Chapter 17

Disability in Middle Childhood and Adolescence

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INTRODUCTION

Worldwide, people with disabilities have difficulty accessing education, health services, and employment. Disability is an economic development issue because it is linked to poverty: disability may increase the risk of poverty, and poverty may increase the risk of disability (Sen 2009). A growing body of evidence indicates that children with disabilities and their families are more likely than their peers to experience economic disadvantage, especially in low- and middle-income countries (LMICs).

Approximately 15 percent of the world's adult population lives with some form of disability (WHO and World Bank 2011). Children ages 0–14 years account for slightly less than 6 percent of persons with disabilities globally, but the number of disabled children is grossly underestimated in LMICs (UNICEF 2008). The estimates for prevalence of disability among children fall in a wide range because the methods for identifying them in surveys have varied (Cappa, Petrowski, and Njelesani 2015). This variation results from the complexity of identifying childhood disability (Meltzer 2010, 2016). However, new international standards offer hope for good quality, internationally comparable data moving forward.

This chapter expands on a central theme of this volume: the need for a multisectoral approach to addressing the complex interactions between child and adolescent development and physical and mental health. In particular, we have focused on the relationship with education—the gateway to participating fully in society, securing a livelihood, and capitalizing on the opportunities that society offers. Children with disabilities are less likely to attend school; when they do attend school, they are less likely to stay in school and be promoted (Filmer 2005; Mizunoya, Mitra, and Yamasaki 2016; WHO and World Bank 2011). They account for a large proportion of children who do not complete a primary education, reducing their employment opportunities and productivity in adulthood (Burchardt 2005; Filmer 2008; Mete 2008).

The literature has focused on advocacy, reflecting the relative neglect of this important area. This focus is beginning to change, at least with regard to the availability of information, and efforts to provide more quantitatively rigorous information are increasing (see, for example, WHO and World Bank 2011). However, information for children and adolescents ages 5–19 years is notably lacking, especially from LMICs. In this age group, the focus has been on schoolchildren and the development consequences of excluding children from education. In the absence of a comprehensive economic analysis or review of disability and development in children and adolescents, this chapter makes extensive use of case studies, which document real-world efforts in LMICs to address disability in this age group in poor communities.

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Through the use of these case studies, this chapter provides examples of how deprivations can become disability if children are excluded from school in LMICs. The case studies emphasize interventions to ensure that children with disabilities gain access to education, and they examine the design of supportive education systems and the use of school health programs to address the needs of children with impairments. Most assessments have focused on physical disability, especially mobility, and they provide this specific perspective on barriers to education. Little is known about these common forms of disability in LMICs; even less is known about the impact of sociobehavioral constraints, such as those associated with autism, which we know to be prevalent and important constraints in high-income countries (HICs). This chapter explores this issue in a case study of a rare program in a lower-middle-income country in Sub-Saharan Africa. Definitions of age groupings and age-specific terminology used in this volume can be found in chapter 1 (Bundy, de Silva, and others 2017).

DISABILITY DEFINITIONS AND MEASUREMENTS

Disability can be defined and measured in several ways. Traditionally, disability was considered a medical issue to prevent or cure (medical model). Later, disability came to be considered a social construct that required societal changes (social model). More recently, interactional models of disability have been developed that combine both medical and social determinants and courses of action. In this bio-psychosocial model, disability is seen as emerging from the interaction between impairments and the environment; environment is understood as going beyond the physical environment to include the cultural and institutional environments. Several interactional models are available (Mitra 2006; Shakespeare 2006); the most influential is the one underlying the International Classification of Functioning, Disability and Health (ICF) (WHO 2002). In the ICF, disability refers to the negative aspects of the interaction between the individual with a health condition and the context of the person (such as physical and attitudinal). Under the ICF, disability is used as an umbrella term for impairments, activity limitations, and participation restrictions. In addition to theoretical definitions for these models, various definitions of disability are used by statistical agencies that collect information on censuses and surveys, as well as by legislative and political bodies to determine eligibility for disability programs or coverage under disability rights laws. The UN Convention on the Rights of Persons with Disabilities uses a concept of disability consistent with the social model.[1]

The differing nuances of the word *disability* and the differing cultural contexts within which people operate have made internationally comparable data on the incidence, distribution, and trends difficult to obtain. Where children are involved, further complexities arise. For example, survey questions developed for adults but used for children may skew the results (WHO and World Bank 2011), and caregivers who complete surveys may not accurately portray children's experiences (Chamie 1994). The setting for data collection can also affect the prevalence estimates for children. For example, HICs often identify disability in medical or educational settings, but many LMICs do not have formal services for identifying children with disabilities (Cappa, Petrowski, and Njelesani 2015).

Progress is being made with respect to measuring disability in an internationally comparable manner, and the United Nations Children's Fund (UNICEF) and the Washington Group on Disability Statistics (WG) have developed a survey for identifying children with disabilities. Data using the child functioning module, or *child questionnaire* have been finalized and ready for use.

The WG has also developed questions for adults that have already been adopted in censuses, general surveys, and disability-specific surveys, creating a growing evidence base for work on disability and development (Altman 2016). Both the WG's adult and the child measures define people with disabilities as those with functional and basic activity limitations that put them at risk of social exclusion due to barriers in the environment (Altman 2016).

Various ethical considerations arise when collecting data on children with disabilities. Data on children come from surveys of mothers or primary caretakers. Caretakers who have responded to questions about children's difficulties functioning might expect that the questions will be followed by services, and a second-stage assessment needs to be linked to service delivery. Another concern is the issue of labeling a child as having a disability. This labeling can cause shame to families in some cultures and can create expectations that limit children. Fortunately, the newer approach to disability identification in surveys, as in the UNICEF/WG instrument, lessens the impact of this issue significantly. The word *disability* is never used, and children are never labeled as having a disability. Children are identified only anonymously in statistical analyses, rather than on a case-by-case basis in person.

