

Éthiopie : traitement de l'autisme

Recherche rapide de l'analyse-pays

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1 Introduction

Le présent document a été rédigé par l'analyse-pays de l'Organisation suisse d'aide aux réfugiés (OSAR) à la suite d'une demande qui lui a été adressée. Il se penche sur les questions suivantes :

1. Existe-il des structures en Éthiopie pouvant prendre en charge et offrir un suivi thérapeutique à des enfants présentant des troubles du développement et du spectre autistique ?
2. Existe-il des écoles qui puissent offrir un encadrement et un suivi adapté pour ces enfants ?

Pour répondre à ces questions, l'analyse-pays de l'OSAR s'est fondée sur des sources accessibles publiquement et disponibles dans les délais impartis (recherche rapide) ainsi que sur des renseignements d'expert-e-s.

2 Possibilités de prise en charge des enfants autistes en Éthiopie

Il y aurait 600 000 personnes autistes en Éthiopie et seulement 300 enfants autistes scolarisés. Le problème de l'autisme est largement ignoré et les moyens sont très limités avec seulement deux pédopsychiatres dans tout le pays. On manque de données sur le nombre d'autistes en Éthiopie, mais selon *Devex*, une plateforme média spécialisée dans les problématiques de développement, il y aurait près 600 000 personnes souffrant de cette maladie dans le pays (*Devex*, 6 novembre 2014). Sur ce chiffre, seuls quelques 300 enfants seraient scolarisés (*All Africa*, 29 avril 2017). Selon *Bethlehem Tekola*, chercheuse au *King's College* de Londres, les possibilités de diagnostiquer et de fournir un encadrement et un accompagnement éducatif aux enfants souffrant d'autisme sont très limitées en Éthiopie et confinées à la capitale, Addis Abeba. Malgré certaines initiatives ces dernière années, notamment l'adoption d'une *Stratégie nationale pour la santé mentale* (2012/2013-2015/16) qui reconnaît les enfants atteints de troubles mentaux comme des personnes vulnérables, ainsi que des campagnes de sensibilisation, il n'y a pas eu de mesures concrètes pour améliorer la prise en charge de l'autisme (*B.Tekola et al.*, 2016). Selon *All Africa*, le problème de l'autisme en Éthiopie est largement ignoré et le gouvernement n'a pas pris de mesures adéquates. D'après des chiffres datant de 2010, le pays ne possède que 60 psychiatres pour 96 millions d'habitants, dont deux seulement sont des pédopsychiatres (*All Africa*, 29 avril 2017). Ce chiffre de deux pédopsychiatres est confirmé par *Dejene Tilahun*, un chercheur de l'*Université d'Addis Abeba* (*Dejene Tilahun*, 27 avril 2016). Les soins psychiatriques ne sont disponibles que dans les hôpitaux régionaux et seuls deux hôpitaux (*Yekatit* et *St Paul*), situés les deux à Addis Abeba, fournissent des soins psychiatriques pour les enfants (*B Tekola et al.*, 2016).

Seuls deux centres peuvent prendre en charge des enfants autistes en Éthiopie. Les deux sont situés à Addis Abeba et ont une capacité commune d'environ 120 enfants. Les deux centres fonctionnent à pleine capacité et ont des très longues listes d'attente.

Une école à Addis-Abeba intègre également un nombre limité d'enfants autistes. Il n'existe actuellement en Éthiopie que deux institutions qui prennent en charge les enfants autistes, les deux se trouvent à Addis Abeba. Il existe également une école, *Basilios*, qui intègre une classe pour enfants souffrant de troubles mentaux, dont l'autisme. L'école est gratuite, mais l'enregistrement, les livres et l'uniforme entraînent des coûts. Il y aurait un roulement important chaque année et ceci pour diverses raisons, comme par exemple le fait que les parents ont du mal à amener leurs enfants (B. Tekola et al., 2016). Le *Joy Center*, a été fondé en 2002 et le *Nehemiah Autism Center* a été fondé plus récemment, en 2012. Selon *Devex*, le *Nehemiah Autism Center* a une capacité de 40 enfants, âgés de deux à douze ans, et il y a deux enfants par enseignant-e-s. Plus de la moitié des enfants viennent de familles pauvres et certains parcourent 20 kilomètres chaque jour pour se rendre au centre et retourner à la maison (Devex, 4 novembre 2014). D'après un courriel envoyé par le *Nehemiah Autism Center* à l'OSAR le 9 août 2018, le centre est actuellement plein. La liste d'attente comporte pas moins de 500 enfants. Selon *Spectrum*, un site de nouvelles spécialisé sur l'autisme, en septembre 2017, le *Joy Center* accueillait 80 enfants avec un encadrement de 50 enseignants. A la fin de 2017, le *Joy center* était à capacité maximale et celles et ceux qui voulaient y intégrer leurs enfants devaient les inscrire sur des listes d'attentes. Un contact téléphonique entre l'OSAR et une représentante du *Joy Center*, le 16 août 2018, a confirmé qu'il n'y avait actuellement pas de place libre et une longue liste d'attente qui peut prendre deux ans. A la fin de l'année 2017, les deux centres avaient ensemble une liste d'attente de près de 500 enfants (Spectrum, 13 décembre 2017). Selon *B. Tekola*, dans les deux centres les parents paient des frais dont le montant dépend de leurs revenus. Il y a également un certain nombre de place pour les enfants dont les parents ne peuvent rien payer. Les centres sont financés en partie par le gouvernement, des donateurs privés et des ONG, mais le financement à long-terme est un problème (B. Tekola et al., 2016). Selon *Devex*, les organisations qui viennent en aide aux autistes rencontrent des problèmes de financement car la plupart des donateurs exigent que le nombre de leurs bénéficiaires soit plus important (Devex, 6 novembre 2014). D'après *Spectrum*, le *Joy Center* a reçu l'autorisation de la part du gouvernement de construire une nouvelle école pour enfants autistes. Cette école, qui s'appellera « *Autist Centre of Excellence* », aura une capacité de 400 enfants. Le financement n'est pas encore assuré et des donateurs sont encore recherchés (Spectrum, 13 décembre 2017).

