



Combating the Costs of Exclusion for Children with Disabilities and their Families

Daniel Mont
Prepared for UNICEF

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Summer of 2019, Maria Alexandrova in a park near her apartment in Dabnika district of Vratsa, Bulgaria. Vratsa has many architectural barriers and remains highly inaccessible for people in wheelchairs. Maria, 17 years old, living with cerebral palsy, is an advocate for other adolescents with disabilities in Bulgaria.

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Table of contents

Introduction	1
Childhood disability prevalence	3
The impact of disability on children	6
Poverty	6
Education	6
Family life	9
The costs of exclusion	10
Indirect costs.....	10
Direct costs.....	11
Combatting the costs	16
Prevention	17
Maternal health	17
Nutrition	18
Inclusion	19
Early childhood development	20
Inclusive education.....	22
Humanitarian crises	25
Conclusion	27





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A young girl being held by a UNICEF staff member at Aziz Abaza Primary School in Alexandria, Egypt is among 5,000 differently-abled children enrolled in 290 inclusive schools in seven governorates across the country. They all benefit from the interventions of the UNICEF-supported and European Union-funded Expanding Access to Education and Protection for At Risk Children in Egypt project.

Introduction

According to the Convention on the Rights of the Child, all children should be “fully prepared to live an individual life in society, and brought up in the spirit of the UN Charter” as an equal member of the human family.¹ As the Convention on the Rights of Persons with Disabilities (CRPD) emphasizes in Article 7, this includes children with disabilities.² Unfortunately, many children with disabilities are not afforded this opportunity. Instead, they face many barriers that exclude them from society. Some barriers stem from inaccessible infrastructure and information, some from policies and institutions, and others from discrimination, attitudes and societal norms.

! These barriers impose many costs on the lives of children with disabilities. Compared with other children, children with disabilities are less likely to receive an education, less likely to be employed as adults, less likely to start their own families and participate in community events, and more likely to live in poverty.³ In many countries, the poverty gap between people with and without disabilities exceeds 20%.⁴ Further, when poverty is measured not merely by income but by multidimensional poverty measures

– including health, living conditions, assets, education, employment, and various forms of social engagement – the gap is even larger.⁵

The exclusion of children with disabilities imposes costs on the whole community. If these children lack the opportunity to be productive, society loses out on what they could have produced. In fact, the employment-to-population ratio of people with disabilities is almost half that of people without disabilities.⁶ When people with disabilities are employed, they are more likely to be self-employed or to work in the informal sector, and so receive a less reliable income.⁷ The barriers faced by people with disabilities can also create more responsibilities for their family members, who may then be forced to work more, possibly at the expense of their education.

The impact of exclusion extends beyond the economic cost. If people with disabilities are absent from public discourse, the community cannot benefit from their ideas. If they are excluded from political participation, the government cannot truly represent the interests of all citizens. People with disabilities are more likely to be the victims of

1 <https://www.unicef.org/child-rights-convention>

2 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

3 World Health Organization and World Bank, *World Report on Disability*, WHO, Geneva, 2011.

4 United Nations Department of Economic and Social Affairs, *Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities*, DESA, New York, 2018.

5 Ibid.; Mitra, Sophie, Aleksandra Posarac and Brandon Vick. 'Disability and Poverty in Developing Countries: A multidimensional study', *World Development*, vol. 41, 2013; Trani, Jean Francois, et al., 'Disability and poverty in Morocco and Tunisia: A multidimensional approach', *Journal of Human Development and Capabilities*, vol. 16, no. 4, 2015, pp. 518–548.

6 *Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities*.

7 United Nations Economic and Social Commission for Asia and the Pacific, *Disability at a Glance 2015: Strengthening employment prospects for persons with disabilities in Asia and the Pacific*, ESCAP, Bangkok, 2015. www.unescap.org/sites/default/files/publications/SDD%20Disability%20Glance%202015_Final_0.pdf

violence,⁸ especially sexual violence against women and girls, more likely to be injured or killed during natural disasters⁹ and more likely to be infected by HIV/AIDS.¹⁰

This paper addresses the costs of the exclusion of children with disabilities, with a focus on the economic impact. Some costs, however, cannot be monetized. For others,

while a dollar amount could be estimated, the data needed to do so is often unavailable.

A growing body of research suggests that the costs of exclusion are high. Fortunately, evidence also demonstrates that there are effective ways to ameliorate these costs. **A strong case can be made for the social and economic benefits of inclusion.**¹¹

- 8 Hughes, Karen, et al. 'Prevalence and Risk of Violence against Adults with Disabilities: A systematic review and meta-analysis of observational studies', *Lancet*, vol. 379, no. 9826, 2012, pp. 1621–1629; Ortoleva, Stephanie and Hope Lewis, 'Forgotten Sisters – A Report on Violence Against Women with Disabilities: An overview of its nature, scope, causes and consequences', *Northeastern Public Law and Theory Faculty Research Papers Series No. 104*, Northeastern University, Boston, Mass., 2012; United Nations Children's Fund, *The State of the World's Children 2013: Children with disabilities*, UNICEF, New York, 2013.
- 9 United Nations International Strategy for Disaster Reduction, *Living with Disability and Disasters: UNISDR 2013 Survey on Living with Disabilities and Disasters – Key findings*, 2014; Mitchell, David, and Valerie Karr, eds, *Crises, Conflict and Disability: Ensuring equality*, Routledge, New York, 2014; Women's Refugee Commission, *Disabilities among Refugees and Conflict Affected Populations*, Women's Refugee Commission, New York, 2008.
- 10 De Beudrap, Pierre, et al., 'Prevalence of HIV Infection among People with Disabilities: A population-based observational study in Yaoundé, Cameroon (HandiVIH)', *Lancet HIV*, vol. 4, no. 4, 23 January 2017, pp. E161–E168.
- 11 Lukkien, Annet, 'A Social Business Case for Disability Inclusion in Development: Why disability inclusion is not only morally right, but also makes economic sense', Dutch Coalition on Disability and Development, December 2018, <https://www.dced.nl/wp-content/uploads/2019/07/DCDD-Article-Disability-Inclusion-in-Development.pdf>.



Rajuma, 6, born with a physical impairment that keeps her from walking far or standing for too long, attends a learning centre in Camp 16 of the Balukhali refugee camp in Cox's Bazar, Bangladesh. An accessible latrine was installed nearby, which is a relief for her as she does not have to painfully squat to use a regular latrine.

Childhood disability prevalence

According to the *World Report on Disability*, approximately 15% of the world's population has a disability, and about four-fifths of those people reside in developing countries.¹² The number of people who are affected on a daily basis by the barriers faced by people with disabilities is even larger when family members are considered; some studies show that, worldwide, about one in four people are affected in this way.¹³ In Bangladesh, one in three people are affected.¹⁴ Clearly, disability directly impacts a significant proportion of the world's population.

Historically, reported prevalence estimates of disability have varied widely due to different definitions of disability and poor quality data.¹⁵ Moreover, most estimates have not been appropriate for children. Determining disability in childhood through surveys is complicated by the natural variance in children's development, the differing cultural standards of expectations of children and the need to use proxy respondents.¹⁶

Recently, UNICEF and the United Nations Statistical Commission's Washington Group on Disability Statistics developed a module for identifying children with disabilities in surveys. This module, known as the Child Functioning Module (CFM), was incorporated into the latest round of UNICEF-supported Multiple Indicator Cluster Surveys (MICS) that

started in 2017. The module avoids questions on impairments or medical diagnoses, and instead focuses on the difficulties children may have in doing basic activities. In an unaccommodating environment, such difficulties limit the participation of children with disabilities in society.

Until recently, data from low- and middle-income countries were often difficult to acquire and of poor quality. Childhood disability prevalence was thought to be higher in these countries, due to factors such as higher rates of poverty, poorer nutrition and lower quality health-care services.¹⁷ However, there are also some factors that increase disability rates in high-income countries. In particular, better medical care and more positive attitudes towards disability mean that the likelihood of surviving with a disability is higher. The introduction of the CFM allows the collection of more accurate and internationally comparable data.

According to the UNICEF publication *The State of the World's Children 2013*, the widely used estimate of disability prevalence of 5% – 1 in 20 children aged 14 or younger with moderate or severe disability – is largely speculative. According to the report, this estimate is “derived from data of quality too varied and methods too

12 *World Report on Disability*.