This chapter defines disability by a person's functional, activity, and participation limitations based on his or her physical, cultural, and policy environments. The concept of disability is not solely equated with a medical diagnosis; it encompasses an environment that restricts a person's activity and participation. A lack of assistive devices, an inaccessible physical environment, negative attitudes, and stereotypes all prevent people from participating in society on an equal basis. Because this chapter is a literature review, it also uses the definitions underlying the studies under review, which may be different from the above definition.

PREVALENCE BY AGE AND TYPE OF DISABILITY

The estimated prevalence of childhood disability varies substantially across and within countries, depending on questionnaires and study designs under use. The prevalence estimates in this chapter are not definitive but rather a reflection of available data. A literature review by Cappa, Petrowski, and Njelesani (2015) found that the prevalence of childhood disability in LMICs ranged from less than 1 percent to almost 50 percent. Unfortunately, census data are not good sources of data on disability among children because census questions—even the short set of WG questions recommended for use in censuses by the United Nations Statistical Commission—are not effective in identifying children with developmental disabilities. A special child-functioning survey module is needed to accurately assess disability status, and this module would be too long for use in censuses.

Despite the shortcomings of the measures used to date, there are a number of estimates of disability prevalence among children. Based on the latest Global Burden of Disease (GBD) data (IHME 2016), on average, a greater percentage of children ages 0–14 years in LMICs are estimated to have a disability compared with children of the same age group in HICs (table 17.1). The IHME statistics define disability in a particular way because it is used as the basis for the estimation of disability-adjusted life years. Disability in this context includes the acute, often temporary, and typically reversible disability that arises from, for example, an episode of influenza, a bout of malaria, or a broken limb, as well as the chronic, often permanent, and typically irreversible conditions within the more usual definitions of disability. As a result, the IHME definition leads to estimates that suggest a much larger proportion of the population is affected.

UNICEF (2005) estimates that 150 million children and adolescents younger than age 18 years live with disability. Mizunoya, Mitra, and Yamasaki (2016), using the WG questions for adults, found that the median prevalence stands at 0.8 percent and 1 percent for primary- and secondary-school-age children, respectively, in 15 LMICs. Disability prevalence in primary-school-age children did not surpass 1.5 percent in 12 of 15 countries, but it was much higher in 3 countries (2.9 percent in Uganda; 4.5 percent in South Africa, and 5.0 percent in Maldives). Disability prevalence rates in secondary-school-age children do not exceed about 2.0 percent in 13 of 15 countries. None of these disability prevalence estimates for children is satisfactory, and more research and data collection are needed in this area.

The GBD estimates are inferred from data on health conditions and impairments alone, using available data on distributions of limitations that may result from health conditions and impairments. Mizunoya, Mitra, and Yamasaki (2016) used a questionnaire developed for adults, which is known to be unable to identify certain disabilities that prevail among children, such as developmental disabilities.

There are many types of disability, with varying degrees of severity. A disability can be physical, cognitive, psychosocial, communicative, or sensory. The nature of the causes of the impairments associated with these disabilities can vary significantly by country context, as can the types of barriers that children with those disabilities face. Attention to the type of disability can add a good deal of depth to the analyses of disability data and the development and implementation of disability policies. *Disease Control Priorities in Developing Countries*, second edition, discusses discuss loss of vision and hearing (Frick and others 2006) as well as learning and developmental disabilities (Durkin and others 2006).

Unfortunately, good-quality data on the type of disability—especially data that are internationally comparable—are difficult to obtain (Cappa, Petrowski, and Njelesani 2015; Maulik and Darmstadt 2007). That is one reason that UNICEF and the WG have developed a module on childhood disability. Even data using the Ten Question Screening Instrument adopted in UNICEF's Multiple Indicator Cluster Survey are of limited use in this regard for several reasons. First, the instrument was not designed for complete disaggregation by type of disability. Second, it was designed as part of a two-stage process. The first stage was to cast a wide net to capture all children who might possibly be identified as having a disability, to be followed by more detailed assessment. The second stage, however, is rarely done, which presumably creates false positives for studies using only the Ten Question Screening Instrument. There is no reason to believe that the false positives in the dataset have the same distribution by type of disability as the true positives. Where follow-up assessments have been used (for example, the 2013 Two-Stage Child Disability Study in Bhutan undertaken by the Bhutan National Statistics Bureau), however, there have been questions about their quality because they require personnel with specific training. The Bhutan report notes that some level of issues arose with the cognitive follow-up assessments.

Table 17.1 Estimated Point Prevalence of Disability and Severity among Children and Adolescents Ages 0–14 across WHO Regions

percent

			Low- and Middle-Income Countries, WHO Region					
Sex and age group (years)	**World**	**High-income countries**	**Africa**	**Americas**	**Eastern Mediterranean**	**Europe**	**South-East Asia**	**Western Pacific**
No disability								
Male 0–14	30	37	22	31	35	36	30	32
Female 0–14	30	37	22	30	33	36	30	31
Very mild disability								
Male 0–14	12	11	13	11	11	13	12	11
Female 0–14	11	12	13	11	11	13	11	11
Mild disability								
Male 0–14	18	15	20	19	18	17	21	19
Female 0–14	20	17	22	21	20	19	23	20
Moderate disability								
Male 0–14	22	23	23	21	19	20	21	21
Female 0–14	22	22	23	21	20	20	20	21
Severe disability								
Male 0–14	15	12	18	15	14	12	15	14
Female 0–14	14	10	17	14	14	11	14	13
Very severe disability								
Male 0–14	2	2	3	2	2	2	2	2
Female 0–14	2	2	3	3	2	2	2	2

Source: IHME 2016.