3 Traitements et encadrement des enfants autistes

Traitements souvent inadaptés et personnel encadrant mal formé ou inexpérimenté. Peu ou pas de monitoring et donc difficultés à évaluer l'efficacité des traitements. Selon *B. Tekola*, les méthodes et les outils utilisés pour traiter l'autisme en Éthiopie ne sont pas adaptées (B. Tekola et al., 2016). D'après *Waganesh A. Zeleke*, professeure associée de psychiatrie clinique à l'*Université de Duquesne* à Pittsburgh, le traitement de l'autisme est mal compris et inadapté dans le pays. Le peu de personnes qui sont traitées reçoivent principalement des cours visant à améliorer leurs compétences pour s'adapter à la vie quotidienne. Il n'y a pas assez d'interventions thérapeutiques sociales, comportementales et éducatives. Les éducatrices et éducateurs sont souvent mal formés (Waganesh A. Zeleke et al., 7 septembre 2017). Selon *B. Tekola*, le *Joy Center* et le *Nehemiah Autism Center* fournissent un mélange de thérapies et de formations autour de la communication, des activités quotidiennes

de la vie et éducatives. Les parents sont également intégrés avec des rencontres régulières et des formations qui leurs sont fournies (B. Tekola et al., 2016). Selon *Devex*, l'objectif de l'encadrement du *Nehemia Autism Center* est de travailler sur les aptitudes comportementales et la communication des enfants pour que ceux-ci puissent être acceptés dans le système éducatif national inclusif, où d'autres enfants souffrant de troubles sont intégrés dans des programmes spéciaux, même si dans bien des cas les élèves souffrant d'autisme ont du mal à être acceptés (Devex, 6 novembre 2014). Selon des chercheurs africains, cités par *Spectrum*, le personnel du *Nehemiah Autism Center* manque souvent de qualifications et de connaissances spécifiques. La plupart ont été engagés sans expérience préalable et pratiquent des méthodes « intuitives » et « informelles ». Dans l'ensemble, il est très difficile d'évaluer l'efficacité des traitements et il manque des outils de monitoring (Spectrum, 13 décembre 2017). D'après *Spectrum*, le *Joy Centre* offre des thérapies occupationnelles, musicales, artistiques et de langage (Spectrum, décembre 2017). Selon *B. Tekola*, l'école *Basilios* se concentre sur l'apprentissage de l'alphabet, des chiffres, la couture et l'hygiène personnelle (B. Tekola et al., 2016).

4 Stigmatisation des personnes souffrant d'autisme et de leurs familles en Éthiopie

Forte stigmatisation des personnes souffrant de l'autisme en Éthiopie, mais aussi de leurs familles. Selon *Devex*, les habitantes et habitants d'Éthiopie sont profondément religieux et quand un enfant montre des signes d'autisme, c'est comme si la famille avait été frappée par une malédiction ou punie pour des actes qu'elle aurait commis. Selon *Yenus*, le directeur du *Joy Center*, cité par *Spectrum*, beaucoup d'enfants atteints d'autisme sont cachés à cause de la stigmatisation liée à cette maladie. Bon nombre de familles n'ont pas de porte de sortie et dans bien des cas, les pères de ces enfants abandonnent vite leurs femmes, les laissant se débrouiller tant bien que mal (Devex, 6 novembre 2014). D'après une personne de contact de l'OSAR, jointe par téléphone le 14 août 2018, la stigmatisation conduit souvent à des conflits de famille et les mères seules sont socialement hors-la-loi. *All Africa* cite l'exemple d'une femme dont le fils souffre d'autisme et qui a rencontré beaucoup de difficultés à trouver un logement à Addis Abeba car les propriétaires ou les voisin-e-s ne voulaient pas que son fils puisse « transmettre » cette maladie à leurs enfants. La méconnaissance de cette maladie engendre souvent de l'intolérance ainsi que des comportements hostiles. Cela rend évidemment la vie de ces familles très difficiles (All Africa, 29 avril 2017). Selon *B. Tekola*, la forte stigmatisation de l'autisme en Éthiopie, et la méconnaissance de ce qui en est la cause, rend le diagnostic mais aussi la prise en charge des personnes qui en sont atteintes particulièrement difficile. Les familles rencontrent un grand nombre de problèmes aussi bien d'ordre psychologiques que pratiques (B. Tekola et al., 2016). Selon *Dejene Tilahun*, l'accès aux services de diagnostic et de prise en charge de l'autisme est rendu très difficile par les attitudes stigmatisantes à l'encontre des autistes et de leurs familles (Dejene Tilahun et al., 25 septembre 2017). La stigmatisation à l'encontre des parents d'enfants autistes est plus forte pour ceux qui cherchent de l'aide de la part d'institutions traditionnelles ou qui pensent que l'origine de la maladie est d'ordre mystique (Dejene Tilahun et al., 27 avril 2016).

