Policy Note

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Leave no one behind: an agenda for action to enhance the full capabilities of adolescents with disabilities in Ethiopia

Authors: Elizabeth Presler-Marshall, Nicola Jones, Workneh Yadete and Kassahun Tilahun

Overview

The government of Ethiopia has made multiple commitments aimed at supporting the rights of those with disabilities, beginning with the country's 1995 Constitution, its 2010 ratification of the UN Convention on the Rights of Persons with Disabilities, and further strengthened by its 2018 commitments to inclusive education at the world's first Disability Summit. However, much work remains to be done if the inclusive society envisioned by the 2012 National Plan of Action of Persons with Disabilities is to achieve its goals. Indeed, in part because disability is heavily stigmatised in Ethiopia and also stemming from the government's definition of disability (see Box 1), even the size and characteristics of the population of people with disabilities is poorly understood. It is estimated, however, that 17.6% of the Ethiopian population – including 2.5 million children – has at least one disability. Most live in rural areas and nearly all (95%) live below the poverty line.

Adolescents with disabilities are significantly more likely than their peers without disabilities to be denied their basic rights, but research aimed at exploring their needs and identifying how best to support their transitions from childhood to adulthood is very limited. While adolescence (10–19 years) is increasingly recognised by scientists and development actors alike as a key window of opportunity,³ given the rapid physical, psycho-emotional, cognitive and social changes that occur during the second decade of life, and disability has moved up the development agenda as part of the 'leave no one behind' mandate, adolescents with disabilities remain largely invisible in policy, programming and research.

This policy note summarises key findings from Gender and Adolescence: Global Evidence's (GAGE) baseline work with adolescents with disabilities in Ethiopia.⁴ Our mixed-methods research involved approximately 350 adolescents – with physical, visual, hearing or intellectual impairments – as well as their caregivers and service providers and policy actors.⁵ Importantly, our work draws attention to the multiple and intersecting capabilities that need to be supported for adolescents with disabilities in Ethiopia to reach their full potential, including education and learning, health and nutrition, and economic empowerment and social protection

Key findings: scope and scale of the challenge

Our research found that adolescents with disabilities in Ethiopia face widespread – but variable – 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 (with the latter suffering the greatest invisibility within policy and service provision)

Box 1: Defining disability

Disability is a heterogenous and evolving concept that is – according to the World Health Organization (WHO) and the World Bank – contested by different actors.⁷ People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments.⁸ 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.

Increasingly, there is global consensus around the so-called Washington Group set of questions which ask respondents to rate the level of difficulty (no difficult, some difficulty, a lot of difficulty or cannot do at all all) they have with six types of activities. The six 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?

- and the severity of the impairment. Context plays a key role as well, with adolescents living in rural areas the least likely to have access to services and support.

Challenges in achieving adolescent capabilities Educational aspirations

Among the cohort of young adolescents (10–12 years) in our research, those with disabilities, despite their sometimes high educational aspirations, were less likely to be enrolled (64% versus 85%) and had completed, on average, a full year less education (3.5 versus 4.6 years). The enrolment gap between those with and without disabilities is shaped by type and severity of disability, with those with intellectual and hearing impairments the most likely to be shut out of school, and increases by both grade level and the child's age, with access to even second-cycle primary school comparatively rare. Our survey also found that adolescents with disabilities have poorer learning outcomes than their peers without disabilities, with boys particularly disadvantaged compared to girls.

Our research identified several key barriers to inclusive education – beginning with insufficient financial resources

to build special needs infrastructure, hire adequately trained special needs teachers, and provide appropriate learning materials. The discriminatory attitudes of parents, teachers and fellow students also limits access to education for adolescents with disabilities. Rural students are markedly disadvantaged compared to their urban peers, some of whom have been provided with access over the last few years to dedicated special needs classrooms (see Box 2).