Note: High-income countries includes Asia Pacific and North America. Western Pacific includes East Asia, South Asia, Central Asia, Oceania, Australasia, and the Western Pacific.

Comparison problems arise in HICs as well. As table 17.2 shows, data on disability among children and adolescents from Australia and the United States are not comparable; the age categories are different as are the categories of types of disabilities assessed. One common result, even with these differences, is that boys have a higher rate of disability. This is a common finding across almost all child disability surveys.

Using its 10-question Multiple Indicator Cluster Survey, UNICEF screened more than 200,000 children ages two to nine years in 20 countries for risk of disability (UNICEF 2008). Between 14 percent and 35 percent of children screened positive for risk of disability in most countries (UN Statistics Division 2010). However, this finding is an overestimate because the questions were designed to be a first-stage screen to be followed by a more detailed assessment that was not conducted.

The surveys revealed important trends in disability risk among children. For example, children in ethnic minority groups, from poorer households, and with limited early childhood education were more likely than their peers to screen positive for disability (UNICEF 2008). Weight and nutrition are risk factors as well (Groce and others 2013). Low birth weight and a lack of essential dietary nutrients, such as iodine or folic acid, are associated with incidence and prevalence of disability (Hack, Klein, and Taylor 1995; UNICEF 2008; Wang and others 1997). The proportion of children at risk for disability increases among children with severe stunting and nutrient deprivation (UNICEF 2008). An estimated 200 million children younger than age five years do not reach their full cognitive, social, and emotional development potential (Grantham-McGregor and others 2007).

Table 17.2 Prevalence of Disability by Type of Disability, Australia and the United States

percent

	Australia			United States		
	Ages 0–14 years			Ages 5–17 years		
	Boys	**Girls**	**All**	**Boys**	**Girls**	**All**
Intellectual or learning	5.2	2.0	3.7	—	—	—
Remembering	—	—	—	5.3	2.8	4.1
Psychiatric	1.5	0.7	1.1	—	—	—
Sensory or speech	4.0	2.1	3.1	—	—	—
Hearing	—	—	—	0.6	0.6	0.6
Vision	—	—	—	0.9	0.8	0.8
Physical	4.2	3.1	3.7	0.7	0.6	0.6
Acquired brain injury	0.5	0.2	0.3	—	—	—
Going outside the home	—	—	—	2.2	1.8	2.0
Dressing	—	—	—	1.2	0.7	0.9
Total	**9.6**	**5.4**	**7.6**	**6.5**	**4.0**	**5.3**

Sources: AIHW 2004; American Community Survey 2014, https://www.census.gov/people/disability.

Note: — = not available. The columns sum to more than the total because some children have multiple disabilities and so are included in more than one row.

DISABILITY AND SOCIOECONOMIC INEQUALITIES: DETERMINANTS, CONSEQUENCES, AND CORRELATION

Disability is both a determinant and a consequence of socioeconomic inequalities. Children in poor families or communities, in LMICs especially, are exposed to poverty-related risk factors that may contribute to the onset of health conditions associated with disability. Low birth weight and cumulative deprivations from malnutrition (Black and others 2008; UNICEF 2008), lack of clean water, and inadequate sanitation can manifest in developmental disabilities (Rauh, Landrigan, and Claudio 2008). In addition, lack of access to health services may convert a health condition into a disability. Finally, a child with a disability might experience further issues that exacerbate the severity of his or her disability (Krahn, Hammond, and Turner 2006). First, certain resources, such as clean water and sanitation or health clinics, may be inaccessible. Second, individuals with disabilities may be subjected to discrimination within their families and receive a disproportionately low share of familial resources (Rosales-Rueda 2014).

Growing evidence suggests a correlation between poverty and disability among children and adults with disability (WHO and World Bank 2011). Overall, in LMICs the evidence points to individuals with disability often being economically worse off in educational attainment; the evidence is more mixed with regard to employment, household assets, and expenditures (Mitra, Posarac, and Vick 2013; Mizunoya and Mitra 2013). However, several studies have provided growing evidence that disability is associated with a higher likelihood of experiencing multiple deprivations simultaneously (Mitra, Posarac, and Vick 2013; Trani and Canning 2013; Trani and others 2015; Trani and others 2016). Although the nature of deprivations may vary across countries, they may include employment, health, educational attainment, household material well-being, social participation, or psychological well-being.

Even with the same levels of income, people with disabilities and their households are likely to be effectively poorer than people without disabilities and their households. This trend is in part due to the direct costs of disability, for example, higher health and transportation costs (Braithwaite and Mont 2009; Cullinan, Gannon, and Lyons 2011; Zaidi and Burchardt 2005). Researchers have attempted to quantify the extra cost of living with a disability, but the findings vary considerably. The costs of disability accounted for an estimated 9 percent of income in Vietnam, 14 percent in Bosnia and Herzegovina, and 11 percent to 69 percent in the United Kingdom (Braithwaite and Mont 2009; Zaidi and Burchardt 2005).

The direct and indirect costs related to disability can worsen social and economic well-being through many channels, including the costs associated with medical care, assistive devices, personal support, and exclusion from employment (Jenkins and Rigg 2003). People with disabilities can be poorer because of the loss of work productivity resulting from various factors including their exclusion from the workforce, as well as from the more limited labor participation of their family members who might have care-giving responsibilities (Buckup 2009; Palmer and others 2015). The estimated cost of lost productivity due to exclusion from employment among individuals with disabilities is as high as 7 percent of gross domestic product (Buckup 2009). Many of the direct and indirect costs could be reduced if inaccessible environments were more inclusive (WHO and World Bank 2011). This two-way causality between disability and socioeconomic deprivations may also combine with other factors, such as violence and conflict, that may lead to both disability and poverty simultaneously.