5 Sources

All Africa, 29 avril 2017:

*«Autism can be one of the most difficult diagnoses to accept for parents. It is particularly due to the challenging symptoms associated with autism spectrum disorder. **As with many things that society does not understand, autism also has a certain stigma attached to it. The negativity can make it quite difficult for families struggling to cope with an individual who has the diagnosis.***

I know a woman named Aster who considers herself as one of the most unfairly welcomed people to this planet. Due to unwanted pregnancy, she became a mother of a boy at the age of 14. She could not continue her education and dropped out of the 8th grade. The father of the kid abandoned her. She had gone through severe discrimination from her family and as well as her relatives and community.

To add insult to injury when her son was one year old, he diagnosed with a seizure. Since then, her primary job became taking him to different places where she assumed he would get treatment or even find a cure.

*However, rather than showing sign of progress, he showed awkward behaviour which was tough to manage. While in this state of confusion about what to do, her close friend who lives in Addis Abeba that knew about autism, brought her to one of the autism centres and her son was diagnosed with autism. She was shocked when she knew what autism is. **What was more frustrated was her lack of hope, to enrol him in the centre because there were many children on the waiting list. Luckily after two years of waiting, Aster could not believe when she was told to come and enrol her son in the centre. She decided to move to Addis Abeba from the regional town where she used to live and register her son in the centre which provides free education including school uniforms and transport.***

*Relying on the promise of her relatives for support of all living expenses, she came to Addis Abeba with a bright future. But things in the capital were not as she had imagined it. She suffered a lot in searching for affordable housing. Finally, she found a place but was evicted after a week due to her son's hyperactive behaviour. **She stayed only fifteen days in the second house and was asked to leave because the landlord and the neighbours believed that her son has a disease that would be transmitted to their children. She faced similar challenges in the third and fourth houses she rented.** In less than three months she was forced to go to the outskirts and rent a one bedroom condominium where many people do not yet live. Although she got relief from the day to day complaints of landlords and neighbours, life was not easy when it came to commuting with her son to the centre. As the centre's bus does not go to the area she lives in. She must take two taxis to reach the centre's bus service.*

Unaffordable taxi fares, the unwillingness of taxi assistants to let her son board, the attitude and reaction of passengers to the odd behaviour of her son became other challenges which thought her there is no room or tolerance for children with autism in the society.

These challenges caused Aster to go back to her family. The magnitude and the type of problems may vary, but none of the families that have children with autism is free from anguish caused by lack of unawareness about autism.

*As a professional working on autism, I feel that accepting and understanding autism, and urging for action is becoming important, now more than ever. Addressing this devastating disorder cannot be left to the government; it demands cooperative support from individuals to institutions. Autism statistics from the United States Centres for Disease Control and Prevention (CDC) identify around 1 in 68 American children as on the autism spectrum - a ten-fold increase in prevalence in 40 years. **Sufficient statistical evidence on the extent and prevalence of ASD is not currently available in Ethiopia but estimated that six hundred thousand children are living with autism whereas the numbers of children with autism who got the opportunity for education are not more than three hundred.***

***Nehemiah Autism Centre and Joy Autism Centre take the lion share in educating the children.** Some of the children with mild autism go to national and private schools. Otherwise, **almost all children with ASD are deprived of education and rehabilitation due to lack of facilities, schools and trained teachers.** In fact, the majority of parents do not know what autism is, and those who know are pessimist regarding their children change through education and training according to the Nehemiah Autism Centre study.*

***Although autism is increasing at an alarming rate, attention given by both the concerned government offices and the society is insignificant. Even the NGOs that are working with children, disability, and women are not giving the required attention to autism.** Bringing awareness to children rights and women equality is important, but in my opinion, it is not as important as addressing and supporting children who are currently suffering from autism. Especially the families and mothers, who are crippled from participating in social issues, and being unproductive due to full-time care of their children with autism. Source: All Africa, Ethiopia: Long Way to Go for Autism in Ethiopia, 29. April 2017: <https://allafrica.com/stories/201705080237.html>*

B.Tekola et al., 2016:

*« **Existing diagnostic and educational services for children with autism are scarce and largely confined to Ethiopia's capital city, with little provision in rural areas. Families of children with autism experience practical and psychosocial challenges, including severe stigma. Informants further raised the lack of culturally and contextually appropriate autism instruments as an important problem to be addressed.** The study informants and local stakeholders provided several approaches for future service provision expansion, including service decentralisation, mental health training and awareness raising initiatives.*

[...]

***Similar to other African countries, Ethiopia has limited autism service provision. The detection of, and care for, children with autism in Ethiopia is further impeded by stigma surrounding mental health (Shibre et al. 2006) and misconceptions about the causes of developmental disability and mental illness (Alem et al. 1999; Abera et al. 2015).** We recently examined the experienced stigma, explanatory models and unmet needs of 102 help-seeking caregivers of children with autism and/or intellectual disability (ID) in Ethiopia (Tilahun et al. 2016). Caregivers provided a mixture of biomedical (e.g. head injury or birth complica-*

tions) and supernatural (e.g. spirit possession or sinful act) explanations for their child's condition. Caregivers also reported high levels of stigma, with higher stigma associated with seeking help from traditional institutions, providing supernatural explanations and affiliation to 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. These findings illustrate the great challenges experienced by families with children with developmental disorders in Ethiopia.