13 Mont, Daniel and Nguyen Cuong, 'Disability and Poverty in Vietnam', *The World Bank Economic Review*, vol. 25, no. 2, 2011, pp. 323–359.

14 Shephard, Andrew, 'Disability, Poverty and Poverty Dynamics: A preliminary analysis of panel data, policies and politics in Bangladesh', Chronic Poverty Advisory Network, Overseas Development Institute, London, 2017.

15 Mont, Daniel, 'Measuring Disability Prevalence', *Social Protection Discussion Paper No. 0706*, The World Bank, Washington, D.C., 2017.

16 United Nations Children's Fund, *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Survey*, UNICEF, New York, 2008.

17 *The State of the World's Children 2013: Children with disabilities*.

inconsistent to be reliable.” Instead, the report presents data from national surveys and independent studies, noting that “even these must be interpreted with caution and should not be compared to one another. This is because definitions of disability differ by place and time, as do study design, methodology and analysis.”¹⁸

New data collected in the latest MICS will help to improve estimates of child disability prevalence in many countries around the world. Survey data for individual countries show wide variation in reported prevalence. For example, the prevalence for children aged 5–17 in Bangladesh is 8.3%, in Montenegro 7.5%, and in Ghana 20.7%.¹⁹

18 Ibid.

19 UNICEF’s forthcoming Global Report on Children with Disabilities planned for release in early 2021 will provide country and global estimates. But preliminary findings suggest that the estimate will be significantly higher than 1 in 20 children.



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Hosten Alemán, 26, watches his daughter Rouss Alemán, 2, swing on playground equipment after an interview in which he discussed the disease Rouss was born with and is overcoming with medical assistance and operations in Jinotepe, Carazo, Nicaragua on 26 August 2020.

The continuation of treatment in times of coronavirus is critical for children with disabilities and their families. With the support of UNICEF, the NGO Los Pipitos uses WhatsApp, videos and phone calls to keep support programmes running.

The MICs are seldomly implemented in high-income countries, but studies there also tend to show a disability prevalence greater than 1 in 20. Based on six countries in the Developmental Difficulties in Early Childhood Survey (DDEC), the prevalence of developmental difficulties in young children ranged from 5% to 12%.²⁰

When reporting disability statistics it is important to address differences in the degree of disability. Some children have mild difficulties in undertaking core activities, while others have very significant difficulties. The barriers faced by the two groups may be very different. For example, a study in the United States of America found that 6.5% of all children were reported as having a disability, of whom only 0.7% were unable to conduct any of the major activities examined. Around 4% of children were limited in their ability to perform at least one major activity, while the remaining 1.8% were limited in other activities.²¹

The United States study also found that disability was unevenly distributed across the population. Poor children had a 9.6% rate of disability, compared with 5.7% of non-poor children. In line with other research, boys had a higher rate of disability: 7.6%, compared with 5.3% for girls. Disability prevalence also increased with age, from 3.3% of children under age 6,

to 7.9% of children aged 6–11 and 8.4% of those aged 12–17. This is due to both additional onset of disability (i.e., children developing disabilities over time) and the fact that milder disabilities are often not identified until children get older and are expected to perform more challenging activities.

The United Kingdom of Great Britain and Northern Ireland has similar rates of disability, with the overall prevalence for children under age 18 measured at 7.2%, broken down as 8.8% for boys and 5.8% for girls. The age distribution was also similar to that seen in the United States, with a 3.7% rate for children aged 4 and under and a range between 8 and 10% for older age categories.²²

The impact of a disability on a child's life may not be directly proportional to the severity of the impairment or the functional limitations at a basic activity level. For example, consider a child whose vision is correctable with glasses. Her functional limitation is small – and easily accommodated – but if she does not have access to glasses, and as a result drops out of school, the impact on her life can still be substantial. **The key factor in determining disability is not the underlying medical condition or its extent, but the interaction between the functional limitation and the environment of the child.**



20 World Health Organization, *Developmental Difficulties in Early Childhood: Prevention, early identification, assessment and intervention in low- and middle-income countries: a review*, WHO, Geneva, 2012.

21 Newacheck, Paul and Neal Halfon, 'Prevalence and Impact of Disabling Chronic Conditions in Childhood', *American Journal of Public Health*, 88, 1998, pp. 610–617.

22 Blackburn, Claire, Nick Spencer and Janet Read, 'Prevalence of Childhood Disability and the Characteristics and Circumstances of Disabled Children in the UK: Secondary analysis of the Family Resources Survey', *BMC Pediatrics*, vol. 10, art. 21., 2010.

The impact of disability on children

Disability affects every part of a person's life. For children, poverty, education and family life are the three areas of life most affected by disability.

Poverty

Studies show that disability is associated, in a two-way causal link, with poverty. This association is especially strong when measured by a multidimensional approach.²³ While data specific to children with disabilities is limited in low- and middle-income countries, data from high-income countries shows a strong link between disability and poverty. In the United States, for example, 28% of children with disabilities live in poverty, compared with only 16% of those without disabilities.²⁴ Even when other factors were taken into account, having a disability increased the chance that a child would be poor by 86%.

According to the CRPD and the Sustainable Development Goals, reducing this poverty is central to the aims of economic development. However, the standard poverty indicators actually understate the correlation between disability and poverty because they do not consider the additional costs of living with a disability. Arguably, this should raise the poverty line

for families living with disability. This issue will be addressed later in this paper (see 'Exclusion').

Education

Children with disabilities are more likely to be out of school and less likely to progress if they are at school.²⁵ This is directly at odds with both Article 24 of the CRPD and Goal 4 of the 2030 Agenda.

A recent study of 15 countries found that, on average, there was a 30 percentage point difference between the primary and secondary school attendance rate of children with and without disabilities. More than 85 per cent of primary-age children with disabilities have never attended school.²⁶ In countries with near-universal primary education, children with disabilities are disproportionately likely to be out of school, demonstrating that policies to improve educational access do not effectively reach these children. This is true regardless of the individual and socioeconomic characteristics of the children.

Studies in Malawi, Namibia, Zambia and Zimbabwe found that while 9% to 18% of children over five years old without disabilities had never attended school, the percentage of children with disabilities

23 Mitra et al., 'Disability and Poverty in Developing Countries: A multidimensional study'; Groce, Nora, et al., 'Disability and Poverty: The need for a more nuanced understanding of implications for development policy and practice', *Third World Quarterly*, vol. 32, no. 8, 2011.

24 Fujiura, Glenn T., and Kiyoshi Yamaki, 'Trends in Demography of Childhood Poverty and Disability', *Exceptional Children*, vol. 66, no. 2, 2000, pp. 187–199.

25 *World Report on Disability*; United Nations Educational, Scientific and Cultural Organization and United Nations Children's Fund, *Fixing the Broken Promise of Education for All: Findings from the Global Initiative on Out-of-School Children*, UNESCO, Paris, and UNICEF, New York, 2015.

26 Mizunoya, Suguru, Sophie Mitra and Izumi Yamasaki, 'Towards Inclusive Education: The impact of disability on school attendance in developing countries', *Innocenti Working Paper* No. 2016-03, UNICEF Office of Research, Florence, 2016.

never having done so ranged from 24% to 39%.²⁷ In India, nearly 40% of children with disabilities were not enrolled in school, compared with between 8% and 10% of children in Scheduled Tribes or Castes.²⁸ The overall enrolment rate was over 90%.

A study of 11 developing countries found that disability is a stronger predictor of educational enrolment than either gender or socioeconomic class.²⁹ In fact, in this study, family income did not have a large effect on enrolment rates for children with disabilities. Overall, children with disabilities

- 27 Loeb, Mitch, and Arne Eide, 'Living Conditions among People with Activity Limitations in Malawi: A national representative study', ch. in *Disability and Poverty*, The Policy Press, Bristol, 2011, pp. 55–71; Eide, Arne, Gert Van Rooy and Mitch Loeb, 'Living Conditions among People with Disabilities in Namibia: A national, representative study', Multidisciplinary Research and Consultancy Centre, University of Namibia, 2003; Loeb, Mitchell, et al., 'Poverty and Disability in Eastern and Western Cape Provinces, South Africa', *Disability & Society*, vol. 23, no. 4, 2008, pp. 311–321.
- 28 O'Keefe, P., and Human Development Unit, South East Asia Region, 'People with Disabilities from India: From commitments to outcomes', Human Development Unit, South East Asia Region, The World Bank, 2007.
- 29 Filmer, Deon, 'Disability, Poverty, and Schooling in Developing Countries: Results from 14 household surveys', *The World Bank Economic Review*, vol. 22, no. 1, 2008, pp. 141–163.



