

ALL IN SCHOOL

**Out-of-School
Children Initiative**

UNICEF AND UNESCO INSTITUTE FOR STATISTICS

CHILDREN WITH DISABILITIES

By Natasha Graham

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Introduction

Most countries engaged in the Global Out of School Initiative (OOSCI) came across a common observation: quality disability data is missing in all five dimensions of exclusion, and in general lack of disaggregated data on children with disabilities was found to be one of the biggest obstacles to understanding the barriers that children with disabilities face.

In most developing countries the number of children with disabilities is grossly underestimated. Children with severe and moderate disabilities may be acknowledged, but children with mild or hidden disabilities are ignored. These children account for a large proportion of children who drop out and do not complete primary education. They have no obvious disability but may experience extreme difficulty with learning in one or more areas. Children with “hidden” disabilities may include those with intellectual disabilities and mental health problems, but may also include children with unidentified disabilities such as hearing loss (UNESCO, 2009).

May 3, 2008 marked an important date for people living with disabilities around the world. It is the date when the Convention on the Rights of Persons with Disabilities (CRPD) entered force. Most countries engaged in the OOSCI are among 145 parties, which ratified the Convention as of today (April 2014). The Convention states that persons with disabilities should be guaranteed the right to inclusive education at all levels, regardless of age, without discrimination and on the basis of equal opportunity (Box 1) (CRPD, 2014).

The CRPD triggered a number of global actions and initiatives. In 2011 the World Report on Disability stated that more than a billion people (or 15%) in the world today experience disability. Estimates for the number of children (0-14 years) living with disabilities range between 93 million and 150 million. This is the only number, although an estimate, that provides any kind of real global insight on the situation of children with disabilities (WHO/World Bank, 2011).

Despite progress made in achieving Education for All goals, it is expected that nearly half of the 57 million children currently out of school will never even make it to school. The reasons for children not making it to school vary, but usually are associated with disadvantages children are born with – poverty, gender, ethnicity, or living in a rural area or a slum. One of the most neglected of such disadvantages is disability (UNESCO, 2013a).

Countries engaged in the OOSCI recognized that children with disabilities represent one of the more excluded from education groups of children. Exclusion is often the consequence of invisibility, and many OOSCI country studies reported that children with disabilities are often excluded from national data collection procedures and thus invisible in national indicators on education.

In some regions, as discussed in UNICEF-UIS CEE/CIS Regional Report, children with disabilities are likely to encompass a large portion of those who are out of school or at risk for dropping out. The report pointed out that an estimated 5.1 million children with disabilities live in the region whose education status is largely unknown, and out of the total 1.5 million children who are registered with a disability only 219,000 (14.5%) attend ‘special’ schools. Based on international estimates there are between 1 and 3.6 million children with disabilities who are still not recognized living in that region (UNICEF and UIS, 2013a).

UNICEF-UIS South and East Asian Regional Report also brought up the lack of information about children with disabilities to be one of the more significant factors contributing to the invisible status which often leads to exclusion of these children from education. In India, for example, the same survey reported 38% rate of children with disabilities ages 6-13 to be out of school, compared to a general 6% rate, which means that children with disabilities are more than 5 times likely to be out of school than the average (UNICEF and UIS, 2014).

Without having disability data, disaggregated by the degree and the type of disability, it is difficult to fully understand the barriers that lead to exclusion, and to plan interventions targeting specific disabilities. Countries engaged in the OOSCI reported that they lack assessment tools and methodologies to identify children with disabilities making it difficult to collect disaggregated disability data, plan and budget for appropriate services, infrastructure and resources.

1. Disaggregated disability data are vital to ensure the inclusion of children with disabilities in education

Globally reliable and comparable disability data are difficult to obtain, and systematic under-reporting of disability is a serious issue. Existing prevalence estimates of childhood disability vary considerably – from under 1% in Kenya and Bangladesh to 20% in New Zealand - because of differences in definitions and the wide range of methodologies and measurement instruments adopted (World Bank, 2007a). Under-reporting is often the product of either stigmatization, which makes parents or caretakers reluctant to report disability, or lack of availability or access to disability assessment and health screening services, which makes parents unaware of children having mild and sometimes moderate disabilities and impairments (Box2).