In recent years however, Ethiopia's mental healthcare system has become the focus of new initiatives. The National Mental Health Strategy (2012/13–2015/16) presents a plan for scaling up mental healthcare and recognises children with mental disorders as a vulnerable group. Training of mental health specialists is being expanded, with in-country psychiatrist, Ph.D., Masters and psychiatric nurse training programmes, and basic mental health training for rural community-based health workers. New initiatives from local non-governmental organisations (NGOs) also contribute to an increase in autism awareness and service provision in Ethiopia.

Although these developments are promising, existing services for children with autism have scarcely been documented. Moreover, little has been done to explore opportunities and challenges to expand services and the most effective ways for future service development. This paper aims to assess the current health and education service provision for children with autism in Ethiopia. It explores the unmet needs, future opportunities and stakeholders' views of the best approach to further develop services. Matched with the views from Ethiopian caregivers of children with developmental disorders (Tilahun et al. 2016), this paper will serve as baseline work for future studies and service interventions and hopes to also inform capacity building strategies in other low-income countries.

[...]

Serving a population of over 96 million, Ethiopia has 60 practicing psychiatrists, of whom two are child psychiatrists. In addition there are 461 psychiatric nurses, 14 psychologists (none trained in child mental health), three clinical social workers, and no occupational therapists (updated from MhGAP-Ethiopia Working Group, 2010).

Primary healthcare in Ethiopia is provided by health centres (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. Child health services (outpatient curative care, vaccination and growth monitoring) are given in 62% of the country's health facilities (Federal Democratic Republic of Ethiopia Ministry of Health, 2015). **Mental healthcare is currently not provided at most primary healthcare facilities and only available in regional or zonal hospitals, typically staffed with psychiatric nurses. Mental health specialists (general psychiatrists) are only found at the regional hospital level. Psychiatrists working in these settings have received training in child mental health, but are not child mental health experts. There are only two governmental specialised 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 specialised 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 2005 regarding special needs education identified 15 special schools, primarily run by NGOs and 285 special classes attached to mainstream government schools (Federal Democratic Republic of Ethiopia Ministry of Education, 2005). More recent data on the exact number of schools are unavailable, but Ethiopia's fifth Education Sector Development Programme (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. The programme presents plans to increase this rate to 75% by 2019/20, though acknowledges a financing gap (Federal Democratic Republic of Ethiopia Ministry of Education, 2015). 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 500+ 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; (ii) centres for children with autism; (iii) mainstream schools with inclusive education programmes; (iv) NGOs and religious charities providing community-based rehabilitation services (see Fig. 1). To further understand the challenges and opportunities related to their activities we conducted in depth interviews with at least one key informant from each type of provider (Table 1).

[...]

Government hospitals and private clinics

The governmental specialised child mental health clinics and private clinics in Addis Ababa are the only locations where a formal autism diagnosis can be obtained. Government clinics charge a small fee except for people with an exemption certificate (the poorest families in a given administrative unit); private clinics charge a higher fee without exemptions. According to all of our clinical informants, autism diagnoses are based on a clinical interview with the caregiver and a behavioural observation, following diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013). Standardised diagnostic instruments are rarely used since these have not been adapted and translated for use in Ethiopia, and lack of professional training and resources to pay the license fees prohibit using the English versions even where parents have fluent English.

Families attending the two government child mental health clinics access these services after referral. The majority are poor and live in urban areas; most families living in remote areas have no access to a referral process and even if referred may not be able to travel to Addis Ababa. The families who go to private clinics have a relatively higher income.

Most children receiving an autism diagnosis at the government clinics were reported to be between 4 and 7 years old, more often male, and usually diagnosed with autism co-morbid with ID. Similarly, the private clinic informant indicated rarely seeing cognitively able children with autism. The clinicians reported that parents give a mix of biological (e.g. head injury, perinatal complications, medication during pregnancy, vaccinations or hereditary factors) and spiritual (e.g. punishment from God, curse, or devil's possession) explanations for their child's autism.

Centres for children with autism

The Joy Center was founded in 2002 by a mother of a child with autism after her child was rejected by many regular schools. Nehemiah Autism Center opened in 2011 after one of the founders experienced similar difficulties finding appropriate schooling for her child.

“...First they promise me to teach him but as soon as they came to know about his condition they told me to take him out. ... I used to pay three or four times the usual school fee but no school was willing to keep him”. (Centre1a)

At both centres parents pay a school fee depending on their income, with a limited number of free places available to families who cannot afford the fees. Both centres started with little support, but now receive some financial support from NGOs, businesses and the government. However, three out of four informants from both centres indicated that long term funding is a problem:

“Nobody wants to fund autism. Funders only support illnesses like HIV/AIDS. So lack of sustainable funds is a major challenge”. (Centre 2b)

Most children enrolled are nonverbal, and many have co-morbid conditions such as epilepsy. Both Joy and Nehemiah provide a mix of therapies and training promoting social and communication skills, daily living skills and academic skills. Both centres hold regular parent meetings and present short-term parent training programmes run by local staff and professionals from abroad. Both centres also engage in awareness raising activities including mass walks, fundraising events, conferences, interviews and documentary films. Informants from both centres indicated that these efforts have helped to improve knowledge about autism and to reduce stigma.

“...I appeared in the media with my child to show people that it is OK to have such a child. Then, people started to come. People started to look out for me.” (Center1a)

Recently, the founder of the Joy Center has started training teachers working in ten mainstream schools in the suburbs of Addis Ababa and five schools in Oromia region, to support mainstream schools in providing inclusive education for children with autism.

