



# Adolescents with disabilities

Enhancing resilience and  
delivering inclusive development

Nicola Jones, Elizabeth Presler-Marshall and Maria Stavropoulou

July 2018

# About GAGE

Gender and Adolescence: Global Evidence (GAGE) is a nine-year (2015-2024) mixed-methods longitudinal research programme exploring the gendered experiences of young people aged 10-19 years. We are following the lives of 18,000 adolescents in six focal countries, two each in Africa (Ethiopia, Rwanda), Asia (Bangladesh, Nepal) and the Middle East (Jordan, Lebanon).

GAGE aims to generate new evidence on 'what works' to transform the lives of adolescent girls and boys to enable them to move out of poverty and exclusion, and fast-track social change. GAGE research involves the most vulnerable adolescents, including adolescent refugees, adolescents with disabilities, those out of school, married girls and adolescent mothers.

The results will support policy and programme actors to more effectively reach adolescent girls and boys to advance their wellbeing and what is needed to meet the Sustainable Development Goals, including the commitment to Leave No One Behind.

The GAGE consortium, managed by the Overseas Development Institute, convenes 35 research, policy and programming partners globally and is funded by UK Aid from the UK government.

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Cover photo 1: An adolescent girl with a hearing impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

Cover photo 2: An adolescent girl, with a hearing impairment, and her brother with a hearing impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

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## Preface

The past thirty years has witnessed a significant global transformation in recognition and understanding of disability, in large part as a result of effective and persistent activism on the part of the disability community. In 1989, the UN Convention on the Rights of the Child broke new ground in its explicit inclusion of disability as a ground for protection from discrimination for the first time in an international human rights treaty. It also contained a dedicated article addressing the situation of children with disabilities. While welcome, its language still perpetuated the focus exclusively on targeting services and support towards children with disabilities rather than removing the barriers that impede the realisation of their rights. It was only with the adoption by the UN of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 that the social and human rights based model of disability was unequivocally recognised, through the introduction of two fundamental propositions. First, it affirms that persons with disabilities are subjects of rights on an equal basis with others. And second, it acknowledges that those rights will never be realised unless and until the economic, social, cultural, attitudinal, communication and physical barriers that serve to discriminate and exclude are removed. It laid to rest the charitable or defectology approaches that treated people with disabilities merely as objects of pity, contempt or medical intervention. Even more recently, explicit recognition of persons with disabilities in the SDGs, as contrasted with their complete absence from the MDGS, has provided further testimony as to the commitment from the global community to action towards overcoming their social exclusion.



Of course, there is a world of difference between on the one hand, international commitments to respect for human rights, and on the other, effective implementation on the ground. Huge progress still needs to be made for all people with disabilities, in almost every country in the world. But, as this report elaborates, for adolescents, particularly girls with disabilities living in low and middle income countries, the challenges can be particularly acute. All too often they are disregarded by policy makers - neither considered in mainstream provisions for children and adolescents, nor in programmes for adults with disabilities. Far too many remain out of school, socially isolated, vulnerable to sexual and physical abuse, living in poverty, placed in institutions, excluded from cultural and artistic life, without access to friendships and recreation, denied a voice, and subject to prejudice and discrimination. For them, the CRPD, if taken seriously, offers real hope. It elaborates detailed obligations on governments to take all necessary measures to ensure their equal enjoyment of all rights and freedoms, including, importantly, the right to be heard. It requires the introduction of inclusive education systems for every child without discrimination, a necessity if the goal of equality of opportunity is to be achieved, and the cyclical trap of poverty and disability brought to an end. And, perhaps most significantly, it elaborates an obligation to collect data to render their lives visible. Without accurate information about the lives of adolescents with disabilities, the extent of discrimination and violations of their rights cannot begin to be understood. Without evidence, it is not possible to design and implement the necessary laws, policies, and programmes, supported by the necessary resources, nor to evaluate the effectiveness of those measures when implemented. The availability of accurate and comprehensive information also strengthens the capacity to hold governments accountable on their commitments.

This report will make an invaluable contribution towards rendering visible what it actually means to be an adolescent with a disability. In so doing, it highlights what action is needed on the part of governments if those adolescents are to realise their rights, to overcome the profound and devastating struggles they face daily, and to be afforded the dignity that is the birth right of every human being.



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## Preface

Global studies suggest that women and girls with disabilities are twice as likely to experience violence. Disability-specific risk factors (e.g. dependency, functional limitations) are compounded by unequal gender relations and their social disadvantage and cultural devaluation. Societal restraints to reporting are aggravated by disability-related barriers which in turn contributes to the invisibility of the problem - among those that promote the rights of persons with disabilities, women's and children's rights as well as in policy dialogues.



Girls and women with disabilities can experience high rates of sexual violence and abuse perpetrated by strangers, and by community and family members. Sexual violence is often driven by unequal power relations, which can occur due to prevailing attitudes towards - and perceptions of - girls with disabilities, and because perpetrators often hold positions of power or authority. This also decreases the likelihood of abuse being disclosed. Girls with sensory or intellectual disabilities often experience higher levels of abuse as challenges communicating mean that they can be less likely, or are perceived to be less likely, to be able to report abuse and so are targeted by some men.

Art. 16 of the Convention on the Rights of Persons with Disabilities, provides the international framework to prevent and respond to violence against women and girls with disabilities. At the national level, formal, legal or policy recognition of the particular vulnerabilities of women and girls with disabilities and violence enacted against them is often limited. While it is still evident that women and girls with disabilities are at a higher risk of experiencing violence, the majority of evidence comes from high-income countries, with quality research from low- and middle-income countries lacking.

Evidence and data on adolescent with disabilities in low-income countries is generally lacking and even more so in the case of evidence about adolescent girls with disabilities. We still lack specific and detailed evidence on the prevalence and patterning of violence against adolescents with disabilities meaning we do not know the real scale of the problem or its full impact and on girls in particular. A lack of evidence on what works to prevent violence and protect and support adolescents with disabilities compounds the issue further.

Evidence presented in this report confirms the urgent need for more research, evidence and data on adolescent with disabilities, especially with regard to adolescent girls, in low- and middle-income countries and on issues including access to protection mechanisms, how adolescents with disabilities can be supported to report abuse and receive support services and ultimately seek justice.



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# Executive summary

## Overview: why a focus on adolescents?

Around the world, there are between 93 million and 150 million children and adolescents living with disabilities (WHO and World Bank, 2011). An estimated 80% live in low- and middle-income countries (LMICs), where 80% of persons with disabilities live below the poverty line (ibid.). While we know that adolescents with disabilities are far more likely than their peers without disabilities to be denied their basic rights to education, health, recreation and general wellbeing, research aimed at exploring their needs and identifying how best to support their transitions from childhood to adulthood is nascent. Even as adolescence has been recognised by scientists and development actors alike as a key window of opportunity (Sheehan et al., 2017; Steinberg, 2015; UNICEF, 2011), given the rapid physical, psycho-emotional, cognitive and social changes that occur during the second decade of life, and even as disability has moved up the development agenda as part of the 'leave no one behind' mandate, adolescents with disabilities have remained largely invisible in policy, programming, and research. The estimated costs of inaction are staggering on multiple dimensions. In China, for example, each additional year of education can raise a child with a disability's income in later life by 8% (Liao and Zhao, 2013).

This report takes stock of current evidence from LMICs, drawing on findings from a thematic evidence review combined with emerging findings from the Gender and Adolescence: Global Evidence (GAGE) survey and qualitative research baseline studies in Bangladesh, Ethiopia, Jordan and Palestine. These interviews involved more than 6,000 adolescents and their caregivers – including approximately 600 girls and boys with physical, visual, hearing or intellectual impairments, alongside service providers and policy actors. The report draws attention to the multiple and intersecting capabilities that need to be supported in order for adolescents with disabilities in LMICs to reach their full potential. It goes beyond a focus on their access to education and health services, and also considers their rights to psychosocial wellbeing, protection from violence, mobility and opportunities to participate within their communities, as well the skills, assets and support they need to become economically independent once they transition into adulthood.

## Key findings: scope and breadth of the challenge

Adolescents with disabilities face a range of challenges in reaching their full capabilities. Our evidence review and mixed methods research confirmed that in most LMIC contexts, they face widespread discrimination, stigma and social exclusion. Adolescent girls with disabilities tend to face intersecting disadvantages because discriminatory gender norms and practices become increasingly salient in adolescence. Adolescent experiences also differ by impairment type – whether physical, sensory or intellectual – and the severity of the impairment. Context can play a key role too, with adolescents with disabilities in rural and humanitarian and conflict-affected settings much more likely to be excluded from services and support.

### Challenges in achieving adolescent capabilities

Adolescents with disabilities in LMICs face multiple and interlinked challenges in realising their full capabilities including with regard to: 1) education and learning, 2) health, sexual and reproductive health and nutrition, 3) psychosocial wellbeing, 4) bodily integrity and freedom from violence, 5) voice and agency, and 6) economic empowerment. We summarise here our key findings and more detail is available in the full report:



**Adolescents with disabilities have poorer educational access overall, and limited access to specialised education services, which is reflected in lower educational outcomes and more limited educational transitions** (UNESCO, 2018; Male and Wodon, 2017). Of the 58 million children who are out of school, it is estimated that one-third – 19 million – have a disability (Saebones et al., 2015). Adolescents with disabilities are less likely to enrol in school and more likely to drop out than their peers without disabilities, due to a range of barriers at the systems, school, and household levels—all of which tend to disproportionately affect adolescents living in rural areas and humanitarian contexts. Aspirations for education notwithstanding, most adolescents with disabilities are out of school and few manage to progress to secondary school. Moreover, evidence suggests that not only are adolescents with disabilities less likely to be in school as they advance by grade level than their peers without disabilities, but also that the education gap between adolescents with and without disabilities is worsening over time (Male and

Wodon, 2017). Gender dynamics are complex and while girls with disabilities remain far less likely than boys with disabilities to attend school in some LMICs, especially at the secondary level, in other LMICs girls with disabilities are now completing primary and lower-secondary school at higher rates than their male peers. Young people with intellectual impairments are generally the most likely to be out of school, and those with physical impairments the least. The estimated costs of not educating young people with disabilities are significant, for individual children and for national economies. For example, the exclusion of children with disabilities from education and their lower earnings as adults are estimated to cost the Bangladeshi economy about \$26 million annually (World Bank, 2008).



**Adolescents with disabilities have poorer overall health and nutritional status than their peers without disabilities** (Kuper et al., 2014; Groce et al., 2013). In addition, due to disability-related stigma, cost, and physical accessibility issues, they also have more limited access to general health information and care, including that related to sexual and reproductive health. Access to disability-related health care remains rare in many LMICs, given resource constraints, and is nearly non-existent in rural areas and humanitarian contexts. Girls with disabilities are in many contexts disadvantaged compared to boys, due to restrictive gender norms, and adolescents with intellectual impairments appear to be more vulnerable than those with other types of impairments. Parents' lack of information about disability is often central to adolescents' poor access to care.



**Adolescents with disabilities face critical challenges to their psychosocial wellbeing.** They experience high rates of social isolation and often feel stigmatised and unsupported even within their own households (Groce and Kett, 2014). As a result, they are more prone to depression, loneliness and low self-esteem than their peers without disabilities. Girls' psychosocial outcomes are generally poorer than boys', due to gender norms that leave them especially isolated from their peers. Adolescents who are deaf tend to have the least emotional support at home, due to communication barriers with parents who do not know how to sign, and those with intellectual impairments often face the most bullying. Adolescents with disabilities who live in rural areas or conflict-affected contexts generally have the poorest psychosocial outcomes because they are the least likely to

be afforded access to schooling and to time with peers that schooling affords. Few adolescents with disabilities have access to either informal adolescent-focused recreational and social activities or formal psychosocial services.



**Adolescents with disabilities are three to four times more likely to experience violence than their peers without disabilities, with multiple and long-term consequences on survivors' physical and psychosocial wellbeing** (Jones et al., 2012). Adolescent girls with disabilities, especially those with intellectual impairments or those living in conflict-affected areas, are especially vulnerable to sexual violence. Adolescents with disabilities often find it especially difficult to access protection mechanisms, report abuse, receive support services and seek justice.



**Adolescents with disabilities are afforded limited opportunities to access voice and agency.** They face significant restrictions to their mobility, due to inappropriate infrastructure and transportation, unaffordable assistive devices, persistent discriminatory attitudes and parental safety concerns, all of which hamper their opportunities for participation in their community. Moreover, adolescents with disabilities frequently have little awareness of their rights and limited say over their lives, and despite their wish to actively participate, they are often excluded from family, school and community activities. In humanitarian and conflict-affected contexts this may be particularly acute, with some young people (especially girls) with disabilities completely confined to the home.



**Finally there is a significant mismatch between the aspirations of adolescents with disabilities and the disadvantages they face vis-à-vis their peers without disabilities in securing access to market-relevant and appropriate skills development programmes, to credit and productive assets, and to decent and productive employment.** This is particularly the case for girls with disabilities and those with intellectual impairments. Adolescents with disabilities also have limited access to social protection that affords them a basic standard of living. Where educational stipends or cash transfers do exist in LMICs, their value is typically much too low to cover the additional costs (e.g. transport, purchasing and maintaining assistive devices, specialised medical care) incurred by adolescents with disabilities and their caregivers.

## Intersecting disadvantage

Even accounting for the wide range of impairment types and severity, adolescents with disabilities are not a uniform group and thus it is critical to understand how young people's experience of disability intersects with other dimensions of social exclusion including gender and context.

The report employs a strong gender lens to better understand the divergent opportunities and challenges that adolescent girls and boys with disabilities have in realising their full potential. It highlights the complex relationship between gender and school enrolment, dropout rates and learning outcomes whereby girls with disabilities are faring worse than their male peers with disabilities in some contexts, but better in other LMICs. The report also draws attention to girls' higher health burdens and lower access to health and SRH care; their higher risk of violence and sexual violence; their very limited mobility and ability to participate within their communities irrespective of their impairment due to discriminatory norms; and their exclusion from skills development and economic empowerment opportunities.

Given the limited evidence base on adolescent girls and boys experiences in conflict-affected contexts in general and about adolescents with disabilities in particular, this report focuses on the specific experiences of adolescents with disabilities in Gaza, the West Bank and the Syrian refugee community in Jordan. It reveals the particular challenges that they face in protracted conflict settings – including conflict-related impairments and mental ill-health caused by trauma – and the dearth of accessible services and support for refugees with disabilities, and especially for girls.

The report also puts a necessary spotlight on rural disadvantage. It highlights that adolescents with disabilities in rural areas are especially likely to have lower educational aspirations and more limited access to education services, as well as poorer health and more limited access to specialised health care. They are also less likely to report violence and tend to have less say in household decision-making.

## Challenges in the enabling environment

**Caregivers**, especially mothers, play a particularly important role, often assuming disproportionate care responsibilities for children with disabilities, often in the context of very limited family, community and state

support. Mothers of children with disabilities face high levels of stigma and social exclusion and some face abuse and abandonment for having produced a child with disability. With limited access to information, support or respite care, caregivers – especially of young people with more severe disabilities – report feeling exhausted, anxious and depressed.

Challenges in the **policy and legal landscape** are also critical, especially with regard to implementation. While there have been significant advances in tackling discriminatory legal frameworks and advancing more rights-based legislation in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) over the past decade, implementation has been a significant challenge in many LMICs. The most glaring gaps include: the absence of coordinating mechanisms to facilitate joined-up cross-sectoral programming and accountability for progress; serious financing gaps to realise inclusive education, health and social protection for adolescents with disabilities; and very limited numbers of trained service providers (from education and health to justice and social work).

Finally, there are significant **evidence gaps** with regards to all domains of adolescents with disabilities' lives and also a dearth of robust evaluations as to what works to support the wellbeing and resilience of adolescents with disabilities' lives. This limited evidence base in turn hinders more tailored and evidence-informed policy and programming to support adolescents with disabilities in many LMICs.

## Implications for policy and practice

There is a pressing case for policy commitments and programmatic action to capitalise on the window of opportunity that is adolescence and to better support adolescents with disabilities. Only through inclusive development will the international community be able to deliver the Sustainable Development Goals (SDGs) and ensure that no one is left behind. Evidence gaps notwithstanding, the research findings in this report suggest that governments, together with development partners, should take action in five key areas to support adolescents with disabilities now, and to set them on a better trajectory for a fulfilled and empowered adulthood.

## 1. Support adolescent capabilities and transitions through an integrated package of disability-tailored support, including:



Develop detailed, costed action plans with measurable milestones towards providing accessible, appropriate and quality inclusive education for all adolescents with disabilities.



Ensure that adolescents with disabilities have access to primary and disability-specific health and nutritional care as well as to context-tailored SRH information and services.



Ensure that safe spaces and recreational opportunities are accessible to adolescents with disabilities, given the critical importance of peer interactions for adolescent development. Also invest in digital technologies and social media-based approaches to reduce their isolation where internet connectivity is accessible and affordable. Simultaneously provide guidance for parents and service providers on how to support young people with disabilities psycho-emotionally, based on their specific situation and impairment(s).



Given heightened risks of age- and gender-based and sexual violence, ensure that adolescents with disabilities, their families and communities are provided with tailored information about the risks of violence, protection measures, and how to report abuse. In tandem, provide training for police and justice sector personnel on how to support adolescents with disabilities who have experienced violence to secure justice.



Invest in awareness-raising with parents, communities and service providers about the importance of supporting young people with disabilities to be listened to and to participate in decision-making in the family, at school and in their community. This should include involving adolescents with diverse impairments in programme design and evaluations as a way of getting their voices heard and strengthening impact.



Ensure that poverty-targeted social assistance programmes provide adequate weighting to cover the additional costs that adolescents with disabilities and their families often incur. Simultaneously invest in skills

building programmes and the provision of credit and other assets necessary for their economic empowerment.

## 2. Address intersecting disadvantages to leave no adolescent behind

Undertake a comprehensive mapping of national and donor programming and services for adolescents with different impairment types to identify gaps and solutions for the hardest-to-reach groups, including those in rural and conflict-affected contexts.

## 3. Engage and support caregivers of adolescents with disabilities

Ensure that caregivers have access to tailored information and guidance to support their adolescents with disabilities as well as access to support networks, including for psycho-emotional support and respite care.

## 4. Tackle data and evidence gaps to improve evidence-informed policy development and programming

Invest in age-, gender- and impairment-disaggregated data, robust evaluations of interventions to better understand what works. Also invest in participatory research to better understand adolescent perspectives and experiences so to support evidence-informed policy development and programming.

## 5. Improve governance and accountability among policy-makers and donors

Establish a strong, national body to ensure effective multi-sectoral coordination among government agencies and cross-referrals to complementary services. In addition, convene national working groups to bring together key government agencies, donors, and non-governmental actors to share information and promote coordination around initiatives to enhance the wellbeing and resilience of adolescents with disabilities. In tandem, develop a disability marker (akin to the OECD- DAC gender marker), to better track funding and hold donors to account, and as part of the 2020 SDG target review, promote reporting among all UN agencies that is disaggregated by age, gender and disability in development and humanitarian contexts.

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# Acronyms

ACPF	African Child Policy Forum
CAB	Children's Advisory Board (Tanzania)
CBM	Christian Blind Mission
CBR	Community-Based Rehabilitation
CDC	Child Development Centre
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
COVAW	Coalition of Violence against Women
CRPD	Convention on the Rights of Persons with Disabilities
DAISY	Digital Accessible Information System
DICAG	Disabled Children's Action Group (South Africa)
DPO	Disabled People's Organisation
ECDD	Ethiopian Centre for Disability Development
ESI	Economic and Social Inclusion of People with Disabilities (Lebanon)
EU	European Union
GAGE	Gender and Adolescence: Global Evidence
GDP	Gross Domestic Product
GEC	Girls' Education Challenge
GER	Gross Enrolment Rate
HEAT	Health Education and Training (Ethiopia)
HEW	Health Education Worker
HRW	Human Rights Watch
ICED	International Centre for Evidence in Disability
ICP	Inclusive Children's Parliament (India)
ICTs	Information and Communication Technologies
ILO	International Labour Organization
IRC	International Rescue Committee
KAIH	Kenya Association of the Intellectually Handicapped
LCD	Leonard Cheshire Disability
LGBTQI	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and Intersex
LMICs	Low- and Middle-Income Countries
MDG	Millennium Development Goal
MoE	Ministry of Education
NDWA	National Disabled Women's Association (Nepal)
NFDN	National Federation for the Disabled Nepal
NGO	Non-Governmental Organisation
PNCTP	Palestinian National Cash Transfer Programme
RMG	Network of Child-Friendly Municipal Governments (Nicaragua)
SDG	Sustainable Development Goal
Sida	Swedish International Development Cooperation Agency
SRH	Sexual and Reproductive Health
STAC	Stimulation and Therapeutic Activity Centre
STI	Sexually Transmitted Infection
TVET	Technical and Vocational Education and Training
UK	United Kingdom
UNCRC	UN Convention on the Rights of the Child

UNDESA	UN Department of Social and Economic Affairs
UNESCAP	UN Economic and Social Commission for Asia and the Pacific
UNESCO	UN Educational, Scientific and Cultural Organization
UNFPA	UN Population Fund
UNHCR	UN High Commissioner for Refugees
UNICEF	UN Children's Fund
UNRWA	UN Relief and Works Agency for Palestine Refugees in the Near East
US	United States
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization
WRC	Women's Refugee Commission



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# Introduction

## Introduction

Around the world, there are between 93 million and 150 million children and adolescents living with disabilities (WHO and World Bank, 2011). Most of those children (80%) live in the global South, where 80% of persons with disabilities live below the poverty line (ibid.). Children and adolescents with disabilities are far more likely than their peers without disabilities to be denied their basic human rights. For example, recent estimates from the UN Educational, Scientific and Cultural Organization (UNESCO) (2018) suggest that in some low- and middle-income countries (LMICs), 26% of adolescents with disabilities of lower-secondary school age are out of school – compared to only 18% of their peers without disabilities. Differences in some countries are far larger. In Bangladesh, for example, of adolescents aged 15–18, those with disabilities are 40% less likely to have completed primary school (Male and Wodon, 2017). In other countries, young people with disabilities remain overwhelmingly unlikely to attend school. Children and adolescents with disabilities are also up to 19 times more likely to have been seriously ill in the past year than their peers without disabilities (Kuper et al., 2014).

However, while both adolescence and disability are moving up the development agenda, as of yet, the needs of adolescents with disabilities have been largely ignored. This report addresses this gap by focusing on adolescents with disabilities in the global South. Synthesising the existing evidence and drawing on primary quantitative and qualitative research from four of the focal countries of the Gender and Adolescence: Global Evidence (GAGE) research programme (Bangladesh, Ethiopia, Jordan and the State of Palestine), we discuss adolescent capabilities and vulnerabilities across six broad domains. Our goal is to contribute to understanding about how to improve the wellbeing and resilience of adolescents with disabilities and ultimately promote more inclusive development. The questions underpinning the report are as follows:

- What factors shape the development pathways of adolescents with disabilities (aged 10–19) in LMICs?
- What are the experiences of adolescents with disabilities and how do they perceive that their wellbeing and resilience could be enhanced?
- How are those experiences shaped by the individual's gender, impairment type and context (e.g. urban versus rural, humanitarian and conflict-affected vs. developmental contexts)?

- What role do laws, policies, programmes and services play in mediating these experiences and supporting the wellbeing and development trajectories of adolescents?
- What examples of promising practice exist from which we can draw lessons?

## Defining disability

Disability is an evolving concept that is – according to the World Health Organization (WHO) and the World Bank (2011) – still quite contested. This is partly due to the heterogeneous nature of disability. People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments (UN, 2006) (see Box 1). They may have acquired those impairments through injury, illness or congenital conditions. Impairments may have mild, moderate or severe impacts on daily functioning, depending not only on the nature of the impairment but also on a wide range of personal (e.g. age, gender, socioeconomic status, ethnicity) and environmental (e.g. physical, social/cultural, political) characteristics. Indeed, even the language used to discuss disability remains in flux (see Box 2).

Although there is no single definition of disability, it is currently accepted that despite the frequent focus on the individual, disability is not a health problem or a personal attribute (WHO and World Bank, 2011). Indeed, according to the CRPD (UN, 2006), it should be understood as a complex and dynamic phenomenon arising from the interaction between the individual with a health condition and contextual factors that pose significant challenges to enjoyment of one's human rights and reaching one's full potential. This human rights model of disability, which shares much in common with the WHO's International Classification of Functioning, Disability and Health (see Figure 1), maintains that people with disabilities should enjoy basic rights on an equal basis with others and requires states to take action to protect these rights and transform discriminatory systems and practices (Rohwerder, 2015).

This rights-based understanding of disability has evolved slowly over time. In many LMICs, the approach is often poorly integrated into national laws and policies and community-level services and programmes, which still reflect earlier approaches to disability despite commitment in principle to the CRPD (Lang et al., 2011). For example, the charity model, most common 'on the ground', focuses on the individual and his or her impairment, and views people with disabilities as passive victims in need

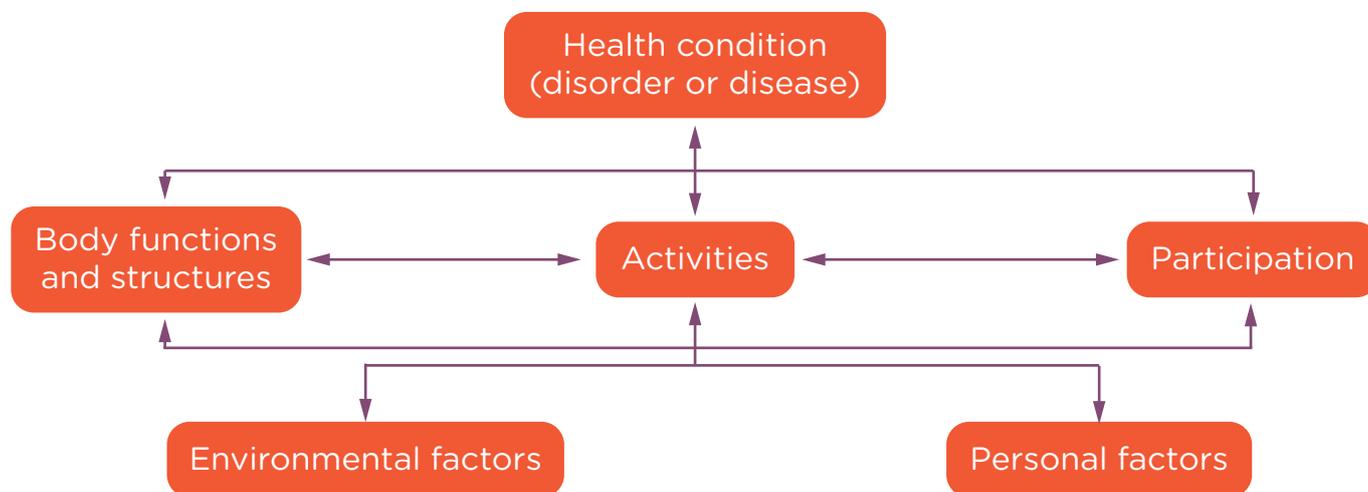
### Box 1: The Convention on the Rights of Persons with Disabilities (CRPD)

The long and intense mobilisation of people with disabilities, the organisations that represent them, and civil society actors, alongside collaboration with national and international bodies for a treaty to promote and protect their rights, culminated in December 2006, when the CRPD was adopted by the United Nations. The Convention, so far ratified by 175 states, is a comprehensive human rights instrument, affirming the rights, freedoms and dignity of people with disabilities, and calling upon states to take all appropriate measures to eliminate discrimination and ensure that persons with disabilities have equal enjoyment of rights in all spheres of life. It comprises 50 separate articles and has the following eight key principles (Article 3):

- Respect for inherent dignity and individual autonomy, including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Source: UN, 2006

**Figure 1: Representation of the International Classification of Functioning, Disability and Health**



Source: WHO and World Bank, 2011

of pity and care. The medical model – still reflected in the policies and services of many LMICs – considers disability as a problem to be solved by medical care, and people with disabilities as objects requiring specialist treatment in stand-alone schools and institutions.

This report is predicated on the rights-based model, which emphasises the institutional, environmental and social factors that prevent individuals with disabilities

from accessing their human rights. Institutional factors include lack of appropriate laws and policies, limited financial and human resources, poor service delivery, and limited investments in monitoring, evaluation and learning. Environmental factors include inadequate physical and built environment, transport, technology, information and communication systems. Social factors include stigmatising attitudes and behaviours.

## Box 2: A note on the terminology used in this report

According to Al Ju'beh, in CBM's Disability Inclusive Development Toolkit, '*Language is important: it is not an exercise in linguistic agility or political correctness but about a fundamental respect for the integrity and dignity of people with disabilities*' (2017: 24). This report uses the terms '*persons with disabilities*' and '*adolescents with disabilities*' in line with the UN CRPD and other recent international agreements. This terminology is known as '*person-first language*', and is based on the need '*to affirm and define the person first, before the impairment or disability*' (ibid.). Cobley notes that this language '*is perhaps now the most commonly used and widely accepted*' (2018: 2), particularly in the global South (Al Ju'beh, 2017; Cobley, 2018).

However, some scholars and organisations, especially in the UK, prefer the term '*disabled people*', which emphasises that '*people do not have disabilities, but rather impairments which become disabling, due to society not being comprehensively accessible and inclusive*' (Al Ju'beh, 2017: 24). Cobley (2018) cites Mike Oliver – a scholar, disability rights activist and disabled person – who stresses that disability should not be viewed as an added appendage, which is what the person-first language might imply, but rather an intrinsic part of a person's identity.

To refer to young people with different forms of disability – visual, hearing, physical or intellectual – in this report, we use the language of '*impairment type*' e.g. '*an adolescent with a visual impairment*'. Where adolescents are without sight or hearing we describe them as blind or deaf (i.e. '*an adolescent who is blind*') to distinguish the severity of their impairment.

Sources: Al Ju'beh, 2017; Cobley, 2018

## Stigma and discrimination

Stigmatising attitudes and behaviours are perhaps the greatest barrier to achieving inclusion. Evidence indicates that negative stereotypes about disability persist around the world (WHO and World Bank, 2011; Groce and Kett, 2014). In many countries, disability is not only associated with misfortune, or even incompetence and incapacity, but also evil and sin. Disability is also sometimes seen as contagious and considered to threaten collective wellbeing. This leaves people with disabilities unsupported, unable to aspire and achieve, socially excluded, and at risk of verbal and physical (and, all too often, sexual) violence. In the most extreme cases, people with disabilities are literally hidden at home by their families – sometimes to protect them from abuse by others in their community, other times to protect their families from the stigma of having a child with disabilities (Groce and Kett, 2014; Division for Social Policy and Development, 2016; Bond DDG, 2017).

There has been considerable research over the past few years that has clarified the concept of social norms and gender norms, and begun to address how those norms might be shifted. Social norms are practices that are held in place because people believe that other people are conforming to them – for example, girls marrying at the onset of puberty – and that if they fail to conform (by delaying age of marriage, for instance), they will be

sanctioned (Harper et al., 2018). The stigma surrounding disability, however – while shaped by norms and fears of exclusion from the community – is, in many contexts, driven by superstitious beliefs that are as deeply held as religious beliefs. Though this makes eliminating stigma even more difficult than shifting social norms, we do not know just how difficult because so few interventions have been designed and tested with that goal in mind. Indeed, the concept of stigma, unlike social norms, remains largely unclarified and without a metric that would allow assessment of any changes.

Thornicroft et al. (2007) argued that stigma is the result of three inter-related problems: the problem of knowledge (ignorance); the problem of attitudes (prejudice); and the problem of behaviour (discrimination). They note that while in Northern contexts there is evidence to suggest that stigma towards mental ill-health can be reduced by direct social contact with people with mental illness and by social marketing approaches that emphasise achieving a social good, the evidence overall is weak. Lusli et al. (2015), in their work in Indonesia with people with leprosy and people with disabilities, noted a tendency of both groups to engage in 'self-stigmatisation', which they concluded illustrated 'the importance of interventions that can challenge deeply held beliefs and assumptions about, for instance, "difference," "illness," and "disability"'.

## Adolescents with disabilities in LMICs

Over the past decade, adolescence has become increasingly seen as an ‘age of opportunity’ (UNFPA, 2014; Steinberg, 2015; Sheehan et al., 2017). A wide range of actors – from neuroscientists to development economists to UN agencies – have begun urging parents, schools, communities and national governments to look past the traditional ‘deficit’ model of adolescence and focus instead on how children’s rapid maturation during the second decade of life can be leveraged to alter and accelerate their adult trajectories. For the development community, the growing focus on adolescents is in part due to their sheer numbers: more than 1.2 billion people – one-sixth of the world’s population – are aged between 10 and 19 (UNICEF, 2011). Nearly 90% of them live in developing countries, and this percentage is expected to rise further given that birth rates in much of sub-Saharan Africa mean that up to half the population there is under the age of 18 (UNFPA, 2014).

The focus on ‘age of opportunity’ notwithstanding, Maxey and Beckert (2017: 59) note that adolescents with disabilities are disproportionately prone to challenges – in part because ‘societal and cultural views of disability can take on additional meaning during the adolescent years’, when young people become increasingly aware of individual differences and young people with disabilities are forced to more directly confront and balance their needs for autonomy and support. Maxey and Beckert further note that even in the global North, there has been little attempt to methodically investigate the nexus of adolescence and disability – an oversight which has left many of the barriers to successful transitions to adulthood opaque and unaddressed. In the development literature, even as adolescence and disability have moved up the agenda, adolescents with disabilities have remained almost completely invisible. Hidden under the broader rubric of ‘children with disabilities’, or sometimes ‘youth with disabilities’, their unique age-related needs and vulnerabilities (e.g. puberty and sexuality education, growing independence, and risk-taking) have scarcely been considered.

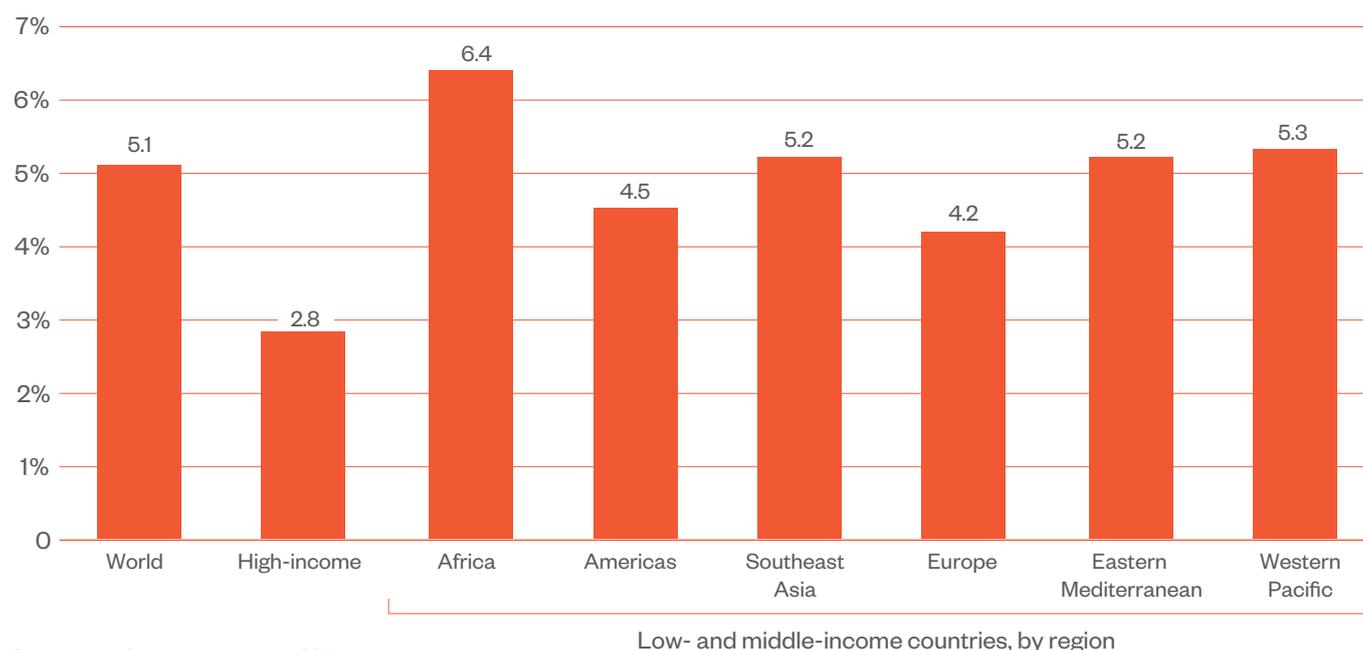
Indeed, partly owing to different definitions and measurement techniques, differing country-level capacity

for accurate data collection, and under-reporting due to disability-directed stigma, we do not know how many adolescents in LMICs have impairments. In 2011, based on two large data sources,<sup>1</sup> WHO and the World Bank estimated that 15% of the global population – over a billion people and disproportionately from the bottom wealth quintile – were living with disabilities. The vast majority (80%) live in LMICs. Using the same data, WHO and World Bank estimated that between 93 million and 150 million children and adolescents under the age of 18 are estimated to have disabilities, with most also living in LMICs – and particularly concentrated in sub-Saharan Africa. It is also estimated that globally, 5% of children and young adolescents (up to age 14) live with a moderate or severe disability (compared to 12% of men and 19% of women aged 15–59) (see Figure 2). Prevalence of disability among adolescents (aged 10–19) is likely to be slightly higher than among younger children (from infants to age 14), given that adolescents have had more years in which to experience a disabling illness or accident. In addition, overall numbers of children and adolescents with disabilities are likely to increase in the coming years as a result of young age structures in many LMICs (WHO and World Bank, 2011; UNICEF, 2013a; 2013b).

Estimating the number of children and adolescents with disabilities is particularly difficult for several reasons. First, while the UN Convention on the Rights of the Child (UNCRC) (1989) recognises that young people under the age of 18 are children, public health data often considers those over the age of 15 to be adults. Indeed, as already noted, the *World Report on Disability*, from which current estimates of disability prevalence derive, included data about children up to age 14 and for adults from age 15 and older (WHO and World Bank, 2011). Second, because the prevalence rate of disability among children is relatively low (compared to adults), large sample sizes are needed in order to achieve meaningful estimates. In addition, most internationally comparable data on disability relies on the Washington Group questions (see Box 3). While these questions standardise definitions and methodologies on disability and usefully classify disability in terms of how it impacts a person’s functioning, applying the questions to children is problematic. Not only are questions meant to be asked directly of the person with disability, which can be difficult for some young people, but the question set

<sup>1</sup> These were the 2002-2004 World Health Survey from 59 countries, representing 64% of the global population, and the Global Burden of Disease study 2004 Update.

**Figure 2: Proportion of children aged 0-14 with a moderate or severe disability, by country grouping**



Source: WHO and World Bank, 2011

### Box 3: Washington Group questions

The Washington Group was established in 2001, under UN sponsorship, to improve the quality and comparability of disability measurements. The short set of questions asks respondents to rate the amount of difficulty they have with 6 types of activities. Ratings are given on a 4-point scale: no difficulty, some difficulty, a lot of difficulty, and cannot do at all. The 6 questions are:

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?

Source: [www.cdc.gov/nchs/data/washington\\_group/wg\\_short\\_measure\\_on\\_disability.pdf](http://www.cdc.gov/nchs/data/washington_group/wg_short_measure_on_disability.pdf)

does not address the developmental and psychosocial problems that are more common causes of disability in childhood or ask questions about age of onset, which can shape the way young people are treated and interact with the world around them.

Estimating disability prevalence for children and adolescents is also difficult because of variance in how disability is culturally understood, which impacts what types of impairment are even on parents' 'radar screens'. Plan International's 2012 cross-sectional survey of over 900,000 sponsored children and adolescents up to the age of 17 living in 30 LMICs provides some interesting

insights into this issue. While not nationally representative (as all children were under sponsorship and thus chosen because of their vulnerability), Plan's survey asked parents if their child had a disability, and if so what type, and found that types of reported impairments were highly variable (Kuper et al., 2014).

Unsurprisingly, given that we do not even have an accurate picture of how many adolescents are living with disability, evidence on how disability shapes adolescents' daily lives is thin and fractured (Groce and Kett, 2014; Engelbrecht et al., 2017; UN, n.d.). Indeed, while the UN Children's Fund (UNICEF) (2013b: 18) notes



that adolescents with disabilities 'are amongst the most marginalised and poorest of the world's youth', Groce and Kett (2014: 3) observe that, 'Of all groups of youth<sup>2</sup>, the group about which we know the least are youth with disabilities'. While there is evidence that young people with disabilities are aspirational about their futures—committed to their schooling and with hopes of having families of their own (Peters, 2009; ACPF, 2011; Leonard Cheshire Disability, 2012; Groce and Kett, 2014; Jones et al., 2016; Bhatta et al., 2018)—there is also evidence that suggests that adolescents with disabilities can struggle to develop a range of capabilities (see also Box 4). They may be excluded from education, particularly vulnerable to violence and abuse, and face significant barriers to

accessing health care (Groce and Kett, 2014; Banks and Zuurmond, 2015; Jones et al., 2016; Bhatta et al., 2018; UN, n.d.). Many also develop low self-esteem and have poor personal relationships, have little or no involvement in decision-making and community life, and find it extremely difficult to obtain decent employment (ibid.). In addition, despite their greater vulnerability and having different needs from both younger children and adults, they typically fall between the cracks of services for children with disabilities and adults with disabilities (WHO and World Bank, 2011; Groce and Kett, 2014). They are also often excluded from broader programming meant for adolescents and youth because of their disability (ibid.).

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2 The authors clarify that youth refers to those aged 15-24 (Groce and Kett, 2014).

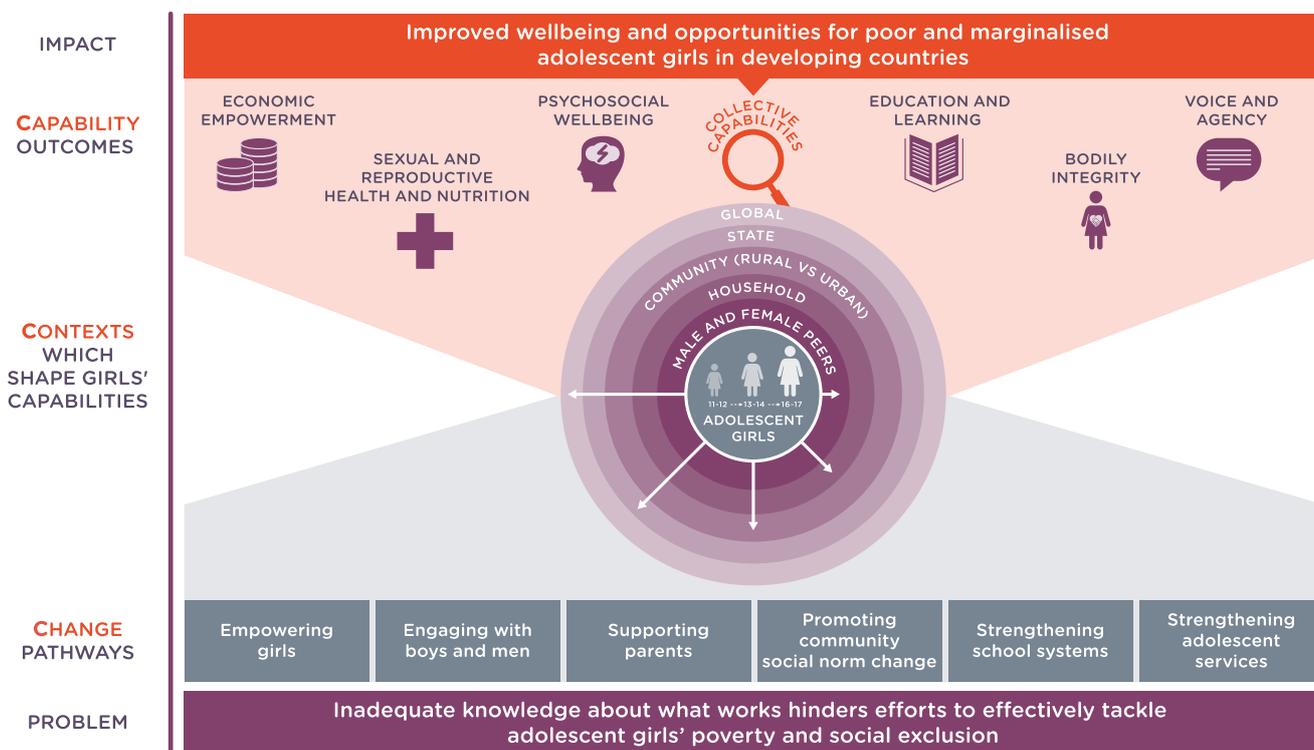
### Box 4: The capabilities approach and GAGE’s longitudinal research with adolescents

The capabilities approach championed originally by Amartya Sen (1984; 2004), and nuanced to better capture complex gender dynamics at intra-household and societal levels by Martha Nussbaum (2011) and Naila Kabeer (2003), has evolved as a broad normative framework exploring the kinds of assets (economic, human, political, emotional and social) that expand the capacity of individuals to achieve valued ways of ‘doing and being’. At its core is a sense of competence and purposive agency: it goes beyond a focus on a fixed bundle of external assets, instead emphasising investment in an individual’s skills, knowledge and voice. As such, it shifts ‘the focus from the specificities of the disabling situation to how to look at establishing equality in terms of possibilities and choices... We look at the interaction between the person, with his/her limitations in functioning (which may or may not be permanent) and the context, which consists of a number of resources as well as expectations, stereotypes and often prejudice and discrimination. As a result, the policies that would be set up would aim at establishing an equality of activity and participation.’ (Bakhshi and Trani, 2006: 6). Importantly, the approach, with its emphasis on ‘freedoms’, can encompass relevant investments in people with diverse trajectories, including the most marginalised and ‘hardest to reach’ such as adolescents with disabilities.

The conceptual framework used by the GAGE multi-country longitudinal research programme is also based on the capabilities approach (see Figure 3). Focusing on six broad capability domains (education and learning; health, sexual and reproductive health (SRH), and nutrition; psychosocial wellbeing; bodily integrity and freedom from violence; voice and agency; and economic empowerment), it posits two levels of final, multidimensional outcomes: those that relate to the capabilities of individual adolescents and those that relate to what Kabeer (2003) calls their ‘collective capabilities’.

The former emphasises the need to invest in adolescents as people, supporting them to choose the kind of life they value and to achieve it (what Sen terms a ‘capability set’) (Nussbaum, 1997; Unterhalter, 2003; Sen, 2004). The latter refers to group-level capabilities that emerge through collective action, which not only help strengthen individual capabilities but can also ultimately benefit others who are not personally involved in these interactions (see Kabeer, 2011; Trani et al., 2011; Ibrahim, 2006).

Figure 3: GAGE 3Cs conceptual framework



Source: GAGE programme, 2017

## Intersecting disadvantage

It is also important to consider the diversity of adolescent experiences, including the ways in which disability may differ by impairment type, and intersect with different forms of social exclusion, including gender, ethnic minority status, rural residence or conflict-affected contexts.

### Impairment type

The concept of disability is extremely broad and encompasses a wide range of physical, mental, intellectual and sensory impairments (UN, 2006). This makes it difficult – even impossible – to draw categorical conclusions. Take, for example, adolescents with visual impairments and adolescents at the far end of the autism spectrum: while both are likely to face stigma and exclusion, their day-to-day experiences and needs are likely to be very different. Very little research has thus far taken this need for disaggregation into account. Indeed, of the countries that report to the UN Committee on CRPD implementation, only a handful disaggregate even school enrolment figures by disability type (UNESCO, 2017).

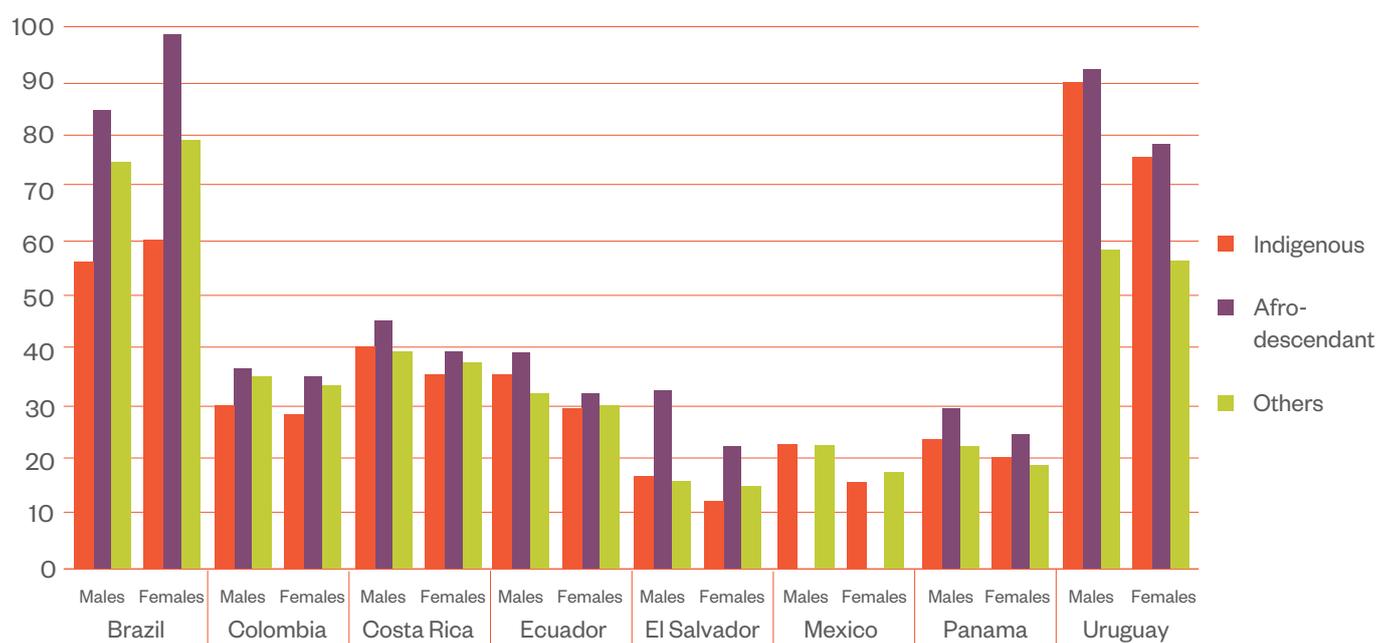
The evidence from LMICs that addresses the impact of impairment type is diverse, if thin. On the whole, it suggests that adolescents with intellectual, multiple or severe impairments (for example) are most likely to be out of school (Jones et al., 2016; Panda, 2016). Not only do they require more complex adaptations to facilitate

their access to school, but sometimes they are especially unlikely to have parental support for education (Jones et al., 2016). Indeed, there is some evidence that they are also deprioritised within the household for nutrition and health care (Jones et al., 2016; see also Chapter 2 on Health, Sexual and Reproductive Health and Nutrition). Adolescents with intellectual impairments, especially girls, appear most likely to experience sexual violence (Frohman and Ortoleva, 2013; Braathen et al., 2017). Adolescents with hearing impairments appear to be the most socially isolated, as they are sometimes unable to communicate even with their own families; where they are also out of school, their social isolation can be nearly complete (Tefera et al., 2015; Jones et al., 2016; Bhatta et al., 2018).

### Gender

While disaggregated estimates of populations are rare, some groups of adolescents are especially likely to experience disability. Others are particularly marginalised and disadvantaged because of their disability (UNICEF, 2013a; 2013b; Aguilar, 2017). For example, boys in most countries are more likely to have disabilities than girls (see Figure 4). Girls, on the other hand, are in many contexts more disadvantaged by disability due to the confluence of restrictive gender norms and disability-related stigma (WHO and World Bank, 2011; UNGA, 2012; UNICEF, 2013a; 2013b; UN, 2016).

**Figure 4: Latin America: prevalence of disability among 0-18 year olds, by sex and ethnicity (per 1000 inhabitants)**



Source: Economic Commission for Latin America and the Caribbean (ECLAC), 2012

Girls with disabilities can face double discrimination on account of both their gender and disability (UNGA, 2012; UNICEF, 2013a; 2013b; Jones et al., 2016; UN, 2016). 'In some LMICs, access to education for girls with disabilities is catching up with that of their male counterparts (Male and Wodon, 2017) – in fact, in a handful of countries with recent comparable data, girls are now significantly more likely than boys with disabilities to complete primary school (68% versus 50%) and are less likely to be out of school at lower secondary age (23% versus 24%) (UNESCO, 2018). Nonetheless, in the poorest countries, girls with disabilities remain starkly disadvantaged compared to their male peers, especially at secondary school level'. In Ethiopia, for example, where the Ministry of Education reports that only 4% of children with disabilities are enrolled in school, the ratio of boys with disabilities to girls with disabilities in preparatory school (grades 11 and 12) is 3:1 (Ministry of Education, 2016).

Girls and women with disabilities are also more vulnerable to all forms of abuse and exploitation, are less likely to have access to good nutrition, or to access health care (including sexual and reproductive health services), and less likely to access rehabilitation and assistive technologies that could increase their independence and

social participation (WHO and World Bank, 2011). They are also over-represented among poor people, as they are less likely to engage in economic activity and earn a decent income (WHO and World Bank, 2011; Mitra et al., 2013; ILO, 2015a; Banks et al., 2017). The gender dimensions of disability are not confined to those with disabilities; their caregivers – almost exclusively mothers and sisters – are also more vulnerable to emotional and physical exhaustion, social exclusion and poverty (Jones et al., 2016).

### Rural areas

Adolescents with disabilities who live in rural areas, or are socially marginalised for other reasons (such as poverty, ethnicity, caste or language) are also far more vulnerable (UNESCO, 2010; WHO and World Bank, 2011; UNICEF, 2013a; 2013b). Not only do they have more limited access to the quality primary health care that might have prevented disability in the first place (UNICEF, 2007), but they are also more likely to experience stigma and discrimination and have extremely limited access to the adapted services that make independent life possible. Schools in rural areas of LMICs, for example, rarely provide any sort of accommodation or support to students with disabilities (Katsui et al., 2014; Burns and Oswald, 2015; Bhatta et



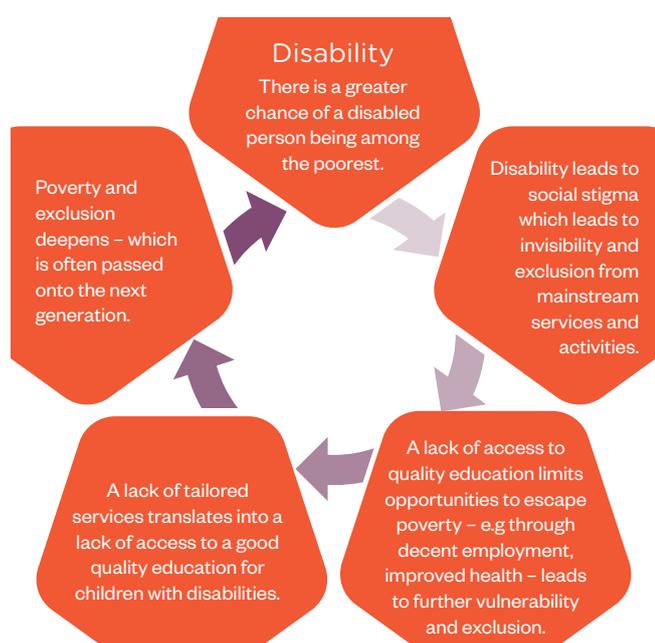
An adolescent boy with a physical impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

al., 2018), while specialised medical services are almost universally situated in urban centres and provided in national languages only (Huq et al., 2013; Eide et al., 2016; Lord et al., 2016; Manara Network, 2011; Tekola et al., 2016).

### Humanitarian and conflict-affected contexts

Adolescents with disabilities living in conflict-affected environments are perhaps the least visible on international and national agendas. With the nature of conflict changing – both in terms of the number of years that conflict drags on and the exposure of civilian populations to violence – budgets are woefully inadequate, leaving those needing extra support to do without (Peters, 2009; UNESCO, 2013; Berghs and Kabbara, 2016; HRW, 2016; Rohwerder, 2017; UNICEF, 2017). UNICEF (2013a) notes, for example, that children and adolescents with disabilities affected by humanitarian crises may be less able to evacuate, excluded from mainstream humanitarian services because of physical barriers to accessing those services, and especially vulnerable to abuse of all types due to the heightened risks in such settings. It is estimated that for every child killed in conflict, three others are injured or permanently disabled. Given this statistic, the longer-term ramifications of the development community's non-engagement with the needs of persons with disabilities is alarming (Syria Relief, 2018).

**Figure 5: Disability and the cycle of poverty**



Source: WHO and World Bank, 2011

## Disability, poverty and development

As the concept of disability has evolved, disability has increasingly become a development priority. In part this is because of the recognition that 80% of persons with disabilities live in developing countries (WHO and World Bank, 2011; Aguilar, 2017). There is also a growing evidence base that underscores the role of disability in perpetuating the cycle of exclusion and poverty (see Figure 5; also Walker et al., 2013). Indeed, research has found links between disability and a wide range of the assets understood to support the development of human capabilities. For example, persons with disabilities (and their families) have been found to be more likely to experience food insecurity, to lack access to safe water and sanitation, to be deprived of their rights to education and health care, to have poor housing, and to have poorer access to decent work, assets and financial services (Yeo and Moore, 2003; WHO and World Bank, 2011). Taken as a whole, it has become increasingly clear over the past decade that it will not be possible to meet international development goals unless there is a direct focus on supporting persons with disabilities to achieve equitable access to their human rights.

Although a handful of studies have found inconclusive results on the direct association between disability and household income or consumption expenditures, the general consensus is that poverty and disability are closely linked, particularly in LMICs, and particularly where disabilities begin in childhood rather than develop in old age (Mont, 2014; Mitra et al., 2013; 2017; Banks et al., forthcoming, cited in Banks et al., 2018). For example, a widely cited study, which used household survey data from 13 LMICs, found that disability is associated with about a 10 percentage point increase in the probability of falling into the two poorest quintiles (Filmer, 2008). This was attributed to children with disabilities being less likely to acquire the necessary education to earn higher incomes in adulthood (ibid.). Another study, using data from 15 LMICs, also found that disability was associated with lower educational attainment and lower employment rates (Mitra et al., 2013).

Apart from low human capital leading to limited employment and low income, disability may also result in additional expenditures, especially for health services or personal support (WHO and World Bank, 2011; Aguilar, 2017; Mitra et al., 2017). Indeed, data from 31 LMICs shows

that given the increased health needs of people with disabilities and their lack of health insurance, they spend a higher proportion of household income on out-of-pocket health care costs compared to people without disabilities (WHO and World Bank, 2011). More than one in four has to make catastrophic health expenditures (i.e. when the costs people have to pay for care consume such a high proportion of their disposable income that it pushes them into poverty) (WHO and World Bank, 2011). Using data from 15 LMICs, another study investigated the links between disability and health expenditures (Mitra et al., 2013). It also found that disability in most of these countries is associated with higher health expenditures. It concluded that people with disabilities are more likely to experience multidimensional poverty than those without disabilities. They are not only more likely to experience deprivations across a range of areas, but the depth of their poverty is more severe (ibid.). Indeed, Amartya Sen (2004) has argued that the poverty line for people with disabilities should be higher than for those without disabilities due to the higher costs associated with disability.

While we are unable to locate estimates for countries in the South, there is evidence from developed countries that the total costs involved in raising a child with disabilities are especially high. In the UK, it costs three times as much to raise a child with disability as it does to raise a child without disability (Gordon, 2000, cited in Mont, 2014). While overall ratios are probably quite different in LMICs, one cost that is probably higher in Southern contexts than in Northern contexts is education – given that children with disabilities in some countries have few options other than expensive, private schools or may require expensive transport. Mont (2014) also notes that for some types of disability,

parents (often mothers) are forced to forgo work in order to provide full-time care (see Box 5) and, as we discuss further in Chapter 3 on Psychosocial Wellbeing, may face relationship breakdown and social isolation.

Apart from investigating the links between disability and poverty, a growing body of literature focuses on estimating the broader economic costs of excluding people with disabilities from social, economic and political life in LMICs. An early study calculated that LMICs lost between \$474 billion and \$672 billion annually from lower productivity of people with disabilities (Metts, 2000, cited in Morgon Banks and Polack, 2014). A more recent study estimated that the economic costs of excluding people with disabilities in LMICs from the labour force reach up to 7% of gross domestic product (GDP) (Buckup, 2009). Country-level estimations also reveal huge losses: of \$1 billion a year in Morocco (cited in Morgon Banks and Polack, 2014), and \$891 million a year in Bangladesh (World Bank, 2008).

As the links between disability and development have become clearer, international organisations, governments, donors and civil society have paid increasing attention to disability issues and supported disability-inclusive policy and programming. The Sustainable Development Goals (SDGs) reflect this growing commitment. While disability was not mentioned at all in the Millennium Development Goals (MDGs) (2000–2015), it is explicitly included in six SDGs that cover education, decent work, inequality reduction, access to transport and safe spaces, and data monitoring (Table 1). Including disability in the SDGs and the Leave No One Behind commitment is expected to enhance and accelerate international and national efforts for disability-inclusive development.

### Box 5: The cost of care

Around the world, mothers provide much of the care for children with disabilities. Depending on the nature of their child's impairment, and the other services available in their community, mothers' commitment may be very demanding – and life-long.

Women pay a high cost – personally and economically – for becoming full-time caregivers for their children with disabilities. Evidence suggests that they have high levels of depression and anxiety, especially where their own extended families blame them for producing a 'defective' child (Azar and Badr, 2006; Motamedi and Noortikhajavi, 2007; Tanabe et al., 2015; Jones et al., 2016).

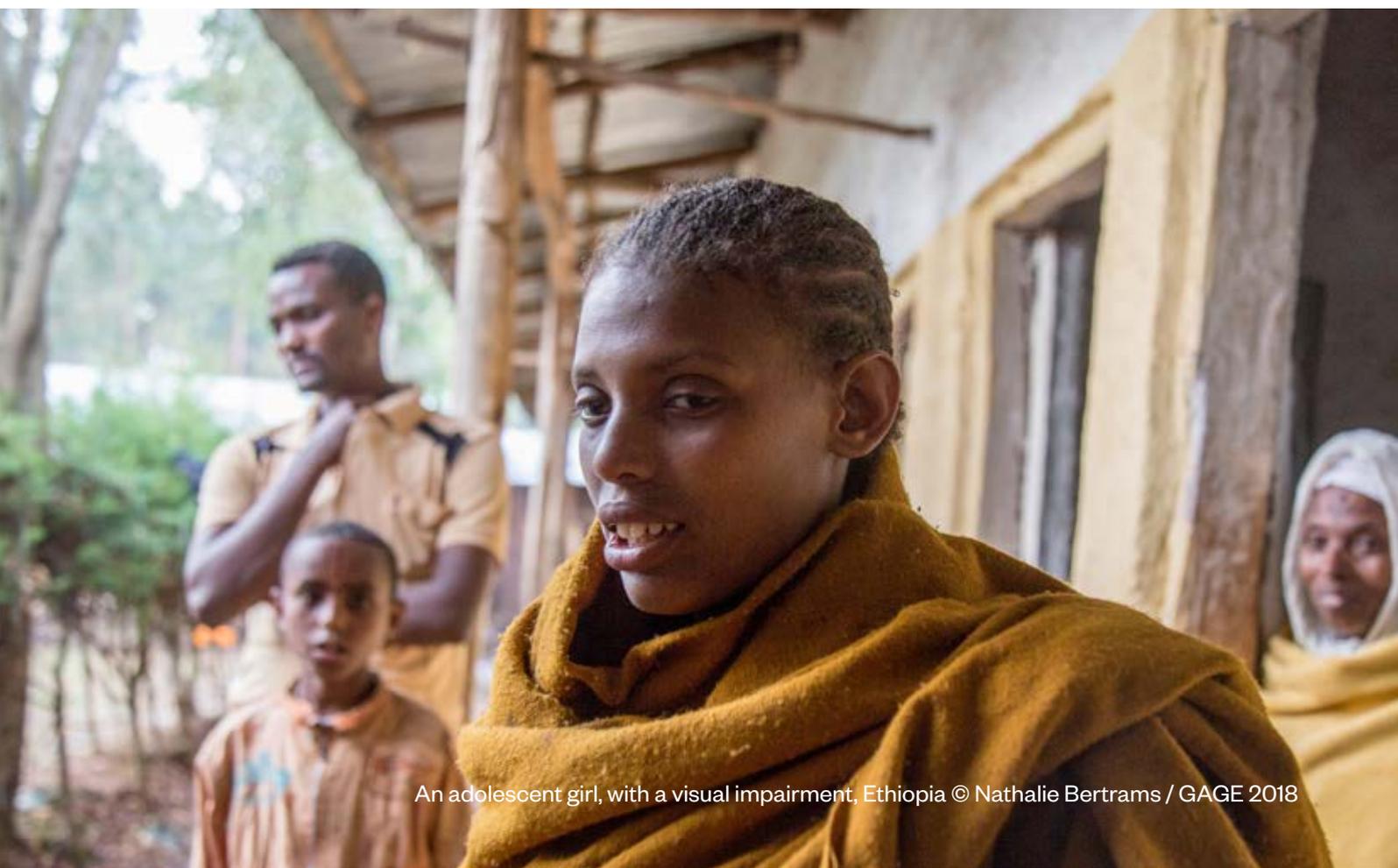
The financial costs of caregiving can also be high, as women are forced to forgo earning in order to care for their child (Mehrotra, 2013). The World Bank (2008) estimated the costs of lost labour productivity of those who care for people with disabilities (typically women). In Bangladesh, this amounted to \$234 million a year for adult helpers and \$28 million a year for children without disabilities whose education and lifetime earnings were negatively affected due to having to support family members with disabilities.

Table 1: The inclusion of disability in the SDGs\*

SDG <sup>i</sup>	Target
<b>SDG4 on quality education</b>	4.5 By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations
	4.A Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, nonviolent, inclusive and effective learning environments for all
<b>SDG8 on decent work and inclusive growth</b>	8.5 By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value
<b>SDG10 on reducing inequalities</b>	10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status
<b>SDG11 on sustainable cities</b>	11.2 By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons
	11.7 By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities
<b>SDG17 on global partnerships on data monitoring</b>	17.18 By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts

\* <https://sustainabledevelopment.un.org/sdgs>

<sup>i</sup> SDG1 on ending poverty does not have any target mentioning disability but does have an indicator: Indicator 1.3.1: Proportion of population covered by social protection floors/systems, by sex, distinguishing children, unemployed persons, older persons, persons with disabilities, pregnant women, newborns, work-injury victims and the poor and the vulnerable.



## Policy and legal landscape

### Legal rights and their implementation

Spurred on by the CRPD and the UNCRC (see Box 6), the disability-related policy and legal landscape in LMICs is evolving rapidly. For example, in 2013, Bangladesh passed a new Rights and Protection of Persons with Disabilities Act, which takes a human rights perspective and covers persons with diverse impairments. It mandates that persons with disabilities are issued with national identity cards, are enrolled in regular schools, have reserved seats on all forms of public transportation, and that there are accessibility provisions in all public places, equal opportunities in employment, and protection of inherited property rights. A number of other Southern governments, including Nepal (through the Disability Rights Bill 2017) and Uganda (through the Persons with Disabilities Act 2006 and subsequent 2009 national implementation guidelines), have brought in analogous rights-based legislation to advance the inclusion and wellbeing of people with disabilities.

However, legal changes remain far from adequate in scale or in scope (Lang et al., 2011; WHO and World Bank, 2011). The analysis by Nakray (2018) of countries which had ratified the CRPD up until 2014 found that a significant number lacked legal guarantees for persons with disabilities to have equal rights to health, work, equality and non-discrimination (see Annex). Indeed, the interplay between the CRPD and national policy appears complex. For example, Grimes et al. (2015) and Tefera et al. (2015) observed that because many policies calling for inclusive education were written largely to demonstrate compliance with international conventions, and were never adequately clarified in national law or sector plans, such policies have, in some cases, slowed implementation

by introducing confusion about what inclusion (versus integration) even means.

