



## Adolescents with disabilities: enhancing resilience and delivering inclusive development

### Overview

Around the world, there are between 93 million and 150 million children and adolescents with disabilities.<sup>1</sup> An estimated 80% live in low- and middle-income countries (LMICs), where 80% of persons with disabilities live below the poverty line.<sup>2</sup> 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,<sup>3</sup> 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. For example, in Bangladesh the estimated costs of foregone schooling by children with disabilities amount to \$26.2 million per annum due to lower lifetime earnings; while in the case of caregivers (usually women) with caring responsibilities for family members with disabilities the costs in terms of foregone income are estimated to reach \$234 million per annum.<sup>4</sup>

This policy note summarises key findings from a new Gender and Adolescence: Global Evidence (GAGE) report which takes stock of current evidence from a thematic evidence review on the wellbeing of adolescents in LMICs combined with survey and qualitative research baseline studies in Bangladesh, Ethiopia, Jordan and Palestine. The research 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. Importantly, 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 for: 1) education and learning, 2) health, sexual and reproductive health (SRH) 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.<sup>5</sup> Of the 58 million children who are out of school, one-third – 19 million – have a disability.<sup>6</sup> Adolescents with disabilities are less likely to enrol in school and more likely to drop out than their peers without disabilities. Aspirations for education notwithstanding, most adolescents with disabilities are out of school and few make it to secondary school. Moreover, some 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.<sup>7</sup> 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.<sup>8</sup>

« We (me and my sister who is also blind) have never been to school in Jordan. 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!... 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)



Adolescents with disabilities have poorer overall health and nutritional status than their peers without disabilities.<sup>9</sup> Disability-related stigma, cost, and physical accessibility issues mean they have more limited access to general health care and to disability-specific health-related information and services. Their access to primary care and SRH care lags behind that of their peers without impairments, and access to disability-related health care remains rare in many LMICs, given resource constraints.



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.<sup>10</sup> As a result, they are more prone to depression, loneliness and low self-esteem than their peers without disabilities. Few adolescents with disabilities have access to either informal adolescent-focused recreational and social activities or formal psychosocial services.

« 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 saw how other blind people manage their lives, and I started having hope again. My friends become the source of my hope.

(Girl who is blind, 18 years, Ethiopia)



Adolescents with disabilities are 3-4 times more likely to experience violence than their peers without disabilities, with multiple and long-term consequences for survivors' physical and psychosocial wellbeing.<sup>11</sup> 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, which hamper 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 kept at home at all times.



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. Adolescents with disabilities also have limited access to social protection that affords them a basic standard of living. Educational stipends or cash transfers are usually 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

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. Using a gender lens, the report aims 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 greater risk of violence; and more limited opportunities to participate within their communities irrespective of their impairment due to discriminatory norms; as well as their exclusion from skills development and economic empowerment opportunities.

Given the limited evidence base on adolescent girls' and boys' experiences in conflict-affected contexts – and specifically the experiences of adolescents with disabilities – the report also focuses on adolescents with disabilities in Gaza, the West Bank, and among Syrian refugees in Jordan. It reveals the challenges 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, leaving many (especially girls) confined to their homes.

In addition, the report 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.

» 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... A father cannot let her outside to attend a training course... 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... But he was the only one who was shot, I thanked God 100 times, 1000 times that none of the females were shot. Because really, how difficult would that be.

(Father of 18-year-old boy with a physical impairment, Syrian refugee in Jordan)

## Challenges in the enabling environment

Caregivers, especially mothers, very often assume disproportionate care responsibilities for children with disabilities. This is 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 even abandonment. With limited access to information, support or respite care, many caregivers report feeling exhausted, anxious and depressed.

Challenges in implementing policy and legal commitments are also critical. Over the past decade there have been advances in the development of rights-based legislation in many LMICs in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), but implementation has been uneven at best. 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.

» No one cares about people with disabilities. I was a part of a group at school, and if a person did not get to fully exercise his rights we would pressure the principal and the ministry to get him what he needs... 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 "inshallah" [God willing]. When someone says *inshallah*, I figure he might not care about the subject and most likely will not do it.

(Boy with a physical impairment, 18 years, West Bank)

Finally, there are significant evidence gaps regarding adolescents with disabilities and the multiple capabilities they need to flourish. There is also a dearth of robust evaluation evidence as to what works to support the wellbeing and resilience of adolescents with disabilities, thus hindering evidence-informed policy and programming.

## 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 adolescent is left behind. Evidence gaps notwithstanding, our research findings 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 to provide 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, and 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.



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 schools and in their community.



Ensure that poverty-targeted social assistance programmes provide adequate weighting to cover the additional costs that adolescents with disabilities and their families often incur, and simultaneously invest in skills and asset building programmes 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, and in participatory research to better understand the perspectives of adolescents with disabilities.

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. 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.

## Endnotes

- 1 WHO (World Health Organization) and World Bank (2011) World report on disability. Geneva: WHO.
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