Mainstream schools with inclusive education programmes for children with autism

According to our informant from the governmental primary school Basilios, the school has one special needs classroom hosting 24 children with different developmental disorders including autism. The curriculum focuses on learning the alphabet, numbers, weaving, assembling things and personal hygiene.

Education at mainstream governmental schools is generally free (though registration, uniform and books may incur costs); Basilios school accepts special needs children based on parents' reports and information from local authorities. When required the school receives medical support from hospitals. The informant indicated the school has a constant turnover of special needs children, for various reasons. Some children drop

out because their parents have difficulty bringing them to school; when children are beyond the school's capacity they are sent to other special needs schools, e.g. to a school for deaf children.

Community-based rehabilitation organisations

*We identified two organisations engaged in community-based rehabilitation activities related to autism in Ethiopia: CBM (previously Christian Blind Mission) works to improve the quality of life of people with disabilities and has been active in Ethiopia for over 20 years; Cheshire Services Ethiopia, founded in 1962, provides orthopaedic and social rehabilitation services for children with disabilities. Community-based organisations serve as a bridge between mental health experts and the community and also work in rural areas. Following training by psychiatrists and psychiatric nurses, both organisations are involved in identifying and referring children with autism. They also provide community members with training on community-based rehabilitation interventions such as daily living and social skills, so that they can work with local families. However, **informants from both organisations conceded that their resources for autism-related work were limited.***

“...generally our impact is very small with regards to autism... recently what our people have started to do is when they suspect that the problem is autism they refer the child saying we don't have the capacity to intervene.” (CBR1)

[...]

*The situational analysis presented in this study provides insight into the current services for children with autism in Ethiopia. **Our results indicate there is lack of knowledge about autism in Ethiopia. The diagnostic and education provision is extremely limited. Most services are confined to the capital and have long waiting lists. Moreover, families face severe psychosocial and practical challenges in caring for their child with autism, including stigma and social exclusion.***

[...]

***Our study identified four types of autism service providers in Ethiopia: clinics; autism centres; schools with inclusive education programmes; and community-based rehabilitation organisations. Most of these service providers are located in Addis Ababa and inaccessible to the majority of the population living in rural areas. There is a great lack of autism awareness and stigma levels are high. Besides improving service provision there is a need for culturally and contextually appropriate autism instruments. The strategies outlined in this paper (see also Table 2) can help to address these gaps in future and may also inform service enhancement approaches in other low-income countries.** » Source: B. Tekola et al., Challenges and opportunities to improve autism services in low-income countries: lessons from a situational analysis in Ethiopia, 2016, p. 1-10: www.ncbi.nlm.nih.gov/pmc/articles/PMC5454792/pdf/S2054425116000170a.pdf.*

Dejene Tilahun, 25 septembre 2017:

« There is a severe shortage of services for children with autism in Ethiopia; access to services is further impeded by negative beliefs and stigmatising attitudes towards affected children and their families. To increase access to services, care provision is decentralised through task-shifted care by community health extension workers. This study aimed to examine the impact of a brief training (Health Education and Training; HEAT) for Ethiopian rural health extension workers and comprised three groups: (1) health extension

workers who completed a basic mental health training module (HEAT group, N = 104); (2) health extension workers who received enhanced training, comprising basic HEAT as well as video-based training on developmental disorders and a mental health pocket guide (HEAT+ group, N = 97); and (3) health extension workers untrained in mental health (N = 108). All participants completed a questionnaire assessing beliefs and social distance towards children with autism. **Both the HEAT and HEAT+ group showed fewer negative beliefs and decreased social distance towards children with autism compared to the untrained health extension worker group, with the HEAT+ group outperforming the HEAT group. However, HEAT+ trained health extension workers were less likely to have positive expectations about children with autism than untrained health extension workers. These findings have relevance for task-sharing and scale up of autism services in low-resource settings worldwide.** » Source: Dejene Tilahun et al., Ethiopian community health workers' beliefs and attitudes towards children with autism: Impact of a brief training intervention, 25 septembre 2017: <http://journals.sagepub.com/doi/abs/10.1177/1362361317730298>.

Dejene Tilahun, 27 avril 2016:

« In Ethiopia, as in many other low-income countries, there are limited services for children with developmental disorders and their caregivers [12]. Out of a population of over 90 million people, nearly half of whom are children, there are only two trained child psychiatrists and the available specialised child mental health clinics are limited to the capital city, Addis Ababa. In planning future intervention programmes for children with developmental disorders it is essential to better understand the perspective of the caregivers. The aim of the present study was to describe the experiences and challenges of caring for children with ASD and/or ID among caregivers, particularly in terms of examining stigma experienced by families, understanding the perceived causes of the illness, mapping out the interventions tried and coping strategies practiced as well as determining the unmet needs of caregivers. A good understanding of these factors is essential for designing and implementing future interventions for Ethiopia and other low resource settings to improve the lives of children with developmental disorders and their families.

[...]

Caregivers of children with ASD or ID in Ethiopia face many challenges, including high levels of stigma and a lack of appropriate provision for their child. Reported stigma was significantly stronger in caregivers who had sought help from traditional institutions or had supernatural explanations for their child's condition. The study has implications for policies to reduce stigma, increase awareness about the causes of developmental disorders and address the needs of caregivers of developmentally disabled children. Interventions to improve awareness about developmental disorders, to decrease stigma, and improve access to appropriate education and support for caregivers are warranted. » Source: Dejene Tilahun et al., Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey, 27 avril 2016, p. 2, 11: www.ncbi.nlm.nih.gov/pmc/articles/PMC4847244/pdf/12913_2016_Article_1383.pdf.