Educational opportunities may mitigate some of the associations between disability and poverty. In a cross-country study of 13 LMICs, disability was associated with a higher probability of being poor, but this correlation was no longer statistically significant once educational attainment was controlled for, suggesting that education could mediate this association (Filmer 2008).

DISABILITY AND EDUCATION

Many children with disabilities have been excluded from mainstream educational opportunities in many parts of the world. Education is particularly important for disabled children, who are often stigmatized or excluded. School attendance helps dispel the misconceptions about disability that serve as barriers to inclusion in other spheres (Bundy 2011). Education bolsters human capital, minimizes barriers to entering the workforce, and improves economic earning potential.

Inclusive education is based on the belief that all children can learn and should have access to a curriculum and necessary adaptations to ensure meaningful educational attainment. Support for inclusive education is gaining momentum in LMICs, with a few countries adapting strategies to fit the local context. Durkin and others (2006) examine interventions likely to improve child development and educational outcomes for children in LMICs. At present, no country has a fully inclusive system (WHO and World Bank 2011).

School Attendance

A large body of evidence shows that adults with disabilities in LMICs have lower educational attainment than adults without disabilities: Bulgaria, Georgia, Moldava, Romania (Mete 2008); 15 countries (Mitra, Posarac, and Vick 2013); Vietnam (Mont and Cuong 2011); Afghanistan and Zambia (Trani and Loeb 2012); Morocco and Tunisia (Trani and others 2015); India (World Bank 2007); 51 LMICs and HICs (WHO and World Bank 2011).

This association, consistently found among adults, may result from lower school attendance among children with disabilities, or it may be due to more frequent onsets of disability among adults with limited educational attainment, for example, via malnutrition, lack of access to health care, and risky working conditions.

There is a small but growing literature on school attendance and disability in LMICs. Much of this literature is descriptive and documents the extent of the gap in school attendance across disability status (Filmer 2008; Trani and Canning 2013). Filmer (2008) documents gaps in school attendance across disability status in 13 LMICs from 1992 to 2005, ranging from 10 percent to 60 percent in middle childhood (ages 6–11 years), and 15 percent to 58 percent in adolescence (ages 12–17 years), although the measures of disability vary substantially. Studies in Malawi, Namibia, Zambia, and Zimbabwe found that, while only 9 percent to 18 percent of nondisabled children older than age five years had never attended school, 24 percent to 39 percent of disabled children had never done so (Eide and Loeb 2006; Eide, van Rooy, and Loeb 2003; Eide and others 2003; Loeb and Eide 2004). In India, close to 40 percent of disabled children were not enrolled in school, compared with 8 percent to 10 percent of children in Scheduled Tribes or Castes (World Bank 2007).

Mizunoya, Mitra, and Yamasaki (2016) explored the gap in enrollment in primary and secondary education between children with and without disabilities using the WG measure for adults. Using nationally representative datasets from 15 LMICs, they found consistent and statistically significant disability gaps in both primary and secondary education in all countries. A household fixed effects model shows that disability reduces the probability of school attendance by a median of 30.9 percentage points, and that neither the individual characteristics nor their socioeconomic and unobserved household characteristics explain the disability gap. This finding indicates that general poverty reduction policies through social transfers to the poor will not contribute to closing the disability gap in schooling. Finally, Mizunoya, Mitra, and Yamasaki (2016) found that the disability gaps for primary-school-age children follow an inverted U-shape relationship with gross national income (GNI) per capita. This result suggests that, as GNI per capita rises and more resources become available for improving access to education, children without disabilities increasingly attend school, whereas the situation of children with disabilities may improve only slowly.

Among children with disabilities, enrollment rates differ according to type of impairment. In Burkina Faso, disabled children were more than twice as likely not to attend school as other children, but only 10 percent of deaf children were in school, compared with 40 percent of children with other physical disabilities (UNESCO 2010). In India, more than 50 percent of children with mental disabilities were enrolled, compared with 70 percent of children with poor vision, presumably because both physical access and their ability to communicate with teachers is higher for the latter group (Mont 2014).

Barriers to Education

Beyond enrollment and regular attendance, studies show that children with disabilities are more successful in schools that are accessible for all learners (Dessemontent, Bless, and Morin 2012; Kalambouka and others 2007; Lindsay 2007; Ruijs and Peetsma 2009). Common barriers to education include gaps in policy regarding inclusive education, including limited resources, insufficient number of trained teachers, lack of adaptive learning materials, and inaccessible facilities:

- *Accessible facilities.* Building accessible schools is vital to making the transition to inclusive education. Children who use wheelchairs need ramps to enter the school, elevators to attend classes on upper floors, and accessible toilets. Building an accessible school costs barely 1 percent more than building an inaccessible school (Steinfeld 2005), but retrofitting an inaccessible school is considerably more expensive. Incorporating universal design in the floor plan enables schools to include disabled children and minimizes the need for separate schools.
- *Teacher capacity.* Many LMICs educate children with disabilities in separate classrooms or mainstream them into regular classrooms but provide little support. Teacher training and access to specialists are at the core of full inclusion, but very few receive training in inclusive education through either pre- or in-service training (Ferguson 2008; Odom, Buysse, and Soukakou 2011). Children also have limited access to specialists and teaching assistants. Effective programs often include training in inclusive education for administrators at the school, district, and national levels and have the resources, personnel, and discretion to implement changes suitable to the local context.
- *Curriculum design.* A hallmark of inclusive education is having a child-centered curriculum (McLeskey, Waldron, and Redd 2014; Rose, Meyer, and Hitchcock 2005). Curricula in many countries are not adapted to the learning needs, challenges, and strengths of individual children. Inclusive education policies can benefit all children because such policies are intended to respond to individual differences and abilities.
- *Environmental barriers outside the school system.* Schools exist within an environmental context, and exclusion may result from barriers not within the school's purview. These barriers can include, for example, inaccessible transportation, poor provision of assistive devices, and inaccessible health clinics that make the health of children with disabilities more fragile. Exclusion can also result from parents being less willing to send their children to school because of low expectations of the utility of that education or from feelings of shame.