An even more daunting challenge, noted by Lang et al. (2011), is implementing policies and laws effectively. Due to the complexity of the issues involved, even when states have strong policy statements supporting the rights of persons with disabilities (whether to protection from economic privation, to receive an appropriate education, to access health care and employment, or to participate in family, community, and political life), the impacts of those policies on the day-to-day lives of adolescents with disabilities on the ground remain minimal. This is because policy formulation is often divorced from implementation, and there is frequently little coordination between different government ministries on cross-cutting issues such as disability – especially as they intersect with other cross-cutting areas of policy, such as gender (Lang et al., 2011). Indeed, even in Italy, which Walker et al. (2013) notes is the only country in the EU educating nearly all students with disabilities in mainstream schools, Ferri (2017: 16) observes that ‘the full realization of a truly inclusive system’ remains a goal rather than a *fait accompli*.

In many contexts, there is no coordinating body to ensure links between young people’s inclusive education needs, basic and specialised health care and assistive devices, transportation support, and social assistance. In Ethiopia, for instance, the Ministry of Women’s and Children’s Affairs leads on the country’s Children’s Policy, which highlights the social and psychological vulnerabilities of young people with different kinds of disabilities as well as their lack of access to services, and commits to improving their rights, participation and safety in line with the rights of all children from birth until the transition into adulthood; the Ministry of Education, in the Education Sector

#### Box 6: The UN Convention on the Rights of the Child

The UNCRC, which entered into force in 1990, is the most widely ratified treaty in the history of the world. Every UN member state except the United States has ratified the convention.

Its 54 articles are based on four general principles: i) non-discrimination; ii) best interests of the child; iii) right to life, survival and development; and iv) right to be heard.

On disability, the UNCRC mandates that children with disabilities are to enjoy the same rights as other children – including self-reliance and active participation in the community. It also recognises children’s rights to ‘special care’; calls for access to education, training, health care services, rehabilitation services, preparation for employment and recreational opportunities to be provided, preferably for free, in a manner that is conducive to the child’s fullest individual development and integration into society; and calls for exchange of information relating to good practices between states.

Sources: UNICEF, 1990; 2018

Development Programme V, emphasises special needs education and inclusive education, offering educational stipends for young people in special needs education; while the Ministry of Labour and Social Affairs carries out assessments for assistive devices and is starting to implement a new social assistance programme to support people with disabilities. The National Plan of Action for the Inclusion of Persons with Disabilities 2012–2021 notwithstanding, there is no coordination mechanism at national or regional (or even district) level between these agencies, nor is there a mechanism for cross-referrals. This means that young people are not receiving joined-up care, and there are also multiple missed opportunities to identify children living with disabilities and to support them to tackle the intersecting vulnerabilities with which they too often contend. Moreover, in the absence of an overarching coordinating body, there is a dearth of accountability to delivering on the commitments of the CRPD.

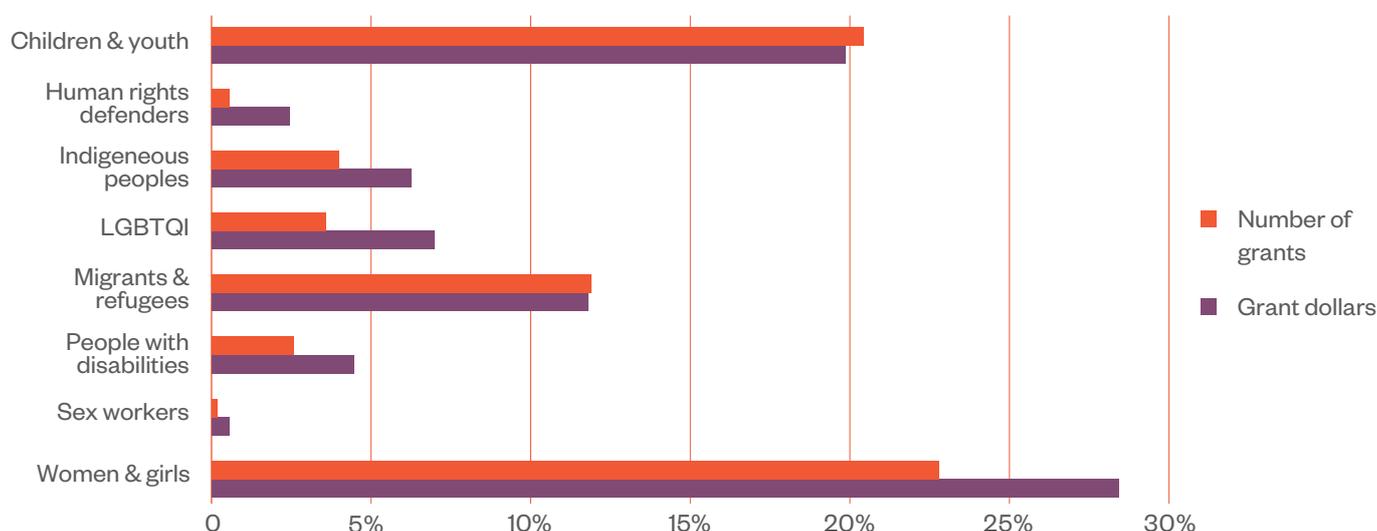
## Financing

Financing is another critical challenge in translating policy and legislative commitments to the rights of people with disabilities into actions. Although data is scarce, from the budget evidence that is available, underinvestment appears to plague multiple actors. The Foundation Center (2018), for instance, found that between 2011 and 2015, only 3% of total human rights funding (\$2.7 billion) was spent on disability, compared to 23% on women and girls, 20% on children and youth and 4% on lesbian, gay, bisexual, transgender, queer or questioning, and intersex (LGBTQI) (see Figure 6). Moreover, a 2016 review of World Bank programmes found

that only 2% explicitly included people with disabilities (Karr et al., 2016). The number of donors working on disability inclusion issues within international development is also limited but growing steadily (see Annex).

Financing gaps appear to cut across sectors. In the case of social assistance, the WORLD Policy Analysis Center (2018), for example, observes that as of 2012, only 3% of low-income and 23% of medium-income countries had any specific cash benefits for children with disabilities (compared to 71% of high-income countries). Where young people with disabilities are targeted because of their disabilities, programmes tend to be either small scale and aimed at very particular groups of children, such as those who are also war orphans or living on the street, or targeted more broadly at elderly people and people with disabilities, where the age-specific concerns of young people are likely to be overlooked (Walsham et al., 2017). Alternatively, where children with disabilities are targeted because they live in poor households, social protection benefits rarely take into account the extra real and opportunity costs that can be associated with disability – and especially childhood disability (WHO and World Bank, 2011; Mont, 2014; Mitra et al., 2017). Among the exceptions to this more general rule are Argentina, where the Universal Child Allowance is higher for children with disabilities than for children without disabilities (\$224 vs \$69) (ILO, 2015) and South Africa, where the (means-tested) Care Dependency Grant provides just over \$115 a month to caregivers of children with severe impairments who need full-time home care (Legal Aid South Africa, 2015).

**Figure 6: Share of total human rights funding, 2011–2015**



Source: Foundation Center, 2018



Inadequate legislative frameworks and limited political will mean that very few governments commit enough resources to ensure disability-inclusive education, according to a recent review by the International Disability and Development Consortium Inclusive Education Task Group (Myers et al., 2016). Citing Development Finance International (2016), they point out that out of 76 LMICs, only 31 have specific budget allocations for children with disabilities or for special needs education. They additionally note that there is seldom transparency as to whether the finances are allocated to special or inclusive education. Human Rights Watch (2015), for instance, cites the example of South Africa, where the promising White Paper 6 on Inclusive Education has largely failed to deliver, due to inadequate financing. Similarly, in Peru, only 0.05% of the total Ministry of Education budget was allocated to special schools, and the 2010 National Budget had no figures for inclusive education activities (CONFENADIP, 2011). In recognition of this, the Global Partnership for Education is now supporting some initiatives to strengthen detailed planning and costing for the implementation of inclusive education policies, including with the Ministry of Education in Ghana and UNICEF Ghana (see Chapter 1 on Education and Learning) (GPE, 2018).

In terms of health, people with disabilities often have extra costs for medical care, assistive devices, personal support or transportation (WHO and World Bank, 2011; Mitra et al., 2017). Indeed, the WHO and World Bank (2011) estimated that persons with disabilities in low-income countries were 50% more likely to experience catastrophic health expenditures than people without disabilities. While these extra disability-related costs are associated with higher poverty rates for people with disabilities (and their families), and can mean that those with disabilities who are poor are poorer than those without disabilities (e.g. the depth of their poverty is greater), it is also the case that higher out-of-pocket costs leave even those people with disabilities who are not poor with less money to spend on other things – and forced to rely on negative coping strategies. For example, in Zimbabwe, Deluca et al. (2014) found that the Basic Education Assistance Module fund, which the government introduced to prevent households from having to rely on strategies such as withdrawing their children from school in response to worsening poverty, was not effectively reaching children with disabilities because its means-testing considered only income rather than costs. This often forced even children with disabilities who were not poor to withdraw from school. Financing options

such as universal free health care, health insurance or cash transfers, which even when not explicitly targeted may be used on health expenditures, are one way to address disability-driven financial barriers, but coverage of such arrangements remains limited in many LMICs. The WHO (2018) estimates, for example, that 97 million households in 2010 alone were pushed below the \$1.90 a day poverty line (using 2011 purchasing power parity) as a result of household expenditure on health. See also Figure 7, which highlights general risks of catastrophic health spending.

### Role of non-governmental actors

Given these resourcing constraints for supporting young people with disabilities across sectors, non-governmental actors – including community-based and faith-based organisations, disabled people’s organisations and non-government organisations (NGOs) – often play a critical role in providing services and programming. They may also act as centres of excellence, providing specialised services for young people with specific impairments (see discussion of promising practices in each chapter).

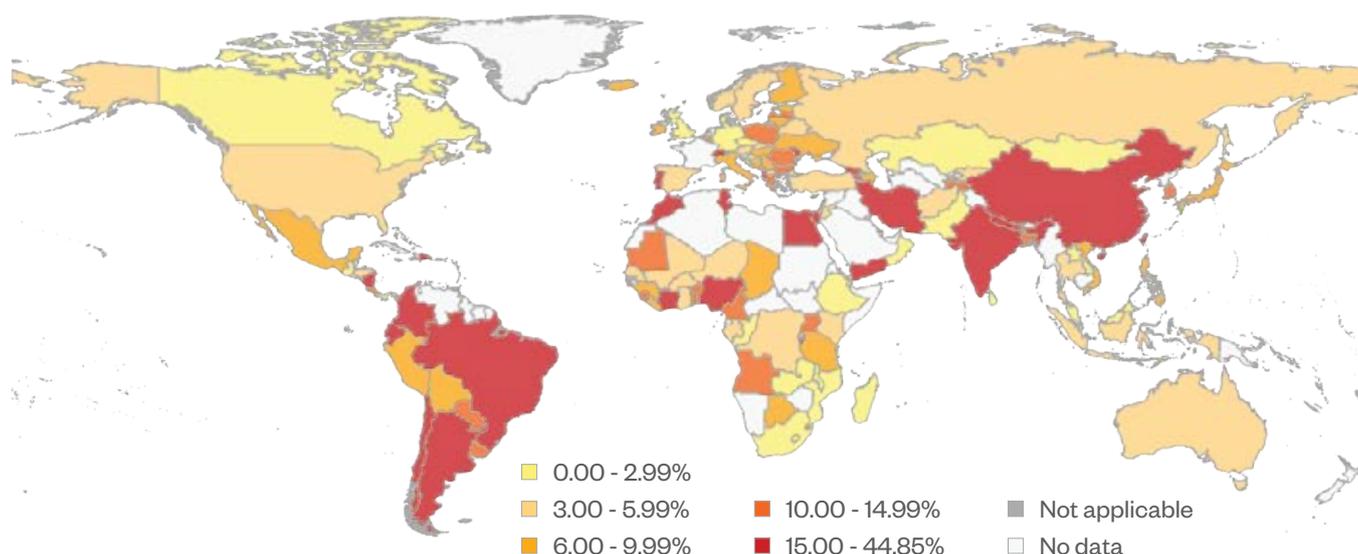
However, apart from inclusive education initiatives, community rehabilitation programming and social assistance programmes, which (although still far from adequate in terms of coverage, as discussed in the main body of the report) are aiming to reach young people with disabilities at some scale, much of the programming undertaken by NGOs is very small scale, fragmented and subject to short timescales.

### Human resources

Part of the reason for poor implementation is the dearth of human resources. In many LMICs, for example, there are not enough trained teachers to meet the educational needs of adolescent with disabilities. UNICEF (2013c) notes that in Niger, for example, there is one adequately trained lower-secondary level teacher for every 1,300 students – compared to 1:16 in the UK. Training for special needs and inclusive education is even rarer (*ibid.*). In Ethiopia, for example, the training curriculum for mainstream classroom educators did not include any courses on disability until 2012 (Tefera et al., 2015) and in Nepal, Rahaman (2017) found that even teachers at schools claiming to be inclusive had never received training on disability. Educators trained to work with children with specific impairment types are rarer still. In Ethiopia, there are only two schools for children with autism – both of them in Addis Ababa (Tilahun et al., 2017).

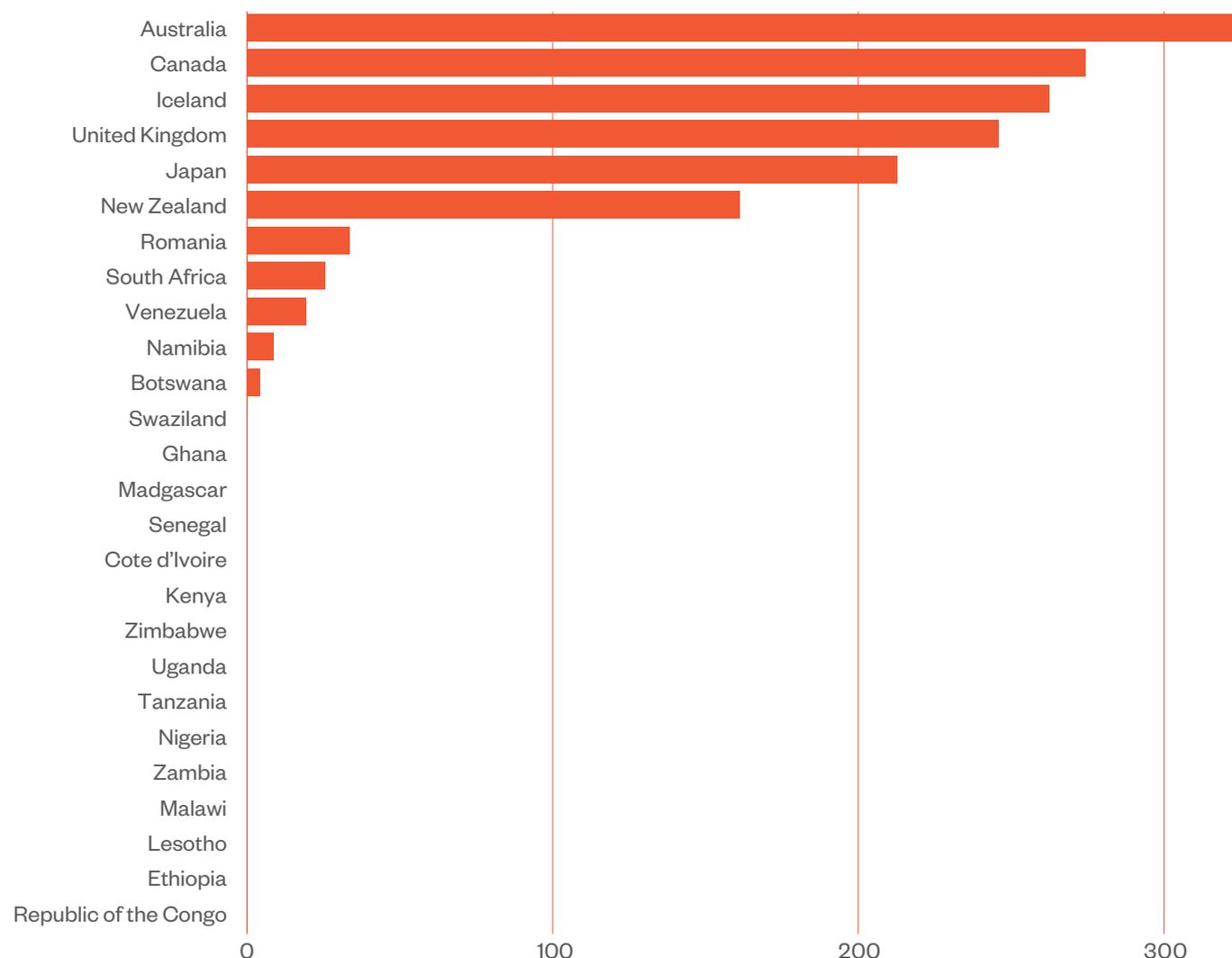
Limited training is also a challenge in the health sector, with the WHO (2017: 1) noting that the current rehabilitation workforce is ‘totally inadequate’. It observes that in Africa and Asia, the number of physical and rehabilitation medicine doctors, physiotherapists, speech and language therapists, and prosthetists and orthotists is less than one-tenth of what is required. Indeed, it notes that in many sub-Saharan African countries, there is not yet a single speech and language therapist (see Figure 8). Furthermore, the health care providers to whom the majority of those with disabilities in LMICs do have access typically have little training in disability. For example, Tilahun et al.

**Figure 7: Universal health coverage: incidence of catastrophic health spending, SDG indicator 3.8.2**



Source: WHO, 2017

**Figure 8: Density of speech and language therapists per 1 million population in 27 countries**



Source: WHO, 2017

(2017) observe that the curriculum for Ethiopia’s Health Extension Worker programme includes no attention to developmental disabilities or the psycho-emotional support needs of caregivers looking after children with disabilities. Disability-specific training was also found to be limited in Palestine, with Jones et al. (2016) reporting that few primary care providers were able to manage disability-specific needs; specialists needed to treat some forms of disability were simply not available.

### Data and evidence to inform policy and practice

Arguably the largest challenge within policy and programming is data and evidence. Despite many LMICs being signatory to Article 31 of the CRPD, which calls for statistics and data collection, few collect the data that could guide the formulation of policy and programming (Bickenbach, 2011; Lang et al., 2011). While figures are

often available on how many children with disabilities are in education and sometimes on how many are receiving social assistance, many LMICs, as noted earlier, do not know how many adolescents with disabilities live within their boundaries – a gap itself due to the reality that disability remains a somewhat contested concept. This means that even if we know how many are enrolled in school, we do not know how many children and adolescents with disabilities are invisible and excluded from existing programmes and services. In addition, as noted in Chapter 2 on Health, Sexual and Reproductive Health and Nutrition – which discusses the potential of community-based rehabilitation for providing disability-specific health care to adolescents with disabilities – we do not even know how many young people with disabilities are successfully accessing services because disaggregated data is not collected.



An adolescent girl, with a physical impairment, West Bank © Rebecca Reid / Overseas Development Institute 2018

Data deficits are further exacerbated by the challenges of bridging the values of the CRPD and indicator development. As Bickenbach (2011) observed, these challenges are both political and technical. On the political side, policy users complain that data is collected only about that which is easy to count, while statistics offices complain that they are asked to deliver figures that are not reliable and are aimed at supporting a political agenda. On the technical side, indicators tend to flow from the wording of specific targets, such as 'Reduce by two-thirds, between 1990 and 2015, the under-five mortality rate'. In the case of many indicators that include disability, however, such as 'ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities', it is unclear how figures should be collected. Not only do we not know the base population size from which to calculate the proportion of young people with disabilities who are in education, but also given the wide range of impairment types and individual capacities, there is uncertainty about what the parameters are for 'equal' and for 'all levels'.

Evaluative evidence of the impact of programmes and services on adolescents with disabilities is especially thin – even for education. As noted in Chapter 1 on Education and Learning, a recent review by Wapling (2016) – initially intended to identify promising practices for educating children with disabilities – discovered that only 1 out of 131 articles covered students' learning outcomes rather than their rights-based access. In part this is because enrolment figures serve as a ready-made indicator (Bickenbach, 2011). However, Wapling (2016) observes that learning outcomes for adolescents with disabilities have arguably been de-emphasised by the way in which the international community's focus on 'education for all' has resulted in a prioritisation of inclusive education rather than of the specific learning needs of students with different types of impairments (see also Kiuppis, 2014; Urwick and Elliott, 2010). Overall, even putative evaluations of interventions in LMICs have tended to focus on the numbers of children included, rather than evaluating the impacts of programmes on adolescent wellbeing. In many cases, there are merely programme descriptions rather than robust evaluations of outcomes and impacts. This

hinders the international development community's ability to identify good or even promising practice in terms of what works to support adolescents with disabilities. There are some important exceptions though (as we discuss in subsequent chapters). In addition to Carew et al. (2018), who found that a teacher training programme increased teacher self-efficacy and produced more favourable attitudes (albeit with no measurable impact on classroom practices), this includes: work done by Motivation, an NGO, on engaging Ugandan adolescents with disabilities in sports (Langford, 2017); a recent training programme for Ethiopian Health Extension Workers that included dealing with developmental disabilities (Tilahun et al., 2017); and a programme to reduce violence in schools in Uganda (Devries et al., 2018).

## Research sample and methods

The research methods underpinning this report combine an evidence review with primary survey and qualitative research from the GAGE longitudinal study.

### Evidence review

The evidence review used a focused, rapid search process. A predetermined set of keywords was used to gather documentation from organisational websites, and Google and Google Scholar. Searches covered all LMICs but were conducted in English only. The keywords used can be found in the Annex. The research team also searched key databases (Web of Science and ERIC<sup>3</sup>). Keyword searches were built into search strings to extract the most relevant articles from the academic databases. The outcomes of each search were recorded, building as we went depending on what terms worked. The review team also searched the organisational websites of key non-governmental actors in the field (see Annex).

We also included searches specific to 7 LMICs so as to better capture evidence from GAGE focal countries, including Bangladesh, Ethiopia, Jordan, Lebanon, Nepal, Palestine and Rwanda. For each country, terms were used to capture evidence from across the six GAGE capability areas (see Figure 10). Material on the capabilities of children with disabilities, adults with disabilities and women with disabilities was downloaded in the absence of specific

documentation on adolescents with disabilities. Any studies that were regarded as insufficiently relevant were excluded from the final group of documents. This process was then complemented by a search for national statistical data, legislation and policy documentation, before snowballing. In total, more than 200 sources were included.

### GAGE primary research

The primary data for this report comes from GAGE's mixed-methods baseline research in Bangladesh and Ethiopia, and from formative qualitative work in Jordan and Palestine (both Gaza and the West Bank). See also Figure 9 for more details of GAGE's research sample. Figure 9 highlights the number of adolescents with disabilities included for each research method: overall, we are including over 5% of adolescents with disabilities in line with global estimates of prevalence in this age group. We also draw on previous primary research we have undertaken in Palestine with UNICEF (see Jones et al., 2016).

### Quantitative data and methods

The GAGE survey follows the Washington Group definition to define disability in six core functional domains: seeing, hearing, walking, self-care, cognition, and communication. We include in our definition adolescents who have a functional difficulty in any of these adolescents, as well as those that have an assistance device that resolves a functional difficulty for seeing, hearing, or walking. The response options include responses of 'has great difficulty' and 'cannot do at all' to capture the severity of the impairment. We include young people who are using assistive devices as we think it is important to better understand who has access to such devices (e.g. urban residents, better educated, higher socio-economic groups), where there are issues in maintaining them (e.g. getting batteries for hearing aids, changing glasses in response to eyesight changes, keeping wheelchairs or crutches in working order) and also to better understand the history of use of assistive devices and the extent to which this shapes outcomes.

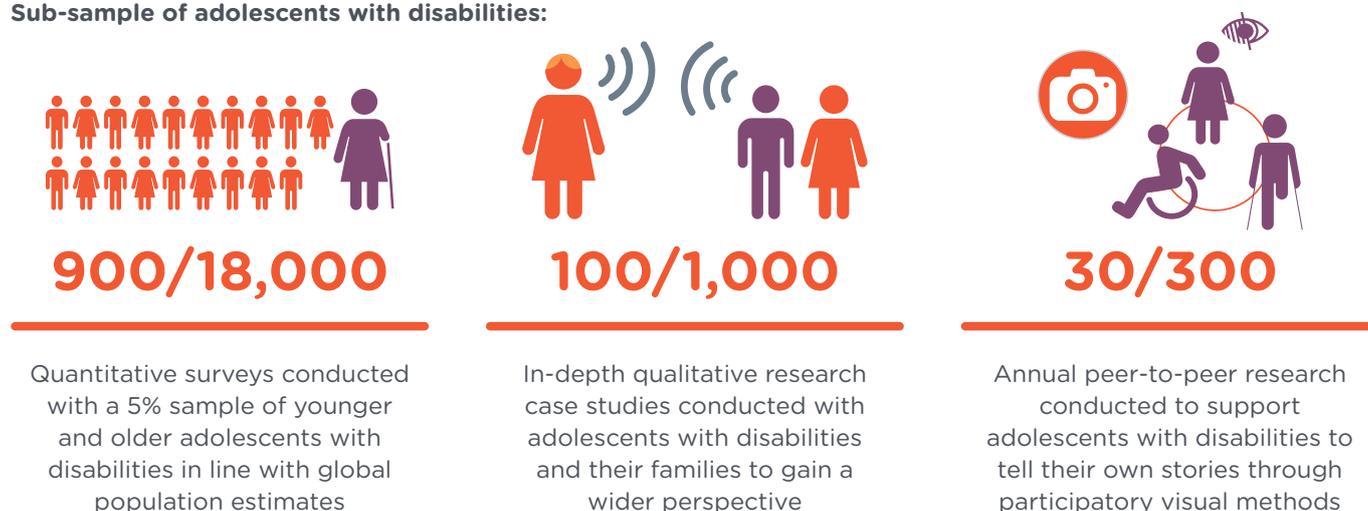
Adolescents with disabilities were included in the quantitative survey in three distinct ways. First, when we undertook our community listing exercise, we included a question on whether the adolescent had any type of disability. This allowed us to both (a) include adolescents

<sup>3</sup> We also undertook an OVID search (which searches through databases such as Medline, PsychLine, etc.) but found the sources too medically focused and the number of outputs too large for a rapid review of this nature.

Figure 9: GAGE's research sample involving adolescents with disabilities

## GAGE multi-country mixed methods longitudinal research design

Sub-sample of adolescents with disabilities:



with disabilities as part of our random sample, and (b) purposely sample additional adolescents with disabilities as needed. Second, because of high levels of stigma and the risk that asking directly about disability can lead to an underestimation of prevalence of people with disabilities, we used key community stakeholders to identify additional hard-to-reach adolescents with disabilities who did not show up in the traditional listing exercise. This involved, for example, working with special needs schools or other such institutions. Third, we used our quantitative data (which used the Washington Group instrument) to further categorise adolescents who were not formally identified during listing as having one or more disabilities (see also Table 2).

As our sampling strategy for the sample of adolescents with disabilities differed from the overall random sample, a simple comparison of means across outcomes of interest is not informative. For example, if the sample of adolescents with disabilities is older on average, then these differences could be due to age, not disability status. In order to understand whether there are

statistically significant differences in outcomes of interest between the two groups, we run simple linear regressions of the outcome of interest on disability status, controlling for gender, location and whether the adolescent is in the younger or older cohort. In this report, we include survey data for Bangladesh and Ethiopia only, involving a total sample of 558 adolescent girls and boys with disabilities and 7,042 without disabilities, adolescents with disabilities representing 7.9% of our sample. Given a smaller sample size for Bangladesh, we focus on overall impacts. For Ethiopia, we look at overall impacts but then also disaggregate by gender and urban or rural residence, and indicate whether there are significant differences.

### Qualitative data and methods

The qualitative research was conducted with adolescent girls and boys (with varying types of impairments – including physical, hearing and visual impairments), as well as their parents, and key informants (including service providers at national and sub-national levels) (see Table 3). Our starting point was to involve adolescents already identified through the quantitative survey (see above); we then supplemented this with snowballing in order to ensure that we included adolescents with diverse impairment types, particularly those with more severe disabilities who tend to be more invisible at community level due to stigma and discrimination, and excluded from services. Researchers used hands-on and participatory tools, including a 'favourite things' exercise, a tool focused on

**Table 2: GAGE sample for Bangladesh and Ethiopia baseline**

	Bangladesh	Ethiopia
<b>Total adolescents</b>	800	6800
<b>Adolescents with disabilities</b>	220	338

**Table 3: Qualitative sample**

	Bangladesh	Ethiopia	Gaza	Jordan	West Bank
<b>Individual adolescents and their caregivers</b>	15	35	12	10	12
<b>Focus groups</b>		6	10		11
<b>Key informants</b>	8	12	15	67	25

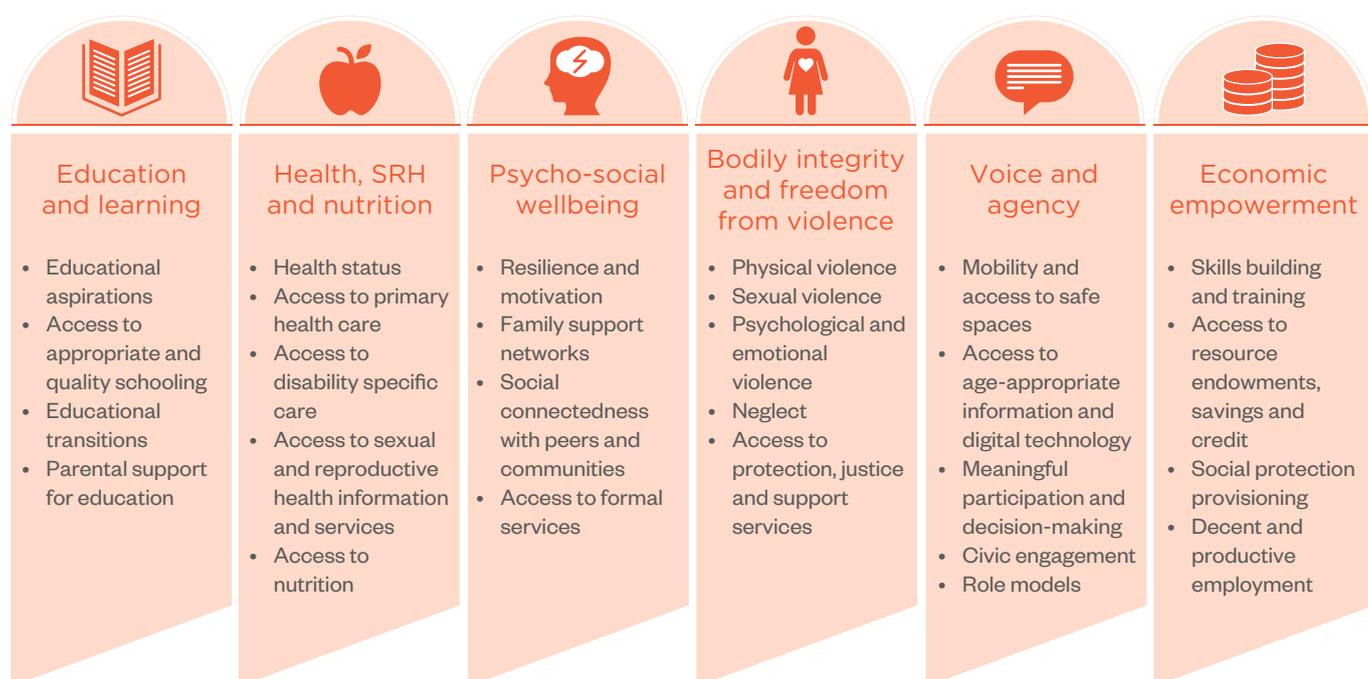
support networks, and a tool on resilience and worries (for individual adolescent girls and boys); group exercises included bodying mapping, community and institutional mapping, and vignette exercises to understand social attitudes towards young people with disabilities. We adapted the participatory tools depending on adolescents' impairment types, and in the case of adolescents with hearing impairments, we worked with local sign language interpreters (or teachers or family members where interpreters were not available) where possible and where the young people involved had some sign language skills.

## Structure of the report

The report is organised around the six core capability domains laid out in the GAGE conceptual framework: education and learning; health (including SRH) and nutrition; psychosocial wellbeing; bodily integrity and freedom from violence; voice and agency; and economic

empowerment (see Figure 10). Chapters 1-6 explore each of the six capability domains, starting with a discussion of the challenges that adolescents with disabilities face in realising their full capabilities. We then to explore gender-, impairment- and context-specific experiences adolescents with disabilities. We complement this with a discussion of the wider enabling environment in which adolescents with disabilities live – including the role of caregivers and service providers. Each chapter also considers key evidence gaps as well as emerging promising practices to tackle the challenges facing adolescents with disabilities in LMICs. We highlight our primary quantitative research findings in coloured textboxes with an icon denoting survey data, and our qualitative research with brighter coloured boxes. The final chapters present our conclusions and discuss the policy and implications of our findings.

**Figure 10: GAGE capability domains**





# 1 Education and learning



## Education and learning

**Recommendation:** Develop costed national action plans with measurable milestones to provide quality inclusive education for all adolescents with disabilities



One-third of children who are out of school – **19 million\*** – have a disability



**Ethiopia:** GAGE survey data found adolescents with disabilities are **14% less likely** to be enrolled and those in school complete half a year less schooling



Girls with disabilities in some low- and middle- income countries face greater educational disadvantages than their male peers



The enrollment gap between those with and without disabilities not only increases by grade level but is also getting worse over time

\* Saebones et al., 2015

## Key messages

- **Overarching challenges:** A disproportionate number of adolescents with disabilities are out of school. They are less likely to enrol in school and more likely to drop out. Moreover, the enrolment gap between those with and without disabilities not only increases by grade level but also appears to be growing over time. The estimated costs of not educating young people with disabilities are significant – for adolescents and for national economies.
- **Gender dimensions:** The relationship between gender, disability and education is complex. In some low- and middle-income countries (LMICs), girls with disabilities are less likely to attend school – especially secondary school – than their male peers, largely due to concerns about sexual violence, demands on girls' time for household and care work, and a lack of accessible toilets that girls with disabilities need to manage menstruation. In other LMICs, existing data suggests girls with disabilities complete primary and lower-secondary school at higher rates than their male peers, a finding which requires further exploration.
- **Impairment-specific challenges:** Adolescents with intellectual impairments are most likely to be out of school, at least in part because of a dearth of specialised teachers and adapted curricula, stigma and limited parent awareness about appropriate schooling options.
- **Context-specific challenges:** Adolescents with disabilities in rural areas are less likely to attend school than their urban peers. Schools in rural areas are less likely to have adaptations and trained personnel that facilitate special needs and/or inclusive education, and transport is also often unavailable. Adolescents in conflict-affected contexts, especially refugees, face additional challenges in terms of limited school facilities appropriate for children with disabilities, as well as security challenges en route to school.
- **Caregiver concerns:** Parental aspirations for and access to information about their children's education can be critical in shaping the level of support adolescents with disabilities receive regarding their education.
- **Evidence gaps:** There is limited evidence on the aspirations and educational outcomes for adolescents with disabilities, gender- and impairment-specific barriers to quality education, and the combination of factors needed to better support the transitions of adolescents with disabilities to secondary and post-secondary education. There is also very limited evidence on what works to support the education of adolescents with disabilities in conflict-affected contexts.
- **Promising practices:** LMICs are making halting steps towards inclusive education, often led by nongovernmental organisations. Efforts are underway in some countries to develop policies linked to costed plans for implementation and in others to scale up teacher training, community awareness and accelerate adapted school infrastructure.

## Introduction

Depending on the nature and severity of their disability, adolescents with disabilities in low- and middle-income countries (LMICs) can require a range of special adaptations and supports if they are to realise their right to education on an equal basis with other students. These include, for example, school buildings and classrooms that are accessible to adolescents with physical or visual impairments, teachers who can use sign language with students who have hearing impairments, and adapted curricula for those with intellectual impairments. Specialised teacher training and awareness-raising campaigns to reduce stigma – targeting parents, peers and school personnel – are also key. Evidence suggests, however, that despite disability-inclusive education policies, few LMICs are delivering quality education to adolescents with disabilities, especially at secondary and post-secondary levels.

## Access to appropriate and quality schooling

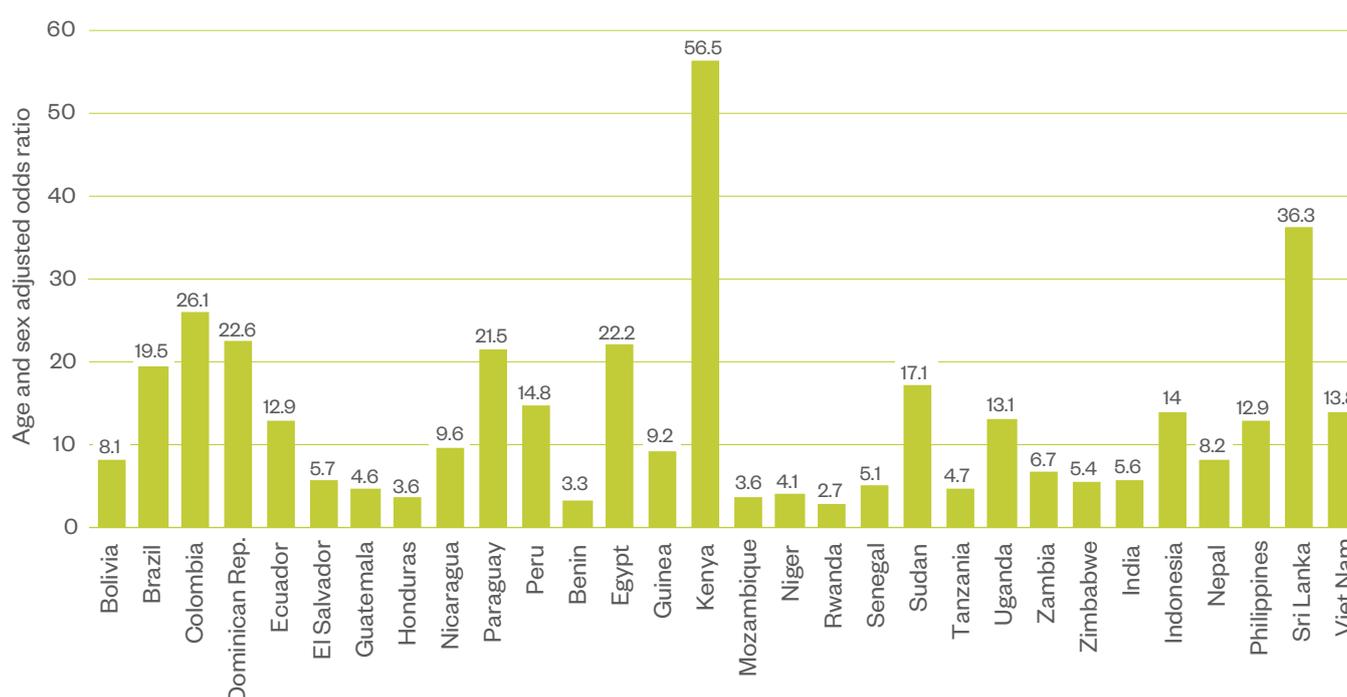
### Enrolment

Children and adolescents with disabilities are more likely to be out of school than any other group (Male and Wodon, 2017; UNESCO, 2018). While the impact of disability on

school attendance varies tremendously – by impairment type and severity as well as between countries – one study found that the negative impact of disability on schooling was in fact larger than that of age, gender, location of residence or socio-economic status (Filmer, 2008; see also Male and Wodon, 2017). In every one of the 30 LMICs in Kuper et al.'s (2014) study, children with disabilities were more likely to be out of school than children without disabilities (see Figure 1.1). The impact of disability on school enrolment was the largest in Kenya and Sri Lanka – where children with disabilities aged 5–18 were 57 times and 37 times more likely to be out of school respectively than their peers without disability. There are also marked differences between countries, driven in large part by how disability and school inclusion are measured. Those most likely to be out of school are also challenged by poverty, living in remote areas or urban slums or belonging to ethnic or linguistic minority groups (UNESCO, 2010). Children with the most complex disability-related health needs are also more likely to be out of school (Banks et al., 2018). The impacts for children, and national economies, are staggering (see Box 1.1).

Disability affects school enrolment rates in two ways: children with disabilities are less likely to ever enrol and more likely to drop out than children without disabilities. Using data from 15 LMICs, Mizunoya et al. (2016) found

Figure 1.1: Effects of disability on school attendance, children 5-17 years



Source: Kuper et al., 2014

### Box 1.1: The costs of excluding children and adolescents with disabilities from education

Excluding children with disabilities from education comes at a high cost – not just for individual children but for their national economies (Grech, 2008; Banks and Polack, 2014).

While people with disabilities remain far more likely to be poor than people without disabilities, education helps to lessen the impact of disability. A study that used data from 13 LMICs concluded that each additional year of schooling for children with disabilities is associated with approximately a 2–5 percentage point reduction in the probability of being in the two poorest quintiles (Filmer, 2008). In China, the impact of schooling is particularly strong for children with disabilities in urban areas. Each additional year of schooling increases adult wages by 5% in rural areas and 8% in urban areas (Liao and Zhao, 2013). In Nepal, wage returns to education for children with disabilities have been estimated to range from 19% to 33% (Lamichhane and Sawada, 2009).

Aggregated impacts on national economies are large. For example, the World Bank (2008) estimated that the exclusion of children with disabilities from education and their lower earnings as adults cost the Bangladeshi economy about \$26 million annually.

that up to 85% of out-of-school primary-aged children with disabilities had never been enrolled. Filmer (2008) found that enrolment gaps between children with and without disabilities start off large and increase as children grow older. In seven LMICs, the disability-associated enrolment gap increased by about 7–10 percentage points between grades 1 and 8 (Filmer, 2008). The UN Educational, Scientific and Cultural Organization (UNESCO) (2018) reports that of the six LMICs that have comparable recent data, only 56% of children with disabilities complete primary school – compared to 73% of their peers without disabilities. They also note that of adolescents of lower-secondary school age (10–13), 26% of those with disabilities, compared with 18% of those without disabilities, are out of school.

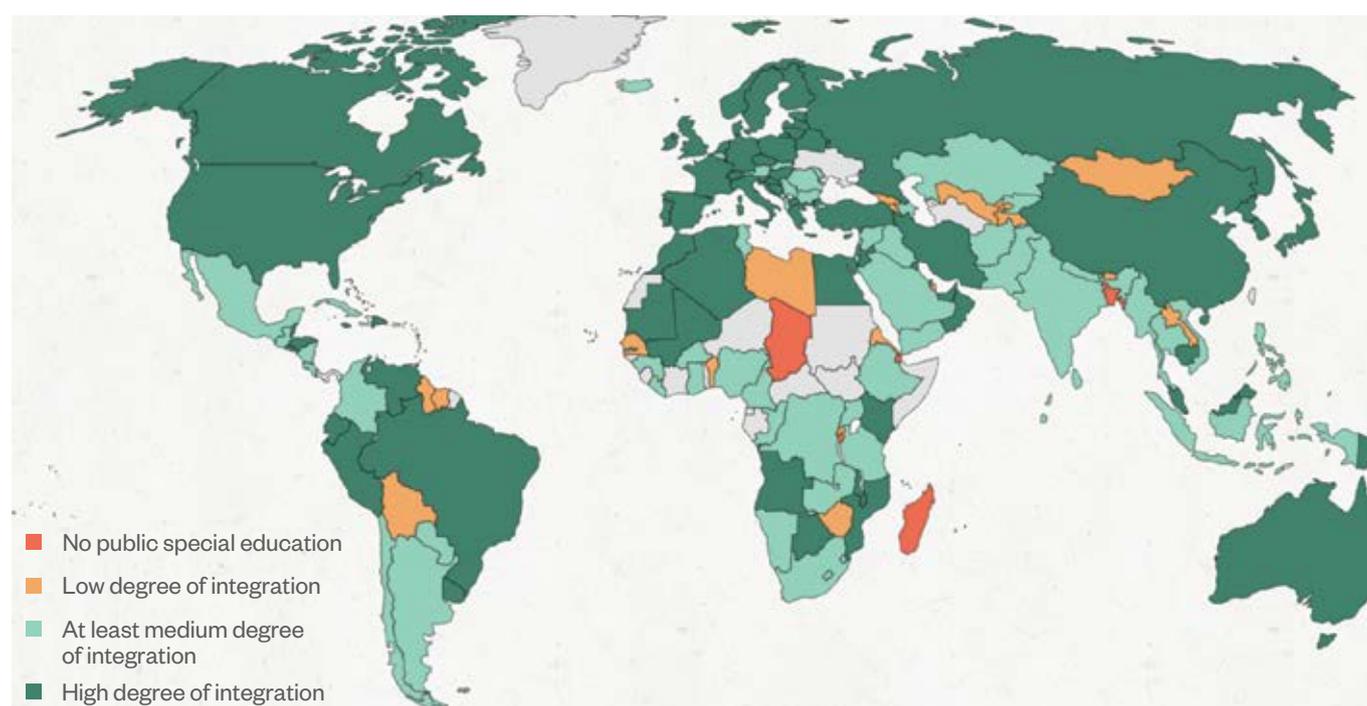
Male and Wodon (2017) found that the enrolment gap between children with and without disabilities not only increases as they grow older, but is also increasing over time – as enrolment rates for children without disabilities are climbing faster than enrolment rates for children with disabilities. Using census data from 19 countries, and focusing on 16-year-old adolescents, they found an almost 18% gap in primary completion rates between boys with and without disabilities, and a 15% gap for girls (Male and Wodon, 2017). Looking at boys and girls together, UNESCO (2018) reports a 17% gap in lower-secondary completion rates (36% for those with disabilities versus 53% for those without).

### Approaches to educating children with disabilities

There are three major approaches to educating children with disabilities in LMICs, which fall within a spectrum: inclusive education, which refers to the inclusion of children with disabilities into regular classrooms in the mainstream school system<sup>4</sup>; integrated education, which refers to having special classes for students with disabilities within mainstream schools; and special needs education, which refers to educating children with disabilities separately from students without disabilities in special schools or institutions (Bakhshi et al., 2013). The WORLD Policy Analysis Center (2018) observes that as of 2014, 51% of middle-income countries and 43% of low-income countries had achieved at least a medium level of integration – and that only a handful made no public provision for special needs education (leaving it to non-governmental organisations (NGOs) or provided only by specialist institutions) (see Figure 1.2). While this represents considerable progress over past years where children with disabilities were largely excluded from education entirely, Walker et al. (2013) highlight that while integration and inclusion are often assumed to be ‘cousins’ (because they are both so different from segregated special needs education), they are in fact very dissimilar, because the former attempts to integrate children with disabilities into existing educational standards and norms while the latter reforms the educational standards and norms to better meet the learning needs of all students, regardless of how they learn. This means that even countries that have

<sup>4</sup> This categorisation reflects where students are educated—not how students are educated. No LMICs can be said to have achieved genuinely inclusive education.

**Figure 1.2: Integration of children with disabilities into public education (where high integration is moving towards inclusion)**



Source: WORLD Policy Analysis Center, 2018

achieved a high level of integration are not necessarily approaching inclusion.

While in many LMICs, there is confusion about what constitutes inclusive education – in part due to governments' drive to demonstrate commitment to the UN Convention on the Rights of Persons with Disabilities (CRPD) by calling the education that they deliver inclusive regardless of whether it is (Walker et al., 2013; Wapling, 2016) – Article 24 of the CRPD spells out what inclusion means. Specifically, genuinely inclusive education means that children with disabilities attend school on an equal basis with other children in their communities, at a local school, and that they are afforded all reasonable accommodations for their individual learning needs, including providing them with the supports (teaching staff, adapted curricula and learning tools, technology, etc.) that they need in order to thrive (Walker et al., 2013). Although it is recognised that children with the most severe impairments – some 2%–3% of the student population – require specialised educational support that cannot (without great difficulty) be delivered in mainstream classrooms (see Box 1.2), research has found that the inclusive education mandated by the CRPD is, at least in the longer term, achievable for the vast majority of students with disabilities. A range of analysts have argued that inclusive education when delivered with adequate

resourcing can also yield educational, social and economic benefits for children with and without disabilities because of the way it raises the 'quality bar' across systems and facilitates the inclusion of a whole variety of marginalised groups (Mattingly and McInerney, 2010; UNESCO, 2010; WHO and World Bank, 2011; Walker et al., 2013; Myers et al., 2016; UNESCO, 2017).

The current conceptualisation of inclusive education, and its focus on a variety of marginalised groups including students with disabilities, is not without critics. Indeed, a review of 131 articles on inclusive education in LMICs, which set out to identify promising practices, found only one (Paul, 2011) that presented any evidence on outcomes in terms of the academic success of students with disabilities (Wapling, 2016). It concluded that the 'promotion of a broad concept of inclusive education' may have made it more, rather than less, 'challenging to focus on the specific needs of children with disabilities' and 'may well have had a negative impact on their overall access to education' (Wapling, 2016: 6; see also Urwick and Elliott, 2010; Kiuppis, 2014). Indeed, Wapling (2016) suggests that the international community needs to more critically analyse the inclusive education approach and ensure that the emphasis remains on the educational needs of children with disabilities rather than the concept of inclusion per se. Given that LMICs are struggling to deliver quality education

### Box 1.2: Specialised education

Because community-based options for schooling for students with disabilities (whether they are ‘inclusive’ or merely integrated) continue to lag in many LMICs, special education schools and institutions continue to play a disproportionate role in educating children with disabilities. In many LMICs, they provide the only services that are appropriately adapted to particular impairment types (e.g. catering for students with visual or hearing impairments). In some cases, parents simply prefer specialist schools over mainstream options because they believe they will better meet their children’s educational and social needs or provide better care (Sagahutu and Struthers, 2014; Banks and Zuurmond, 2015). In most LMICs, specialist schools are also critical to providing disability-related training for mainstream classroom teachers and in some, they provide itinerant teachers who bring special skills to rural classrooms on a rotating basis (Wapling, 2016).

The quality of special educational institutions varies considerably, in part depending on who funds and runs the programme and how closely institutional goals are aligned with modern understandings of disability. Many of these schools, which were often founded by colonial era missionaries, are still using older, more medical definitions of disability, rather than focusing on inclusion and equal opportunity (EDT, 2016) and have been criticised for their teaching methods and overall care (Thomas, 2005). With children, even very young children, often living at school away from their families for months at a time, incidents of abuse are not uncommon (HRW, 2015).

Critically, no country has enough special schools to meet the needs of children who need adapted education (Walker et al., 2013). Nepal, with a population of nearly 30 million, has only about 30 special schools – mostly for children with visual or hearing impairments (Lamichhane, 2013). The quality of programming is generally low. Lord et al.’s (2016) survey found that only 12% of people with a disability reported Nepali special education programmes to be either ‘good’ or ‘adequate’. Ethiopia, with a population over 100 million, has only 164 special schools that serve a very limited number of children with hearing, visual and intellectual impairments. There are only two schools for students with autism, both of which are in Addis Ababa (Tilahun et al., 2017). Bangladesh, with a population of nearly 165 million, is particularly poorly equipped with special schools. The CRPD Monitoring Report (GoB, 2017) lists only 62 schools for children with intellectual impairments, 11 schools (all urban) for children with autism, 5 schools for children with visual impairments and 5 schools for children with hearing and/or speech impairments.

to children without disabilities – a struggle so acute that it has been dubbed a ‘learning crisis’ (Perlman-Robinson, 2011; World Bank, 2018) – moving too quickly to include children with disabilities in mainstream classrooms is likely to only exacerbate quality gaps, especially for those students with disabilities who need the most support.

### Educational supply-side barriers

Supply-side barriers that keep children with disabilities from accessing their right to education begin at the systems level. They include a lack of political will and clear national policies that spell out incentives and penalties, and insufficient financial resources (including for the construction of inclusive school infrastructure but also for the continued support that it takes to educate children with special learning needs). Limited hiring and training of both special needs and mainstream classroom teachers, and poor provision of appropriate learning materials are also critical challenges, as are weak monitoring and reporting systems (WHO and World Bank, 2011; Walker et al., 2013; Wapling, 2016). For example, Rwanda still lacks

a formal system for classifying children with disabilities (Sida, 2014; EDT, 2016) and has only one trained official in charge of planning and implementing inclusive education nationwide (Talley and Brintnell, 2015). In Bangladesh, while the Ministry of Education (MoE) and the Ministry of Primary and Mass Education are both working to meet the goal of providing free primary and secondary education to all children by 2030, children with disabilities fall under the purview of the Ministry of Social Welfare, meaning that the educational needs of students with disabilities are

 **My teachers didn’t realise my illness. Instead of supporting me, they were beating me with a stick because I was not able to hear and accordingly respond to their questions. They scolded me for not responding. I don’t have any intention to return back to school.**

(Boy who is deaf, 12 years, Ethiopia)



effectively siloed away from those in charge of education. In addition, while the Education Policy 2010 and the Comprehensive Early Childhood Care and Development Policy 2013 both address children with disabilities, there are far fewer initiatives that address the needs of secondary students with disabilities (UNICEF, 2014). In Ethiopia, Tefera et al. (2015) conclude that despite the government's commitment to 'education for all', it is effectively delivering 'education for none' by leaving classrooms so overcrowded and under-resourced that few students are able to learn.

Barriers at the school level, which affect students with different types of impairments in different ways, include social and physical access – or lack thereof. Indeed, evidence suggests that discriminatory attitudes and practices, including violence by teachers and fellow students against those with disabilities, are in many cases the key barrier to education for adolescents with disabilities at the school level (Devries et al., 2014; 2018; Alkazi et al., 2015; Banks and Zuurmond, 2015; Burns and Oswald, 2015; Tefera et al., 2015; Singh, 2016; Wapling, 2016; Bhatta et al., 2018) (see Box 1.3). In Palestine, for example, Jones et al. (2016) found that nearly a third of Gazan children with disabilities had left school due to negative teacher attitudes and behaviours. In Nepal, where programmes to change teachers' attitudes have been

▶▶ I learned sign language only for 15 days. It was short-term training. I decided to take it because I myself am a disabled person. Now I am teaching sign language at the special need class and we taught and trained more people.

(Special needs teacher explained that the training that special needs teachers received was too short, Ethiopia)

taking place on a project-by-project basis (HRW, 2011), the National Federation of the Disabled Nepal (NFDN) (2013) and Plan International (2014) both report that students with disabilities experience continued exclusion and bullying. While it is often assumed that inclusion will necessarily reduce exclusion, vis-à-vis fostering social familiarity through physical proximity, there is clear evidence that this is not necessarily what happens in practice – potentially leaving students with disabilities at greater risk of psychosocial distress and violence when they are placed in mainstream classrooms (see Chapter 3 on Psychosocial Wellbeing and Chapter 4 on Bodily Integrity and Freedom from Violence) (Rydstrom, 2010; Ngcobo and Muthukrishna, 2011; de Boer et al., 2012; Wapling, 2016).

### Box 1.3: Violent classroom discipline in mainstream education

In Ethiopia, the physical violence meted out by mainstream classroom teachers (but not by special needs teachers) emerged as a concern among some adolescents with disabilities. While violence is a common disciplinary technique in Ethiopia's overcrowded classrooms (Save the Children, 2011; Pankhurst et al., 2016), its use against students with disabilities because of their disabilities requires further exploration and monitoring:

*A 12-year-old boy who is deaf explained: 'My teachers didn't realise my illness. Instead of supporting me, they were beating me with a stick because I was not able to hear and accordingly respond to their questions. They scolded me for not responding. I don't have any intention to return back to school. I have attended till grade 4. Because of the illness with my ears, there is huge discharge from my ear and I have faced a problem of hearing, thus I couldn't listen to what people said.'*

*A 17-year-old boy who is deaf similarly noted: 'The teachers didn't understand the behaviour of the students and didn't interact accordingly. We used to be punished using forced sport, kneeling, and beating on our hands when we failed to respond for the questions asked by the teacher in a classroom or when we failed to completely accomplish our homework.'*

Adolescents with visual impairments also faced challenges with teacher understanding: *'When I am in the rural area for regular school, during exam time, because I can't just read, then I ask my friend to read for me. The teacher assumes that we are discussing during the exam and they disqualify our exam sheet and even they hit us.'* (Boy who is blind, 17 years, Ethiopia).

Poor teacher training is also a major barrier at the school level, as it limits both technical teaching skills and drives continued stigma (de Boer et al., 2010; Das et al., 2013; Deluca et al., 2014; Banks and Zuurmond, 2015; Tefera et al., 2015; Wapling, 2016) (see Box 1.4). However, few schools in LMICs have regular access to special education teachers, which means that not only are students with disabilities not receiving the individual-level support they may need – especially if they must be taught sign language or Braille or have more severe intellectual impairments – but also that mainstream classroom teachers are often not receiving the support they need to deliver quality education to students with milder impairments who are being taught in mainstream classrooms (Wapling, 2016). Without that support and encouragement, mainstream teachers often have only limited expectations about what students with disabilities can accomplish – and little guidance about how

to foster achievement. Indeed, qualitative evidence from Bangladesh found that even schools that were claiming to be implementing inclusive education had teachers who had not received inclusivity training and were unaware of how to meet the needs of students with disabilities or how to integrate them into class (Rahaman, 2017). In India, research consistently highlights the confusion and lack of confidence among mainstream teachers regarding teaching children with disabilities, as special needs education is not included in the standard teaching diploma (Giffard-Lindsay, 2007; Bhatnagar and Das, 2013; Das et al., 2013; Singal, 2015). The situation is similar in Rwanda, leaving many teachers afraid to teach classes that include students with impairments (Talley and Brintnell, 2015).

Schools in LMICs also rarely have access to the specialised curricula and learning materials that some students with disabilities need (de Boer et al., 2010; Das et al., 2013; Deluca et al., 2014; Banks and Zuurmond, 2015; Tefera et al., 2015; Wapling, 2016). Research in Bangladesh, for example, has found that even students who are completely blind often lack Braille materials (Khan and Anisizzaman, 2011; NGDO et al., 2015). In Kenya, Lynch et al. (2011) found that large print books were missing from mainstream classrooms. This is also the case in Palestine, where Jones et al. (2016) found that two-thirds of Gazan students with disabilities felt that school materials were poorly adapted to their needs; and in Ethiopia, where Tefera et al. (2015) note that even basic disability-friendly

 No materials have been supplied this school year. Even the *woreda* [district] Education Office could not help us out. I am having to teach with locally prepared Braille bound with glue.

(Special needs teacher, Ethiopia)

### Box 1.4: Under-investment in special needs education teacher training in Ethiopia

In Ethiopia, as in other LMICs, teacher training and classroom resourcing remain far from adequate. While this is true across the board, it is especially the case with regard to disability-specific training and resourcing.

One special needs teacher explained that the training that special needs teachers received was too short: *'I learned sign language only for 15 days. It was short-term training. I decided to take it because I myself am a disabled person. Now I am teaching sign language at the special need class and we taught and trained more people.'*

Another noted that while it was difficult to meet the diverse needs of students with different types of impairments, he did his best: *'Last year we had only one special needs education teacher – that was me. So I taught the deaf, the intellectually impaired and blind students all together in one class. It is difficult to manage all types of disabled adolescents in one class because they have different needs.'*

In other cases, while the school would like to provide more support for students in upper primary school, due to human resource constraints, currently the focus must remain on the earliest grades: *'There is a shortage of teachers. We can't teach above grade 4, it is difficult even to teach those below grade 4. There is grade 1, 2 and 3. We teach grade 2 both in Amharic and Afan Oromo. All these classes are run by just 2 teachers but it is just not sufficient.'*

An 18 year old boy who is deaf, who had been part of a pilot programme aimed at older special needs students, observed that for the upper grades, teachers need to know more than sign language—they also need to be solid on their content. When they are not, it created issues for both students and teachers: *'As our teachers only know sign language and have difficulty with subject-specific knowledge, we couldn't learn and acquire knowledge like other non-disabled students. The problem is that, for instance, a teacher who was a graduate in Mathematics previously and wanted to join teaching using sign language may be trained and assigned to teach a different subject and thus he may lose interest in teaching.'*

Teachers and students were also clear that even special needs classrooms did not have the learning materials that students need: *'No materials have been supplied this school year. Even the Woreda [district Education Office] could not help us out. I am having to teach with locally prepared Braille bound with glue.'*

learning materials that could be locally produced are often lacking from classrooms.

Many schools in LMICs, especially those in rural areas, are inaccessible for adolescents with physical impairments or with severe visual impairments (UNESCO, 2010; WHO and World Bank, 2011; Walker et al., 2013). The schools may not offer transport to and from school, may lack ramps that would make it easier for children to get into the building, or fail to make shared spaces inside the building (such as computer labs or cafeterias) accessible. In Bangladesh, research has found that poorly adapted school infrastructure is a major reason why children with disabilities leave school (Khan and Anisizzaman, 2011; NGDO et al., 2015). In Lebanon, there are just a handful of public schools nationwide (one per governorate) that have been made accessible for children with physical impairments (UNESCO, 2013). In Nepal, there are not yet 400 schools in the entire country that are considered appropriately adapted for the needs of those with disabilities (Plan International, 2014; GoN, 2015; Bhatta et al., 2018). In Ethiopia, where Tefera et al. (2015) highlighted a wide range of accessibility deficits, 16% of parents of out-

of-school students reported that the school is physically inaccessible to their child (ACPF, 2011) (see also Box 1.5).

The lack of adapted toilets at school has particular ramifications, especially for adolescent girls, given their need for menstrual management facilities (Groce et al., 2011; Noga and Wolbring, 2012; Banks and Zuurmond, 2015; Bhatta et al., 2018). In Palestine, Jones et al. (2016) found that 20% of children with disabilities in the West Bank – and 31% of their peers in Gaza – did not have an adapted toilet at school. In Ethiopia, the African Child Policy Forum (ACPF) (2011) found that only 60% of adolescents with disabilities who were enrolled in school had access to a toilet. It also found that even those with putative access

 **There is no school for children like my daughter who is deaf in this area. If there is education for children with hearing disabilities, then I would be happy to educate her.**

(Mother of two out-of-school girls who are deaf, Ethiopia)



### Box 1.5: School enrolment barriers in Ethiopia: the role of transportation and infrastructure

The GAGE survey found that in Ethiopia, adolescents with disabilities were 14% less likely to be enrolled in school than their peers without disabilities. They had also, on average, completed half a year less schooling than age-matched peers. Our qualitative work found that a range of transportation and infrastructure barriers were often a key factor in both school non-enrolment and educational delays.

In some areas there simply are no schools that can accommodate particular types of impairments, as this mother explained: *'There is no school for children like my daughter who is deaf in this area. If there is education for children with hearing disabilities, then I would be happy to educate her.'* (Mother of two out-of-school girls who are deaf)

Even in urban areas, where schools are available, lack of transportation can make it difficult for adolescents to get to school. As one 15-year-old girl with a physical impairment explained: *'It is very painful (to walk). And especially when the road is made of gravel, my whole body is feeling the pain.'*

An 18-year-old girl who is blind noted: *'I sometimes have to skip school because I can't get people who take me to school. That is the most difficult, not getting a guide. Even the Bajaj [three-wheel taxis] refuse to give us a ride. And on Mondays, there are carts on the road. It makes it difficult for us to walk around.'*

Access barriers do not end on school grounds. Schools themselves are often challenging for adolescents with disabilities to negotiate: *'The school is not well adapted. The school environment is not conducive for them, the class is too narrow and they can't accommodate wheelchairs, the grounds are muddy, and the school community do not give the same attention to their needs as they do to other students.'* (Special needs teacher, Amhara)



faced barriers (e.g. toilets were often at the far end of the school and difficult for those with visual impairments to navigate) (ACPF, 2010). In Nepal, Bhatta et al. (2018) found that Nepali girls with disabilities had a difficult time accessing toilets at school hostels.

## Education transitions

While evidence is extremely thin, because enrolment figures are most closely tracked at primary and lower-secondary levels, it is clear that adolescents with disabilities have particularly limited access to secondary and post-secondary education—especially when they live in rural areas (see Box 1.6). This is because they face

not only the standard barriers common in LMICs (such as distance to school, high costs for tuition and fees, etc.) but also disability-specific hurdles (Kuper et al., 2014; UNESCO, 2014; 2018; Male and Wodon, 2017; UN, n.d.). In addition, and mirroring the situation at the primary level, as children without disabilities have benefited from increased access to secondary school over the past few years, completion gaps between children with disabilities and children without disabilities at secondary level have grown. Male and Wodon (2017) estimate the gap to be over 10% for girls and over 14% for boys.

In Ethiopia, for example, where enrolment rates at secondary level grew over 50% between 2006 and 2011

### Box 1.6: The importance of context in shaping educational outcomes for adolescents with disabilities

While context shapes the access of all young people to school, especially at the secondary level, it matters even more for adolescents with disabilities. Rural schools, for example, are unlikely to be adapted or to have teachers with disability-related training. Schools in humanitarian situations are often overwhelmed by need, meaning that those who require extra support are often overlooked. Political will, however, also matters.

In both Bangladesh (Burns and Oswald, 2015) and Rwanda (Lewis, 2009; EDT, 2016), nearly all special education facilities are located in urban areas, which means that rural children with some forms of disability are unable to access a school that can meet their needs. The impact of this on enrolment is evident in Ethiopia, where urban children with disabilities are twice as likely to attend school as their rural peers (4.6% vs 2.3%) (MoE, 2012, cited in Katsui et al., 2014). Indeed, Katsui et al. (2014) observed that as of 2012, there was not a single classroom tailored to the needs of children with disabilities in all of Afar, Dire Dawa, Gambella and Harari. The impact of living in an urban area is even more pronounced in Ethiopia at the secondary level. While the national gross enrolment rate at the secondary level for children with disabilities is only 1.5%, in Addis Ababa it is 6.6% (MoE Ethiopia, 2017).

In Nepal, school participation among children with disabilities is higher in Provinces 1–5 and lower in Provinces 6 and 7 (Eide et al., 2016), primarily because the former have better educational facilities and stronger human resourcing. Schools in the Mid-Western and Far-Western provinces are not only more rural – and in more mountainous terrain – but also serve the poorest families with the highest rates of disability, driven by the reality that many cannot afford to access timely health care for their children when they are ill or injured (see Chapter 2 on Health, Sexual and Reproductive Health and Nutrition). Disability-directed stigma also tends to be higher in the more remote provinces, which both prevents children with disabilities enrolling in school and encourages them to drop out early if they do.

In Lebanon, where the government admits that data on education and disability is inadequate (Government of Lebanon, 2015), and it appears that 50% of Lebanese children with disabilities are out of school because government schools have still not recovered from the civil war (MoE Lebanon, 2016), refugee children are even more disadvantaged. It is estimated that up to 80% of adolescent Syrian refugees with disabilities are not enrolled (MoE Lebanon, 2016; see also WFP, 2015; HRW, 2016). Impacts on child refugees are staggering: of Palestinian child refugees with disabilities living in Lebanon's camps, Save the Children (2006) found that 61% of 10–14-year-olds and 58% of 15–19-year-olds were illiterate.

In India, although some states have seen significant improvements in enrolment, other states are seeing regression, possibly due to differing political commitments to inclusive education. Chhattisgarh (0.51%–1.87%), Andhra Pradesh (0.56%–1.59%), Kerala (2.94%–4.58%), and Odisha (1.27%–2.04%) demonstrate large increases in enrolment of children with special needs. Haryana (0.40–0.13), Madhya Pradesh (0.57–0.50), Rajasthan (0.98–0.93), and Puducherry (0.73–0.66), on the other hand, have seen declines in enrolment (Alkazi et al., 2015).

