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Educational Quality Improvement Program
Policy ▪ Systems ▪ Management

Educating Children with Disabilities: Who Are the Children with Disabilities?

Disability and EFA

Over the past decade, the international community has adopted the World Declaration on Education for All (EFA), which entitles every child—including those with disabilities—to an education. EFA was first endorsed in 1990 by more than 1,500 government officials, policymakers, researchers, NGO representatives, and key international donors at the World Conference on Education for All in Jomtien, Thailand. Subsequent events, such as the 1994 Salamanca World Conference on Special Needs Education and the 2000 Dakar World Education Forum, reaffirmed the goal of EFA, and the international community has increased its commitment to promote policies that support educational opportunities for all.

Students with disabilities are a subpopulation noted under the EFA initiative, though they are largely excluded from educational development programs and initiatives. In particular, students with the most involved intellectual and developmental disabilities, such as cerebral palsy and autism, are frequently not considered within the parameters of educational programs supported by USAID and other international donors.

This Issues Brief concerns the classification of children with disabilities in educational systems, including how such classifications vary across countries. The implications of the differing classification criteria affect the provision of educational opportunities for every child, regardless of the nature or level of his or her physical, mental, or sensory disability.

Developing and implementing educational opportunities for children with disabilities require a commitment to promoting and advancing the rights of all children, as well as recognizing that some children require additional support to realize their rights. The 1994 Salamanca Statement and Framework for Action defined such children as having special education needs (SEN): "children and youth whose needs arise from disabilities or learning difficulties." The Salamanca principles and the rights of children and adults with disabilities have been endorsed in resolutions at conferences and conventions sponsored by international disability organizations—such as the Disabled Peoples' International, Inclusion International, and Rehabilitation International—as well as the United Nations, The World Bank, regional development banks, and other international aid organizations. Among these international agencies, USAID's disability policy is as follows:

> *To avoid discrimination against people with disabilities in programs which USAID funds and to stimulate an engagement of host country counterparts, governments, implementing organizations, and other donors in promoting a climate of nondiscrimination against and equal opportunity for people with disabilities.*

Inadequate human and fiscal capacity and attitudinal and cultural barriers are among the hurdles that must be surmounted for children with disabilities to be included within the goals of EFA. However, the lack of data on students with disabilities is one of the most immediate barriers. Individual country policies pertaining to the classification of disability confound this deficit. Decisions about who is educated—versus who is habilitated or treated—are often tied to classification. Classification criteria may also determine which children enroll in regular schools and which must go to special schools. To ensure that all children with disabilities receive educational opportunities, policymakers and program administrators first need to understand the variability in definitions of disability.

Who Are the Children with Disabilities?

Most children with disabilities who require special educational services can be classified into two broad groups: 1) those with defined medical conditions and syndromes, including severe intellectual, physical, and/or sensory disabilities; and 2) those with judgmental or socially constructed disabilities.

Children within the first group are typically identified at birth, during the early preschool years, or at the onset of a disability acquired later in childhood. Identification follows clear medical diagnostic criteria. Children with judgmental disabilities do not have clear medically defined characteristics and are typically not identified until they enter school, where they may demonstrate problems speaking or learning to read and write. They may also exhibit emotional and behavioral problems. On the basis of school behaviors, such children are classified as "learning disabled," "mildly mentally retarded," or "emotionally disturbed." Following are four examples of school-age children with disabilities.

Alicia

Alicia was born with a physical impairment that resulted in her knees inverting together. Although she can walk, she cannot run or walk as quickly as other boys and girls. She does not have a cognitive or emotional disability, but the principal of the community public school could not see beyond her physical disability and refused to enroll her. Instead, the principal recommended that Alicia be sent to a cross-categorical day school that primarily admitted children with significant disabilities or sensory impairments. Alicia's mother knew her daughter did not need to attend a special school but enrolled Alicia in the special school—a 40-minute bus ride away—after several principals refused to admit her. This example highlights the consequences of lack of awareness about physical disabilities.

Otun

"What is the point of feeding him? He is a spirit." Otun's father spoke these words when his son was born with severely deformed limbs and a cleft palate. The infant's mother did not care to hold or nurse him and left to starve, but his father took pity and gave Otun some powdered milk. The baby was given no formal name, but "otun," in Borneo, means "cut off," referring to his arms and legs. Now five, Otun is cared for mostly by his grandmother and lives with his extended family. The other children look out for him although he does not talk and is considered very slow. Otun does not attend school nor has he received even informal education. This is an example of how cultural beliefs and attitudes have deep repercussions throughout a child's life. Early intervention with Otun and his family is critical to changing attitudes at the community level.