Addressing these issues requires both policy- and school-level changes, as well as an action plan (McGregor and Vogelsberg 1998; Bundy 2011). Perhaps the most important requirement is school- and policy-level leadership committed to educating all children.

Several avenues are available for financing special needs education. Brazil used the national budget to establish a special national fund; Pakistan allocated funding from its national budget to finance a special education network of schools. Nicaragua and Panama dedicate a fixed amount of the overall education budget, 0.92 percent and 2.3 percent, respectively, to special needs education. Chile and Mexico cover the financial costs of special needs institutions, including materials, training, and teaching aids. Denmark, Finland, Hungary, and New Zealand help individuals offset the additional costs of educating a child with special needs. Switzerland and the United States have implemented combined approaches (Hartman 1992; Parrish 1994).

MEASURING ECONOMIC RETURNS OF INCLUSIVE INTERVENTIONS

Measuring the economic returns to inclusive education is complex because the costs are incurred in the short term, but the benefits accrue in the long term. Rigorous evaluations and economic analyses of how to invest in inclusive education programs or the returns generated by inclusive education are not yet available. As a result, the return on investment, children's income potential, and the increase in caretaker productivity are not well known.

In Nepal, education has a bigger impact on the future earnings of children with disabilities than on those of other children (Lamichhane and Sawada 2013). Gains in functional capacity can be largest when interventions occur early in children's development. Early detection of developmental delays can improve development and school readiness (WHO and UNICEF 2011). Removing barriers early can minimize the compounding effects of multiple barriers. One approach is to use education as an equalizing platform, especially in the formative years.

The returns to inclusive education, rehabilitation services, or any other intervention depend on future barriers that individuals with disabilities will face as adults. If significant barriers to employment are coupled with discrimination, transportation difficulties, and weak labor laws, the return on childhood interventions may be small.

Following this line of reasoning, countries with fewer barriers to adult activities will gain higher returns from child services. One sectoral reform by itself may not have a substantial return, but improving inclusion in multiple sectors creates synergies that will increase those returns in the future.

CASE STUDIES

These six case studies provide a nuanced look at both the progress in and the barriers to improving educational provision and participation for children with disabilities. They illustrate how the first steps to inclusive education have been taken in different settings. Observing the positive effects of inclusive education in schools and in communities can spur the development of equitable policies in other sectors.

Case Study 1. Vision, Learning, and Free Eyeglasses

Elisabetta Aurino, Lesley Drake, Paul Glewwe, Imran Khan, and Kristine West contributed this case study.

Poor vision can affect the development of children and adolescents and the economic prosperity of a country, costing the world more than US$200 billion a year (Fricke and others 2012).[2] However, data on the prevalence of visual impairments in school-age children and adolescents are limited and varied. In one 2004 study, 1 percent of school-age children ages 5–15 years (almost 13 million) were visually impaired (Resnikoff and others 2008). Country-specific estimates range from 1 percent in Malawi (Lee 2016), to 13 percent in China (Glewwe, Park, and Zhao 2016), and 31 percent in high-poverty school districts in the United States (Glewwe, West, and Lee 2015).

Poor vision may lead to poor educational outcomes (Bundy and others 2003). Primary schoolchildren in Northeast Brazil with poor vision had a 10 percentage point higher probability of dropping out and an 18 percentage point higher probability of repeating a grade (Gomes-Neto and others 1997). In rural China, poor vision lowered students' academic performance 0.2–0.3 standard deviation, equivalent to a loss of 0.3 year of schooling (Glewwe, Park, and Zhao 2016). In high-poverty counties in the United States, students with poor vision who received free screening and eyeglasses had a 3.4 and 5.0 percentage point higher probability of passing standardized tests in reading and math, respectively, than similar students in control schools.

Skilled eye care personnel and infrastructure are lacking in LMICs, and schools have become a platform for delivering eye care services in various contexts (Limburg, Kansara, and d'Souza 1999; Sharma and others 2008; Wedner and others 2000; Zhang and others 2011). In Cambodia, teachers were trained to assess whether children and adolescents needed an eye examination (Ormsby and others 2012). Within four weeks, fewer than 100 teachers screened 13,175 students and referred 44 to a team of refractionists, who provided ready-made or customized glasses.

The costs per child were minimal, including operational costs (travel, per diems, training), vision screening kits, and glasses (about US$2–US$3 for ready-made and US$3–US$7 for custom-made glasses). Teachers' time was covered by their salaries, while equipment was borrowed. The cost of eyeglasses can vary by the type of glasses and the region or country. In eight delivery models, eyeglasses cost between US$2.59 and US$7.06 per pair (Wilson 2011). Costs were similar in Zanzibar (Laviers and others 2010). In China, costs ranged between US$2 and US$15 (Glewwe, Park, and Zhao 2016). In the United States, screenings cost about US$2, and examinations and glasses cost about US$100 (Glewwe, West, and Lee 2015).

Baltussen, Naus, and Limburg (2009) modeled the cost-effectiveness of interventions to determine the prevalence of visual impairment by age and enrollment in Africa, America, Asia, and Europe. They also evaluated cost-effectiveness for 10 years and found that annual screening was more cost-effective for adolescents (ages 11–15 years) than for children (ages 5–10 years) because of differences in prevalence and enrollment. Screening at broad age intervals was more cost-effective than screening at single age intervals.

