

AUTISM AND RELATED DEVELOPMENTAL DISABILITIES IN HEALTH AND EDUCATION POLICIES IN ETHIOPIA

POLICY BRIEF

NIA FOUNDATION | JOY CENTER FOR AUTISM

REVIEW MADE BY: MENGISTUWOLDE

BACKGROUND

Autism is a lifelong developmental disability that affects how a person communicates with and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism experience three main areas of difficulty sometimes referred to as the 'triad of impairments'. These are social interaction, social communication and social imagination.

This policy brief review focused on overseeing frameworks in Ethiopian Health and Education sectors with special emphasis on the opportunities, challenges and approaches in light of promoting holistic and integrated sexual and reproductive health rights for youth and adolescents with developmental and intellectual disabilities with a particular focus on Autism. The National Adolescent and Youth Reproductive Health Strategy and Inclusive Education strategy are the themes of this review dwells on policy, demonstrated support and commitment to the advancement of adolescent sexual and reproductive health in Ethiopia. The National Adolescent and Youth Reproductive Health Strategy (2016-2020) aims to improve the overall health status of Ethiopians in the national development agenda of the nation and is believed to enhance and sustain the mainstreaming of youth and adolescent health and show the government's commitment from 2016 to 2020 aligned with Sustainable Development Goals (SDGs). The purpose of this strategy is aim is in order to robust the implementation.

Internationally, literature depict that approaches to engage people with autism in Sexual and reproductive health services vary across countries and experiences

from nations to nations. Healthcare providers and educators play critical roles in supporting healthy sexuality development for youth with an autism spectrum disorder. There is limited information about the sexual behaviour of these youth about their access to sexuality education or health care services as there is limited access to get the mainstream population with a disability included in a national service provider of national information management systems. As a group, youth and adolescents with autism and related disorder are amongst the most marginalized and poorest youth in the world. Their basic rights are not well met and societal acceptance is often out of reach. People with disabilities also have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than non-disabled people. One reason for this disparity is that people with Autism have barriers to accessing services. These difficulties are exacerbated in less advantaged communities.

To family planning and reproductive health service providers often overlook the needs of women and female youth with Autism, making little or no attempt to reach this population due to a lack of awareness and motivation. Yet there are an estimated over 15 million people with disabilities exist in Ethiopia, and over 1 million estimated population with autism and other developmental and intellectual disability based on global estimates of the Center for Disease Prevention and World Health Organization much hasn't been done to unpack this massive multifaceted health, psychological, and social disparity in Ethiopia. This spectrum of society includes young men and women with autism and other disabilities. Proper rehabilitation and education are very important for Autism Spectrum Disorder children to achieve their full development and experience improved prognoses. It is evident that the vast majority of people with autism and related developmental disability live in developing countries, often under poor conditions, lacking the basic support and services that would improve their lives considerably. Education is critical for all children to realize their full potential. However, UNESCO estimates only 1-2 % of children with disabilities in developing countries attend school. By the time they

enter adolescence, many youth and adolescents with autism and related disorder run a high risk of being illiterate, leading to restricted opportunities for further education, employment, and income generation. Some families do not feel that children with disabilities should receive an education, often believing that young people with disabilities are incapable of learning (Groce, 2014). In societies that favour males, young women with disabilities are at a particular disadvantage, as families may be reluctant to allocate resources to them. According to a UNESCO report, boys with disabilities attend school more frequently than girls with disabilities which result in latter illiteracy and lack of access in a continuously changing world to compete and get access and opportunities.

Access to reproductive health information is often not disseminated or available to youth and adolescents with autism and related disorder. For example, in several developing countries youth and adolescent with autism and related disorder often do not have autism-friendly sexual and reproductive health services, detailed manuals or lack of working materials is not available, and providers are unable to communicate with people with autism. Moreover, most healthcare professionals have limited awareness and, consequently, feel unwilling or unable to address their issues.

Society tends to think that people with autism should be non-sexual. In many cases, sexuality education is withheld because it's assumed the person 'won't need it'. Some people hold the misconception that people with disability shouldn't have fulfilling sex lives or have access to sexuality education, in case it 'gives them ideas' People with autism also find that information on sexual and reproductive health is not only inaccessible but also not contextualized and user friendly for the families and people with autism. Adolescents and youth with autism and other developmental disability in Ethiopia are generally at an increased risk of sexual and reproductive health (SRH) related problems. Despite these immense problems, they have limited access to quality sexual and reproductive health services. Also, there are only a few national programs specifically targeted to address the needs of this group under the adolescent and youth health strategy, the Ministry of Health of Ethiopia.