Devex, 6 novembre 2014:

« Ethiopia is a deeply religious nation, and people ascribe much of what happens in life to God's will. So when a child who displays behavioral or developmental differences is diagnosed with autism — assuming the family has access to such a diagnosis — it can

be equivalent to learning that a family or parent has been cursed by God for some sin they are assumed to have committed.

That perception, combined with a desperate lack of health services — particularly in rural areas — and limited accommodation for autistic children in schools, can leave parents feeling like they have no way out. Fathers of autistic children often abandon their wives to start over, and mothers often find themselves alone to balance an extremely demanding home life with the need to put food on the table.

And those few aid organizations that do provide services to Ethiopia's autistic children face a difficult paradox: Their students require highly individualized, focused attention and low staff-to-child ratios, while most donors want to see big beneficiary numbers before they agree to provide any financial support.

"I was shocked," Rahel Abayneh told Devex, recounting her realization that she was a parent of an autistic child as we drove through the construction-torn streets of the Ethiopian capital Addis Ababa, a bustling hub of African development and security coordination.

Abayneh noticed that her second child of three, a boy, displayed behavior consistent with depictions of autism she had seen in public service advertisements on TV. She spoke to a doctor, who confirmed the diagnosis.

"I cut off my hair," she said. "I didn't want to see anybody."

*In far too many cases, that's where the story ends. But for Abayneh, though, it was a beginning. After the initial shock wore off, she surveyed her options. **They were limited to one — one center for autistic children in a country of nearly 95 million people. The wait list at that center was 491 students long.***

*Instead of waiting indefinitely, Abayneh sought out other parents of autistic children. **She found five others in her village, and together they became the six founding partners of the Nehemia Autism Center.***

Now there are two centers for autistic children in Ethiopia.

Fighting stigma

In 2011, the six founding mothers together rented a house for 11,000 Ethiopian birr (about \$500) a month. The house was unfurnished except for a television. The six children played on mats while the mothers discussed their challenges and shared their experiences. It began as more of a space for mutual support than a formal behavioral and educational center.

An initial private donation allowed Nehemia's founders to undertake a more concerted fund-raising campaign. A dinner event garnered further support, and the group received a one-time donation of 200,000 birr from World Vision.

Today, the Nehemia Autism Center occupies a small compound not far from central Addis Ababa. It employs staff and volunteers to provide services to 40 autistic kids aged 2-12 at two students per teacher.

More than half the students come from low-income families and attend the center for free, Tewedros Getye, the Nehemia Autism Center's program manager, who holds a degree in psychology, told Devex in the center's sparse main office. Some of them travel 20 kilometers every day to get there and back, no small feat given the often poorly maintained and congested roads.

An estimated 600,000 Ethiopians are living with autism, he said.

*That estimate is actually somewhat lower than global autism rates would suggest, and the number for Ethiopia could be significantly higher, Getye noted. **A general lack of knowledge — even among Ethiopia's health professionals — about what autism is, the fact that data from rural areas is largely missing, and the sad reality that autistic children are often concealed from public view due to the stigma attached to mental disability in Ethiopia all combine to impede accurate reporting.***

Getye cited instances of autistic children in rural villages who have been locked away — even chained — indoors, or taken away for religious treatment instead of for medical diagnosis and mental health and behavioral care.

"So we don't hear about them," Getye said.

Families with autistic children also tend to move around a lot. Many Ethiopians rent their homes from landlords who share the same house are not always tolerant of autistic children living there. The center's program manager recounted the story of one mother of an autistic child who was forced to change houses eight times.

Getye showed Devex the classrooms, where students — most of them in pairs with intensely focused staff volunteers — were working on matching pictures with words, on art projects or on maintaining eye contact. The kind of familiarity with each of the students, their background, progress and struggles can only come from a lot of time and energy.

That close attention and low staff-to-student ratio is both vital to the quality of the Nehemia Center's services and an obstacle to its growth and sustainability, according to both Abayneh and Getye.

Funding challenge

The center, Abayneh explained, has so far relied on a precarious combination of self-funding and one-off donations from organizations and individuals. It does not serve enough students to qualify for sustained aid from big international donors.

She recounted a meeting she was able to secure — after much effort — with an official from the U.S. Agency for International Development's Ethiopia mission. When she requested financial support for Nehemia, the official asked her how many students were enrolled, and when she told him there were fewer than 50, he responded that they would need to serve at least 5,000 in order to receive funding from USAID.

"Can you imagine 5,000 students with autism?" Abayneh asked.

Getye noted that USAID advised Nehemia to form a network with other autism support centers in order to make their case as a more robust potential aid recipient. But, as Abayneh encountered when she first explored options for her son, **there is only one other autism center in the entire country, despite the fact that the need for those services is much, much higher.** For now, Nehemia's networking prospects remain slim.

"Although USAID does not have any autism specific programs in East Africa, it does not mean that we do not include persons with autism in our programming," Charlotte McClain-Nhlapo, USAID coordinator for disability and inclusive development, wrote in response to an inquiry from Devex. "The agency's approach is to support disability in its diversity. USAID disability policy requires programs to reach all persons with disabilities including persons with intellectual/developmental disabilities."