Censuses and surveys take very different approaches to measuring disability, and often different instruments within the same country report very different rates of disability. The purpose of measurement determines the definition of disability to be used and questions asked. Three major purposes for collecting data on disability include: monitoring the level of functioning in population, designing service provision, and assessing the equalization of opportunity (World Bank 2007b).

Factors such as limitations of censuses and general household surveys to capture childhood disability, the absence of civil registries in most low and middle-income countries, and poor access to culturally appropriate clinical and diagnostic services contribute to lower estimates (UNICEF and University of Wisconsin, 2008). As a result many children with disabilities are unlikely to be identified or receive special services.

Since 2005, Multiple Indicator Cluster Surveys (MICS) have used a tool with 10 questions to screen children aged 2-9 for the risk of various type of impairment. This information points to a risk of disability ranging from 3% in Uzbekistan to 49% in the Central African Republic. While data on the risk of disability may overestimate the number of children actually living with a disability, they throw some light on barriers that children at risk of disability face getting to school. Analysis of Multiple Indicator Cluster Surveys from four countries shows that children at higher risk of disability are far more likely to be denied a chance to go to school. In Iraq, for instance, 10% of 6-to 9-year-olds with no risk of disability have never been to school in 2006, but 19% of those at risk of having a hearing impairment and 51% of those who were at higher risk of mental disability had never been to school (UNESCO, 2013b).

2. Barriers for inclusion of children with disabilities in education

Most importantly the decision to provide education to all children, including children with disabilities, requires a commitment from government to accept that all children have an equal right to education. Inclusive education policies would benefit all children as they developed ways of teaching that respond to individual differences and diverse abilities.

Although the concept of inclusive education has been promoted internationally for more than a decade many countries engaged in the OOSCI reported the presence of multiple barriers that contribute to exclusion of children with disabilities from education. These factors extend beyond the boundaries of the school and classroom.

- Negative attitudes: the barriers which keep children with disabilities out-of-school are often attributed to negative attitudes and systems, and societies that discriminate against them. In some countries it is a common belief that a child with a disability is a punishment to the family for past mistakes. Sometimes parents are unaware of the rights of their children to education and may accept the community view that these children cannot learn.

Several OOSCI country studies pointed out to the presence of negative attitudes towards children with disabilities to be one of the most significant barriers that affects children within all five dimensions of exclusion. Ghana country study, for example, pointed out that a high degree of stigmatization continues to be associated with disability in Ghanaian communities. A recent study carried out in northern rural Ghana discovered that children with disabilities are viewed by parents as not having any or a very limited capacity to learn. These perceptions act as a barrier in schools where teachers and head teachers do not promote inclusive education (UNICEF and UIS, 2012). Similar situation was observed in Kyrgyz Republic where public perception of disability is a significant social barrier preventing children with disabilities from going to school, and children with disabilities often face teasing and bullying at school (UNICEF and UIS, 2012a).

- Policy is not clearly stated and terms such as inclusive education not clearly defined, or policy is not implemented. Countries reported that some schools were not aware of inclusive education policy and did not receive any training on how it should be implemented.
- Inaccessible physical environments, including toilet facilities prevent access and learning for children with physical disabilities. Environments with inadequate light, or noisy environments prevent children with visual or hearing impairments from learning. Problems with transport prevent children with disabilities from accessing school.

In Kyrgyz Republic, for example, almost all school buildings and classrooms are not accessible to children with disabilities. Also transportation needs for children with disabilities were reported to be too costly for families, and a small monthly allowance provided by the government is not sufficient to cover these costs (UNICEF and UIS, 2012b).

- Inflexible curriculum and exam systems combined with non-inclusive teaching methods prevent many children with disabilities from learning and achievement in school.

Kyrgyz Republic among other countries reported that very few teachers have received training in inclusive education, and the school programme and teaching materials have not been adapted to the needs of children with disabilities (UNICEF and UIS, 2012c).