Sherwin

Sherwin, 16, is not permitted to leave his house. He has never gone out to play with other children, been to the store, or attended school. Although he has never been diagnosed, Sherwin's family has known that he was different from other children since he was a young child. By comparison to children his age, Sherwin's development appears stalled. Every morning, he sits in the open window of his house watching people pass by. He shouts to them, jumps up and down, and smiles and laughs. By keeping him at home, Sherwin's family believes it is protecting him from harassment and other dangers. Sherwin appears happy, but he has no opportunity to realize his potential. In many countries, children like Sherwin remain largely hidden, without any educational opportunities. Increasing awareness about children like Sherwin would better equip families to provide a healthy environment promoting social and intellectual development.

Damir

Damir, 12, attends a primary school in a small suburb outside Sarajevo, Bosnia-Herzegovina, that is home to many refugees. Damir is in the fourth level at school and wants to become a locksmith. But he spends his days in class sitting silently and is often seen wringing his hands and tearing at his nails. His mother hanged herself after the family was expelled from Sbrebrenica. His father is missing and is assumed dead. Damir and his sister were placed in several foster homes after their mother's death, but were taken out by their uncle several years later. Damir now lives in a small flat with his uncle, young cousin, and elderly grandmother. Damir's uncle says, "We wanted to take him and his sister right in, but we were living in a tent at the time." Because Damir rarely speaks or responds to questions, his teachers are concerned that he is not progressing in school. He can read and do some math, but is at a different grade level from his peers. His teachers believe is speech-impaired, and a speech therapist has given him some articulation therapy. But Damir's uncle says that Damir used to speak well and was a happy little boy. The teachers want Damir to be categorized as mentally retarded so he can attend a special school in the city. Damir's uncle does not know how he could get Damir to the special school, as a bus ride would cost money. Damir's uncle does not have a steady job; he repairs cars when he can or works at a construction site. This example highlights potential problems with classification systems that result in inaccurate labeling of children and segregation from the mainstream.

Incidence of Disabilities and International Classification

The World Health Organization (WHO), United Nations, and USAID generally agree that approximately 10 percent of the total population have a physical, mental, or sensory impairment (Metts 2000). However, reported estimates on the proportion of disabled persons in the population range from 5.2, percent according to the United Nations Development Programme, to between 13 and 20 percent, according to the Roeher Institute in Toronto, Canada. In addition, Peters (Inclusive Education 2003) estimates that 80 percent of persons with disabilities reside in developing countries and that conditions such as poverty, violence, abuse, and HIV/AIDS result in a higher proportion of disabled persons. WHO also states the percentage of persons with disabilities cannot be determined more accurately because of classification systems used to determine who is disabled.

No common definition of special education has been adopted by any country, and it is difficult to conceive of a method that would generate consistent and comparable statistics from one country to another. SEN is nonstigmatizing terminology that refers to children who require specialized or more intensive educational resources, but it has not been universally adopted and lacks the precision needed for policy, resource allocation, and program accountability. Accordingly, programs and delivery mechanisms to provide educational services to mentally, physically, or emotionally disadvantaged students and other groups with special learning needs vary from country to country.

Though school enrollment data for students with disabilities are largely unavailable in most countries with developing educational systems, the Organisation for Economic Co-operation and Development (OECD) collects education statistics in over 60 countries. These provide internationally comparable data on key aspects of education systems, including the cost and types of educational resources. But only 16 countries collect data on students enrolled in general education who receive additional special education resources (OECD 2004). These data provide an indication of the variation in disability classification and educational models. Among the 16 countries, the proportion of students receiving special education resources varies from 0.6 percent in Mexico to 4.6 percent in the United States. These data do not include students with a learning disability or students who are emotionally or behaviorally disabled.

The International Classification of Functioning

To address the need for a universal classification system for disability, WHO developed the International Classification of Functioning and Disability (ICF), released in 2001. The ICF represents a major revision of the 1980 International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was developed as a tool for classifying the consequences of disease. The current version is intended for use in education, health, rehabilitation, statistics, and policy.

The ICF conceptual framework is based on the social model of disability. It defines disability in three parts: 1) the particular body function or structure that has been lost or is functioning abnormally; 2) the activities and/or participation in daily living restricted or limited by 1); and 3) the level of severity of the limitation. In this model, "disability" is a condition that is constructed through interaction between the individual and the environment. Thus, the ICF requires that individuals with physical or mental impairments be considered in terms of how such impairments limit their ability to function, whether in education, home, community, or workplace. For children with learning impairments, how they function in the environment is important. For example, a child who is having difficulty learning to read will have difficulty in school, but is unlikely to have substantial limitations functioning in home and other environments.