(MoE Ethiopia, 2012) and topped 2.1 million in 2014/15 (MoE Ethiopia, 2016), there were only 6,000 students with special needs enrolled in 9th and 10th grades across the entire country that year (ibid.). There were fewer than 1,300 enrolled in 11th and 12th grades and fewer than 1,500 in higher education (undergraduate and graduate levels) (ibid.). The situation is similar in Rwanda, where 80% of students with disabilities are excluded from the school system before reaching secondary school (MINEDUC, 2011) and only 1% of secondary students have impairments. In 2016, across the whole country, there were only 532 adolescents with disabilities enrolled in the last year of secondary school (out of 67,000) (MINEDUC, 2016). That same year, there were only 432 adolescents with disabilities enrolled in tertiary education (out of 91,000) (ibid.).

Access to secondary school is similarly poor in the South Asia and Middle East and North Africa regions. In India, half of all enrolled children with disabilities drop out between primary and secondary school (Alkazi et al., 2015) and in Jordan, only 9% of adolescents with disabilities are enrolled in secondary school (ILO, 2017). In Palestine, nearly 50% of 15–18-year-old adolescents with disabilities are out of school (compared to 30% of younger adolescents) – primarily because older students simultaneously require more adaptations, given the more difficult content they are expected to master, and are given less support as they transition into less flexible secondary schools (Jones et al., 2016). Where young people with disabilities are in secondary school, hurdles to their success are considerable (see Box 1.7).

### Box 1.7: 'I want to do it myself'

Alia is 14 and is in her first year of public secondary school in the West Bank – after years in a private school for children who are blind (which does not offer secondary education). She has found the transition to be very difficult. *'On my first day of school I was terrified and very scared.'* While she is no longer scared, she is still frustrated and lonely. The school is not safe for her to move around alone and she is rarely offered help. After falling many times, breaking both a tooth and a hand, she has mostly given up on all but essential movement and often spends lunch and break time in her classroom because it is safer to stay where she is.

She also reported that her teachers are not really equipped to teach children who are blind, that there had been a long delay in getting Braille books, and that she is prevented from using her Braille typewriter because other students find the sound irritating. *'They asked me not to use the typewriter because it is annoying. I don't like this.'* While the teachers at Alia's school have offered to take dictation, and let her give verbal responses to what they then write down, Alia wants to prepare her work *'by myself'*.

Special needs class, Ethiopia © Nathalie Bertrams / GAGE 2018



## Learning outcomes

There appears to be effectively no evidence that addresses the learning outcomes of children with disabilities in LMICs. The literature almost exclusively revolves around rights-based arguments for the access of children with disabilities to education rather than their learning outcomes per se (Wapling, 2016). The thin evidence we were able to locate suggests, however, that children with disabilities have especially weak learning outcomes (see also Box 1.8). In Malawi, for example, Banks and Zuurmond (2015) found that three-quarters of students with disabilities had repeated a grade and, on average, students with disabilities were nearly three grade levels behind the national standard for their age. In parts of India, children with disabilities are six times more likely to have repeated a grade than children without disabilities (IOED, 2014). In Nepal, Plan International's (2014) study found that it was common for children with disabilities to be held back or to be promoted up a grade without passing their current grade. While research in Northern contexts has emphasised that it is not helpful to treat students with disabilities as a homogenous group – and found that for some types of impairment (including visual, hearing and learning impairments) actual disability 'explains little (about achievement) in a statistical sense once we take into account the other characteristics of the student' (such as age, sex and educational background) – we have been unable to locate this sort of detailed evidence regarding outcomes for children with disabilities in LMICs (Karmel and Nguyen, 2008: 10).

## Educational aspirations

Research on the educational and occupational aspirations of adolescents with disabilities in Northern contexts has produced mixed results. Some research finds that adolescents with disabilities tend to have lower aspirations than those without disabilities (e.g. Rojewski, 1996; Friedmann and Lazarová, 2013). Other research finds that adolescents' aspirations remain high – but that parental expectations are lower (e.g. Shandra and Hogan, 2009) or that the aspirations of young people with disabilities wane over time as they fail to achieve (e.g. Burchardt, 2005). However, evidence on the aspirations of adolescents with disabilities in LMICs is scarce, given that research has tended to focus on disability rather than ability (UNICEF Innocenti, 2007) and is complicated by the range of impairment types, severity of impairment, and differences in contexts. In Nepal, Bhatta et al. (2018) found that adolescents with disabilities were committed to their schooling and saw education as central to their futures. In Ethiopia, the ACPF (2011) found that the majority of children and adolescents with disabilities were hopeful that they

▶▶ My wish is to be a doctor... From childhood I have a wish that I will give treatment for free. That's one of my wishes... My aim is to achieve golden (A+; excellent result).

(Girl who has a physical impairment, 15 years, Bangladesh)

### Box 1.8: Learning outcomes from GAGE

The GAGE survey found that the learning outcomes of Ethiopian adolescents with disabilities, as measured by the Raven's Progressive Matrices (a non-verbal test of abstract reasoning and fluid intelligence), were overall lower than those of adolescents without disabilities. Rural students with disabilities had significantly lower scores than their urban peers, which is not surprising given that previous research has found that learning outcomes in rural areas are generally lower due to higher demands on children's time, lower parental education, and higher poverty rates (Young Lives, 2017; Cuesta, 2018). Interestingly, given that boys in Ethiopia are often prioritised for schooling and tend to have significantly higher scores on national exams (Harper et al., 2018), the GAGE survey found that boys with disabilities are disadvantaged relative to their female peers on a number of fronts. Specifically, they have lower Raven's scores, are less likely to feel that they can speak up in school, and are somewhat more likely to experience bullying. These findings, like those that indicate that girls with disabilities in some countries are now more likely to complete primary and lower-secondary school than their male peers (UNESCO, 2018; Male and Wodon, 2017), need further exploration – though the most recent findings from Young Lives (a longitudinal study following children in several LMICs) suggest that they may be related to shifting gender patterns in Ethiopian learning outcomes more generally. That data highlights that while girls were much less likely than boys to be able to accurately answer math questions in 2009, by 2016 girls had caught up – and even surpassed – boys in several regards (Young Lives, 2017).



would be able to find a good job, support their caregivers, and start a family of their own in the future. World Vision (2015) found that most wanted to attend school. In Jordan, Peters (2009) found that young adolescents with impairments were highly aspirational and creative about their future, but lacked wider social support to enable them to achieve their goals. In Palestine, while Jones et al. (2016) did not specifically ask young people with disabilities about their educational aspirations, they found that of those still in school, many spontaneously volunteered that they hoped to become medical professionals and specialise in

disability – to ensure that other children like themselves had more positive experiences (see also Box 1.9).

**▶▶ I want to live by my own; because I am no different and inferior from others. And so I want to do what others do. I want to make a living just like others. I want to have a (university) degree. Anything that gets me a job.**

(Girl who is blind, 18 years, Ethiopia)

### Box 1.9: Mixed evidence on aspirations in different contexts from GAGE



GAGE's research found mixed evidence in regard to the educational and occupational aspirations of and for adolescents with disabilities. Our qualitative work found almost universally high aspirations—in both Bangladesh and Ethiopia—from both adolescents themselves and their parents. In Ethiopia, however, our quantitative work found that adolescents with disabilities had lower educational aspirations (by half a year) than their peers without disabilities, despite the fact that parental aspirations were similar. Differences were driven by younger adolescents in rural areas and need further exploration.

In Bangladesh, the aspirations of both adolescents with disabilities and their parents were focused on the medical profession:

*'My wish is to be a doctor... From childhood I have a wish that I will give treatment for free. That's one of my wishes... My aim is to achieve golden (A+; excellent result), but even if I get plus (only A+, not golden A+, very good result), that will be okay even. I cannot fail anyhow.'* (Girl who has a physical impairment, 15 years, Bangladesh)

*'I have very big dreams for my daughter – that she will become a doctor. And her father says "Let her keep on studying. I will educate her so that she can even get government jobs." So she will get support from everywhere. She is the hope for our family. We have a lot of dreams built around her. My daughter spends her entire day with books. I don't put any pressure on her. I don't make her do big tasks. I want her to study.'*

(Mother of a 12 year old girl who has physical and visual impairments, Bangladesh)

In Ethiopia, while many adolescents with disabilities wanted to improve the lives of those with disabilities, by pursuing careers in medicine or teaching, aspirations were overall broader. Indeed, recognising the high youth unemployment rate in Ethiopia, several adolescents told us that they would pursue whatever option would guarantee paid work and independence.

*'I need to be a doctor. Especially I need to be a doctor to give support to those who are physically disabled. The sole agenda we have is education.'* (Girl who is blind, 11 years, Ethiopia)

*'I want to be doctor. I will do it with a translator.'* (Boy who is deaf, 12 years, Ethiopia)

*'I want to be a nurse, a person who cures people from different diseases. I want to heal people who are suffering from different diseases in my locality and also to care for myself and my family, to teach others to protect themselves from different diseases.'* (Boy who has a physical impairment, 13 years, Ethiopia)

*'I want to become a teacher, since I want to support individuals with a hearing disability.'*

(Girl who is deaf, 16 years, Ethiopia)

*'I want to live by my own; because I am no different and inferior from others. And so I want to do what others do. I want to make a living just like others. I want to have a (university) degree. Anything that gets me a job.'*

(Girl who is blind, 18 years, Ethiopia)

## Parental support for education

Parental support for the education of children with disabilities appears to be mixed. Most research emphasises household-level constraints, including disability-related stigma, and highlights parental non-support. However, there is also evidence that some parents – especially mothers – invest a great deal of time, energy and resources to help their children with disabilities access education.

In many households across the global South, poverty constrains active parental support for education (UNESCO, 2010; WHO and World Bank, 2011). Not only are households that include someone with a disability especially likely to be poor – with Banks et al. (2017: 11) concluding that there is ‘strong evidence to support the link between disability and economic poverty’ – but the relationship between child disability and poverty may be particularly strong (Mont, 2014). Mont (2014) notes that this is partly because young people with impairments require more care, which constrains parental work, and partly because it costs more to raise a child with disabilities. In the UK, for example, it is estimated to cost three times as much to raise a child with disabilities as it does to raise a child without disabilities (Gordon, 2000, as cited in Mont, 2014). While overall ratios are likely to be quite different in LMICs, one cost that is probably higher in Southern contexts – at least among the children who are attending school – is education, given that children with disabilities in some countries have few options other than to attend expensive, private schools or need transportation to get to and from school. In Bangladesh, Lamichhane and Kawakatsu (2015) found a correlation between household income and the enrolment of children with disabilities, leading them to conclude that when resources are tight, parents prioritise the schooling of children without disabilities. In Palestine, Jones et al. (2016) found that 43% of children with disabilities reported that it was ‘very difficult’ to access transportation, with nearly half of out-of-school children with disabilities in the West Bank reporting that they left school because their families were unable to provide adequate transport.

Economic poverty, however, is only part of the story; far more important are parental beliefs about disability. Stigma about disability shapes the way parents allocate not only economic resources but also encouragement and support (Burns and Oswald, 2015; Tefera et al., 2015; Jones et al., 2016; Bhatta et al., 2018). In Ethiopia, 10% of parents of

out-of-school students with disabilities reported that they believe their child is not capable of learning (ACPF, 2011) and, due to beliefs that disability is the result of some ‘moral wrongdoing’, parents are often ashamed of their children with disabilities and undermine their ‘potential to learn and lead an independent life’ (Tefera, 2006, as cited in Katsui et al., 2014: 42). This belief has also been documented in Bangladesh (Burns and Oswald, 2015), where Plan International (2014) found that children with disabilities were sometimes kept out of school to earn money or work around the house. In the West Bank, one-third of children with disabilities report that their parents are unsupportive of their education, mostly because they feel it is unlikely to ever translate into employment (Jones et al., 2016). In India, even where children with disabilities attend school, their disability is sometimes not disclosed due to parents’ perceptions of stigma, which prevents those children getting the educational support they need to thrive (see also WHO and World Bank, 2011). Banks et al. (2018) also documented this in Nepal, with some parents not seeking a disability card for their child, even though it would entitle the child to an educational stipend, solely due to fear of disclosure. Ahmad (2015) also found that the parents of children without disabilities were implicated in keeping children with disabilities out of school, as they were afraid that it would slow down their own child’s learning.

While research overall highlights parents’ non-investment in the education of their children with disabilities, for some young people, parents’ support is

 I do not want to describe my children as having a disability and this is my right. I tend to use “special needs” because they need someone who takes into consideration their special needs... I started my journey with my first son and my first challenge was to find a school. My determination was great. I sent my son to a school in Jordan for 3 years, and then I sent him to Helen Keller school in Jerusalem. The money was not a hurdle as much as accessing the information. No one visited me to ask me about what I was doing for my son

(Mother of 3 children with disabilities, West Bank)

central (see also discussion on promising practices below). In Lebanon, for example, Hatoum (2010) interviewed 12 mothers of children with Down syndrome and noted that in the absence of educational infrastructure, mothers were the driving force behind securing educational services for their children. Khochen (2012) similarly found that families of special needs learners had to fight to get a place for their children in mainstream schools and pay additional expenses, sometimes with the support of NGOs working in schools. Parents' efforts to support their children's schooling are also central to successful outcomes for children with disabilities in Palestine (see Box 1.10).

## Experiences shaped by gender

Evidence suggests that in most contexts, girls with disabilities face greater educational disadvantage than boys with disabilities (UN, 2016; UNESCO, 2016). In many countries, girls with disabilities are less likely to enrol and more likely to drop out because – according to qualitative research – they receive less support from parents and teachers (including being given less access to assistive technologies), face more stigma and violence, and have a greater need for infrastructure adaptations such as toilets due to hygiene requirements for menstrual management (UNESCO, 2010; Groce et al., 2011; Noga and Wolbring,

2012; UNICEF, 2013; Katsui et al., 2014; LCD, 2017a; 2017b). In addition, adolescent girls with disabilities also face the same restrictive gender norms that shape the lives of their peers without disabilities. They shoulder an disproportionate share of domestic and care work, are kept close to home in order to guard their purity and family honour, and can be seen as less valuable to their natal families simply because it is assumed that they will become the property of their marital families upon marriage (Harper et al., 2018).

Global disparities are stark – but also suggest recent change. Looking across age groups, data from 51 countries indicates that only 42% of women with disabilities have completed primary school, compared to 51% of men with disabilities, 53% of women without disabilities, and 61% of men without disabilities (WHO and World Bank, 2011). Looking only at younger people, however, girls' and boys' outcomes are converging in some LMICS – and girls are surpassing boys in others. Male and Wodon (2017), using census data from 19 LMICs, found that while girls with disabilities lag far behind their peers without disabilities in terms of enrolment, completion and literacy, they no longer lag behind their male peers with disabilities. Indeed, looking only at those with a disability, girls are now slightly more likely than boys to be literate by the age of 12 (60% vs 59%) and to have completed primary school by the age of 16 (48% vs 47%) (see Figure 1.3). UNESCO (2018), using

### Box 1.10: Pulling out all the stops in Palestine

*'My name is Huma, and I am a mother of three children with disabilities. I do not want to describe my children as having a disability and this is my right. I tend to use "special needs" because they need someone who takes into consideration their special needs. My eldest son has a visual impairment and is in his 11th grade. He studies at Terra Santa school. My other son is autistic and blind, he is 11 years old. My third son has developmental delays.*

*I started my journey with my first son and my first challenge was to find a school. My determination was great. I sent my son to a school in Jordan for 3 years, and then I sent him to Helen Keller school in Jerusalem. The money was not a hurdle as much as accessing the information. No one visited me to ask me about what I was doing for my son.*

*Now, my 11-year-old son is autistic and I couldn't find anyone to provide me with guidance on the schools that I can send him to. When I sent my oldest son to Terra Santa school for his 11th grade, I went to the school and met the teachers and students to tell them about his young brother's situation and to speak with them about how the school could accommodate him. No one accompanied me to the school.*

*I read the Ministry of Education's integration instructions by myself and learned how the marks of students with disabilities are counted. None of the teachers knew how. I went through all this without anyone even trying to approach me or give me any information.*

*My blind son is on a football team in Ramallah. He is a member of the World Blind Union. He is working with a blind Italian and other American students on developing a video game for the blind.'*

(Mother of 3 children with disabilities, West Bank)



An adolescent girl, with a visual impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

a small set of 6 LMICs that have recent comparable data, found even larger gaps in girls' favour. They report that of students with disabilities, two-thirds of girls but only half of boys completed primary school. Patterns were similar among those countries at the lower-secondary level. Of girls with disabilities, 56% completed lower-secondary, compared with only 47% of boys with disabilities.

Country-specific enrolment gaps between girls and boys with disabilities highlight the importance of not relying on global aggregates. In India, while gender parity has nearly been achieved for students without disabilities,

among those with impairments, only 75 girls are enrolled for every 100 boys (Alkazi et al., 2015). In Rwanda, of students with disabilities, girls constitute only 45% at the primary level (CRPD, 2015). Because they are slightly more likely to transition to secondary school than boys, at the secondary level, girls make up 48% of students with disabilities (ibid.). By the last year of secondary school, however, patterns have reversed, such that only 42% of students with disabilities are female (MINEDUC, 2016). In Ethiopia, gender patterns also change over time (MoE Ethiopia, 2017). In early primary school (grades 1-4), the

**Figure 1.3: Disability gaps for the most recent age cohorts (%)**

	Ever enrolled (11 years old)		Primary completed (16 years old)		Secondary completed (20 years old)		Literacy (12 years old)	
	Men	Women	Men	Women	Men	Women	Men	Women
<b>No disability</b>	85.33	84.64	64.69	63.57	46.93	42.88	75.16	75.09
<b>Disability</b>	72.18	71.94	47.09	48.13	32.47	32.44	58.94	60.04
<b>Disability gap</b>	13.15	12.70	17.60	15.44	14.46	10.43	16.22	15.05

Source: Male and Wodon, 2017

**In the rural areas, girls are not encouraged to go to school. And the disabled girls are less encouraged to be students than boys.**

(Local government key informant, Ethiopia)

gross enrolment rate (GER) of boys with disabilities is slightly higher than that of girls (11% versus 10%). In upper primary school it evens out: 5% of both boys and girls with disabilities are enrolled. At the secondary level, boys are again more likely to be enrolled than girls. The GERs are 1.7% versus 1.3% respectively. The gender gap in Ethiopian upper-secondary school enrolment is larger still: the ratio of boys to girls with disabilities is 3: 1 (MoE Ethiopia, 2016).

Reasons for girls' non-enrolment vary. In Jordan, a recent UN Children's Fund (UNICEF) (2015) study found that parents of girls with disabilities who were out of school cited distance to school – and fears about their daughters' safety – as the primary reason for non-enrolment. Parental concerns are not unfounded given that research from Uganda suggests that young adolescent girls with disabilities are twice as likely to experience sexual violence at school as their peers without disabilities (24% versus 12%) (Saebones et al., 2015) (see also Chapter 4 on Bodily Integrity and Freedom from Violence). Research in Ethiopia has also found that parents prefer to keep girls with disabilities at home – partly so that they can do household chores but also to protect them from abuse (Teferra, 2005; Jennings and Poppe, 2012, both cited in Katsui et al., 2014) (see also Box 1.11). Lebanese parents also cite safety concerns, although Lebanese girls reported caring for ill relatives as a reason for school-leaving (Wehbi, 2014). Among Syrian refugees living in Lebanon, Human Rights Watch (HRW) (2016) documented that school

attendance by girls with disabilities was impacted by their lack of access to toilets.

As noted above, recent evidence suggests that in some LMICs, girls with disabilities are now more likely to enrol in primary school, complete primary school, enrol in lower-secondary school, and complete lower-secondary school than boys with disabilities (Male and Wodon, 2017; UNESCO, 2018). Patterning, however, is far from simple. In Uganda, of primary school-aged children with disabilities, 18% of boys but 29% of girls are out of school (UNESCO, 2018). For lower secondary-aged children with disabilities, however, the enrolment advantage is reversed: 31% of girls are out of school versus 35% of boys. Completion rates highlight girls' success. Nearly half of girls with disabilities ultimately complete primary school in Uganda, compared to less than a quarter of boys (ibid.). What is driving these emerging patterns appears to be unexplored and needs further research, especially given the depth of research that has explored the vulnerabilities that continue to truncate the trajectories of adolescent girls in LMICs more generally. It may be related to demands on boys' time for paid labour, or to boys' greater exposure to bullying and physical violence at school, or it may be related to boys' disengagement with formal learning because they do not see school as translating into more (or better) employment options. As we discuss in the section below on evidence gaps, this is a key area requiring further investigation.

**There is no place where we [girls with disabilities] could change our pads. The toilets are dirty, there is no water in the compound and the smell is horrible.**

(Girl with a physical impairment, 16 years, Ethiopia)

### Box 1.11: Gender disadvantage in education

Our qualitative findings from Ethiopia highlight that gender disadvantage for adolescent girls with disabilities in education is multi-pronged and not solely related to the risk of sexual violence discussed in detail in Chapter 4 on Bodily Integrity and Freedom from Violence. As one local government key informant noted: *'In the rural areas, girls are not encouraged to go to school. And the disabled girls are less encouraged to be students than boys.'* And even where schools provide supplementary tutorial classes for girls, *'girls with disabilities cannot come back to take advantage of the classes... since they live in a rented house far from the school because the house rent there is relatively cheap'*.

Girls with disabilities also experience the dearth of accessible toilets to support menstrual hygiene as an important barrier to regular school attendance: *'There is no place where we [girls with disabilities] could change our pads. The toilets are dirty, there is no water in the compound and the smell is horrible.'*

(Girl with a physical impairment, 16 years, Ethiopia)

## Experiences shaped by impairment type

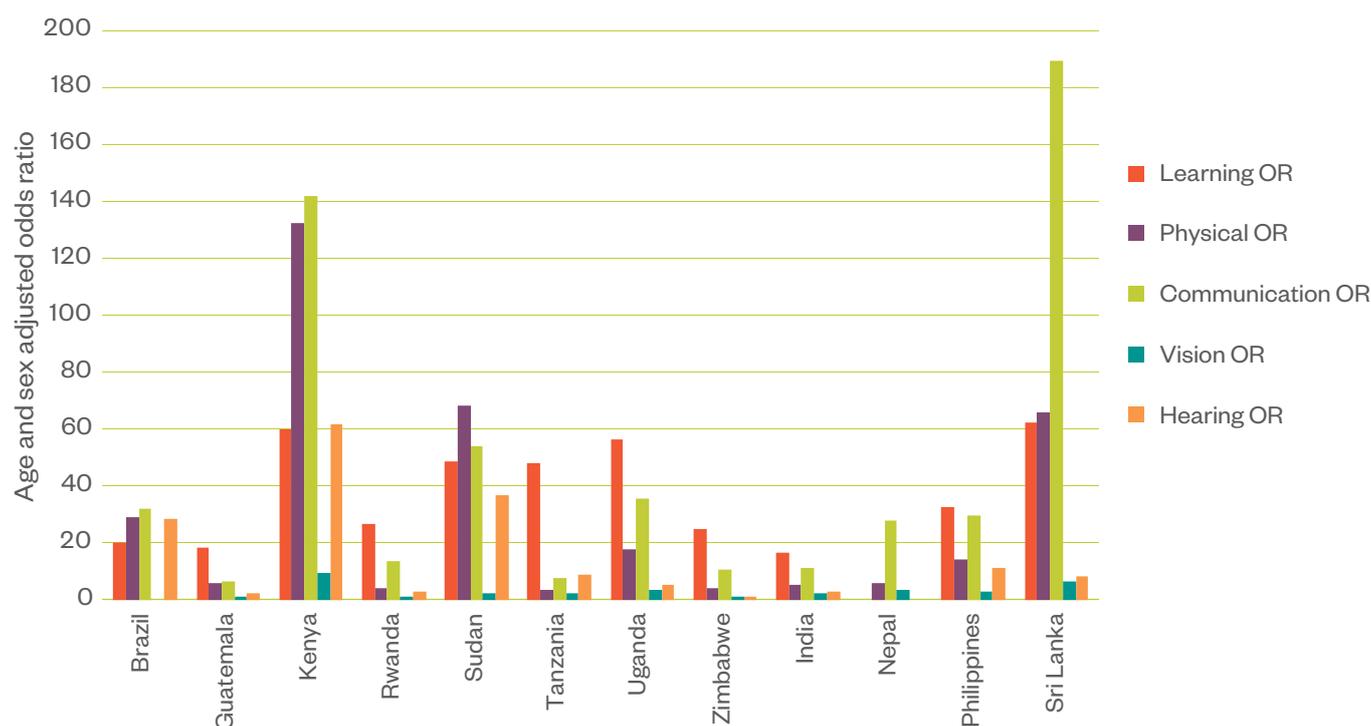
While evidence is thin because enrolment figures are rarely disaggregated by impairment type, it appears that some types of impairments are more likely to limit adolescents' access to schooling than others. This is evident in global literacy figures, which show that children with visual, multiple or intellectual impairments (and children with severe impairments of all categories) are especially unlikely to be literate (Panda, 2016).

In Kuper et al.'s (2014) cross-sectional research with nearly 1 million children in 30 LMICs, all of whom were under sponsorship by Plan and nearly 10,000 of whom had a disability, children with learning and communication impairments were most likely to be out of school. In some countries (e.g. Dominican Republic, Kenya, Uganda and Sri Lanka), they were more than 50 times less likely than children without disabilities to be enrolled (see Figure 1.4). Children with physical impairments were also especially likely to be out of school in some countries. Of children with disabilities, those with hearing impairments were the most likely to be enrolled.

Specific patterns vary by country. In Rwanda, for example, while children with learning impairments are vastly more likely to be out of school than those with hearing impairments (odds ratios of 26.8 and 2.9 respectively), children with visual impairments are the least likely to be denied an education (odds ratio of 0.8). This is reflected in student headcounts. In 2016, there were 1,576 students with visual impairments enrolled in Rwandan secondary schools, compared to only 641 with hearing impairments and 253 with learning impairments (MINEDUC, 2016). Indeed, across African countries, and in line with our own primary research, children with hearing impairments are generally more likely to be out of school than those with visual impairments. Some countries exhibit staggering gaps. In Kenya, for example, while children with visual impairments were 9.4 times more likely than their peers without disabilities to be out of school, children with hearing impairments were nearly 62 times more likely to be non-attenders (Kuper et al., 2014).

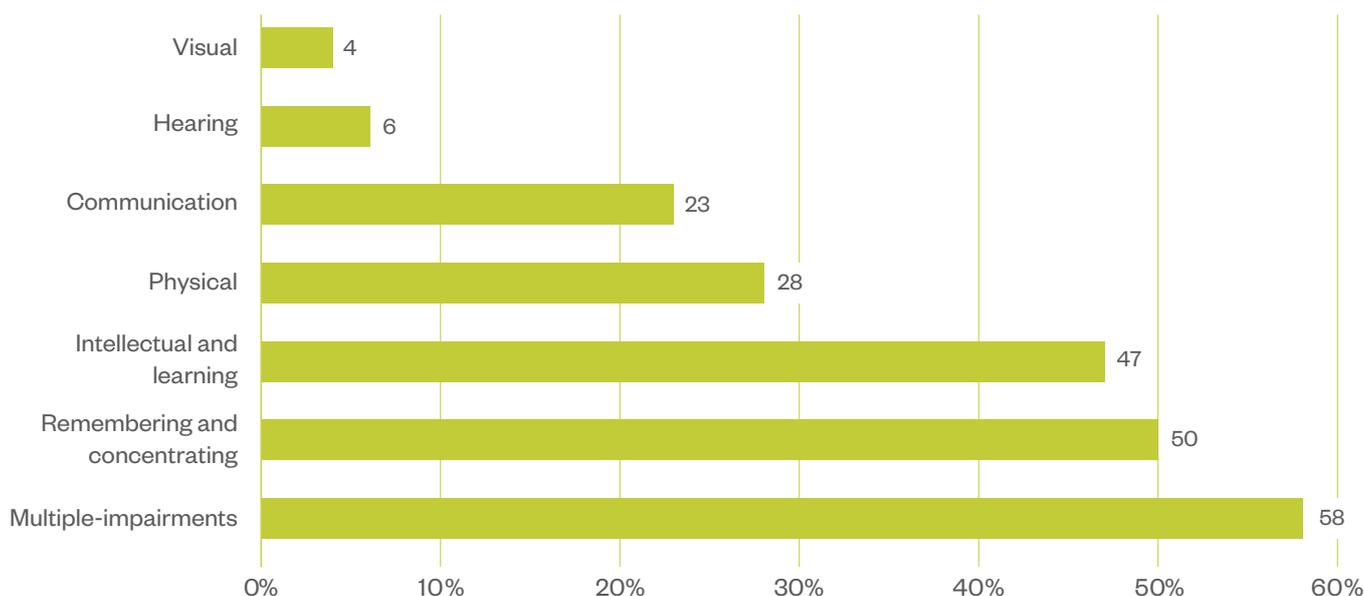
In Palestine, out-of-school rates are highest for children with multiple impairments (58%) and lowest for children with visual impairments (4%) (Jones et al., 2016) (see also Figure 1.5). Children with hearing impairments (74% peers

**Figure 1.4: Effects of disability on school attendance for children aged 5–17, by impairment type, given in odds ratio**



Source: Kuper et al., 2014

**Figure 1.5: Percentage of children who are out of school in Palestine, by impairment type**



Source: Jones et al., 2016

and 59% teachers), visual impairments (64% peers and 78% teachers), and physical impairments (52% peers and 57% teachers) were most likely to say that their peers and teachers are actively supportive – in part because there are special schools for children who are blind and deaf that offer very comprehensive services for the students able to get places there. A full 40% of children with multiple impairments or communication and intellectual impairments, on the other hand, reported that they left school because of negative teacher attitudes, probably because they were in mainstream schools.

## Evidence gaps

Overall, the evidence base on education and adolescents with disabilities – at least in terms of access – is relatively more robust than the evidence relating to other capability domains affecting their lives. This is partly due to reporting mandated by Education for All, the global commitment made in 2000 at the World Education Forum, where 164 governments pledged to provide basic education for all children by 2015, and by the CRPD. However, education evidence gaps remain large. Not only do many countries still not report educational statistics by disability (e.g. Palestine and Jordan), but even when they do report they often do so only at an aggregate level, not only considering disability as a single category, but effectively hiding the needs of younger children versus adolescents by reporting only by grade level rather than by age. In addition, while

enrolment figures for students with disabilities are occasionally reported at a gross sub-national level, they appear to never be disaggregated by caste or ethnic- or linguistic-minority status. Critically, as noted by Wapling (2016), even where enrolment rates appear credible, there is yet to be any sustained attention to the educational outcomes of children with disabilities. Indeed, even the World Bank’s (2018) recent call to action about the learning crisis in LMICs merely includes disability in a longer ‘laundry list’ of vulnerabilities and offers no specifics about what evidence might be needed to understand the scale and scope of need, much less develop the interventions that support student growth (see also Table 1.1).

UNESCO (2017) figures make it clear how rare detailed reporting is. It observes that only 56 of the world’s countries provided information to the UN Committee on CRPD implementation about the numbers of students with disabilities in education – despite the fact that nearly all countries make explicit reference to the right to education of persons with disabilities in their constitutions, laws

**Extreme variance in reported enrolment rates – driven at least in part by how disability is defined – makes it clear that figures need to be interpreted with caution.**

(Lewis, 2009:13)

**Table 1.1: Evidence gaps on education and learning among adolescents with disabilities**

<b>Broader gaps</b>	Disability is rarely incorporated into monitoring systems (e.g. education management information systems), meaning that in some LMICs even enrolment is not tracked. Where it is tracked, it can be unclear what figures mean, especially at the secondary level, as figures are rarely disaggregated by age and we know that adolescents with disabilities are especially likely to be over age for grade. There is also effectively no evidence that speaks to adolescent aspirations or learning outcomes. We do not know, even for enrolled students, whether they are learning the skills they will need for independent adult life. Evaluative evidence is even thinner; very little research has examined what works to foster inclusivity or learning.
<b>Gender-specific gaps</b>	We do not know why in some LMICs girls with disabilities are now out-enrolling and out-performing their male peers.
<b>Gaps regarding impairment type</b>	Enrolment figures are rarely reported by impairment type; we know almost nothing about which impairments are most likely to prevent young people with disabilities from accessing a quality education.
<b>Context-related gaps</b>	While it is clear that young people with disabilities in rural areas are considerably disadvantaged compared to those in urban areas, enrolment figures for children with disabilities are often reported at only the broadest level, making it difficult to identify pockets of particular need. Enrolment figures in humanitarian contexts do not appear to report by disability at all.
<b>Policy and service gaps</b>	While we know what sorts of adaptations to physical infrastructure and curricula are needed in order to help children with disabilities succeed in the classroom, we have little understanding of the kind of social interventions that might reduce the stigma that keeps many children with disabilities (especially girls) from realising their right to an education. We also know very little about how to facilitate adolescents' transitions to secondary and post-secondary education or how interventions might be tailored to meet girls' and boys' specific needs.

and policies. Of those 56 countries, only 23 produced disaggregated data by impairment type (UNESCO, 2017). Leonard Cheshire Disability (LOD) (2017c: 13) notes that only 13 countries 'actually provide data on the situation of people with disabilities and education'. Other data sources are similarly lacking. While household surveys such as Demographic and Health Surveys do collect data on school enrolment and attendance, the vast majority either do not provide specific information on children with disabilities, or their sample sizes are too small to draw any accurate conclusions (UNESCO, 2014).

As was highlighted in the introduction to this report, UNESCO (2017: 194) notes that in large part, the failure to disaggregate data in a way that would make children with disabilities more visible is driven by the lack of a 'clear, internationally established definition of disability'. Even high-income countries such as Austria reported that they were uncertain how to differentiate relevant concepts for accurate reporting. Overall, as Lewis (2009: 13) noted in her analysis of education for people with disabilities in Ethiopia and Rwanda, figures 'are likely to be misleading and should be treated with extreme caution' (see Box 1.12).

## Promising practices

There is clear international consensus on the importance of providing students with disabilities with a quality education on an equal footing with their peers without disabilities. Over the longer term, there appears to be a similar consensus that this education should be provided as inclusively as possible. The timing of inclusion – and the benchmarking for achieving 'as inclusively as possible' – remains somewhat contested though (Urwick and Elliott, 2010; Kiuppis, 2014; Wapling, 2016). Given the resource gaps facing educational systems in LMICs and the need to improve quality across the board (World Bank, 2018), it is vital that the day-to-day needs of today's students with disabilities are not relegated to the back seat as donors and governments strive to meet laudable longer-term goals.

While we know what the components of inclusive educational systems include (appropriate legislative frameworks, adequate budgets, accessible infrastructure, teacher training, adapted curricula and pedagogies, programming that challenges stigma and discrimination, the provision of aids and supportive technology, and the collection of disaggregated data), building those systems

### Box 1.12: Data mismatches

Extreme variance in reported enrolment rates – driven at least in part by how disability is defined – makes it clear that figures need to be interpreted with caution. In Bangladesh, for example, where government education reports do not include enrolment rates for students with disabilities (the report simple headcounts), various studies have produced extremely different estimates. The Disability Rights Watch Group (2009), for example, found that only 4% of the country’s 1.6 million children with disabilities were enrolled in school. Llewellyn et al. (2012), on the other hand, in their re-analysis of the Bangladeshi Multiple Indicator Cluster Survey data, found that 72% of children with disabilities were currently attending school – although Mactaggart and Murthy (2013) suggest that progression, even to lower-secondary school, is comparatively rare. Findings from Nepal – while unanimous that children with disabilities are less likely to be enrolled than those without disabilities – are similar, with studies variously reporting the enrolment of students with disabilities to be 54,000 (HRW, 2011), 74,000 (Eide et al., 2016), or 179,000 (MoE Nepal, 2014–2015). In Ethiopia, the MoE (2016) reports that only 4% of children with disabilities are attending school, but Erulkar et al.’s (2010) survey of young people aged 12–24 found that 23% of girls with disabilities and 48% of boys with disabilities were attending school.

will take time, given that LMICs are only now beginning to reach out to children with disabilities and scale up interventions and adaptations aimed at facilitating their enrolment (Walker et al., 2013; UNICEF, 2017). Indeed, while Tefera et al. (2015: 79) argue that ‘the envisaged “education for all” that is enshrined in Ethiopian policy is ‘imposed externally rather than coming up from within unlike in western countries’, even in the global North, inclusivity has not yet arrived. As of 2013, Walker et al. (2013) observed that Italy was the only European country educating nearly all of its students with disabilities in mainstream schools. Ferri (2017: 16) adds that regardless of where students with disabilities are educated, ‘the full realization of a truly inclusive system’ even in Italy has not yet been realised. Promising practice examples from LMICs therefore tend to be relatively modest in terms of outcomes. Government efforts are nascent and not yet delivering at scale; NGO efforts tend to be geographically targeted or aimed only at students with particular impairment types.

### Government efforts

Several LMIC governments are making concerted efforts to reform their educational systems to better to support the educational rights of children and adolescents with disabilities, and from which lessons can be learned. Ghana is inching towards the inclusive education envisioned by the CRPD, by focusing on reforming its educational system to better meet the needs of all learners, rather than ‘ring-fencing small allocations for “special” education’ (Myers et al., 2016: 9). Not only does its Educational Sector Plan 2010–2020 call for all children with non-severe physical and intellectual disabilities to be educated in mainstream schools and for special educational facilities to be used

only for children with the most severe impairments, but its policies are increasingly linked – thoughtfully and specifically – to implementable actions that support consistent results which build over time, meaning that while progress is slow, it is sustainable (Global Partnership for Education, 2018). The country’s 2015 Inclusive Education Policy has four objectives formulated around specific barriers to inclusion. These are: adapting systems and structures; promoting learner-friendly educational environments; developing a well-trained human resource cadre; and ensuring sustainability. The implementation plan explains how these objectives are to be accomplished: by screening all children for disability, developing minimum standards by which schools can be considered disability-friendly, reviewing and modifying all curricula, building capacity among stakeholders on inclusivity, and setting up an inter-ministerial coordination committee (including the ministries of Education and Health, Gender, Children and Social Protection, and Local Government and Rural Development), to ensure consistent implementation.

In Ethiopia, where the MoE (2016: 46) recognises that ‘the great majority of children with disabilities can study in ordinary schools and classes, if there is sufficient support available’ and hopes in only a decade to have 75% of children with special needs enrolled in primary school (up from a reported 8% now)(MoE, 2017), the NGO Humanity & Inclusion (formerly Handicap International) has been working alongside the government to operationalise its 2010 commitment to inclusive education. With funding from the US Agency for International Development, the NGO developed and piloted a model of ‘disability-friendly schools’, which is now being scaled up around the country (Humanity & Inclusion, n.d.) (see Box 1.13). It includes

### Box 1.13: Ethiopia moves forward on ‘inclusive’ education

Our research found that Ethiopia is making progress towards improving adolescents with disabilities’ access to education. While still reaching too few students for too few years, the Ministry of Education’s efforts are multi-pronged and, especially for children with visual impairments, beginning to pay off.

The focus on educating children with disabilities is relatively new in Ethiopia. According to key informants, it was not until 2012 that universities and colleges of teachers’ education and training included special needs education in their curriculum. Since then, special needs teachers reported, the proportion of children with disabilities who are enrolled in school has climbed from 4% to 8% and *‘adolescents with disabilities in particular have better education opportunities’*.

As well as launching a teacher training programme, the government is also beginning to scale up *‘disability-friendly’* schools, primarily by establishing integrated *‘resource’* classrooms to provide extra help to children with visual, hearing and intellectual impairments. Schools – primarily in urban areas and disproportionately located in the regions of Oromia and SNNPR (Ethiopia MoE, 2016) – are now offering special classes for children through grade 4. These classes, which are taught by teachers trained in Braille and sign language and sometimes provide a separate caregiver for each child with an intellectual impairment, focus on teaching children how to read and communicate. At the end of 4th grade, when children are assumed to have mastered the fundamentals of literacy in the language they require (sign language or Braille), students are moved into regular classes at those same schools.

Key informants at one school noted that *‘students flood to our school’*, coming from *‘far distant areas’* because rural schools often have no special needs teachers. Another explained that demand for education is so high that most of the students with disabilities who are enrolled in lower primary classes *‘are above 15’* and there are even *‘first graders who are 20 years old’*.

Students and parents also explained that they had been enthusiastic to avail themselves of the opportunity to join inclusive education schools. One 18-year-old boy who is deaf told us that he had tried to attend school back in his own village, but after 3 years had given up because *‘I could not understand the teachers’*. The mother of several children who are deaf noted that while she had never wanted her children to *‘become illiterate like me’*, there had previously been no options for them to attend school. A 16-year-old boy who is blind similarly explained that he had dropped everything and moved to town to attend school as soon as he knew it was an option: *‘One day I heard that there is aid for disabled people in this town, so I came here’*.

Students and teachers are clear that Ethiopia’s special needs classrooms require multiple improvements, lacking both adequate teaching staff and learning materials. They are agreed, however, that the biggest problem with the way Ethiopia is currently educating children with disabilities, is that they effectively lose all support and accommodations when they leave self-contained resource classrooms at the end of 4th grade. The practical support that students with disabilities – and especially students with hearing impairments – need to succeed in regular classrooms is simply not available. As one 16 year old boy who is deaf summarised: *‘Things were simple when I was in special needs education’*.

Students who are deaf told us that once they joined regular classes, *‘education was provided with voice and no sign language’*, and while *‘lip reading is good’*, it is problematic when *‘teachers speak turning to face the blackboard’*. They also explained that particular subjects were challenging, especially science and English, which require special vocabulary that makes lip reading impossible. Several noted that while it would be easier for students with hearing impairments to sit together, so that they could explain things to one another, the *‘teacher put them in a different place and group so we don’t have a chance to communicate with each other in a classroom’*.

Special needs education teachers are of the view that while *‘we follow our students at all levels’*, the current system is setting students up to fail because the *‘policy of inclusiveness’* is not taking students’ learning needs into account. Agreeing with their students, they observed that the system is especially failing students with hearing impairments, because *‘blind students can use the voice recorder in addition to Braille in the class’*.

Students’ options remain especially limited if they wish to pursue secondary education – as the schools hosting special needs resource classrooms are all primary schools. The mother of a 15 year old girl who is blind told us that her daughter was currently out of school, after completing 8th grade, because *‘when we asked other schools they don’t want to accept her because they do not know her’*.

building wheelchair ramps and other accessibility features, providing resource centres and adapted materials such as Braille books, and training teachers and administrators on how to best meet the needs of young people with different impairment types. It has also worked to identify young people with disabilities, who are often hidden at home, and to encourage their parents to send them to school. In all, the pilot reached nearly 7,000 students with disabilities, nearly 200,000 students without disabilities (who have benefited from improvements to infrastructure such as playgrounds and toilets), and provided training to more than 1,600 teachers. Participants – children and parents alike – report that the project has changed their lives for the better.

Nepal's efforts to improve educational access and outcomes for children with disabilities are also broad, in part because its School Sector Reform Plan (2009–2015) was independently evaluated – and found lacking – using Organisation for Economic Co-operation and Development criteria (Poyck et al., 2016). As well as expanding the number of classrooms that are tailored

▶▶ 'Students flood to our school', coming from 'far distant areas' because rural schools often have no special needs teachers.

(Key informant interviews, Ethiopia)

to the needs of children with disabilities (now available in 380 schools across the country) (Plan International, 2014; GoN, 2015), and running an information campaign to raise awareness of disability (NCE, 2014), the government also provides a stipend to offset some of the costs of educating children with disabilities (Lord et al., 2016). Available to students in grades 1-8 who have a disability card, regardless of where they attend school, there are four tiers of funding, ranging from 1,000 to 30,000 Nepalese rupees a year depending on level of dependency, severity

▶▶ We follow our students at all levels.

(Special needs education teachers, Ethiopia)



of disability, and geographic location (Banks et al., 2018) (see Figure 1.6). The 2016–2022 School Sector Reform Plan set a target of providing scholarships to 13,000 students, and while Lord et al. (2016) note that demand often exceeds available funding, Plan International (2014) found that scholarships meant that costs were rarely the cause of dropout. The government is also working to provide schools with interactive pedagogical material for children with disabilities and to strengthen training for those running the 1,400 resource centres in schools across the country (MoE Nepal, 2016).

### NGO efforts

In Bangladesh, where CRPD implementation has lagged far behind policy commitments and the government has only recently announced plans to train 50,000 teachers on disability (GoB, 2017), NGOs have been delivering the majority of education to students with disabilities. For example, in order to help students with disabilities access mainstream government schools, the Centre for Disability in Development has been training teachers on inclusive education and providing disability-specific learning materials such as Braille books (Walker et al., 2013). The NGO BRAC, which delivers education to over a million of Bangladesh's students, has also been actively supporting inclusive education. BRAC estimates that since 2003, over 200,000 children with disabilities have graduated from their schools and another 50,000 are currently enrolled (BRAC, 2016). Children with disabilities are taught in the same classrooms as other children and BRAC's education programme also provides access to assistive devices such as wheelchairs and hearing aids.

More recently, BRAC has begun providing specialised education to the children who cannot easily be folded

into mainstream education, such as those with autism, intellectual disabilities, Down syndrome and cerebral palsy. BRAC's educational centres offer a wide array of programming – not just academic content but also 'co-curricular' activities such as sports, medical care, and physical therapy. They have built connections to local government and non-government schools to help children transition into mainstream classrooms when they are ready, and facilitate children's participation in regional and national sporting and cultural events. BRAC's initial evaluation of these centres found marked positive impacts in only a few years. For example, enrolled students had better communication skills, easier physical movement, a better understanding of hygiene, and better behaviour – a notable outcome for children who can struggle with sensory overload. They also had improved self-esteem, more enjoyment of their time with peers, and were beginning to become literate and numerate. Parents not only had more time to work, which reduced financial stress on the family, but also felt less frustrated, due to their children's better communication skills and behaviour and their own access to education and support. BRAC also found improved community attitudes towards people with disabilities.

LCD is also providing educational opportunities for Bangladeshi children with disabilities (Benoy et al., 2016). Its project, 'Promoting rights through community action: improved access to inclusive education for children with disabilities', is taking a multi-pronged approach that engages with children with disabilities, their families, and government agencies (including schools and health centres) to address the barriers to inclusive education. Using a rights-based, participatory approach, the project identifies children with disabilities and encourages their parents to enrol them in school. Children are carefully

**Figure 1.6: Nepali stipends for students with disabilities**

Category	Eligibility	Amount (per month, for 10 months of year)
<b>A</b>	Students with disabilities who board at the school, residential provision	NR 3000 [US\$29] (mountain districts) NR 2500 [US\$24] (hill, Terai districts)
<b>B</b>	Students with disabilities who require assistive devices and personal assistance while in school, non-boarding	NR 500 [US\$5]
<b>C</b>	Students with disabilities who use assistive devices or transportation to commute between home and school	NR 300 [US\$3]
<b>D</b>	For all other school-going children with disabilities, non-boarding	NR 100 [US\$1]

Source: Bank, 2018



An adolescent boy, with a visual impairment, Bangladesh © Marcella Pasotti / GAGE 2018

assessed and have their own individual rehabilitation plan that includes access to assistive devices and therapeutic services, with free transport where necessary. Parents receive classes and information to raise their awareness. Teachers have also been trained on inclusive practices, using curricula revised under the aegis of the project, and schools have been made more accessible. Local authorities, including leaders of children's clubs and civil society organisations, have also been sensitised to the needs of those with disabilities. Inclusive education resource centres were also established to ensure that ongoing training and services are available at the community level.

A formal evaluation found that the project was highly successful, reaching more than 2,100 children at more than 260 schools at a cost of \$636 per child (Chowdhury and Gomes, 2015). Parents reported that more than 70% of students with disabilities would not have been enrolled without project support – and the proportion of children with disabilities who attended regularly rose dramatically from 18% in 2012 to 98% in 2014. Success was found to be due to the unique way that the project prepared the child, the family, the school, and the community – all of which fostered local ownership and ensured longer-term

sustainability. The project was less successful at retaining girls, due to parents' concerns about their daughters' safety as they reached puberty. The dropout rate for girls was nearly twice that of boys (5.7% versus 3.1%), suggesting a need for more gender sensitivity in the future.

LCD is also promoting inclusive education in Kenya. As part of the UK Department for International Development-funded Girls' Education Challenge (GEC), it has worked in the Lakes Region to pioneer strategies to improve enrolment and retention rates for girls with disabilities, increase awareness and capacity among parents and teachers, and improve the quality and accessibility of mainstream schools. Over four years, and in collaboration with government education assessment and resource centres, which provided girls with the assistive devices they needed, the GEC supported more than 2,000 girls with disabilities to enrol in 50 mainstream schools (Carew et al., 2016). It also supported nearly 100 already enrolled girls to sit the exam for entrance to secondary school, and trained 250 male mentors, usually fathers, about the importance of inclusion and the impact of gender. It was found that teacher training reduced concerns and improved attitudes towards inclusion, but did not significantly change classroom practices (Carew et al., 2018).



## 2 Health, sexual and reproductive health, and nutrition

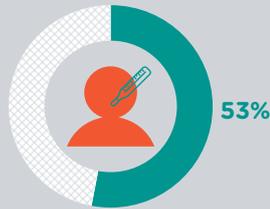


## Health, sexual and reproductive health and nutrition

**Recommendation:** Ensure that adolescents with disabilities have access to primary and disability-specific health care, information and services



Due to disability-related stigma, cost, and physical accessibility, adolescents with disabilities have poorer access to health care



**Bangladesh and Ethiopia:** GAGE survey data found adolescents with disabilities are **53% more likely** to experience significant illness or injury



Girls with disabilities have significantly poorer access to sexual health information and services, due to restrictive gender norms



The nutritional needs of adolescents with disabilities are poorly addressed, with some at risk of undernutrition, especially due to poverty

## Key messages

- **Overarching challenges:** Adolescents with disabilities tend to have poorer health status, yet more limited access to health care and information, and (in some contexts) poorer nutrition. Due to disability-related stigma, cost, and physical accessibility issues, the access of adolescents with disabilities to primary care and sexual and reproductive health (SRH) care lags behind that of their peers without disabilities. Access to disability-related health care remains rare in many LMICs, given resource constraints.
- **Gender dimensions:** Girls with disabilities are doubly constrained due to restrictive gender norms. They have both poorer access to sexual and reproductive health information and services, and poorer health and nutrition outcomes.
- **Impairment-specific challenges:** Adolescents with intellectual impairments appear especially likely to have limited access to all types of health care information and services, due to the limited number of providers who know how to meet their needs – and parents' more restricted investment in their wellbeing.
- **Context-specific challenges:** Health services in rural areas, and especially in humanitarian contexts, tend to be more poorly tailored to meet the needs of people with disabilities and arguably adolescents in particular. Access to disability-specific care is especially limited outside of urban centres.
- **Caregiver concerns:** Providing parents with information about the causes and nature of their child's impairment, as well as guidance about impairment-specific care and services available that can support their children's wellbeing and development is critical.
- **Evidence gaps:** There is limited evidence on the health, SRH and nutritional status and experiences of girls compared to boys with disabilities, of adolescents with different impairment types, and by stage of adolescence (e.g. 10-14 years, 15-19 years). The evidence base is also very weak in terms of understanding what works in overcoming the barriers to primary and disability-specific health care for adolescents with disabilities, as well as SRH information and services, and nutritional support.
- **Promising practices:** Promising practices include providing free/ subsidised health care or insurance; training community health care workers to better engage with young people with disabilities; scaling up access to disability-specific care in regional centres; ensuring that adolescents with disabilities have access to SRH information at school and in community clinics; and engaging with parents who can play a key role in the absence of other provisioning.

## Introduction

Adolescents with disabilities need access to a range of health care information and services if they are to enter adulthood not only in good health, but with the knowledge and habits that can help them maintain that good health over time. They need access to preventive and curative care (including sexual and reproductive health (SRH) care), a nutritious diet, information about how their bodies are changing, and girls need support to manage menstruation. However, while the basic health-related needs of adolescents with disabilities are similar to those of their peers without disabilities, many adolescents with disabilities not only have a number of unique disability-related health care needs, but face daunting disability-related barriers to accessing that care. Many require more regular, specialised, and expensive health care services and face at least some physical, institutional, or social impediments that limit their access to services and information.

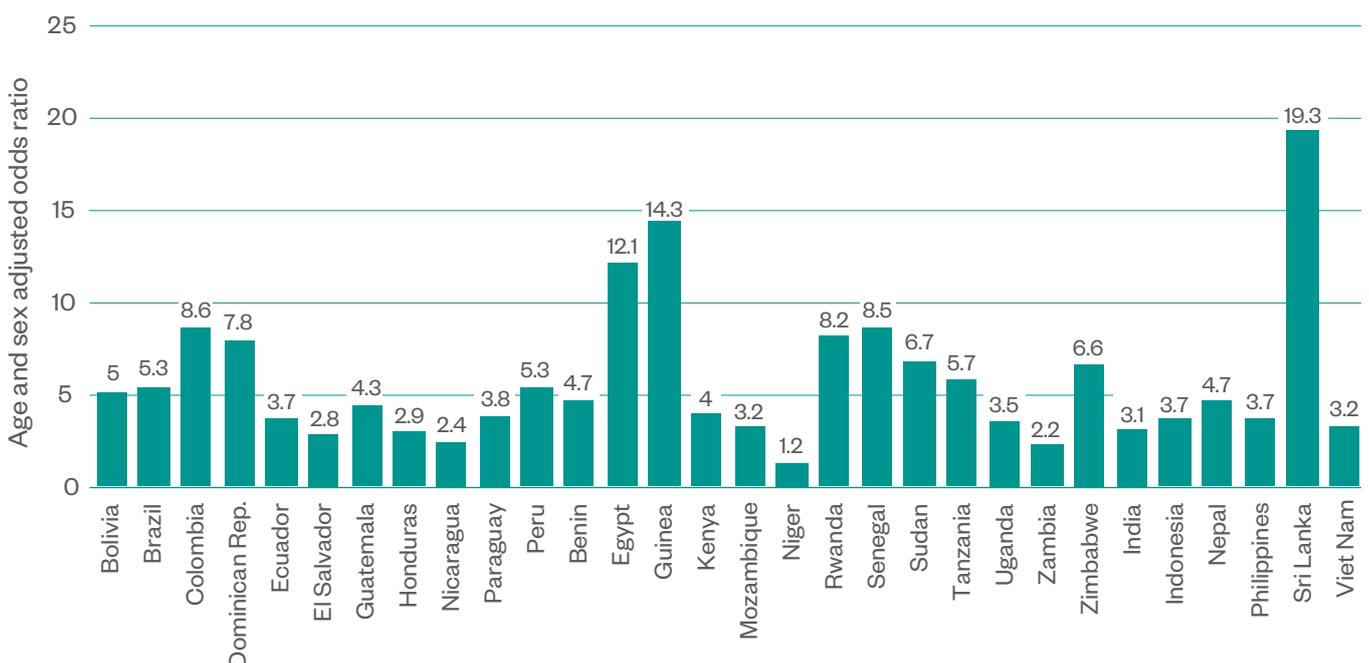
## Health status and access to primary health care

While evidence is rarely disaggregated, and little is known about adolescents with disabilities per se (UNICEF Innocenti, 2007) – much less adolescents with particular

types of disabilities – persons with disabilities generally tend to have greater unmet health care needs and poorer levels of health than the general population, in large part because they face greater difficulties in accessing even primary health care (WHO and World Bank, 2011). Indeed, Kuper et al. (2014), in their cross-sectional study of nearly a million children under the age of 18 with and without disabilities in 30 LMICs, found that in 29 of those countries, children with impairments were more likely to have been seriously ill in the past year than children without impairments (Niger being the exception). In nearly half of those countries, the odds ratio was above 5, and in three countries (Egypt, Guinea and Sri Lanka), it was above 10 (ibid.) (see Figure 2.1 and Box 2.1).

While Kuper et al.'s (2014) research was unable to address the impact of disability on care-seeking (because most children attended treatment for their illness), cost is generally found to be the largest barrier that prevents those with disabilities from obtaining the health care they need. The World Report on Disability, which uses data from 51 countries, found that just over half of people with disabilities cannot afford care, compared to approximately one-third of people without disabilities (WHO and World Bank, 2011). The World Report on Disability also found that health care uptake by people with disabilities is restricted

**Figure 2.1: Effects of disability on odds of serious illness in past year, among children 0-18 sponsored by Plan International in 30 LMICs**



Source: Kuper et al., 2014



### Box 2.1: Poorer health status among adolescents with disabilities in the GAGE survey

In Bangladesh, the GAGE survey findings revealed that adolescents with disabilities are 53 percent more likely to have experienced a significant illness or injury in the last 12 months. The survey also found that they were no less likely than their peers without disabilities to have sought care over the last year. This likely means that adolescents with disabilities are receiving less health care than they need.

In Ethiopia, compared to their peers without disabilities, adolescents with disabilities in the GAGE survey also reported poorer health. They were, for example, 31 percent less likely to say that their health is very good, 23 percent more likely to have a health symptom, and 53 percent more likely to have had a serious illness or injury in the past year. While there were no significant differences between girls and boys, younger and rural adolescents were more disadvantaged in terms of self-reported health. Rural adolescents were additionally disadvantaged in terms of having had a serious illness or injury.

While Ethiopian adolescents with disabilities were 20 percent more likely to have sought health care over the last year than their peers without disabilities, given their much poorer reported health, their needs for care are likely still under-served.

not just by physical accessibility issues (such as a lack of transport or ramps) but by the attitudes and skills of health care providers, which all too often are shaped by discrimination and stigma (WHO and World Bank, 2011) (see Box 2.2).

Lack of information can also preclude access to health care for those with impairments (Eide et al., 2016). For example, in Rwanda, where Kuper et al. (2014) found that disability is associated with less care-seeking when ill, health care infrastructure is often not wheelchair-friendly and clinics can be so distant as to preclude accessibility for those with special transport needs, especially those who live in rural areas (SIDA, 2014; NCPD, 2014). In Jordan,

some parents are forced to seek help from local workers like cart-pushers and vendors to help transport their child to a health centre, incurring additional costs (International Rescue Committee, 2013). In Ethiopia, children with impairments can be afraid to go to government health facilities because some health workers do not understand their needs (Sorsa, 2013). In Nepal, Eide et al. (2016) found that some people with disabilities do not seek care because they are not aware that services are available to them – a theme also common in Palestine, where parents did not know what services were available for autism in particular (Jones et al., 2016).

### Box 2.2: Palestinian adolescents speak out about health care deficits

In Palestine, we found few adolescents with disabilities who had had positive encounters with medical professionals. Interestingly, many wished to become doctors themselves, to provide better care to the next generation of young people with disabilities.

*'I dream of being a surgeon in the future, so that I can treat children with disabilities like me who don't have any hope. The doctors are useless, they don't provide us with any support.'*

(Girl with a visual impairment, 15 years, Palestine)

*'I travelled to Israel before for treatment. I had lots of fun there. They have adaptations everywhere. There, I felt like I do exist. And that I am only a normal human being, without feeling inferior or insignificant. The first thing I'd like to achieve is to study medicine in order to treat people with disabilities. I don't want them to live the same experience I've had when the doctors neglected me. Also, I want to treat myself. Sometimes I see myself treating people. It'd be great to help them and give them the medicine needed.'* (Boy with a physical impairment, 17 years, Palestine)

*'I want to complete my education and wish to be a nurse to help myself as I get older because no one helped when I was young, so I want to be the one who cares about myself and to need no one.'*

(Girl with a visual impairment, 18 years, Palestine)

## Access to disability-specific care

People with certain impairment types often require access to specialised services that provide rehabilitation and assistive devices such as artificial limbs, wheelchairs or hearing aids. However, those types of services tend to be quite limited in LMICs, especially in rural areas and conflict-affected contexts, where health services are primarily designed for the 'average person' (NCPD, 2014) and assistive devices are expensive and rarely publicly provided (Tekola et al., 2016; Lord et al., 2016; Huq et al., 2013; UNICEF Innocenti, 2007). WHO (2017) estimates that in LMICs in Asia and Africa the number of physical and rehabilitation medicine doctors, physiotherapists, speech and language therapists, and prosthetists and orthotists is less than one-tenth of what is required. In addition, WHO and World Bank reported that in LMICs, only 3% of need for hearing aids is met. Access issues are particularly acute for children and adolescents with impairments, given that they can require specialised paediatric services (ibid.) and require regular replacement of assistive devices due to growth (Groce and Kett, 2014).

In Ethiopia, for example, fewer than 16% of children surveyed had access to specialised rehabilitation services such as occupational therapy, physiotherapy, speech therapy and audiology (ACPF, 2014). In addition, crutches cost \$8 (on average) and a wheelchair costs \$224, which is unaffordable for the average Ethiopian (ibid.). Similarly, in

Palestine, more than a quarter of children with impairments who need access to specialised medical care or speech and language therapy are unable to obtain it – and one-third of children who need hearing aids do not have them because their family cannot afford them (Jones et al., 2016). In Rwanda, there are no community-based rehabilitation programme (CRPD; 2015; NCPD, 2014) and in Nepal – a country of 30 million people – Norad (2012) found that there were 400 physiotherapists, but only 8 speech therapists.

It is important to note that while disability drives ill health and can preclude access to health care, ill health and lack of access to health care is also – in LMICs in general and humanitarian contexts in particular – a major driver of disability (UNHCR, 2016; UNICEF, 2015, 2007). In Ethiopia, for example, ACPF (2014, 2011) found that while 35% of children with disabilities were born with their disability, many others became disabled because of inadequate nutrition and health care during early childhood. They found that 60% of children with visual impairments, for instance, acquired them from preventable diseases. Our own work found that lack of timely treatment after accidents also causes a great deal of permanent disability (see Box 2.3).

As well as causing some forms of disability, lack of adequate health care can exacerbate other forms of disability by failing to identify them in a timely manner – ruling out early treatment and intervention (UNICEF, 2007) (see also Box 2.4 and Box 2.5).

### Box 2.3: Disability as a result of accidents

In Ethiopia, our qualitative research found that a significant number of young people with disabilities had acquired them as a result of accidents, ranging from maiming by a crocodile while crossing the river in search of water for livestock, to falling out of trees while playing.

*'My eye was damaged by a ball, that was about five to six years ago. This happened while I was playing football in our village.'* (Boy who is blind, 17 years, Ethiopia)

*'I became deaf when I was swimming with my brother in the lake. I sank and was saved, after that I became deaf.'* (Boy who is deaf, 17 years, Ethiopia)

*'I got burnt. A boy pushed me into a fire. We were burning the garbage at school and they shoved me. He didn't know. He also fell with me.'* (Boy with an intellectual impairment, 11 years, Ethiopia)

Other adolescents did not really understand what had caused their impairments, as these quotes highlight:

*'While I was working, there is a moon during that night, and I think that the reflection of the moon creates a problem in my eye.'* (Focus group with adolescent girls who are blind, Ethiopia)

*'When I was chatting with friends under a tree, there was a tornado-like wind and it is because of that I am exposed to be blind.'* (Focus group with adolescent girls who are blind, Ethiopia)

### Box 2.4: Financial barriers to health care

Our qualitative research findings highlighted that financial barriers were critical impediments to families' ability to seek health treatment for their adolescents with disabilities, as these quotes from Bangladesh illustrate:

*'My friend asked why I didn't go to a doctor. I explained that at that time we have financial problem.'*  
(Girl with a visual impairment, 17 years, Bangladesh)

*'In order to make it straight, an operation needs to be done. If I have an operation, then it is solvable. However, that is not possible now, since we have faced a shortage of money.'* (Girl with physical impairment, 17 years, Bangladesh)

In other cases, parents sought medical advice from traditional healers due to a dearth of money to seek modern medical help:

*'They dug a large hole full of water and made me submerge my leg in it for a long time... They made a deep hole like that. They put me inside it... They came to visit and told me to keep my leg inside water; they said my legs need to be submerged into the water. So they did that.'* (Boy with a physical impairment, 15 years, Bangladesh)

### Box 2.5: Parental attitudes towards health care uptake

Parental attitudes can also play a significant role in impeding health care uptake for adolescents with disabilities. In Ethiopia, GAGE's qualitative work found significant fatalism on the part of parents – and even more significant stigma-related underinvestment. Participants reported:

*'When I was in grade 3, I felt pain in my eyes. It started looking like a boiled meat. It was painful and I had blurred vision. I was complaining to my parents that I was in pain. But you know how rural parents are; they just gave me a deaf ear. When they took me to the hospital, it was already too late. They told them the lenses are not working.'*  
(Girl who is blind, 18 years, Ethiopia)

*'I didn't try any medical help and support for my daughter's problem. It was Allah who created her as she is.'*  
(Mother of a 13-year-old girl who is deaf and also has an intellectual impairment, Ethiopia)

*'They are God's gift, I accept it. So if God hates you, there is no place you hide yourself. Who can open the ear closed by God? I had interest to take them to health centre but their father refused. He believes that those children born with problem will not be cured by treatment after birth. So one of the persons who prohibited me to take these children to health centre was their own father. So if they had had good father, I would have taken them to health centre for treatment.'* (Mother of two adolescents who are deaf, Ethiopia)

 My friend asked why I didn't go to a doctor. I explained that at that time we have financial problem.  
(Girl with a visual impairment, 17 years, Bangladesh)

 They are God's gift, I accept it. So if God hates you, there is no place you hide yourself. I had interest to take them to health centre but their father refused. He believes that those children born with problem will not be cured by treatment after birth.  
(Mother of two adolescents who are deaf, Ethiopia)

## Access to sexual and reproductive health information and services

For adolescents with disabilities, evidence on their sexual experiences and access to SRH health care information and services is thin and fractured. Most research has been conducted in high-income settings, primarily North America and Western Europe, and research in the global South has been disproportionately linked to sub-Saharan Africa's HIV epidemic. The Special Rapporteur on the rights of persons with disabilities, Ms Catalina Devandas Aguilar, notes that the dearth of evidence is largely due to the refusal of the broader community to acknowledge that people with impairments are sexual beings (Aguilar, 2017; see also Addlakha et al., 2017; Rugoho and Maphosa,

2017; Tanabe et al., 2015; Maxwell et al., 2007). The Special Rapporteur has urged the global community to recognise the needs of people with disabilities to be informed and enabled to make autonomous choices about their own SRH; she also observes that the legal environments of many states are disabling. Some, for example, require parental notification and consent before providing SRH information and services to adolescents; others allow medical procedures such as sterilisation without free and informed consent (Aguilar, 2017).

Evidence suggests that adolescents with disabilities tend to have low levels of SRH knowledge – and ‘much interest in learning more’ (Tanabe et al., 2015: 418; see also Burke et al., 2017; UNICEF, 2013b). In Ethiopia, for example, 70% of young people with disabilities in Kassa et al.’s (2016) study did not know when during the menstrual cycle a

pregnancy was most likely to occur – though 85% had heard of at least one method of family planning. In Nigeria, Otte et al. (2008) found that adolescents with visual impairments were more ‘prone to misunderstanding’ about how HIV is spread than their peers without impairments. In Senegal, Burke et al. (2017) found that young people with disabilities had ‘very low’ knowledge about SRH.

Young people’s lack of knowledge of SRH issues is due to the reality that adults have failed to teach them. While this is true both of young people with disabilities and young people without disabilities, it is especially the case for those with disabilities. Not only are children with disabilities less likely to attend secondary school (where sexuality education tends to be provided), but parents are more hesitant to engage in conversations about SRH with their children with disabilities due to the common misconception that they will not marry

### Box 2.6: Mothers play a key role in providing information about puberty and SRH

The adolescents with disabilities included in our qualitative research in Gaza reported surprisingly detailed information about sexual and reproductive health, given the conservative social milieu, and were willing to be very frank with us about what they knew. This was true of girls and boys alike, married and unmarried adolescents, and regardless of impairment type. Mothers emerged as a main source of information for most adolescents.