The health-seeking behaviour of young Ethiopians, particularly in relation to their sexual and reproductive health, is very limited even when compared to many African countries. Some of the behaviours and challenges can be attributed to the lack of youth-friendly services that reassure confidentiality, service providers' biases against this section of the population,

and low levels of awareness among members of the community. Youth and adolescents with autism and related disorder in Ethiopia, as in other developing countries, have an increased risk of SRH-related problems, as they are more likely than the general population to be illiterate, unemployed and impoverished. They often lack equal access to information and education for reasons ranging from physical access to classrooms and service areas to varied special learning needs.

With regard to the education sector review report (2020) confirms that Ethiopia has started the movement towards inclusive education and it is at its infant stage. Although there are some positive changes registered towards inclusive education; there are a number of challenges that need to be addressed in the future by implementing the ratified conventions and policies. Women and men with disabilities can and want to be productive members of society. In both developed and developing countries, promoting more inclusive societies and employment opportunities for people with disabilities requires improved access to basic education, vocational training relevant to labour market needs and jobs suited to their skills, interests and abilities, with adaptations as needed. Many societies are also recognizing the need to dismantle other barriers making the physical environment more accessible, providing information in a variety of formats, and challenging attitudes and mistaken assumptions about people with disabilities. There is key international legislation that advocates for a more inclusive society such as the International Labour Organization (ILO) Convention concerning Discrimination in Respect of Employment and Occupation, ratified, on 11 June 1966. ILO Convention concerning Vocational Rehabilitation and Employment (Disabled Persons), ratified, 28 January 1991. United Nations Convention on the Rights of Persons with Disabilities (2006) and Optional Protocol, ratified, 7 July 2010.

Accordingly, Ethiopia as a nation also adopted laws, policies and standards pertaining to people with disabilities. The main one are the Constitution of the Federal Democratic Republic of Ethiopia, adopted in 1995. Article 41(5) of the Constitution sets out the State's responsibility for the provision of necessary rehabilitation and support services for people with disabilities. Proclamation concerning the Rights to Employment for Persons with Disabilities, No. 568/2008, makes null and void any law, practice, custom, attitude and other discriminatory situations that limit equal opportunities for persons with disabilities. It also requires employers to provide appropriate working and training conditions; take all reasonable

accommodation measures and affirm active actions, particularly when employing women with disabilities; and assign an assistant to enable a person with a disability to perform their work or follow training. The Federal Civil Servant Proclamation No. 515/2007, provides for special preference in the recruitment, promotion, and deployment, among others, of qualified candidates with disabilities. This provision is applicable to government offices only. Labour Proclamation, No. 377/2003, amended by Labour Proclamation No.494/2006, makes it unlawful for an employer to discriminate against workers on the basis of nationality, sex, religion, political outlook or on any other conditions. Proclamation on Definition of Powers of Duties of the Executive Organs of the Federal Democratic Republic of Ethiopia, No. 691/2010, provides for conditions of equal opportunities and full participation of persons with disabilities and those living with HIV/AIDS. The National Plan of Action for Persons with Disabilities (2012-2021) aims at making Ethiopia an inclusive society. It is believed that all these legislative, and policy frameworks try to address the needs of persons with disabilities in Ethiopia for comprehensive rehabilitation services, equal opportunities for education, skills training and work, as well as full participation in the life of their families, communities and the nation.

In Contrary studies show evidence that the vast majority of people with disabilities live in rural areas where access to basic services is limited. In Ethiopia, 95 per cent of all persons with disabilities are estimated to live in poverty. Many depend on family support and beg for their livelihoods. Studies show that in Ethiopia, 55 per cent of the surveyed persons with disabilities depend on family, neighbours and friends for their living, while the rest generate meagre income through self-employment, begging and providing housemaid services.

Delivering short and long-term training, applying Differentiated Instruction, allocating resources, improving inclusive service delivery, strengthening collaborations with stakeholders, and conducting research work to improve inclusive policies and practices in the Educational sector and platforms in the country to better address the needs of children with autism and other developmental disability. It gives an inspirational dedication to the Ministry of Education that the current inclusive education strategy in Ethiopia has been put under thorough revision and it is with great expectation that stakeholders in the Developmental and Intellectual disability sector believe the issues of equal opportunity, awareness, priority of Autism and related

developmental issues were well captured to the revised version policy of inclusive education in Ethiopia. Similar to most African countries, Ethiopia has limited autism service provision outlets. The early detection, notification, treatment care and rehabilitation for children with autism in Ethiopia are further impeded by the stigma surrounding mental health and misconceptions about the causes of developmental disability and mental illness. Studies show that caregivers provided a mixture of biomedical (e.g. head injury or birth complications) and supernatural (e.g. spirit possession or sinful act) explanations for their child's condition. Caregivers also reported high levels of stigma, with the higher stigma associated with seeking help from traditional institutions, providing supernatural explanations and affiliation with the Orthodox Christian faith. The majority (75%) of caregivers reported unmet needs regarding their child's educational provision and many (47%) also indicated an unmet need for support from health professionals. According to (Be Tekola 2016) these findings illustrate the great challenges experienced by families with children with developmental disorders in Ethiopia to come up with the proper sexual and reproductive health provisions in systems established to serve.