According to the ICF model, a child may have a physical impairment that results in a severe speech disorder and affects his or her ability to communicate. But since the disorder does not impair the ability to learn, with some supports, the child can learn in an inclusive classroom and fully participate in the community. Though this child may require specialized therapies, he or she does not have learning disabilities and should not be excluded from school or given a specialized curriculum. Another example is a child who has difficulty walking, thus requiring physical accessibility and transportation to and from school, but not special education.

A number of countries and the World Bank have adopted the ICF classification framework as their definition of disability. However, the application of the ICF model, including how one assesses across domains, is very complex and requires extensive training. The ICF is thus not particularly suited for use in schools. Nonetheless, many countries are using a social model similar to the IFC when defining disability in their laws and policies. Other countries use a medical model, based on strict categories of impairments and conditions.

Zimbabwe

Zimbabwe's Disabled Persons Act defines a disabled person as "a person with a physical, mental or sensory disability…which gives rise to physical, cultural, or social barriers inhibiting him from participating at an equal level with other members of society." This definition is somewhat circular, as it uses "disability" to define a disabled person. The law does not emphasize the extent of a person's impairment. Rather, it looks at how that impairment "gives rise to" or results in "barriers" that inhibit "equal" participation, as compared with society at large.

Venezuela

Venezuela used a social model approach in its 1994 Law of Integration of Persons with Disabilities. The law defines persons with disabilities as "those whose opportunities for social integration are diminished, due to a physical, sensory, or intellectual impediment of differing levels or degrees that limit his or her ability to carry out any activity." The law focuses on how opportunities for social integration are limited by the person's disability, rather than emphasizing the need to show a particular level of functional impairment for purposes of qualifying for protection under the statute.

Hungary

The definition in the 1998 Hungary Equalization Opportunity Law incorporates a social model with medical restrictions on who is protected. The law defines a "person living with a disability" as "anyone who is to a significant extent or entirely not in possession of sensory—particularly sight, hearing—locomotor, or intellectual functions, or who is substantially restricted in communication, and is thereby placed at a pertinent disadvantage regarding active participation in the life of society."

China

In China, a person with a disability is defined as "a person who has lost all or part of his/her ability to perform normal activities, due to loss or impairment of psychological or physiological functions." Categories are visual impairment—blindness or low vision, which each have two levels of severity; hearing and speaking impairment—deafness or hardness-of-hearing, which each have two levels of severity; physical disability, which includes four levels of severity; intellectual disability; and psychiatric disability.

Thailand

Thailand's Rehabilitation of Disabled Persons Act defines a disabled person as one "with physical, intellectual, or mental abnormality or impairment, of which the type and criteria are designated in the ministerial regulation." Types of disability are impairments of vision, hearing or communication, physical ability or locomotion, mental ability or behavior, and intellect or learning ability. Impairment of mental ability or behavior is defined as "psychological abnormality or malfunctioning of a certain part of the brain associated with perception, emotion, and thought, which causes inability to control behavior necessary for self-care or living with others." Impairment of intellectual or learning ability is the "abnormality or malfunctioning of the brain or intelligence, which causes inability of a person to learn through a regular educational system."

India

India's 1995 Persons with Disabilities Act defines a person with a disability as a person who is "suffering from not less than 40 percent of any ability as certified by a medical authority." The law identifies four categories: locomotor disability, hearing impairment, mental retardation—defined as a "condition of arrested or incomplete development of a person's mind"—and low vision or no vision.

Cultural Barriers

Despite recent pressure on countries to adopt disability rights policies and more forward-thinking definitions, long-standing cultural beliefs about disabilities continue to interfere with efforts to educate all children. According to Ingstad and Whyte (1995), many cultures view impairments as a personal failure: a child is considered bad or irreparably tainted. In some cultures, individuals with physical abnormalities are considered deserving of life, but the survival of children born with conditions such as dwarfism and hydrocephalus may be much less valued. Cultures such as the Masai do not view impairment as a defect, per se. Only if the condition interferes with an individual's ability to be part of the group—to marry and have children—is it viewed negatively.

Buddhist teachings hold that disability results from a vice a person had in a previous life, though also extols mercifulness for the weak. Though donations to disabled beggars or charities might be regarded as a good practice that supports persons with disabilities, it can also be viewed as preventing persons with disabilities from joining society on an equal footing.

Why Is Classification Important?

Disability advocates and some international organizations challenge the need to categorize children with disabilities because labeling perpetuates the medical approach to disability and stigmatizes children. Yet, it remains important to appropriately distinguish children with disabilities from those requiring more intensive educational supports due to poverty, lack of educational opportunity, or similar environmental factors.