In Gaza, open discussions about sexual topics, particularly with strangers, are culturally fraught. Because of this, all of the adolescents we interviewed were well past puberty. The youngest was a 17-year-old girl with Down syndrome. All research participants were clear that they had known about puberty before it began. They told us that they knew that girls grew breasts and began menstruating – and that boys grew beards and developed lower voices. Some even knew that puberty could be associated with ‘angry and violent’ feelings, though this was not universal. A 19-year-old boy with a physical impairment told us that while he was well prepared for acne and strength, the emotional changes of puberty had surprised both him and his family. *‘I did not know at the beginning what happened with me and why I get angry for nothing. My family was shocked and wondered about what happened with me.’*

All of the adolescents with disabilities that we interviewed told us that their mothers were central to what they knew about SRH. A 19-year-old girl with a physical impairment explained, *‘My mother is the best resource for my knowledge as she will understand my questions and gives me the sufficient answers. The mother is the second school.’* Another 19-year-old girl, also with a physical impairment and now divorced after a short marriage, agreed:

*‘My mother was the first one to educate me about menstruation and hygiene. She explained to me that my body will change and that I will get my period each month. She continues to raise awareness about my body even after my marriage.’* A 19-year-old boy with an acquired physical impairment added: *‘My mother is my life. My father did not play any role in my puberty stage. I and most of my peers feel very shy and embarrassed to ask their fathers about anything related to puberty and body changes.’*

While the literature suggests that girls with intellectual impairments are the least likely to have good access to SRH education, in our small sample, it was the mother of the 17-year-old girl with Down syndrome who stood out as the most forthright:

*‘When you have children with disabilities you need to be more careful and give them more information... Most people say it is embarrassing, but I want to educate her to know what is right and what is wrong... I prefer to use the internet nowadays because I can find good images that make it easier to explain things... in a simple and comprehensible way.’*

Her daughter, who has only minimal literacy, told us that she had used the internet herself. After she talked to her mother, and using words she found in her younger sister’s text book, she *‘Googled it to know more’*.

or lead sexual lives (Kassa et al., 2016; UNICEF, 2012; WHO and World Bank, 2011; Maxwell et al., 2007) (see Box 2.6). In Bangladesh, for example, Andrae (2015) found that parents of children with disabilities generally think they do not need sexuality education. In Ethiopia, of the 426 young people (aged 10–24) with disabilities in Kassa et al.'s (2016) study, only 22% had ever had a discussion with their parents on an SRH topic – a figure markedly lower than a similar sample of adolescents without disabilities (40%). The mismatch is similar in Nigeria, where 58% of adolescents with no visual impairment but only 42% of adolescents with a visual impairment had received information about HIV from their parents (Otte et al., 2008).

Adolescents and young adults with disabilities are also excluded from SRH education interventions by programme designs that do not take disability into account. In Rwanda, Habinshuti et al. (2017) found that those with hearing impairments had difficulty listening to radio messages or following workshops that failed to provide sign language interpreters. Those with visual impairments were rarely provided with Braille materials (ibid.). In Nigeria, Otte et al. (2008) found that while over 90% of adolescents with no visual impairment learned about HIV from billboards and

 When you have children with disabilities you need to be more careful and give them more information... Most people say it is embarrassing, but I want to educate her to know what is right and what is wrong... I prefer to use the internet nowadays because I can find good images that make it easier to explain things... in a simple and comprehensible way...

(Mother of a 17-year-old girl with Down syndrome, Gaza)

posters at school, less than 9% of adolescents with a visual impairment had access to HIV messages from such mass media platforms.

In contexts where particular impairment types (e.g. hearing impairments, muscular dystrophy) are common due to consanguineous marriage, comprehensive sexuality education that includes counselling for young people (and their parents) on the importance of partner selection could play an important role in preventing disability (see Box 2.7)

### Box 2.7: The disability-SRH connection

In many countries in the Middle East and North Africa (MENA), a lack of comprehensive sexuality education is driving disability. Where consanguineous marriages are common, a significant proportion of congenital disability could be prevented with education aimed at encouraging young people to marry non-relatives (Bener and Mohammad, 2017; Sirdah, 2014; Othman and Saadat, 2009). Indeed, in Egypt, where The Economist (2016) reports that 40% of the population marries a cousin – and where Bener and Mohammad (2017) found that 23% marry a first cousin – it is estimated that 90% of cases of some impairment types (e.g. microcephaly, cystic fibrosis and thalassaemia) are caused by consanguinity. In Jordan, where a 1992 survey found that 32% of marriages are between first cousins and a further 17% are between more distant cousins (The Economist, 2016), recent efforts to reduce cases of thalassaemia via pre-marital counselling are paying off: rates dropped 50% between 2004 and 2011 (Manara Network, 2011).

The magnitude of impacts on individual lives can be seen in the story of one woman, a Palestinian mother struggling to raise multiple children with impairments in Gaza's Nusirat Jadeed refugee camp:

*'I had four disabled children who all suffered from cerebral palsy; two of them died suffering from different diseases and I still have another two disabled. I didn't know that these disabilities were because of relatives marrying (cousins) as none of our relatives had the same disabilities in such a number. When I had the first child, I was almost living in hospitals because he suffered a lot from different diseases (coughing, blue baby when born, infections)... until he died. For the second baby, it was even more shocking as I couldn't believe for less than 1% that such a disability will recur. Every time I gave birth to a disabled child I felt so traumatised, sometimes I felt dizzy and fainted on the ground. I stayed in my room by myself for days and days thinking of my destiny... Later, doctors told us that because of relatives marrying, the disability percentage would appear in our children as 25% disability–75% healthy. Every time I give birth to a child, I say to myself, "The child will be most likely from the 75%", but it is Allah's will that the majority of our children came under the 25% and were disabled!'*

Source: Jones et al., 2016

– though given that these same contexts often provide only the most minimal SRH information to young people until after they are married, this will be difficult.

Research has largely ignored the experiences of young people with disabilities when it comes to accessing SRH services – although there is some nascent evidence that, as with SRH information campaigns, they are often poorly tailored to meet the needs of adolescents with some impairment types (UNICEF, 2013b; TARSHI, 2010; Tanabe et al., 2014; 2015). For instance, in Ethiopia, Kassa et al. (2016) found that 52% of young people with disabilities reported that SRH services are not available to them. In some cases, this is due to physical accessibility issues. In Senegal, for example, Burke et al. (2017) found that a significant barrier to uptake is that young people with disabilities need someone to go with them to clinics, which reduced – or eliminated – confidentiality. Evidence also suggests that stigma on the part of service providers both limits and shapes access (Plan, 2017; Burke et al., 2017; Tanabe et al., 2015; Frohmader and Ortoleva, 2013; UNGA, 2017). Braathen et al. (2017) report that health care practitioners are often more hesitant to discuss

sexual issues with young people with disabilities, and that pregnant women with disabilities sometimes face hostile attitudes from providers (see also WHO and World Bank, 2011). Forced contraception, sterilisation and abortion are also not unknown, due to the perception that women with disabilities cannot adequately perform as mothers (UNGA, 2017; Tanabe et al., 2014; Frohmader and Ortoleva, 2013).

Research has found that people with disabilities in LMICs face significant difficulties in accessing the water, sanitation and hygiene (WASH) facilities that help maintain dignity and prevent infection (Wilbur et al., 2018; FANSA and WSSCC, 2015; WaterAid, 2010, 2008; ACPF, 2011; Dhungana, 2006). The particular challenges they experience vary according to their location (greater difficulties in rural settings and informal settlements), existing infrastructure and policies, prevalent norms, household income, and impairment type. For example, latrines may be too far away or too small for wheelchairs to fit in, may lack support bars, or have slippery floors. In settings where disability is highly stigmatising, other people may not want people with disabilities to use communal latrines. While there is almost no age-disaggregated,



An adolescent girl, with a hearing impairment, Bangladesh © Marcella Pasotti / GAGE 2018

country-level evidence about access to WASH for adolescents with disabilities, Wilbur et al. (2018), in their work with adolescent girls and young women in Nepal, found that they had a difficult time accessing both toilets and water for cleaning their bodies and clothes. Toilets were often far from homes and water was difficult to carry. Access was especially difficult during menstruation, due to the more regular need for sanitation, and girls and young women reported that barriers impacted their safety, security and dignity.

## Access to nutrition

Despite the crucial role of nutrition for health and wellbeing, and evidence that people with disabilities are more likely to be food insecure than people without disabilities (WHO and World Bank, 2011), the few available sources stress that the nutritional needs of children with disabilities 'are scarcely addressed' (Groce et al., 2013: e180; Groce et al., 2014). Some young people with disabilities are at risk of undernutrition (Kisia et al., 2014; Groce et al., 2013; 2014; UNICEF, 2013b). Where disability is stigmatised, and particularly when resources are scarce, children with disabilities may be offered less food or less nutritious food than their siblings without disabilities. Also, when they require assistance to eat, they may become malnourished if family members lack the time required to adequately feed them. Poor caregiver knowledge about disability may also drive malnutrition, if, for example, special positioning or foods are required (ibid.).

In Palestine, where disability is stigmatised and families are large, leading to time pressures on caregivers, nearly one-third of parents reported that their children with disabilities ate less than their children without disabilities (55% reported that the children ate the same and 15% reported that their children with disabilities ate more than the others) (Jones et al., 2016). Overall, 13% of Palestinian families reported that the nutritional status of their children with disabilities was poor (Jones et al., 2016). In Kenya, where parents often have only a limited understanding of the causes of disability, and largely attribute it to divine intervention, Kisia et al. (2014) found that children with disabilities were more likely than their peers without disabilities to be malnourished and that even if they were enrolled in school, they were less likely to be included in school feeding programmes. In Malawi, a study following severely malnourished children found that underlying disability was second only to HIV as a risk factor for mortality (Kerac et al., 2014).

While disability can shape nutritional needs and access to healthy food, poor nutrition (like poor health care) also drives disability (UNICEF, 2013a; Groce et al., 2013, 2014). In Rwanda, for example, vitamin A deficiency is the leading cause of blindness and iodine deficiency the leading cause of learning disabilities (Abbott, 2013). In Bangladesh, where only 58% of households use iodised salt, iodine deficiency is the leading cause of preventable intellectual and psychomotor impairments in young children (icodr, b, et al. (2013). Rates of child anaemia, which causes neurological damage, are also high: 19% for those aged 6–11 and 17% for those aged 12–14 (ibid.).

## Experiences shaped by gender

In many contexts, disability interacts with gender to leave females with disabilities with especially limited access to both primary and disability-specific health care (Human Rights Watch, 2015; UNICEF, 2013b; World Bank, 2009). Due to the confluence of restrictive gender norms, stigma directed at disability, and traditional age hierarchies, adolescent girls with disabilities appear to be particularly disadvantaged (Save the Children, 2008). In part, this is due to gender norms that limit girls' and women's mobility and their interactions with male health care providers (World Bank, 2009). It is also, however, because when resources are scarce, some families prioritise their sons over their daughters (Groce and Paeglow, 2005; Abu-Habib, 1997).

## Access to primary health care

Girls with disabilities have been found to have both higher incidence of illness and poorer access to primary care. In Rwanda, Plan (2013) found that girls with impairments were especially likely to be ill. Their study found that while boys with disabilities were 5.1 times more likely to have had a serious illness (e.g. malaria, ear infections, and acute respiratory infections) than boys without disabilities in the past 12 months, girls with disabilities were 10.8 times more likely to have been seriously ill than girls without disabilities. In Nepal, Groce and Paeglow (2005) found that while girls and boys had similar rates of poliomyelitis, boys were twice as likely to survive as girls because they were provided with better food and medical care. In Jordan, Save the Children (2008) reported that girls' access to health services lagged behind that of boys, while in Lebanon, Abu-Habib (1997) reported that sons were prioritised over daughters.

## Access to disability-specific care

Girls' access to disability-specific health services is also limited. In Nepal, for example, Dhungana (2006) reported approximately twice the number of boys as girls being brought to such services. Boys and men are also more likely to have access to assistive devices than girls and women. Eide et al. (2016) found that 16.7% of male respondents over the age of 15 had an assistive device compared with only 11.6% of female respondents. This pattern is repeated in India, where women's lesser use of assistive devices has been linked to the low number of women technicians in a context where gender segregation is the norm (WHO and World Bank, 2011).

## Access to SRH information and services

Women and girls with disabilities have especially limited access to SRH rights due to the confluence of stigma surrounding women's sexuality and the sexuality of people with disabilities-- as well as their greater risk of sexual violence (UNGA, 2017; Braathen et al., 2017; Mactaggart, 2015; WHO and World Bank, 2011). Generational hierarchies leave adolescent girls at the highest risk. Indeed, Plan (2017) notes that due to pervasive gender discrimination, girls with disabilities are 'the least likely to enjoy their sexual and reproductive health and rights' (see Box 2.8).

Research has found, for example, that because Indian girls with impairments are not typically prescribed a reproductive and nurturing role, they are seen as not needing information about sexuality (FST, 2016; TARSHI, 2010; Addlakha et al., 2017; Mohapatra and Mohanty, n.d.). Indeed, in Nepal, three-quarters of boys with disabilities and only half of girls with disabilities were even aware of the changes that occur during puberty (Rana et al., 2008). Boys' greater knowledge appears to be related to their greater exposure to non-familial sources of information. They were, for

 I was shy at the beginning and scared but my mother supported me; she told me my husband is now my partner. She also told me about sexual intercourse and the blood I will have during the first intercourse. She gave me strength and I even knew more than my ex-husband though he is 30 years old, thanks to my mother.

(19-year old divorced girl, Gaza)

example, more likely than girls to learn from friends (60% vs 46%), school (29% vs 18%) and the media (11% vs 4%) (ibid.). Kassa et al. (2016) found a similar pattern in Ethiopia, where only 40% of girls with disabilities, compared to 60% of boys with disabilities, had heard of a sexually transmitted infection or of an SRH service.

Furthermore, while not age-disaggregated, on a global basis, evidence suggests that women with disabilities are 10 times more likely to experience sexual abuse than their peers without disabilities (UNFPA, 2016), with anecdotal reports in many locations suggesting that adolescent girls with intellectual impairments are at the highest risk (Tanabe et al., 2015). Girls and young women are also more vulnerable to emotional manipulation. Research has found, for example, that in South Africa, young women with disabilities often make choices based on 'their need to be loved and accepted', rather than on factual knowledge about sexuality and sexual risks (Wazakili et al., 2006). Rwandan and Ugandan girls with impairments reportedly feel less confident to ask a partner to use a condom compared to their peers without disabilities (Yousafzi and Edwards, 2004). This leaves them at heightened risk for HIV (FST, 2016). In Rwanda, while the national incidence of HIV stands at 3%, among people with impairments it is 3.5% (CRPD, 2015).

## Access to WASH services

In terms of access to WASH facilities by girls with disabilities, a 2009 UNICEF study on equity in sanitation in India found that adolescent girls with disabilities were among the most disadvantaged (see also Narayanan et al., 2012). This is partly because they may face a high risk of attack and abuse when using communal latrines, especially before dawn or after sunset.

## Access to nutrition

As with access to health care, gender can shape access to healthy food – for adult women and girls alike (Groce and Paeglow, 2005; Groce et al., 2013; Groce et al., 2014). For example, in India, Mohapatra and Mohanty (n.d.) found that only 40% of women with disabilities are afforded the opportunity to eat together as a family – implying that most eat alone after their families have finished eating. In Rwanda, Plan (2013) found that girls with disabilities were more likely to experience malnutrition than boys with disabilities and girls and boys without disabilities. Similarly, in Turkey, Nogay (2013) also found that among adolescents with intellectual impairments, girls were more likely to be stunted than boys.

### Box 2.8: Gender norms and their influence on puberty and SRH experiences in Gaza

In Palestine, GAGE's qualitative work found that while boys sometimes struggled with the changes that their bodies underwent during puberty, they were overall positive about the experience because being seen as an adult gives them license (in Palestine's age hierarchical culture) to fight back against those who bully them for their disabilities. A 19-year-old boy with spina bifida told us,

*'I was very happy because I became an adult and I became mature. Children with disabilities are exposed to many insults from people, but when they become older, everybody start to respect them. Now if anybody tried to insult me, I know to deal with him because I became an adult not a child anymore.'* A 19-year-old boy with a physical impairment acquired through an accident agreed that even though *'the best pros from reaching your puberty that family and community stop dealing with you as a child and they start to look to you as an adult'*, it had taken time for him to *'accept those changes'* because he had been *'happy with my smooth voice and my body shape when I was younger'*.

Palestinian girls, on the other hand, were more distressed about puberty – in large part, agreed both girls and boys, because of the restrictive social norms that shape girls' experiences. For girls, puberty education involves clear guidelines not only about the changes their bodies are undergoing, but about the behaviours they must change. A 17-year-old girl with Down syndrome told us that she had learned that getting her period meant that she was *'no longer young'*, she had *'become a woman like her mother'*, which required that she *'be polite and wear a hijab'* and *'not tell anyone that I have my period because it is a private thing that girls should keep confidential'*. A 19-year-old with a physical impairment explained that her teachers had taught that *'there are many changes in our life happen after puberty'*. Girls were taught to *'protect our bodies'*, *'don't talk with strangers'*, *'stop playing outside with boys'*, and to *'start using wide clothes to cover our body and wear the head cover'*. She added that she was so distraught by these restrictions that she *'refused to head cover directly when I got my period'*. Boys also spoke of the tight restrictions facing girls after puberty. A 19-year-old with spina bifida, who explained how free he felt to be becoming an adult, told us that he missed being able to talk to his female cousin, even though he understands that she had to stop speaking to him *'after puberty as I have sisters and I would not accept any male even from cousin contact with my sisters'*.

Two of the girls we interviewed had already been married, apparently due to their parents' insistence, and several adolescents reported being related to (or knowing) boys who had married, at their own insistence, as adolescents. A 19-year-old boy told us that his younger brother was already married and that while his parents had tried to refuse, *'they had to accept later when he tried to burn himself'*. Another boy reported that his classmate was engaged, *'but his family would not let him get married till he becomes 19 years old'*.

The two married girls in our sample had both received some minimal level of preparation for marriage, though the 19-year-old with a hearing impairment noted that her husband was more prepared than she was because *'he used the internet and watched several movies'*. Both reported that their mothers and sisters had told them what to expect on the wedding night. One – divorced after only two months – told us, *'I was shy at the beginning and scared but my mother supported me; she told me my husband is now my partner. She also told me about sexual intercourse and the blood I will have during the first intercourse. She gave me strength and I even knew more than my ex-husband though he is 30 years old, thanks to my mother.'*

The other, who told us that her sister had explained pain and blood and told her *'not to be scared and not to cry'*, highlighted exactly how minimal *'marriage education'* can be. While she is pleasantly surprised at how good her marriage is after the first year, given that before marriage she *'thought that marriage is very difficult and that I would go through many challenges'*, she also explained that she has *'hard time at night because I still feel great pain when we have sex... He is too violent with me during sex and I can't say anything... It is family issue that should remain confidential.'* Indeed, her marriage education, rather than arming her with skills or providing her with resources, seems to have engendered resignation. *'My father told me that men liked to have sex, and that's why I endure pain.'* After first saying that she saw no point in going to *'institutions'* for support, when she had family to help, she later admitted that *'separate discussion and awareness-raising meetings should be conducted with women and men'* and that *'sexual violence is a possible topic and other fruitful and important topics about relationships'*.

## Experiences shaped by impairment type

Although the data is very limited, adolescents with some types of impairments may face special health care vulnerabilities. In some cases this is probably related to the more complex health needs of those with severe impairments (e.g. those that require special feeding protocols or have severe muscle contractures). In other cases, vulnerability appears to be related not to physical needs but to social and environmental barriers that preclude communication. For example, in Rwanda, Plan (2013) found that children with visual and hearing impairments were especially likely to have had a serious illness in the past month – compared not only to children without disabilities, but also to children with other types of impairments. In Palestine, Jones et al. (2016) found that children with multiple impairments and hearing impairments had the most ‘sick days’ over the course of the past month, at 6.3 days and 6 days respectively. The figures were much higher than for children with difficulty remembering and concentrating (3.7 days) or children with intellectual impairments (3.6 days).

### Access to primary and disability-specific health care

The factors that drive these differences in health outcomes appear to vary. In Nepal, research has found that the absence of sign language interpretation and other adaptations limits the uptake of health services among people with hearing impairments (NFDN, 2013) and there are few public treatment options for those with intellectual impairments (Norad, 2012). In Rwanda, children with intellectual impairments are significantly less likely to be insured than either children without disabilities or children with physical impairments – perhaps because their parents are unaware of what supports exists (Abbott, 2013).

In Palestine, Jones et al. (2016) found that impairment type is linked to less favourable outcomes in a range of areas. For example, children with multiple impairments (82%) and intellectual impairments (80%) are less likely to have received all their vaccinations on schedule compared to children with hearing (100%) or visual (95%) impairments. According to parents, this is primarily because children with multiple and intellectual impairments are much less likely to have access to a school-based vaccination clinic (because they were not enrolled). On the other hand, children with visual and hearing impairments are the most

likely to need – and to have not received – assistance to purchase assistive devices such as hearing aids and Braille readers. Children with visual impairments were found to have the worst access to appropriate rehabilitation services. Only one-quarter of children (or their parents) reported that it was ‘not difficult’ to access services, compared to 45% of children with hearing impairments and 65% of children with multiple impairments. Jones et al. (2016) also found that stigma on the part of providers is often far more severe for those with intellectual, rather than physical, impairments – and that families of children with intellectual impairments are most likely to report that they needed health insurance for their child but had not received it. Nearly 20% of parents reported that they still needed health insurance for their child with an intellectual impairment, compared to only 3% of parents with a child with a hearing impairment. Unsurprisingly, parents of children with intellectual impairments reported that their families were especially likely to experience financial problems due to the costs of meeting the child’s needs.

### Access to SRH information and services

While evidence is nascent, it appears that some impairment types have greater impacts on access to SRH information and services. Some of these impacts are driven purely by the physical aspects of disability. Dickson et al. (2018), for example, observe that puberty often occurs early in girls with cerebral palsy but may be delayed for girls on the autism spectrum. They also observe that good menstrual hygiene may be more difficult to achieve for girls who have some types of physical and learning impairments, who may be incontinent, lack required mobility, or have difficulty understanding. Other differential impacts are driven more by the stigma of parents and providers.

Overall, the literature suggests that girls and young women with intellectual impairments have the least SRH knowledge and are the most vulnerable to abuse, discrimination and stigma – including forced contraception, sterilisation and abortion (Braathen et al., 2017; Frohmader and Ortoleva, 2013). While girls’ lack of knowledge is largely due to that stigma and discrimination – which also includes beliefs that they are especially likely to be ‘overly sexual’ (Frohmader and Ortoleva, 2013: 5) – it is also due to over-protectiveness on the part of their parents, who are simultaneously trying to legitimately keep their daughters safe as well as guard family honour. UNFPA (2009) also noted that girls with intellectual impairments

need information that is carefully tailored to their capacity – something which is all too often not available in Southern contexts (see below for an important exception, run by Community Based Rehabilitation Network Ethiopia).

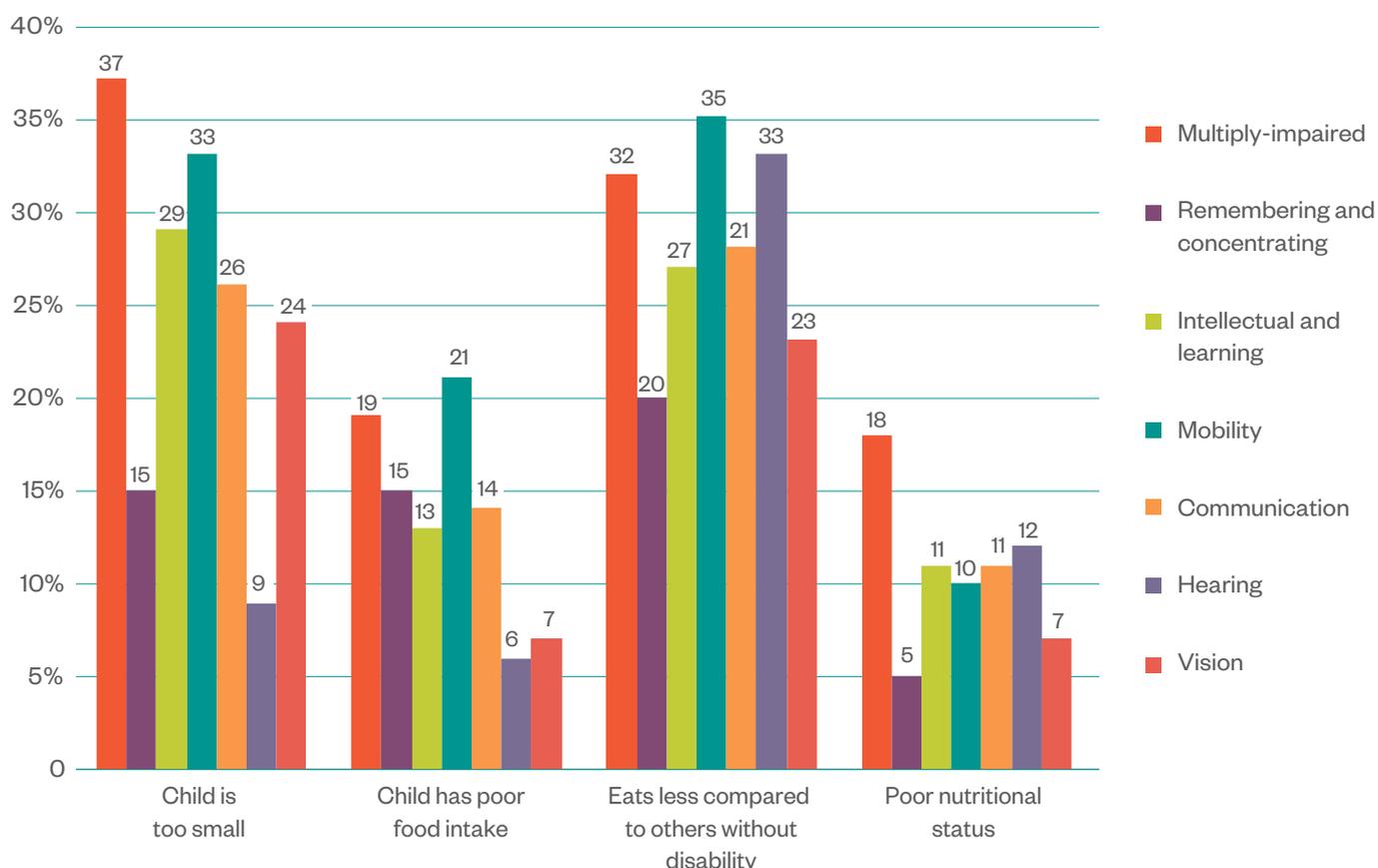
### Access to nutrition

Children and adolescents with different impairment types can face very different nutritional vulnerabilities. In terms of undernutrition, Jones et al. (2016), working in Palestine, found that children with multiple impairments tended to be considered 'too small', to have 'bad' food intake, and to have 'bad' nutritional status more often than children with single impairments (see Figure 2.2). Children with physical impairments were also often seen by their parents as poorly nourished. While not solely related to nutrition, children with multiple impairments were far more likely to be considered by their caregivers to have bad overall growth and development – 26%, compared to only 5%

for those with visual impairments and 3% for those with hearing impairments.

Although research and policy has tended to focus on the risk of undernutrition, adolescents with some impairment types may be at risk of becoming overweight. While we were unable to locate any research from LMICs that addressed this topic, it is well documented in Northern contexts and, given rising rates of obesity among children and adolescents in developing countries (WHO, 2016), is likely to hold true in LMICs as well. For example, Rimmer et al. (2011) found that adolescents with physical and intellectual disabilities have obesity rates approximately one-third higher than their peers without disabilities. Similarly, Grondhuis and Aman (2014) found that young people with developmental disabilities are so much more likely to be overweight and obese than those without disabilities that they issued a 'call to action' for health professionals to prioritise nutrition and weight management.

Figure 2.2: Parents' report on child's nutrition, by impairment type, Palestine



Source: Jones et al., 2016



## Experiences shaped by context

Across LMICs, people with disabilities in rural areas have less access to health care services and information than their urban peers. Those living in conflict-affected and humanitarian contexts, especially refugees, generally have the least access of all.

### Access to primary health and disability-specific health care

For people with disabilities who live in rural areas, access to care is shaped by a number of factors. Rural facilities are less likely to be physically accessible, and healthcare providers in rural areas may be less likely to have had training on disability. Access to disability-related care is especially limited for people in rural areas because those types of specialised services are typically only available in urban centres. Indeed, our qualitative work in Ethiopia, where Tekola (2016) notes that services for autism are almost entirely confined to Addis Ababa, highlighted that people with disabilities living in towns outside of regional capitals or Addis Ababa struggled to access specialist care. Spatial inequalities are also borne out

by other research. For example, in India, only 6% of villages had access to rehabilitation services within 10 km (WHO, 2012) and in Jordan, while there are specialised disability diagnosis centres in cities (including Amman and Karak), these are generally absent in rural areas (UNICEF, 2007). In Nepal, health care and rehabilitation facilities are largely centralised at the national and district levels, and assistive devices are largely unavailable in rural areas as there are typically only one or two technicians per district (Lord et al., 2016). This is also the case in Bangladesh, where Huq et al. (2013) found that distance, cost, and stigma mean that even devices such as hearing aids are difficult for rural residents to access.

Unsurprisingly, in humanitarian contexts, people with disabilities also tend to have particularly limited access to both primary care and disability-specific care. In Lebanon, for example, there are no governmental medical institutions that offer specialised services for people with disabilities, owing to the legacy of the civil war (UNESCO, 2013). Private institutions are under strain, as they are struggling to serve the Lebanese population as well as cope with the influx of refugees from Syria (Berghs and Kabbara, 2016). Indeed, UNHCR (2016) observed that

**Families focus more on the ones without disability. They think that those with disabilities are not wise and they can threaten family honour.**

(Key informant from UNRWA, Palestine)

the needs of refugees with disabilities are scarcely met at all. They are not granted access to private specialised services on the same basis as Lebanese nationals, and the emergency nature of the humanitarian response means that health centres are only able to cover urgent life-saving procedures and do not offer longer-term rehabilitation (WRC, 2013). With only 5 health centres and 12 doctors per 100,000 refugees, supply cannot meet demand (UNHCR, 2016; Sayrafi, 2013). Some refugees report paying for surgical and rehabilitation services from their own funds (Pearce, 2015). Moreover, Nour (2005) estimated that 20% to 30% of disabilities could have been cured if treated early enough, and UNHCR (2016) noted that living conditions in

refugee camps have been connected to health problems that cause disability.

## Access to SRH information and services

Humanitarian settings limit girls' and women's access to SRH care and WASH, and can have significant impacts on their SRH outcomes. While impacts are probably multiplied for those with disabilities (Frohman and Ortoleva, 2013), evidence is effectively non-existent – in large part because girls and women with impairments are often excluded from research. For example, Schmitt et al. (2017), who examined menstrual health hygiene management challenges faced by displaced women and girls in Lebanon and Myanmar, specifically excluded people with disabilities from their analysis.

We found only a few studies that examined the SRH needs of refugee adolescents with disabilities (see also Box 2.9). The broadest, led by the Women's Refugee Commission (WRC), included nearly 90 adolescents with

### Box 2.9: Palestinian adolescents' mixed access to SRH information

In Palestine, as in many LMICs, most adolescents with disabilities have only limited access to SRH information and services. Part of the issue, as reported by a key informant at the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), is that *'frankly, adolescence period is a weak area in health care provision. They are not clearly defined in any specific programmes except in condition if the adolescent is married or has chronic disease'*. This is compounded, by the reality that *'the SRH topic is taboo... There is no single place that is adolescent friendly, that provides information, counselling and answers adolescents' enquires related to their SRH needs.'* (Service provider, Gaza)

Even within Palestine's limited service framework, however, key informants agreed that adolescents with disabilities are the most likely to fall through the gaps: *'Their rights to know are ignored and undermined by all, including by service providers.'* (Service provider, Gaza) Another provider noted that *'Adolescents are mostly outside of school when they are older than 12... Given that sexuality education is not offered to students until at grade 8 (16 years), this means that children with disabilities are largely shut out of even the limited school-based classes which are taught by teachers who are "not qualified to talk about these issues" because they are "embarrassed"... Associations dedicated to persons with disabilities don't provide information about sexual and reproductive health.'*

Parents often provide too little information, according to a key informant from the Atfaluna Society for Deaf Children. They are 'afraid' and 'underestimate children with disabilities' needs and desires'. A key informant from UNRWA agreed: *'Families focus more on the ones without disability. They think that those with disabilities are not wise and they can threaten family honour.'*

While married adolescent refugees can ostensibly access SRH services through UNRWA clinics, key informants agreed that this was likely to be difficult for many of those with disabilities. Indeed, a key informant at UNRWA admitted that the organisation does a very poor job at providing SRH care to adolescents with disabilities: *'No specific package of services is available about disability. At clinics, we don't talk about these SRH issues at all. We don't.'* As well as failing to provide adequate information, UNRWA services are poorly adapted to the needs of those with disabilities: *'Health facilities are not adapted. Like most antenatal care units are in second or third floor, with no elevators. Also, how many of the staff can use the sign language? We don't have health material printed for people with vision impairment.'*

varying types and degrees of impairment living in refugee camps in Kenya, Nepal and Uganda (it also included over 200 adults with disabilities as well as 65 caregivers) (Tanabe et al., 2015). It found that in-school adolescents in Kenya had better knowledge of SRH, and that refugees who were isolated in their homes had especially limited knowledge. It also found that provider attitudes were the single largest barrier to care – with girls and women with disabilities who became pregnant discriminated against and scolded. Adolescent girls were at especially high risk of sexual violence, with some in Nepal wary of entering into a romantic relationship for fear that they might be exploited.

## Evidence gaps

We know very little about the health care needs and experiences of adolescents with disabilities in the global South. While it is clear that their access to information and services is restricted compared to their peers without disabilities, there is very little research that speaks to gender differences, and almost no evidence that addresses age differences, differences by type and

severity of impairment, or how parents, providers and systems might be supported to deliver better care even in low-resource settings. Because of the way that people with disabilities have been historically sidelined in research – or viewed through a lens which emphasises disability rather than focusing on a ‘people first’ rights-based approach – existent evidence on adolescents’ health and health care is so thin and fragmented that only the contours of need are yet visible (see Table 2.1).

## Promising practices

Efforts to improve health care for adolescents with disabilities in LMICs are nascent compared to efforts to improve education. While some countries provide free health care or free health insurance for people with disabilities, and others are scaling up – usually with the help of NGOs – their efforts to provide disability-specific care or to address SRH deficits, our research suggests that overall, broad health policy statements are being poorly translated into practical progress for adolescents with disabilities.



An adolescent boy, with a hearing impairment, with his father, Ethiopia © Nathalie Bertrams / GAGE 2018

**Table 2.1: Evidence gaps on health, sexual and reproductive health and nutrition among adolescents with disabilities**

	Health	SRH	Nutrition
<b>Broader gaps</b>	The role of poverty, parental and health care provider attitudes towards impairment in shaping adolescents' access to health care and health outcomes is unknown. We do not know whether adolescents and younger children with disabilities experience different access to services and information or whether children with disabilities' poorer access and health outcomes tend to improve or worsen as they move through adolescence.	Research has largely failed to address the experiences of adolescents with disabilities vis-a-vis sexuality - including how and what they learn about puberty, menstruation, and healthy relationships. We also know very little about their access to and experiences with SRH services.	It is unclear whether the poorer nutritional outcomes of adolescents with disabilities are due to parents' underfeeding their children or whether it is because disability makes it inherently more difficult to ensure adequate nutrition for some young people.
<b>Gender-specific gaps</b>	It is unclear to what extent gender differentials in health outcomes and access to health care are driven by parental preference for sons versus gender norms that restrict girls' and women's mobility and interactions with male medical staff.	Although researchers note that girls with disabilities tend to have worse access to SRH services than boys, it is unclear what this means given that boys rarely seek SRH care.	We do not know why girls are less well-nourished. There also appears to be no research that looks at the nutritional outcomes of adolescent girls with disabilities specifically, which – given that they are approaching childbearing years – is a significant lacuna.
<b>Gaps regarding impairment type</b>	There is some minimal evidence that those with intellectual impairments tend to fare the worst in terms of access to health care, but research is nascent and we do not understand what might drive this difference.	There is some evidence that those with intellectual impairments fare worse than those with other types of impairments, but evidence is too thin to draw conclusions.	Research has apparently not addressed how different impairment types may have different impacts on feeding practices and nutritional outcomes.
<b>Context-related gaps</b>	There is comparatively strong evidence that access to impairment-responsive health care and health outcomes are worse in rural and humanitarian contexts, albeit largely limited to smaller studies undertaken by NGOs.	There is no evidence about how different contexts impact SRH care and outcomes for adolescents with disabilities. Indeed, little is known about impacts on people with disabilities more generally.	There has apparently been no research aimed at exploring how different contexts might have different impacts on the nutritional outcomes of young people with disabilities.
<b>Policy and service gaps</b>	There is minimal evidence of policy and programme impact. Indeed, outside of NGO-led demonstration projects, which are often small but effective, little research has addressed how best to scale up services in either developmental or humanitarian contexts.	The barriers preventing adolescents with disabilities accessing SRH care are largely unexplored, let alone how those barriers might be overcome.	While there is good evidence that different types of nutrition interventions can reduce impairment, there appears to be no evidence about what works to improve the nutrition of young people with disabilities.

## Primary health care

Adolescents with disabilities are first and foremost adolescents. While they tend to require less preventive and curative care than younger children, they still need vaccinations and periodic check-ups and are prone to a range of injuries that may need treatment. Evidence suggests that young people with disabilities are less likely to have access to even the day-to-day treatment needed to support good health. Barriers to accessing care include cost, poorly adapted physical infrastructure, and the stigmatising attitudes of health care providers and even the adolescents' own parents (WHO and World Bank, 2011).

Some LMICs provide subsidised or free health care or health insurance for people with disabilities (see Box 2.10). For example, the 2011 Persons with Disabilities Act of Sierra Leone entitles every person with disability to free medical services in public health institutions (ACPF, 2014). Similarly, the 2003 Kenyan Persons with Disabilities Act requires the government to provide essential health services to persons with disabilities at an affordable cost. Rwanda, the Central African Republic, and Burkina Faso have similar legislation (ibid.), as do Jordan and Lebanon. Lebanese Law 220/2000 mandates the provision of full

medical coverage to all people with disabilities (Lebanon Ministry of Health, 2016).

Dismantling the barriers that make it difficult for young people with disabilities to access primary care requires collaboration with health care providers and close attention to local realities. This is the approach taken by the Nepali NGO, National Disabled Women's Association (NDWA) (NDWA, 2018). Working with service providers to identify the health care needs of women and children with disabilities, NDWA aims to help providers not just to plan for inclusive care but also to implement it. It offers a wide range of solutions, from infrastructure adaptations and the provision of personal assistants (including interpreters), to counselling and mobile services. Its work covers all elements of good health, including information, direct medical services, and the provision of medication, but it is difficult to discuss effectiveness as its programming does not appear to have been evaluated.

The Dutch NGO Karuna Foundation is working to improve access to primary care in Nepal, with the ultimate goal of preventing disability through better nutrition and better uptake of health care (Karuna, 2018; Brandt, 2015). Launched in 2011, and apparently not yet evaluated, Karuna's Inspire2Care and Share&Care projects target

### Box 2.10: Promising practices in Palestine

Some LMICs are improving access to health care for people with disabilities by providing free medical services or health insurance; Palestine provides both. Under the 1999 Disability Law, people with disabilities are guaranteed free health insurance, as well as access to a wide range of community-based rehabilitation services. They are also legally entitled to assistive devices, with no more than a 25% co-payment. While research has found that young people's access to assistive devices is extremely limited, and that health insurance does not go far enough towards making health care affordable – mainly because it does not cover disposables such as nappies or transport to and from clinics – it has also found that parents and adolescents are very appreciative of the free care they receive. The father of an adolescent girl with a physical impairment reported:

*'The health insurance is important for my daughter, with this insurance we could do the surgery for one of her legs, and any time she is ill we send her to a doctor and the health insurance cover the fees.'* A key informant from the National Society for Rehabilitation added, *'One day, a CT [cash transfer] beneficiary told me "I spend a lot of money buying medications". He wasn't aware about health insurance and finally he got it and saved that money for something else.'*

While insurance is provided by the government, specialised rehabilitation services are almost exclusively provided by national NGOs. The Princess Basma Hospital for Children with Disabilities is the only national-level centre that primarily targets children. It provides comprehensive rehabilitation for children with physical impairments and autism, including offering an inclusive school and accommodation for parents. It also runs mobile clinics that provide early diagnostics in rural areas, trains local service providers, and offers support to caregivers. Another organisation, the Atfaluna Society for Deaf Children, meets the needs of children with hearing impairments. It specialises in early diagnosis and treatment and provides funding for hearing aids.

Source: Jones et al., 2016.



Two adolescent girls with hearing impairments, Ethiopia © Nathalie Bertrams / GAGE 2018

primary, secondary and tertiary prevention of disability by training local health care providers, strengthening local leadership, mobilising local funds, and promoting pregnancy registration, antenatal care, and screening and awareness-raising activities. They also aim to inspire communities to provide better care for children with disabilities. They help identify children with disabilities and develop individual rehabilitation plans to address their needs. They also actively promote equal rights for people with disabilities – including the right to education and employment – and work to reduce stigma.

In Ethiopia, there are recent efforts to upgrade the training of health extension workers (HEW) to sensitise them to disability and developmental delay. Since the programme's inception, in 2003, nearly 40,000 HEWs have completed a one-year training course that allows them to offer even the most rural communities an array of services ranging from vaccination to contraception. However, the basic HEW training package is far from comprehensive. It includes, for example, no training on mental health or developmental disorders (Tilahun et al., 2017). This means that the vast majority of children with neurodevelopmental disabilities such as autism have no access to a health care provider who has been sensitised to their needs.

The Ministry of Health and the Open University have recently partnered to address this gap, developing a Health Education and Training programme aimed at upgrading the skills of HEWs. A recent evaluation, which compared the basic HEAT training (which includes a single session on child development and child mental health) to training that also includes a video on developmental disorders and a mental health 'pocket guide', was found to be effective at reducing provider stigma and also encouraged positive thinking about the potential for developmental progress. Specifically, HEWs who completed the training were much less likely to believe that children with autism needed to be chained up at home and more likely to think that they could develop language skills with the right help. While a key outcome of the training project is developing a cadre of health care providers who can provide non-stigmatising care, the researchers who evaluated the project also noted that it has significant potential for improving the psychosocial wellbeing of people with disabilities and their families, because it allows HEWs – who are already heavily engaged in community outreach – to raise awareness about disability and begin to reduce community stigma.

### Disability-specific health care

Any list of promising practices supporting access to disability-specific health care in LMICs must begin with CBR, which was developed by the World Health Organization (WHO) and aims to enhance quality of life for people with disabilities and their families in low-resource environments. We know that the CBR model is widespread in Southern countries, including Ethiopia, Nepal, Palestine and Rwanda. We know how CBR works – by leveraging existing resources, including people with disabilities, their families, and government and NGO providers, who deliver health, educational, vocational and social services (WHO, n.d.). We know that CBR focuses on all aspects of health – including promotion, prevention, medical care, counselling and rehabilitation (Rahman, 2018). We also know that CBR improves the clinical outcomes and daily functioning of people with disabilities (Iemmi et al., 2016). What we do not know, however, is whether CBR works to improve the health of children and adolescents with disabilities. Iemmi et al.'s (2016) review found only one study that evaluated the impacts of CBR on young people. That study, which focused on children with intellectual impairments in Viet Nam and was an educational intervention, found no impact after one year (Shin et al., 2009).

Another approach to scaling up access to disability-specific care involves bringing that care to locations outside of the largest cities. Bangladesh, for example, has a large network of regional centres that provide disability-specific care to children and adolescents. Child development centres (CDCs) represent one of the first movements in this regard. They were launched by the Dhaka Shishu Hospital in 1992 and have been replicated in more than two dozen hospitals. Aiming to prevent disability but also to optimise the development of children with disabilities, CDCs are staffed by teams (including medical doctors, psychologists, speech and language therapists, physiotherapists, and disability affairs officers) and provide diagnosis and management of a range of neurodevelopmental disorders in children under the age of 17 (Khan et al., 2017). An evaluation has found that the CDCs based in government hospitals are primarily serving the poor and are delivering significant improvements in outcomes for children with disabilities (Khan et al., 2017). More two-thirds of children using CDCs were found to have improvements in their functional skills, adaptive behaviours, and cognitive function (ibid.). Jatiyo Protibondhi Unnayan Foundation's (JPUF) 'one-stop centres' are also bringing

disability-specific care into smaller urban areas, albeit with no specific focus on young people. With World Bank support, 68 centres were set up between 2009 and 2013. As well as providing early diagnoses, each offers physical, occupational, and speech and language therapy; hearing and vision tests; and assistive devices and mobility aids – all free of cost (UNICEF Bangladesh, 2014; CRC, 2014). In 2014, it was estimated that the one-stop centres had already reached more than 100,000 people (ibid.).

The Bangladeshi government is working to bring disability-specific health care to more remote rural communities. For example, it is expanding CDCs across the country, using a tiered system of home-based screening, community- and clinic-based functional assessment, and CDC-based diagnosis, support, and referral (Khan et al., 2017). To ensure that autism is diagnosed in a timely manner, the government is training community health workers and has begun a pilot project on screening and early detection in community health clinics. It also recently completed piloting of home-based screening of autism and neurodevelopmental disabilities in children from birth to nine years in seven sub-districts around the country. Related to this pilot, the Ministry of Health and Family Welfare has also provided some training and awareness-raising for parents and caregivers of children with autism and other neurodevelopmental disabilities (UNICEF Bangladesh, 2014).

In Ethiopia, there are similar disability-specific health care outreach services but they are on a much smaller scale and led by NGOs. For example, Light for the World is among the major actors in the country's 'eye health' sector, supporting 28 units at primary level, 13 units at secondary level, and 2 units at tertiary level (Light for the World, 2018). Cheshire Services also works in Ethiopia, serving young people with a range of conditions, such as club feet, cerebral palsy and learning impairments (Cheshire Services Ethiopia, 2018). Their teams – which include physiotherapists, orthopaedic technologists and social workers – offer mobile outreach services in some rural areas. Teams also provide follow-up services for children who have been discharged from rehabilitation centres, monitoring their care and replacing worn-out walking aids and devices.

### Sexual and reproductive health care

Adolescents with disabilities, like their peers without disabilities, require access to sexuality education that helps

## Box 2.11: SRH programming in Palestine

Our research in Palestine found that even in socially conservative, conflict-affected environments, there are some avenues where adolescents with disabilities have access to some information, and which might provide lessons for scale-up. A number of the adolescents we interviewed in Gaza reported having received surprisingly thorough education about SRH in their classes at mainstream schools. A 19-year-old boy told us that counsellors had come to his classes in 7th, 8th, and 9th grade to discuss not only the physical side of puberty, but the emotional side. Boys were told that *'being aggressive'* could be a *'symptom'* of puberty and *'advised to try control our behaviours and to tolerate with our peers and avoid problems as much as we can till we pass that stage of our life'*. Another boy, also 19 and with spina bifida, told us that his religion teacher was very well-qualified and invited many questions. He had learned not only about nocturnal ejaculation and menstruation, but also that in Islam *'it is forbidden to describe any woman who has her period with dirty "Nijisa" like other religions do'*. Indeed, he had been taught that even if a woman *'might feel fatigue during her period, it does not mean to exclude her from the social life'*. He felt these classes to be invaluable, as *'tomorrow both genders will get married and each husband needs to have knowledge'*. A 19-year-old girl with a physical impairment noted that religious teachings had been important to her learning about puberty as well, since cleanliness *'is a merit of the religious faith'*.

Our research in Palestine also found that several NGOs are on the cutting edge of delivering SRH information to adolescents with disabilities. While programming remains small scale at this point, practices are promising.

The Atfaluna Society for Deaf Children, for example, is tackling adolescents' need for SRH education head-on. Acknowledging that the issue is *'very sensitive, requires heavy investment, strategic direction, and long-term intervention'* and admitting that *'we are being accused of destroying the cultural norms'*, a key informant was adamant that the *'topic is important'* because a lack of knowledge *'damages people's lives'*.

SRH classes offered at Atfaluna, which are only for those with hearing impairments and serve mostly adolescents – in a gender-segregated environment given the sensitivity of the topic – cover basics such as *'sexuality and menstruation and hygiene'*, but also offer engaged or married partners *'individual counselling to talk about everything'*. Adolescents' reactions to these sessions about sexuality describe them as *'great and funny'* and demand is growing rapidly. *'People with disabilities are stronger than before, they ask for information.'* Atfaluna – recognising that adolescents with hearing impairments can *'be easily deceived because the perpetrator thinks that the deaf can't talk about that or tell others when s/he is exposed to harassment, therefore they tend to sexually abuse them'* – has also developed a child protection policy and works to train staff and parents about how to protect their children.

The Aisha Association for Women and Child Protection is also engaging adolescents with disabilities about SRH. It offers sexuality education classes for children, including those with disabilities, and their parents. Age-segregated classes are available for young people aged 6–18 (e.g. 6–9, 10–13, and 14–18) and are divided into three modules. The first module is designed to teach children about puberty and covers topics ranging from physical growth to hygiene to mental health. It specifically discusses human rights. The second module covers the concepts of gender, gender-based violence (GBV), child marriage, and STIs. The third module focuses on the prevention of sexual violence. A key informant explained that while staff were initially *'afraid parents won't be interested because we are addressing sensitive topics... to the contrary, parents were interested'*. While Aisha's scale remains small, reaching only about 120 families a year with SRH education, their focus on adolescents with disabilities is notable due to outreach efforts that include both adolescents with physical disabilities and adolescents with intellectual disabilities, as well as their provision of *'other psycho-support sessions conducted for people with disabilities'*.

The Women's Health Centre in Jabalia is also working to improve access to SRH education for young people with disabilities. Noting that while the centre's mainstream SRH programming *'accepts and serves all types of disabilities... The problem is that they don't come... due to stigma and the costs of transportation'*, our key informant explained that the centre offers a class just for girls with intellectual impairments. *'We care about their health status including SRH, their hygiene, self-help, awareness, education, provision of hygienic kits; that programme is specifically developed for them.'*

 ‘We are being accused of destroying the cultural norms,’ a key informant was adamant that the ‘topic is important’ because a lack of knowledge ‘damages people’s lives’.

(Key informant from Atfaluna Society for Deaf Children, Palestine)

them understand how to care for their maturing bodies. When they become sexually active, they need access to SRH care so that they can protect themselves from sexually transmitted infections (STIs) and either prevent (or prepare for) pregnancy (see Box 2.11). As with primary care, however, evidence suggests that adolescents with disabilities have more limited access to SRH care than their peers without disabilities, largely due to stigmatising beliefs that people with disabilities are asexual.

In Rwanda, the NGO UWEZO Youth Empowerment, which was set up in 2013 to develop the capacities of youth with disabilities, provides in-school adolescents aged 10–14 with SRH education (UWEZO, 2018). Its Imbere Heza project in Kigali City uses drama, debates, art, and music to encourage young adolescents to develop ‘positive SRH practices’. It is also developing comprehensive and inclusive SRH manuals that can be used by teachers, community health workers, and parents to educate young people about sexuality.

Elsewhere, the Community Based Rehabilitation Network Ethiopia has partnered with Light for the World to target those with the greatest unmet need for SRH education: girls and young women with intellectual disabilities (CBRNE, 2016). They are working with CBR providers, health care providers, and parents, supporting them to develop the skills they need to discuss and teach girls and young women with intellectual disabilities about sexuality. The partnership grew out of the realisation that while CBR field workers are trained to work with persons with intellectual impairments, they are not trained to discuss sexuality and SRH, and while health extension workers are trained to disseminate SRH information, they are not trained on how to tailor their services to those with intellectual impairments. When developing teaching methods and messages, the organisations were careful to consider the large differences between girls in terms of how they take in, process and retain information. CBR field workers conducted follow-up visits and parents were also trained so that they could continuously reinforce messages.

The project, while small in scale, was reported successful by all types of participants. CBR field workers and health extension workers appreciated the opportunity to learn from one another about how to best organise and deliver SRH services for girls and young women with intellectual impairments. Girls and their parents also very much appreciated the support they received. As the mother of a 15-year-old girl with an intellectual impairment said:

*‘When she gets her period, she gets very angry, and this training has taught me how to handle that anger, how to help her wash her pants, to change the clean pads and stuff like that. I didn’t know how to handle all of that.’*

The Ethiopian Centre for Disability Development (ECDD) is also working to improve access to mainstream SRH services for people with disabilities (particularly girls and women) (ECDD, 2018). Tackling the demand side of the equation, it is working with disability support organisations to encourage people with disabilities to recognise their SRH needs and to access care. On the supply side, it is working with providers, including HEWs at health clinics and posts, to raise their awareness of people’s needs and how best to extend services to meet those needs. Cognisant of the fact that rates of HIV among people with disability are significantly higher than for the general population (4.5% versus 2.4% in Tigray regional state, for instance), ECDD has also been working to train health workers (in Addis Ababa and Oromia) in voluntary counselling and testing using sign language, so that services are more accessible to those with hearing impairments (Relief Web, 2012).

## Nutritional programming

While there is some evidence that children and adolescents with some types of impairments may be especially prone to malnutrition, there is scant evidence that the nutrition needs of those with disabilities are recognised in policy and programming. The most common programming approach aimed at the nexus of disability and nutrition is to prevent disability by ensuring adequate nutrition.

In Nepal, recognising that the links between nutrition and disability cut both ways, the government and NGOs are working together to improve nutrition for children, adolescents, and adults with disabilities and also working to prevent disability through micronutrient supplementation. Supported by UNICEF, the government’s Multi-Sectoral Nutrition Plan targets vulnerable children and women with disabilities (UNICEF, 2013c). Research undertaken to refine implementation highlighted the importance



An adolescent girl, with a hearing impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

of gender norms in nutrition outcomes. This has led to equity-focused and disability-friendly nutrition plans being developed. A nutrition surveillance working group has also been formed to track implementation progress and improve early detection of malnutrition. Coupled with the scale-up of community health workers – who have been trained in both nutrition and the early detection of disability – the government hopes to significantly reduce many of the leading causes of disability in children (e.g. deficiencies in vitamin A, iodine and iron) and ensure that children receive timely access to interventions that can mitigate the severity of any impairment.

In the Philippines, Stimulation and Therapeutic Activity Centres (STACs) have been set up in 14 regions by the NGO-led Breaking Barriers Project, providing a wide array of support to children with disabilities up to the age

of 15 (KAMPI, n.d.). While their main health care services are therapeutic and aimed at rehabilitation (e.g. physical and occupational therapy and the provision of assistive devices), STACs also provide supplemental feeding and medical and dental clinics, to ensure that children with disabilities are not malnourished and have access to primary preventive and curative care.

In Ghana, a small community-based parent training programme for caregivers of younger children with cerebral palsy improved feeding practices (ICED, 2017). The programme – which helped train (almost exclusively) mothers over the course of 10 months in how to provide adequate care for their children, as well as providing social support – also improved women's self-esteem, self-efficacy, and patience with their children.



### 3 Psychosocial wellbeing



## Psychosocial wellbeing

**Recommendation:** Provide age-appropriate guidance for parents, teachers, healthcare workers and social workers on how to support adolescents with disabilities psycho-emotionally and provide opportunities for peer interactions



Adolescents with disabilities experience social isolation and often feel stigmatised within their own households



**Bangladesh and Ethiopia:** GAGE survey data found adolescents with disabilities have **substantially different** psycho-emotional development test scores than peers without disabilities



Girls with disabilities are particularly likely to be isolated and lack psychosocial support, due to restrictive gender norms



Refugees with disabilities face high levels of exclusion from services and social isolation

## Key messages

- **Overarching challenges:** Adolescents with disabilities experience high rates of social isolation – and often feel stigmatised and unsupported even within their own households. As a result, they are more prone to depression, loneliness and poor self-esteem than their peers without disabilities.
- **Gender dimensions:** Girls with disabilities are more likely to be isolated and lack psychosocial support, due to restrictive gender norms. They tend to have lower self-esteem and happiness levels than boys with disabilities.
- **Context-specific challenges:** Refugees with disabilities face especially high levels of exclusion from services and are more likely to be socially isolated, partly because over-stretched budgets preclude outreach efforts.
- **Impairment-specific challenges:** Adolescents who are deaf appear to have especially limited psycho-emotional support from their families, because few parents can use sign language, those with the most severe physical impairments have the fewest opportunities to engage with peers, as many are confined to the home, and those with intellectual impairments may be at heightened risk of stigma and bullying from their peers.
- **Caregiver concerns:** Caregivers often lack information and guidance as to how best to support adolescents with specific impairment types. Caregiving responsibilities in the context of inadequate resources, support and services can also take a psychosocial toll on caregivers, and especially women who are typically the primary caregivers for adolescents with disabilities.
- **Evidence gaps:** There is very limited evidence on factors that support psychosocial resilience among adolescents with disabilities, the effects of psychosocial isolation over the course of adolescence and differential experiences by gender, impairment type and context.
- **Promising practices:** Access to quality schooling is critical to self-esteem and peer interactions. Other promising practices include community-based adolescent programming with peers with and without disabilities, such as clubs and sporting teams, social media and online platforms, and parent groups that provide information, guidance and emotional support for caregivers.

## Introduction

Psychosocial wellbeing encompasses adolescents' sense of self and ability to set their own goals and demonstrate resilience in the face of setbacks. It recognises the importance of both internal emotional capacity and external social support. Because social connectedness is central to adolescent wellbeing, adolescents who feel connected – at home, at school, to their friends, and to their communities – report greater wellbeing than those who are not connected, across a wide variety of metrics (Jose et al., 2012). Conversely, adolescents who lack close social ties appear to be at increased risk for mental ill health (Lamblin et al., 2017). While impairment does not shift this developmental imperative, evidence suggests that young people with disabilities are far more likely to be socially isolated than their peers without disabilities. Research has found that the primary driver of psychosocial ill-being for adolescents with various types of impairments is isolation and social exclusion driven by stigma and discrimination directed at people with disabilities (WHO and World Bank, 2011) (see also Box 3.1). Where cultural myths associate disability with sin or witchcraft (which is relatively common in some Southern contexts), social exclusion can be especially marked, as families often hide children at home to protect them from harassment and violence – and to preserve family reputation (ACPF, 2011; Ron-Balsera, 2011; Talley and Brintnell, 2015; DSPD, 2016; Bond DDG, 2017). As a result of this stigma and of resource constraints, access to psychosocial and mental health services is very limited.

There are also strong location-specific and gender dimensions to this social exclusion. Those living in rural areas generally face more stigma, while adolescent girls with disabilities are especially likely to be kept at home due to concerns about vulnerability to sexual harassment and abuse, and associated risks to family honour. In addition, primary caregivers (almost always mothers) are typically at risk of blame, social exclusion and (in some cases) abuse and/or abandonment as the result of the stigma facing their children with disabilities.

## Resilience and motivation

There is very limited evidence on the psychosocial wellbeing and mental health outcomes of adolescents with disabilities, especially for the most marginalised adolescents. An even smaller proportion of that evidence focuses on factors that shape adolescent resilience and motivation. In Jordan, for example, Peters (2009) found that young people are aspirational about their futures. In Ethiopia, despite stigma and shame, 80% of young people with disabilities reported believing that they will live independently and have a life equal to a person without disabilities (ACPF, 2011). Evidence suggests that in order to support young people with disabilities to develop resilience and motivation, access to school and to other opportunities for social inclusion is critical (see Box 3.2). A multi-country study of children and adolescents with disabilities in sub-Saharan Africa, for example, found that active involvement in family life and regular play with peers

### Box 3.1: GAGE survey findings on psycho-emotional development

The GAGE survey looked at adolescents' psycho-emotional development, using – among other tools – an international Personality Trait Taxonomy (John, 2008). It found substantial differences between adolescents with and without disabilities.

How to interpret the findings requires further exploration in Southern contexts. In Northern contexts, adolescents with disabilities have been found to lag behind their peers without disabilities in terms of psychosocial development (Maxey and Beckert, 2017). Their interactions with peers are more limited, which affords them less time to practice their social skills and fewer opportunities to evaluate relationships, they are more likely to be bullied, and they have less opportunity to develop autonomy and establish identity due to parental over-protectiveness (ibid.). There is also some evidence that particular impairment types can have 'profound' impacts on the development of personality, as repeated failures can lead young people to be less open to new experiences and more willing to look to others for solutions (Webb, 2014). Key, however, is not disability per se, but rather how young people perceive themselves and their abilities versus their disabilities (Top et al., 2013) There is also some existent work in low- and middle-income countries (LMICs) which has found that young people with disabilities have lower scores than their peers without disabilities in terms of the personality factors captured by various taxonomies, probably because of the daily stigma they experience, which leaves them lonely, bullied, and reminded on a daily basis of what they cannot do (Jabeen et al., 2016).



### Box 3.2: My determination and persistence have grown up with me

Shaima is a 19-year-old girl from Gaza's remote and marginalised Khazaa area. Quadriplegic since birth, due to spinal paralysis, she was further injured in the 2014 war with Israel, during which Khazaa was heavily bombed. Despite her impairments, however, Shaima is fiercely committed to her education and is now studying for a university degree in speech therapy. Facing down odds that at times seemed almost unsurmountable, Shaima reported that as she has grown up, her determination and persistence have grown up too.

Shaima's disability has made it difficult for her to get an education. Indeed, the director at her secondary school initially refused to accept her, because the school has three floors and no lift system for her wheelchair. But Shaima insisted, and her father adapted the school building himself. Even then, school was a struggle. She often arrived very late because of difficulties with transportation. *'Because I use a wheelchair 'drivers don't pick me up, they just ignore me at the taxi stations'.* Even worse, she added, other children taunted her and refused to be near her because of her disability. *'At school, I felt as if I was not a full human being. I cried many times as little support is provided by classmates and because teachers don't show sensitivity to disability'.* Shaima's grades were always excellent, despite the hostility she faced on a daily basis.

While Shaima's family finds it hard to make ends meet financially, because *'people with disabilities have extra expenses for medication, transportation and special equipment'*, they have always fully supported her dreams. Most importantly, explained Shaima, is that her family *'respects my opinion and consults me exactly the same as my other sisters'.* *Unlike most people with disabilities, she is not considered 'a source of shame' and hidden away to protect the family from community stigma. 'I am lucky that I have supportive family that cares a lot about me,'* she explained.

While Shaima knows that she is a *'strong, productive person who can be of high value to the community'*, she wishes that her fellow citizens understood her value, trusted her decisions and supported her independence. Indeed, now that she is at university, she is focusing her determination and persistence on mitigating the longstanding stigma directed at people with disabilities. *'I will graduate and become a specialist and help others. It is important to advocate for the weaker ones in the society.'*

improved children's outcomes. Respondents stressed that being accepted in peer activities and having friends that recognised their abilities, rather than their disabilities, helped them build their self-esteem (ibid.).

The bulk of the evidence on the psychosocial status of adolescents with disabilities focuses on the stressors that they face – and the negative impacts that those stressors have on them – including the fact that they appear more likely than their peers without disabilities to experience loneliness, stress, anxiety, depression, low self-esteem and poor body image (UNICEF, 2013a; UNICEF Innocenti, 2007; Hadi and Mutoni, 2012; Halder and Datta, 2012; Llewellyn et al., 2012; World Bank, 2013; Groce and Kett, 2014; Kodali and Charyulu, 2014; Bhatta et al., 2018). In Ethiopia, for example – where adolescents with disabilities can be both shamed and blamed for their impairments – sadness, anger, and despair are not uncommon (Fafchamps and Kebede, 2008; Moges, 2017), and up to 30% of young people with disabilities report that they are unhappy (ACPF, 2011). This is also the case in Palestine, where Jones et al. (2016) reported that only 40% of children with disabilities consider their lives enjoyable and 60% report having felt so bad in the past

month that they did not want to do anything. Indeed, only 15% of young Palestinians with disabilities said that they were happy with themselves the way they are. In India, Sahu and Sahu (2015) found that long-term exposure to discrimination and stigma leads to the internalisation of negative stereotypes among children with disabilities (see also World Bank, 2013). In Nepal, Burns and Oswald (2015) found that adolescents with disabilities feel that they are a burden on their families due to their dependence on others for day-to-day activities, while Bhatta et al. (2018) found that depression, anxiety and suicidal ideation are not uncommon.

### Family support networks

Family support is critical to adolescent wellbeing, regardless of whether adolescents have a disability. Our research, however, found mixed evidence about the level of support adolescents with disabilities received from their families (see Box 3.3). Some adolescents with disabilities reported close ties to their families. Others felt over-protected or ignored. In some cases, well-meaning parents keep their children with disabilities at home to protect them from bullying and verbal abuse (UNICEF, 2013b;

Burns and Oswald, 2015). In other cases, however, parents keep their adolescents with disabilities (particularly girls) socially isolated in order to protect the family, rather than the child, from disability-related stigma (Ron-Balsera, 2011; Groce and Kett, 2014; World Bank, 2013; WRC, 2013; Jones et al., 2016; Bond DDG, 2017). As well as isolating children with disabilities from their peers and broader community, research has also found that some parents fail to provide their children with adequate food and health care and

some are even abusive towards their child (ACPF, 2011; World Bank, 2013; Jones et al., 2016). Some children and adolescents are abandoned by their families – occasionally encouraged to do so by doctors who hold discriminatory views – leaving millions of children with disabilities around the world to languish in institutions where their physical and emotional needs are almost entirely ignored (UNICEF, 2013a; 2013b; Mrisho and Fakhri, 2016).

### Box 3.3: Mixed family support

Our findings indicated quite mixed levels of family support for adolescents with disabilities. In some cases, adolescents did not feel emotionally supported by family members, and this was a cause of considerable stress for them. A 17 year old Ethiopian girl who is deaf spoke negatively of the care she received from her parents: *'On one hand they (my parents) are economically poor and they didn't give support to me, on the other hand, in fact it is not the money that matters the most, but it is the thinking and the advice that I expect from them. They are too careless for me.'* An 18 year old girl with a physical impairment from the West Bank, on the other hand, felt that her parents did not recognise her abilities and need for independence: *'I do not like anyone to give me a special treatment or make me feel like I am a subject of pity. I am very competent, and I am not lacking anything. I feel that the thing that troubles me the most is that no one listens to me, like my father or my stepmother. I feel like I am nothing to them. I have nothing wrong with me. I feel like they treat me in a special way. The disability is in the mind, not the body.'*

In other cases, however, adolescents spoke very positively about the emotional support they receive from their parents – especially their mothers. A 17 year old Bangladeshi girl with a physical impairment told us, *'My closest friend is my mother and no one else. My mother is very good. She understands everything, even if I do not tell her. And I share everything with her'*. A 12-year-old Bangladeshi girl, who also has a physical impairment, explained that her relationship with her mother is similar: *'I share everything with my mother.'* Indeed, she added that sometimes she talks so much, even about 'cute' boys, that her mother says, *'I can't take any more of this!'*

A 15 year old boy, from Bangladesh and with a physical impairment, told us that he is particularly close to his uncle. *'He is very knowledgeable. He is very intelligent. He takes care of everyone. He leads an honest life,'* the boy explained. Most importantly, though, the uncle reminds him that his disability *'was done according to God's (Allah) plan,'* which makes him feel better about being different. He also loves that his uncle treats him as if he is not different and goofs around with him just like he goofs around his brothers. He excitedly told us that his favourite memory involves his uncle – and mud: *'After I fell down, my uncle helped me to get up and I smeared mud all over his clothes. We started laughing about it!'*

Some parents, against mostly mothers, also talked about the considerable lengths they go to in order to support the wellbeing of their children with disabilities, as these two examples highlight:

*'Once we thought it was something with my daughter's brain, but she invented a language for herself, she combined them both. That's what made me know that she is clever... There was many problems between me and the management of the school because of not allowing her to register in the school. Even after the school confirmed that she is capable, the Ministry of Education refused to register her... so I sat on the floor in the middle of the Ministry, and told them I am not leaving... Then after a while someone from the management told us we could register her but that a parent has to stay with her. So I go with her and my husband takes care of the other kids.. But then they started to cause trouble for me by saying you can't get in here or you are not supposed to be here... We had many problems with the school.'*

(Mother of a 10-year-old girl who is blind and deaf and a 13-year-old boy who is blind, Jordan)

*'When my daughter came into our life, I saw life differently. She made me open my eyes to another life, another experience...'* (Mother of 13-year-old girl who is blind, Jordan)

▮▮ I do not like anyone to give me a special treatment or make me feel like I am a subject of pity. I am very competent, and I am not lacking anything. I feel that the thing that troubles me the most is that no one listens to me, like my father or my stepmother. I feel like I am nothing to them.