3. A way forward: Recommendations, areas of action and planned activities

Although progress has been made to include children with disabilities in education, there is still a lot that remains to be done. Countries engaged in the OOSCI identified common challenges, which contribute to exclusion of children with disabilities from education. Children with disabilities encounter different forms of exclusion depending on factors such as the type of disability they have and where they live, as well as the culture or class to which they belong. Lack of disaggregated disability data remains a global challenge, and came across as one of the biggest obstacles to understanding the barriers that children with disabilities face.

Strengthening statistics on children with disabilities

To improve disability data collection it is recommended that countries ensure that disability is defined suitable for developing internationally comparable measurement procedures in order to provide comparable prevalence rates. A checklist of good measurement practices for measuring disability for general prevalence estimates in censuses (World Bank, 2007c) could be used:

- (1) Questions should be based on functionality;
- (2) Questions should focus on basic core activities;
- (3) The word “disability” should not be used. Avoid derogatory language;
- (4) Responses should be scaled rather than yes/no;
- (5) A range of prevalence should be reported for various levels of severity, rather than a single prevalence rate.

In the past several years UNICEF and its partners have undertaken a number of initiatives to address the need for comparable and reliable data on children with disabilities. The following products are expected to be available to countries in the near future:

- Manual for production of statistics on children with disabilities, which will provide guidance for those considering collecting data on children with disabilities. The draft manual is expected to be finalized by the end of 2014.
- New survey module and manual on child functioning and disability are expected to be ready for actual data collection and use by countries in the second half of 2014.
- New survey module on school environment and participation is expected to be ready in early 2015.
- Toolkit for the assessment of activity limitations and participation in children is being developed and expected to be ready for use by countries in late 2014.

Inclusion of children with disabilities in mainstream policies, systems and services

Several recent publications and reports have addressed the situation of children with disabilities by recommending some key actions that could be taken by governments. The following areas of action, which are aligned with Convention on the Rights of Persons with Disabilities and draw on the recommendations in the World Report on Disability and 2013 State of the World's Children Report provide a basis for further discussion, expert consultation, advocacy and mobilization effort, and planning (WHO, 2012):

1. Promoting inclusive education for children with disabilities at all levels including early childhood education, supporting the practice and culture of inclusion across education systems by reviewing national policies in relevant sectors – health, education and social – to ensure they are aligned with international conventions and commitments and inclusive of children with disabilities;
2. Analyzing sector wide strategies, programmes and budgets to determine whether they include concrete actions to support children with disabilities and their families;
3. Developing (assessing, if there is existing), implementing and monitoring a comprehensive multisectoral national strategy and plan of action for children with disabilities that addresses family support, community awareness and mobilization, capacity of human resources, coordination and service provision;
4. Establishing clear lines of responsibility and mechanisms for coordination, monitoring and reporting across sectors;
5. In the education sector: ensuring that inclusive education strategy and action plan is part of an existing Education Sector Plan; Building or retrofitting schools that are accessible for children with disabilities. Ensuring curricula and learning materials, processes and assessments are accessible to all; Training teachers and providing orientation to foster a commitment to inclusion across schools and communities;
6. Evaluating and identifying gaps in existing service delivery addressing the needs of children with disabilities; Advocating for and seeking sustainable financial and technical support to address the service delivery gaps that have been identified. Linking disability data collection with service provision;
7. Collecting data about disability to fill gaps and monitor progress on the education of children with disabilities.

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Box 1.

Convention on the Rights of Persons with Disabilities: What does it mean for children living with disabilities?

The Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities. The Convention has served as the major catalyst in the global movement from viewing persons with disabilities as objects of charity, medical treatment and social protection towards viewing them as full and equal members of society, with human rights. It was adopted on 13 December 2006 at the United Nations Headquarters in New York. The Convention entered into force on 3 May 2008, and as of April 2014 has 158 signatories and 145 parties.