Health and nutrition

Our research suggests that many permanent disabilities in Ethiopian adolescents are caused by poor nutrition and limited care seeking – and that the health and nutrition of adolescents with disabilities is significantly compromised compared to their non-disabled siblings and peers. We found, for example, that 60% of adolescents with visual impairments had acquired them from preventable diseases and that those with disabilities were more likely than their peers without disabilities to be too short for their age, which suggests long-term malnutrition. We also found that adolescents with disabilities were more than twice as likely to have had a serious illness or accident in the last year

Box 2: Special needs education in Ethiopia

Ethiopia has recently launched multi-pronged efforts aimed at special needs education. As well as initiating a teacher training programme, the government is 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 are now offering special classes, taught in Braille or sign language as appropriate, for children through grade 4. Recognising that most of the students who are attending special needs classes are from out of town, the government also provides a small stipend to cover some basic living costs.

Key informants at one school in South Gondar noted that 'students flood to our school', coming from 'far distant areas'. Indeed, a 16-year-old boy who is blind noted 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.' According to the adolescents in our research, access to trained teachers and peers with disabilities is transforming lives. An 18-year-old girl who is blind explained: '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.'

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 has an intellectual impairment)

(36% versus 16%). Barriers to health and nutrition for young people with disabilities are primarily related to limited service availability, especially in rural areas and for disability-specific health care, poverty and parents' poor knowledge about – and stigma towards – disability. Within this context, a reliance on traditional and faith healing was not uncommon among the families in our sample.

Employment and economic empowerment

GAGE research has found that Ethiopian adolescents with disabilities have extremely limited access to the training and microfinance programmes and employment opportunities that would support independent futures. Technical and Vocational Education and Training (TVET) courses require 10th grade completion, which is not possible for most young people with disabilities given the limited availability of special needs education. Moreover, due to the stigma directed at disability, young people with disabilities are not generally encouraged or supported to consider employment.

Adolescents with disabilities' access to social protection is also highly limited. Families are not prioritised for PSNP support, ⁹ even though disability often entails higher costs (for medication, transport, specialised nutrition, education materials etc.). In addition, although those with visual and hearing impairments are provided with a stipend to partially offset their cost of living while they are studying at urban special needs schools, stipend amounts are low (200–350 birr per month, depending on the type of impairment), not available for those with physical disabilities, and can be coopted by caregivers for general household use. As a result, many adolescents with disabilities are compelled to balance school with work or in some cases begging. Parents in rural areas often do not (due to discrimination) or cannot (due to household poverty) provide additional support.

Description Even their family does not consider them as productive, instead they consider them as dependent.

(SNE teacher, Debre Tabor)

Challenges in the enabling environment

We identified three overarching issues that need to be addressed so as to create an enabling environment which supports adolescents with disabilities to not only survive but thrive. First is the pervasive and entrenched nature of disability-directed stigma. In Ethiopia, as in many low- and middle-income countries, young people with disabilities are all too often shunned by their communities and their families, because disability is not only associated with misfortune and incompetence, but also evil and sin. 10 Second, challenges in implementing policy and legal commitments are also critical. For example, while multiple national policies call for inclusive and accessible education to facilitate the full political, economic and social participation of those with disabilities, only 0.01% of teachers have been trained in special needs education. 11 Finally, there are significant evidence gaps regarding adolescents with disabilities and the multiple capabilities they need to flourish. Outdated definitions of disability have not only precluded an accurate census - but even hidden strengths. Government figures show a primary gross enrolment rate for students with disabilities of less than 8%, 12 far below the GAGE survey findings of 64%, which suggests a need for further exploration.