(Girl with physical impairment, 18 years, West Bank)

In Nepal, Bhatta et al.'s (2018) recent research with adolescents with disabilities found that while supportive families are important to children's wellbeing, many adolescents feel completely unsupported and unvalued by their families. Similarly, in a multi-country study in sub-Saharan Africa, a significant number of adolescents with disabilities reported being excluded from family and religious events as a result of their impairment. Many were prevented from attending school by their families, and nearly a third felt that their impairment was causing fighting in the family (ACPF, 2011). In Ethiopia, where reported exclusion rates were the highest, one in five young people with disability said that they were never supported with

▮▮ When she came into our life, I saw life differently... But she [daughter who is blind] made me open my eyes to another life, another experience...

(Mother of 13-year-old girl who is blind, Jordan)

activities that were difficult for them, two-thirds reported that their family did not invest in their wellbeing because of their impairment, and one in eight were of the view that they had nobody in their household to turn to for support when they felt sad, upset or in need of advice (ibid.).

Contrary to assumptions, evidence suggests that better-educated, wealthier households may be more likely to hide or mistreat young people with disabilities than less-educated, poorer households. In Rwanda, for example, adolescents with disabilities in poorer households have been found to have more visible, active places in the family than their better-off peers – perhaps because poorer families simply lack the space to hide them (Karangwa et al., 2007; Lewis, 2009; Talley and Brintnell, 2015). Similarly, in Palestine, Jones et al. (2016) found that better-off households were more likely to hide their children with disabilities from public view, because they had more social standing to lose should their child's impairment become known.



## Social connectedness with peers and communities

Research suggests that adolescents with disabilities have far fewer opportunities to socialise with peers than do those without disabilities (ACPF, 2011; HRW, 2011; Ron-Balsera, 2011; Plan International, 2014; 2017; Talley and Brintnell, 2015; Jones et al., 2016; Heys et al., 2017; Bhatta et al., 2018) (see also Box 3.4). Most importantly, as was noted in Chapter 1 on Education and Learning, they are far less likely than their peers to be enrolled in school, which deprives them of hours each day in the company of age-mates (UNESCO, 2016; 2018; The International Commission on Financing Global Education Opportunity, 2017). Due to community beliefs about the causes of impairment, however, adolescents with disabilities are also more likely than their peers without disabilities to face social exclusion and verbal and physical violence when they are with those age-mates (WHO and

World Bank, 2011; World Bank, 2013) (see Chapter 4 on Bodily Integrity and Freedom from Violence).

In Palestine, for example, Jones et al. (2016) found that only 60% of children with a disability had had an opportunity to play with a friend in the past month. Only one-third had participated in any sort of sports activity. Indeed, the qualitative component of that research found that many children with disabilities are kept at home. Not only are there few organised recreational activities that

▶▶ **None of my cousins come to me and I can't go to them because I can't see and can't go alone. I sit only at the door and I don't go away. I just play close to my house door. If I go away, I will be lost.**

(Adolescent boy with a visual impairment, 11 years, Palestine)

### Box 3.4: Social isolation

While peer interactions are critical to adolescent psycho-emotional development, many adolescents with disabilities lack the opportunities to interact with peers without disabilities. In some cases it is a matter of stigma and exclusion at school, as these adolescents explain:

*'I don't play. I sit alone when it is break time. I sometimes study or read.'*  
(Boy with an intellectual impairment, 11 years, Ethiopia)

*'If there is no one to help me, I have to stay at home. I cannot move from place to place without the help of other people.'* (Boy who is blind, 10 years, Ethiopia)

*'I do not have friends. I do not tell anyone when I feel sad and have worries. I just keep quiet and sit.'*  
(Girl who is blind, 15 years, Ethiopia)

In other cases, adolescents' social isolation stems from exclusion from non-formal education and/or recreational activities and from social stigma in the community:

*'I went to school in Syria for two years and then stopped due to transport problems... Here, I have never been... I know only how to write my name. As for reading, I would like to learn... I have this tablet. I play games. I open YouTube a little then close it. I just look at, for example, Bab Al-Hara, Touq Elbanat [a Syrian series], things like that... [And do you watch it with anyone?] No by myself, of course... I wake up at 11am. I sit and use the tablet. I mean, there is nothing else. I watch TV, that's it.'* (Girl with physical impairment, 19 years, Syrian refugee in Jordan).

*'None of my cousins come to me and I can't go to them because I can't see and can't go alone. I sit only at the door and I don't go away. I just play close to my house door. If I go away, I will be lost.'*  
(Adolescent boy with a visual impairment, 11 years, Palestine)

*'I don't leave home much because I don't want to. I go to shops near our house alone but I don't want to go long distance alone. My father always tells me to go out with my mother but I really don't want to. They let me go where ever I want but I don't have places to go to.'* (Girl with a physical impairment, 16 years, Ethiopia).

*'I feel for not attending this type of social activities and not to play with friends on their way to migrate and also other plays that need you to be able to run fast.'* (Boy with physical impairment, 12 years, Ethiopia)

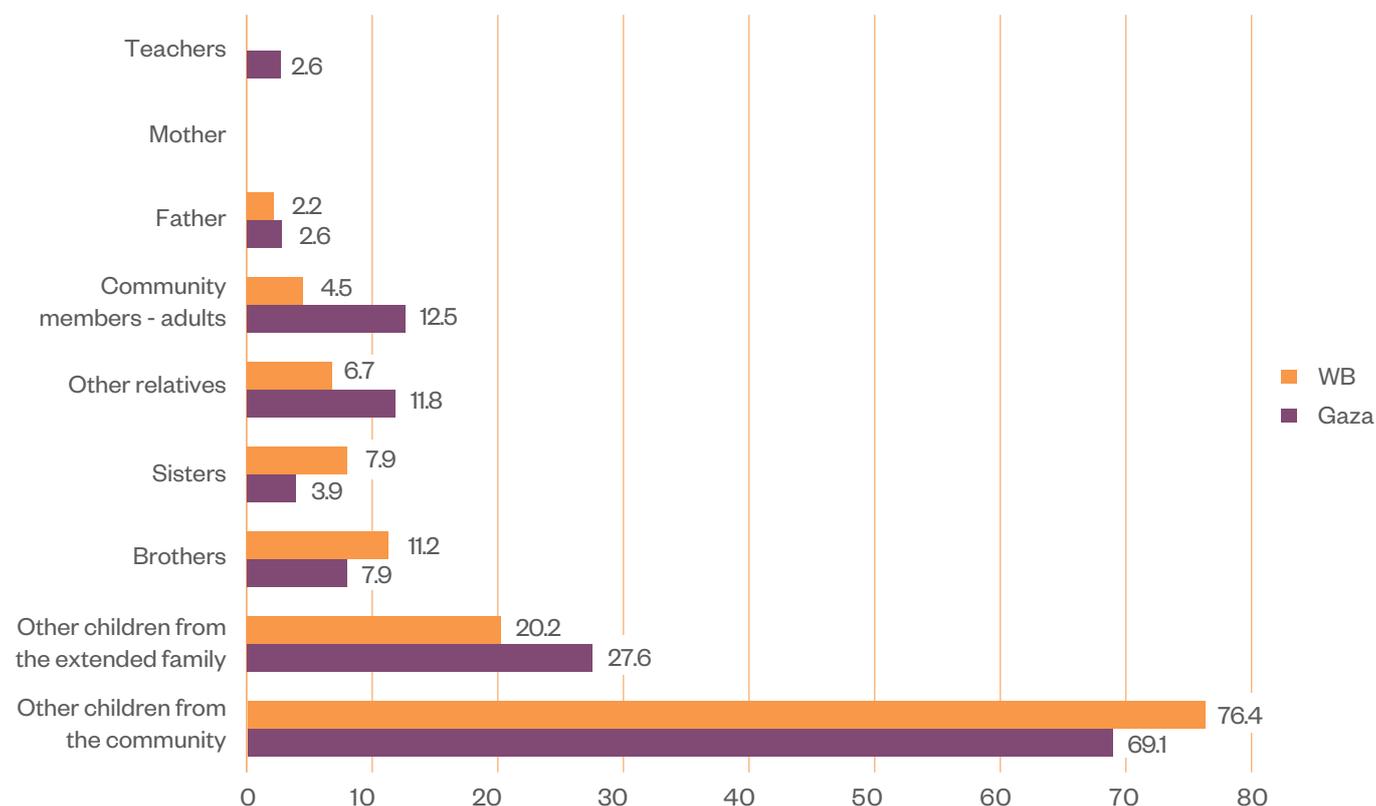
are inclusive, but because of the challenging physical environment, many children and adolescents with disabilities are unable to take part in the spontaneous activities that engage their friends. Adolescents who have visual impairments, for example, are not safe playing in the streets, and children with physical impairments often have no way to leave their apartments, which are typically multi-storey with non-adapted staircases.

Jones et al. (2016) also found that Palestinian children with impairments are kept at home by disability-related bullying and stigma. Specifically, they found that only 45% of Palestinian children with disabilities feel that their peers at school and neighbours are supportive of them, less than a third feel integrated into the community, and nearly 30% are called names due to their impairment – almost always by other children in the community (see Figure 3.1). More than 40% of Palestinian children who had dropped out of school reported negative attitudes from peers as the reason. Research with older adolescents and youth with disabilities in 12 LMICs found that young people with disabilities see the largest gains in their wellbeing when they are supported to join the broader community (which includes people without impairments) because it can help those with disabilities feel accepted and appreciated

(UNDESA, 2012). In Palestine, Jones et al. (2016) found that adolescents with disabilities also very much enjoyed activities tailored to their needs. Indeed, the qualitative research suggests that in terms of helping adolescents with disabilities feel good about themselves and their capacities, access to disability-tailored programming may be important – especially in environments where non-tailored programming is rife with discrimination.

The importance of access to peers also emerged in our research in Ethiopia, where previous work has highlighted the social exclusion that young people with disabilities face. One-third of the young people with disabilities in the Population Council’s Youth Survey, for example, reported that they did not make friends easily (31%). In addition, nearly half of the children with disabilities in the African Child Policy Forum’s (ACPF’s) (2011) research said that they sometimes or always felt socially isolated (45%). In our own qualitative work, adolescents with disabilities spoke of their enrolment in formal education as the event that delineated their lives into ‘before’ and ‘after’ – with many drawing bright lines around the support they received from their peers with and without impairments, usually highlighting that it was only around the former that they felt secure and supported (see Box 3.5).

Figure 3.1: Who calls you names?



Source: Jones et al., 2016

### Box 3.5: My friends became my source of hope

Our qualitative work in Ethiopia found that school enrolment was often the event that turned adolescents with disabilities' lives around. Young people who had been isolated and depressed told us that school provided them with mentors, friends and hope. Many told us that meeting other adolescents with disabilities had been critical to their wellbeing – because for the first time, they understood that they were not alone. This was also supported by the GAGE survey findings, which suggested that adolescents with disabilities are no less likely than their peers without disabilities to indicate that they have a friend that they trust.

An 18-year-old girl who is blind told us that before she started school she was *'psychologically depressed because I felt inferior to my colleagues'*. An out-of-school 15-year-old girl, who is also blind, explained that she spent her days alone, isolated with her own feelings: *'I do not have friends. I do not tell anyone when I feel sad and have worries. I just keep quiet and sit.'* A 16 year old girl with a physical impairment, when asked where her parents would allow her to go, replied that before school, *'I didn't have places to go to'*. A 16-year-old girl who is deaf told us that while her parents were overall supportive of her, before she met other children who are deaf and learned sign language, *'no one listened to me because I cannot communicate with individuals that listen. This meant I could not have someone to share the issue with.'*

For many adolescents with disabilities, going to school transformed their world. As an 18-year-old girl who is blind summarised: *'It is only when we are at school in the morning that we feel free'*. A special needs teacher further explained: *'In the past, disability students learned in a separate room and they faced segregation. The education system was not inclusive. Now, they learn in the same class inclusively. Now a sense of social and friendship is created. Students start to communicate together because awareness creation is done.'* Another teacher noted: *'Even after students with physical issues reach the gate, then the other students also carry them in their back to help them to reach the clas room.'*

The most important thing about special needs education, for the adolescents involved in our research, was the chance to develop friendships with other young people with disabilities. *'I used to imagine I am the only person that have problem of hearing. Now I do not stress myself like before,'* said a 16-year-old girl who is deaf. An 18-year-old girl who is blind concurred: *'I thought I was dead, but not anymore. After I started school here, I now believe I can be just like any other person. I am looking for the future than the past. After I saw how blind people manage their lives, I started having hope again. My friends became source of my hope.'*

Many Ethiopian adolescents with disabilities also spoke enthusiastically about the emotional support they received from their special needs teachers, which made them feel – sometimes for the first time – emotionally valued (see Box 3.6).

For older adolescents, integration into the community via employment has been found to be central to young people's self-esteem and resilience. In both Nepal and Ethiopia, research found that employment allowed older

adolescents with disabilities to lead 'dignified' lives and prevented them from feeling as if they were 'parasites' (NFDN, 2013; Groce et al., 2014).

## Access to psychosocial services

Adolescents with disabilities in LMICs have only limited access to either formal or informal psychosocial support services (see Box 3.7). Government provisioning tends to be weak in developing countries and while non-governmental organisations (NGOs) are struggling to fill the void, most offer programming that is relatively small scale and not sufficiently resourced to engage in either significant outreach or tailoring of services to needs. This is especially the case in rural areas and humanitarian contexts. Indeed, the most recent edition of the Humanitarian Exchange, which is a special feature on mental health and psychosocial support in humanitarian crises, does

**▶ After I started school here, I now believe I can be just like any other person. I am looking for the future than the past. After I saw how blind people manage their lives, I started having hope again. My friends became source of my hope.**

(Girl who is blind, 18 years, Ethiopia)

### Box 3.6 The importance of feeling emotionally valued by adults

Used to parents who are often “careless” of them, Ethiopian adolescents with disabilities told us that the support they received from their special needs teachers felt noticeably different. A 16 year old boy who is blind explained that, *‘they are really supportive’*. A 16 year old girl who is blind clarified that he was not simply talking about educational support. She explained, *‘I feel really happy when I meet my teachers. They call us on the holidays and during the summer on school break. They give us advice on what to do’*. Indeed, the adolescents in our research told story after story of teachers who contributed money to pay for medical care, to help students who had been robbed, or to buy shoes or school supplies. An 11 year old boy with an intellectual impairment, who was accidentally burned, told us that *‘teachers contributed 400 ETB for me’*. Another adolescent boy, who is blind, reported, *‘I have been in Bahir Dar for the past 6 months to get a treatment for my leg and they are paying for my medicines’*. Evident in the way the stories were told, adolescents with disabilities feel that their teachers care about them not just as students, but as people.

This care and attention shown through in the way special needs teachers spoke about students as well. Recognising that most had come from rural areas, where they often received little family support and had few community role models, teachers were working hard to build adolescents’ self-confidence. One explained, *‘We can increase the self-confidence of these disabled children and they feel that they are capable to learn and to be competitive.’* Another added that he was helping students understand that in time they could become teachers themselves: *‘I also give them (the deaf students) the chance to teach in the class. When you tell them you can become like that if they study hard, they become really happy.’* Indeed, added a third, *‘Looking after for them and cultivating them is on the shoulder of us’*.

### Box 3.7: Access to formal services

Overall, adolescents in our sample had very limited access to formal psychosocial services. In Ethiopia, schools with special needs classrooms offer ‘guidance and counselling’. However, this is through the personal commitment of individual special needs teachers—who have not been formally trained as counsellors—rather than through any particular programme or service. Mostly, teachers told us, they worked hard to make sure that young people with disabilities understood, regardless of community beliefs, that *‘disability is not because of Satan, Evil spirit or from curse’* (focus group discussion with special needs teachers, Ethiopia).

In Jordan, among the Syrian refugee community, although many people have suffered enormous trauma on account of the war and subsequent displacement, access to psychosocial services in general – and particularly for adolescents with disabilities who are often kept at home – also appeared to be very scarce, as this example attests:

*‘When I’m sad or annoyed I sit and don’t talk to anyone. I sit alone or use the tablet, something like that... I sometimes stop eating and drinking... No one outside my family has ever asked me about my feelings – I wish someone would.’*  
(Girl with a physical and intellectual impairment, 19 years, Syrian refugee in Jordan)

Only adolescents who had developed an impairment as a result of war-related injuries spoke of formal counselling services, but even this was not widespread, as this adolescent refugee boy emphasised:

*‘A friend of mine is a counsellor, he had counselling for a case similar to mine, he was also shot and became paralysed like me, and then he also trained and took courses in psychological training... I know more than one person like that... I would go to a counsellor if I had the opportunity...’*  
(Boy with a physical impairment, 18 years, Syrian refugee in Jordan)

not mention the psychosocial needs of adolescents with disabilities at all (Humanitarian Exchange, 2018).

Formal mental health care services are rarely available in the South, with the World Health Organization (WHO) and World Bank (2011) reporting that between 76% and 85% of people with even the most serious mental health

conditions receive no treatment. Indeed, in Palestine, social work caseloads are more than 10 times higher than they are in the UK, which can preclude quality care even for those technically under care (Jones et al., 2016). Treatment for those with disabilities is even rarer, in part because of the way disability care has been siloed in most LMICs, leaving



Two adolescent girls with visual impairments, Ethiopia © Nathalie Bertrams / GAGE 2018

many 'mainstream' providers unsensitised to the needs of those with disabilities. In Palestine, for example, mental health professionals assume that all the care needed by those with disabilities should be handled by disability-related organisations, regardless of whether the need is actually disability-related (Abu-Hamad et al., 2015). For adolescents with disabilities who struggle with depression, anxiety and other mental health issues, options to receive age-tailored, disability-sensitive professional care are rarer still, given their evolving needs as they approach adulthood (UNICEF, 2007; Burns and Oswald, 2015). In Ethiopia, for example, Groce and Paeglow (2005) reported that young people are often treated alongside adults, rather than receiving services tailored to their developmental needs. While we were unable to locate any evidence that speaks to the efficacy of formal mental health services in improving the wellbeing of adolescents with disabilities, Purgato et al. (2018) concluded that even for the broader population of adolescents without

▶▶ When I'm sad or annoyed I sit and don't talk to anyone. I sit alone or use the tablet, something like that... I sometimes stop eating and drinking... No one outside my family has ever asked me about my feelings - I wish someone would.

(Girl with a physical and intellectual impairment, 19 years, Syrian refugee in Jordan)

disabilities, evidence that psychological treatment produces long-term effects is weak.

Across LMICs, the access of young people with disabilities to the types of programming that could provide informal psychosocial support appears to also be poor (Jones et al., 2016; Bhatta et al., 2018; Groce and Kett, 2014). Indeed, while a growing body of research notes that adolescents with disabilities are socially excluded, socially isolated, depressed and anxious (UNICEF Innocenti, 2007; Hadi and Mutoni, 2012; Halder and Datta, 2012; Llewellyn et al., 2012; UNICEF, 2013a; World Bank, 2013: 82; Groce and Kett, 2014; Kodali and Charyulu, 2014), research appears to largely ignore the extent to which adolescents with disabilities could be served by community-based adolescent-focused recreational programming. Outside of a few NGO-supported sports activities, which can be transformational for those (primarily boys) who are able to access them, there are few recreational activities aimed at adolescents with disabilities (Jones et al., 2016; Bhatta et al., 2018). In addition, the broader programming that provides young people with safe spaces to interact with one another and trusted adults rarely engages in the outreach and adaptation that would be required to ensure the inclusion of adolescents with disabilities into the fold (ibid.). While supporting caregivers of adolescents with disabilities to come together and support one another would appear to be a relatively low-cost option, such initiatives appear rare. Despite evidence that such groups can do much to relieve the stress and isolation

that caregivers experience (Miles et al., 2012; ICED, 2017), NGOs – not schools or health clinics – appear to be driving most of the small-scale, existent efforts.

## Experiences shaped by gender

Around the world, adolescent girls and women have higher rates of depression and anxiety than boys and men. In 2010, global incidence rates for depression were 5.5% for females and 3.2% for males (Albert, 2015). Because rates of mental ill-health are similar for girls and boys before puberty, and because differentials between males and females are similar in developed and developing countries, it is believed that differences stem primarily from biology and are related to oestrogen levels (ibid.). Gendered patterns of mental ill health have also been found among adolescents with disabilities, with girls more at risk than boys. In Ethiopia, for instance, 37% of girls with disabilities reported being unhappy, compared to 22% of boys with disabilities (ACPF, 2011). Similarly, in India, Hussain (2006) found that the self-esteem of girls with disabilities was lower than that of their male peers.

As well as biological differences between girls and boys, girls' greater vulnerability to poor psychosocial outcomes is likely to be impacted by the fact that girls

with disabilities are doubly constrained socially – by both disability-related stigma and restrictive gender norms. They consequently face greater social isolation than do boys with disabilities and, in some contexts, less hope of ever achieving the central feminine markers of adulthood: marriage and motherhood (see Box 3.8) (Mehrotra, 2006; Save the Children, 2008; UNDESA, 2012; Coe, 2013; Plan International, 2014; 2017). Again, while some parents mean well and are trying only to protect their daughters from harm (especially sexual violence), other parents underinvest in daughters with disabilities because of son preference or because they are afraid that their daughter's disability risks their siblings' marriage prospects (Burns and Oswald, 2015; Jones et al., 2016).

In Ethiopia, for example, research has found that girls with disabilities are more likely to be denied their right to an education, are overburdened with chores, and are less often permitted to socialise with non-family members (Cherinet and Mulugeta, 2003). As a result, girls with disabilities are more likely to report having no friends (25%) compared to other groups of young people (Erulkar et al., 2010). Gender impacts are similar in Nepal, where girls and women with disabilities are dissuaded from pursuing vocational education, are excluded from social visits, and often prefer not to marry because they fear disability-related violence at the hands of potential marital families (Dhungana, 2006;

### Box 3.8: Marriageability is highly gendered

In Bangladesh, girls with disabilities face restricted options in terms of marriage, which can impact their psychosocial wellbeing because of the way that marriage and motherhood are seen as central markers of adulthood for women. Their mothers told us that they are planning ahead, and trying to save enough money to provide a dowry so large that *'we will be able to buy a boy'*. However, when households are very poor, this can be a nearly insurmountable challenge. The mother of a 15-year-old with a physical impairment explained, *'there will be problem for her leg... Will anyone take her so easily? Won't I have to suffer for her?'* The mother of a 12-year-old, also with a physical impairment, clarified: *'Nowadays when you get a girl married, they don't say you have to give dowry, they say, you have to give a gift.'* Given her daughter's disability, she added, *'I will have to give more for my daughter's marriage than others have to give for theirs. If in your case, you had to give two, I will have to give four for my daughter.'*

In Palestine, there was similarly a general consensus among respondents that while it was acceptable for males with a disability to get married, it was much more challenging for females. The following quotes from a mother-in-law and wife of an adolescent boy with a physical impairment both highlighted this:

*'A male would have a better chance. But a female is likely to stay unmarried. There are males with disabilities who marry girls from outside the city. I know of a girl who got married to someone with canes and she does not have any children. I think of my son's wife as one of my daughters.'*

(Mother-in-law of young man with a physical impairment, Gaza)

*'Praise be to Allah... it [my marriage] is fine... He is nervous. Sometimes I can't tolerate that... But a girl with disabilities can't get married. It is hard. No guy will agree.'* (Wife of adolescent male with a physical impairment, Gaza)

▶ The problem is not because I have two disabled children. I also have two non-disabled, who want me to take care of them like their siblings. I'm not an octopus; I can't take care of all of them.

(Mother of 11-year-old boy who is deaf, Jordan)

see also Puri et al., 2015; Tanabe et al., 2015; Lord et al., 2016). Similar impacts are also reported in Lebanon, where girls with disabilities are viewed as unmarriageable and asexual, leading to feelings of frustration and despair (El-Helou, 2005). Plan International (2017) notes that when Nepali girls with disabilities do marry, they can find it particularly difficult to establish social networks when they move to another community because of superstitions about the 'bad luck' that females with impairments might bring to community

activities (Dhungana, 2006). In India, girls and women with disabilities are more likely to be kept at home than boys and men with disabilities, because family members are more willing to help the latter to get out and about (Mehrotra, 2006; Adaikalasamy, 2014). This is also the case in Jordan, where Save the Children (2008) found that girls with disabilities lose almost all chance of leaving the home.

Key also to understanding the gender-specific psychosocial impacts of disability is looking at impacts on caregivers – who are nearly always mothers. In some contexts, mothers are blamed for producing 'defective' children, leading to social exclusion and abandonment and high levels of gender-based violence (Box 3.9). In nearly all contexts, mothers of children with more severe impairments are often exhausted and may experience depression and anxiety (see Box 3.10).

### Box 3.9: Intra-familial violence and disability in Palestine

In Palestine, where impairment rates are high due to consanguineous marriage – and disability is deeply stigmatised – Jones et al. (2016) found that social ostracism and intra-familial violence directed at women and children with disabilities is common. Mothers may also be blamed for producing 'defective' children.

One Palestinian mother, with four children with various impairment types, told us that her husband had taken a second wife in order to produce healthy children:

*'My husband never mentioned that he was going to divorce me or marry another woman till I delivered the third child. One of his friends convinced him, saying that "You are becoming older and older. See how you don't have any healthy boys who can carry your name and family name! Why you don't marry another woman to bring healthy boys?" So he decided to marry again after that.'*

Another told us that her husband had divorced her – at the urging of his mother:

*'My mother-in-law's pressures heavily increased on my husband once she started to notice the disability symptoms in my child. She advised him several times to divorce me and she wanted to marry him to another woman. Thus my husband succumbed to her demands and divorced me.'*

A mother of many children, four of whom have disabilities, reported that her husband is violent and her sons dangerous: *'Before I am so nervous about my situation – I have 11 children and four children with hearing impairments and one who is blind – I had decided to commit suicide. My husband has a neurological disease, he beats me, he shouts all the time and he beats the children and this impacts them a lot. I hated life, I wanted to burn myself. But then I thought about to whom I would leave my children, who would care for them, and so I handed myself to God and I trust in him to take care of me... My nightmare is my daughters, I am so worried about them as we heard a lot of stories about girls – stories of sexual harassment by men against girls here. My situation is so difficult – if my husband left the house, my sons will rebel against their sisters and exploit them, the father ironically now is like a protection for them.'*

A mother from the West Bank similarly explained that both she and her children, two of whom have disabilities, are beaten:

*'My husband hits me and my children for no reason... Whenever he wants. Violence is here. I have been asking for help at MoSD [Ministry of Social Development] but no one helps... I feel insulted in front of my children. Women should never be beaten by their husbands. It is insulting. Whenever he gets angry – from work, from people – if anyone upsets him he uses his family as a way to express his anger... I understand why. I understand the situation is very bad but this is not a way to express your feelings towards us. The father used to beat the children – the deaf child too – maybe the fear they have of their father is why they are now so afraid of beatings from their teacher.'*

### Box 3.10: Caregiver responsibilities and the psycho-emotional toll they take

Mothers in our sample, particularly those with multiple children and those with children with severe impairments, often face full-time caregiving with very little support.

*'I'm often so tired and anxious. When I get upset, I try to sit down, do some prayers, until I calm down. The problem is not because I have two disabled children. I have another two non-disabled, who want me to take care of them like their siblings. I'm not an octopus; I can't take care of all of them.'* (Mother of 11-year-old boy who is deaf, Jordan)

*'My husband doesn't help me at all in taking care of my children with disabilities, I do all the required care, starting from feeding, showering and providing physiotherapy myself. He doesn't like to do that, so I ask my eldest daughter to help me.'* (Mother of four children with various impairments, West Bank)

Our findings highlight that this dearth of support for women caregivers is especially marked in crisis-affected settings.

*'I read the Quran, and ask God continuously for help and for my children, the sick ones especially, I am scared about the girls. I get sad, as we were living normally before the crisis. My children had everything in Syria, from treatments, even the bus used to take them and bring them back. In Homs, they had a lot of treatments. They even had a monthly salary: 17,000 Syrian pounds... Now I can scarcely cope... I have a brother in Syria, he called me yesterday asking for 80 JD to get out, as he is at the street, because there is a war now. I told him if I can get that money, I'll send you.'*

(Mother of three children aged 10, 11 and 27 years, all with severe intellectual and physical impairments and two with epilepsy, Syrian refugee in Jordan)

*'My parents live just 100 metres from our home. But I'm rarely able to visit them as the care demands of my children are never-ending. Especially my older son, he needs be turned even every hour during the night because of his respiratory problems. There is just no respite.'* (Mother of three sons with muscular dystrophy, West Bank)

Others highlighted the inter-related physical and psychosocial challenges of caregiving in the context of displacement. For adolescents with physical impairments, a number of mothers noted that they had to resort to carrying their adolescents down multiple flights of stairs to even leave their apartment and then, even if they did have a wheelchair, struggled to navigate the streets due to a lack of adapted sidewalks. Ground-floor apartments are both limited and more expensive, and few felt they could rely on neighbours to help them because of the stigma attached to being a parent of a child with a disability.

*'She would like to go to school, but, because I have to carry her and our house has a staircase, I found it so hard... The school in normal circumstances is 10 minutes' walk but it is uphill and going up is hard... She has a wheelchair but it's old. And transferring her in and out of it is difficult as she is heavy now... I have neighbours but I don't like to ask them... and they don't offer to help... Now I'm looking for a house that's on the ground floor. If I found one close by, I want to send her to school. But if it is on the ground floor, its expensive, you know.'*

(Mother of 12-year-old girl with cerebral palsy, Syrian refugee in Jordan)

*'He takes up so much of my time that I can't care about myself; sometimes I don't even have time to comb my hair.'* (Mother of 11-year-old with multiple impairments, West Bank)

## Experiences shaped by impairment type

Evidence that speaks to psychosocial vulnerabilities based on impairment type is especially thin – although the evidence that does exist suggests that adolescents with complex and communication impairments are particularly vulnerable (WHO and World Bank, 2011). In the case of the latter, qualitative research from Ethiopia, Nepal and Palestine suggests that a key issue is that adolescents

with hearing impairments are often unable to communicate even with their own family members because parents do not learn sign language (Tefera et al., 2015; Jones et al., 2016; Bhatta et al., 2018) (see Box 3.11).

Detailed, country-level, quantitative data from Palestine indicates that children with multiple or psychological impairments and mental health illnesses are especially disadvantaged and that social isolation is probably the key factor shaping outcomes (Jones et al., 2016). The same study found that half of Palestinian children with

### Box 3.11: Communication for children who are deaf can be especially challenging in low-resource settings

GAGE's qualitative work found that across countries, in both urban and rural areas, adolescents who are deaf are often extremely isolated – not only from their peers, but from their own families. Because parents only rarely know sign language, adolescents who are deaf often have no way to communicate their needs and feelings to their parents. In some cases, parents had not thought to learn to sign. In others, they had had no opportunity.

*'Parents don't think to learn sign language because their child has a hearing impairment. Such thinking does not exist here.'* (Ethiopian teacher)

*'I have not learned sign language and so our communication is limited. I try to get them to watch me speak and also to use pictures and take them by the hand and show them so they know what I mean but it's very challenging to understand their real needs and thoughts... I have not learned sign language... I am too tired taking care of my other children too... But I know I should.'* (Mother of two children with hearing impairments, Jordan)

*'Look at those houses; I draw them far away from each other because people in our community have difficulty in communicating and supporting each other, so they are far away from each other...'* (Girl who is deaf, 15 years, Gaza)

*'I feel worried when I am not able to explain what I am feeling to others and I also feel worried when I'm unable to understand others' feelings too. I try to explain my pain to my younger brother. My brother can't understand everything inside me because he doesn't understand sign language. The only thing that I can do is to tell him that I feel sick. It is my younger sister who lives in the rural area who can use sign language and she is the one who tries to explain my feelings to my parents. I also explain my worries to my teachers.'* (Girl who is deaf, 17 years, Ethiopia)

In other cases, especially in group settings, adolescents may self-isolate because of communication barriers, as this Ethiopian girl's case highlights:

*'If my daughter goes to other people's houses during social events like wedding or 'mahibers' [saints festivals] then she will not act like other children. She doesn't ask for food. Even if she asks for food, who will understand her? She simply sit in one place. If somebody did not provide food, she returns back to home without eating.'*

(Mother of girl who is deaf, 12 years, Ethiopia)

Even when adolescents do have peers with whom they can communicate, for adolescent girls outside of school, their access to peers is often very limited due to conservative gender norms, which limit their freedom to move around the place where they live:

*'I want to visit my friends who have hearing disability, but my parents do not allow me to go. Since no one listen to me, I do not have someone to share the issue with.'* (Girl who is deaf, 15 years, Ethiopia)

psychological impairments and mental health illnesses reported that their quality of life was bad – compared to 35% of those with communication impairments, 29% of those with multiple impairments, and 21% of those with physical or hearing impairments. They also found that over

**Parents don't think to learn sign language because their child has a hearing impairment. Such thinking does not exist here.**

(Ethiopian teacher)

40% of those with multiple impairments felt that they face 'a lot' of difficulty integrating into the community, compared to 30% of those with intellectual impairments and 11% of those with physical constraints. Indeed, a quarter of adolescents with multiple, communication and intellectual impairments felt that they had 'a lot' of difficulty in fulfilling their emotional needs, compared to 9% of those with hearing impairments and 3% of those with visual impairments. On the KIDSCREEN quality of life tool, Jones et al. (2016) reported that scores were lowest, on average, for those children with multiple and psychological and mental health impairments (2.8/5) and highest for children with hearing (3.4/5) and visual (3.3/5) impairments. Differences were primarily driven by variance in access to friends.

## Experiences shaped by context

Within the broader population of young people with disabilities, some groups are especially marginalised and excluded from community life and access to services. This includes those living in rural areas (where stigma is often especially strong), those from ethnic and linguistic minorities, and refugees with disabilities (UNICEF, 2013b; WHO and World Bank, 2011). We were, however, unable to locate research examining the age-disaggregated impacts of these delimiters on psychosocial wellbeing.

WHO and World Bank (2011) noted that people with disabilities who live in rural areas have the least access to psychosocial care, as resources and facilities tend to be concentrated in urban settings. Disability-related stigma also tends to be especially pervasive in rural areas, where awareness of what causes disability tends to be lower, the absolute number of those with disabilities is smaller, and overall social connections tighter, meaning that those who are excluded can feel it more acutely. It has also been observed that to the extent that stigmatisers are often extended family members, and extended families have traditionally lived near one another in rural villages, moving to an urban area – away from extended family – can reduce stigma.

In Nepal, people with disabilities who belong to the Dalit caste are especially likely to be excluded by the community, because members of other castes are often unwilling to touch them if they need assistance (NFDN, 2013).

The UN Children’s Fund (UNICEF) (2013b: 29) noted that refugee children with disabilities are ‘among the most hidden, neglected and socially excluded of all displaced people’. In Lebanon, Palestinian refugee women reported that they are less likely to leave their homes than their peers without disabilities – a situation that is probably similar for girls, given prevailing gender norms (Sayrafi, 2013). Syrian refugees – many of whom also struggle with post-traumatic stress disorder due to exposure to violence – face similar constraints, especially those with intellectual impairments, whose families can feel that they must hide them in order to prevent them being exploited (WRC, 2013; Pearce, 2014; Sida, 2014).

## Evidence gaps

The psychosocial wellbeing of adolescents with disabilities in the global South is very poorly researched. While evidence suggests that these young people tend to experience stigma, discrimination and social isolation in their daily life – with negative effects on their wellbeing – that evidence is limited and fragmented (see Table 3.1).

**Table 3.1: Evidence gaps on the psychosocial wellbeing of adolescents with disabilities**

<b>Life-cycle gaps</b>	It is clear that adolescents with disabilities are more socially isolated than their peers without disabilities. However, we know very little about specific psychosocial impacts and how these change and evolve as children grow to adulthood.
<b>Gender-specific gaps</b>	Although evidence suggests that girls with disabilities are more isolated and have poorer psychosocial outcomes than boys, we do not know to what extent gender differences are driven by restrictions on girls’ physical mobility versus greater levels of social stigma.
<b>Gaps regarding impairment type</b>	There is very little evidence that speaks to the psychosocial needs of adolescents with different types of impairments or how adolescents experience physical versus social isolation.
<b>Context-related gaps</b>	There has been very little research that has addressed the psychosocial wellbeing of adolescents with disabilities across contexts. While rural adolescents with disabilities are probably more isolated than their urban peers, and refugee adolescents with disabilities presumably have worse outcomes due to multiple stressors, these issues seemingly remain unexplored.
<b>Policy and service gaps</b>	Outside of supporting children’s access to school, and the social interactions that occur there, there is also little evidence about how to scale up the services that improve the psychosocial wellbeing of young people with disabilities. While a variety of ‘inclusive toolkits’ have been produced, primarily by NGOs working in the sector, there is little evidence of them having been used, much less creating impact.

## Promising practices

Despite evidence that in many LMICs adolescents with disabilities face daily stigma and discrimination, tend to have few sources of psychosocial support, and are more likely to be depressed and anxious than adolescents without disabilities, there are very few programmes addressing their age- and disability-specific psychosocial needs. Disability-tailored social and recreational opportunities are few and far between, and while broader programmes targeting adolescents often claim to be inclusive, there is little evidence that they are.

As with health services in general, mental health services are often not accessible or appropriately tailored for those with disability-specific needs. This is sometimes because they are simply not available (especially in rural areas), and sometimes because providers lack training on disability-related issues or because health workers themselves reinforce stigma through how they treat

people with disabilities. There are also few programmes (formal or informal) that address families' and caregivers' psychosocial needs. Given that they play a crucial role in supporting (or not supporting) the needs of adolescents with disabilities, this means that adolescents' social and emotional safety nets can become frayed.

## Resilience

There is an increasing focus, especially by the humanitarian sector (given that recent conflicts tend to be longer term and disrupt lives for years and even decades), on how to support adolescents to develop the personal resilience that can help them cope on a day-to-day basis and successfully transition to adulthood. There is no evidence, however, that this type of programming is being delivered, even on a small scale, to adolescents with disabilities. Indeed, our research found that the programmes that deliver curricula on resilience are largely not inclusive of

### Box 3.12: Building resilience, but not inclusivity

In Jordan, UNICEF's Makani programme is working to provide adolescents – mostly Syrian refugees – with access to psychosocial support services that are carefully designed to foster the resilience that young people need in order to recover from the trauma of conflict and live with day-to-day uncertainty. Using safe spaces that allow young people to develop friendships and form ties with trained mentors, Makanis also provide a structured life-skills curriculum that aims to help adolescents believe that they can navigate both success and failure, that the world can be a better place, and that they have a role in shaping the future. Unfortunately for adolescents with disabilities, while Makanis are succeeding at scale in reaching adolescents without disabilities, our research suggests that despite the programme's inclusive language, very few adolescents with disabilities are participating.

A number of factors appear to be at play according to interviews with Makani centre heads and facilitators: first, until recently, programme participants had largely been those who self-registered rather than being identified through outreach initiatives; second, outreach initiatives had not specifically sought to include adolescents with disabilities and did not (for example) involve collaborating with organisations targeting people with disabilities; third, because the Makani centres are housed in existing buildings and not purpose-built for adolescent programming, they are often not adapted to accommodate young people with physical impairments; and fourth, programme facilitators have not received any specific training on disability-sensitive teaching approaches. In addition, a number of Syrian refugee parents of adolescents with whom we talked noted that either they had no awareness of Makani services and thus had not registered for them, or that their children had been registered by Makani centres but they had never received a confirmed place, which they interpreted as evidence of discrimination against children with disabilities.

*'I know about UNICEF but I don't know about Makani. No one called us or asked for them... It sounds nice but if it's far and we have to pay for transportation... It's hard. There is no father. There is no man.'* (Mother of 12-year-old girl with cerebral palsy, Syrian refugee in Jordan)

*'I registered all three of my children but they only called back about places for my two daughters without disabilities, not my daughter in the wheelchair. I asked about her again but they said there were no classes suited to her.'* (Mother of daughter with physical impairment, Syrian refugee in Jordan)

*'There is a Makani centre in this neighbourhood but I never realised they would also offer services for young people with disabilities. I never heard about this and no one from the centre ever contacted us.'* (Father of 18-year-old boy with a hearing impairment, Syrian refugee in Jordan)



An adolescent girl with a physical impairment, Bangladesh © Marcella Pasotti / GAGE 2018

DD I registered all three of my children but they only called back about places for my two daughters without disabilities, not my daughter in the wheelchair. I asked about her again but they said there were no classes suited to her.

(Girl who is blind, 18 years, Ethiopia)

adolescents with disabilities, despite language aimed at inclusivity (see Box 3.12). The Women’s Refugee Commission (WRC) (2017) has also noted this gap, and the wider tendency of humanitarian actors to view people with disabilities as a homogenous group, taking little account of their age- and gender-specific needs. WRC has recently produced a guidance note to help actors strengthen resilience-based programming for children and youth with disabilities in order support them to cope, adapt, recover and thrive (see Figure 3.2).

Figure 3.2: The vulnerability resilience continuum



Source: WRC (2017)

### Social connectedness with peers

Adolescents with disabilities, like their peers without disabilities, need regular social interactions to foster healthy emotional development. Evidence overwhelmingly suggests that adolescents with disabilities in LMICs (especially girls) are socially isolated, largely due to stigma. Many lack regular access to recreational time with their peers without disabilities; most even have little interaction with other children with disabilities which, according to our research, may be particularly important in reducing feelings of emotional isolation.

One approach to fostering social connectedness with peers, which grew out of the Special Olympics programme first launched in the United States in 1968, is sporting programmes for children and adolescents with disabilities. As Harknett (2013) noted, not only are sports fun and relaxing and a proven antidote to depression, but they can begin to break the cycle of segregation that separates those with and without disabilities (see Figure 3.3). For young people with disabilities, who are particularly susceptible to low self-esteem and self-confidence (due to stigmatising attitudes and practices that range from bullying to over-protection), sports programming can

provide both a chance to engage in something new and to participate in regular age-appropriate activities – thereby fostering emotional resilience and social connectedness in one.

Aimed at scaling up young people with disabilities' access to sports programming, Handicap International-Sri Lanka has produced a manual on how to include children and youth with disabilities in school- and community-based

**Figure 3.3: The cycle of segregation**



Source: Harknett, 2013



An adolescent girl, with a hearing impairment, with her father, Ethiopia © Nathalie Bertrams / GAGE 2018

sports programming (Harknett, 2013). Designed for a wide range of audiences, including PE teachers, NGOs, local authorities, sports club staff, and those running children's and youth clubs, the manual lays out how to best include children and adolescents with disabilities by using national examples such as Sri Lanka's sitting volleyball team. It covers a range of impairment types, and demonstrates

how different types and degrees of impairment require different adaptations and levels of inclusion to foster success and build self-confidence (see Figure 3.4). Most importantly, it helps sports coaches to focus on ability rather than disability, and to encourage independence by adapting spaces, tasks and equipment to help everyone have fun and do their best.

Figure 3.4: Levels of inclusion



Source: Harknett, 2013

The impact of sports programming on the psychosocial wellbeing of young people with disabilities in Uganda was recently evaluated, where only 9% of children with disabilities attend primary school, due to inaccessible educational infrastructure and the stigmatising attitudes of teachers and classmates. Starting in 2011, an NGO, Motivation, worked with partners to set up a sports league aimed at helping adolescents with disabilities have fun, and to demonstrate to themselves, their families and their communities what they can do (Langford, 2017). Motivation trained coaches to work with young people with disabilities and developed a network of peer mentors who used the

A caregiver of an adolescent boy with a physical impairment, West Bank © Rebecca Reid / ODI 2018





A caregiver of an adolescent boy with a psychosocial impairment and a girl with a physical impairment, West Bank  
© Rebecca Reid / Overseas Development Institute 2018

league to identify vulnerable children and adolescents with disabilities. Once the most vulnerable young people had been identified, and trust was established, mentors began making home visits. They aimed to help the young people and their families understand their rights, advocate for themselves, and access community activities – turning fun and games into an entry point for building resilience and voice.

The three-year pilot programme showed a marked impact on adolescents with disabilities. Nearly all (95%) had increased confidence, 78% demonstrated an improved understanding of their rights and how to defend themselves, 70% felt more included in community activities, and 50% were able to identify incidents from their own lives where they advocated for themselves. Langford also noted that parents became more aware of their children's abilities rather than disabilities, and that some children were subsequently enrolled in school for the first time. The sports league also improved community awareness of disability and helped those without disabilities focus on what those with disabilities can do rather than what they cannot do, as participants with disabilities have been encouraged to take part in school competitions and public tournaments alongside their peers.

The importance of recreation and play to young people's psychosocial wellbeing is also evident in Gaza, where the Atfaluna School for Deaf Children runs a summer camp for its students. The camp provides

hands-on activities such as painting, sports and computer classes, which help children with hearing impairments engage with one another and play on an equal footing with their peers without a hearing impairment. Atfaluna school psychologists note that camp activities help the children enhance their imagination and self-confidence and give them some relief from the pressures and challenges of daily life, which are considerable given the stigma associated with disability in Gaza.

Digital technologies also offer increasing scope for contributing to social inclusion and improving the broader psychosocial wellbeing of adolescents with disabilities (UNICEF, 2012; 2017; Groce and Kett, 2014). Not only do they allow young people with disabilities to interact with the wider world on an equal footing with their peers without disabilities, because 'online we are all able bodied' (Obst and Stafurik, 2010), but digital technologies can also help those with disabilities to educate the public about disability and to form friendships with others like themselves – allowing them to build community in environments where disability-related stigma leaves them socially isolated and at risk of poor psychosocial outcomes. While digital communities are most advanced in Northern countries with good digital infrastructure and the higher incomes that facilitate ownership, this is shifting rapidly in Southern contexts as costs come down (Groce and Kett, 2014).

The albino community in Ghana is a case in point (Thompson-Hernández, 2018). Albinism in Ghana is deeply

stigmatised. Those with the condition, who are usually visually impaired in addition to being physically distinctive, tend to be social outcasts and are at very high risk of violence, given that the wider community has traditionally regarded their body parts as having magical powers. Using platforms such as Facebook and WhatsApp, Ghanaians with albinism have recently forged online communities that are allowing them to make friends and support one another:

*'It feels great to know that I have a community of people now because we motivate each other,'* said Mr Kabu (aged 22), who maintains close ties with other people with albinism through Facebook and WhatsApp. *'There's a real sense of belonging. We give each other advice on how to deal with discrimination from the blacks so that we don't get discouraged.'*

While our research suggests that adolescents with disabilities living in conflict-affected contexts are especially socially isolated, as they are largely excluded from psychosocial support programming targeting adolescents more generally, in Lebanon there are plans to close this gap. The Lebanon Crisis Response Plan 2017–2020 specifically recognises that children and adolescents with disabilities are among the most vulnerable people. The recently released Disability Inclusion in Psychosocial

Support Programs in Lebanon: Guidance for Psychosocial Support Facilitators also aims to strengthen the inclusion of children and adolescents with disabilities in a range of psychosocial activities (UNICEF and WRC, 2018). Existing community-based psychosocial support activities, which include drama, crafts, storytelling and sports, are being strengthened and broadened so as to better include young people with disabilities. The guidance suggests key actions and tools to improve outreach and identification of children with disabilities for psychosocial activities, as well as ways to make such activities more inclusive. It also includes mechanisms for supporting those children and adolescents with disabilities who are at medium-to-high risk of child protection concerns.

### Support for families

Given the central role of parents (especially mothers) in supporting children with disabilities to thrive, Jones et al. (2016) found that the crucial element of many 'promising practice' programmes was not the services they provide directly to children with disabilities, but the support they provide to caregivers (see Box 3.13). This support ranges from educational programming (which can help parents understand the nature of their child's disability

#### Box 3.13: Supporting Palestinian parents to support their children with disabilities

Jones et al. (2016) found that while programming aimed at parents of Palestinian children with disabilities was quite limited, impacts were substantial. One Bedouin mother of two children with disabilities reported that for her, access to a support group had been a lifeline:

*'My two children with disabilities, we send them to the Hope Centre. I have been part of a support group all these years – mothers come together and have snacks and leave behind their chores in this group. Sadly, because of building works and the lack of a room, we don't meet any more. I miss the group; I feel that it made me become younger. I was 36 years old, I felt 19 or 20 when I was in this group – it reduced my stress. If we don't have this support we can go crazy with stress... Everything that was in our minds we talk about! Still we talk by phone – when we meet in the school we say "where is the fun that we used to have..." Before the group I was very angry and very sad about my situation with my children but when I joined the group suddenly I started to turn on another life. I saw those with worse conditions in the group – I realised God sent these children to us because we are strong – these children will take us to heaven.'*

Another woman, whose daughter has a physical disability, explained that it was the opportunity to learn from other mothers that was especially powerful in terms of helping women feel less alone – and ultimately providing better support to their children:

*'The National Society for Rehabilitation, in cooperation with Palestine Future for Childhood Foundation, gave us training and awareness sessions, and then they selected five caregivers with children with disabilities to conduct a workshop for other mothers on how to deal with children with disabilities. I was selected among them, where I gave five training sessions (each session 20 women) where I trained myself on the training material under their guidance and support... It was a tremendous experience for me as we are all mothers or caregivers of children with disabilities; so it was better for us to listen and learn from each other as we all share the same sufferings and burdens.'*

and how to advocate for their child in order to maximise independence) to emotional support to offset caregivers' isolation and exhaustion.

Often supported by NGOs, this approach is starting to expand in LMICs. In the Philippines, for example, the Breaking Barriers for Children Project, which was launched in 1995 with the coordinated efforts of local and Dutch NGOs, provides educational and support programming for parents. These include teaching parents about child development, training on the impacts of specific impairments, opportunities for parents to socialise with one another, and formal counselling (BBCY, 2011a). The Breaking Barriers project also runs in-service classes for parents outside of its main catchment areas, as well as mobilising parents on a national level to advocate for their children – and the legislation that supports their children's needs (BBCY, 2011b; 2011c). The project's efforts were central to the passage of House Bill 6509, which mandates that the government establish 'city and municipal rehabilitation centers for children and youth with disabilities that will ensure a more meaningful, productive, and satisfying life for children and youth with disabilities' (BBCY, 2011c; Republic of the Philippines, 2012). Similar though smaller-scale programming is common in

other LMICs as well. In Viet Nam, for instance, the NGO Children of Vietnam trains community care workers to support parents of children with disabilities (IRIN, 2013; Children of Vietnam, n.d.). Care workers not only liaise with parents to help them access government services for their children (such as education, health care, rehabilitation, and accessible housing) but also bring parents together to support one another.

In Southern contexts where it remains difficult for children with disabilities to access education, many parent support groups first form around improving that access. The Disabled Children's Action Group (DICAG), for instance, was set up in South Africa in 1993 by a handful of parents of children with disabilities specifically to open up opportunities for schooling (DSD et al., 2012; DICAG, 2016; 2018). Though its impact on educational policy and programming has been slow, reflecting limited political buy-in and poor government resourcing, its impacts on parents have been large. DICAG notes that in the beginning, most parents were suspicious when contacted about receiving support; they were afraid of being victimised if it became widely known that they had a child with a disability. Using face-to-face home visits to build trust, the organisation, which now has tens of thousands of members, has



An adolescent boy, with a hearing impairment, with his family, Bangladesh © Marcella Pasotti / GAGE 2018

empowered parents 'with knowledge and life skills to be able to respond to their children's rights and needs'.

While parent support groups are an increasingly common intervention, there are few formal assessments of impact thus far. Indeed, even the largest organisations, such as DICAG, appear to invest few resources in documenting their growth, actions and impacts. There is, fortunately, evidence from both Ghana and Bangladesh – albeit mostly from the parents of younger children. In Ghana, International Centre for Evidence in Disability (ICED) (2017) reports that a training programme for mothers of children with cerebral palsy, which provided information on how to care for children as well as social support, resulted in very significant improvements in mothers' quality of life. Overall quality of life scores went up 30%, as mothers reported more self-efficacy in terms of how to care for their children, more patience with their children's behaviour, and greater self-esteem as a result of feeling that they and their child were more valued. The authors report that 'mothers' understanding that "they were not on their own" was key to effecting this change' (p. 23).

In Bangladesh, Miles et al. (2012) evaluated a similar intervention and found that when asked to identify the most significant change that had occurred due to group participation, parents reported a wide range of positive effects – for their children and themselves. These included: increased knowledge and confidence, resulting in better care for children; stronger peer relationships, resulting in better support for parents; increased confidence in interacting with and educating the community; improvements in child functioning, including better social opportunities; parents having more free time; and improvements in parents' attitudes towards the child as well as the community's attitudes toward the child and the family.

Social media is also helping parents of children with disabilities connect with one another. In Malaysia, for example, the Autisme Malaysia Facebook group, which is almost entirely (90%) used by the mothers of young people with autism, is allowing them to support one another through the challenges of parenting. Mustafa et al. (2015) found that mothers used the group to share both personal stories and concrete information – about how to seek out a diagnosis, coping with issues at school, and the stigmatising attitudes they and their children face.

## Psychosocial support services

Evidence suggests that adolescents with disabilities are more likely to need formal psychosocial support services than their peers without disabilities. Due to the stigma and discrimination that many adolescents with disabilities face, the normal developmental challenges of adolescence are amplified, while access to informal support from family members, friends and teachers is limited. There is little evidence, however, of any formal services which hone in on the age- and disability-specific needs of adolescents with disabilities.

Where programming is mentioned, it appears to be almost exclusively provided by a handful of special needs schools. In Gaza, for example, the Atfaluna Society for Deaf Children has its own independent social service unit, which provides children and adolescents with hearing impairments with the social and psychological support they and their families need in order to enjoy good mental health and integrate into the community (Atfaluna, 2018). Services for young people are tailored to help them as they enter and progress through school and then into vocational training or employment.

Aimed at the providers of both community-based and more focused formal psychosocial support, UNICEF and WRC (2018) recently produced guidelines on how psychosocial support facilitators can better include children and adolescents with disabilities in their work. Critical in environments where education and training rarely include any attention to disability, the guidelines not only include general guidance about disability, but also a set of eight tools that offer explicit instructions on topics ranging from how to identify the skills and capacities of children with disabilities to how to develop inclusive outreach messages. Among the young people identified as likely to need more formal support are those with new disabilities, who are still struggling to move through the stages of shock, denial, anger/depression and acceptance (see Taormina-Weiss, 2012) and those with intellectual disabilities, who may not be able to communicate (except negatively, through their behaviour) their experiences with violence and trauma.



## 4 Bodily integrity and freedom from violence

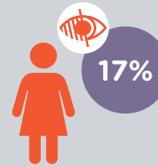


## Bodily integrity and freedom from violence

**Recommendation:** Provide adolescents with disabilities, their families and communities with information about risks of violence, protection measures and how to report abuse whilst strengthening justice sector responses



Adolescents with disabilities are **3–4 times more likely\*** to experience physical, sexual and emotional violence than peers without disabilities



GAGE survey data found among adolescents with disabilities, **12% were less likely to self-report violence at home, rural adolescents 17% and girls 17%**. Evidence shows adolescents with disabilities find it difficult to report abuse and seek justice



Evidence suggests adolescents with intellectual impairments are at increased risk of violence

\* Jones et al., 2012

## Key messages

- **Overarching challenges:** Children and adolescents with disabilities are 3–4 times more likely to experience violence than their peers without disabilities, with multiple and long-term consequences for their physical and psychosocial wellbeing. Adolescents with disabilities often find it difficult to access protection mechanisms, report abuse, receive support services and seek justice.
- **Gender dimensions:** Adolescent girls with disabilities are particularly vulnerable to sexual violence and abuse, as they are perceived to be an easy target and less likely to report the incident and be believed. They are also more likely to face neglect in settings with strong son preference.
- **Impairment-specific challenges:** Adolescents with intellectual impairments are more likely to face increased risk of violence.
- **Caregiver concerns:** Adolescents with disabilities are at heightened risk of violence, but caregivers often have insufficient tailored information about protection measures and how to support their adolescent to report violence and secure justice if it does happen.
- **Evidence gaps:** Evidence on the prevalence and patterning of violence against adolescents with disabilities is very limited, as is evaluation evidence on what works to prevent violence and protect and support adolescents with disabilities.
- **Promising practices:** Promising practices include disability mainstreaming within broader child protection initiatives along with specific targeted responses for girls with disabilities or adolescents with particular impairments. Other promising initiatives include working with adolescents and their families, traditional and community leaders, service providers, disabled people's organisations and civil society to raise awareness about risks and community-tailored mitigation measures in developmental as well as humanitarian settings.

## Introduction

Despite their right to protection and freedom from exploitation, violence, abuse and neglect, adolescents with disabilities are highly vulnerable to violence at home, in school, in residential care and in the community (UNICEF, 2005). A widely cited systematic review on the prevalence and risk of violence against children and adolescents with disabilities concluded that they are 3–4 times more likely to experience any type of violence than their peers without disabilities (Jones et al., 2012). Several studies in LMICs confirm that adolescents with disabilities are more vulnerable to violence (ACPF, 2010; Ellery et al., 2011; Plan International and London School of Hygiene & Tropical Medicine (LSHTM), 2016) and its adverse consequences (see Box 4.1). This increased vulnerability is not the result of the actual impairment itself, but largely derives from the interaction of stigma and misconceptions with social, environmental and institutional barriers. Most importantly, in settings where disability is closely associated with stigma, discrimination and social isolation, adolescents with disabilities may be perceived as having little value and being easy targets for abuse (UNICEF, 2005; ACPF, 2010). Girls with disabilities and adolescents with intellectual impairments are more likely to face increased risk (UNICEF, 2005; Jones et al., 2012; Plan International and LSHTM, 2016). Violence, abuse and neglect reinforce discrimination and social exclusion, violate the rights of adolescents with disabilities and damage the development of their capabilities.

## Physical violence

Children and adolescents with disabilities are more vulnerable to various forms of physical violence at home, in school, in institutional settings and in the community. According to a systematic review of studies in high-income settings, they are 3.6 times more likely to experience physical violence compared to their peers without disabilities (Jones et al., 2012). In a multi-country study in sub-Saharan Africa, children and adolescents with disabilities reported that family members and peers in school or in the neighbourhood were the main perpetrators of physical violence (ACPF, 2010).

In communities where disability is highly stigmatising, parents may use physical violence to deal with the stress and the shame that having a child with a disability brings on the family. In particular, in settings with high stigma, scarce resources and limited support, caring for a child with a disability can increase the financial and emotional strains on the household and consequently the risk of family members using violence against adolescents with disabilities who are perceived to be a shame and a burden (UNICEF, 2005; Pinheiro, 2007; ACPF, 2010). In our research, younger adolescent boys and girls alike noted that they were subject to age-related violence by family members, but did not see this as specific to their disability (see Box 4.2).

In some extreme cases, parents may even commit so-called ‘mercy killings’ in the name of ‘ending their child’s suffering’ or because they are afraid that as they grow older or become ill, they would be unable to protect their child, leaving them open to neglect or abuse (UNICEF, 2005). In other cases, adolescents with disabilities may face

### Box 4.1: Consequences of violence for adolescents with disabilities

Violence has significant, multiple and long-term impacts on survivors’ physical and psychosocial wellbeing. Most importantly, while disability increases the risk of violence, violence can also increase the severity of pre-existing impairments. The commonly reported difficulty of accessing necessary care services exacerbates the consequences of violence against persons with disabilities.

In addition, adolescents with disabilities who experience violence at home may be forced to leave: in a study in five sub-Saharan African countries, 25% of youth with disabilities (50% in Ethiopia) reported leaving home before the age of 18, with most stating that they chose to do so to end the abuse. Several of these young people ended up living on the streets, lacking adequate care and protection, and more vulnerable to exploitation, violence and abuse.

Anecdotal accounts of violence and impunity in various settings can breed fear and force concerned parents to keep their children with disabilities (particularly girls) at home in order to protect them. However, this serves only to increase their isolation and marginalisation, and thus their vulnerability to violence, while it also affects their opportunities to access education and skills development – an issue that needs further examination.

Sources: UN Committee on the Rights of the Child, 2007; ACPF, 2010; HRW, 2010; UNGA, 2012; van der Heijden and Dunkle, 2017

#### Box 4.2: Physical violence experienced by adolescents from family and community members

Younger adolescent boys and girls both noted that they were subject to age-related violence by family members but did not see this as specific to their disability:

*'My father beats me up when he is mad... He keeps on telling me to go to the house and sleep... otherwise he will beat me a lot.'* (Boy with a physical impairment, 12 years, Bangladesh)

*'As I have said I don't listen to her, then she (mother) beats me. Everyone's mother beats their children, in the same way my mother beats me too.'* (Girl with a physical impairment, 15 years, Bangladesh)

On the other hand, adolescent boys in our sample in Bangladesh, Ethiopia and Jordan noted that they were often subject to violence by peers at school and even employers in their community as a result of their disability:

*'He beats with a piece of rubber... Like this, only beats me on my buttocks... if I am late or make mistakes... though he doesn't beat me in front of my father.'* (Boy with a physical impairment, 12 years, Bangladesh)

*'We used to get into fights with other students while attending high school, as the other students used to tease and harass us while we were communicating using sign language and they seemed to see us like dolls as if we were acting out a drama.'* (Boy who is deaf, 16 years, Ethiopia)

In Jordan, most of the adolescents in our sample were either attending specialised schools for pupils with visual or hearing impairments or, in the case of Syrian refugees, were completely excluded from school. However, Jordanian students in inclusive education environments also reported facing risks of violence, as this quote from the mother of a boy who is deaf highlights:

*'We suffered a lot in this school; the fees of the kids were paid by the Ministry of Social Development, and there was no care at all from the teachers' side. The kids with disabilities were playing in the same playground as the youth, so they were in danger. There was no care at all. The cochlea was transplanted for my son through an operation in his head, and we paid thousands of dinar, so I didn't want to put him at risk of falling or being beaten by other students. So, I wanted to move him out of this school.'* (Mother of 11-year-old boy who is deaf, Jordan)

severe physical violence such as violent beatings as part of exorcisms or other traditional practices performed to free them from the evil spirits that allegedly possess them, as evident by their impairment (ibid.).

Adolescents with disabilities who live in institutions are also at high risk of physical violence. There are several accounts of young people with disabilities being confined in cells or chained to their beds, being heavily medicated and physically abused by staff and inmates (UNICEF, 2005; Ellery et al., 2011). They are also at risk of undergoing behaviour modification treatments, such as electroconvulsive treatment or electric shocks, without their free and informed consent (UNICEF, 2013).

Adolescents with disabilities are also vulnerable to physical violence in school. For instance, a study with young adolescents in Ugandan schools found that students with disabilities were more likely to experience physical violence from staff and peers compared to students without disabilities (Plan International and LSHTM, 2016).

Adolescents with disabilities who work are also at risk of physical violence, including those doing domestic work or engaged in begging (UNICEF, 2005; ACPF, 2010).

 We used to get into fights with other students while attending high school, as the other students used to tease and harass us while we were communicating using sign language and they seemed to see us like dolls as if we were acting out a drama.'

(Boy who is deaf, 16 years, Ethiopia)

Some destitute families may force their children with disabilities to beg or even sell them to criminal gangs who exploit them as beggars on the streets (UNICEF, 2005). Adolescents with disabilities who are engaged in begging may be subjected to further violence either by members of the public (who see them as easy prey) or by those who exploit them; the latter may frequently abuse them because they do not earn enough or in order to make them look more worthy of charity. In some contexts, it is reportedly common practice to physically maim children and youth and turn them into beggars (UNICEF, 2005; Pinheiro, 2007).

## Sexual violence

Adolescents with disabilities are particularly vulnerable to sexual harassment, violence and abuse (ACPF, 2010; WHO and World Bank, 2011). Accurate and comparable data remains unavailable as such incidents are rarely reported and aggregated. However, a systematic review estimated that children and adolescents with disabilities are nearly three times more likely to experience sexual violence than their peers without disabilities (Jones et al., 2012). In a large study in five sub-Saharan African countries, 37% of respondents with disabilities revealed having experienced forced sexual intercourse. While children with disabilities are also at risk of sexual violence, the study pointed out that this risk heightens as soon as they reach puberty. All respondents identified that it was at this point that they started being exposed to all forms of sexual violence, with most incidents having taken place between the ages of 14 and 17 (ACPF, 2010). While boys with disabilities are also at risk of sexual violence and abuse, girls are more likely to experience it (ACPF, 2010; Groce and Kett, 2014).

Adolescents with disabilities are at greater risk of sexual violence as they are perceived to be an easy target, less able to escape or defend themselves, and less likely to report the incident and be believed. They can be targeted at home, on their way to and from school, in school, and in their community (UNICEF, 2005). Even when their families choose to keep them at home for safety reasons, they can be assaulted by family members, neighbours or strangers if they are left alone (Burns and Oswald, 2015). Evidence from sub-Saharan Africa also indicates that perpetrators include peers, adult neighbours, relatives, teachers and strangers (ACPF, 2010). Perpetrators take advantage of the new opportunities offered by technology: participatory research in Bangladesh revealed that they use their mobile phones to record the abuse and then threaten the victim to make the photos public (Burns and Oswald, 2015).

Parental overprotection often ends up enhancing adolescent vulnerability. Being socially isolated, without access to education and information, with low self-esteem and awareness of what is acceptable and what is not, adolescents with disabilities can be emotionally needy and desperate to make friends. They may thus be easily manipulated and tolerate abusive behaviours in their intimate relationships (UNICEF, 2005; ACPF, 2010). For instance, almost all respondents in another multi-country study in sub-Saharan Africa – including survivors, carers and professionals – failed to recognise verbal sexual

abuse, sexual assault and pornography as types of sexual violence (Ellery et al., 2011).

Children and adolescents with disabilities are indeed vulnerable to child pornography and child prostitution (UN Committee on the Rights of the Child, 2007), including being trafficked into prostitution (UNGA, 2012). In a study in Cameroon, 30% of respondents with disabilities revealed having been forced into prostitution (ACPF, 2010). In particular, girls with disabilities are at risk of being targeted and either trafficked or sold into prostitution, under the assumption that their impairment makes them more compliant and less able to escape (UNICEF, 2005).

In some settings, adolescents with disabilities have been vulnerable to particular risks. For instance, in the context of the HIV epidemic in sub-Saharan Africa, they have been vulnerable to 'virgin rapes'. In some countries, it is common belief that if an HIV-positive person has sexual intercourse with a virgin, it transfers the virus to the latter, thus curing the former. Children and adolescents with disabilities are thought to be sexually inactive and have thus been targeted by some desperate HIV-positive people (UNICEF, 2005; WHO and UNFPA, 2009).