Sustainability and other constraints can be challenging. Eyeglasses need to be replaced regularly, especially in children. Supply constraints relate to lack of trained personnel and poor eye care infrastructure. Demand constraints include lack of awareness of need and societal views that eyewear is unattractive (Kodjebacheva, Maliski, and Coleman 2015). In China, take-up was 65 percent, while in the United States it was 75 percent. The main impediment in all studies was failure to gain parental permission for the exam.

In summary, school-based approaches provide an economically attractive intervention to correct visual impediments that hinder child development.

Case Study 2. Childhood Disability, Education, and Poverty in Vietnam

Daniel Mont contributed this case study.

The WG is the international standard setter for measuring disability at the national level. It identifies the likelihood of disability using the ICF. The questionnaire identifies difficulties that people have in undertaking basic activities (box 17.1). It is also useful for disaggregating socioeconomic indicators by disability status (Loeb 2016).

In 2006, Vietnam based disability questions on the WG questionnaire and included them in the Vietnam Household Living Standards Survey, which was administered to a nationally representative sample of households. The result was a high-quality dataset on both disability and socioeconomic indicators (Mont and Nguyen 2013b).

The poverty rate in Vietnam was 22 percent for people with disabilities and 15 percent for people without disabilities (Mont and Cuong 2011). The poverty gap was even higher for younger people. Poverty was nearly twice as high for children with disabilities, after adjusting for the extra costs of living with a disability, as for other children (table 17.3).

Having a childhood disability was also associated with having less education. Children with disabilities were 41 percent less likely to attend school; excluding children with mild disabilities, that figure rose to 47 percent. Overall, having a disability in childhood was found to significantly reduce the chances of completing school for older children and adolescents regardless of the definition of disability or type of school. Having a childhood disability also lowered the level of completed education. Moreover, having a parent with a disability reduced the chances that children without disabilities would attend school (Mont and Nguyen 2013a).

Including the WG questions on both the census and household survey allowed for small-area estimation of the relationship between poverty and disability. The poverty gap between households with and without a disabled member varied significantly and was lower in areas with better infrastructure and health care services (Mont and Nguyen 2013b).

This dataset from Vietnam adds weight to the relationship between disability and poverty. As the questionnaires are administered more widely, policy makers can better determine where the link between disability and poverty is strongest and what the most promising and appropriate avenues are for designing interventions to weaken that link.

Case Study 3. Disability-Inclusive School Health and Nutrition Programs

Sergio Meresman and Cai Heath contributed this case study.

School health and nutrition programs have increasingly been recognized for their educational impact on the most vulnerable learners (PCD 2015). Inclusive education encompasses children who have difficulty seeing or hearing, limited mobility, or difficulty learning in classrooms designed for children without disabilities. *Disability-inclusive school health and nutrition* refers to educational approaches designed to meet the needs of all children who are vulnerable to dropping out or being excluded from education,

Box 17.1

Washington Group Short Set of Questions on Disability

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example, understanding or being understood?

Possible responses for all questions are no difficulty, some difficulty, a lot of difficulty, and cannot do at all.

Table 17.3 Poverty Rates for People in Vietnam, with and without Disabilities, 2006

percent

Current age (years)	People without disabilities	People with disabilities	People with disabilities after accounting for extra costs of living with a disability
5–18	19.3	31.1	36.2
19–40	15.1	24.7	31.4
41–62	9.2	11.9	15.3
Older than 62	14.5	17.0	22.8

Source: Mont and Cuong 2011.

Table 17.4 Pillars of the FRESH Framework

FRESH pillar	Key concepts for inclusion	Practical implications
Equitable school health policies	Inclusive development; universal design	Gather and disaggregate data on children with disabilities; require adequate and sustainable funding; make policy makers aware and trained
A safe learning environment	Physical access; stigma-free environment	Follow accessibility standards; promote human rights, equity, and diversity to remove attitudinal barriers
Skills-based health education	Curriculum adaptations; information, education, and communication materials in accessible formats (Braille, sign language, easy reading)	Adapt methodologies and content to the learning needs of all children; provide accessible learning materials
School-based health and nutrition services	Inclusive delivery of health and nutrition services; cross-sector collaboration; integrated approaches to programming	Train teachers and health workers in inclusive school health and nutrition; provide health screening and appropriate assistive devices; conduct high-quality context analysis; support inclusive homegrown school feeding programs; provide inclusive water, sanitation, and hygiene programming; engage families and organizations to support outreach and delivery of services

Source: Meresman and others 2015.
Note: FRESH = Focusing Resources on Effective School Health.

including children with disabilities, orphans, migrants, those affected by human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), those who do not speak the language used in the classroom or who belong to a different religion or caste, and those who are sick, hungry, or not excelling academically.

In 2000, the Education for All goals and Focusing Resources on Effective School Health (FRESH) framework were launched at the World Education Forum in Dakar (FRESH Initiative 2000). The framework outlines approaches that support effective school health programming (table 17.4).

The FRESH framework is helpful for designing and implementing disability-inclusive school programs because it addresses the needs of the learners from multiple angles. For more information on FRESH, see chapter 20 in this volume on school as a platform for addressing health (Bundy, Schultz, and others 2017).

Although a disability-inclusive approach to school health and nutrition programming is a recent concept, the need for these strategies in education sector planning has long been apparent. Kenya's 2005–10 Education Sector Plan identified two key gaps: a lack of clear guidelines on the implementation of an all-inclusive education policy and a lack of reliable data on children with special needs (Republic of Kenya 2005). Zanzibar's 2008–16 Education Sector Plan noted, "Enrollment of children with special needs is low [and] this results in insufficient support to people with special needs." Key strategies included designing all education interventions in a disability-inclusive manner, collecting more accurate data, and improving training for teachers (Government of Zanzibar 2007).