THE OPPORTUNITIES

In recent years, however, Ethiopia's mental healthcare system has become the focus of new initiatives. The National Mental Health Strategy presents a plan for scaling up mental healthcare and recognizes children with mental disorders as a vulnerable group. Training of mental health specialists is being expanded, with in-country psychiatrists, P.h.D., Master and psychiatric nurse training programmes, and basic mental health training for rural community-based health workers (HSTP 2018). New initiatives from local non-governmental organisations (NGOs) also contribute to an increase in autism awareness and service provision in Ethiopia. More recently efforts made by Haromaya University to incorporate disciples directly dealing with Developmental and Intellectual disabilities in their undergraduate program puts an opportunity to fill the policy gap created in addressing the needs of this spectrum of the population.

Currently, with over population of over 120 million people, Ethiopia has Primary healthcare provided by health centers (1/15000–25000 population) and their

satellite health posts (1/3000–5,000 population) connected through a referral system. These are staffed with nurses and health officers with satellite health extension workers providing prevention and promotion services to the community this would be the ideal place to have policy mainstreaming through early detection and notification with Child health services (outpatient curative care, vaccination and growth monitoring) are given in 62% of the country's health facilities (the Federal Democratic Republic of Ethiopia Ministry of Health, 2015). There are also two governmental specialized child mental health clinics, in Addis Ababa's Yekatit 12 and St. Paul's hospitals. In addition, there are private clinics with some limited child mental health expertise. Each of these specialized clinics is located in the capital and therefore inaccessible to the majority (85%) of families who live in Ethiopia's rural areas.

Services for children with disabilities and preventive and community-based rehabilitation programmes are primarily given by NGOs and religious charities (Federal Democratic Republic of Ethiopia Ministry of Labour and Social Affairs, 2010). As will be further explained below, their work on autism is limited. A situational analysis from 2015 regarding special needs Ministry of education has education identified 15 special schools, primarily run by NGOs and 285 special classes attached to mainstream government schools. (the Federal Democratic Republic of Ethiopia Ministry of Education, 2015).

More recent data on the exact number of schools are unavailable, but Ethiopia's fifth Education Sector Development Programme (the Federal Democratic Republic of Ethiopia Ministry of Education, 2015) indicates that currently only 4% of children with special needs are enrolled in primary school education. Attendants of our stakeholder meetings indicated that some of the special schools, especially those for children with ID (including the private Bruh centre and a school affiliated to the Ethiopian Evangelical Church Mekane Yesus), educate some children with autism. There are two autism-specific schools: The Joy Center hosts 80 children with 600+ children on a waiting list; the Nehemiah Autism Center enrolls 40 children with 250 children on their waiting list. Both centres only serve families from Addis Ababa and its surroundings. In sum, the limited services currently available for children with autism in Ethiopia come from four main types of providers:

- (i) Governmental and private clinics, such as
- (ii) Centers for children with autism,
- (iii) Mainstream schools with inclusive

education programmes;

- (iv) NGOs and religious charities providing community-based rehabilitation services.

THE APPROACH

Why is Now a good time to have policy dialogue this time? To better capitalize on individual strengths and disabilities, the World Health Organization's International Classification of Functioning, Disability and Health (ICF) offer an internationally accepted, comprehensive and integrated framework incorporating personal, societal and environmental factors affecting the sexual and reproductive health of the wellbeing of autistic individuals. Expanding the focus from diagnosis to functioning, which is now also an essential feature of the autism description to have interventions to deal with the needs of youth and adolescents and promote a framework for improving sexual and reproductive wellbeing in developing strategies supporting the inclusion of those with unique abilities, as well as profound disabilities. The following three approaches to better understand the challenges and policy implications around this issue:

1

First, a scoping review of the scientific literature examining educational, health and other policies related to SRH in autism was conducted, revealing that the overwhelming majority of research to date has focused on approaches targeting the symptoms of autism, rather than modifying the integration to the existing systems.

2

There must be an integration strategy for health facilities, schools and other centres for Developmental and intellectual disabilities to promote holistic interventions for youth and adolescents with autism to have family planning and sexual and reproductive services.

3

Finally, the Ministry of Health, Ministry of Education, stakeholders and care providers, seek their views in relation to issues pertinent to autism and sexual and reproductive health, the factors facilitating successful sexual, and reproductive education and rights and the barriers or challenges autistic individuals face to fullest wellbeing.

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