The Nehemia Autism Center serves students from ages 2-12. The goal is to work with them on behavior and communication skills so that the students can be accepted into the national education system's inclusive learning schools, where children with other learning disabilities are accommodated in special education programs.

But even in those inclusive programs, teachers and administrators are often unwilling to accept students with autism, due to the unique and demanding behavioral challenges they often pose.

Nehemia's waiting list is now 190 students long, and the center, will hold another fundraiser on Jan. 26 next year.

Getye said that if they are able to raise enough money to strengthen the center and secure its future, the next step will be to open others, including centers to serve students older than 12 who do not make it into the country's inclusive learning schools. They are also hoping to purchase their own vehicles to provide transportation for some of the center's more distant students.

Nehemia trains its own staff and suffers from a lack of available professionals, Getye — who is beginning a masters degree in developmental psychology — explained. But professional opportunities for psychologists are lacking in Ethiopia, so few regard the field as a viable career path in the country.

That is the case across many professions, Getye said, "except accounting." » Source: Devex, For aid to Ethiopia's autistic, the numbers don't add up, 6 novembre 2014: www.devex.com/news/for-aid-to-ethiopia-s-autistic-the-numbers-don-t-add-up-84732.

Spectrum, 13 décembre 2017:

« Many African children with autism are hidden away at home – sometimes chained up, almost always undiagnosed. Efforts to bring the condition into the open are only just beginning

The eight-year-old girl's head droops like a wilted flower as she sits slumped in a wooden chair in her mother's kitchen. Her wrists are swollen from the dingy white shoelace that binds them behind her back. The girl's mother, Aberu Demas, weeps as she unties her child.

Earlier that day, Demas had arrived unannounced at **the Joy Centre for Autism in Addis Ababa, Ethiopia**. A single mother living on the outskirts of town, Demas didn't know what autism was or if her daughter, Fikirte, had it, but she was desperate for help. Fikirte could not speak or feed herself, and Demas had no family or friends to look after the girl when she needed to work or run errands.

It had taken Demas several hours to get to the centre by bus. **Because she didn't have an appointment, she had to wait about three hours until Zemi Yenus, the centre's founder, could see her. The centre was at maximum capacity, so when they finally met, Yenus told Demas she could only put Fikirte on the waiting list.** Demas began to cry, and confessed that she had left her daughter tied up and alone at home.

[...]

In the 10 years since then, Yenus says she has encountered hundreds of children locked away or tied up. Like Demas, many parents resort to these extreme measures because they have no other choice. Others hide their children, fearing stigma, which is pervasive in many parts of Africa and casts any disability as the sign of a curse.

Many children with autism across Africa stay out of sight for another reason: Few clinicians have the skills or experience to identify the condition, if they are even aware that it exists. In all of Ethiopia, with its nearly 100 million inhabitants, there are about 60 psychiatrists, and only one who specialises in child psychiatry. Only two public clinics provide mental health services, and both are located in Addis Ababa, where a scant 15 per cent of the population lives. In 2015, there were about 50 child and adolescent psychiatrists for the more than one billion inhabitants in all of Africa.

Yenus, whose adult son was diagnosed with autism in England, is a beautician by training, but she has made informal diagnoses for many children in her care, including Fikirte. She founded the Joy Centre, the first of its kind, in 2002. She and other parents of children with autism have spent the past 15 years trying to raise awareness of autism in Africa. With little guidance available to them, they have also resorted to creating their own treatments to help children on the spectrum learn to communicate and master basic skills. None of these homegrown therapies have been validated, but these families simply cannot afford to wait. "I'm not saying we don't need that, but that's not what we need right now," Yenus says. "What I need is to free those children."

The help these families need has been slow to come, but researchers are beginning to pick up the pace. Some are tailoring diagnostic methods and treatments to African populations and devising ways to reach rural communities faster. In September, the International Society for Autism Research held a meeting in South Africa – the first of its kind on the continent – to highlight research there. Hundreds of researchers, therapists and family members met for the first time at the three-day event. "My hope is that this will not be a one-off event, but the start of an ongoing process of building networks and connections within Africa," says conference co-organiser Petrus de Vries, professor of child and adolescent psychiatry at the University of Cape Town. Even the wealthiest parts of Africa have a long road ahead, however. "What we have here [in Cape Town] may probably be as good as it gets in Africa," De Vries says. "And yet our services for people with autism are almost non-existent."

Missing children

British psychiatrist Victor Lotter published some of the first descriptions of people with autism in Africa in a 1978 paper. He screened more than 1,300 children at institutions for people with intellectual disability in six African countries; he found 9 children who qualified for a diagnosis and 30 others with features of autism. Lotter reported that, as with children he had studied in the United Kingdom, autism in Africa appeared more often in boys than in girls. But compared with their British peers, African children with the condition were less likely to show repetitive and stereotyped behaviours.

It was a promising start. But “since then, not much has happened”, De Vries says. Last year, he and his colleagues laid out all of the peer-reviewed studies ever published about autism in the 46 countries of sub-Saharan Africa. They found only 53 analyses, from just nine countries. About 80 per cent of the studies focused on South Africa and Nigeria, two of the wealthiest countries on the continent.

Their analysis did not support Lotter’s claim: The studies found that autism is fundamentally no different in Africa than it is anywhere else in the world. Researchers in Kenya had reached the same conclusion after a similar review the year before. “Personally, I have not come across any indication that there’s anything different about the presentation [of autism in Africa],” says Amina Abubakar, a research fellow at the Kenya Medical Research Institute in Kilifi, who led the Kenyan analysis.