School health and nutrition programs are becoming more disability inclusive. In Kenya the government's homegrown school feeding program (discussed in chapter 12 in this volume, Drake and others 2017) sought to improve targeting and data collection for all vulnerable children, sensitize teachers and parents, and provide vocational training to improve economic outcomes (PCD 2013).

Case Study 4. Early Childhood Monitoring to Screen for Disability in the Lao People's Democratic Republic

Sally Brinkman contributed this case study.

The Lao People's Democratic Republic is a predominantly rural low-income country. More than two-thirds of the country's 6.5 million people live in rural areas, where the poverty rate is almost 30 percent (Lao Population and Housing Census 2015; Lao Statistics Bureau 2014). Most rural children have never seen a doctor, and less than one-fifth of the population lives in villages with health centers; three in four villages have primary schools (Lao Population and Housing Census 2015). Little is known about the situation of children with disabilities (Evans and others 2014).

In April 2014, the Early Childhood Education Program received funding to improve child development and school readiness and establish a monitoring system to measure child development. The program includes a two-phase process. First-phase screening is part of a population-wide system for monitoring childhood development. Second-phase screening is provided to children who were identified in the first phase as having a disability or impairment (World Bank 2014).

The project is collecting baseline data using the WG short set of questions on disability, with data to be collected on an estimated 6,500 children across five provinces. The results will demonstrate the questionnaire's effectiveness in Lao PDR and determine the prevalence of childhood disability—both important steps in filling the current knowledge gap regarding children with disabilities.

The most likely impediment to scale-up of the program will be the expense and service capacity needs associated with second-phase screening, which must be covered by the health care system, nongovernment agencies, or families. Analyzing the results of first-phase screening against the diagnostic tests to assess the costs of scaling up to the national level will be important.

Case Study 5. Autism Spectrum Disorders: Providing Inclusive Education in Kilifi, Kenya

Amina Abubakar, Andy Shih, Joseph Gona, and Amy Daniels contributed this case study.

The prevalence of autism spectrum disorders has grown considerably in recent decades. Today an estimated 1 in 68 children in the United States has autism (CDC 2014), and estimated prevalence is comparable in other regions (Elsabbagh and others 2012). Autism is typically a lifelong condition characterized by impaired social interaction and communication and the presence of restrictive or repetitive behavior. Children with autism are significantly more likely to have intellectual disabilities and other mental and physical conditions than other children. Autism can severely affect the quality of life of autistic persons and their caregivers.

In the United States, autism was estimated to cost US$1.4 million for individuals over a lifetime and US$137 billion for society per year (Buescher and others 2014). Less is known about the costs of autism in LMICs (Wang and others 2012; Xiong and others 2011).

In Kenya, inclusive education has been a major government policy for many years, but most children with disabilities continue to receive their education in special schools and units (Adoyo 2007; Kenya Ministry of Education 2009). To investigate some of the factors that have hindered the success of inclusive education, Autism Speaks conducted a small qualitative survey of stakeholders, including teachers, placement officers, and representatives of a community-based organization, in Kilifi, Kenya. The discussions centered on the challenges facing the mainstreaming agenda and the steps that could be taken to facilitate inclusive education. Questions were asked about children with autism, although the interview also touched on other forms of disability.

The survey revealed that inclusive education in Kilifi faces four principal challenges: teacher-related problems (lack of training; poor attitude toward inclusion), family obstacles (preference for separate education; tendency to delay the start of school for children with disability), inadequate resources (inadequate facilities; large class sizes), and government policies (motivation allowances for teachers in special units but not for teachers with disabled students in regular schools; former practice of basing school resources on test results). Teachers in mainstream schools identified lack of adequate training for handling children with disabilities as the major hindrance to inclusive education.

What needs to be done to facilitate inclusive education in Kenya and other low-resource settings? Participants from the study highlighted four areas that have the potential to be scaled up in Kenya and other countries:

- Train and provide teachers in mainstream schools with the skills required to handle students with special needs

- Ensure that children with limited mobility can move around the school comfortably
- Initiate parent-based interventions aimed at raising awareness and encouraging them to time school matriculation properly, reinforce skill-building techniques at home, and become engaged in inclusive education efforts
- Make special needs education mandatory for all teacher trainees and critically evaluate the current teacher education curriculum in colleges and universities to ensure an all-inclusive curriculum.

Taking steps to implement the policy and provide adequate infrastructural support for learners with special needs will contribute toward a more inclusive educational setting in Kilifi, Kenya, specifically, and in other low-resource settings more generally.

Case Study 6. Targeting HIV Prevention and Sexual Health Education for Young People with Hearing Loss in Brazil and Uruguay

Sergio Meresman contributed this case study.

Persons with disabilities are at high risk of HIV/AIDS exposure and are disproportionately affected by the epidemic in communities worldwide (World Bank 2003). The main drivers of the epidemic are strongly associated with disability, including a high prevalence of poverty (Inclusion International 2006; Watermeyer 2006), lack of education (Helander 1999; Muthukrishna 2006; World Bank 2003), and lack of access to sexual and reproductive health education or services (DenBoer 2008; Katoda 1993; WHO and UNFPA 2009). Once persons with disabilities become infected, many structural and social factors linked with disability significantly decrease the likelihood that they will receive the treatment, care, and support available to other people living with HIV/AIDS (World Bank 2004).

