Children, however, are likely to have difficulties in some such areas, especially at the lower age ranges, and hence it would not be reasonable to use them as disability screens.
- **Applicable in a wide range of cultural contexts.** The very simple functions covered in the ten questions are relatively nonculturally specific.
- **Can be linked to the ICF framework.** As demonstrated in the Bangladeshi study it is feasible to translate the question answers to ICF codes.
- **Has demonstrated validity and reliability.** Durkin provides details of the results of validation procedures which are in general terms fully acceptable. Chamie (1994) reports that it has been found that children who had been previously tested and/or treated for vision and hearing problems were more likely to be reported by the child's caretaker to have problems of vision and hearing. Children with hearing and vision problems who had never been tested or treated were more likely to be reported erroneously as not having any visual or hearing disability when the 10 basic questions were asked. This finding suggests a possible modification to the procedure with the caretaker being asked about any services that the child has already received.

### **Disadvantages in its use for the purposes of the study**

- **Its provenance is medical rather than educational.** However the functional approach taken covers areas of obvious pedagogical relevance to the education of young children and, indeed, might be seen as useful for educational purposes at preschool and primary levels of schooling.
- **It does not appear to provide a means of picking up a child with a mental health disability.** For example bipolar or unipolar depression.
- **Simple screens of this type do not explicitly address a range of conditions and syndromes which can have serious impacts on schooling.** For example ADHD, ADD, dyslexia, Praeder-Willi, Asperger's Syndrome.
- **The age range (2 to 9 yrs) does not match the years of schooling.** For children with disabilities coverage of early years is a substantial advantage. Educational intervention at preschool level for children likely to experience problems in successfully accessing the normal school curriculum reduces such problems. Ideally an instrument capable of covering the full age-range through to adult life would be desirable. There are examples of the use of basic functional questions similar to those in the Ten Questions Screen which have been used to screen adult populations (United Nations, 1990). However, the priority is undoubtedly preschool and the early years of schooling.