## Psychological and emotional violence

Children and adolescents with disabilities often experience emotional violence. A systematic review concluded that they are 4.3 times more likely to experience emotional abuse than their peers without disabilities (Jones et al., 2012). Indeed, adolescents with disabilities report being teased, ridiculed, verbally insulted or humiliated by other family members, peers and people in domestic and public spaces. For instance, they are often called not by their name but by their impairment, and can be bullied regularly by their parents and siblings or classmates and staff at school (UNICEF, 2005; Pinheiro, 2007; CREA, 2012; Burns and Oswald, 2015) (see Box 4.3).

In a multi-country study in sub-Saharan Africa, all youth with disabilities indicated that they had experienced emotional violence, which was thus the most frequent form of violence they experienced during childhood and adolescence (ACPF, 2010). In Ethiopia, 41% of adolescents and youth with disabilities reported having been teased or harassed because of their impairment (Population Council and UNFPA, 2010). Similarly, in Uganda, nearly 30% of children and adolescents with disabilities reported being verbally abused by family members (ACPF, 2011).

### Box 4.3: Bullying at school

Our findings highlight that adolescents with disabilities are particularly vulnerable to bullying at school. In Bangladesh, adolescents with disabilities told us that they were often teased and bullied by their peers. In Mohammadpur, a 17-year-old girl with a progressive visual impairment reported that her response was always passive: *'I don't say anything, sometimes I cried at home.'*

A 15-year-old boy with a physical impairment from the same community similarly explained that most of the time he, too, simply retreated: *'Because I have problem [disability] in my leg they have done terrible things to me, they have verbally abused me.'* Because of this abuse, his favorite possession is a music player that his brother bought him. *'When I used to go to others' house to listen... people used to be rude to me... Since we have our own, I can stay at home and I don't need to go to other people's houses anymore.'* Sometimes he pushes back against his tormentors, but when he is in a better mood he simply reminds them that it *'is all in Allah's hands'*. When he is angry, however, he told us, he replies in kind – using scathing language to disparage not only those bullying him but also their families.

In Ethiopia, adolescents with different types of impairments also complained of bullying. A 16-year-old boy, who is blind, noted, *'I was frequently facing such incidents in the school. I was insulted and harassed by both female and male students and mostly male students who were my own classmates and from other class.'*

Ethiopian special needs education teachers admitted that adolescents with intellectual impairments often were the targets of bullying by peers and that inadequate staffing meant that the teachers struggled to support these young people to cope with integrated classrooms, thereby further highlighting their difference. Other students encircle students with intellectual impairments and consider them different. *'For instance, this student was crying due to the actions of other students towards her. So they are frustrated to come to school. Sometimes the young students kick them.'*

Apart from reinforcing stigma and discrimination, such behaviours have a negative impact on adolescents' self-perception and their belief in their abilities and aspirations about adult life. Recalling the derogatory comments she heard during childhood at home and in school, a young Indian woman with a visual impairment noted that they *'used to make us feel like, really we are not capable of anything'* (CREA, 2012: 62). Similarly, an adolescent girl with a visual impairment in Gaza stressed that when her father calls her using bad nicknames: *'I hate that, he really hurts me a lot'* (Jones et al., 2016: 62).

 *'Because I have problem [disability] in my leg they have done terrible things to me, they have verbally abused me.'* Because of this abuse, his favorite possession is a music player that his brother bought him. *'When I used to go to others' house to listen... people used to be rude to me... Since we have our own, I can stay at home and I don't need to go to other people's houses anymore.'*

(15-year-old boy with physical impairment, Bangladesh)

 They were calling him deaf, speechless, and unable to walk. You know how are our community and their perception about the disabled... So, I wanted to move to another house to have more time for my son.... They were calling me the mother of the deaf. Usually, when I come back from the hospital, because I was either with him or with his brother who has asthma, I heard them saying "you deserve all of that"

(Mother of 11-year-old boy who is deaf, Jordan)

It is also important to highlight that psychological or emotional violence is not limited to adolescents with disabilities themselves but can also be directed towards their parents or caregivers who, as we also discuss in Chapter 3 on Psychosocial Wellbeing, may be ostracised for having a child with a disability and be subject to psychological and possibly physical violence by family members (Jones et al., 2016) (see Box 4.4).

#### Box 4.4: Emotional violence experienced by caregivers

In some contexts, female caregivers are the targets of emotional violence by family members who attribute blame to the mother for having given birth to a child with a disability, as this quote highlights. Such violence leaves women in these situations socially isolated, as there is typically a dearth of support networks, let alone formal services, including counselling:

*'We did not have a house previously and we were living at my aunt's house; it was small, and they were bullying my son... They were calling him deaf, speechless, and unable to walk. You know how are our community and their perception about the disabled... So, I wanted to move to another house to have more time for my son.... They were calling me the mother of the deaf. Usually, when I come back from the hospital, because I was either with him or with his brother who has asthma, I heard them saying "you deserve all of that". I don't like to mingle with any of them, all what I care about is only my family, I'm not selfish, but that's what I care about... We moved to a rented house, and we sold our car, so our living condition is getting worse, but still it brought me peace of mind. I'm happy with all what God gives me, even my disabled son, it is his destiny. I moved out only to have more time for him.'*

(Mother of 11-year-old boy who is deaf, Jordan)

## Neglect

Children with disabilities face the risk of neglect since birth and throughout their life. A systematic review found that children and adolescents with disabilities have a 4.6 times higher risk of neglect than those without a disability (Jones et al., 2012). Some are abandoned by their parents: in Ethiopia, children with disabilities can be left in churches, market places or on the street (SDD, 2010). They may receive less (or less nutritious) food, inadequate medical care, and less supervision and other support necessary

for their wellbeing (UNICEF, 2005; Pinheiro, 2007). Indeed, in a multi-country study in sub-Saharan Africa, 17% of respondents reported having been denied food more than 10 times (ACPF, 2010). In India, neglect during childhood and adolescence was a common form of violence reported by women with disabilities, with some parents not paying enough attention to or neglecting the health needs of their daughters with disabilities (CREA, 2012).

Adolescents with disabilities in institutions are also vulnerable to neglect. In several countries, children with



An adolescent girl, with a visual impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

disabilities are abandoned and placed in institutions. In some Central and Eastern European countries, the UN Children's Fund (UNICEF) has estimated that a child with disability is almost 17 times more likely to be placed in an institution compared to those without disabilities (UNICEF, 2013). Where institutions face serious financial and human constraints, children and adolescents with disabilities may experience poor living conditions and neglect, including having to live in overcrowded and dirty wards, being malnourished, or being heavily medicated as the only way to control them (UNICEF, 2005; Ellery et al., 2011). In the early 2000s, a Human Rights Watch report (2001) noted that in some countries in Eastern Europe where institutionalisation was the norm, children with disabilities living in institutions had high death rates.

## Experiences shaped by gender

Although gender-disaggregated data is scarce, evidence indicates that in most settings, adolescent girls with disabilities are more likely than boys with disabilities and girls without disabilities to face increased risk of violence, especially neglect, sexual violence and abuse, and intimate partner violence.

In contexts characterised by strong son preference, girls with disabilities are at greater risk of neglect than boys with disabilities. In Nepal, the survival rate for boys some years after they had poliomyelitis was twice that for girls. The reason is that despite having similar rates of infection, girls had less access to food, medical care and other resources required to survive. In such contexts, girls with disabilities are also more vulnerable to 'mercy killings' (UNICEF, 2005).

While adolescent boys with disabilities are also vulnerable to sexual violence, girls with disabilities are at higher risk. For instance, a study in five sub-Saharan African countries found that they were more likely to experience sexual violence more frequently than boys with disabilities – 28% of girls reported experiencing sexual violence more than 10 times compared to 16% of boys with disabilities (ACPF, 2010). In Ethiopia, 33% of sexually experienced adolescent girls and young women with disabilities reported having been forced to have sexual intercourse, compared to 15% of those without disabilities and 2% of boys and young men without disabilities (Population Council and UNFPA, 2010). Similarly, younger adolescent girls with disabilities in Ugandan schools

 If girls walk through the streets, many unruly boys make weird facial gestures and do eve-teasing [sexual harassment]. Once a boy told me he will do something to me so that I cannot show my face in society. I walk straight past and don't say anything, but sometimes I cried at home.

(Girl with a physical impairment, 17 years, Bangladesh)

reported experiencing significantly more sexual violence (24%) compared to girls without disabilities (12%) and boys with disabilities (7%) (Devries et al., 2014). School-related sexual violence is a major reason for girls with disabilities dropping out of school (Abu Al-Ghaib et al., 2017). Our findings in Bangladesh and Gaza indicate that adolescent girls with disabilities are likely to be especially vulnerable to sexual harassment due to limited awareness of the risks and ways to protect themselves (see Box 4.5).

Adolescent girls with disabilities are also more vulnerable to particular risks. As noted earlier, they have been more vulnerable to 'virgin rapes' in the context of the HIV epidemic (UNGA, 2012). They are also more vulnerable to being trafficked for prostitution and exploitation (Pinheiro, 2007; UNGA, 2012). Given their vulnerability to sexual violence and abuse and their limited knowledge of sexual and reproductive health (SRH) issues, girls with disabilities may be subjected to forced contraception or forced sterilisation, either as protection from unwanted pregnancies, a mechanism for menstrual management or as part of eugenics efforts (WHO and UNFPA, 2009; UNICEF, 2013; UNGA, 2017). They may also be subjected to forced or coerced abortions at the request of their parents or health professionals (Frohman and Ortoleva, 2013). Although such practices are still legal in many countries, they constitute gross violations of girls' right to physical integrity, and have adverse and lifelong physical and psychosocial consequences (UN Committee on the Rights of the Child, 2007; UNGA, 2017).

Girls with disabilities from ethnic, linguistic and other minorities – as well as those from indigenous populations that tend to face marginalisation and exclusion – may be particularly vulnerable to violence due to intersecting disadvantages (UNGA, 2012).

On the other hand, boys with disabilities may be more vulnerable to corporal punishment and physical violence

### Box 4.5: Adolescent girls with disabilities risk sexual harassment

Across country contexts, adolescents, caregivers and teachers all noted that adolescent girls with disabilities were likely to be especially vulnerable to sexual harassment as a result of limited awareness of the risks and how to protect themselves, and also in some cases to deception and sexual abuse, as these quotes illustrate:

*'I want to work in the garment factory, but... when girls are on their way to office, bad people throw bad comments, throw bricks, pull scarves. But they do most with garment workers. Also garment line manager and other male staff touch women's bodies.'* (Girl with a physical impairment, 18 years, Bangladesh)

*'If girls walk through the streets, many unruly boys make weird facial gestures and do eve-teasing [sexual harassment]. Once a boy told me he will do something to me so that I cannot show my face in society. I walk straight past and don't say anything, but sometimes I cried at home.'* (Girl with a physical impairment, 17 years, Bangladesh)

*'I used to wait for her [my daughter] to finish classes at school and bring her home as she was being harassed on the way home. My son called that boy one day and took care of it. My older son told him, "We better not see you doing this again".'* (Mother of adolescent girl with disability, Bangladesh)

*'Adolescents constitute around 70% of our beneficiaries. Adolescents with hearing impairments tend to be easy going and they can be easily manipulated. They are more vulnerable and tend to be easily deceived sometimes. They could be easily sexually abused, and exploited. In Gaza, we are a closed community, people know little about it and the deaf people know even less than what others know about sexuality. We developed a child protection policy to protect them, we train the staff and their parents on that policy. Because they are unable to communicate they are more vulnerable than others – 2 to 8 times more exposed than others. The perpetrator thinks that the deaf can't talk about that or tell others when s/he is exposed to harassment, therefore they tend to sexually abuse them.'* (NGO service provider, Gaza)

in some contexts compared to their female peers. In Afghanistan, boys with disabilities were more likely to report corporal punishment than girls with disabilities (van der Heijden and Dunkle, 2017). And in Ethiopia, 6% of adolescent boys and young men with disabilities reported having been beaten or hit compared to 2% of boys without disabilities and 1.5% of girls and young women with disabilities (Population Council and UNFPA, 2010).

### Harmful traditional practices

Although it is often assumed that adolescent girls and young women with disabilities do not marry, this is a misconception; the truth is that they are also at risk of child and forced marriage in several LMICs (UNGA, 2012). Accurate data is unavailable and it is debatable as to whether adolescent girls with disabilities are at higher risk than their peers without disabilities (CSID, 2002; Rana et al., 2008; NGDO et al., 2015). However, studies from South Asian countries with high rates of child marriage have highlighted that adolescent girls with disabilities can marry early. For instance, a study of adolescents and youth with disabilities in a remote district in western Nepal found that 23% of female respondents with disabilities were married – 83% of them having married in adolescence (Rana et al., 2008).

While some are love marriages, evidence indicates that in several cases, parents may perceive their daughter with a disability as a burden and try to marry her off early against her will so that somebody else takes care of her. Yet this practice increases girls' risk of experiencing abusive relationships as men often marry girls with disabilities for financial reasons (Burns and Oswald, 2015; UNGEI and LCD, 2017). Husbands may also be forced by their families to marry a girl with disability in order to access her dowry or property (CREA, 2012). Evidence from Bangladesh and India suggests that parents of girls with disabilities may actually be asked to pay higher dowries to compensate prospective husbands for their daughters' 'imperfection' (Groce et al., 2014; Burns and Oswald, 2015; NGDO et al., 2015). In Bangladesh, it is commonly believed that women with disabilities cannot manage their household effectively and that they will give birth to children with disabilities. Due to social status issues, wealthy families are more likely to face difficulties in marrying their children with disabilities compared to families on lower incomes (Burns and Oswald, 2015).

If, after such a marriage, parents are unable to pay the agreed dowry, husbands tend to become violent with their wives (Hasan et al., 2014). Even when the dowry is

paid, the husband may still become abusive to his wife (CREA, 2012; Burns and Oswald, 2015). In settings where polygamous marriages/unions are common, including in some sub-Saharan African countries, adolescent girls with disabilities can become second or third wives (Yousafzi and Edwards, 2004; Groce et al., 2014). Some young women with disabilities report that they are willing to accept a partner who might mistreat them (UNGA, 2017).

Girls with disabilities are also vulnerable to female genital mutilation/cutting, even in countries where such practices are illegal (UNGA, 2012; 2017). In a study in Ethiopia, 57% of girls with disabilities reported having been cut (ACPF, 2010).

### Intimate partner violence

In settings where child and forced marriage is common, married girls and young women with disabilities are at high risk of intimate partner violence (NGDO et al., 2015). In a study with married adolescent girls and women with disabilities in Bangladesh, the vast majority reported having experienced at least one act of intimate partner violence either because of their impairment, their family's inability to pay satisfactory dowry to the husband, or poverty. While almost all reported experiencing verbal abuse, many revealed severe physical violence due to dowry payment problems, failure to follow the husband's instructions properly, or for no apparent reasons (Hasan et al., 2014). In India, women with visual impairments and low-income women with disabilities reported higher rates of violence compared to peers with physical impairments and better socio-economic status. Most girls and women with disabilities reported having experienced emotional and physical violence and some revealed sexual abuse from intimate partners because of their impairment (CREA, 2012).

Evidence from high-income settings indicates that adolescents with disabilities, particularly girls, are more likely to experience violence in their intimate relationships

('dating violence'), leading to increased risk of poor mental health outcomes and substance abuse compared to their peers without disabilities (Mitra et al., 2013).

## Access to protection, justice and support services

Despite their increased vulnerability to violence, children and adolescents with disabilities encounter significant challenges to access protection mechanisms, while survivors of violence are often unable to report abuse, access support services and demand justice. Most countries have legal systems and protection mechanisms in place to prevent and address violence against children, including those with disabilities. However, limited evidence from LMICs indicates that laws are often not enforced, protection mechanisms remain unresponsive, survivors are left unsupported, perpetrators are not prosecuted and abuse is tolerated (UNICEF, 2005; Plan International and LSHTM, 2016) (see Box 4.6).

Providing evidence and persisting in demanding justice can be extremely difficult due to combined social, attitudinal, environmental and institutional barriers (Plan International and LSHTM, 2016). Children and adolescents with disabilities and their families may be unaware of their right to be treated with dignity and respect, and to be protected; they may be unaware of what is acceptable and non-acceptable or abusive behaviour, and may even consider what happened to them as justified on the grounds of their disability. In some cases, they may be dependent on the perpetrator, and may risk further violence or lose support if they report and seek help (UNICEF, 2005; ACPF, 2010; Ellery et al., 2011; UNGA, 2012).

Children and adolescents with disabilities may also be unaware of where and how to access assistance and pursue justice. Additional barriers include accessibility issues such as long distances to legal and judicial services,

### Box 4.6: Adolescents with disabilities are less likely to report violence and abuse



Existing evidence suggests that adolescents with disabilities are more likely to experience violence and abuse, as they are perceived to be an easy target and less likely to report the incident. However, the GAGE survey revealed no statistically significant findings in our Bangladesh sample in terms of the likelihood of adolescents with disabilities experiencing or witnessing violence at home, while in Ethiopia, girls (17%), younger adolescents (12%) and rural residents (17%) with disabilities were all less likely to say they had experienced or witnessed violence at home. This finding needs further exploration: it could mean that they are at lower risk at home; or that they are less likely to self-report violence due to gender and age-related norms; and/or that adolescents with certain impairments face challenges in communicating what has happened to them.



An adolescent girl, with a hearing impairment, Bangladesh © Marcella Pasotti / GAGE 2018

and lack of or limited accessible transportation and facilities; most importantly, they often face discriminatory and insensitive attitudes on the part of child protection, police and court officials who tend to lack training on how to work with (and communicate with) children and adolescents with disabilities, and are reluctant to assist them to access justice (NGDO et al., 2015; Plan International and LSHTM, 2016). In particular, girls and young women with disabilities are more likely to face difficulties accessing justice when they have been subject to sexual and gender-based violence (UNGA, 2012; 2017). For instance, in Bangladesh, 59% of survey respondents reported that the investigation officer appointed to collect evidence from children and women with disabilities in cases of violence and abuse did not carry out the interview (NGDO et al., 2015).

Even when adolescents with disabilities report abuse, they often have to go through a lengthy and demanding formal process to bring their case to court. Even then, they may be deemed incompetent to provide reliable evidence at trial (especially those with visual and intellectual impairments), and they may either withdraw the case or the alleged perpetrator may be acquitted (Plan International and LSHTM, 2016).

In a study in five sub-Saharan African countries, over half of respondents who had experienced rape reported the incident; yet the majority felt that nothing had been done as a result of their action, with only 23% of girls and 9% of boys with disabilities being satisfied with the way their case was dealt with. In addition, 45% of those who had experienced physical violence told someone about the incident, but fewer than 1% reported it to the police

(ACPF, 2010). In a similar study in four other sub-Saharan African countries, the majority of survivors stressed 'an overwhelming lack of support' in both urban and rural settings, with the family and the community providing some help instead of local authorities and service providers (Ellery et al., 2011: 15). However, this breeds 'a culture of chronic impunity' within which adolescents with disabilities and their families are repeatedly let down, their rights violated, their vulnerability compounded, and discrimination is systematically perpetuated and reinforced (ibid.).

In some contexts, the perpetrator of sexual abuse resorts to informal dispute resolution mechanisms and settles the issue out of court by providing money to the survivor's family or, in the case of a girl with disability, by marrying her (Burns and Oswald, 2015; NGDO et al., 2015). For instance, in Bangladesh, a survey found that in 61% of cases, the dispute was settled through the traditional mechanism (shalish), with girls with disabilities being forced to marry the man who raped them in order to preserve their family honour (CREA, 2012; NGDO et al., 2015).

Limited evidence from LMICs also indicates that support services and programmes for survivors with disabilities, including specialised and accessible shelters, are lacking, let alone being age- and gender-appropriate. In several cases, government or NGO services for survivors do not include adolescents with disabilities, particularly those from poor households who are unable to afford the required support (UNICEF, 2005; UNGA, 2012; Plan International, 2017). For instance, half of respondents in a survey in Bangladesh reported that there were no counselling services available for survivors (NGDO et al., 2015).

## Experiences shaped by impairment type

Although the number and severity of a young person's impairments may increase the risk of exclusion and abuse, and particular impairments may increase vulnerability to specific forms of violence, overall evidence indicates that adolescents with physical, sensory and intellectual impairments are at increased risk of violence.

However, several studies suggest that those with intellectual or psychosocial impairments may be at greater risk (Plan International and LSHTM, 2016). A widely cited systematic review of studies in high-income settings concluded that adolescents with intellectual or psychosocial impairments are 4.6 times more likely to experience sexual violence, 4.3 times more likely to experience emotional abuse and 3.1 times more likely to experience physical violence than those without any impairment (Jones et al., 2012).<sup>5</sup> A number of studies in LMICs also confirmed that children and adolescents with intellectual impairments are more vulnerable to physical violence (ACPF, 2010) and sexual violence and abuse (Burns and Oswald, 2015); in a small survey in Orissa, India, one in four girls and women with intellectual disabilities had been raped (Ellery et al., 2011). However, a multi-country study in sub-Saharan Africa found significant variation between countries, with adolescents with intellectual impairments more vulnerable to sexual violence in one country but not in another (ACPF, 2010).

In some contexts, a common belief is that those with intellectual impairments are possessed by powerful spirits that can make other people wealthy or successful in the community. Those who have sexual intercourse with a person with such an impairment are thus able to benefit from exceptional powers. Alarming, a study in South Africa reported a similar belief that people with intellectual impairments are unable to feel pain or pleasure, thus they cannot suffer from sexual abuse (Braathen et al., 2017).

As already noted, adolescent girls and young women with intellectual impairments are also more vulnerable to forced contraception, forced sterilisation and forced abortions at the request of their parents or health professionals (Frohman and Ortoleva, 2013; UNICEF, 2013; UNGA, 2017). Limited data suggests that sterilisation rates for these girls and women are higher than the rate for the general population (UNGA, 2012; 2017).

Those with psychosocial impairments may be more vulnerable to physical violence within their own family. In Bangladesh, they may be perceived as unmanageable or violent, and as some community members like to provoke them, their families often tie them up inside the house (Burns and Oswald, 2015). Similarly, in Ethiopia, those with psychosocial impairments face greater stigma and may be chained inside the home, while those with epilepsy may be beaten when they have seizures as people are unaware of how to handle them (SDD, 2010).

In East Africa, misconceptions about children and adolescents with albinism and their exceptional powers not only make them vulnerable to violence and abuse, but can be life-threatening. Some communities believe that having sexual intercourse with a person with albinism brings good luck, wealth or success (Aley, 2016). Participatory research in Tanzania reported that as a result of these beliefs, persons with albinism experience harassment, torture and sexual abuse, and their lives are in danger, as they may be killed and their limbs amputated to be used for good fortune, or their organs removed to be used in sorcery rituals (Mrisho et al., 2016).

Evidence also suggests that adolescents with sensory impairments that result in communication difficulties are also particularly vulnerable to violence (Plan International and LSHTM, 2016). Those with speech impairments are often perceived to be an easy target to be assaulted or abused as they may be less able to reveal who the perpetrator was, while those with visual impairments may find it difficult to provide an accurate description of their attacker (UNICEF, 2005; Burns and Oswald, 2015). Those with physical impairments may also be less able to escape if assaulted (UNICEF, 2005).

As a result, children and adolescents with physical or visual impairments, especially girls, are often vulnerable to being trafficked into forced begging, as a visible disability tends to generate sympathy and charity; in other cases, girls with disabilities are forced into prostitution on the assumption that they are less able to leave (UNGA, 2012). For instance, owners of establishments with sex workers in Thailand sought out girls with hearing impairments as they were less able to communicate and escape (Pinheiro, 2007).

<sup>5</sup> The other systematic review on the risk of violence against persons with disabilities aged 18 years and older found that those with no specific impairments are 1.3 times more likely to experience violence than those without disabilities, those with intellectual impairments 1.6 times more likely, and those with mental health conditions nearly 4 times more likely (Hughes et al., 2012).

## Experiences shaped by context

Adolescents with disabilities in humanitarian contexts often remain invisible; their right to protection and freedom from violence is neglected, and their needs are overlooked by mainstream assistance programming. They are vulnerable to violence during flight, when they are trying to escape, as well as in camps and organised settlements, but also in urban settings where there are fewer community protection mechanisms and refugees remain hidden from authorities, with greater difficulty in accessing necessary support (WRC, 2008; UNICEF, 2013).

In such contexts, adolescents with disabilities, especially girls, are at greater risk of physical, sexual and emotional abuse, neglect and exploitation (Rohwerder, 2017). A study by the Women's Refugee Commission (WRC) in Lebanon identified the increased vulnerability of Syrian refugee children and youth with intellectual impairments: in some cases, families were using physical and medical restraints to prevent them from leaving the shelter due to fear and stigma; in other cases, family members were using physical violence against them as a means of controlling their behaviour (WRC, 2013). In similar studies in other refugee and displaced contexts, children and adolescents with

disabilities (especially those with intellectual impairments) and their caregivers report being emotionally abused by peers without disabilities and thus reluctant to attend school (WRC, 2014).

While boys and young men with disabilities are more likely to report physical and psychological violence, adolescent girls and young women and their caregivers across diverse settings – from sub-Saharan Africa to the Middle East and South Asia – stress their greater risk to sexual violence and abuse, particularly for those with intellectual and psychosocial impairments (WRC, 2014; Tanabe et al., 2015). Sexual violence against boys with intellectual impairments was reported in Burundi and Jordan, yet to a lesser extent than for girls and young women. Conflict and displacement exacerbate the discrimination and vulnerability experienced by adolescents with disabilities, and the breakdown of existing structures and networks of support, along with difficult living conditions, heightens the risk of sexual violence and exploitation. Respondents noted that girls with disabilities are vulnerable to sexual assault and rape, both in their own shelter and in camp spaces, on a regular basis; some spoke of exploitation by community members, whereby girls and women with disabilities engage in survival sex (WRC and IRC, 2015).



An adolescent girl, with a physical impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

Evidence suggests that survivors often do not report cases of violence and do not access support services due to discrimination and negative attitudes, not only on the part of family and community members but also among humanitarian staff and service providers. The latter may question their credibility (especially for refugee girls and women with impairments that make communication difficult), and fail to maintain confidentiality, while they frequently lack sufficient knowledge or skills to communicate with and support those with particular impairments (WRC and IRC, 2015; Marshall et al., 2017).

## Evidence gaps

This capability area has attracted considerable research and policy attention in recent years. However, most evidence comes from high-income settings, and there is a lack of rigorous research and accurate data from LMICs, where the vast majority of adolescents with disabilities live. For instance, there are two systematic reviews on the risk of violence against two particular groups of persons with disabilities: Jones et al. (2012) focused on children with disabilities, while Hughes et al. (2012) focused on adults with disabilities (aged 18 years and over). Both concluded that disability increases the risk of violence. Although both reviews have been widely cited, both are based on a small number of studies that took place in high-income countries. Jones et al. (2012) included 17 studies, all of which were conducted in just six high-income countries. Similarly, Hughes et al. (2012) used 25 studies from six high-income countries and just one from a middle-income country (South Africa). Commenting on the evidence base, both reviews emphasised that studies are characterised by methodological weaknesses such as poor design and measurement standards. Thus significant knowledge gaps remain and robust evidence is scarce, particularly from LMICs, where available information suggests that children and adolescents with disabilities, especially girls, are highly vulnerable to violence.

Indeed, several reports by international and regional NGOs present evidence about the challenges that adolescents with disabilities experience in their daily lives in diverse contexts, from sub-Saharan Africa to South Asia. However, in most cases this evidence is based on small-scale qualitative and quantitative research that typically focuses on children with disabilities without disaggregating data by age, location, ethnicity or type of impairment. Although it appears that as soon as children reach puberty their vulnerability to sexual violence increases

(ACPF, 2010), there has been no explicit attention paid to the particular threats and needs of adolescents with disabilities, as most often, adolescents are lumped together with children. There is also very little information about adolescents with disabilities in institutional settings. Regarding the forms of violence that threaten adolescent wellbeing, there is more information about physical, sexual and emotional abuse than about neglect, with a focus on the risk of such violence, but very little knowledge on the lived experiences of violence, the factors that build adolescent resilience, and the particular needs and support mechanisms of adolescents (see Table 4.1).

Limited evidence from LMICs also suggests that existing child protection mechanisms may not adequately cover children with disabilities, although community-based programmes tackling violence for all children could also benefit children with disabilities (Plan International and LSHTM, 2016). However, evidence on what works to prevent and reduce violence against children and adolescents with disabilities is lacking. A systematic review of the effectiveness of interventions to prevent and respond to violence against persons with disabilities by Mikton et al. (2014) found only 10 studies which met the inclusion criteria; nine were from high-income countries and only one was from a middle-income country (South Africa). Only two studies focused on children: one examined an intervention with parents of preschool children with disabilities, the other an intervention with families with children with disabilities. Moreover, the majority of studies assessed interventions for persons with intellectual impairments. Most importantly, all studies had weak quality and none could be considered effective due to high risk of bias. Thus Mikton et al. (2014) concluded that the current evidence base offers little guidance about what works; more and better-quality evidence is needed, particularly from LMICs, and on adolescents with other impairment types such as physical, sensory and psychosocial impairments.

Similarly, as part of the global What Works to Prevent Violence Against Women and Girls programme, van der Heijden (2014) identified only nine interventions to prevent violence against women with disabilities; most of these prevention programmes were implemented in high-income countries and either did not include evaluation results or their evaluation had small sample sizes and minimal desired behavioural outcomes. Van der Heijden thus concluded that there is a lack of rigorous evidence, pointing out the need to generate more evidence about

**Table 4.1: Evidence gaps on bodily integrity and freedom from violence among adolescents with disabilities**

<b>Broader gaps</b>	Research has rarely focused on adolescents with disabilities as a particular group with specific vulnerabilities and needs. Large-scale, accurate and comparable data is missing, as violence is under-reported. Existing data is not disaggregated by age, gender, location or ethnicity, with adolescents usually lumped together with children or with youth/adults. We know more about adolescents' vulnerability to violence and abuse than their vulnerability to neglect. Apart from estimations of the risk of violence, we know very little about adolescent experiences of different forms of violence, its immediate and long-term impacts on their capability development, and resilience factors.
<b>Gender-specific gaps</b>	Adolescent girls have greater vulnerability to sexual violence, yet we know little about how disability intersects with gender and other factors to increase the risk of violence in diverse settings. We also need to know more about boys' risk of physical and sexual violence and exploitation.
<b>Gaps regarding impairment type</b>	Evidence suggests that all impairment types increase the risk of violence, especially intellectual and psychosocial impairments. Apart from general estimations from high-income countries, and small-scale qualitative evidence, the evidence base is extremely thin.
<b>Context-related gaps</b>	Data is rarely disaggregated by location. Thus there are very significant evidence gaps about the risks facing adolescents in rural and urban areas, in residential care, or in crises settings
<b>Policy and programming gaps</b>	Evidence on what works to prevent violence and protect and support adolescents with disabilities in general, and with specific impairments in particular, is lacking.

how to effectively prevent and respond to violence against women and girls with disabilities.

## Promising practices

Despite their increased vulnerability to violence, abuse and neglect, adolescents with disabilities in LMICs have typically remained invisible and are thus often let down by existing child protection mechanisms and programming. However, in recent years, several programmes implemented by international or national NGOs, in collaboration with local communities, to protect marginalised children from violence have also included children with disabilities. Some small-scale or pilot NGO-led programming has also explicitly targeted women with disabilities along with girls, given their higher risk of sexual and gender-based violence. While evidence on good practices to prevent and protect adolescents with disabilities from violence is lacking – let alone evidence on differences according to age, gender and impairment type – there are a few initiatives that provide insights about components and approaches that hold some potential.

### Programmes targeting vulnerable children and adolescents

One common type of intervention uses a broader approach and targets the most vulnerable children and adolescents, including those with disabilities, aiming to promote a safe

and inclusive environment. Such interventions employ a wide range of activities, such as interactive activities with children in schools, training of parents and service providers, improving coordination, improving disability-inclusive referral procedures and services for survivors of violence, and community awareness-raising on child protection and wellbeing.

The 'Ubuntu care regional project: confronting sexual violence against girls and boys, including children with disabilities' is a multi-country project launched in 2013 and implemented by Humanity & Inclusion (formerly Handicap International) in Burundi, Kenya and Rwanda. (In Bantu, the word 'Ubuntu' means 'I am what I am because we are', emphasising the close linkages between the individual and the community.) The project uses an inclusive child protection framework to protect children and adolescents, especially those with disabilities, against sexual violence, and to support survivors and their families. It organises interactive activities with girls and boys with all types of impairments to make them aware of the risks and to empower them by developing skills and taking part in recreation activities, children's clubs and protection committees. It also works with families and communities to change negative attitudes and enable them to better protect and support children. It collaborates with service providers to strengthen access to and quality of education, health, psychosocial and legal services, and uses data to



An adolescent boy, with a visual impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

advocate for more effective protection systems, including laws and policies that prevent and address sexual violence (Humanity & Inclusion, 2017; n.d.).

The Ubuntu care project is now in its second phase. In Rwanda, where it is implemented in Rutsiro district, Western province, the project collaborates with the National Commission for Children, two local NGOs, a specialised centre for children with disabilities, and local authorities. In 2017, it targeted 18,000 children at risk of sexual violence and assisted 1,200 survivors of sexual violence and/or isolated children with disabilities, along with 4,800 members of their families. It also: created inclusive children's clubs in schools; set up a district children's advisory committee; organised training for teachers on sexual violence, disability and the rights of the child; organised training for health facilitators and community focal points on psychosocial support; and organised training for justice professionals on the management of sexual violence against children with and without disabilities. Finally, it initiated a task force to improve management of cases of sexual violence and promoted and improved collaboration between service providers. As a result, coordination and management have improved, and nearly 70% of identified cases have

received treatment, been referred to the police and received support to be reintegrated into the community. This includes survivors with visual and hearing impairments who were usually left unsupported due to communication problems and the lack of capacity of service providers to collect evidence and provide assistance (Humanity & Inclusion, 2017; 2018a; n.d.).

### **Programmes targeting girls and women with disabilities**

Another common intervention for women and girls with disabilities focuses on increasing their awareness of rights, risks and services in relation to sexual and gender-based violence. Such interventions also aim to strengthen women's and girls' capacity to protect themselves, while also working with their families, service providers, traditional and community leaders, disabled people's organisations and women's organisations to prevent and respond to sexual and gender-based violence (see Box 4.7).

Set up and run by family members of persons with intellectual impairments, the Kenya Association of the Intellectually Handicapped (KAIH) collaborated with the Coalition of Violence against Women (COVAW), a women's rights organisation, on a project in two counties in Kenya

### Box 4.7: Awareness-raising is key to protecting adolescent girls with disabilities from harassment and abuse

Our research findings indicate that, through awareness-raising efforts at schools and by civil society organisations, adolescent girls with disabilities are learning how to protect themselves more effectively, as these quotes from adolescents and teachers attest:

*'Girls with disabilities used to die while trying to have unsafe abortion. Not because of forced sex, rather it is voluntary but they are deceived. It could be students with hearing disability or non-disability students, but usually the students without a disability who deceive them in the name of long-time love relationship or marriage. Girls used to lack awareness, but now they have the awareness and are not exposed for such problems.'*

(Boy who is deaf, 16 years, Ethiopia)

*'I read a book. The title was "Meyeder Protibad Korar Shikkha" ("A Lesson for Women on How to Protest"). Protestation is but part of life. If someone says something to you and you don't protest then it will encourage him to tease you even more. He will keep annoying you every day. Many similar issues are discussed in the book. That's how I learnt how to protest.'* (Girl with a physical impairment, 16 years, Bangladesh)

*'Apart from this, we teachers provide advice for the special needs students on how they should protect them from HIV and sexual abuse. This is because they are easily tempted by simple gifts.'* (Special needs teacher, Ethiopia)

in 2013. It aimed to improve awareness and to enhance access to justice for girls and women with intellectual impairments who had survived gender-based violence. It engaged with a wide range of stakeholders (such as legal and disability experts and gender activists) and aimed to bring change at local, national and international levels. While KAIH engaged closely with communities, traditional leaders and families to identify girls and women survivors with disabilities, COVAW provided survivors with psychosocial and legal support and protection through partnerships with the Gender-Based Violence Recovery Centre at the local national hospital, with psychologists and psychiatrists, and a network of lawyers offering free advice and representation. The project helped with funding for the relocation of survivors in need of protection (Humanity & Inclusion, 2018b).

Participants with intellectual impairments became more aware of their rights and became more confident to take action, including reporting cases of violence or abuse to the police. Families also started to report abuse instead of keeping silent to avoid further stigma, and were less likely to accept informal settlements of their case by traditional leaders. Community dialogue sessions and training sensitised community members on the vulnerability of girls and women with intellectual impairments, and improved the awareness and engagement of traditional leaders. Training for health workers, police and the judiciary built their capacity to support survivors to access services and seek justice, and

 I read a book. The title was "Meyeder Protibad Korar Shikkha" ("A Lesson for Women on How to Protest"). Protestation is but part of life. If someone says something to you and you don't protest then it will encourage him to tease you even more. He will keep annoying you every day. Many similar issues are discussed in the book. That's how I learnt how to protest.

(Girl with a physical impairment, 16 years, Bangladesh)

resulted in greater willingness on the part of police and the judiciary to investigate reports of abuse and to take cases to prosecution. Family members and social workers were also trained to become intermediaries and assist survivors or witnesses of violence. Indeed, two cases of sexual violence against two young adolescent girls with disabilities were prosecuted and perpetrators were sentenced to 20 years in prison, thus ending a culture of impunity and setting a legal precedent (ibid.).

In addition, COVAW engaged in reviewing judicial procedural obligations, regarding reasonable accommodations for persons with disabilities in the bench book for criminal proceedings. Proposed changes were incorporated into the draft book, which has since been validated and is awaiting official launch. Advocacy

efforts also culminated in COVAW's submission of the alternative report to the implementation of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) in Kenya. The submission was integrated into the 2017 concluding observations of the CEDAW Committee, which called on the government to protect girls and women with disabilities from all forms of violence and ensure the prosecution and punishment of perpetrators (ibid.).

Despite these positive changes, some challenges remained: discriminatory terminology in legal and policy documents held back progress sometimes; local media had to be involved to avoid cases getting stuck in the system; many families could not afford to go through the legal process and thus had to be assisted in participating in other income-generating projects; and boys and young men had to also be explicitly targeted not only because they were also vulnerable to sexual abuse but as their support



and engagement was necessary for tackling the problem of gender-based violence (Handicap International, 2015).

Similar initiatives involving the police and judicial authorities have been reported in other LMICs, from sub-Saharan Africa to South-East Asia. In Uganda, the National Union of Disabled Persons has trained 32 women with disabilities as paralegals who help survivors of gender-based violence to report their cases and do follow-up so that they can secure justice (UNGA, 2017). In Cambodia, ADD International has worked with local communities and disability activists to educate villagers about the rights of girls and women with disabilities and gender-based violence, including domestic violence and trafficking for prostitution. It also supports at-risk families through home visits, and trains police officers and local councillors on national and international legal frameworks on the protection of girls and women. In Cambodia and Bangladesh, projects included provision of safe houses to remove at-risk girls and women with disabilities or survivors (Andrae, 2016).

### Programmes targeting adolescents with disabilities in humanitarian settings

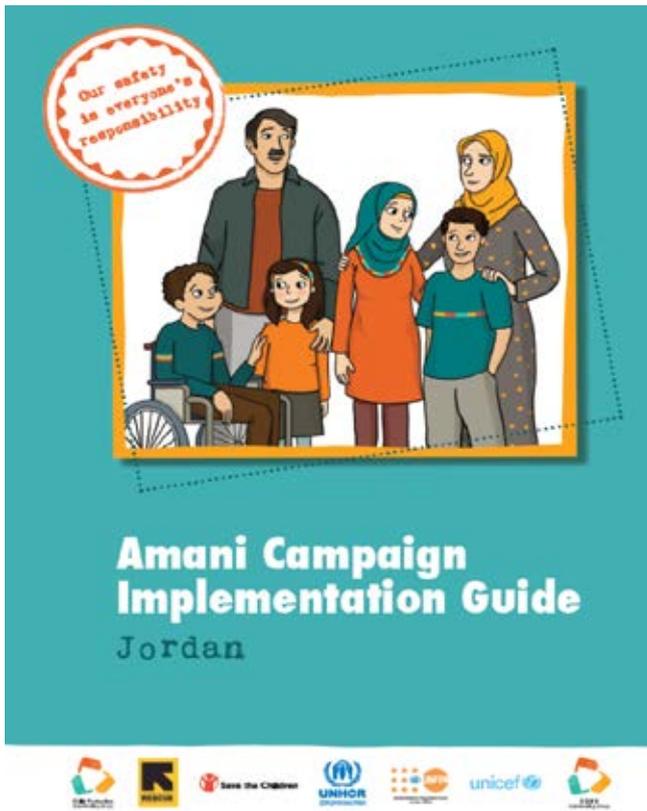
Increasing attention is being paid to girls and women with disabilities in conflict and crisis situations who are more vulnerable to violence and more likely to be excluded from services and programming. With financial support from the Australian Aid Programme, the WRC and the International Rescue Committee (IRC) undertook a project in conflict-affected communities in Burundi, Ethiopia and Jordan between 2013 and 2015. Using a participatory approach, the project consulted girls, boys, women and men with disabilities, and their caregivers, to inform the development of tools and activities, and then designed and assessed disability-inclusive pilots that were adapted to the needs of girls and women with disabilities in each setting (WRC and IRC, 2015).

Thus in Burundi, the project provided economic activities for persons with disabilities and their caregivers, recruited women with disabilities as community mobilisers for gender-based violence activities, and conducted community awareness-raising activities on the rights of

persons with disabilities. In Ethiopia, the project included 'coffee discussions' with women at the homes of persons with disabilities that enabled caregivers to access information on gender-based violence. It also strengthened women's peer networks, carried out home visits to disseminate relevant information to people isolated in their homes, and improved the physical accessibility of community buildings and latrines in the camp. In Jordan, disability inclusion was integrated into inter-agency child protection and gender-based violence case management training, and in a violence prevention campaign (see Box 4.8), while discussions with female caregivers raised awareness of the needs of children with disabilities (*ibid.*).

Most importantly, the project used a participatory assessment to identify positive practices for disability inclusion in gender-based violence programming in humanitarian settings. As a good prevention strategy, it identified the need to build peer networks for adolescent girls and women with disabilities and for their caregivers, creating groups in safe spaces and providing opportunities to meet to share ideas and information, and build trust and support, thereby reducing their social isolation. Taking part in activities with children without disabilities also opened up opportunities to girls and young women with disabilities to share their views and opinions, start being valued beyond their impairment, and reduce their vulnerability. Apart from increasing representation of persons with disabilities (including adolescent girls and young women) in community activities, their inclusion in carefully designed economic-strengthening activities also appeared to have positive impacts on their status and independence. Community activities promoting non-discrimination and awareness led to improved attitudes. The project set up home visits and home-based activities to reach those with intellectual and/or multiple impairments who are often isolated at home, raising their awareness of violence and available support services. The assessment also stressed the need to build the capacity of gender-based violence practitioners, who often need training so that they can better tailor services to survivors, through home visits, home-based activities and specialised case management approaches (WRC and IRC, 2015).

Box 4.8: The Amani campaign in Jordan



The Amani Campaign in Jordan aims to change the knowledge, attitudes and behaviours of children and adolescents, parents and communities about violence, abuse and exploitation. It also aims to contribute to preventing such acts, and ensure that survivors are supported and access available services. Launched in 2014, the inter-agency campaign was developed within the context of the Syrian refugee emergency response by the Child Protection and Sexual and Gender-Based Violence sub-working groups, which include UN agencies, international and national NGOs, ministries and national institutions, in collaboration with refugees and host communities. Drawing on best practices and lessons learned from other contexts, the campaign tested and adapted these practices in Jordan in both the Zaatari camp and in urban settings.

The campaign is built around Amani, a 15-year-old Syrian refugee girl, and her family and friends. Amani means ‘my safety’ and the campaign promotes the message that ‘our safety is everyone’s responsibility’. Amani has a brother who was injured in Syria and now uses a wheelchair, and she has friends with disabilities.

The campaign has 10 key units and messages, including one on persons with disabilities, the problems they face (broken down by age and by gender), and the services available in the community. The unit pays explicit attention to those with physical and intellectual impairments and the fact that some types of impairments can increase vulnerability to abuse or exploitation. The main message is: ‘Our abilities are different but our rights are always the same’. The campaign asks children and adolescents to speak up and report the abuse they experience or witness, so that they can get the help they need.

Key campaign tools include facilitator cards, posters, short animated films, brochures, contact cards, notebooks, bags and t-shirts. Activities include community conversations, events, storytelling using theatre, puppeteering, songs and performances, radio sketches, and use of social media. For instance, Amani contact cards include hotline telephone numbers for child protection and sexual and gender-based violence; these cards, along with Amani posters, are distributed in refugee registration centres. As a result, UNHCR has recorded an increase in the number of calls received on the InfoLine and the Protection hotline numbers that appear on the Amani contact card.

Sources: Child Protection Sub-Working Group et al., 2014a; 2014b



## 5 Voice and agency



## Voice and agency

**Recommendation:** Raise awareness of the importance of and opportunities for supporting adolescents with disabilities to be listened to and to participate in decision-making



Adolescents with disabilities, especially girls, face mobility restrictions due to inappropriate infrastructure, unaffordable assistive devices and discrimination



**Ethiopia:** GAGE survey data found adolescents with disabilities were **8% less likely** to have a say in household decision-making than peers without disabilities



Digital technologies can facilitate access to information and promote peer communication and self-expression, but access for adolescents with disabilities needs to be improved



Adolescents with disabilities are often unaware of their rights to equality and non-discrimination, and thus cannot claim or exercise them

## Key messages

- **Overarching challenges:** Adolescents with disabilities face significant restrictions to their mobility, due to inappropriate infrastructure and transportation, unaffordable assistive devices, persistent discriminatory attitudes and parental safety concerns, which hamper their opportunities for participation. They also frequently have little awareness of their rights and limited say over their lives, and despite their wish to actively participate, they are often excluded from family, school and community activities.
- **Gender dimensions:** Adolescent girls with disabilities are particularly disadvantaged in terms of voice and agency due to conservative gender norms, which limit their mobility irrespective of the type of impairment they have, and often preclude opportunities to participate in activities outside their home.
- **Impairment-specific challenges:** There is some evidence to suggest that adolescents with intellectual and psychosocial impairments may be more likely to face greater barriers to participation in their communities.
- **Context-specific challenges:** Information and communication technologies (ICTs) have the potential to facilitate access to information and promote peer communication and self-expression, especially for adolescents with disabilities who may be otherwise excluded from services. However, digital technology is often inaccessible and unaffordable for adolescents with disabilities in impoverished households and in rural settings.
- **Caregiver concerns:** Many parents do not adequately recognise the capacities of their adolescents with disabilities and their need to express their views, build self-confidence and start making independent choices and decisions. As a result, they may inadvertently risk infantilising their adolescent, and reinforcing their dependency and vulnerability.
- **Evidence gaps:** Although there is emerging participatory research with adolescents with disabilities, there is a dearth of rigorous evaluation evidence on what works to empower adolescents with disabilities, to enable them to participate in family and community life, to develop skills for civic engagement, and to facilitate their access to information and use of digital technology.
- **Promising practices:** Promising practices include involving adolescents with disabilities in age-appropriate decision-making structures and research, providing textbooks in accessible formats, building adolescents' awareness of their rights, enhancing their self-confidence to voice their needs and advocate for change, and sensitising local communities and authorities to address stigma and low expectations about what adolescents with disabilities can and should be allowed to do.

## Introduction

Despite growing awareness of the right of persons with disabilities to enjoy a full life, adolescents with disabilities in LMICs continue to face significant attitudinal, social, environmental and institutional barriers that hinder their access to physical spaces and information and prevent them from becoming aware of their rights (see Box 5.1). These barriers also prevent them from having a say in decisions that affect their lives and making age-appropriate choices, often isolating and excluding them from school and community activities. Lack of supportive physical and policy environments, poverty, and, most importantly, persistent stigma and discrimination, misconceptions about their capacities, and parental overprotection, serve to narrow the opportunities available to adolescents with disabilities, especially girls, to develop their social skills, exercise their voice and build their agency for a successful transition into an empowered adulthood.

▶ You know how people in the rural areas are. Once you are sick, nobody loves you. Losing part of your body means you are dead and buried. They see me as a dead person. They don't see me getting an education, with a job, married and having a life of my own.

(Girl who is blind, 16 years, Ethiopia)

### Box 5.1: Adolescents with disabilities face significant disadvantage in developing voice and agency



In Ethiopia, the GAGE survey found adolescents with disabilities scored 8% lower on an index of reported feelings on their say in household decision-making than adolescents without disabilities; younger adolescents scored 13% lower and rural adolescents 17% lower than their counterparts without disabilities.

As one adolescent girl with a visual impairment in our qualitative research sample highlighted,

*'You know how people in the rural areas are. Once you are sick, nobody loves you. Losing part of your body means you are dead and buried. They see me as a dead person. They don't see me getting an education, with a job, married and having a life of my own.'* (Girl who is blind, 16 years, Ethiopia)

## Mobility and access to spaces

Although accessibility is one of the eight general principles of the Convention on the Rights of Persons with Disabilities (CRPD), which obliges states to take appropriate measures, persons with disabilities continue to face significant difficulties in accessing the built environment and transportation, in urban and rural areas alike, with negative consequences for their equal participation in social, economic and political life. In several studies in LMICs, persons with disabilities, including adolescents and youth, have voiced their frustration. In Bangladesh, adolescents with disabilities point out the lack of disability-friendly infrastructure and facilities in hospitals, schools, workplaces and recreational settings (Burns and Oswald, 2015; NGDO et al., 2015). Similarly, in Nepal, adolescents with disabilities stress that the physical environment of their houses, schools, health clinics and community spaces is inaccessible and, in some cases, unsafe. One-third of survey respondents emphasised the challenge of having either no toilet or an inaccessible toilet and bathing facilities at home – an issue of particular concern for girls with disabilities (Bhatta et al., 2018). In Latin America, only 20% of schools in Brazil and less than 10% of schools in Mexico are accessible for children with disabilities (ECLAC et al., 2013). In Palestine, adolescents with disabilities also report that the physical landscape is very challenging, with schools and communities lacking the necessary adaptations to accommodate their needs (Jones et al., 2016). Similarly, in camps and settlements, refugee youth with disabilities, especially girls, have identified serious accessibility problems, including physical access to shelters, food distribution points, water points, latrines, schools, health clinics and community facilities (WRC, 2008) (see also Box 5.2).

Transportation is also identified as a major barrier. Half of respondents in a survey in Bangladesh noted that public transportation is not disability-friendly (NGDO et al., 2015). Nearly a third of children and adolescents in Palestine also identified public transportation as a significant problem, and over 40% revealed that the cost is either too high or they do not have anybody to accompany and help them, despite having to go to school or visit medical and social support facilities (Jones et al., 2016). Another problem is that public transportation staff often lack appropriate training. For instance, bus drivers do not know how to help passengers with disabilities get on board (WHO and World Bank, 2011).

### Box 5.2: Mobility constraints in conflict-affected contexts

Mobility is a prerequisite to the exercise of voice and agency. However, many adolescent girls and boys with disabilities in our qualitative research in Gaza, Jordan and the West Bank highlighted the multiple challenges of poorly adapted physical infrastructure but also – in some cases – their determination to overcome those challenges:

*'The street infrastructure must be adapted, this is the first thing... Now if I want to go somewhere, I spend 10 minutes trying to call the shop owner, because the street isn't adapted for me to go up the street in my wheelchair.'*

(Boy with a physical impairment, 18 years, Syrian refugee in Jordan)

*'My aspiration is to go to school but I scarcely leave the building... It is hard for my mother to carry me down the stairs... I can only look at the other children out the window.'*

(Girl with a physical impairment, 13 years, Syrian refugee in Jordan)

*'The worst year was the 11th... The transportation got harder. Sometimes I wet myself on my way home. The school was very far, and it was hot... I would leave school at 1:30 pm and reach home at 3:00 pm... My parents used to give me more money for a taxi, but the cars didn't stop for me.'*

(Girl with a physical impairment, 18 years, West Bank)

*'I leave for school at 7:30 am and I get there by 8:30 am. Sometimes there are checkpoints and I arrive at school late. There are Israeli soldiers on the way and it is dangerous. I feel scared of the soldiers, but that does not prevent me from going to school.'*

(Girl with a hearing impairment, 15 years, West Bank)

Assistive devices such as crutches, canes, wheelchairs, prosthetic devices or visual and hearing aids can increase individuals' mobility and enable participation (ibid.). However, many persons with disabilities in LMICs cannot afford to purchase and maintain such devices. For instance, in Asia and the Pacific, one-third of persons with disabilities – that is, 7.5 million people, of all ages – do not have access to assistive devices (UNESCAP, 2018). A survey in Uganda found that only 5% of children and adolescents with disabilities had access to an assistive device, mostly those living in urban areas. Yet the majority of respondents in Ethiopia reported having an assistive device as they were enrolled in community-based rehabilitation programmes (ACPF, 2011). Assistive devices such as wheelchairs are often prohibitively expensive and spare parts unavailable, with the necessary equipment often imported (ACPF, 2011; Burns and Oswald, 2015). In Palestine, over 16% of children and adolescents with physical impairments do not have a wheelchair and over a third of those who need hearing aids do not have them (Jones et al., 2016). In Latin America and the Caribbean, low-income families often refrain from buying the devices their children need as they will soon have outgrown them, making the expenditure seem wasteful (ECLAC et al., 2013). Support should also cover costs of the maintenance of devices that have been provided. In Palestine, some families of children and adolescents with disabilities who were given support in the form of wheelchairs or hearing aids reported being unable

to afford the high maintenance costs such as new wheels, parts or batteries (Perezniето et al., 2014).

In settings where disability is highly stigmatising, parents may reduce the mobility and social interactions of their children with disabilities in an effort to protect them from discriminatory attitudes and harmful behaviours. In Palestine, better-off families are likely to curtail the mobility of their adolescents with disabilities and hide them from public view in order to maintain the family's social status and prestige (Jones et al., 2016). Similarly, in Rwanda, better-off families in urban areas are more likely than poor households to hide their children with disabilities at home (Lewis, 2009). In some cases, adolescents with disabilities report isolating themselves and choosing to remain at home most of the time to avoid facing stigma and discriminatory attitudes (Jones et al., 2016; Bhatta et al., 2018).

## Access to age-appropriate information and digital technology

Accessibility also refers to access to information, including access to appropriate languages and devices, such as Braille and sign language or speech-generating devices, and alternative scripts and modes, such as audio and large-print materials. The UN Convention on the Rights of the Child (UNCRC) emphasises that access to information is required to fulfil the child's right to freedom of expression. However, access to appropriate materials

can be limited in many cases. For instance, only 0.5% of books in LMICs are available in the accessible formats required for those with visual, intellectual and learning impairments (UNESCAP, 2018). In Uganda, only 11% of students requiring Braille, audio-recorded or enlarged print received it (ACPF, 2011). In Nepal, students with disabilities requested more teachers trained to use Braille and visual learning materials with subtitles in inclusive school settings (Bhatta et al., 2018).

Accessibility also refers to access to information and communication technologies (ICTs) – i.e. the application and integration of enhanced and technology-facilitated processes to meet the specific needs of persons with disabilities (WHO and World Bank, 2011; UNESCAP, 2016). It is widely accepted that ICTs can be particularly helpful in the daily life of persons with disabilities, enabling those

with specific impairments to become more independent, facilitating their access to information and promoting their interaction with others (UNESCAP, 2016). In particular, ICTs, including digital platforms, hold promising potential for adolescents and youth with disabilities: they open up opportunities for them to access information and training; to support their learning and develop their skills; to connect on an equal basis with peers and participate in wider social networks, thus reducing their isolation and exclusion; and to express themselves, exchange views and campaign for their rights. Indeed, in participatory research in 12 LMICs, older adolescents and youth with disabilities spoke favourably about how computers and mobile phones have improved their daily lives (UNDESA, 2012) (see also Box 5.3). However, the potential of ICTs can only be realised if they are accessible (in both urban and rural areas),

### Box 5.3: Accessing information through the internet and social media

In our research sample, adolescents with diverse impairments – and girls in particular – are too often confined to their homes. Mobile and internet connectivity can facilitate access to information and contact with the outside world for these young people and give them a sense of purpose and psychosocial wellbeing. These quotes highlight the promise of digital technology across a range of contexts (albeit primarily still urban) for boys and girls with physical, visual and hearing impairments:

*'I learn how to invent and make new creations... I even learn Zumba.'*

(Girl with muscle atrophy, 12 years, Syrian refugee in Jordan)

*'My favourite thing was my phone – it had Braille and I could listen to music and lectures on YouTube but it broke and my world has shrunk again.'* (Girl with a visual impairment, 19 years, Syrian refugee in Jordan)

*'I post things on Facebook when I am depressed and that helps me... Sometimes I search for videos on YouTube about how to reduce sadness.'* (Girl with cerebral palsy, 18 years, West Bank)

*'The reason why I selected my mobile phone as my favourite object is that, as I have hearing disability and people don't know the sign language, it helps me to easily communicate through text messages. Even when I am ill, it helps me to easily communicate with my parents through text messages. I communicate with other people with hearing disability living abroad and have better awareness than me to get more clarification when I face problem. I share the different experiences and situations in my country to another person and the other person in turn share me his country's experiences and situations.'* (Boy who is deaf, 18 years, Ethiopia)

*'I use it [the mobile] for Facebook. I do not use it to call. I use text messages to communicate with my parents, sisters and brother.'* (Boy who is deaf, 17 years, Ethiopia)

*'I have a channel on YouTube... I like to make videos on it, and I like to upload them... It's still new. I've been doing it for about a year. And now, when I finish studying and my exams, God willing, I will go back to it and start a new video... The thing I video most are challenges – my brother and I challenge each other... We make slime and challenge each other to eat foods that are really hard to eat... and things like that... I mostly win!... I share the video on Facebook. I have just 10 likes at the moment but I have a plan to develop and promote the videos – to market them and to put up advertisements to attract more people... I listened to a lot of videos on YouTube and I got excited. So, what's nice is that my phone really helps me to make a video in case I want to take the video myself.'*

(Girl who is blind, 13 years, Jordan)



affordable, age-appropriate, and suitable to the specific needs of their users, including having features that facilitate the use of assistive technology (UNDESA, 2012; UNICEF, 2012; 2017).

Evidence from LMICs indicates that the digital divide in terms of access to and use of digital technologies persists: ICT products and services are often limited or inaccessible, user costs are high, and policy frameworks weak. In 2014, only a third of those living in Asia and the Pacific had access to the internet, and although data on internet access by persons with disabilities is unavailable, those with disabilities were probably less likely to access the internet (UNESCAP, 2016). For instance, in Bangladesh, 54% of respondents with disabilities reported that they could not use mobile and internet services, and 11% felt that electronic services (including news bulletins, emergency police numbers, health information or national helplines) were not disability-friendly. In addition, 79% replied that persons with disabilities are unable to work from home, thereby not benefiting from the new opportunities created by ICTs (NGDO et al., 2015).

Such services also remain limited for most children and youth with disabilities – particularly those in marginalised contexts such as rural areas without access to technology, in settings with scarce resources and low literacy rates,

» I have a channel on YouTube... I like to make videos on it, and I like to upload them... It's still new. I've been doing it for about a year. I have just 10 likes at the moment but I have a plan to develop and promote the videos – to market them and to put up advertisements to attract more people... I listened to a lot of videos on YouTube and I got excited.

(Girl who is blind, 13 years, Jordan)

and in households who cannot afford the required devices or are unaware of the potential of ICTs (UNDESA, 2012; UNICEF, 2017). In Palestine, only 21% of children and adolescents with disabilities reported using the internet to access information, while only 18% used social media and 26% emailed friends and family or used the phone or mobile (Jones et al., 2016).

On the other hand, access to information also needs to ensure that children and adolescents with disabilities are protected from harmful information that puts them at risk and promotes stigma and discrimination (UN Committee on the Rights of the Child, 2007). In particular, ICTs can pose certain risks, especially if adolescents with disabilities are not provided with training to understand how best to use them without putting themselves in danger. Evidence from high-income countries shows that adolescents with disabilities are more likely to experience risk online (UNICEF, 2017).

## Meaningful participation and decision-making in family, community and school life

According to the CRPD, adolescents and youth with disabilities have the right to enjoy a full life on an equal basis with other children and youth, including the right to express their views freely on matters affecting them in accordance with their age and maturity, and to participate in play, recreation and sports activities (UN, 2006). This is also in line with the UNCRC, which speaks about the need for children to exercise their rights in a manner consistent with their evolving capacities. Lansdown (2005) highlights that it is important to recognise children and adolescents as subjects of rights with gradual and growing agency in exercising these rights, to fulfil children's optimum

capacities by enabling them to develop their competencies and to take increasing responsibility for themselves, but also to protect them from risks inappropriate to their level of capacity. However, adolescents with disabilities frequently have little or no say over their lives, and are excluded from social activities (see Box 5.4). They may be denied the right to be educated, to access sexual and reproductive health information and services, to live a life free from violence, to participate in family and community activities, and to get married and have their own family (Groce and Kett, 2014). Decisions about their schooling, health or marriage are made by parents, carers or professionals, typically without the young person's involvement or consent. Their participation in social events is often limited due to concerns for their safety, or misconceptions and low expectations about what they can achieve (UNICEF, 2013b). In an effort to protect their child with a disability, many parents fail to recognise the child's capacity and their need to express their views and wishes, build their self-confidence and start making their own choices and decisions. They thus infantilise the child and deny their right to personal growth and self-determination, which merely ends up reinforcing the child's dependency and vulnerability (UNICEF, 2012; 2013b).

Limited evidence from LMICs confirms these points. Although in many contexts, children and adolescents

(because of their age) typically have little say over decisions affecting them, those with disabilities are even less likely to do so. In a multi-country study in sub-Saharan Africa with nearly 1,340 children and adolescents with disabilities in rural and urban areas, most of those in Ethiopia reported being excluded from household decisions always or sometimes, while 40% admitted never making their own decision. However, most families were supportive, and children with disabilities participated in many family events. Furthermore, over two-thirds of children and adolescents with disabilities in Ethiopia and Uganda reported being allowed to play with other children and to invite them to their homes to play (ACPF, 2011). Similarly, in Palestine, 61% of surveyed children and adolescents with disabilities reported playing with peers,

» I took her to a Makani [non-formal education] centre and they don't accept her. I went to a centre close to us as it is challenging to get around with a wheelchair but they didn't accept her; they accepted her sisters and they didn't accept her.

(Mother of adolescent girl with a physical impairment, Syrian refugee in Jordan)

#### Box 5.4: Accessing safe spaces

Providing the opportunity to participate in recreational and leisure activities as well as life skills training is a key part of supporting adolescents to develop their voice and agency. However, such opportunities are too often denied to adolescents with disabilities as a result of physical and social inaccessibility, as these quotes from the GAGE focal countries attest:

*'Last year for three months a centre affiliated with Doctors Without Borders used to come and take me once a week to play sport... There was everything, balls, movements, sport and such... I enjoyed it a lot! Even my mood got better.'* (Girl with cerebral palsy, 13 years, Syrian refugee in Jordan)

*'I took her to a Makani [non-formal education] centre and they don't accept her. I went to a centre close to us as it is challenging to get around with a wheelchair but they didn't accept her; they accepted her sisters and they didn't accept her.'* (Mother of adolescent girl with a physical impairment, Syrian refugee in Jordan)

*'I am not a member of any clubs. All the activities are done outside the class and in an office area. I don't like to go there and here. I didn't feel ashamed of my physical disability. The only factor that hinders me is my tiredness to go here and there.'* (Girl with a physical impairment, 17 years, Ethiopia)

While boys generally have greater access than their female peers to community spaces, recreational opportunities are often lacking and can be highly dependent on funding cycles, as this quote from a Syrian refugee in Jordan notes:

*'In the sport centre, there is table tennis every Sunday. A group of my friends used to go there, and they told me about it. I used to go all the time but it stopped two months ago. They stopped the club, there are no more donations so they stopped it.'* (Boy with a physical impairment, 16 years, Syrian refugee in Jordan)

and 74% reported visiting relatives and friends (Jones et al., 2016). The sub-Saharan African study noted that when children with disabilities are supported by their families and fellow students, and when they are included in activities with peers and their abilities and worth are recognised, they feel a strong sense of inclusion and are encouraged to continue participating. However, adults tend to emphasise that these children are different and have special needs and vulnerabilities, thus creating barriers that would not exist otherwise, while the children themselves focus more on similarities with their peers without disabilities, and shared needs and aspirations (ACPF, 2011).

Nonetheless, adolescents with disabilities can also encounter multiple difficulties, including stigma and discrimination, and be excluded from family events and from school, social and religious activities (see Box 5.5). In India, youth with disabilities reported experiencing

» I do not like anyone to give me special treatment or make me feel like I am a subject of pity. I am very competent, and I am not lacking anything... The thing that troubles me the most is that no one listens to me... I have nothing wrong with me but I feel like they treat me in a special way.

(Girl with a physical impairment, 18 years, West Bank)

negative attitudes when they try to participate in social events (ICED, 2014). In Palestine, high transport costs, lack of accessible facilities and fear of discrimination often hindered children and adolescents with disabilities from participating in recreational activities and public

### Box 5.5: Limited opportunities to exercise voice and agency within family and school

GAGE qualitative research in Jordan and Palestine found that opportunities for adolescents to exercise voice and decision-making were limited to the family at best. In some families, focal adolescents were able to exercise a say in daily activities, but often within narrow perimeters (e.g. having limited say over schooling).

*'She likes to wear whatever she wants, and sometimes I feel like I have to put up with her so she does not feel hurt. She likes to dress better than anyone. If she could talk, I might be able to reason with her when it comes to buying her clothes.'* (Father of girl with a hearing impairment, West Bank)

In other families, adolescents complained of voicelessness and a sense of being infantilised:

*'I rarely get to decide anything... I wish someone would ask me questions.'*  
(Girl with cerebral palsy, 13 years, Syrian refugee in Jordan)

*'I do not like anyone to give me special treatment or make me feel like I am a subject of pity. I am very competent, and I am not lacking anything... The thing that troubles me the most is that no one listens to me... I have nothing wrong with me but I feel like they treat me in a special way. The disability is in the mind, not the body... I don't like people to be worried too much or care too much. I want them to care about me and worry about me, but not in a way that makes me feel helpless. I would like to think on my own.'* (Girl with a physical impairment, 18 years, West Bank)

In school settings, adolescents also expressed frustration that they were not consulted or listened to:

*'They [the school staff] didn't care about girls with disabilities. If there was some contest, or clubs, they just would consult the first in class and the smart girls. They didn't talk to us.... They should care more about people with disabilities. They should care more than one day a year about us.'*  
(Girl with a physical impairment, 18 years, West Bank)

*'No one cares about people with disabilities there. However, in my school, I was a part of a group along with other six members, and if a person does not get to fully exercise his rights we would pressure the principal and the ministry to get him what he needs... I tried and talked to my principal and he said I need a paper from the Minister of Education. Six months ago, I got to meet the minister and told him about this idea of a council for people with disabilities, however, he said he does rounds on his own. I believe he's been to Hebron, but he has not gotten to come to our school yet... But he said "inshallah" [God willing]. When someone says inshallah, I figure he might not care about the subject and most likely not to do it.'* (Boy, 18 years, West Bank)



meetings (Jones et al., 2016). Similarly, 45% of children with disabilities in Ethiopia reported being always or sometimes excluded from family events, while 40% reported being excluded from religious events (ACPF, 2011). In Nepal, nearly a quarter of young people with disabilities aged 16–26 reported not being involved in social events; over 42% of all respondents also reported having never participated in sports activities (Adhikari, n.d.). In participatory studies, adolescents with disabilities state their wish to play with friends and be active, yet sports activities in schools are not inclusive and very few activities are provided for children with disabilities (Bhatta et al., 2018). In Bangladesh, school children with disabilities may not be allowed to participate in school events and sports activities because some teachers assume that they are unable to do so (Burns and Oswald, 2015). In Palestine, 35% of children with disabilities reported participating in sports, yet only 2% were members of a sports team; less than half (40%) participated in religious events and only one in four took part in community work (Jones et al., 2016).