Atika, 12, a girl with an intellectual disability, is seen with her mother and her teacher, Ika Setyawati, in front of her home in Ungaran, Central Java, Indonesia.

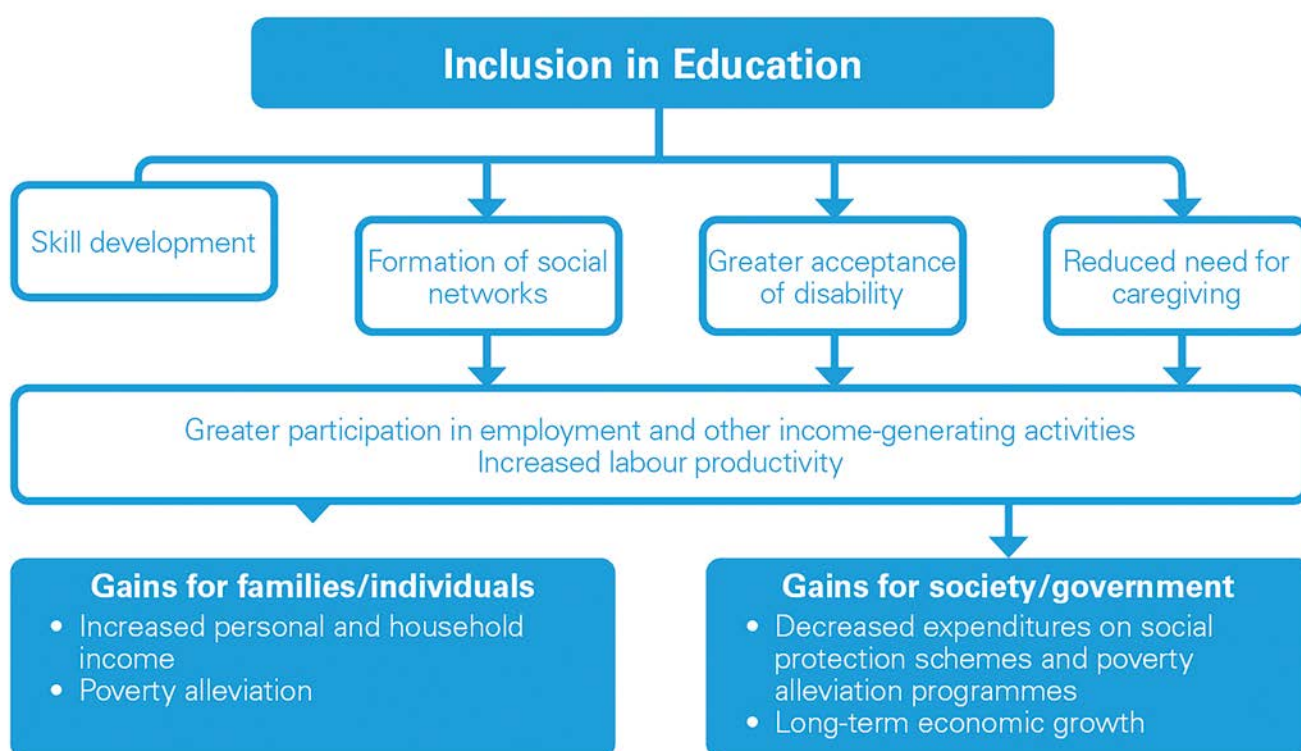
were less likely to start school and in some countries were less likely to transition from one grade to the next.

Accessibility is key. People with disabilities report that over one quarter of schools in their countries are not accessible.³⁰ Even if children with disabilities are in school, there can be various barriers to learning, or they can be segregated into special schools where expectations and opportunities to learn are limited. In 49 United Nations member states, learners with disabilities are not allowed to be taught in the same classroom as their non-disabled peers.³¹ For people with disabilities, barriers to schooling can have a significant impact on earning

capacity (and possibly their level of civic engagement) for the rest of their lives.

The diagram below illustrates the various ways in which inclusive education can impact a person's life and potentially reduce the costs of exclusion for both the individual and for society at large.³²

Education contributes to economic growth. It therefore leads to increased government revenues and a reduction in the reliance on social protection schemes. A study of long-term per-capita gross domestic product (GDP) growth in 88 countries found that primary school enrolment was the biggest positive



Source: Banks and Polack (2014).³⁰ Reproduced with permission.

30 *Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities.*

31 *Ibid.*

32 Banks, Lena M., and Sarah Polack, 'The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from low and middle income countries', CBM, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, London, 2014.

contributing factor to economic growth. On average, just one additional year of schooling increased long-term economic growth by 0.58%, with most benefit seen in low-income settings.³³

These studies are of education in general. However, the fact that without an education people with disabilities are not only poorer but more in need of social protection suggests that the economic returns of additional schooling could be significant. In Nepal, for example, there is some evidence that the returns to education are higher for children with disabilities.³⁴ In China, one additional year of schooling for people with disabilities is estimated to lead to a wage increase of approximately 5% in rural areas and 8% in urban areas.³⁵ **Less time in education has been shown to be significantly correlated with poverty among people with disabilities.**³⁶

In Bangladesh, “the World Bank estimated that reductions in wage earnings attributed to lower levels of education among people with disabilities cost the economy

US\$26 million per year. They estimate that a further US\$28 million is lost from children who forgo schooling to care for a disabled person.”³⁷ These figures demonstrate the substantial economic losses that occur when people with disabilities are excluded from education.

Family life

The extra psychological, physical and financial costs of having a disability – especially in a world that is not inclusive, not accessible, and even hostile to children with disabilities – can cause stress for families, increasing the probability of family break-ups and (typically) single motherhood.³⁸ Children with disabilities are also more likely to suffer from abuse.³⁹ In Cambodia, for example, children with disabilities are 1.8 times more likely than non-disabled children to be neglected, 1.6 times more likely to be physically abused, and 2.2 times more likely to be sexually abused.⁴⁰ They are also more likely to face stigma and shame, which is not directly identified by social indicators.

33 Hanushek, Eric, and Ludger Woßmann, *The Role of Education Quality for Economic Growth*, World Bank Policy Research Working Paper, The World Bank, Washington, D.C., 2007.

34 Lamichhane, Kamal, ‘Disability and Barriers to Education: Evidence from Nepal’, *Scandinavian Journal of Disability Research*, vol. 15, no. 4, 2013, pp. 311–324.

35 Liao, Juan, and Jinbo Zhao, ‘Rate of Returns to Education of Persons with Disabilities in Rural China’, *Proceedings of the 2013 International Conference on Applied Social Science Research*, August 2013, pp. 230–233.

36 *World Report on Disability*.

37 Banks and Polack, ‘The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from low and middle income countries’.

38 Magadi, Monica, and Sue Middleton, ‘Severe Child Poverty in the UK’, Save the Children, 2007, <https://resourcecentre.savethechildren.net/library/severe-child-poverty-uk>.

39 Stalker, Kirsten, and Katherine McArthur, ‘Child Abuse, Child Protection and Disabled Children: A review of recent research’, *Child Abuse Review*, vol. 21, no. 1, 2012, pp. 24–40.

40 Van Leit, Betsy, Samol Channa and Prum Rithy, ‘Children with Disabilities in Rural Cambodia: An examination of functional status and implications for service delivery’, *Asia and Pacific Disability Rehabilitation Journal*, vol. 18, no. 2, 2007.

The costs of exclusion

Disability is associated with social, psychological and economic costs. While this section discusses the economic costs of disability, the non-economic costs are no less important, only more difficult to quantify. Personal sovereignty, dignity, freedom from discrimination and abuse, and a feeling of belonging to the community are all essential human rights that are fundamental to one's quality of life. Most studies of the costs of disability avoid the problematic task of assigning a cost to these qualities. In the discussion of economic costs, however, they should not be forgotten.