The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Consisting of 50 articles, article 7 is dedicated specifically to children with disabilities:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

In addition, there are several references to children with disabilities throughout the text of the Convention. For example:

- Article 4 refers to the need to consult children with disabilities in the development and implementation of legislation and policies implementing the Convention;
- Article 8 covers the need to raise awareness and foster among children respect for the rights and dignity of persons with disabilities, particularly within the education system;
- Article 16 highlights the need for child-focused legislation and policies;
- Article 18 underscores the need for children with disabilities to be registered immediately after birth, and reinforces the right to have a name from birth, acquire a nationality and the right to know and be cared for by their parents;
- Article 23 refers to the right of children with disabilities to retain their fertility and their right to equal respect of family life; and states that children are not to be separated from parents with disabilities against their will;
- Article 24 states that persons with disabilities should be guaranteed the right to inclusive education at all levels, regardless of age, without discrimination and on the basis of equal opportunity, and children with disabilities shall not be excluded from free and compulsory primary education, or from secondary education on the basis of disability;
- Article 30 talks about ensuring that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system.

Box 2.

What is disability: Evolving definitions

The obstacles that children face depend on the type of disability they experience.

The concept of disability is complex, and there are historical, social, legal and philosophical influences on its interpretation. Different countries have different definitions of disability. World Health Organization (WHO) defines “disabilities” as an umbrella term, covering impairments, activity limitations, and participation restrictions.

An impairment is a problem in body function or structure; *an activity limitation* is a difficulty encountered by an individual in executing a task or action; while *a participation restriction* is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives (WHO, 2011).

In the past it was interpreted as a medical model, which means that disability was linked to various medical conditions. In some regions, for example in Central and Eastern Europe, disability is still largely treated as a medical condition with little differentiation made between impairment, illness and disability (UNICEF and UIS, 2013a).

This medical model has been replaced by the social model of disability, which conceptualizes disability as arising from the interaction of a person’s functional status with the physical, cultural, and policy environments. The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization served as a starting point in measuring functional capacity (WHO, 2001).

In 2007 the World Health Organization (WHO) published a derived classification system from the ICF specifically for children and youth – an International Classification of Functioning, Disability and Health Children and Youth (ICF-CY) (WHO, 2007). The ICF-CY is the first unifying framework that attempts to describe the effects of context on child functioning and includes several environmental factors to examine as facilitators or barriers when recording profiles of child functioning.

Box 3.**Country focus: Situation of children with disabilities in Cambodia**

Cambodia makes an interesting case study, because in the Cambodian language “Khmer” there is no clear distinction between “impairment” and “disability” adding to the complexity of making a distinction between the two concepts.

While collecting disability data it is important to develop consistency in deciding whether the child has impairments or not and whether any identified impairments should be classified as a disability. For example, in a country such as Cambodia where children often do not have access to assistive devices (e.g. eyeglasses to correct low vision), a child with uncorrected visual impairment may be classified as a child with a disability. A child with uncorrected low vision may be excluded from education simply because he or she may not be able to ride a bike to school or to be able to see clearly what is written on the board.

According to the 2008 Census of the National Institute of Statistics 1.44% of the country’s population is disabled (Cambodian National Institute of Statistics, 2008). People with disabilities are required to have a certified document of disability issued by the Ministry of Health. It is quite common that responsibility to provide services for people with disabilities is divided between different ministries. In Cambodia six ministries are responsible, and many different disability classification systems are being used.

In 2010 Cambodian Ministry of Education Youth and Sport (MOEYS) implemented a national survey to better understand the needs of excluded from education children including children with disabilities. Children who have been identified as potentially disabled at the household level, were referred for a multi-professional assessment carried out by a team of doctors and psychologists, as well as hearing and vision specialists to confirm the presence of an impairment or a disability and to provide treatment and referral where necessary.

This survey calculated an impairment prevalence rate of 15.6%, and a disability prevalence of 10.1%. This included children who on examination on that day had a health condition either acute or chronic e.g. from conjunctivitis or earwax to gross motor disabilities or cerebral palsy or mental retardation. The results of this study show that a large number of children have easily treatable health conditions such as partial hearing loss due to untreated ear infections, and that about 5% of children are not able to participate in school simply because they need eye glasses. Most of these conditions have been previously undiagnosed.

Having disaggregated disability data made children with disabilities more visible, and enabled the Cambodian MOEYS to increase enrollment of children with disabilities through targeted, evidence-based interventions.

“Knowing the situation about children with disabilities will allow Cambodia to plan and provide quality education for ALL of Cambodia’s children.” – His Excellency Nath Bunroeun, Secretary of State for Education, Youth and Sport.