Self-exclusion to avoid stigma and negative public attitudes towards disability is a recurrent theme in the narratives of adolescents with disabilities across LMICs. More than half of respondents in Nepal described the difficulties they encounter when trying to participate in community life, which made them sad; one-third revealed

that they rarely leave the house as a result (Bhatta et al., 2018). Similarly, in Palestine, 30% of children with disabilities report avoiding participating in social activities because of negative public attitudes towards them (Jones et al., 2016).

## Civic engagement

The CRPD obliges states to guarantee all persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, including the right to participate fully in public affairs, to vote and be elected. However, persons with disabilities in LMICs often face substantial legal, informational, attitudinal and physical barriers to exercise their rights as citizens and engage in civic and political activities.

Evidence indicates that even when countries have disability-inclusive laws and policies promoting the participation of persons with disabilities in public affairs, these may not be enforced. On the other hand, some countries continue to have constitutional and legal provisions that deny or restrict people with certain types of impairment (especially intellectual or psychosocial impairments) from having the right to vote (see Box 5.6). Many persons with disabilities also lack access to appropriate information, remain unaware of their rights and entitlements, and thus cannot claim and exercise them.

### Box 5.6: Civil and political rights for persons with disabilities: significant gaps remain

Although since 2010 more states have included provisions for persons with disabilities within their constitution, only 24% of 193 countries guarantee equality and non-discrimination for persons with disabilities; on the other hand, more than three times as many constitutions explicitly guarantee equality and non-discrimination on the basis of gender, ethnicity and religion.

In 2014, less than 10% of constitutions explicitly guaranteed civil rights to persons with disabilities, while 19% specified that the right to liberty can be denied to those with psychosocial impairments and 2% allowed restrictions on their right to freedom of movement.

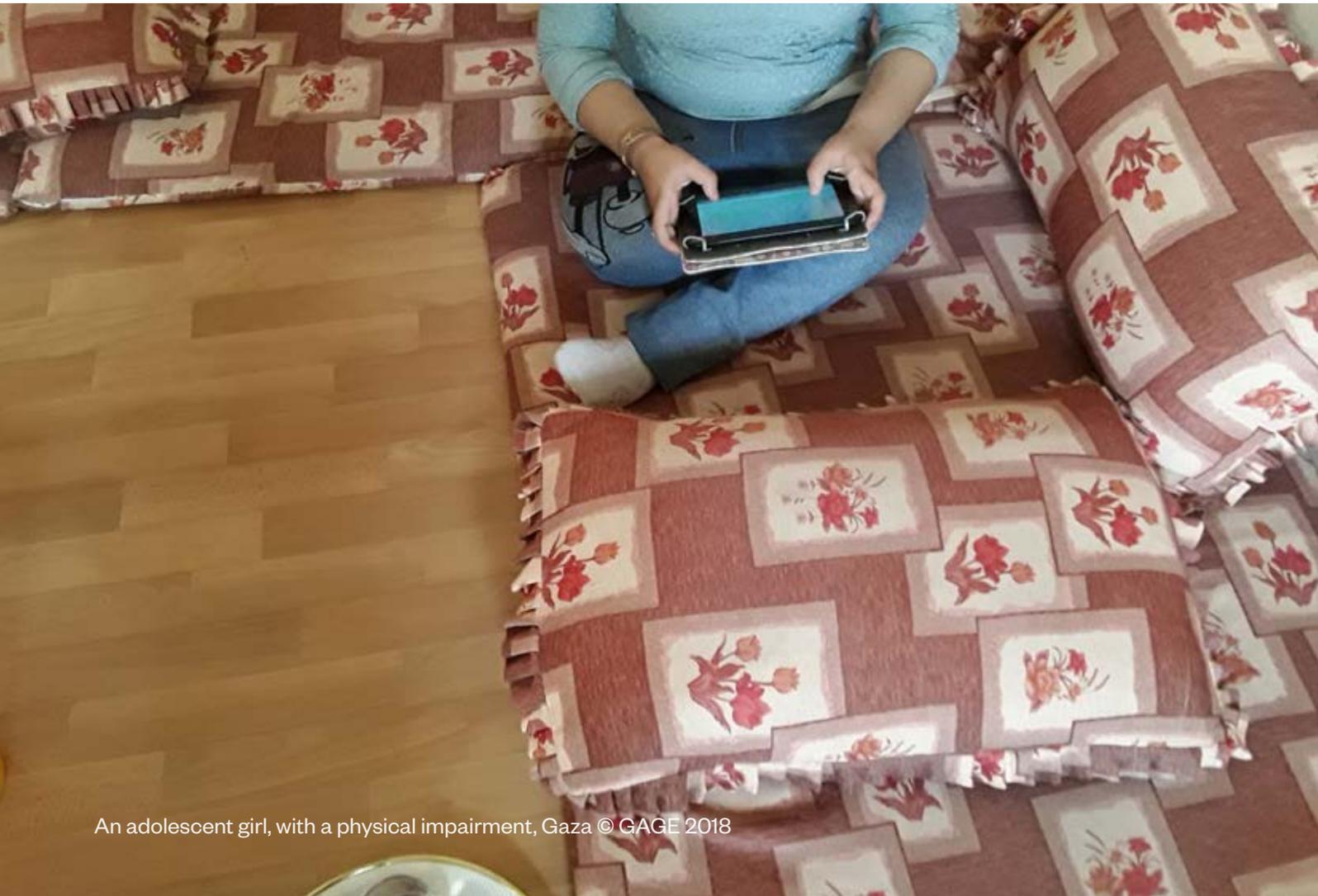
Only 22% of constitutions guarantee voting rights for persons with disabilities, and just 3 countries have included constitutional provisions to facilitate voting for persons with disabilities. Yet 22% of constitutions allow for persons with psychosocial impairments to be denied their right to vote, and 31% allow for the denial of the right to hold public office, with some provisions being too broad and thus creating the potential for unfair and arbitrary denials.

Source: WORLD Policy Analysis Center, 2016

Those confronted with survival challenges on a daily basis may also not view their political participation as a priority (Virendrakumar et al., 2017).

A particular issue is that persons with disabilities in LMICs are not always registered and thus have no ID cards and as a result remain invisible in official data. Registration of children with disabilities at birth provides them with an identity and thus it is closely linked to their social, civic

and political participation in later life. However, children with disabilities are disproportionately vulnerable to non-registration at birth (UN Committee on the Rights of the Child, 2007); in several countries, the proportion of those registered is significantly lower than the national average and alarmingly low for children with multiple impairments (ACPF, 2011).



Communities also frequently perceive persons with disabilities to lack autonomy and be in constant need of support and charity. For instance, most respondents in a 2014 survey in Tanzania felt that persons with disabilities need to be cared for most of the time, thus failing to perceive them as active citizens. Nonetheless, 85% of respondents also stated that they could imagine such a person becoming a leader of change in the local community, thus recognising their positive potential (Schipper et al., 2014). Persistent stigma and discrimination towards persons with disabilities, misconceptions about their abilities, untrained staff, and lack of access to information about their rights, along with issues of physical accessibility and availability of opportunities, result in them being perceived as objects of others' decisions and not as holders of rights and therefore full citizens (UNGA, 2012).

Persons with disabilities also experience physical accessibility barriers to participation in public and civil affairs. In Bangladesh, 44% of respondents in a survey said that voting centres are inaccessible without ramps and polling booths are located on the second or third floor. Thus 76% stressed that persons with disabilities cannot participate in the election process, especially those 'of unsound mind' (NGDO et al., 2015). In Nepal, 68.5% of persons with disabilities reported not participating in community meetings (Eide et al., 2016). As a result, they have low levels of civic and political participation. For instance, latest data from Asia and the Pacific shows that persons with disabilities comprise only 0.4% of national parliamentarians (UNESCAP, 2018).

In order to promote the participation of persons with disabilities, several LMICs have tried to create an enabling environment such as improving the physical accessibility of public meetings, polling stations and voting mechanisms,

» Yes, I have heard that people with disabilities have equal rights but I do not care about rights – these rights are not real and achievable in our society; that's why I don't care about them. Not knowing them is even better.

(Girl with a visual impairment, 18 years, Gaza)

providing accessible information and voter education, and training electoral staff (WHO and World Bank, 2011; PPUA Penca, 2013). Individuals and organisations that support these measures, including disabled people's organisations, which advocate for the rights of persons with disabilities, argue that increased political participation is crucial for the realisation of the rights of persons with disabilities and the promotion of more disability-inclusive public policies (WHO and World Bank, 2011; UNESCAP, 2018). However, in LMICs with strong movements advocating for the rights of persons with disabilities, evidence on the role or engagement of adolescents and young adults with disabilities is lacking.

Although they are entitled to participate in public affairs and social movements on an equal basis with others (see Box 5.7), youth with disabilities face considerable challenges to access information, become aware of their civil rights, make informed choices, and set the foundations for becoming active citizens (UNDESA, n.d.). Consequently, they are largely excluded from civic and political activities in their communities (Groce and Kett, 2014), and from the design and implementation of policies and programmes that affect their lives. Adolescents with disabilities are also excluded from initiatives aiming to empower children and

### Box 5.7: UNCRC urges respect for the views of children with disabilities

In a general comment aiming to provide guidance and assistance to states in implementing the rights of children with disabilities, the UNCRC acknowledges that children (and adolescents) with disabilities are most often left out of decision-making processes that affect their lives. It thus urges state parties to ensure that children's voices are heard in all procedures affecting them and that children's views are respected in accordance with their evolving capacities. Therefore, they should be represented in various bodies where they can voice their views and participate in decision-making so that not only are policies targeted to their needs and desires but also social inclusion is promoted through such participatory procedures. In order for this to happen, state parties are required to: provide children and adolescents with all modes of communication necessary to facilitate them expressing their views; and to support training for families and professionals on enabling children and adolescents with disabilities to take increasing responsibility for the decisions that shape their own lives.

Source: UN Committee on the Rights of the Child, 2007

### Box 5.8: Rights and their implementation

A number of adolescents with disabilities (especially refugees) and their parents in the GAGE qualitative research in Jordan and Palestine reported some awareness of their rights, but their negative experiences made them question the value of rights in conflict-affected contexts and hesitant about demanding them.

*'Yes, I have heard that people with disabilities have equal rights but I do not care about rights – these rights are not real and achievable in our society; that's why I don't care about them. Not knowing them is even better.'*

(Girl with a visual impairment, 18 years, Gaza)

*'When I was in different centres after I was injured, I heard about the rights of the disabled and that people with disabilities have rights in health, education... I was encouraged [to demand my rights] but where would I demand them here as a refugee?! Where am I going to ask for my rights? School is not even accepting me.'*

(Boy with a physical impairment, 18 years, Syrian refugee in Jordan)

*'A citizen is very different than a refugee... we faced a great hardship when we first came here... of course for a citizen they would put in so much more effort, to make a section for him at the school and teach him, even if it was by himself... We found first challenges when we came for the treatment, and, look, we are refugees, we haven't been allowed to work... And the teacher said that when we have a bigger number of students with disabilities we can open up a section and we will call you, but they didn't pay that much attention to his case or make it an important issue... I mean, when a person is a citizen, he would do 20 wasta [go through personal contacts] to get his child into the school!'*

(Father of 18-year-old boy with a physical impairment, Syrian refugee in Jordan)

adolescents, build their citizen skills and enable them to voice their concerns and demand action. The 2011 report of the Secretary-General on the Status of the Convention on the Rights of the Child pointed out that children with disabilities still face difficulty in having their voices heard, as they are excluded from school or municipal councils, children's parliaments and consultations, while their capacities for participation are ignored (cited in UNICEF, 2013a). Similarly, initiatives designed to empower youth often overlook the needs of those with disabilities, let alone include them in activities (UNDESA, n.d.).

Once again, data is scarce but sheds some light on the situation (see also Box 5.8). In Nepal, three-quarters of adolescents and youth aged 16–26 with physical and visual impairments reported not being affiliated with any political organisation; more than one in three reported not being involved in community meetings, and more than half had not voted in the most recent elections (Adhikari, n.d.). In Ethiopia, only 19% of adolescents and youth with disabilities reported being a member of a group for persons with disabilities (Population Council and UNFPA, 2010). In Palestine, only 53% of respondents understood and respected the rights of children and adolescents with disabilities, who, despite having some awareness of their rights, generally lacked confidence that they have the same rights as other children. Bedouin children with disabilities appear to be particularly vulnerable as their communities have especially limited awareness of disability rights

and where to seek services (Jones et al., 2016). Similarly, about a third of children and adolescents with disabilities in Ethiopia, Senegal and Uganda were unaware of their basic rights, including their right to free education, health care, protection from violence, and equal opportunities (especially those in countries with lower access to basic services); some communities were also unaware of existing government disability policies (ACPF, 2011).

### Role models

Role models can have a tremendous influence on adolescents. At this critical stage of their lives, as they grow up and become more open to ideas, models and directions in their life, positive role models can shape adolescent aspirations and motivate them to take on challenges and achieve admirable goals. Persons with disabilities, including peers, who are able to enjoy a full life can become concrete examples for adolescents with disabilities and their families that they can achieve something similar, and that they should not accept discriminatory notions that limit their potential. The CRPD and the General Comment on Inclusive Education explicitly asks states to invest in and support the recruitment and education of teachers with disabilities as they 'contribute to breaking down barriers and serve as important role models' (UNCORPD, 2016: 13).

Indeed participatory research with adolescents with disabilities in Nepal suggests the importance of positive role models. Youth with disabilities who have completed



their education, earn a living and participate actively in the community, motivate them to plan for a better life; they also persuade the adolescents' families about their potential and the need to encourage and support their children and their aspirations, instead of lacking hope and being anxious about a presumed bleak future (Bhatta et al., 2018). Similarly, in Bangladesh, a researcher with disabilities working for an NGO reported that after completing his education and starting work, he became an example to youth in his village (Burns and Oswald, 2015). In Palestine, students with disabilities who managed to transition to university and persons with disabilities in important organisational positions have also become positive role models (Jones et al., 2016).

However, such role models are hard to find: in Ethiopia, only 18% of adolescent girls and young women with disabilities said they had a role model who is a person with a disability, along with 29% of their male counterparts (Population Council and UNFPA, 2010) (see also Box 5.9).

A recent global report found that only 3% of organisations working with youth with disabilities have introduced role models as part of their leadership training, although the majority of surveyed youth reported that role models have been the most helpful for demonstrating leadership skills (Akram et al., 2018).

» But the thing that excites me the most is that my parents are always standing by me, like for example, there is an activity that I want to participate in, I go back home, I tell my mom I want to join this thing, they let me. Like, they really encourage me. I have friends whose parents don't really do this

(Girl who is blind, 13 years, Jordan)

### Box 5.9: Role models

In general, if the adolescents in our sample identified role models, these tended to be either family members or teachers; very few named role models outside their community or role models with disabilities. While we asked adolescents across the four contexts, the adolescents from the Syrian refugee community were least likely to identify a role model, as so much of their world had shifted as a result of the conflict and displacement.

In terms of family role models, adolescents emphasised family members who were knowledgeable and took an active interest in their lives:

*'I want to be like my uncle. My uncle talks about a lot of things. He is very knowledgeable. He is very intelligent. He is very responsible. He takes care of everyone. He never gets involved in bad things, he leads an honest life... He adores children... Uncle visits often.... we talk about a lot of fun things. Stories about his work. When something happens to me then I tell him... When we were living in our village we were walking in the mist on a winter morning. I fell down while walking. We were all laughing. After I fell down my uncle helped me to get up and I smeared mud all over my uncle's clothes during that process and we started laughing about it.'*

(Boy with a physical impairment, 15 years, Bangladesh)

*'My father is my role model because he is an aware person and my mother also. Thanks to God that my parents are aware and educated and they know how to treat their kids.'* (Boy who is blind, 13 years, Jordan)

*'But the thing that excites me the most is that my parents are always standing by me, like for example, there is an activity that I want to participate in, I go back home, I tell my mom I want to join this thing, they let me. Like, they really encourage me. I have friends whose parents don't really do this.'* (Girl who is blind, 13 years, Jordan)

In the case of teachers, adolescents admired teachers for providing detailed guidance about their future trajectories and what they needed to focus on to accomplish their goals:

*'I like my teacher a lot, my English teacher. I like everything about her. She talks very nicely. She can explain things well. If she sees anything wrong happening, she can protest. The thing I like her about the best is that she is very hardworking. That is what I like about her... I want to be a doctor when I grow up. If you want to be a doctor you have to take Science. But people say that not everyone can study Science. So I tell my teacher that. So she said, "you should have faith in yourself. Do you have faith in yourself or do you trust what people say?" She explains it to me.'*

(Girl with a physical impairment, 12 years, Bangladesh)

*'My role model is my teacher. He is very good at teaching. I want to be like him. He can speak all languages... all... He tells us many things. For instance, he tells us about the life of Hazrat Mohammad [prophet], how he received Nubuwwah, inside which cave and other things. We can learn those things from books. But it's much more fun when someone tells it like a story... He said, "If you want to be like me, you need to study attentively. You need to grow your interest in study." He also said, "When I was of your age, I used to be like you. But as I grew older, my interest in study grew too. That's how I became what I am today".'* (Girl with a visual impairment, 12 years, Bangladesh)

## Experiences shaped by gender

Adolescent girls with disabilities tend to face greater disadvantage than boys in expressing their views, participating in decision-making over their lives and building their agency. Most often, they experience greater restrictions on moving around freely or interacting with friends, are frequently forced to stay at home, dependent on and controlled by fathers or other family members without any opportunity to build their competences, self-esteem and confidence – all of which they need to make

a successful transition into adulthood (UNDESA, 2012). Indeed, in Palestine, many adolescent girls with disabilities reported feeling 'voiceless' and unable to question paternal authority and decision-making power. They emphasised their forced isolation at home due to parental safety concerns, fear of sexual assault and family dishonour. In some cases, their families kept them hidden so that they do not bring shame and prevent their siblings from finding marriage partners (Jones et al., 2016) (see also Box 5.10). In Nepal, 30% of older adolescent girls and women with disabilities reported never participating in social events, including festivals, rituals and celebrations (Adhikari, n.d.).

### Box 5.10: Adolescent girls face significantly greater mobility constraints than their male peers

Our findings highlighted that, in conflict-affected Middle Eastern contexts, adolescent girls' mobility constraints are markedly different from those of boys, as the following quotes highlight:

*'We (me and my sister who is also blind) have never been to school in Jordan. But it has now been a year since we even left the apartment... Boys can leave the house but without anywhere to go, the life for girls who are blind is unimaginably restrictive!'* (Girl with a visual impairment, 19 years, Syrian refugee in Jordan)

*'For a girl with a disability it would be very different. Even getting to and from a physiotherapist, it's different for a boy and a girl. If she were to come and go it would be really different – she wouldn't be allowed to go alone of course... And then a father cannot let her outside to attend a training course like my son... So everything is different. To have a disabled boy is less a problem than to have a disabled girl... When my son was shot, he was with 19 other people – his sisters-in-law, and their daughter, and other women and children. When he was shot, four machine guns were shooting them, and without God's mercy, all of them would have been either injured or dead. All of them. But he was the only one who was shot, I thanked God 100 times, 1,000 times that none of the women were shot. Because really, how difficult would that be. Because if we wanted to treat her, and she would need to come and go all the time, that would have been a big problem.'*

(Father of 18-year-old boy with a physical impairment, Syrian refugee in Jordan)

In Bangladesh, although adolescent-specific evidence is limited, 27.5% of women with disabilities reported being excluded from social events such as weddings, funerals, celebrations and other occasions, 17.5% reported being excluded from religious activities, and nearly 13% revealed facing exclusion even from family activities such as cooking, eating together or sleeping in the same room with other family members (CREA, 2012).

Young women with disabilities also reported difficulty in using public transportation. In a study in Bangladesh, young women revealed being prevented from using public transport sometimes by other passengers who are in a hurry; 81% of respondents also reported never using public transportation after dark to avoid being harassed (CREA, 2012). Girls with disabilities are also more vulnerable to sexual harassment online: a study in a high-income setting



An adolescent girl, with a hearing impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

» We (me and my sister who is also blind) have never been to school in Jordan. But it has now been a year since we even left the apartment... Boys can leave the house but without anywhere to go, the life for girls who are blind is unimaginably restrictive!

(Girl with a visual impairment, 19 years, Syrian refugee in Jordan)

estimated that adolescent girls with special education needs are nearly three times more likely than boys to report online unwanted sexual solicitation (UNICEF, 2017).

As already noted in Chapter 2 on Health, Sexual and Reproductive Health and Nutrition, girls and women with disabilities also have greater difficulty securing access to assistive devices. For instance, a survey in Nepal found that significantly more men with disabilities used an assistive device, especially in urban areas, compared to their female peers (Eide et al., 2016).

Although data is again scarce, evidence indicates that adolescent girls and young women with disabilities in LMICs are also less involved in public and political affairs – a trend that continues in later adult life. Indicative of the situation is that in Asia and the Pacific, women with disabilities comprise just 0.1% of MPs; and only 2.7% of members of national machineries for gender equality in the region are persons with disabilities (UNESCAP, 2018). Although young women participate in various organisations for women’s empowerment in Bangladesh, those with disabilities are often left out (Burns and Oswald, 2015). Similarly, in Kenya, young women with disabilities are unable to benefit from legal provisions promoting women’s political engagement and those who try to vote face considerable challenges (Virendrakumar et al., 2017). Data also shows that only 59% of women with disabilities participated in the Cambodian national elections compared to 99% of women without disabilities (Handicap International, 2015). And in Nepal, where, as already noted, three-quarters of adolescents and youth with physical and visual impairments reported not being affiliated with any political organisation and more than one in three reported not being involved in community meetings. Girls and young women with disabilities reported lower rates than their male peers with disabilities (Adhikari, n.d.).

» To have a disabled boy is less a problem than to have a disabled girl... When my son was shot, he was with 19 other people – his sisters-in-law, and their daughter, and other women and children. When he was shot, four machine guns were shooting them, and without God’s mercy, all of them would have been either injured or dead. All of them. But he was the only one who was shot, I thanked God 100 times, 1,000 times that none of the women were shot. Because really, how difficult would that be.

(Father of 18-year-old boy with a physical impairment, Syrian refugee in Jordan)

## Experiences shaped by impairment type

Evidence on the challenges that prevent adolescents with specific impairment types from enjoying a full life, voicing their opinion and participating in decision-making is extremely limited. In general, it is acknowledged that those with different types of impairments face specific challenges around mobility and physical accessibility. Adolescents with visual impairments are often unable to move alone and require the help of other people, while those with hearing impairments cannot hear car horns and can be knocked down by cars. Those with physical impairments may be unable to climb steps to get on and off buses or other forms of transport (Burns and Oswald, 2015). Indeed, several sources emphasise that not only is the physical environment (including schools) inaccessible to young people with disabilities, but it can also be dangerous and unsafe for adolescents with sensory (especially visual) and physical impairments (Bhatta et al., 2018).

Access to and use of impairment-specific devices can have a substantial impact on daily life for adolescents with disabilities, facilitating their inclusion in family, school and community life. For instance, adolescents with communication difficulties, such as hearing or speech impairments, need access to hearing aids and alternative modes of communication (WHO and World Bank, 2011). On the other hand, lack of assistive devices exacerbates

physical accessibility issues, forcing youth to remain isolated at home or depend on others to help or even carry them: a 19-year-old girl in Nepal admitted with discomfort that her brother still has to carry her to community events (Bhatta et al., 2018). In some cases, persons with some impairment types are more likely to access the required assistive devices: for instance, most devices in southern Africa are for persons with physical impairments, while other impairment types may have been neglected (Eide, 2012).

Scarce evidence on this capability area also indicates that persons with intellectual and psychosocial impairments face greater disadvantage in enjoying their political rights and are often excluded from voting processes (WHO and World Bank, 2011; WORLD Policy Analysis Center, 2016).

## Evidence gaps

Despite the critical role of voice and agency in enabling adolescents with disabilities to build their competences and transition confidently into adulthood, this capability area has attracted the least research and policy attention. There is thus extremely limited evidence on the voice and agency of adolescents with disabilities in LMICs, although both the UNCRC<sup>6</sup> and the CRPD explicitly recognise their right to be heard in decisions that affect them and to have their views respected (UNICEF, 2012). This scarce

evidence almost never differentiates between younger and older adolescents with disabilities, between adolescents with different impairment types and their specific needs, those living in different settings (including those living away from their families or in institutions), or those belonging to groups with increased disadvantage such as ethnic minorities or refugees. However, studies from high-income countries indicate that adolescents from different social groups face particular difficulties and have different needs and vulnerabilities. There is also no robust evidence on best practices to tackle stigma, enhance participation of young people with disabilities, and empower them to confidently voice their concerns and claim their rights (see Table 5.1).

## Promising practices

Adolescents with disabilities often face difficulty accessing spaces and information and taking part in social activities, and are excluded from public affairs and decision-making about issues that affect their lives. They are also typically excluded from programming that targets adolescents and seeks to empower them to voice their concerns and claim their rights. Therefore, evidence on good practices to empower adolescents with disabilities is lacking. However, there have been some initiatives across LMICs that aimed to tackle accessibility barriers and include adolescents

<sup>6</sup> In particular, UNCRC General Comment No. 9 (2006) on the Rights of Children with Disabilities (UN Committee on the Rights of the Child, 2007).



An adolescent boy, with a visual impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

**Table 5.1: Evidence gaps on voice and agency among adolescents with disabilities**

<b>Broader gaps</b>	Large and reliable data is lacking, let alone data disaggregated by age or location. Adolescents are most often lumped together with children (on issues of family and school participation) or young adults (on issues of voice and participation in social and public life). There is a severe knowledge gap regarding adolescents' awareness of rights and their civic engagement.
<b>Gender-specific gaps</b>	Adolescent girls with disabilities face greater disadvantage due to discriminatory gender norms about gender-appropriate roles and behaviours. Girls' voices about the problems they face at different ages and in diverse contexts (especially with regard to their participation in social life, awareness of rights and decision-making) are missing.
<b>Gaps regarding impairment type</b>	Apart from a general indication that persons with intellectual and psychosocial impairments face greater discrimination and the need for impairment-specific devices, the existent evidence base on impairment-specific experiences is almost non-existent.
<b>Context-related gaps</b>	Data is rarely disaggregated by location, socio-economic status or ethnicity. Thus there are severe evidence gaps about adolescents in rural and urban areas, in residential care, or in crises settings.
<b>Policy and programming gaps</b>	There is a dearth of rigorous evidence on what works to empower adolescents with disabilities, enable them to participate in family and community life, and facilitate their access to information and awareness of their rights. Gaps also remain around their safe access to and use of digital technology, as well as what works in campaigning and programming with parents, teachers and communities to address stigma, misconceptions and low expectations about what adolescents with disabilities can and should be allowed to do.

with disabilities in decision-making structures and processes so that their voices start to be heard. UNICEF (2012) notes that children and adolescents with disabilities can get involved in school councils, local youth parliaments and child municipal councils, media initiatives and targeted consultations, attend peer education groups, monitor local services or carry out research to inform policy and service provision. Most often led by NGOs in collaboration with local governments or organisations, these rather small-scale initiatives have not been rigorously assessed and thus we know little about the numbers of adolescents with disabilities taking part and the quality of their involvement. Nonetheless, they have reportedly had some positive outcomes in terms of facilitating greater access to schools, community spaces and information, and providing opportunities for adolescents with disabilities to develop skills, build their confidence, voice their opinions and call for change.

### Promoting mobility and access to spaces

In a number of LMICs, governments have taken some measures to improve access to the physical environment and public transportation, which is vital if adolescents with disabilities are to realise their right to a full life and participate in society. Thus some governments offer help with public transport for persons with disabilities (either subsidised or free). For instance, in Nepal, the government

subsidises public transport by 50% and requires that a number of seats are reserved for persons with disabilities (Eide et al., 2016). Similarly, in Bangladesh, 5% of seats in public transport are reserved for persons with disabilities by law (NGDO et al., 2015). While laws and policies are necessary, their enforcement often proves challenging.

As transportation is crucial for children with disabilities to be able to access education, several initiatives across LMICs have tackled this head-on. The Brazilian city of Curitiba pioneered an innovative transport system back in the 1980s. After listening to requests from parents unable to afford transport to get their children with disabilities to school, city planners put in place a system operated by the same bus company that provided general public transportation but which was subsidised by the municipal transport system, apart from the costs of attendants on the buses, which were covered by rehabilitation and charitable organisation. Since then the pilot system has expanded and has become a school transport system for children and adolescents with physical and intellectual impairments. Bus services are operated by the Integrated Special Education Transport System, with 60 buses operated by 9 companies. The buses are fully accessible, with wheelchair lifts and two attendants to accompany and help students get on and off. Drivers and attendants are trained and retrained every year. Buses run on 55 routes daily, taking 2,500 students with disabilities to and from 35 special education schools. While 34 routes transfer



An adolescent boy, with a physical impairment, Palestine © AFSC 2018

students directly from their homes to schools, the other 21 routes connect with a terminal where students from different neighbourhoods are transferred between buses and proceed to their specialist school, which caters for young people with their particular type of impairment. The service is free to parents and caregivers, funded entirely by Curitiba's Municipal Department of Education (Access Exchange International, 2017).

In other contexts, governments provide subsidies to parents to help them pay for transportation for their children. In Costa Rica, the government subsidises transport for nearly 3,000 low-income parents and caregivers, mostly in rural areas, who would otherwise not be able to afford to transport their children with disabilities to and from public schools (Access Exchange International, 2017).

As part of efforts for disability-inclusive urban development, there have also been initiatives to improve accessibility to urban spaces, including to accessible housing and built infrastructure. In Rio de Janeiro, Brazil, RIOincludi brought together architects and social workers to provide accessible housing for children and youth with disabilities living in poor conditions in the city. Funded by donations, the project built 64 houses by 2013, improved the physical infrastructure and supported 320 children and

adolescents with disabilities and their caregivers. Many children with disabilities, including those with physical impairments, were able to leave their homes and access community spaces and schools (UNDESA, 2016).

### Promoting access to age-appropriate information / digital technology

Other efforts have focused on improving access to information and textbooks. In collaboration with a youth-led non-profit organisation, the Bangladesh Prime Minister's Office launched an initiative in 2013 to support students with visual or other impairments that make it difficult for them to learn using standard books and materials. The initiative, taken forward by the National Curriculum and Textbook Board and the Department of Social Services, converts textbooks for students in grades 1 to 10 into DAISY full text and full audio multi-media digital talking book format. These DAISY standard books are uploaded to an online repository, from which students can access their course materials in a format that meets their specific learning needs. To date, it is estimated that 100,000 students with visual and other impairments have benefited from the initiative (UNESCAP, 2016).

A similar initiative took place in the Indian states of Bihar and Madhya Pradesh. Non-profit organisations and

▶▶ We (me and my sister who is also blind) have never been to school in Jordan and until last year we didn't have a single book in Braille... last year we went to a Koranic class and got the Qur'an in Braille. We were so happy!

(Girl with a visual impairment, 19 years, Syrian refugee in Jordan)

the state-owned textbook publishing boards converted existing textbooks into DAISY<sup>7</sup> format and created accessible e-books for students with disabilities; by mid-2015, 180 textbooks had been converted. The positive impact prompted state publishers to create digital versions of new textbooks in accessible formats and provide them online to students with disabilities. State governments have also provided many students with DAISY players or mobile phones free of charge so that they could access electronic textbooks. The initiative has already expanded into the states of Punjab and Uttar Pradesh (ibid.).

### Promoting civic engagement

Several initiatives in LMICs have aimed to facilitate and promote the participation of adolescents with disabilities in decision-making structures so that they increase awareness of their rights and become actors of change. Implemented by international development agencies in collaboration with local authorities and disability organisations, these initiatives have apparently led to some positive change.

In Rwanda, UNICEF has collaborated with the government to organise the annual National Children's Summit, where around 450 adolescents and youth from all districts voice their concerns to policy-makers. For the first time in 2012, 30 adolescents with physical, sensory and intellectual impairments living in residential care were included to represent the views of children with disabilities in the country. These adolescents raised two issues: the importance of growing up in a caring family instead of an institution; and the need for children and youth with disabilities to be represented at every child forum, as they bring a unique perspective on the barriers they face and how to overcome them. Their arguments were successful;

and an adolescent with a hearing impairment was even elected as the Summit President (UNICEF, 2012).

In India, the Neighbourhood Community Network and Christian Blind Mission (CBM) have implemented the Inclusive Children's Parliament (ICP). First initiated in the state of Tamil Nadu and then expanded throughout India, the ICP brings together and empowers children and adolescents with disabilities to become actively involved in their own development and that of their communities, thus creating the foundations for meaningful civil participation in adult life. Adolescent girls and boys can participate in ICPs and be elected as Child Ministers, leading state-level advocacy efforts on various themes, including a Child Minister for Disability Concerns. Indeed, the initiative enabled boys and girls with disabilities to get involved. For instance, a 13-year-old girl with a visual impairment became the Prime Minister of the State Parliament for Children, advocating for children's rights and promoting the inclusion of children with disabilities globally. In 2013, she attended the 57th Session of the UN Commission on the Status of Women (CBM, 2014).

In Palestine, 'Towards active youth with disability bringing positive change in the West Bank' is a project implemented by a local NGO in collaboration with the General Union of Persons with Disability and supported by Diakonia and the Norwegian Association of Disabled. It targeted 75 youth with disabilities in the West Bank and provided them with training about their rights, about international conventions, as well as campaign management and life skills. The aim was to empower them and enable them to become actors of positive change in their communities. Participants formed a committee to organise a conference for youth with disabilities in Palestine. In late 2017, the first National Conference for Youth with Disabilities took place in Ramallah, with more than 150 young people taking part. Under the slogan 'I am a part', participants chose priority issues to discuss and focused on accessibility and the need to integrate persons with disabilities in all aspects of life. Government representatives promised to liaise with national and local authorities to improve access to infrastructure, including the provision of relevant funding. The conference ended with the election of a committee of youth with disabilities with the mandate to follow up the recommendations and agreed outcomes of the conference (Diakonia, 2017).

7 DAISY (Digital Accessible Information System) is a platform that allows books and written text to be read in different ways, such as large-size fonts with easy-to-see colour contrasts, audibly and via Braille displays.



An adolescent girl, with a hearing impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

In Nicaragua, Save the Children partnered with the Network of Child-Friendly Municipal Governments (RMG) and the Municipal Commissions on Child and Adolescent Affairs to establish municipal children's participation councils. These enable children and adolescents to organise around their interests, advocate for their rights and present their demands to local authorities. Some municipal commissions explicitly promoted the inclusion of adolescents with disabilities; one municipality established a quota that 25% of members had to be children with disabilities, to strengthen disability-inclusive municipal capacity (Larios, 2015).

A qualitative assessment by Save the Children and RMG found that the participation of children and adolescents with disabilities in the municipal children's councils led to positive changes for participants and the wider community. Children with disabilities who became members of the councils have learnt about their rights and how to claim them, and have also improved their self-esteem. As rights-holders, they asked local and central government bodies to implement awareness-raising campaigns to challenge discriminatory attitudes, create more spaces for children with disabilities to express their views, and take action to tackle barriers to their participation. Their families have also become more confident in the children's abilities, seeing what they can achieve. At community level, there has been greater recognition of children and adolescents

with disabilities as rights-holders instead of passive objects of support. Stronger links have been formed between children with disabilities and children without disabilities, participation of children with disabilities in local councils has been sustained and even increased, while municipal authorities have become more sensitised to the needs of children with disabilities and more responsive to their requests for support (ibid.).

Similarly, in Zanzibar, Save the Children Tanzania implemented the 'Child Participation Initiative: Children's Advisory Board project'. With funding from the Swedish International Development Cooperation Agency (Sida) and the Oak Foundation, the project aimed to enable all children, including children with disabilities, to actively engage in the planning processes of programming for children and adolescents through the establishment of an inclusive Children's Advisory Board (CAB). Established in 2010, the first CAB consisted of 15 adolescent girls and boys, elected from local children's councils, including three adolescents with impairments. Their inclusion, along with participatory consultations with other adolescents with disabilities, has resulted in increased awareness of their needs. In particular, adolescents with disabilities were involved in consultations for the Children's Bill, which contains clear provisions on the rights of children and adolescents with disabilities in key capability areas. Following up the issues they raised, the NGO undertook



Two adolescent girls, with hearing impairments, Ethiopia © Nathalie Bertrams / GAGE 2018

research on the vulnerability of children with disabilities to sexual violence in Zanzibar, developed a Plan of Action, managed to include disability in the data collected by police stations, and supported a number of initiatives to promote the rights of children with disabilities in collaboration with the Department of Disability Affairs and other stakeholders. In recognition of its contributions, the CAB has officially been incorporated into government structures such as the National Child Consultation Group under the Ministry of Labour, Youth, Women and Children Development (UNDESA, 2011).

### Promoting participation in research

Apart from their inclusion in child parliaments and councils, participatory methodologies are also increasingly being used in research and programming, so that the voices and perspectives of adolescents with disabilities can be heard and taken into consideration in policy and programmes (UNDESA, 2012; UNICEF, 2012). Current efforts to put persons with disabilities at the heart of research also include engaging them as co-researchers. The Voices of the Marginalised study in Bangladesh, led by a group of

international NGOs,<sup>8</sup> involved 18 persons with disabilities (including some older adolescents) as peer researchers, who were supported to collect stories from 'people like you'. They learnt new skills, were able to highlight sensitive issues such as sexual violence against persons with disabilities, felt confident to speak about their positive experiences of carrying out research, and felt empowered by their experiences (Burns and Oswald, 2015).

A similar project in Nepal<sup>9</sup> by the International Centre for Evidence in Disability (ICED), working with NGOs focused on adolescents with disabilities, sought to understand what is important for their wellbeing. It also worked with a team of young researchers with physical and sensory impairments who received training to help conduct the research, putting youth with disabilities at the core of the research, based on the principle 'nothing about us without us'. As in Bangladesh, peer researchers in Nepal also reported acquiring new skills, increasing their self-confidence and becoming role models, both for the adolescents they interviewed and their parents; they thus felt that their involvement in the research had been a strong and empowering experience (Bhatta et al., 2018).

<sup>8</sup> The project was funded by Sightsavers and involved a consortium formed of Sightsavers, HelpAge International, ADD International and Alzheimer's Disease International. The NGOs worked together with the Institute of Development Studies (IDS) in Brighton to collect data and understand the experiences of marginalised people, including persons with disabilities.

<sup>9</sup> This project was a collaboration between the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine, OBM Nepal and Plan International Nepal, with support from local NGOs.

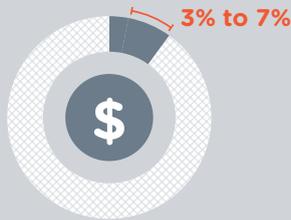


## 6 Economic Empowerment



## Economic empowerment

**Recommendation:** Ensure social assistance programmes cover the additional costs that adolescents with disabilities incur. Simultaneously invest in skills and asset building programmes necessary for their economic empowerment



The costs of excluding persons with disabilities from work range from **3% to 7%** of Gross Domestic Product in low- and middle- income countries (ILO)\*



Training and skills development opportunities for adolescents with disabilities are limited and do not match labour market demands



Adolescents with disabilities, particularly girls, have lower access to decent employment opportunities



Older adolescents with disabilities are often excluded from microfinance schemes and denied their inheritance rights

\* ILO 2009

## Key messages

- **Overarching challenges:** Despite their aspirations, older adolescents with disabilities have lower economic participation rates compared to their peers without disabilities. This is due to significant and widespread disadvantage in accessing appropriate and market-relevant skills development opportunities, credit, productive assets and opportunities to engage in decent and productive economic activities.
- **Gender dimensions:** Adolescent girls with disabilities are especially likely to face limited opportunities to develop market-relevant skills and to engage in decent and productive employment due to discriminatory gender norms.
- **Impairment-specific challenges:** Adolescents with intellectual or psychosocial impairments face multiple and deeper disadvantages.
- **Evidence gaps:** Rigorous evidence on what works to develop the economic skills and capabilities of adolescents with disabilities is lacking. There is also a dearth of evidence on what measures can help to address their limited access to credit and productive assets.
- **Promising practices:** Promising practices include initiatives that adopt a multi-component approach and engage with diverse stakeholders to provide skills training to older adolescents with disabilities and facilitate their access to wage and self-employment. Social protection measures that enable adolescents with disabilities to enjoy a basic standard of living, including access to education, training, assets and employment opportunities, are also critical to monitor, evaluation and draw lessons.

## Introduction

The economic empowerment of persons with disabilities is critical, both for their individual empowerment and inclusion as well as for the economic development of low- and middle-income countries (LMICs) – and as such appears as a key priority on the policy agenda. However, evidence demonstrates that they continue to face multiple barriers and are unable to access the required resources with which to participate in economic activities on an equal basis with others. Given their exclusion from education, older adolescents with disabilities often have low human capital, exacerbated by their limited access to appropriate training and skills development opportunities, economic and financial resources, and social capital. They thus end up having low participation in economic activities and those that are employed often encounter difficult working conditions. Young people with intellectual or psychosocial impairments, and adolescent girls with disabilities, face multiple and deeper disadvantages in labour markets. In recent years, social protection programming has been expanded to also target persons with disabilities and facilitate their access to basic services, opportunities and assets. Despite the potential of such schemes, they have limited coverage and the benefits provided are of low value; a comprehensive approach combining social assistance with complementary programmes is lacking.

Groce and Kett (2014) have noted that it is easier to discuss what is not known than what is known about youth with disabilities. This is even more so when we talk about adolescents with disabilities and their economic capabilities in LMICs, as existing evidence is limited and often fails to distinguish between adolescents and youth or adults with disabilities. Aiming to synthesise the available body of evidence, this chapter presents knowledge and data on the opportunities adolescents with disabilities have to access skills training, credit, social assistance and decent work. Where specific data exists, it is presented and compared to relevant data about adolescents without disabilities. In order to identify particular vulnerabilities shaped by gender and type of impairment, such evidence is also presented. However, wherever we are unable to provide age-specific data, we include some key data on youth (often defined as those aged 15–24) with disabilities and, in a few cases, on adult women and men with disabilities as indicative of the challenges adolescent girls and boys with disabilities may also face in terms of economic empowerment.

## Skills building and training

Quality technical and vocational or business training, along with the development of a broader set of life and work skills, are central to the economic inclusion of young people with disabilities (WHO and World Bank, 2011; ILO, 2017a). While this need is widely recognised, the availability, accessibility and adaptability of such opportunities to the specific needs of adolescents and young people with different types of impairments is limited, especially in rural and remote areas in many LMICs. Training centres tend to be based in urban areas and provide a limited range of traditional technical skills, such as carpentry or handicrafts, without considering and matching labour market requirements – often under the assumption that persons with disabilities are capable of only a few occupations and trades (WHO and World Bank, 2011; Kett, 2012). Programming also neglects the fact that many adolescents and young people with disabilities have not completed their basic education, have low literacy and numeracy skills, and lack self-confidence and essential work skills. Thus the provision of technical or business training should be combined with the acquisition of life and work skills, such as self-management, communication and problem-solving (ILO, 2017a). In addition, few programmes have provisions in place to tackle transportation barriers, link graduates with potential employers, provide ongoing support, facilitate access to the necessary capital for business development, or create links with awareness-raising campaigns to tackle stigma. Community-based vocational rehabilitation services that provide training, counselling and placement are often limited (WHO and World Bank, 2011; ILO, 2017a).

Limited evidence suggests an extremely challenging situation. In Asia and the Pacific, persons with disabilities account for only 3.4% of participants in government-funded

 For his future I think that if he learns to do a craft or something, but for education, he doesn't have the option anymore... I asked some charities but they said what shall we do, there is nothing to do, and I asked them what do you think about his future, what shall he do, they said that we should try to find something to work in.

(Father of 16-year-old boy with a physical impairment, Syrian refugee in Jordan)



An adolescent boy, with a visual impairment, with his mother, Ethiopia © Nathalie Bertrams / GAGE 2018

vocational training (UNESCAP, 2018). In Rwanda, young people with disabilities accounted for just 1.5% of all those enrolled in vocational training centres in 2016, with over one in four having speech impairments but none having multiple impairments (MINEDUC, 2016). In southern Africa, nearly half or more of adolescents and young people with disabilities aged 15–29 reported needing but not accessing vocational training services (Eide, 2012). In Nepal, nearly a third of adolescents with disabilities questioned the quality of available training courses and asked for a wider choice of training options (Bhatta et al., 2018). Similarly, in Jordan, government and NGO training courses offer limited places and often fail to meet the needs of trainees and of the labour market. Many courses focus on teaching youth with

disabilities to make basic handicrafts and, in some cases, the training provided does not enable trainees to find employment and generate their own income. Ineffective training schemes apparently act as a disincentive for other young people with disabilities to attend them (UNESCWA, 2009). In another study in Nepal, young people with disabilities who attended skills development sessions reported difficulty in accessing capital to start their own business and apply the skills they had acquired. Thus many continued to be economically inactive and dependent on their families (Eide et al., 2016). Evidence on particular groups with increased vulnerability, such as young refugees with disabilities, is severely limited (see Boxes 6.1 and 6.2).

### Box 6.1: Skills training opportunities for adolescents with disabilities are limited

Overall, among the older adolescents in the GAGE qualitative sample, we found a strong interest in skills training, but that very limited opportunities were available, as these parents and service providers emphasise:

*'For his future I think that if he learns to do a craft or something, but for education, he doesn't have the option anymore... I asked some charities but they said what shall we do, there is nothing to do, and I asked them what do you think about his future, what shall he do, they said that we should try to find something to work in.'*

(Father of 16-year-old boy with a physical impairment, Syrian refugee in Jordan)

*'Persons with disabilities need economic empowerment because in most cases they feel they are a burden on others. We provide persons with disabilities with rehabilitation to empower them economically to be able to start a small project that generates money that meets their basics and needs from food and clothes like any other person.'*

(Service provider, Gaza)

*'We advise and recommend to facilitate vocational education for the deaf. They are good and capable to train. However, the government facilitated the vocational training only for those who completed grade 10 and above but there should be similar training that fits their level of understanding for them... It should be mandatory for the technical and vocational school to [have a] curriculum for the deaf students. Even it is better to give special support for the deaf students to participate in vocational work by giving financial support for them.'*

(Special needs teacher, Ethiopia)

We did, however, encounter several exceptions of adolescent boys with access to skills development opportunities, whose cases underscore the empowering potential of such initiatives. It is important to note that opportunities for adolescent girls seem to be even scarcer:

*'I am taking a STEM (Science, Technology, Engineering, and Mathematics) class and programme robots, but still I'm not an expert. I assemble the robot, and after that I implement a code to program it. Some robots we install sensors on them if we want them to follow a specific route, we install a sensor so the robot could follow the route... I want to continue my studying to achieve high educational levels and to be a robot programmer, the only problem is that there are no universities here that offer a major like this, we take courses at STEM, but as universities here to have a PhD there is no one, I want to ask for a scholarship.'* (Boy who is blind, 13 years, Jordan)

*'I did a training... with an organisation called Syrians without Borders... They taught me to design paintings and to design frame from stones... It is just for boys – older boys – some are in their 20s. I didn't see any girl at the centre. My goal is to be a good trainer in that mosaic course.... It will be for about 5 or 6 months and when I finish it, I want to try to find another course in the same profession, to work... I want to be a trainer and start producing... I would advertise myself, bring people and train them.'* (Boy with a physical impairment, 18 years, Syrian refugee in Jordan)

### Box 6.2: Training and employment opportunities for young refugees with disabilities

Many refugees with disabilities want to learn new skills and be productive, yet they face additional barriers because of the interaction of disability with refugee status. Young refugees with disabilities have limited and varied access to vocational and skills training opportunities. Such opportunities are usually not available at all, and when they are, they may not consider the particular needs of participants and fail to make the required adaptations, while trainers often lack specialised training and the skills they are teaching are inappropriate. However, there are a few cases where young refugees with disabilities have been able to access training, learn useful skills and start a small business. In general, it is relatively easier for young refugees with disabilities to start an income-generating activity or find some employment in camps and settlements (where NGOs may have positive employment policies) than in urban settings. In many countries, refugees are not legally allowed to work outside the camps and there is far greater competition in the open labour market.

Source: WRC, 2008

 I am taking a STEM (Science, Technology, Engineering, and Mathematics) class and programme robots, but still I'm not an expert. I assemble the robot, and after that I implement a code to program it... I want to continue my studying to achieve high educational levels and to be a robot programmer, the only problem is that there are no universities here that offer a major like this...

(Boy who is blind, 13 years, Jordan)

## Access to resource endowments, savings and credit

Given that self-employment is often the only option available to young people with disabilities to earn a living in LMICs, they need start-up capital and access to financial services. However, they are often unable to access such services or participate in microfinance schemes. According to a global survey of 50 microfinance providers, only 0.5% of their clients had a disability (Handicap International, 2006). Microfinance institutions rarely target people with disabilities, either on the assumption that such clients are particularly risky and highly unlikely to pay back the money borrowed, or due to reluctance to adapt their services and products to potential clients' specific needs and to provide the necessary support and

staff training (see Box 6.3). Similarly, savings and lending groups have usually not included persons with disabilities among their members. For instance, in Bangladesh, persons with disabilities have frequently been excluded from microfinance programmes. Some disabled people's organisations offer special group schemes but these tend to be relatively small in size, provide small amounts, and their sustainability is uncertain. On the other hand, young people with disabilities, especially those in rural areas, may lack access to appropriate information and self-confidence that would enable them to take up mainstream services or join savings groups. They can also find it difficult to provide the required collateral, to attend meetings, keep accounts and make the required repayments (Cramm and Finkenflügel, 2008; Rohwerder, 2015; Sarker, 2015).

Inheritance, and transferring property and other assets between generations, can also provide young people with some economic independence and strengthen their productive capacity and participation in intra-household decision-making. Nonetheless, in many LMICs, young people with disabilities – especially those with psychosocial or intellectual impairments – are often denied their inheritance rights through formal, customary or informal practices (Groce et al., 2014b). For instance, in Uganda, customary law prohibits persons with disabilities from inheriting land, while in Bangladesh, land and property tend to be inherited by the siblings of persons with disabilities (Groce et al., 2014b; Burns and Oswald, 2015). Not only are persons with disabilities excluded from inheritance by other family members, but they also find it difficult to access relevant information and support to assert their rightful claims in courts (Groce et al., 2014b).

### Box 6.3: Lack of access to credit for older adolescents

Lack of access to credit emerged as a significant concern among our Bangladesh sample of older adolescents in terms of hindering their business or educational plans, as these quotes illustrate:

*'When I grow up I want to open a shop where I will do business. I will sell grocery items and many other things. I will tell my mother first. She doesn't have that kind of money that she can manage it right now. That's why I didn't tell her.'*  
(Boy with a physical impairment, 15 years, Bangladesh)

*'I want to study engineering. In order to study science, at a certain level, a lot of money is needed... After Intermediate, I want to do a part-time job and continue my studies side by side. Any job will do as long as they give me the time to study.'* (Girl with a physical and a visual impairment, 17 years, Bangladesh)

*'I want my daughter to be a doctor... I will let her study for two or three more classes... then after that, if I cannot manage, then I will get her into a garments factory... What else can I do? I keep on telling her, "You keep on studying... you keep on going ahead... if it's necessary I will take loan from people and provide for your education".'*  
(Mother of girl with a physical impairment, Bangladesh)

## Social protection provisioning

Given that persons with disabilities are often among the poorest and most vulnerable in their communities, their inclusion in social protection programmes is increasingly promoted by government and development agencies (Schneider et al., 2011; Rohwerder, 2014). Such programmes can offset higher poverty rates associated with disability, enable persons with disabilities to actively participate in education, employment and society, and foster social inclusion (Devandas Aguilar, 2017; ILO, 2017b). In particular, social protection measures can help adolescents and young people with disabilities overcome barriers and access health and education services, meet some of the costs for assistive devices, transport and care, improve their living standards and even transition to productive, independent and sustainable livelihoods (see Box 6.4).

There are different types of disability-related assistance with particular objectives, including cash transfers for education, food assistance, medical care, housing subsidies, transport subsidies, wage subsidies, subsidised assistive devices, opportunities in public works schemes, and tax exemptions. Cash transfers account for the majority of benefits for persons with disabilities. Some transfers are provided to the whole household or to parents of children with disabilities, while others target

the individual with the disability. Evidence from southern Africa indicates that disability grants can indeed increase access to education and health care. However, it is also acknowledged that a comprehensive approach is required – one that combines disability grants with other complementary assistance such as access to information, transportation and specific services, as well as the creation of livelihood opportunities and a wider disability-inclusive policy framework (Schneider et al., 2011; ILO, 2017b; UNESCWA, 2017).

Such an approach is currently lacking, and most persons with disabilities in LMICs, including adolescents, face great difficulty in accessing social assistance. Globally, most countries provide disability benefits only through contributory schemes, thus not reaching people with disabilities who are outside the formal economy, including

▶ We ask the agents/relatives/caregivers to buy them uniforms. They say ok to us but we know they already used the money for themselves. Because they live in poverty, they need the money... In the rural area parents give support to regular children instead of supporting the special needs children.

(Teacher, Ethiopia)



An adolescent boy, with physical impairment, with his mother, Syrian refugee @Medair/EU/ECH/Kate Holt

### Box 6.4: Social protection for special needs education in Ethiopia

Recognising that most of the students who are attending special needs classes are from out of town, the government provides a stipend to cover basic living costs. Because the government assumes that young people with hearing impairments can work more easily than children with visual impairments, *'For visually impaired students, they get 360 ETB [\$13 USD] per month plus 600 ETB [\$22 USD] for school uniform. For students with hearing impairments, it is 200 ETB [\$7 USD] per month and 400 ETB [\$13 USD] for school uniform'* (service provider, Ethiopia). Teachers note, however, that students with physical impairments are largely shut out of the current special needs system, as *'There is no separate class... and nobody supports them either financially or materially.'*

Although the stipend is limited in value, it has attracted students to special needs education classes, as highlighted by the large number of over-age students we encountered during the GAGE baseline research – students who previously did not have an opportunity to get an education. The stipend, however, is for the four years of special needs education instruction only, and only if students make good progress. One teacher explained that students were kept in the same class until they had solid communication/literacy skills: *'If they are not competent to pass to the next grade, we make them repeat.'* While there are valid reasons for this policy – namely, that *'They need to be well educated for them to understand what they are taught later on'*, it can create significant financial hardship: *'If a student repeats a grade twice, his financial aid stops. He can attend school for free but will be provided with no money.'* Moreover, once students finish the four grades of special needs education and move on to the 'inclusive education' system, they no longer receive a stipend.

The value of the stipend while it lasts is also low and, as one special needs teacher explained, *'The education stipend [for students enrolled in special needs education] is meagre and barely pays the rent... We often try to help them find work after school.'* Another teacher noted that part of the challenge was a dearth of financial support from parents:

*'Many of the students are from the rural villages, parents don't cover the children's expenses... The parents' assumption is that the government has a responsibility to take care of them after they enrol to the school. After they gave [their child] to the government they didn't take any responsibility to look after them. To make matters worse, hostel owners where the students stay usually take all the stipend. They don't even keep them clean. They don't care if they pass or fail.'*

Teachers further explained that, even when teachers sought to intervene on behalf of the students to obtain support from the family, they were often unsuccessful:

*'We ask the agents/relatives/caregivers to buy them uniforms. They say ok to us but we know they already used the money for themselves. Because they live in poverty, they need the money... In the rural area parents give support to regular children instead of supporting the special needs children. Even parents get divorced because of having such special needs children. Even fathers didn't support their special needs children. Some children come to school without any food and fall asleep in the classroom.'*

children and adolescents with disabilities. Moreover, the current popularity of means-testing approaches (providing benefits only to those persons with disabilities who can prove that they are 'unable to work') can create disincentives, discourage participation in employment, cultivate dependency and reinforce negative stereotypes (Devandas Aguilar, 2017; ILO, 2017b).

Instead, social assistance programming should focus on enabling persons with disabilities to become full and productive citizens through ensuring a basic income security, facilitating access to education and decent work, and promoting an independent and active life (ILO, 2017b). In the case of adolescents with disabilities, schemes should provide them with grants and support to access education,

meet their basic health and nutrition needs, and help them access the required rehabilitation services and assistive devices. They should also facilitate adolescents' transition into productive and independent adulthoods through cash assistance covering training costs, grants towards workplace adjustment costs, targeted wage subsidies to employers to encourage their recruitment, and the provision of subsidised loans or assets required to start a business (ILO, 2015).

In recent years several LMICs have started introducing or enhancing non-contributory disability benefits or including persons with severe disabilities in broader social assistance schemes (ILO, 2017b). While this is a positive development, allocated resources are often too low to be

effective (UNDESA, 2018). For instance, data from 29 LMICs indicates that the amounts received through tax-financed schemes tend to be less than 15% of per capita GDP (ibid.). As a result, disability benefits have low coverage; only 28% of persons with severe disabilities globally receive benefits, with considerable variation between regions and countries. Only 9% of persons with disabilities in Asia and the Pacific are covered by social protection measures, and regional estimates are unavailable for Africa and the Arab states. At country level, 64% of persons with severe disabilities in South Africa receive a grant, 18.5% in Bangladesh, 16% in Kenya, 5% in India, and just 0.1% in Mozambique (ILO, 2017b); in Yemen, national data shows that 66.5% of persons with disabilities receive no support, with men having higher coverage than women (UNESCWA, 2017). In particular, very few LMICs provide social assistance to low-income families with an adolescent child with a severe disability. As of 2012, only 3% of low-income and 20% of middle-income countries had any specific benefit for adolescents with a severe disability (compared to 67% of high-income countries) (see Figure 6.1).

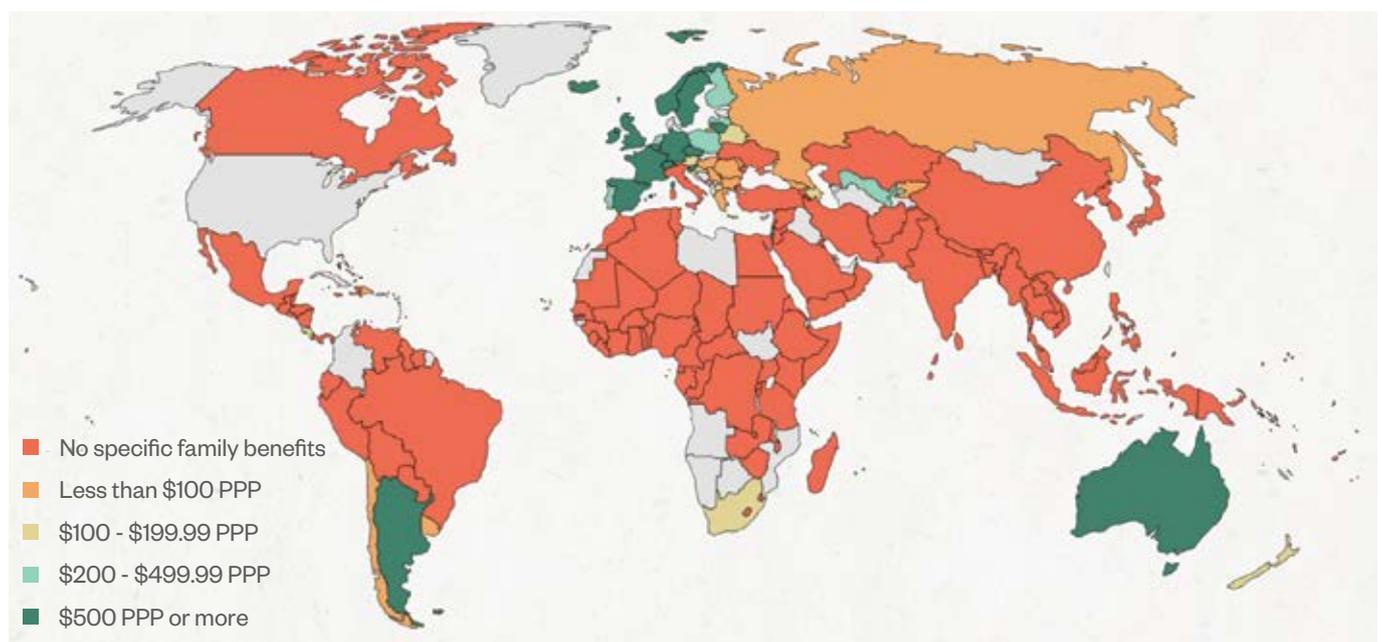
A related problem is the low value of benefits. In many LMICs, households with persons with disabilities often report that grants or transfers are inadequate to cover the costs of disability-relevant expenses and support services required for their specific needs (Oddsdottir, 2014; Rohwerder, 2015; UNESCWA, 2017; UNDESA, 2018).

They cut the cash 11 months ago... I honestly don't know why... each month, 20 JD [\$28 USD] for each child for the children in school. They cut it. We want someone to tell them to give it back, because our children at school need a lot of money... I swear I didn't have a choice but to wipe stairs, I worked with vegetables... and to pay for their books and school fees and for their needs. I make *molokhia* [a Syrian dish], hollow out zucchini, and make *kibbeh* [another Syrian dish], I clean kitchens...

(Mother of three children, 10, 11 and 27 years, all with severe intellectual and physical impairments and two with epilepsy, Syrian refugee in Jordan)

Indeed, many children and adolescents with disabilities in Palestine face significant difficulties to access services, assistive devices, transportation and medications (see Box 6.5). Not only are more resources required (and more efficient management of those resources), but there is also a need for accurate data for evidence-based policies and improved estimations about the multiple needs of persons with disabilities. For instance, the ILO (2017b) explicitly advocates for the addition of disability-related costs to

**Figure 6.1: Cash assistance to low-income families with an adolescent child with a severe disability**



Source: WORLD Policy Analysis Center, 2012

### Box 6.5: Social assistance for children and adolescents with disabilities in Palestine

Although the Palestinian National Cash Transfer Programme (PNCTP) is not designed to target persons with disabilities but rather households living below the poverty line, it serves as a de facto disability programme. Jones et al. (2016) found that 53% of surveyed children and adolescents with disabilities receive some social assistance as part of the PNCTP. While the programme improves the lives of children with disabilities and their caregivers, it is not delivering adequate support because it fails to account for both the higher and multiple costs of disability (especially medical costs) and the ways in which children and adolescents with disabilities are allocated resources within the family – often overlooked in a setting of scarce resources.

Thus, even with the cash transfer, nearly 40% of households with children with disabilities had monthly incomes about half the extreme poverty line and more than three-quarters of families reported that it was ‘very difficult’ to make ends meet because of the costs of disability. Thus 76% of respondents stressed that they experience significant financial difficulties; 65.5% face difficulty in accessing required services; 51% require support to purchase assistive devices; 43% have great difficulty accessing rehabilitation services; 42% face serious problems accessing transportation; and 39% find it difficult to get the required medications. Also, the vast majority of respondents expressed the need for more information about the services available for children and adolescents with disabilities: only 0.4% had received such information and 49% were unaware of community-based rehabilitation programmes.

An alarmingly high proportion of respondents – 89% – reported that they had not been consulted at all about disability-related programming and their needs. Lack of coordination and fragmentation among government and non-government agencies has affected service provision and prevents optimal use of resources in a context of scarcity, deepening uncertainty and high needs.

Source: Jones et al. (2016)

An adolescent boy with a psychosocial impairment, with his sister, West Bank © Rebecca Reid / ODI 2018



 My sons need this medicine and special milk formula every month. It costs 25 JD [\$35 USD] so I can only get one each for them every four to five months. I can't always get it and not two every month. This is a medicine for epilepsy... The UNHCR visit us a lot to write down what we drink and eat... If they paid for my children's medicine and gave us back the school stipend, I could stop working at houses. I can barely take care of these children.

(Mother of three children, 10, 11 and 27 years, all with severe intellectual and physical impairments and two with epilepsy, Syrian refugee in Jordan)

monetary poverty rates. Very few countries have flexible systems that cover disability-related costs, while in most cases, provided benefits are static and fail to consider the individual's particular situation and needs to maintain a basic standard of living and not to fall into or exacerbate poverty (Devandas Aguilar, 2017) (see also Box 6.6).

Persons with disabilities also need better information about existing support and how to access it, especially about getting the disability card, which enables them to access related assistance. In Morocco, only 9% of persons with disabilities report being aware of government support services, and in Egypt and Tunisia, many were confused about where and how to access assistance (UNESCWA, 2017). In Tunisia, only 51% of girls aged 0–14 years with disabilities have a disability card (ibid.), while in Nepal, adolescents with disabilities reported administrative difficulties in obtaining the card and thus delays in accessing support (Bhatta et al., 2018).

#### Box 6.6: Limited social assistance for adolescents with disabilities in humanitarian settings

While some of the Syrian refugee households with adolescents with disabilities in our Jordan GAGE qualitative research sample are receiving social assistance, it appears that weighting for disability to cover related costs (e.g. transportation, assistive devices, specialised medical care) is very limited and that, in the context of significant funding shortages for the Syrian response in Jordan currently, even these households may be subject to reductions or cuts in social assistance, as these two powerful examples highlight:

*'She used to take her medicine – a calcium injection for osteoporosis – every four months. But now, it's been a year and a half since she has not taken her medicine dose. Each dose costs 800 JD [\$1,128 USD] because it is not at the public hospital – we need to go to a private hospital to get it. Each time she has to stay in the hospital for three days... But they treat her well. They say, "The hospital has become brighter now that you're here."... They [UN] don't offer advice or support, they came for evaluation. The fingerprint [for cash transfer registration] was still not issued. So, they came to check if it's true that my daughter's situation is like this. That there is no man [male household head]. And what the house is like and how the kids are and such things.'*

(Mother of 12-year-old girl with cerebral palsy, Syrian refugee in Jordan)

*'They cut the cash 11 months ago... I honestly don't know... each month, 20 JD [\$28 USD] for each child for the children in school. They cut it. We want someone to tell them to give it back, because our children at school need a lot of money. I mean, the children's studies at school require a lot of burden. We used to pay all of the school fees. I swear I didn't have a choice but to wipe stairs, I worked with vegetables... and to pay for their books and school fees and for their needs. I make molokhia [a Syrian dish], hollow out zucchini, and make kibbeh [another Syrian dish], I clean kitchens. Of course, we went to the UNICEF office but they didn't let us enter for an interview at all. We called them; we have some numbers for them. My husband called them, he called them each month, hoping to get it back next month, but nothing happened... There was police at the gate and he didn't let me enter. He gave me about seven or eight numbers. I called them all, but they were closed... My sons need this medicine and special milk formula every month. It costs 25 JD [\$35 USD] so I can only get one each for them every four to five months. I can't always get it and not two every month. This is a medicine for epilepsy... The UNHCR visit us a lot to write down what we drink and eat... If they paid for my children's medicine and gave us back the school stipend, I could stop working at houses. I can barely take care of these children.'*

(Mother of three children, 10, 11 and 27 years, all with severe intellectual and physical impairments and two with epilepsy, Syrian refugee in Jordan)

## Decent and productive work and employment

Youth with disabilities have the right to work on an equal basis with others and to participate in work environments that are open, inclusive and accessible (UN, 2006). Access to decent, productive and sustainable work opportunities is essential for income generation and economic independence, improved self-confidence and social status, increased social inclusion and cohesion. In addition to these positive consequences for individuals, households and communities, there is now growing recognition that the economic inclusion of persons with disabilities also has considerable macroeconomic benefits for LMICs. Several studies have revealed the large costs to national economies of keeping persons with disabilities out of the workforce (see Box 6.7), let alone the additional lost income by family members, usually women, who are unable to work due to their care responsibilities, as already discussed in Chapter 3 on Psychosocial Wellbeing.