The economic costs of exclusion to a family include both direct and indirect costs. Direct costs consist of extra expenditures related to a child with a disability, for example extra health-care costs. One United States study found that the yearly costs of a child with a disability were in excess of US\$30,000.⁴¹ The only example available from low- and middle-income countries is from South Africa (see page 14). The most significant indirect cost is a loss of earnings due to the added responsibilities of supporting a person with a disability, which can limit opportunities to engage in paid employment.

This section covers the indirect costs of disability to the economy and the direct costs to a family of having a member with a disability, regardless of age.

Indirect costs

The indirect costs of disability primarily consist of lost income resulting from the presence of a disability. People with disabilities are more likely to be either unemployed or out of the workforce, because of both barriers in the workplace and a lack of education. When people with disabilities do work, they often receive lower wages.⁴²

When the gap between what people with disabilities earn, and what they would be expected to earn if not disabled, is summed over all people with disabilities, the result is a measure of the loss in GDP caused by disability. A report by the International Labour Organization (ILO) estimated that the loss to GDP in the countries they studied ranged between 1 and 7% of GDP.⁴³ While those estimates are the result of lower earnings among adults with disabilities, many of whom acquired their disability after childhood, they do not account for the fact that people without disabilities might also be working less to care for family members with a disability.

If family members of a person with disabilities are employed, the type and extent of work they can do might be limited. Caring for a family member for only a few hours a day can preclude paid work, depending on the flexibility of scheduling. In one qualitative study of the additional costs of disability in Viet Nam, some family members reported taking lower-quality jobs that, either because of proximity to home or flexibility in

41 Stabile, M., and S. Allin, 'The Economic Costs of Childhood Disability', *The Future of Children*, vol. 22, no. 1, 2012, pp. 65–96.

42 *World Report on Disability*.

43 Buckup, Sebastian, 'The Price of Exclusion: The economic consequences of excluding people with disabilities from the world of work', *Employment Working Paper* No. 43, International Labour Organization, Geneva, 2009.

hours, allowed them to maintain their care responsibilities.⁴⁴

Reducing the indirect costs of foregone income can increase a country's tax base. For example, in the Philippines excess unemployment among individuals with unrepaired cleft lips and palates was estimated to have cost the Government US\$8–9.8 million dollars in lost tax revenue. In Scotland, it was estimated that every £1 spent on a supported employment project led to a savings of nearly £6, mostly because of a lower need for disability benefits and an increase in tax income.⁴⁵

Direct costs

The direct costs associated with disability consist of expenditures made on both disability-specific items, such as assistive devices, rehabilitation services, personal assistance, or adaptations to housing and vehicles, as well as non-disability specific items that may be needed because of a person's disability – for example, medical services or taxi rides. Box 1 describes one example from Bangladesh that shows how medical expenses associated with hearing difficulties can impact a family.

Box 1: Example of medical expenses in Bangladesh

R was born in 1986 with a hearing impairment. She was first taken to the doctor at the age of five. From then on, treatment of her ears continued. Almost all the [local doctors] in their hometown were consulted. R was also taken to a well-known doctor in Mymensingh, costing Tk1500 per visit. There was no improvement.

R's brother said, "There is no account of how much we spent on treating her ears. I gave money for her treatment, so did my father and elder brother. We family members jointly took the decision on where to take her for her treatment. My elder brother helped me take the decision. When we saw doctors, they say medicines will heal her, but nothing worked."

R's mother reported that in 2014 alone the family spent about Tk25,000 on R's treatment. The family sold land that they had inherited to pay for this.

Source: Shephard, A., 'Disability, Poverty and Poverty Dynamics: A preliminary analysis of panel data, policies and politics in Bangladesh: Synthesis', Chronic Poverty Advisory Network, Overseas Development Institute, London, 2017.

44 Palmer, Michael, et al., 'The Economic Lives of People with Disabilities in Vietnam', *PLOS ONE*, 2015, <https://doi.org/10.1371/journal.pone.0133623>.

45 Banks and Polack, 'The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from low and middle income countries'.



Ongerusenge lyle, 17, is a Burundian refugee living in Mahama Camp in Rwanda's Eastern Province. As a speaker at the TEDxKids event, lyle discussed her struggles growing up with a physical disability, and how her father did not want to support her right to education as he believed it a waste.

Measuring the total extra expenditures of households with children with disabilities involves extended consultation. Drawing up a list of disability-specific items is a time-consuming process; estimating what portion of the costs of non-disability specific items is due to a child's disability is particularly difficult. Two studies, one from South Africa and one from New Zealand, have done this. Table 1 shows the estimated extra costs from South Africa. It should be noted that there can be a wide range in these costs depending on the type and degree of disability. They result from added expenditures on assistive devices, health care, transportation, personal assistance and other areas.

The South Africa study primarily covered adults, with a subsample of children. For people with mild to moderate difficulties with remembering, concentrating and learning, extra costs ranged from US\$29 to US\$198 per month. For those with severe difficulties in those areas, extra costs ranged from US\$88 to US\$341 per month. The monthly costs for children with a physical disability ran from about US\$64 to US\$246 when an unpaid family assistant was used, or approximately US\$290 to US\$531 with a paid assistant. Without a paid assistant, another family member was assumed to be providing care and was therefore not available for work. In fact, households with children with disabilities in South Africa earn on average 30% less than households with children without disabilities.⁴⁶

Table 1. Extra costs of disability in South Africa

Diversity of persons with disabilities	Monthly disability-related out-of-pocket cost in US dollars	
	Min	Max
Blind persons	36	287
Deaf persons	10	926
Persons with deaf blindness	27	970
Person with physical disability		
Moderate level of support needs	46	231 and up
High level of support needs	152	462 and up
Persons with intellectual disability with moderate support needs	21	254
Persons with uncontrolled epilepsy	62	278
Persons with autism		
High functioning	13	242
Low functioning	34	242
Persons with psychosocial disabilities	2	277

Source: Hanass-Hancock and Deghaye (2016).⁴⁷

⁴⁶ Hanass-Hancock, J., and N. Deghaye, *Elements of the Financial and Economic Costs of Disability to Households in South Africa*, National Department of Social Development, South Africa, 2016.

⁴⁷ Ibid.



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Za'atari refugee camp, Jordan: Aseel, 8, was left partially paralysed after undergoing surgery at eight months old. UNICEF provided her with a customized wheelchair making it easier for her to move independently and focus in school.

A New Zealand study also measured the extra costs of disability, but without a focus on the costs associated with children. However, looking only at non-workplace related extra costs, the researchers found that the range of costs can vary significantly, depending on whether there are support needs.⁴⁸ When people need support, those costs far exceed the weekly minimum wage. For people with high physical needs, the extra costs are close to the minimum weekly wage, even if support needs are excluded.

An alternative approach to estimating extra costs is known as the Standard of Living (SOL) method. This approach uses

regression analyses to estimate the extra income needed for a person with a disability to reach a given standard of living.⁴⁹ While the method in the South Africa and New Zealand studies attempted to measure which goods and services are needed, the SOL approach estimates what expenses are actually incurred.

The SOL method operates as follows: the assumption is made that households with the same level of income and other characteristics (for example, household size and region of residence) should be able to accumulate the same level of assets. If there is a gap in assets between households with

48 Wilkinson-Meyers, Laura, et al., *The Cost of Disability: Final report*, Disability Resource Centre, New Zealand, 2010.

49 Zaidi, A., and T. Burchardt. 'Comparing Incomes when Needs Differ: Equivalization for the extra costs of disability in the UK', *Review of Income and Wealth*, vol. 51, no. 8, 2005, pp. 9–11.

similar income and other characteristics, that gap is likely to be due to the extra expenditure of the households with people with disabilities, compared to those without.