Most agree that children of different genders, races, or ethnicities have the right to access a publicly funded education, though this cannot be said about children with disabilities—particularly those with severe limitations in intellectual and physical functioning. Arguments against educating such children raise questions regarding the cost and benefit of establishing special programs and the lack of technical expertise to provide them. Often, concerns are expressed about protecting such children, with the focus on their safety precluding their attendance at school.

Sometimes a larger issue is what constitutes education, and whether it is viewed as synonymous with officially sanctioned curriculum or subject matter. Children who may require specific instruction in functional skill areas—such as basic communication, toileting, or self-care—are viewed as needing something other than education. Thus, they may not be allowed to enroll in school or may be required to attend a special school or facility with a special curriculum.

Labels or classifications do not inform teachers or schools about what a child may need, and inappropriate or unnecessary classification can result in long-term consequences. Such labels may contribute to the assumption that all children in a category function in the same way or require the same instruction. Yet, from an educational policymaking perspective, it is important to have a universal understanding of what constitutes a "child with disability."

Who may be included in a country's data and the data's comparability across countries both need to be understood. This is required for emerging educational indicator systems and accountability mechanisms. Classification systems are important for administrative and program planning. Understanding who and where children with disabilities are is also required for educational needs assessments and determinations of ministerial responsibilities. For instance, a ministry of education may be accountable only for children with mild or moderate educational disabilities, while children with more severe disabilities may be the responsibility of a ministry of health or social protection.

Classification affects resources. In many developing countries, communities and NGOs assume responsibility for providing the resources and implementing educational programs for children with disabilities, particularly those with more severe disabilities (Metts 2000). The 2000 Global Assessment of Education For All reported that 63 percent of all education costs worldwide are paid by the government, 35 percent by the private sector, and 2 percent by external support. However, according to Hegarty (1995), special education funding comes from a mixture of government, voluntary organizations, NGOs, and parents, and these funds may be restricted to one class of students, such as the sensory-impaired. Programs and initiatives may be disproportionately focused in one area, while other children with disabilities are ignored or underserved. It is insufficient to simply document the numbers or types of programs without some knowledge of the children they serve.

Criteria for Classification Systems

Debates about classification or students with disabilities are not new, nor have they been resolved. In their 1975 paper "The Definition of Disability," Cromwell, Blaskfish, and Strauss identified several criteria for any classification system, including the following:

Reliability. A specific condition or characteristic should be identifiable in different contexts, in different children, and by different examiners or individuals. Unreliable criteria, assessment instruments, and procedures create problems. One consequence is that children living in extreme poverty and those belonging to an ethnic or language minority are at particular risk for being inappropriately identified as having a disability. Children who come to school lacking certain prerequisite skills and then confront classrooms with ill-equipped teachers and poorly organized curricula are at great risk of failure. Schools overwhelmed with large numbers of such children may seek a way of sorting them based on the severity of the academic deficiency and then classify some as disabled. Unreliable or ambiguous classification procedures exacerbate these issues.

Coverage. Criteria used in classification systems should be observable and understandable to teachers and families. Criteria should also include all possible conditions or symptoms across a variety of settings. In large part, the ICF was developed to respond to the need for a comprehensive classification schema and process that could be implemented across countries and encompass all situations.

Usefulness. The criteria should clearly link to educational services and interventions. Medical and similar terminology used to define a disability do not convey educationally relevant information. The terms "learning disability," "special education needs," and "intellectual disability" are so broad as to risk becoming meaningless to teachers, parents, and policymakers. Assessment information that is not educationally relevant is an unnecessary cost.

Conclusions and Recommendations

Throughout the world, more children with disabilities are being offered educational opportunities than ever before. However, many remain unschooled and largely hidden from society. It is therefore critical to work with ministries, NGOs, community groups, parents, and others to understand the wide range of conditions and characteristics of children with disabilities.

To advance educational opportunities for all students and meet EFA goals, educational policies and programs need to be designed and implemented from their inception to accommodate all children, including children with disabilities and even those with significant intellectual disabilities.

To achieve this goal, EQUIP2 recommends:

- Conducting in-country reviews of disability terminologies and classifications;
- Conducting assessments to determine the number of children with disabilities served in general education schools and other settings, as well as the range of special education programs available and the resources dedicated to support services for children with disabilities;
- Developing or revising cohesive and reliable educational classification systems that yield cross-country, comparable data on children with disabilities and permit the tracking of types of services, programs, and resources;
- Subjecting classification systems to periodic review to ensure they are valid and useful, continue to reflect best practices, and are acceptable to all;
- Promoting the guiding principle of the Salamanca Statement and Framework for Action—that every child has a fundamental right to an education—in all educational initiatives to break down attitudinal barriers and create universal acceptance that children with disabilities are not an afterthought or a special project; and
- Working within the educational community to increase awareness about children with disabilities and their abilities.

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