Despite these multiple benefits, persons with disabilities, including older adolescents and young adults, continue to experience significant and widespread disadvantage in accessing and sustaining work. Thus they may be forced to take up any job even if it does not align with their skills or aspirations. They also have consistently

lower employment rates, higher underemployment and unemployment rates, higher part-time employment rates, lower earnings and less prospect of advancement than workers without disabilities (WHO and World Bank, 2011; Groce and Kett, 2014; UNESCAP, 2015; Handicap International, 2016).

### Box 6.7: The costs of excluding persons with disabilities from work

Although studies use different methodologies, they all find that excluding persons with disabilities from the workplace leads to significant losses in gross domestic product (GDP) each year. An early study by the World Bank calculated an annual loss for LMICs of between \$474 billion and \$672 billion, while a 2009 study by the International Labour Organization (ILO) in 10 LMICs estimated that the economic costs in Asia range between 3% of GDP in Viet Nam to 4.6% in Thailand; in sub-Saharan Africa, the costs range from 3% of GDP in Malawi to 7% in South Africa. Additional country-level studies showed similar losses of 1.3% of GDP (\$891 million) in Bangladesh and of 2% of GDP (\$1 billion) in Morocco.

Sources: World Bank 2008; Buckup, 2009; Morgan Banks and Polack, 2014

An adolescent boy, with a physical impairment, Ethiopia © Nathalie Bertrams / GAGE 2018



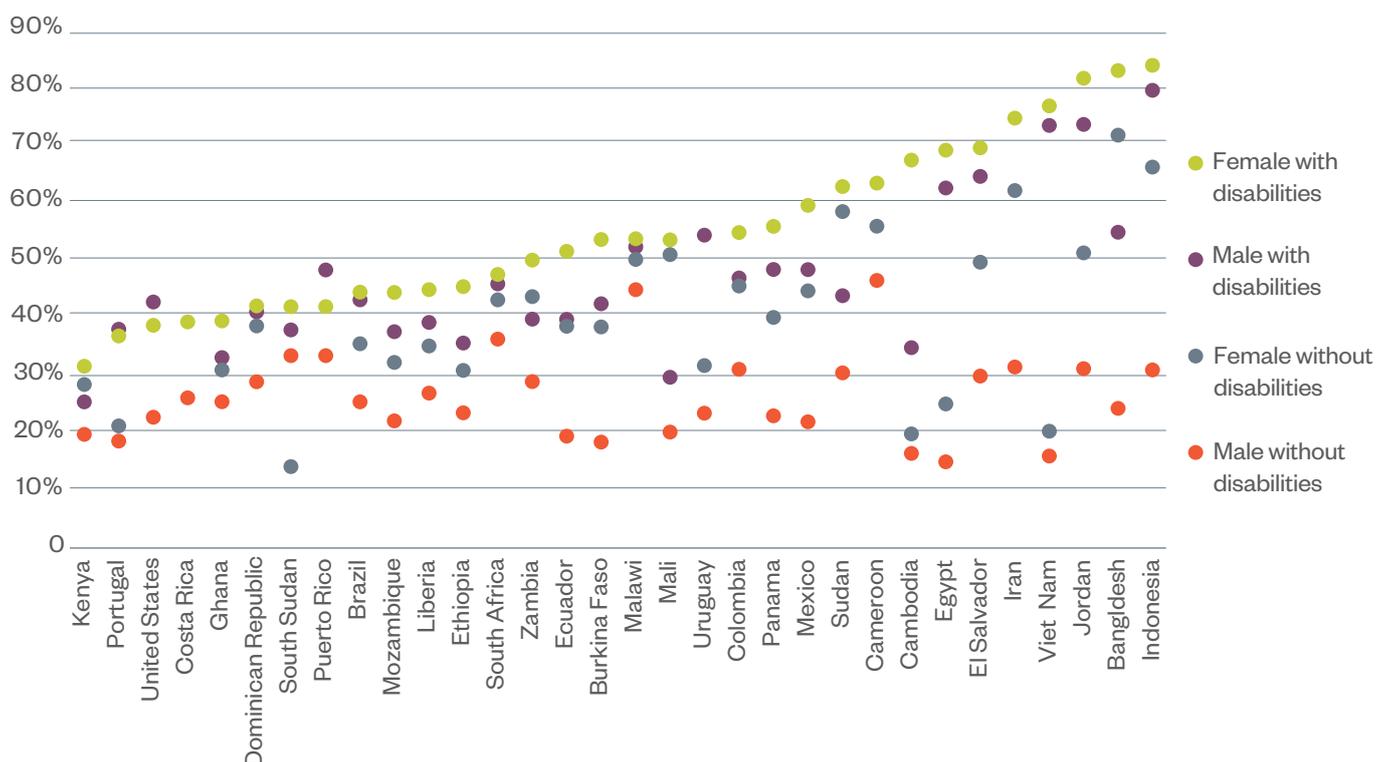
While there is a lack of accurate and comparable data disaggregated by type and severity of impairment, geographic location, age and gender, some general estimates are indicative of the alarming situation for people with disabilities when it comes to finding work. The ILO (2015) reports that of the approximately 785 million men and women of working age who are living with disabilities, most are not officially counted as economically active. Based on census data from 23 LMICs and four high-income countries, the UN Department of Social and Economic Affairs (UNDESA) (2016) estimated that the labour force participation rate of persons with disabilities is, on average, 20 percentage points lower than that of the rest of the population. Using data from 15 LMICs, Mizunoya and Mitra (2013) found that persons with disabilities have lower employment rates in 9 out of 15 countries, while the disability employment gap is significant and larger in middle-income than in low-income countries. Based on survey data from Asia and the Pacific, the UN Economic and Social Commission for Asia and the Pacific (UNESCAP) (2015) confirmed that this gap is larger in higher-income countries in the region.

There is 'strikingly little information' on the employment of young people with disabilities and relevant general data is hard to find in national household surveys (Kett,

2012: 5). Often, the term 'youth' in various LMICs refers to those aged 15–24 or 15–30 who are beginning to engage in economic activities. This is in line with the ILO, which collects data about young women and men aged 15–24 years. It does, however, acknowledge that the general minimum age for admission to employment or work is 15 years and that this work should not affect adolescents' health and personal development or interfere with their schooling as then it is dangerous and harmful and should be considered as child labour.

Existing evidence about older adolescents and youth with disabilities suggests that they experience significant difficulty in finding employment (Roggero et al., 2005). For instance, a 2009 pilot survey in urban Sierra Leone estimated that adolescents and youth with disabilities aged 15–25 were 8.5 times less likely to work compared to their peers without disabilities (Kett, 2012). Using census data from 2005 or later from 32 countries, UN Women (2018) found that older adolescent girls and young women with disabilities have the highest rates of economic exclusion in all 27 LMICs studied. In particular, female youth with disabilities aged 15–24 in Bangladesh, Indonesia and Jordan face the highest rates of economic and social exclusion (see Figure 6.2).

Figure 6.2: Youth not in education or employment by gender and ability status, 2005–2015



Source: UN Women, 2018

In many LMICs, where youth unemployment rates are high, youth with disabilities face far greater difficulties in finding decent work. Most persons with disabilities who are economically active in LMICs tend to be engaged in the informal economy (Mizunoya and Mitra, 2013; Handicap International, 2016), often in self-employment under poor conditions without social security benefits. Up to three-quarters of the working-age population with disabilities in Asia and the Pacific are employed in the informal economy, and more than half of them work in agriculture (UNESCAP, 2018). In India, for example, the employment rate of persons with disabilities was estimated to be 38% compared to 62.5% for the overall population, with 87% of the former working in the informal economy (WHO and World Bank, 2011; ILO, 2015). In Indonesia, more than 63% of working persons with mild disabilities are self-employed compared to 34% of their peers without disabilities (UNESCAP, 2015). Even when their activities are not always captured in official statistics, many adolescents and youth with disabilities cannot afford to stay unemployed so they do work, either at home, in the family farm or business, and in various types of casual or menial work (Groce and Kett, 2014). According to a 2008 national survey in Kenya, 14% of youth with disabilities aged 15–24 worked in the family business but only 8% worked for pay (UNESCO, 2012).

Many children and adolescents with disabilities are also involved in begging. The literature has identified a strong association between poverty, disability and begging, and many children and adolescents with disabilities, with limited schooling and skills, work as beggars in urban areas, often prompted by their families or coerced by criminal gangs who abuse and exploit them (Groce et al., 2014a). In Bangladesh, poor and illiterate parents may believe that their children

with disabilities are incapable of learning or may undervalue the importance of education for them and thus prefer to send them out to beg. Those with no education, support or alternative means to obtain food and survive are also forced to beg (Burns and Oswald, 2015). In Addis Ababa, Ethiopia, the tradition of inviting beggars outside churches or mosques to funerals and weddings provides a steady source of food and money to persons with disabilities who have no other livelihood option (Groce et al., 2014a).

There is a lack of robust empirical evidence on the linkages between disability and child labour and, in particular, about whether children and adolescents with disabilities are more vulnerable to entering child labour. In settings with scarce resources, young adolescents with disabilities may engage in child labour to contribute to household income. Indeed, between 17% and 23% of children and adolescents with disabilities surveyed in Ethiopia, Senegal and Uganda had to work to support their families, who were living in poverty (see also Box 6.8). All were in informal and poorly paid jobs, including begging for money or goods; nearly one in three reported that their working conditions were dangerous. Although most stated that they would prefer having more time for school than work, far more reported enjoying contributing to the household, as this made them feel independent, worthy and socially accepted, while they also made friends and had increased social interactions. Children and adolescents with disabilities were also involved in doing household chores. While most reported being happy to support their household, one in five felt that chores prevented them from schooling and social interactions, and a further one in five reported that chores were strenuous and painful for them (AOPF, 2011) (see also Box 6.9).

### Box 6.8: Child labour and disability in urban Bangladesh

Ahmed is a 12-year-old boy with a physical impairment living in urban Bangladesh. He has never been to school because his family is so poor that he must work to help support them. He works in a garage, as a mechanic's apprentice. Ahmed has many concerns.

First, he is worried about whether he will *'be able to make enough money to support my parents'*. He believes that this problem is solvable, however, if he is only able to work hard enough.

Second, while he initially reported that he did not experience violence, he later admitted that *'The man who owns the garage screams at me and beats me with a piece of rubber when I make mistakes or if I'm late for work...'* This is a problem because he is already in *'pain after walking for a while'*.

Ahmed's biggest concern, however, is that he wants – but cannot afford – a bicycle. A bike, he believes, would solve his problems. It would allow him to move around the community quickly, and without pain. This would let him get to work on time and also let him play with his friends more comfortably. *'A cycle is our favourite thing. But I don't have a cycle.'*

### Box 6.9: Adolescents with disabilities and domestic work

Adolescents with disabilities in Ethiopia, especially in rural areas, told us that despite their disabilities, they were expected to help around the farm and home:

*'I was doing good things and I was supporting my mam. I was cleaning the house and dishes and I was working on different kinds of tasks.'* (Boy who is deaf, 17 years, Ethiopia)

*'I am unable to walk fast and I have to take care of the baby at home.'*  
(Girl with a physical impairment, 11 years, Ethiopia)

*'I wash my clothes and clean the floor. I also wash the household utensils. I wash my clothes, my brother's clothes and my mother's clothes. I know which parts of clothes are clean and not. The bottom parts and areas under the armpits and neck are not clean. I clean those using a brush.'* (Girl who is blind, 15 years, Ethiopia)

*'We don't play running but we play while sitting together. I prepare a meal for my uncle, and clean the house. My sister leaves the house early in the morning so I need to do the house work.'*  
(Girl with a physical impairment, 16 years, Ethiopia)

Key informants noted that it was common for children with disabilities, but especially girls, to be late for school – or to be absent entirely – because of household chores and care work:

*'It is more evident among female students as they are expected to take part in various domestic works.'*  
(Teacher, Ethiopia)

A handful of adolescents with disabilities in our sample had never been sent to school, as they were kept home to work instead:

*'I have never attended school. I am busy with household chores. I don't have time to attend the school.'*  
(Girl with multiple impairments, 12 years, Ethiopia)

*'I was forced to look after my family and begun to keep livestock.'* (Boy with a physical impairment, 13 years, Ethiopia)

Others explained that young people with disabilities often drop out of school entirely in order to work.

*'I started to support my father. I also started to work as a daily labourer and support my family's livelihood from the income I generate.'* (Boy who is deaf, 12 years, Ethiopia)

*'Many deaf students drop out of school. They want to earn money before school. So, we advise them to work in the afternoon and come to school in the morning.'* (Special needs education teacher, Ethiopia)

Some evidence from Cameroon and Ecuador has suggested that disability can be a push factor into child labour: girls (and especially boys) with disabilities aged 5–17 spent, on average, more hours working per week compared to their counterparts without disabilities. However, a rapid ILO assessment in Indonesia found that most children and adolescents with disabilities who were out of school did not engage in income-generating activities. Context, economic pressure and attitudes to disability partly explain why parents may keep their children at home, away from the public eye in some cases, while in other contexts they opt to push them into begging and other income-generating activities (ILO, 2011).

The disadvantage that young people with disabilities systematically face in finding work is the combined effect of several interconnected factors that operate within

and beyond the workplace (UNESCAP, 2015; Handicap International, 2016). As already discussed in Chapter 1 on Education and Learning, poor outcomes in primary education and exclusion from secondary education result in low levels of education and training, including life skills development, and thus increased difficulty to access employment (WHO and World Bank, 2011; Kett, 2012); yet, as pointed out in Chapter 1, there are high rates of wage returns to education for youth with disabilities across LMICs. Other barriers include accessibility issues, linked not only to infrastructure and transportation but also to work-related information and communication services (Roggero et al., 2005). Indeed, many young people with disabilities report being unaware of available training and livelihood opportunities (Kett, 2012). Adolescents with disabilities in Nepal revealed having aspirations of getting

a good job, yet they lacked awareness of how best to transition to the workplace and what opportunities and career paths were available to them (Bhatta et al., 2018). Other barriers include lack of job search and placement support services, along with isolation and limited social networks that could also assist the process of finding work (WHO and World Bank, 2011; UNESCAP, 2015). Limited access to financial services and start-up capital also narrows the economic opportunities of many young people with disabilities in LMICs where informal self-employment is the norm (Handicap International, 2006).

Another major barrier to young people with disabilities finding decent work is the persistent discrimination and misconceptions that still pervade labour legislation and workplace attitudes. Over 58% of youth with disabilities in Kenya reported that stigma and discrimination are key barriers to finding employment (Kett, 2012), whereas a survey in Tanzania found that almost half the respondents were aware of employment discrimination against

persons with disabilities (Schipper et al., 2014). Many countries have not yet taken legal measures specifically to protect persons with disabilities from discrimination, and governments may even be unaware of the importance of such measures (UNESCAP, 2015). Thus some labour laws continue to restrict the participation of persons with disabilities in certain types of employment (ibid.). In Morocco, for example, where the national employment rate of persons with disabilities is 14%, the Constitution bans discrimination, yet the law limits the types of employment that persons with disabilities are allowed to access (Handicap International, 2016; UNESCAP, 2017). In addition, laws may prescribe lower minimum wage rates for persons with disabilities; in India, they may be excluded from certain provisions of the Minimum Wages Act, while in the Philippines it is fixed that remuneration for persons with disabilities may not be less than 75% of the legal minimum wage (ILO, 2014a).

While most young people with disabilities are able to acquire the necessary skills and be productive, employers often equate impairment with limited capacity, lower productivity or high costs to make workplace adaptations, and thus prefer to hire young people without disabilities (WHO and World Bank, 2011). The types of employment offered to persons with disabilities may also be shaped by stereotypes about what persons with disabilities can and should do (Handicap International, 2016). And even when the law requires employers to pay the minimum legal wage, some provide lower wages to workers with disabilities; in Bangladesh, 72% of respondents in a survey reported that workers with disabilities tend to get paid less than others, especially in manual jobs (NGDO et al., 2015). Colleagues may also mistreat young people with disabilities: in Uganda, 38% of adolescent respondents revealed that they had been attacked and insulted by fellow workers because of their disability, and 64% felt that they were treated unequally by their employers (ACPF, 2011).

Interestingly, there is evidence that some employers in LMICs are willing to provide opportunities if certain conditions are met, including the provision of incentives (Engelbrecht et al., 2017). Most importantly, reasonable workplace adjustments and supportive policies are often less costly than initially thought and can also benefit workers without disabilities as they promote more inclusive work environments. For instance, South African companies report that persons with disabilities are reliable and productive employees with low absenteeism rates when they are provided with reasonable accommodations



An adolescent boy, with a visual impairment, Ethiopia  
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(Handicap International, 2016). Anecdotal evidence also suggests that employing people with disabilities can have a positive impact on changing attitudes in the workplace and in society at large (WHO and World Bank, 2011).

Family members may also undervalue the capacity of adolescents with disabilities and discourage them from having career aspirations and seeking employment (UNESCAP, 2015). On the other hand, young people with disabilities may have internalised such beliefs, demonstrate low self-confidence and low self-expectations, and thus avoid applying for training or employment opportunities, or attempting to start their own business (WHO and World Bank, 2011; Handicap International, 2016). Indeed, in Bangladesh, some people with disabilities reported not applying for work as they felt they would be rejected because of their disability (Huq et al., 2013).

## Experiences shaped by gender

Adolescent girls and young women with disabilities are more likely to face greater discrimination in accessing training opportunities, developing their skills, and engaging in decent work. Disability intersects with gender and age, and, as already noted (see Figure 6.2), the scarce available data suggests that adolescent girls and young women with disabilities have the highest rates of economic exclusion in several LMICs. Similarly, the economic participation rates of women with disabilities are often significantly lower than those for men with disabilities. Data from 51 countries shows employment rates of 53% for men with disabilities and 20% for women with disabilities, compared to 65% for men without disabilities and 30% for women without disabilities (WHO and World Bank, 2011). Recent UN reports from the Arab region and from Asia and the Pacific confirm that women with disabilities face greater exclusion (UNESCAP, 2015; UNESCWA, 2017).

This exclusion is the combined outcome of several factors. Adolescent girls and young women with disabilities are more likely to have limited opportunities for education, are usually overlooked by skills training and empowerment initiatives, and have greater difficulty accessing appropriate training opportunities compared to their male peers. Not only do girls and women with disabilities face greater educational disadvantage, lack basic literacy and numeracy skills, and have low self-confidence and aspirations, they also have greater difficulties socialising and moving freely around their community due to

discriminatory gender norms and the overprotective attitudes and safety concerns of their families (ILO, 2017a). Even when they are able to gain access to training opportunities, their parents and trainers may still have low expectations and perceive girls with disabilities to be passive, dependent and incapable of succeeding or actively seeking employment (Rousso, 2003; ILO, 2015).

Some skills training courses also tend to reinforce gender stereotypes by offering training in trades and occupations considered appropriate for women, such as sewing and handicrafts, which tend to provide lower wages and poorer working conditions (Rousso, 2003; ILO, 2017a). On the other hand, business skills development schemes often pay inadequate attention to the barriers women face in starting up a business (ILO, 2017a). Indeed, in Lebanon, women with disabilities felt that the vocational training courses offered to them were ‘too traditional and of questionable value’, teaching them sewing and cooking, while men with disabilities learnt computer skills and electrical engineering (Nagata, 2003). In Nepal, women with disabilities reported being offered some skills training that was irrelevant to the work opportunities available locally or to what trainees would like to do (Dhungana, 2006).

Adolescent girls and young women with disabilities tend to have fewer options for economic participation and are more likely to engage in unpaid domestic activities; indeed, in a multi-country study in sub-Saharan Africa, girls with disabilities were more likely to engage in household chores, and for longer than boys, having to work most or every day (ACPF, 2011). Young women with disabilities are also more likely to spend more time searching for a job and have greater difficulty keeping the job, and experience occupational segregation and poor working conditions. They also typically earn less than their male counterparts, although gender pay gaps may be less marked in LMICs for men and women with disabilities (WHO and World Bank, 2011; UNICEF, 2013; ILO, 2015). Young women with disabilities are also vulnerable to sexual harassment. In Lebanon, the few women with disabilities in formal employment often reported wage discrimination along with verbal, physical and sexual harassment at the workplace and when using public transport (Nagata, 2003).

Young women with disabilities who engage in business activities also face multiple difficulties. For instance, in Ethiopia, young women entrepreneurs with disabilities emphasised the discrimination they face because of their impairments, their increased difficulty to attract customers and avoid being exploited, as well as their



enhanced vulnerability to verbal abuse and harassment by customers, traders and law enforcement officers (Phororo and Verick, 2009).

Young women with disabilities also have limited access to the financial and productive resources that are critical for becoming independent and engaging in economic activities. Despite the proliferation of microfinance schemes targeting marginalised women, those with disabilities have often been excluded from accessing finance and relevant services from banks, micro-lenders and peer-lending groups, as they are deemed 'bad risks'. Many report lacking information about such schemes or not applying to join them under the belief that they are not eligible to participate (Lewis, 2004). Those who do manage to get loans may be vulnerable to family pressures to control and use the funds (Lewis, 2004; Burns and Oswald, 2015). Indicative of the situation is that in Nepal, just 29% of women with disabilities reported being a member of a savings group (Adhikari, n.d.).

Girls and women with disabilities are also at higher risk of being denied their right to family land or property by older family members and community leaders. In settings where productive resources are limited, they thus face increased risk of economic insecurity and poverty. Indeed, in Nepal, women with disabilities have great difficulty accessing their legitimate share of ancestral property. The law is not systematically enforced, many have limited access to information and are thus unaware of their rights,

and support services are lacking (NFDN, 2013). Given that in many contexts, girls and young women access property and assets during marriage through dowry – considered to be a pre-mortem inheritance for daughters – those with disabilities also find it difficult to obtain a marriage partner and are thus less likely to access land, property or other economic assets (Groce et al., 2014b).

## Experiences shaped by impairment type

Evidence suggests that persons with intellectual and psychosocial impairments have the lowest employment rates, and are 3–4 times less likely to be employed than those without disabilities (WHO and World Bank, 2011). Those with multiple disabilities also have lower employment rates compared to persons with a single disability (Mizunoya and Mitra, 2013). On the other hand, those with physical and sensory impairments are more likely to find employment in some settings. In Colombia, persons with physical and visual impairments reported higher employment rates than those with other impairments (Handicap International, 2016). In Turkey, having higher education and Braille literacy increased the chances of employment for persons with visual impairments (Bengisu et al., 2008).

Context and household needs appear to play a key role in what children and adolescents with specific

impairments are allowed to do. A study in Ethiopia, Senegal and Uganda noted that children and adolescents with hearing impairments were significantly more involved in household chores than those with other impairments (ACPF, 2011). In Sierra Leone, children with severe disabilities in urban areas were more likely to be responsible for household tasks than go to school or work outside the house, while half of those with mild disabilities in rural areas were working in agriculture (Kett, 2012).

The type of employment opportunities open to persons with particular impairments is also shaped by stereotypes about what they can do; for instance, those with visual impairments are typically placed in call centres as switchboard operators, while those with physical impairments tend to be confined to administrative jobs (Bengisu et al., 2008; Handicap International, 2016).

Persons with intellectual and psychosocial impairments, including youth and women, also face discrimination in accessing resources. As we already noted, in many LMICs, they are denied inheritance rights through formal or customary practices. For instance, in Bangladesh they may be legally declared incapable of managing their share of family property (Groce et al., 2014b; Burns and Oswald, 2015); in a study, 73% of Bangladeshi respondents reported that women with intellectual impairments are denied inheritance rights (NGDO et al., 2015).

## Evidence gaps

While adolescents and young people with disabilities in high-income countries are often assisted to join the labour market, in LMICs, their employment needs are often overlooked. More policy and research attention is paid to adults with disabilities, such that research on young people with disabilities is 'even more limited or altogether absent' (Engelbrecht et al., 2017). Evidence is even more limited for the economic capabilities of adolescents with disabilities, who tend to fall through the cracks between two groups – youth in general and adults with disabilities. Furthermore, the available evidence focuses on older adolescents with disabilities. With the exception of some scarce evidence on child labour, younger adolescents remain invisible in the existing evidence base, with quantitative data typically focusing on those aged 15 and over. Overall, data is scarce and rarely disaggregated by type and severity of impairment, or by age, gender, ethnicity, socio-economic status or location – factors that intersect with and exacerbate the economic disadvantage facing particular groups of adolescents with disabilities. Most importantly, the voices of adolescents with disabilities – about their career aspirations, needs and barriers to building their economic capabilities – are missing from the evidence base (see Table 6.1).

**Table 6.1: Evidence gaps on the economic empowerment of adolescents with disabilities**

<b>Broader gaps</b>	There are major evidence gaps in this capability area. Adolescents with disabilities remain largely invisible in the evidence base, which focuses on the economic participation of youth or adults with disabilities and the key factors of their disadvantage. Both quantitative and qualitative data is lacking, along with adolescent voices about their career aspirations, training needs and barriers to developing their economic capabilities.
<b>Gender-specific gaps</b>	Evidence indicates that girls with disabilities tend to be more disadvantaged due to the intersection of disability with gender and age.
<b>Gaps regarding impairment type</b>	In general, persons with intellectual or psychosocial impairments tend to face greater discrimination. Yet we know almost nothing about adolescents with different types of impairments, the particular challenges they face in accessing resources and opportunities, their aspirations, and what they need to be able to build their skills for an independent and decent livelihood.
<b>Context-related gaps</b>	Available data is not typically disaggregated by location, ethnicity or socioeconomic status (SES), so we know very little about the particular challenges that adolescents with disabilities face in each case. Improving data on SES is arguably especially important to support programming targeting the more vulnerable.
<b>Policy and programming gaps</b>	There is a real lack of evidence on what works to develop the economic capabilities of adolescents with disabilities as they grow older and transition into adulthood in diverse contexts.

There is also a dearth of evidence about what actually works to support adolescents with disabilities to develop their economic capabilities. A recent systematic evidence review of interventions supporting the labour market inclusion of adults with physical and sensory impairments in LMICs concluded that rigorous evidence is lacking. Indeed, highlighting the notable evidence gaps that exist, the review was unable to identify any evaluation of disability-inclusive legal or policy frameworks or of interventions for workplace accommodations, flexible working practices, provision of financial grants and microfinance schemes. Nor did it find any evaluation of interventions specifically targeting women with disabilities, despite the greater difficulties and discrimination they face in labour markets (Tripney et al., 2015).

## Promising practices

Persons with disabilities face significant and multiple barriers to realise their right to decent work and employment, which is fundamental to lift them out of poverty, ensure their wellbeing, promote their inclusion, and stimulate economic growth. Thus various legal and policy initiatives such as international conventions, national anti-discrimination legislation, quota systems and financial

incentives for employers have been implemented along with programmes providing skills training, access to credit, job placement and on-the-job support, disability management, workplace adaptations, and information and awareness-raising campaigns. There is thus a considerable body of literature on relevant programmes led by governments, civil society, international organisations and the private sector (in countries where there is a high corporate social responsibility (CSR) culture) and on good practices to empower persons with disabilities and promote their economic inclusion (Handicap International, 2006; 2016; ILO, 2015; Sightsavers, 2016; Leonard Cheshire and Humanity & Inclusion, 2018).

However, most of these programmes focus on adults with disabilities. Despite the challenges facing adolescents with disabilities in finding work, there is a dearth of rigorous evidence on what works for the economic empowerment of youth with disabilities in LMICs. Nonetheless, there are many (typically small-scale) initiatives that provide adolescents with disabilities with skills training and facilitate their access to wage and self-employment. Several of these projects include older adolescents with disabilities, as their stated target group is youth – often defined to include those aged 15-24 or 15-30. Some of these initiatives have been

Adolescent girls in special needs class, Ethiopia © Nathalie Bertrams / GAGE 2018



going on for several years, using promising strategies and achieving some positive results. Social protection measures for adolescents with disabilities are also gaining more policy attention, including cash assistance to ensure basic income security or to access training and participation in public works schemes.

### Programmes promoting access to training and economic opportunities

There are several initiatives led by NGOs in collaboration with various stakeholders, including government ministries or local authorities, which provide older adolescents and youth with disabilities in LMICs with technical and soft skills training and job guidance. While these initiatives lack robust evaluations, they suggest some benefits from adopting a wider approach, engaging with multiple stakeholders, including parents and disability organisations, and providing constant support and guidance to trainees.

The Lebanese Physically Handicapped Union has been implementing the Economic and Social Inclusion (ESI) of People with Disabilities programme in partnership with Christian Aid UK and YMCA, with funding from the European Union (EU) and Christian Aid, with an estimated annual budget of 250,000 euros. The programme seeks to empower and improve the livelihoods of youth with disabilities aged 18–24, while also promoting a culture of inclusion and diversity within the workplace and among relevant stakeholders. To this aim, ESI provides community-based skills training, rehabilitation and job coaching to youth with disabilities and facilitates their access to the labour market. It also raises awareness of disability issues among employers and collaborates with them to make jobs and training internships available to youth with disabilities (UNICEF MENARO, 2015).

The first phase of the programme started in 2005. Participants were identified through community outreach, relying on government support centres in collaboration with local municipalities, the UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), and similar agencies. Social workers from these institutions who were familiar with the communities visited families and negotiated – successfully in most cases – with parents who had resisted their child taking part, especially in the case of girls and young women with disabilities. The programme also held sessions with parents where they gave them information on disability and the rights and capacities of children with disabilities to learn and work. Youth with disabilities were involved in the planning, implementation

and assessment of programme activities through focus group discussions where they talked about their needs and ways to address them. The programme also held consultative meetings with municipalities and private sector actors, along with annual meetings with members of the Union for Disabled Persons (UNICEF MENARO, 2015).

The programme used a broader approach that included activities at four levels. First, implementers have advocated for the implementation of national legislation and policy, pushing for decrees to activate existing law on the rights of persons with disabilities and to provide training on disability inclusion into the workplace. Second, the programme has built networks with private sector companies across Lebanon, provided awareness-raising sessions, and helped revise their employment and internal policies, train staff, and help them meet required accessibility criteria. Third, ESI provides skills training, career guidance, job matching and follow-up, dividing trainees into groups based on their education and work experience. They then receive training in computer skills, literacy, English language, graphic and computer design, as well as two-month basic skills training that includes ‘soft’ skills (including leadership skills), career guidance and disability-related information. Trainees are then supported to apply for work opportunities in the companies collaborating with the programme, where they receive further training on specific vocational skills. The programme also includes training of trainers of all partner organisations that provide vocational training to youth with disabilities. Fourth, the programme has developed resources so that civil society organisations working with persons with disabilities can improve the support they offer (*ibid.*).

The programme has been endorsed by the Lebanese Ministry of Social Affairs and in its second phase was replicated in Palestine. An assessment found that it provided a steady number of job opportunities; in its first phase, 25% of participants found employment in the formal sector, 50% of whom were young women. All participants reported a significant change in their lives, including developing their skills, boosting their self-esteem, increasing their social interactions, being valued as individuals, and enjoying better family and community relationships (UNICEF, MENARO, 2015). In its second phase (2012–2015), nearly 1,000 youth with disabilities attended vocational training and more than 200 found employment in the open labour market. Examples of employment include: administrative assistant, human resources assistant, receptionist, secretary, call centre officer, archive officer, data entry officer, and restaurant



Special needs teacher, Ethiopia, © Nathalie Bertrams / GAGE 2018

chef (Zero Project, 2017). Ministry representatives became aware of the need to promote employment for persons with disabilities and an Accessibility Decree was issued, mandating the application of accessibility criteria in all public buildings (UNICEF MENARO, 2015). In 2017, ESI was recognised as an innovative practice to help persons with disabilities gain meaningful employment by the Zero Project (2017), a platform that supports the implementation of the Convention on the Rights of Persons with Disabilities and identifies innovative and effective practices to improve the lives of persons with disabilities.

Similarly, the EmployAble programme is a multi-country action-learning programme implemented in Ethiopia, Kenya and Rwanda. Led by Light for the World in collaboration with local partners and with funding from the government of the Netherlands, it provides older adolescents and youth with disabilities aged 16–30 with technical and vocational training, and promotes their employment through links between training institutions and the open labour market. Thus the programme has targeted not only youth with disabilities but a broad set of stakeholders, including local training institutions, disabled people's organisations, community-based rehabilitation (CBR) providers, disability-specific NGOs, private sector actors and government representatives in order to achieve systemic change, on the basis that inclusion is a shared

responsibility. The programme also worked closely with parents or guardians to ensure that they did not resist their children's participation or progress due to overprotection, low expectations or unsupportive attitudes (Baart and Maarse, 2017).

At the beginning, the programme conducted stakeholder consultations to analyse government priorities and identify economic sectors with available work opportunities. In collaboration with disabled people's organisations, CBR programmes, schools and local institutions, EmployAble sought to inform youth with disabilities about the opportunity to enrol in technical and vocational education and training (TVET) programmes. Prospective students were screened to ensure that they were genuinely interested in training, underwent consultations about their needs, interests and ambitions, and participated in needs assessments (to identify any specific needs for assistive devices, equipment or medical assistance). They were then provided with coaching and assistance to register with TVET centres. The programme used innovative techniques, such as collecting stories from participants about their experiences through story tables to generate knowledge about how best to support their participation in training and their transition to employment in each context (Baart and Maarse, 2017).

EmployAble also provided disability awareness training for all TVET staff and trained teachers in inclusive methods, along with accessibility audits and disability inclusion assessments that led to reasonable adjustments to accommodate the particular needs of the trainees. During the courses, the programme team monitored participation. Apart from technical skills, participants were also provided with soft skills such as self-determination, positive attitude, teamwork, networking and professionalism (ibid.).

Graduates were linked to potential employers and provided with coaching and assistance to find internships to gain work experience or access support for self-employment, such as start-up capital and equipment. For instance, in Rwanda, the programme linked up with the National Employment Programme, which provided start-up equipment to graduates. Graduates also received follow-up guidance and support for a limited time to ensure that they did not drop out from the workplace or stop running their business (ibid.).

This multi-country programme helped several hundred youth with disabilities develop new skills and find wage or self-employment. It also encouraged training institutions and employers to make adaptations for disability-inclusive environments. For instance, in Ethiopia, EmployAble activities were linked to government policies and the programme provided advice on the development of

national TVET guidelines and revision of TVET manuals, while it also collaborated with the federal TVET agency to provide disability awareness training to TVET staff (ibid.).

In the first phase (2014--2016), 448 youth with disabilities were enrolled in training courses such as electricity, masonry, tailoring, hairdressing and catering (59% of participants were male, 41% female). Over half had physical impairments, a quarter had hearing impairments, 14% visual impairments, 3% had multiple impairments and only 1% had intellectual impairments. One year after graduation, 71% were already working and 18% were involved in job pre-training. Of those employed, the majority (43%) were self-employed, 23% found wage employment, 19% were engaged in farming activities and 15% in temporary jobs. Graduates reported improved livelihoods, increased participation in the community and greater optimism: while 53% participated in community activities at the pre-training phase, 90% did so one year after the training; and while 52% reported having trust in their future at pre-training phase, 86% said they had a lot of trust one year after training (ibid.). In 2016, EmployAble was featured as an innovative practice by the Zero Project (2016), while the programme is now in its second phase and is planned to continue until 2019.

A different approach has been used in Shanghai, China. The Novotel Atlantis Hotel has been providing youth with



An adolescent girl, with a visual impairment, Ethiopia © Nathalie Bertrams / GAGE 2018

disabilities aged 18–20 years with on-the-job-training through a one-on-one ‘buddy system’. The hotel began its Disabled Trainee Internship and Placement Programme in 2003 in close collaboration with a community-based disability organisation and the parents or guardians of candidates. Potential skills among youth with disabilities were identified and paired with employment tasks in the hospitality business. Candidates are typically graduates from a specialised vocational school for students with disabilities and live close to the hotel. Most have psychosocial impairments, and some have hearing impairments. Candidates have to go through a number of interviews during which their interest and personality traits are assessed for programme compatibility. Those who are admitted to the programme are assigned to a ‘buddy’ – an experienced staff member with specialised training and skills such as sign language who in some cases is also a graduate of the programme. Each buddy assists trainees in learning their responsibilities over a six-month period. Trainees are offered positions based on their skills, aptitude and impairment, with most placed in housekeeping, and food and beverages. Upon completing the programme, trainees attend a career fair where they explore employment opportunities in relevant industries, while some are hired by the hotel (ILO, 2014b).

By 2014, 233 trainees had graduated from the programme and 60% had obtained employment at the hotel or other local companies. The programme was the first of its kind in Shanghai and in 2005 received accreditation from the Shanghai government as a Training Centre for Youth with Disabilities in Hospitality Services. Graduates reported being able to develop strong self-esteem and their employer recognised that they were doing exceptional work, valued by their colleagues. Three graduates also competed in the Special Olympics and one was awarded the title of the most valuable player (ILO, 2014b).

## Social protection measures for adolescents and their caregivers

Several LMICs provide various types of social assistance to persons with disabilities, including adolescents and youth. For instance, South Africa provides the Care Dependency Grant, which covers children with disabilities from birth until adulthood (18 years of age). This grant of nearly \$125 monthly aims to help low-income parents or guardians of a child with a severe disability in need of full-time and special care (South African Government, 2018).

Many countries also provide assistance to students with disabilities. For instance, in Bangladesh, Ethiopia and India, the respective governments provide stipends for students with disabilities studying in public schools at different education levels. Governments also provide assistance for skills development (see Box 6.10) as well as employment opportunities in public works schemes. In South Africa, the Working for Water project, a component of the Expanded Public Works Programme, provided training and short-term jobs, with a 5% quota reserved for persons with disabilities (Strietska-Ilna et al., 2011). India has developed a manual for administrators on how to ensure that persons with disabilities participate in the national public works scheme, the Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS), which provides 100 days of guaranteed employment for poor households in rural areas (ILO and IDA, 2015). Rigorous evidence on the effects of social assistance programmes on the lives of adolescents with disabilities is lacking and it is often stressed that such programmes typically have limited coverage and provide benefits of low value. However, such measures are increasingly gaining attention by governments, donors and policy-makers, and they appear to hold a promising potential.

### Box 6.10: India’s new National Action Plan for building the skills of persons with disabilities

In 2015, India launched its latest National Action Plan for Skills Training of Persons with Disabilities. Prepared by the Department of Persons with Disabilities in collaboration with the Ministry of Skill Development and Entrepreneurship, the plan commits to provide financial assistance for skills training to persons aged 15–59 who have at least 40% disability, as certified by a medical authority; 30% of places are reserved for girls and women with disabilities. The scheme will cover training costs, provide trainees with a stipend and transport allowance, and offer incentives to training partners for achieving high placement rates. The aim is to provide quality skills training to 2.5 million persons with disabilities by 2022.

Source: Ministry of Social Justice and Empowerment, 2015



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# Conclusions

## Conclusions

This report has contributed to expanding the limited evidence that speaks to the diverse experiences and needs of adolescents with disabilities in low- and middle-income countries (LMICs) through an explicit focus on differences based on gender, impairment type and context. However, significant gaps still remain and as such any conclusions need to be seen as tentative. We summarise key points emerging from the report about what the challenges are to promoting inclusive development and ensuring adolescents with disabilities in LMICs reach their full capabilities. In the final section of the report we then discuss implications for policy and practice.

## Adolescent capabilities and resilience

To promote inclusive development and enhance the wellbeing and resilience of adolescents with disabilities, attention needs to be paid to multiple and intersecting capability domains as follows:



### Education and learning

**Educational access:** Of the 58 million children who are out of school in LMICs, an estimated 19 million (one-third) have one or more disabilities. The enrolment gap between those with and without disabilities is growing over time, as LMICs are closing in on universal primary education for children without disabilities, but failing to include those with disabilities.

In many countries, restrictive gender norms and disability-related stigma mean that adolescent girls with disabilities are especially likely to be out of school – though in other LMICs, girls with disabilities are more likely to complete primary and lower-secondary education than their male peers. Although evidence is limited, young people with intellectual impairments are often significantly more likely to be out of school than those with physical impairments. Children with visual, multiple or intellectual impairments (and children with severe impairments of all categories) are especially likely to be illiterate.

Transport (availability and/or cost) is a major barrier to schooling. Children with disabilities who live in rural areas are far less likely to attend school than their peers in urban areas simply because they cannot get there. Transport is also a significant barrier in humanitarian and conflict-

affected contexts, where mobility is limited due to safety concerns; this is often especially so for adolescent girls, who may be at greater risk of sexual and gender-based violence in such settings.

**Educational quality:** Inclusive education services in LMICs are of poor quality due to under-resourcing, inadequately trained teachers (both specialist and mainstream), and inadequate teaching materials and aids. Adolescents with disabilities who are in school also often face discrimination and stigma (even violence) from teachers and classmates. These shortcomings are more acute in rural areas and in humanitarian settings.

**Educational aspirations:** Research findings on the aspirations of adolescents with disabilities (and their parents' aspirations for them) are mixed, highlighting the need for further investigation. GAGE's primary research from Bangladesh and Ethiopia suggests that adolescents with disabilities often have high educational aspirations, and while our survey findings did not find statistically significant differences between the caregivers of children with and without disabilities, our qualitative research suggests that their aspirations were often similarly high.

**Educational transitions:** Adolescents with disabilities are not only less likely to enrol in school, they are also more likely to drop out. This is particularly the case at the secondary level and by the post-secondary level very few adolescents with disabilities are still in school. The costs of not educating children with disabilities on par with their peers are staggering. In China, for example, each additional year of education can raise a child's income in later life by 8%. In Bangladesh, aggregate impacts on the economy are estimated to be \$26 million a year.



### Health, SRH and nutrition

**Primary and disability-specific health care:** Adolescents with disabilities have limited access to both primary and disability-specific health care and information and, in some contexts, have poorer health outcomes and nutrition than their peers without disabilities. Barriers that prevent them accessing appropriate care include stigma, cost of (often specialist) services or acquiring and maintaining assistive devices, and physical accessibility issues (such as lack of ramps or Braille materials). In many contexts, issues are particularly acute for girls, given gender norms that restrict their mobility or their interaction with male health care providers. Adolescents with intellectual impairments

seem to have very limited access to all types of health care information and services.

For health, as for the other capability domains, context matters: health services in rural areas, and especially in humanitarian contexts, tend to be poorly adapted to meet the needs of people with disabilities (let alone adolescents with disabilities), and access to care for specific impairment types is very limited.

**SRH information and services:** Few services (particularly SRH services) cater for adolescents, let alone adolescents with disabilities, who are often incorrectly thought unlikely to have or incapable of having sexual relationships in later life. This is particularly the case for adolescents with intellectual impairments. Girls with disabilities are doubly constrained: social factors (discriminatory gender norms and stigma) may combine with constraints arising from their disability (e.g. no access to public transport with necessary adaptations) to restrict their ability to leave the home, leaving them with little or no access to health information and services.

**Nutrition:** In some contexts, and particularly in impoverished households, adolescents with disabilities – especially girls – have less access to nutritious food. This may be due to unequal intra-household allocations of food and limited availability of specialised nutrition products for young people with specific impairments.



## Psychosocial wellbeing

**Support networks:** Many adolescents with disabilities feel very isolated socially. They often face stigma, discrimination or even violence, sometimes from within their own families. As a result, they are more prone to depression, loneliness and poor self-esteem than their peers without disabilities. Where cultural beliefs or myths associate disability with sin or witchcraft, children with disabilities may be confined to the home to protect them from harassment and violence, and to preserve the family's reputation. This makes it even more challenging for services to reach these children and provide necessary support to them and their family. While some adolescents with disabilities may experience isolation or abuse within their family, especially when they are deaf and their families do not know how to use sign language, for many others, the support they receive from their family – especially female caregivers – is critical to their wellbeing.



## Bodily integrity and freedom from violence

**Physical violence:** Adolescents with disabilities are very vulnerable to violence – at home, in school, in residential care and in the community. Evidence suggests that overall they are 3–4 times more likely to experience any type of violence than adolescents without disabilities. Girls with disabilities are at greater risk of violence and neglect than boys with disabilities, and adolescents with intellectual impairments are thought to be at greater risk than adolescents with other types of impairment. Adolescents with disabilities living in institutions are at particularly high risk of physical violence. Violence has significant, multiple and long-term consequences for adolescents' physical and psychosocial wellbeing and can damage their capability development.

**Emotional violence:** Many adolescents with disabilities report experiencing neglect and emotional violence or bullying by family members, peers, at school or in other public spaces.

**Sexual violence:** Adolescents with disabilities, and most especially girls with intellectual impairments, are particularly vulnerable to sexual violence and abuse. This is because they are often perceived to be an easy target and less likely to report an incident or to be believed. Difficulty accessing protection and justice mechanisms exacerbates these problems, as does the dearth of justice sector personnel trained to provide specialist support to young people with disabilities.



## Voice and agency

**Safe spaces:** Although in many contexts adolescents (because of their age) typically have little say over decisions that affect them, those with disabilities are even less likely to do so. Despite wanting to be active members of their families and communities, adolescents with disabilities in LMICs are often excluded from family, school, community and political events.

Multiple factors may make it more challenging for adolescents with disabilities, especially girls, developing their social skills, having their voice heard and building their agency (i.e. their ability to take independent decisions in line with their evolving capacities as they age) for a successful transition into a fulfilling and empowered adulthood. The biggest factors include physical access constraints, communication barriers, persistent stigma, discrimination and discriminatory gender norms, misconceptions about the capacities of children and young people with disabilities, and parental overprotection.

**Accessing information safely:** Information and communications technologies, alongside the internet and mobile phone connectivity, can increase adolescents with disabilities' access to information and social networks and may be especially significant for adolescent girls in settings where conservative social norms mean that they are not allowed to leave the home to meet with their peers. Even so, for many adolescents with disabilities, and especially those in rural settings where technology penetration is low, access is limited.

**Civic participation:** In many contexts, adolescents with disabilities are perceived to be dependent, passive recipients of support rather than citizens with rights. Lack of access to information means they (and their families) are often unaware of their entitlements and thus unable to claim their rights. Again, though evidence is scarce, it seems that people with intellectual and psychosocial impairments are

even less likely to access their civic rights, and are often excluded from civic spaces and voting processes.



## Economic empowerment

**Market-appropriate skills:** The exclusion of children and adolescents with disabilities from education has severe knock-on effects on their ability to find (and keep) decent work as they become older. Older adolescents with disabilities tend to have low human and social capital (personal skills and connections), and limited access to appropriate training and skills development opportunities on account of stigma and limited mobility. Not only are these development opportunities for adolescents with disabilities limited, but also those that do exist are often not well matched to labour market demands. Young people with intellectual or psychosocial impairments, and adolescent girls with disabilities, face substantial disadvantages in labour markets.

**Resource endowments:** Despite their need to access capital for self-employment activities, older adolescents with disabilities are often excluded from formal and informal microfinance schemes. In many contexts, adolescents with disabilities (particularly those with intellectual impairments) are denied their inheritance rights and share of parental property.

**Social protection:** Social assistance can enable adolescents with disabilities to access education, training, assets and employment opportunities by reducing their real costs, yet such programmes are limited in scope. Programmes also tend to offer insufficient levels of support to meet the needs of adolescents with disabilities, given their often higher costs for medical care, assistive devices, transportation, education, etc.

## Intersecting disadvantage

Even accounting for the wide range of impairment types and severity, adolescents with disabilities are not a uniform group and thus it is critical to understand how young people's experience of disability intersects with other dimensions of social exclusion including gender and context. Using a gender lens to understand the divergent opportunities and challenges that adolescent girls and boys with disabilities have in realising their full potential, this report has highlighted the complex relationship between gender and school enrolment, dropout rates and learning outcomes whereby girls with disabilities are faring worse



An adolescent girl with a hearing impairment, with her mother, Bangladesh © Marcella Pasotti / GAGE 2018

than their male peers with disabilities in some contexts, but better in other LMICs. The report also highlights girls' higher health burdens and lower access to health and SRH care; their higher risk of violence and sexual violence; their very limited mobility and ability to participate within their communities irrespective of their impairment due to discriminatory norms; and their exclusion from skills development and economic empowerment opportunities.

To contribute to the extremely limited evidence base on the experiences of adolescent girls and boys with disabilities in conflict-affected contexts, the report's case studies concerning adolescents with disabilities in Gaza, the West Bank and the Syrian refugee community in Jordan reveal the particular challenges that adolescents with disabilities face in protracted conflict settings. These include including conflict-related impairments and mental ill-health caused by trauma – and the dearth of accessible services and support for adolescent refugees with disabilities, and especially for girls.

The report has also put a necessary spotlight on rural disadvantage. It has highlighted that adolescents with disabilities in rural areas are especially likely to have lower educational aspirations and more limited access to education services, as well as poorer health and more limited access to specialised health care. They are also

less likely to report violence and tend to have less say in household decision-making.

## Enabling environment

Beyond a focus on adolescents with disabilities themselves, it is also critical to consider the broader enabling environment in which they live. The report has paid attention to caregivers' vulnerabilities and needs; policy and legal landscape shortcomings, especially with regard to the implementation of rights; and last but not least data and evidence gaps, especially with regard to evaluation evidence on what works.

## Caregiver vulnerabilities and needs

Depending on the nature of their impairment, adolescents with disabilities often have additional physical, health, financial and psycho-emotional care needs. These may be exacerbated in resource-constrained contexts where there is typically a dearth of accessible services and public spaces. In many contexts, adolescents with disabilities also face widespread discrimination, stigma and social exclusion. Given the limited social assistance available, family members (most often mothers) who care for adolescents with the most severe disabilities may feel

exhausted, anxious, depressed and socially excluded, lacking any access to information, support or respite care. They may also be subject to intimate partner violence and/or abandonment by male partners.

### Policy and legal landscape to support adolescents with disabilities

There have been significant advances in tackling discriminatory legal frameworks and advancing more rights-based legislation in line with the United Nations Convention on the Rights of Persons with Disabilities over the past decade. However, while there remain legislative gaps (especially around rights to health care, employment and social protection), implementation has been a far greater challenge. Among the most glaring gaps are:

- the absence of coordinating mechanisms to facilitate joined up cross-sectoral programming and accountability for progress;
- serious financing gaps to realise inclusive education, health and social protection for adolescents with disabilities;

- very limited trained service providers (from education and health to justice and social work); and
- the lack of incentives (or penalties) to promote enforcement.

### Evidence gaps around adolescence and disability in LMICs

Arguably one of the most significant challenges in terms of the enabling environment relates to data and evidence. Across the six capacity domains, we still know very little about the experiences of different groups of adolescents because data does not tend to be disaggregated by age, location, place of residence, gender, ethnic group, or other forms of identity e.g. refugee, displaced person. Where studies have been carried out, they tend to be small scale and sometimes lack rigour. Existing datasets typically lump adolescents together with children and/or youth or adults, further obscuring the needs of different groups of adolescents. There is also very scarce robust evaluative evidence about what programming approaches are effective in supporting the wellbeing and resilience of adolescents with disabilities.

An adolescent girl, with a visual impairment, Ethiopia © Nathalie Bertrams / GAGE 2018





# Implications for policy and practice

## Implications for policy and practice

Our research findings – both the secondary evidence review on the wellbeing status of adolescents with disabilities and existing programming practices as well as our survey and case study findings – highlight that there is a pressing case for policy and programmatic action to ensure more inclusive development in line with the Sustainable Development Goals. While there are still very significant data and evidence gaps to address, our findings suggest that governments together with development partners including donors, UN agencies and non-governmental actors could consider taking action in five key areas to support adolescents with disabilities now and to set them on a better trajectory for a fulfilled and empowered adulthood.

### 1. Support adolescent capabilities and healthy, safe and empowered transitions



#### Education and learning

Develop detailed, costed action plans with measurable milestones to provide quality inclusive education for all adolescents with disabilities. On the demand side, key priorities should include addressing cost-related barriers that hinder adolescents' uptake of education (e.g. through educational stipends, safe and affordable transportation), especially at secondary and post-secondary levels, where services are further away. Efforts should also be made to work with parents and communities to highlight the value of investing in education for their children with disabilities. On the supply side, teachers (mainstream and specialists) need to be supported with adequate training (including in Braille and sign language) as well as in awareness-raising about the rights and needs of adolescents with disabilities and in the use of non-violent teaching approaches. Ensuring sufficient teaching materials and aids, and that education facilities are physically accessible is also critical.



#### Health, SRH and nutrition

Ensure that adolescents with disabilities have access to primary and disability-specific health care. Primary healthcare workers and service providers need access to training in disability issues, while outreach programmes can bring

services to adolescents who may have difficulty leaving the home or travelling to reach services. Investments should also be made in the scaling-up of community-based rehabilitation services that include adolescents with disabilities, especially in light of very limited specialist disability-specific health services.

Ensure that adolescents with disabilities have access to context-tailored SRH information and services. Because adolescents with disabilities are more likely to be out-of-school than their peers without disabilities promote SRH messaging through local health clinics and other non-school platforms including non-formal education and recreational services, through web-based communication tools, and also through parental outreach sessions given the key role that mothers in particular can play in supporting their adolescents' knowledge of SRH issues and services.

To address adolescents with disabilities' risk of under-nutrition, consider investing in nutrition supplementation and school feeding programmes, in nutritional counselling at local health clinics as well as in social safety nets that help support families living in poverty better support the nutritional requirements of their adolescents with disabilities.



#### Psychosocial wellbeing

Ensure safe spaces and recreational opportunities are accessible to adolescents with disabilities, given the critical importance of peer interactions for adolescent development. This should include promoting access to safe spaces and recreational opportunities, especially for out-of-school adolescents with disabilities, and investing in digital technologies and social media-based approaches to reduce their isolation where internet connectivity is accessible and affordable.

Provide guidance for parents and service providers on how to support young people with disabilities psycho-emotionally. Invest in tailored guidance and training for teachers, health care workers and social workers so they can provide effective psycho-emotional support for adolescents with disabilities, based on their specific situation and impairment.



#### Bodily integrity and freedom from violence

Given heightened risks of physical, psychological and sexual violence, ensure that adolescents with disabilities, their families and

communities are provided with tailored information about the risks of violence, protection measures and how to report abuse. This entails supporting adolescent girls with age-appropriate information about the risks of violence through school and non-school platforms (e.g. girls clubs), how to protect themselves and to report abuse. It is also essential to invest in awareness-raising among parents and communities about how best to protect children with disabilities from violence.

In tandem, provide training for police and justice sector personnel on how to support adolescents with disabilities who have experienced violence to secure justice. Within this, efforts need to be made to work with diverse stakeholders (caregivers, local authorities, police, local courts) to create safer local communities and to improve reporting and prosecution rates. Justice sector personnel require training on how to support adolescents with disabilities who have experienced violence – and their caregivers – to report abuse and secure justice.



### Voice and agency

Raise the awareness of parents, communities and service providers about the importance of supporting young people with disabilities to be listened to and to participate in decision-making in the family, at schools and in their community. Undertake awareness-raising initiatives at community level, through communication for development approaches and digital and social media strategies targeting parents, communities and service providers to support adolescents with disabilities to get their voice heard and develop agency in line with their evolving capacities. As part of such efforts, support adolescents with diverse impairments to be consulted about and input into programme design and evaluations as a way of getting their voice heard and strengthening impact.



### Economic empowerment

Ensure poverty-targeted social assistance programmes provide adequate weighting to cover the additional costs that adolescents with disabilities and their families often incur. This should involve calculating the value of social assistance programmes so they are able to cover costs, for example, for the transportation, specialised health and the purchase and implementation of assistive devices. Social assistance programme implementers should also provide cross-referrals during household vulnerability assessments to

complementary services that will support the wellbeing and resilience of adolescents with disabilities (e.g. education, health, counselling services, recreational activities).

Simultaneously invest in skills building programmes and the provision of credit and other assets necessary for economic empowerment. Skills building programmes need to be tailored to the skill sets of adolescents with disabilities and tie in with local labour market demands, in partnership with the private sector. Young people with disabilities must also be supported to have equitable access to credit and inheritance rights.

## 2. Addressing intersecting disadvantages to leave no adolescent behind

Undertake a comprehensive mapping of programming and services for adolescents with different impairment types to identify gaps and solutions for the hardest-to-reach groups. Particular attention needs to be paid to extending services to adolescents with disabilities in rural areas, given high levels of exclusion from basic services in these areas, as well as to developing appropriate and accessible programming and services for adolescents with intellectual impairments. In humanitarian and conflict-affected contexts, particular efforts are needed to tackle the invisibility of adolescents with disabilities, to involve them in planning and programming, and ensure that programme evaluations assess the impacts of targeted and mainstreamed interventions alike.

## 3. Engaging and supporting caregivers of adolescents with disabilities

Ensure that caregivers have access to tailored information and guidance to support their adolescents with disabilities as well as access to support networks for psycho-emotional support. Caregivers need adequate information about the nature of their child's impairment(s), the support and services their child needs and how they can access those services. Caregivers also need support networks, linking them (in person or online) with other parents who have adolescents with similar impairments, and providing them with information and guidance on how best to support adolescents with disabilities. As such, caregiver networks can play an important psycho-emotional support role, as well as facilitate referrals to complementary services and respite care.

#### 4. Tackling data and evidence gaps to support evidence-informed programming

Invest in data and evidence to enhance robust evidence-informed programming. Age- and gender-disaggregated data is needed to make adolescents with disabilities (particularly girls) much more visible on policy and programming agendas, across every sector. Greater investments in research about the patterning of disability and the experiences of adolescents with disabilities are urgently needed, as are robust evaluations of good practice. To achieve this, all programming for adolescents with disabilities – whether government, NGO or UN-initiated – must invest in monitoring, evaluation and learning to generate robust evidence on what works and to help scale-up. Participatory research can also help generate a deeper understanding of the experiences of adolescents with disabilities, and what factors enhance their resilience. Finally, a global repository of emerging evaluation evidence and data on adolescents with disabilities should be set up to facilitate the sharing of promising practices emerging from the South and the North.

#### 5. Promoting better multi-sectoral coordination and accountability

Establish a strong, national body to ensure effective multi-sectoral coordination among government agencies and cross-referrals to complementary services. This coordinating body should be mandated to develop costed action plans (that include progress milestones) on implementing the commitments contained in the CRPD and UNCRC with respect to adolescents with disabilities. Also convene national working groups to bring together key government agencies, donors and non-governmental actors to share information and promote coordination around initiatives to enhance the wellbeing and resilience of adolescents with disabilities. In tandem, undertake budget monitoring and develop a disability marker (akin to the OECD-DAC gender marker), to better track funding and hold donors to account, and, as part of the 2020 SDG target review, promote reporting among all UN agencies that is disaggregated by age, gender and disability in development and humanitarian contexts. Last but not least, ensure that adolescents are included in monitoring and evaluation processes so as to promote greater accountability to young people with disabilities regarding the international community's commitments to inclusive development.

An adolescent boy with a physical impairment boy, Bangladesh © Marcella Pasotti / GAGE 2018





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# Annexes

## A1: A mapping of donor policy commitments towards adolescence, disability and gender

A limited number of donors explicitly include attention to inclusive development for persons with disabilities within their policy priorities. Preparatory to this report, we undertook a mapping in which we examined the policy commitments and programming of major donors, private foundations, and global funds for inclusion of people with disabilities. We used a four-way categorization to highlight intentions and action: little to no disability-related programming, disability-related programming, disability-related programming that addresses the age-specific needs of adolescents, and disability-related programming that addresses both the age-specific needs of adolescents and pays attention to gender dynamics. We then applied these four categories across GAGE's six capability domains.

Clear from our mapping is that donors are more invested in inclusive education than other domains. While only DfID, Education Cannot Wait, and the Global Partnership for Education have programming aimed at the nexus of disability, age, and gender, the majority of the donors included in our mapping are making disability-related commitments. Donors are also fairly active in supporting the economic empowerment and voice and agency of people with disabilities, although with less attention to adolescents' age-specific needs. The Ford Foundation stands out for considering both age and gender in its work across these two domains.

Donors' commitments to the health and nutrition, psychosocial wellbeing and – most especially – the bodily integrity and freedom from violence of people with

disabilities appears limited. Only the Ford Foundation is working on the disability-age-gender nexus in terms of health and nutrition, with other donors having no programming that considers either age or gender. There are no donors working on the disability-age-gender nexus in terms of supporting psychosocial wellbeing, and only two—NORAD and USAID—targeting young people with disabilities. Our mapping found no evidence that any donors have even the broadest disability-related programming directed at bodily integrity and freedom from violence.

Clear from our mapping exercise is that not only is there a relatively limited number of donors working on disability issues, but that very few donors have any programming that addresses the age- and gender-specific needs of adolescents with disabilities. Equally concerning, as noted by Myers et al., (2016) are the 'gulfs between commitments on paper and programmes on the ground'. For example, while DfID has committed in theory to demonstrating "*new global leadership on education for children with disabilities*"<sup>10</sup>, in practice this strategy appears linked only to a commitment to give "*53,000 highly marginalised adolescent girls in Commonwealth countries, who have never attended or dropped out of school as a result of poverty, early marriage and pregnancy, disability or conflict, a second chance to learn literacy, numeracy and other vital life skills.*"<sup>11</sup> In order to meet the 'leave no one behind' commitments embedded in the Sustainable Development Goals, progress will need to be carefully monitored.

<sup>10</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/685536/DFID-Education-Policy-2018a.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/685536/DFID-Education-Policy-2018a.pdf)

<sup>11</sup> <https://www.gov.uk/government/news/uk-is-making-sure-one-million-girls-across-the-commonwealth-get-a-quality-education>

	GAGE capability domains					
	Education and Learning	Bodily Integrity & Freedom from Violence	Health, SRH and Nutrition	Psycho-social Wellbeing	Voice and Agency	Economic Empowerment
<b>Donors</b>						
DFAT						
DFID						
GIZ						
Irish Aid						
JICA						
Ministry of Foreign Affairs Finland						
NORAD						
USAID						
<b>Private Foundations</b>						
BMGF						
CIFF						
Ford Foundation						
Hewlett Foundation						
NOVO Foundation						
Open Society Foundation						
The Rockefeller Foundation						
<b>Global Funds</b>						
Education Cannot Wait						
Global Education Fund						
Global Partnership for Education						

**Key**

Very little or no disability related programming

Disability related programming

Disability related programming which specifically addresses young people

Disability related programming which specifically addresses young people and gender dynamics



## A 2: Evidence review search protocol: search terms for sources on the capabilities of adolescents with disabilities

Country	Population	Capability terms	Additional terms
Bangladesh	Disabled / Disability / Disabilities	Education	Study
Ethiopia	Adolescen*	“Inclusive education”	Research
Jordan	Girl* OR Boy*	School*	Review
Lebanon	Youth / Young	Primary OR Secondary OR Elementary	Policy
Nepal	Child*	Violence	Legislation
Palestine/ Occupied Palestinian Territories/ West Bank/ Gaza	Impairment	Physical violence	Data
Rwanda	Intellectual / Mental disab*	Sexual violence	Experience
	Physical disab*	Domestic violence	Discrimination
	Hearing disab*	Intimate Partner Violence (IPV)	Exclusion OR Inclusion
	Visual disab*	Emotional/ Psychological violence	Marginalisation
		Neglect	Norms
		Child marriage	Gender
		FGM/ C	Refugees
		Health	Rural / Urban
		Physical health	Poverty
		Services	
		Nutrition OR Malnutrition	
		Diseases OR Illnesses	
		Sexual reproductive health (SRH)	
		Sanitation OR Menstruation	
		Sterilisation	
		Psychosocial	
		Confidence OR Self-Esteem	
		Isolation OR Stigma	
		Participation	
		Aspirations	
		Voice	

Country	Population	Capability terms	Additional terms
		Work OR Labour OR Labor	
		“Social protection”/ “cash transfer”	
		Employment OR Self-employment	
		Entrepreneurship	
		Credit	
		Inheritance	
		Begging	
		Training / Skills development/ business training	

## A3: Organisational websites searched

Organisations	
3ie	Save the Children
Action on Disability and Development (ADD) International	Sightsavers
Christian Blind Mission (CBM)	UN Department of Economic and Social Affairs (UNDESA)
Department of Foreign Affairs and Trade (DFAT)	UN Development Programme (UNDP)
Department for International Development (DFID)	UN Economic and Social Commission for Asia and the Pacific (UNESCAP)
Economic Commission for Latin America and the Caribbean (ECLAC)	UN Educational, Scientific and Cultural Organization (UNESCO)
Humanity & Inclusion (former Handicap International)	UN Economic and Social Commission for Western Asia (UNESCWA)
Human Rights Watch (HRW)	UN Population Fund (UNFPA)
International Labour Organization (ILO)	UN Girls' Education Initiative (UNGEI)
Inclusion International	UN High Commissioner for Refugees (UNHCR)
International Disability Alliance (IDA)	UN Children's Fund (UNICEF)
International Disability and Development Consortium	UNICEF Innocenti
International Foundation of Applied Disability Research	UN Women
International Network of Women With Disabilities (INWWD)	US Agency for International Development (USAID)
International Rescue Committee (IRC)	World Health Organization (WHO)
Leonard Cheshire	Women Refugee Commission (WRC)
Leonard Cheshire Research Centre at UCL	World Bank
Light for the World	WORLD Policy Analysis Centre
International Centre for Evidence in Disability (ICED) - LSHTM	World Vision
Plan International	Zero Project
Rehabilitation International	

## A4 Legal provisions for persons with disabilities in LMICs, based on data from the World Policy Analysis Center at University of California at Los Angeles Fielding School of Public Health

Clusters	Countries
Cluster 1: Fair Constitutional Guarantees + Financial Assistance to Low Income Families	Albania; Angola; Argentina; Azerbaijan; Belarus; Bolivia; Bulgaria; Cape Verde; Costa Rica; Dominican Republic; Georgia; Hungary; Kyrgyzstan; Macedonia; Mauritius; Moldova, Republic of; Montenegro; Romania; Serbia; South Africa; Tajikistan; Turkmenistan; Ukraine; Uzbekistan.
Cluster 2: High Constitutional Guarantees + No Financial Assistance to Low Income Families	Egypt; Ecuador; Fiji; Gambia, the; Guyana; Haiti; Honduras; Kenya; Malawi; Maldives; Morocco; Mozambique; Niger; Panama; Paraguay; Peru; Swaziland; Thailand; Timor-Leste; Tunisia; Uganda; Venezuela; Zimbabwe; Venezuela; South Sudan; Rwanda; Mexico; Armenia; Ghana; Brazil; Burundi; Colombia; Congo, Democratic Republic of the Congo, Republic of the Congo.
Cluster 3: Low Protection	Afghanistan; Algeria; Bangladesh; Belize; Benin; Bhutan; Bosnia-Herzegovina; Botswana; Burkina Faso; Cambodia; Cameroon; Central African Republic; Chad; China; Comoros; Cote d'Ivoire; Cuba; Djibouti; Dominica; El Salvador; Eritrea; Ethiopia; Gabon; Grenada; Guatemala; Guinea; Guinea-Bissau; India; Indonesia; Iran, Islamic Republic of Iraq; Jamaica; Jordan; Kazakhstan; Kiribati; Korea, Democratic People's Republic of Laos; Lebanon; Malaysia; Mali; Marshall Islands; Mauritania; Micronesia, Federated States of Mongolia; Myanmar; Namibia; Nauru; Nepal; Nicaragua; Nigeria; Pakistan; Palau; Papua New Guinea; Philippines, the; Samoa; Sao Tome / Principe; Senegal; Seychelles; Sierra Leone; Solomon Islands; Somalia; Sri Lanka; St. Lucia; St. Vincent / Grenadines; Sudan, the; Suriname; Syria; Tanzania, United Republic of; Togo; Tonga; Turkey; Tuvalu; Vanuatu; Vietnam; Yemen; Zambia

Source: Nakray, 2018; WORLD Policy Analysis Center, 2016



## About GAGE

Gender and Adolescence: Global Evidence (GAGE) is a nine-year longitudinal research programme generating evidence on what works to transform the lives of adolescent girls in the Global South.

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