Studies using the SOL method usually find that the extra expenditures associated with disability range from 12 to 40% of a country's average wage.⁵⁰ One SOL study in China made separate estimates for children with a disability, finding a similar range of extra costs of about 18 to 31%.⁵¹

If the extra costs measured by the SOL method are used to establish the poverty line for people with disabilities, the estimated poverty rates increase significantly: for example, from 18% to 34% in Cambodia, 17.6% to 23% in Viet Nam and 21.1% to 30.8% in Bosnia and Herzegovina.⁵²

The SOL method has several limitations. First, the results can be sensitive to the choice of asset indicator. Current studies find a very large range of cost estimates. A recent study that improved the method of constructing the asset indicator still found that results were sensitive to the type of analysis conducted and the questions used to identify people with disabilities.⁵³

As people can only spend money on what is available, estimated expenditures

may understate the true needs of people with disabilities. A person may need a wheelchair, but if they cannot buy one then it is not a cost. As a country develops and access to assistive devices and assistive services improves, the direct costs of disability may increase. Ideally, however, this will be associated with fewer indirect costs. As assisted goods and services become available, they should allow people with disabilities to become more independent and more successful in the labour market. Finally, unlike the studies from South Africa and New Zealand, this approach does not disaggregate extra expenditure by the types of goods and services being purchased, and thus gives less guidance on how policies could address those needs.

Adjusting poverty lines for the direct costs of disability allows a better understanding of the well-being of families with disabled members. However, the well-being of people with disabilities could still be overestimated if resources within the household are not distributed equally. Measures of poverty assume that all members of a household have an equal stake in family resources, but evidence shows that sometimes people with disabilities are discriminated against when resources are allocated within the family.⁵⁴

50 Mitra, Sophie, et al., 'Extra Costs of Living with a Disability: A review and agenda for research', *Disability and Health Journal*, vol. 10, no. 4, 2017, pp. 475–484.

51 Loyalka, Prashant, Lan Liu, Gong Chen and Xiaoying Zheng, 'The Cost of Disability in China', *Demography*, vol. 51, no. 1, 2014, pp. 97–118.

52 Braithwaite, Jeanine, and Daniel Mont, 'Disability and Poverty: A survey of World Bank poverty assessments and implications', *Alter*, vol. 3, no. 3, 2009, pp. 219–232; Mont, Daniel, and Nguyen Viet Cuong, 'Disability and Poverty in Vietnam', *The World Bank Economic Review*, vol. 25, no. 2, 2011, pp. 323–359; Palmer, Michael, Jenny Williams and Barbara McPake, 'Standard of Living and Disability in Cambodia', *The Journal of Development Studies*, vol. 55, no. 11, 2019, pp. 2382–2402.

53 Mitra, Sophie, et al., 'Extra Costs of Living with a Disability: A review and agenda for research'.

54 Rosales-Rueda, Maria, 'Family Investment Responses to Childhood Health Conditions: Intrafamily allocation of resources', *Journal of Health Economics*, vol. 37, 2014, pp. 41–57.

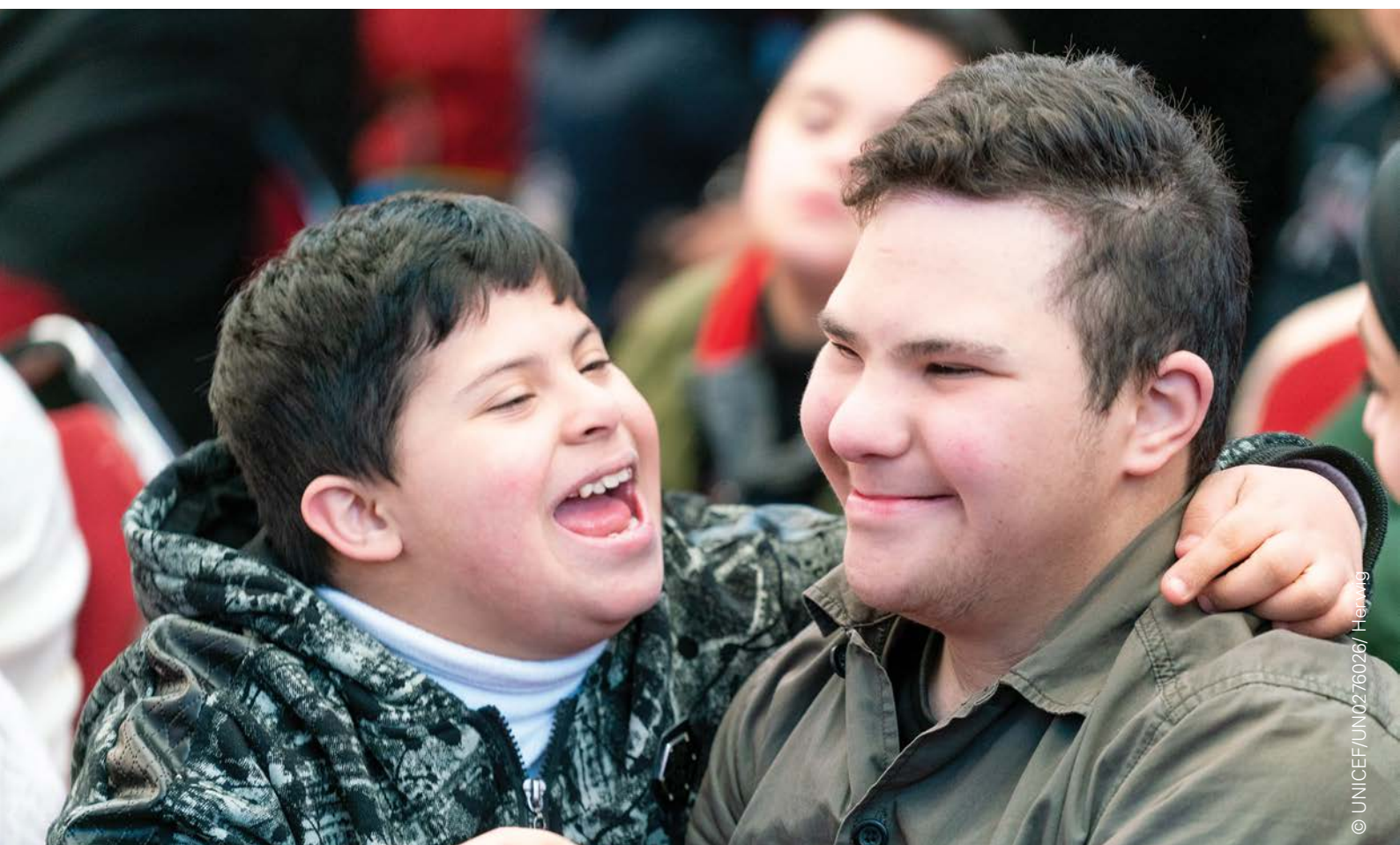
Combatting the costs

Children with disabilities and their families experience significant costs: psychological, social and economic. The impact on the overall economy is measured at a few per cent of GDP. In this section, some key approaches that may significantly reduce costs are considered.

There are two types of policies or programmes that can reduce disability-related costs. The first type aims to reduce the prevalence of disability. Poor maternal health and poor nutrition, for example, can create impairments in children. Poor health care can also lead to disability.

The prevention of secondary disabilities should also be considered. If children with a disability lack access to health care, good nutrition or safe transportation, for example, they are at greater risk of acquiring an additional impairment, or an increase in the severity of their original impairment.

The second approach is the removal of barriers and bottlenecks that prevent children with disabilities from full participation in society. This approach is vital. Preventing children from having primary disabilities in the future does not help children who already have a disability.



Children with disabilities, their parents and disability rights activists joined UNICEF in a Makani centre in Zarqa, Jordan, supported by UNICEF Jordan and run by the Jordanian Ministry of Social Development.

In addition, no degree of economic development and prevention programmes will eliminate disability. The disability prevalence rates in the richest countries in the world attest to that. Inclusion must be central to reducing the costs of exclusion.

Prevention

There are many ways to prevent impairments associated with disability. Alleviating poverty lessens the conditions that lead to disability. Safe water and sanitation, improved traffic safety, and accessible, quality health care are also important. This section focuses on two factors that are particularly important for children: maternal health care and nutrition. The importance of prevention, with the goal of inclusion of people with disabilities, is also considered. For example (as mentioned below), if maternal health care is not accessible, the children of women with disabilities are more likely to experience poor health and higher disability rates.