Key actions to accelerate progress

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 government of Ethiopia and 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 action in five key areas is necessary 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. This should build on current efforts to scale up special needs education, being undertaken in conjunction with a number of NGOs, and include detailed, costed action plans with measurable milestones to provide accessible, appropriate and quality inclusive education (including access to better-resourced special needs classrooms, materials and trained teachers) for all adolescents with disabilities.¹³ Adolescents with disabilities also require expanded access to primary, sexual and reproductive, and disability-specific health care, as well as stepped up nutritional support. With appropriate training, health extension workers and Ethiopia's new cadre of social workers would be well placed to deliver basic services

and refer more complex cases for further care. Critically, to reduce community-level stigma and ensure that adolescents with disabilities are not deprioritised within the household, it is necessary to invest in awarenessraising with parents, communities and service providers about the causes of disability, the rights of those with disabilities, and the importance of supporting young people with disabilities to aspire to - and work towards - their own independent futures. Social assistance programmes must be adequately targeted and weighted to ensure that households are able to cover the additional costs that adolescents with disabilities and their families often incur, and simultaneously invest in the skills and asset building programmes necessary for their economic empowerment, including though tailored TVET.

- 2. Engage and support caregivers of adolescents with disabilities, who in Ethiopia are often stigmatised and excluded themselves. Ensure that caregivers, even those with limited literacy, 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.
- 3. Address intersecting disadvantages to leave no adolescent behind by undertaking a comprehensive mapping of national government, NGO and donor programming and services for adolescents with different impairment types to identify gaps and solutions for the hardest-to-reach groups, including for example mobile clinics for those in remote areas.
- 4. Tackle data and evidence gaps to improve evidence informed policy development and programming. The government of Ethiopia should align its definition of disability with international standards (e.g. the Washington Group questions) and invest in up-to-date 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. Partnerships with longitudinal research programmes such as GAGE and RISE can help to address some of these evidence lacunae.

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 government agencies, NGOs and donors to account. Finally, 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.
- 2 ILO International Labour Organization (2013) 'Inclusion of People with Disabilities in Ethiopia'. Fact Sheet. (https://www.ilo.org/wcmsp5/groups/public/@ed_emp/@ifp_skills/documents/publication/wcms_112299.pdf).
- 3 WHO and World Bank (2011) World report on disability. Geneva: WHO.
- 4 UN (2006) 'Convention on the Rights of Persons with Disabilities and Optional Protocol'. Webpage. UN (www.un.org/disabilities/documents/convention/conventprot-e.pdf)
- Muz, J., Baird, S., Hamory Hioks, J., Faiz Rashid, S., Sultan, M., Yadete, W., and Jones, N. (2018) Finding the Hard to Reach: A Mixed Methods Approach to Including Adolescents with Disabilities in Survey Research. London: CROP Secretariat.
- 6 Jones, N., Presler-Marshall, E. and Stavropoulou, M. (2018) Adolescents with disabilities: Enhancing resilience and delivering inclusive development. Report. London: Gender and Adolescence: Global Evidence.
- 7 UNICEF (2011) Adolescence: an age of opportunity. New York: UNICEF.
- 8 We also draw on Jones, N., Presler-Marshall, E. and Stavropoulou, M. (2018) Adolescents with disabilities: Enhancing resilience and delivering inclusive development. Report. London: Gender and Adolescence: Global Evidence.
- 9 Approximately 28% of GAGE adolescents in Ethiopia belong to households that receive PSNP support, but notably those with a disability are less rather than more likely to receive support, especially among the older age cohort.
- 10 WHO and World Bank (2011) World report on disability. Geneva: WHO; Groce, N. and Kett, M. (2014) Youth with disabilities. Working Paper 23. London: Leonard Cheshire Disability and Inclusive Development Centre, University College London.
- 11 MoE Ministry of Education Ethiopia (2018) 'Education statistics annual abstract, 2009 E.C. (2016/17)'. Addis Ababa: Federal Democratic Republic of Ethiopia.
- 12 MoE Ethiopia (2018) 'Education statistics annual abstract, 2009 E.C. (2016/17)'. Addis Ababa: Federal Democratic Republic of Ethiopia.
- 13 This should be in line with the commitments in the MoE (Ministry of Education). 2016. A Master Plan for Special Needs Education/Inclusive Education in Ethiopia 2016–2025. Addis Ababa: Government of Ethiopia.