Because of the misconception that individuals with disability are not exposed to sexual violence and abuse and not at risk of contracting sexually transmitted infections (Berman Bieler and Meresman 2010), prevention campaigns and educational programs frequently overlook this population, making it more vulnerable to the risks of transmission (Groce 2003). A long chain of barriers and taboos—combined with the poverty and exclusion that disproportionately affect persons with disabilities and their families—deprives disabled persons of access to sexuality education suited to their age and needs, to HIV/AIDS programs, and to health services in general.

In South America, the deaf and hard-of-hearing population is one of the largest groups omitted from HIV/AIDS education. In Uruguay, a country with more than 30,000 people who have severe hearing impairments or are deaf (MIDES 2011), most children and adolescents with disabilities attend school but are not involved in health and sexuality education programs (Meresman and others 2015). In Brazil, a country with more than 5 million people who have impaired hearing (CONADIS 2010), HIV/AIDS education has involved marginalized communities for many years, but materials in sign language and inclusive programming have yet to be developed.

Since 2010, the Inter-American Institute on Disability and Inclusive Development, the Center for Health Promotion, and the Partnership for Child Development have been working with deaf organizations in Brazil and Uruguay to promote inclusive approaches to HIV/AIDS education and information on reproductive health. This partnership established the Everyone's School (Escola de Todos) Program, which is administered in collaboration with the national education and health authorities and the national HIV/AIDS programs in both countries. Everyone's School provides access to reproductive health and HIV/AIDS education in sign language for deaf youth. Educational resources were prepared by deaf participants and distributed throughout the deaf community in Brazil and Uruguay. The set included posters, postcards, and quick response (QR) code messages—a digital media platform that is increasingly being used in inclusive school health and nutrition projects—aimed at deaf people. Two workshops were conducted. In each, about 20 participants adapted and translated key messages on health, prevention, and effective condom use into Brazilian and Uruguayan sign language.

As a result of the positive outcomes of the Everyone's School Program, task forces were created with the goal of improving accessibility to programs and services. Such interest spawned new initiatives, including an inclusive prevention grant made available by the National Prevention Program of Uruguay to support training and to design accessible campaigns around sexually transmitted diseases and unwanted pregnancies. A group of deaf youth trained in the initial program is preparing to implement the new initiative.

CONCLUSIONS

The definition of disability has changed over the years and is now commonly used to describe the interaction between impairments and the physical, cultural, and institutional environments. Progress on defining disability has not been matched by efforts to provide standardized estimates of the prevalence of disability. The differing nuances used by statistical agencies, legislative, and political bodies has made it difficult to collect comparable data on prevalence and severity of disability in both LMICs and in HICs, alike.

Education is the gateway into society, but that gateway is not fully open to children with disabilities. Developing polices that equalize the opportunity to receive a quality education requires a deeper understanding of the scope and nature of children with disabilities' exclusion and the barriers they face. Recent development in how we conceptualize and measure disability are beginning to make a difference in our ability to do that.

Introducing inclusive education is the start of a process to increase the ability of individuals with disabilities to participate in their communities. The path to implementing and achieving inclusive education is complex and is likely to be country specific. However, meaningful steps can be taken at all stages of development.

Establishing inclusive education may be slow, but cross-sectoral collaborations will be critical to achieving progress and to documenting and disseminating successes. The impacts of disability are cross-sectoral, and an approach that focuses on a single sector will be less successful than an approach that takes into account the full range of challenges facing a disabled child. Policies that promote access to education will be more fruitful if school-to-work transition programs are in place to promote employment and inclusion for people with disabilities.

Several publications and reports have outlined key actions that governments can take to support children with disabilities (Thomas and Burnett 2013; UNICEF 2013, 2015). The following actions, which are in line with the recommendations of these publications and those outlined in the *World Report on Disability* (WHO and World Bank 2011) and in the *State of the World's Children 2013* (UNICEF 2013), should form part of a successful platform designed to meet the needs of all learners:

- Undertake situational analyses to better understand the nature and scope of the barriers children with disabilities face when it comes to attending school. These studies should rely on the bio-psychosocial model of disability that conceptualizes disability as arising from the interaction between a children's impairments and the environmental barriers they face.
- Promote inclusive education for children with disabilities at all levels, including early childhood education, and review national policies in relevant sectors—health, education, and social—to ensure that they are aligned with international conventions and commitments and inclusive of children with disabilities
- Collect high-quality data about disability and the school environment via administrative data systems consistent with international standards to fill gaps and monitor progress on the education of children with disabilities.
- Analyze sector-wide strategies, programs, and budgets to determine whether they include concrete actions to support children with disabilities and their families
- Develop, implement, and monitor a comprehensive multisector national strategy and plan of action for children with disabilities that addresses family support, community awareness and mobilization, human resources capacity, coordination, and service provision
- Establish clear lines of responsibility and mechanisms for coordination, monitoring, and reporting across sectors
- Ensure that an inclusive education strategy and action plan are part of the education sector plan, including building or retrofitting schools that are accessible for children with disabilities; creating accessible curricula and learning materials, processes, and assessments; and training teachers to foster a commitment to inclusion in schools and communities
- Evaluate and identify gaps in service delivery, advocate for and seek sustainable financial and technical support to address the gaps identified, and link the collection of disability data with service provision

NOTES

World Bank Income Classifications as of July 2014 are as follows, based on estimates of gross national income (GNI) per capita for 2013:

- Low-income countries (LICs) = US$1,045 or less
- Middle-income countries (MICs) are subdivided:
  a) lower-middle-income = US$1,046 to US$4,125
  b) upper-middle-income (UMICs) = US$4,126 to US$12,745
- High-income countries (HICs) = US$12,746 or more.

1. In the Convention on the Rights of Persons with Disabilities, "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."
2. The authors wish to thank Hasan Minto, Vilay Pillay, and David Wilson of the Brien Holden Vision Institute for information regarding the cost of glasses.

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