Maternal health

Improved maternal health, mentioned in Article 25 on health and Article 6 on women in the CRPD and in Sustainable Development Goal 3, can reduce the prevalence of congenital disabilities in children. If pre-natal care is of poor quality

or not available, children are more likely to experience physical and mental disabilities as a result of difficulties in the labour and delivery process.⁵⁵

General maternal health also impacts fetal development.⁵⁶ For example, one study found that maternal asthma, diabetes and urinary problems all posed mild or moderate risk for increased intellectual disability in children. Anaemia increases the risk of severe intellectual disabilities. Even the presence of obesity in mothers can increase the risk of congenital anomalies.⁵⁷ Less well known is that mental health during pregnancy is also a risk factor for babies being born with disabilities. Studies have found that depression and anxiety are correlated with obstetric complications, with implications for fetal and neonatal well-being and behaviour.⁵⁸

Access to good-quality health care, neonatal care and mental health care is crucial in limiting disability at birth. Unfortunately, women with disabilities often lack access to this care due to the inaccessibility of health-care systems, and even an incorrect presumption that women with disabilities do not have sex and therefore are unlikely to become pregnant.⁵⁹ Women with disabilities are three times more likely to have unmet health-care needs than those without disabilities.⁶⁰ Nearly 30% of births

55 Ickovics, Jeanette, et al., 'Group Prenatal Care and Perinatal Outcomes: A randomized controlled trial', *Obstetrics and Gynecology*, vol. 110, part 2.1, 2007, pp. 330–339.

56 Leonard, Helen, Nick de Klerk, Jenny Bourke and Carol Bower, 'Maternal Health in Pregnancy and Intellectual Disability in Offspring: A population-based study', *Annals of Epidemiology*, vol. 16, no. 6, June 2006, pp. 448–454.

57 Stothard, Katherine, Peter Tennant, Ruth Bell and Judith Rankin, 'Maternal Overweight and Obesity and the Risk of Congenital Anomalies', *JAMA*, vol. 301, no. 6, February 2009, pp. 636–650.

58 Alder, Judith, et al., 'Depression and Anxiety during Pregnancy: A risk factor for obstetric, fetal and neonatal outcome? A critical review of the literature', *The Journal of Maternal-Fetal and Neonatal Medicine*, vol. 20, no. 3, 2007, pp. 189–209.

59 *World Report on Disability*.

60 *Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities*.

by mothers with disabilities are not attended by a skilled health worker.⁶¹ Mothers with disabilities are also more likely to be poor and less educated, potentially reducing their likelihood of receiving health care. The lack of access to reproductive and sexual health services has many implications, including a higher rate of HIV/AIDS, among girls with mental disabilities.⁶²

Nutrition⁶³

Studies show that countries with high rates of malnutrition tend to have higher rates of disability.⁶⁴ Of course, the causality could go both ways: poor nutrition can lead to disability, but people with disabilities might also have less access to good nutrition.

Both micronutrient and macronutrient malnutrition in children are linked to

61 Ibid.

62 De Beudrap et al., 'Prevalence of HIV Infection among People with Disabilities: A population-based observational study in Yaoundé, Cameroon (HandiVIH)'.

63 The section on nutrition draws heavily from Groce, Nora, et al., 'Malnutrition and Disability: Unexplored opportunities for collaboration', *Paediatrics and International Child Health*, vol. 34, no. 4, 2014, pp. 308–314.

64 World Health Organization, *Developmental Difficulties in Early Childhood: Prevention, early identification, assessment and intervention in low- and middle-income countries – A review*, WHO, Geneva, 2012, https://apps.who.int/iris/bitstream/handle/10665/97942/9789241503549_eng.pdf;jsessionid=DC1B3C4269B82A217CD52729AC7152B9?sequence=1.



Lucas and his brother Jordão both have albinism, which makes their skin very sensitive, their eyesight poor, and their appearance a little different from their brothers and sisters.

disability. Micronutrient malnutrition is associated with a wide range of conditions, including polyneuropathy, blindness, cognitive delays, behavioural problems and epilepsy. Macronutrient malnutrition can prevent normal growth (stunting), which in turn is linked to physical and cognitive delays. In 2013, one in four children worldwide had stunted growth.⁶⁵ Girls may be even more likely to suffer from stunting, which can lead to suboptimal pelvic growth and increase the chances that their children will be injured during birth.

Childhood disability is also related to maternal nutrition. Poor nutrition of a mother can affect fetal development – for example, the absence of micronutrients, especially during key stages of the gestation process, can cause developmental difficulties.⁶⁶ One study showed that if all mothers received the recommended amounts of folic acid, neural tube defects in low-income countries could be halved.⁶⁷ A lack of the micronutrients vitamin D, calcium, iodine and iron can also cause impairments. A general lack of macronutrients can also cause significant mental and physical impairments.

As malnutrition can lead to disability, disability can lead to malnutrition, which is why this link is mentioned in several articles of the CRPD pertaining to children, health and social protection. Secondary disabilities

may also arise as a result of malnutrition. Difficulties with motor activities, for example, can limit a child's food intake. Parents may not be knowledgeable enough to know how to feed their children with issues such as severe cerebral palsy, which can make swallowing difficult. Also, children with disabilities sometimes have associated medical conditions that require additional nutritional intake. Finally, the negative attitudes towards disability can mean that limited family resources are not spent on children with disabilities.

A clear need exists for an improved understanding of the relationship between malnourishment and disability, and improved nutrition services aimed at the two-way causal link.

Inclusion

Building an inclusive society will reduce the costs of disability. Accessible design of public spaces, transportation systems, information and technology, workspaces, etc., should reduce the costs of disability. Policymakers often perceive the costs of inclusion as high, but there are many examples of how inclusion can be achieved in a cost-effective manner.⁶⁸ Allotting 2–7% of a programme budget can allow development organizations to raise awareness and make infrastructure accessible.⁶⁹

65 See United Nations Children's Fund, 'Malnutrition', UNICEF, New York, March 2020, <http://data.unicef.org/nutrition/malnutrition>

66 Black, Robert, et al., 'Maternal and Child Undernutrition: Global and regional exposures and health consequences', *Lancet*, vol. 371, no. 9608, 19 January 2008, pp. 243–260.

67 Blencowe, Hannah, Simon Cousens, Bernadette Modell and Joy Lawn, 'Folic Acid to Reduce Neonatal Mortality from Neural Tube Disorders', *International Journal of Epidemiology*, vol. 39, suppl. 1, 2010, pp. i110–121.

68 Rohwerder, Brigitte, *Disability Inclusion: Topic guide*, University of Birmingham, UK, 2015; Walton, Oliver, 'Economic Benefits of Disability-Inclusive Development', *GSDRC Helpdesk Research Report 831*, GSDRC, Birmingham, 2012.

69 Bruijn, P., et al., 'Count Me In: Include People with Disabilities in Development Projects – A practical guide for organisations in North and South', Light for the World, Veenendaal, 2012.

Incorporating accessibility at the design stage is key. This both reduces costs and prevents accessibility being viewed as an 'extra' expense; instead, it is simply part of good design. According to one study, "inclusive approaches are more cost-effective than separate piecemeal disability interventions, which do not remove all the barriers people with disabilities face."⁷⁰

Often, the costs of designing for accessibility are not substantial.⁷¹ The World Bank estimates that the construction of accessible schools adds about 1% to

construction costs and benefits not only learners with disabilities but all staff and students.⁷² The costs of including people with disabilities "are far outweighed by the long-term financial benefits to individuals, families and society."⁷³

Two factors that are particularly important in childhood are early childhood interventions (ECI) and inclusive education.

Early childhood development

The early childhood period provides the foundation for the social and intellectual

70 Rohwerder, *Disability Inclusion: Topic guide*.

71 Coe, Sue, and Lorraine Wapling, 'Practical Lessons from Four Projects on Disability-Inclusive Development Programming', *Development in Practice*, vol. 20, no. 7, 2010, pp. 879–886.

72 World Bank, 'Education for All: Building the schools', *Education Notes* No. 26889, The World Bank, Washington, D.C., 2003.

73 CBM, *Inclusion Made Easy: A quick program guide to disability in development*, CBM, Bensheim, 2012, pp. 10.



Syaiful, 12, a child with a physical impairment, studies at home with his mother Nurhidayah in Banyumas, Central Java, Indonesia. Syaiful cannot freely move his lower body or his right hand.



development of a child.⁷⁴ For children with disabilities, ECI can have lifetime consequences for their well-being and inclusion in society. These interventions can also allow society at large to benefit from the talents and skills of people with disabilities.⁷⁵ For this reason, UNICEF, the Organisation for Economic Co-operation and Development and other international agencies have continually called for investment in early childhood development.⁷⁶

Research suggests that ECI are especially important for children with disabilities and can often produce dramatic results.⁷⁷ For example, ECI for children with Down syndrome can potentially completely prevent the cognitive deterioration that typically occurs between the ages of 12 and 18 months. Effective ECI can also aid social development.

Unfortunately, sometimes children with developmental risks, delays and/or disabilities are not diagnosed in early childhood. Early identification and intervention are crucial: studies suggest that the earlier the intervention, the more positive the impact.⁷⁸

Early interventions can also be highly cost-effective. In one United States example, the impact of a quality programme for 0–5-year-olds from disadvantaged families had a 13% per child, per year return on investment, through better outcomes in education, health, crime and employment. These positive outcomes led to lower public costs in government programmes and enhanced workforce competitiveness.⁷⁹

Currently, UNICEF has several entry points to address ECI. According to one UNICEF report, these include:

[Integrated Management of Childhood Illness and early childhood development actions, including the Care for Child Development \(C4CD\) Intervention initiative; child friendly school promotion and inclusive education including the emerging focus on strengthening transitioning; family/parenting capacity-building and rights promotion, and others.](#)⁸⁰

Inclusive ECI consists not only of classroom activities, but “extends beyond the boundaries of classrooms and into a

74 Britto, Pia, Patrice Engle, and Charles Super, eds., *Handbook of Early Childhood Development Research and its Impact on Global Policy*, Oxford University Press, Oxford, 2013.

75 Rafferty, Yvonne, Vincenza Piscitelli and Caroline Boettcher, ‘The Impact of Inclusion on Language Development and Social Competence among Pre-schoolers with Disabilities’, *Exceptional Children*, vol. 69, no. 4, 2003, pp. 467–479.

76 Bellour, Flora, Paul Bartolo and Mary Kyriazopoulou, eds., *Inclusive Early Childhood Education: Literature review*, European Agency for Special Needs and Inclusive Education, Odense, Denmark, 2017.

77 Bailey, D.B., and T. Powell, ‘Assessing the Information Needs of Families in Early Intervention’, in *The Developmental Systems Approach to Early Intervention*, edited by M.J. Guralnick, Paul H. Brookes Publishing, Baltimore, 2005, pp. 151–183; Guralnick, M.J., ‘Effectiveness of Early Intervention for Vulnerable Children: a development perspective’, in *Early Intervention: The essential readings (essential readings in Developmental Psychology)*, edited by Maurice A. Feldman, Blackwell Publishing, Malden, Mass., 2004; World Health Organization, *Early Childhood Development and Disability: A discussion paper*, WHO, Geneva, 2012.

78 Bellour et al., *Inclusive Early Childhood Education: Literature review*.

79 García, Jorge Luis, James Heckman, Duncan Leaf and Maria Prados, ‘The Life-cycle Benefits of an Influential Early Childhood Program’, *NBER Working Paper* No. 22993, National Bureau of Economic Research, Cambridge, Mass., 2016.

80 Lumpkin, G., ‘Inclusive Early Childhood Development and Disability’, UNICEF Country Office Programme Guidance Notes, UNICEF Latin America and Caribbean Regional Office, February 2014.

broad range of activities and settings that typically involve developing children in their homes, neighbourhoods, communities and cultures.”⁸¹ An inclusive early childhood development programme needs to focus not only on the children’s individual needs, but also on providing support to families and communities. The child’s entire situation, their disability and other personal, family and community factors should be considered. A wide array of examples exists.⁸²

Inclusive education

Education is the gateway to full participation in society. When children with disabilities are excluded from education, they may face a lifetime of exclusion. Conversely, education has been shown to demonstratively improve the life chances of children with disabilities. The only study of the economic returns of an education for children with disabilities in a developing country (Nepal) showed that children with disabilities actually received a much higher return on their education, compared with children without disabilities.⁸³

It is not enough for children with disabilities to simply attend school. If schools cannot meet their needs or adapt to the challenges and strengths of children with disabilities, those children will not benefit from education.⁸⁴ In fact, they may even drop out of school altogether.

In developed countries, studies show that inclusive education programmes yield a modest positive impact on the academic success of children with disabilities, but a stronger impact on social success.⁸⁵ However, these studies may understate the impact of inclusion in developing countries where (a) the basic education system is initially less inclusive, in terms of attitudes to children with disabilities and the flexibility of the classroom and curriculum, and (b) dropping out of primary and lower secondary school is much more common.

One concern of inclusive education sceptics is the cost of inclusion. However, the available literature suggests that inclusive education is not

81 Odom, S., ed., *Widening the Circle: Including children with disabilities in preschool programs*, Teachers College Press, New York, 2002.

82 Kyriazopoulou, Mary, et al., eds., *Inclusive Early Childhood Education: New Insights and Tools – Contributions from a European Study*, European Agency for Special Needs and Inclusive Education, Odense, Denmark, 2017.

83 Note that this does not mean that children with disabilities out-earned their non-disabled counterparts, only that the gain they received from attending school was larger than the gain received by the non-disabled children. Lamichhane, Kamal, ‘Disability and Barriers to Education: Evidence from Nepal’, *Scandinavian Journal of Disability Research*, vol. 15, no. 4, 2013, pp. 311–324.

84 United Nations Children’s Fund, 2015, UNICEF Inclusive Education Booklets and Webinars (English Version), www.unicef.org/eca/education.

85 Lindsay, Geoff, ‘Educational Psychology and the Effectiveness of Inclusive Education/Mainstreaming’, *British Journal of Educational Psychology*, vol. 77, 2007, pp. 1–24; Dessementent, R.S., G. Bless and D. Morin, ‘Effects of Inclusion on the Academic Achievement and Adaptive Behaviour of Children with Intellectual Disabilities’, *Journal of Intellectual Disability Research*, vol. 56, part 6, 2012, pp. 579–587; Kalamouka, A., P. Farrell, A. Dyson and I. Kaplan, ‘The Impact of Placing Pupils with Special Education Needs in Mainstream Schools on the Achievement of their Peers’, *Educational Research*, vol. 49, no. 4, 2007, pp. 365–382; Ruijs, Nienke, and Thea Peetsma, ‘Effects of Inclusion on Students with and without Special Educational Needs Reviewed’, *Educational Research Review*, vol. 4, 2009, pp. 67–79.

only less expensive than non-inclusive approaches, but also more sustainable than a separation of general and special education.⁸⁶ While hard estimates from developing countries are scarce, one review concluded that, in middle-income and developing countries, inclusive education can cost up to 41% less than the traditional parallel system. Box 2 gives an example from Tajikistan that shows how special education funding can be more efficient if incorporated into regular schools, while at the same time improving

children's education and changing attitudes towards disability.

For a move from a special education system to an inclusive system to work, the proper groundwork must be laid. Simply moving children with disabilities into regular classrooms without the proper support or preparation for teachers is not inclusion. Inclusion involves moving from a teacher-centred classroom to a child-centred classroom, with associated flexibility in pedagogy and assessment.⁸⁷



86 Sibanda, Patrick, 'The Dynamics of the Cost and Funding of Inclusive Education in Developing Countries', *Scientific Journal of Pure and Applied Sciences*, vol. 7, no. 9, 2018.

87 Schuelka, Matthew J., Christopher J. Johnstone, Gary Thomas and Alfredo J. Artiles, eds, *The SAGE Handbook of Inclusion and Diversity in Education*, SAGE Publications, Washington, DC, 2019.



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Farzona Abdurazoqova, a mother of two boys with visual impairments, is part of the Community Rehabilitation Programme in Rasht district, Tajikistan, funded by UNICEF. She joined the project to learn more about disability, and she wanted to know how to better support her children. She says that even after the project her knowledge on disability and rights will help her keep up her campaign to bring people with disabilities into community life.

Box 2: Moving funds to finance inclusion – An example from Tajikistan

In Tajikistan replacing a system of home education with inclusive education actually saved money. A teacher typically worked 6 hours per week with a child, earning TJS 320–600 per month for that child.

... the teacher could come and work for 10 minutes or just chat with the child's mother and then leave. There is no assessment of what the student has learned. But public money pays for this.

After the passage of an inclusive education law in 2013, a project provided teacher training. Children were put in classrooms of six children, costing at least TJS 1,920 monthly under home education, but only TJS 320 in the school. When children who had gone through a preparatory class to help them transition to a regular school were placed in mainstream classes teachers received a 15% bonus.

Well, the teachers went looking for children [registered for home education] themselves. Even the children whom we said were not ready for school – even them they brought to class. And they work with them. And when people in other communities (*jamoats*) heard about this, parents sent two children from other communities, regardless of the road, to attend that [inclusive] school. Those children were registered for home education by order of the education department. That means the school near their home receives money for them. Now they go to our inclusive school and the principal says he should get the funds from the other school district because the children are studying in his school. When the school that receives the funds for [these two children], learned that the 640 TJS per month allocated for home education would be given to another school, the principal said she wouldn't give up the budget because she also wanted to open inclusive classes. She said that she did not want to lose her budget to someone else because they know how to work with CWDs [and she does not].

Schools report challenges in the transition to inclusion, but most importantly, the

... principal now enrolls and happily works with children with disabilities because he knows that this will save money in his budget. With these savings, they want to open extracurricular groups for vocational learning.

Source: Lapham, K., 'Including Children with Disabilities in Tajikistan's Education System: Global ideas, local tensions', in *Globalization on the Margins: Education and post-socialist transformations in Central Asia*, 2nd ed., edited by I. Silova and S. Niyozov, Information Age Publishing, Charlotte, N.C., 2019.

In Afghanistan, an inclusive education project aimed to prepare students with disabilities for schools – by teaching basic life skills, building the capacity of school staff (teachers, directors and other staff), and vocational training – cost less than means-tested disability benefits.

For half of the cost of the [disability] welfare payment, the project has provided sustainable skills training, employment, education up to Grade 12, better family and child wellbeing and increased acceptance in the community. This would suggest that the project was cost effective.⁸⁸

Humanitarian crises

Children with disabilities are especially vulnerable during humanitarian crises.⁸⁹ Humanitarian crises of all types, whether caused by armed conflict or natural disasters, can lead to the forced displacement of millions of children, increasing the risk of family separation, weakened support networks and

economic loss, and children's vulnerability to violence, exploitation, neglect and abuse.⁹⁰

People with disabilities are also at greater risk of dying during humanitarian crises.

For example, after the 2011 earthquake and tsunami in Japan, the mortality rate among people with disabilities was twice that of the rest of the population.⁹¹

The difficulties of caring for children with a disability during a humanitarian crisis have received limited attention.⁹² In part this has been because of the limited data collected on disability. Fortunately, Humanity and Inclusion has developed a toolkit for collecting data on disability. The toolkit uses the Washington Group Questions and has been tested in Jordan, the Democratic Republic of the Congo and the Philippines.⁹³ **Moving forward, humanitarian efforts must explicitly focus on developing fully inclusive relief efforts, to avoid leaving the most vulnerable behind.**



88 Hayes, J., *Integration and Participation of Children, Youth and Young Adults with Disabilities in Society through Education and Skills Training: Final evaluation report*, Swedish Commission for Afghanistan, June 2012.

89 Brown, Harry, Nicola Giordano, Charles Maughan and Alix Wadeson, *Vulnerability Assessment Framework: Population study 2019*, UNESCO, Jordan, 2019.

90 Bermudez, Laura, Katherine Williamson and Lindsay Stark, 'Setting Global Research Priorities for Child Protection in Humanitarian Action: Results from an adapted CHNRI exercise', *PLoS One*, vol. 13, no. 8, e0202570.

91 Government of Japan, 'Column 4: Mortality rate of people with disabilities in the Great East Japan Earthquake', in *Annual Report on Government Measures for Persons with Disabilities*, Government of Japan, 2012.

92 Zuurmond, Maria, et al., 'Childhood Disability in Turkana, Kenya: Understanding how carers cope in a complex humanitarian setting', *African Journal of Disability*, vol. 5, no. 1, 2016, p. 277.

93 Humanity and Inclusion, 'Disability Data Collection: A summary review of the use of the Washington Group Questions by development and humanitarian actors', Leonard Cheshire, and Humanity and Inclusion, London, October 2018, <https://reliefweb.int/report/world/disability-data-collection-summary-review-use-washington-group-questions-development>

Box 3: Fiji Education Management Information System (FEMIS)

The FEMIS is a good example of how data collection driven by the social model of disability can be used in a concrete fashion, to not only develop and monitor policies but also to help in their implementation. FEMIS collects data on children's functional difficulties and their school environment to better understand their interactions and how children's needs can be met.

The Student Learning Profile, based on the UNICEF/Washington Group Child Functioning Module, collects information on the child's difficulties in functioning and on the need for assistive technology and learning supports. Teachers use it to make referrals to available services after discussions with the child's parents. Importantly, a separate record is maintained for each child, unlike systems where only aggregate data is collected.

A cross-sectional diagnostic accuracy study was undertaken comparing parent and teacher responses to clinical assessments that showed that the Child Functioning Module (CFM) can be well used by teachers with a couple of minor modifications.⁹⁴

The School Accessibility and Inclusion Form collects information on school infrastructure, transport and efforts towards inclusion. It was developed in line with UNICEF guidelines on disability disaggregation of Education Management Information Systems.⁹⁵

FEMIS also collects information about qualifications and professional development of school staff related to disability-inclusive education. This can be used to assess knowledge about inclusion and cross-match student needs with staffing data.

Instances when a child's needs cannot be met because of lack of services or accessibility are noted and costs can be estimated for meeting those needs. So, the school system knows: what difficulties each child has, what their support needs are, the extent these can be met in the school or through referrals, and the costs of filling existing gaps.

A set of resources, including the forms mentioned in this box, are available at www.education.gov.fj/index.php/school/special-inclusive-education-resources.

94 Sprunt, B., and M. Marella, 'Measurement Accuracy: Enabling human rights for Fijian students with speech difficulties', *International Journal of Speech-Language Pathology*, vol. 20, no. 1, 2018, pp. 89–97; Sprunt, B., M. Hoq, U. Sharma and M. Marella, 'Validating the UNICEF/Washington Group Child Functioning Module for Fijian Schools to Identify Seeing, Hearing and Walking Difficulties', *Disability and Rehabilitation*, vol. 41, no. 2, 2019, pp. 201–211.

95 *Technical Guidance Guide for Including Disability in Education Management Information Systems*, UNICEF Education Section, Programme Division, New York, February 2016.

Conclusion

The barriers faced by people with disabilities impose significant costs on families and on the economy in general. The International Labour Organization estimates that barriers to schooling and employment lead to a loss in productivity of between 1 and 7% of GDP due to lost labour market productivity. However, this estimate is probably too low, as it does not consider the lost productivity of family members who must care for their relatives with disabilities because of the barriers to independent living.

The impact on families from the direct costs of disability is also highly significant. As these costs are usually not considered in determining poverty lines, the true poverty rate of families with members with disabilities (adjusting for these costs) is probably higher. In addition, children with disabilities may sometimes get less than their share of family resources, further affecting their well-being. The poverty gap is even larger when multidimensional aspects of poverty are considered, like



Students at G.S. Nyagahandagaza, learn under the UNICEF-supported inclusive education programme, where children with disabilities sit integrated in normal classrooms.

assets, health, water and sanitation, living conditions, education and labour market participation, and social engagement. Finally, monetary costs do not begin to include the mental health costs of exclusion, and other outcomes such as higher levels of abuse and family break-up.

There are two approaches to reducing the costs of exclusion. The first is to try to prevent childhood disability, for example through improved nutrition and maternal health programmes. These efforts must be inclusive, in that they remove barriers to participation and provide adequate supports. Health, nutrition and other related programmes that do not reach people with disabilities can create secondary disabilities,

as well as new disabilities for family members. However, prevention efforts will never fully address the costs of exclusion because they neglect the millions of existing children with disabilities and the millions of children with disabilities that will – even with prevention efforts – be born in the future. For these children and their families, inclusive development is key. We must break down the barriers that prevent people with disabilities fully participating in society. In this regard, two particularly important policies for children are early childhood interventions and inclusive education. These approaches can help children with disabilities to reach their potential and enjoy their rights as full and equal members of society.



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