The biggest differences are who gets diagnosed and when. Children with autism in Africa tend to be diagnosed around age eight, about four years later, on average, than their American counterparts. More than half of African children with autism are also diagnosed with intellectual disability, compared with about one-third of American children on the spectrum. This suggests that only the most severely affected children are being picked up: Those who are diagnosed often speak few or no words and require substantial help with everyday tasks such as eating or going to the bathroom. By contrast, in the US, the largest diagnostic increases over the past few decades have been on the milder end of the spectrum.

These findings seem to be in line with the belief that autism is more severe in African children than in children elsewhere. However, the studies that offered up this idea were small – the largest included only 75 participants. And they focused predominantly on children brought to neurology or psychiatry clinics. “The children who end up there are almost by definition the more severely affected kids,” De Vries says.

[...]

Raising awareness

Most Africans are largely unaware of autism, despite its prevalence. In surveys conducted in Kenya, Nigeria, Tanzania and Ethiopia, healthcare workers and families frequently attribute its features to a curse (brought on by a taboo act such as cheating on a spouse) or to being possessed by an evil spirit.

[...]

In April 2002, Yenus used her savings from her work in the beauty industry to rent a small house in Addis Ababa, where she opened the Joy Centre for Autism. She started with just four students, including her son. As demand grew, she admitted more children and hired staff. Within a year and a half, the school had outgrown its original location

and moved to its current site: A house tucked away behind a tall green fence in a quiet residential neighbourhood in the southwestern part of the city. As of September, the school has 80 students and 53 staff.

*Yenus is a well-known figure in Ethiopia and recognised elsewhere in Africa. She appears regularly on TV and radio. "I think you can credit her with being the main person responsible for raising autism awareness," says Rosa Hoekstra, lecturer in psychology at Kings College London. "She's really a very powerful, inspiring figure." But Yenus remains dissatisfied. **In Ethiopia, as in other African countries, there are no laws to guarantee children with autism or other special needs the right to public education. To date, there are only two schools in Addis Ababa that specialise in autism – the Joy Centre and the Nehemiah Centre, opened by a group of families with children on the spectrum in 2011. Together, the two schools have more than 500 children on waiting lists.***

The schools provide some therapies that are loosely derived from evidence-based approaches, such as applied behavioural analysis, but other offerings are not. At the Joy Centre, for example, children receive occupational therapy, music therapy and art lessons, as well as a speech therapy called "Abugida phonetics", which Yenus developed for her son. It involves teaching children how to speak by breaking words down into simple syllables and showing them pictures of mouths making each sound. The idea is that the children learn to mimic those movements.

Yenus credits this technique for her son's ability to say simple phrases. But experts say it's unclear whether these homemade treatments help. "I think I understand why people are driven to generating their own [treatments] when the system doesn't provide it," De Vries says. But at the same time, he says, few people try to use proven therapies or collect the types of data needed to validate their homegrown treatments.

Some African researchers, including Waganesh Zeleke, are hoping to collect this data. Zeleke worked as a staff psychologist at the Joy Centre before earning her doctorate in the US, and she returns each year to try to evaluate the treatments offered there and at the Nehemiah Centre. She has found that most of the staff at these schools lack any knowledge of autism or experience providing autism treatments prior to being hired. "Most of their knowledge comes out of self-learning," says Zeleke, now assistant professor of clinical mental health counselling at Duquesne University in Pittsburgh. "It's all informal, intuition-based."

Both centres also lack documentation about what the treatments entail or formal assessments of children's behaviours before and after receiving the therapies. Without this information, Zeleke says, it's impossible to tell whether any of the treatments are effective. She's working with staff at both schools to teach them how to assess and measure their methods rigorously.

Cultural lessons

As the meeting in September made clear, researchers in Africa are primarily focused on long-term scientific goals – but recognise families' acute need for help. "It's pointless to do neuroscience if people don't get access to diagnosis and treatment," De Vries says. "It's pointless

to do a prevalence study if all it does is to say how big our problem is, and we have no solutions for the problem.”

*He and others have started to **collaborate with local communities to make more immediate gains. Hoekstra, for example, has partnered with Ethiopia’s Federal Ministry of Health to educate its nearly 40,000 health extension workers about autism. These workers travel to rural areas to provide primary health services, but they have historically received no training in mental health or developmental conditions. “What we are trying to do is to go from a close-to-non-existent services situation to a situation where we can actually start offering families some handles or supports,” Hoekstra says. Her results so far show that the training reduces stigma and misconceptions about autism among the workers. The team is evaluating whether it also results in more children being diagnosed with autism.***

Other projects sidestep the lack of trained autism experts and focus on helping parents directly – teaching them to provide evidence-based therapies to their children rather than relying on trips to doctors or other experts. For instance, Lauren Franz at Duke University in Durham, North Carolina, is adapting a therapy called the Early Start Denver Model for use in South Africa. The therapy uses play routines to help children with autism learn skills such as speaking and socialising. Another team, led by Nola Chambers at the University of Cape Town, is adapting an online tool called the Autism Navigator, which uses videos to teach parents strategies for helping their children.

These researchers are incorporating what they are learning about African views and experiences. Because literacy in Ethiopia is low, Hoekstra’s team has developed oral training sessions. They also no longer tell Ethiopians that autism is highly genetic. “You could cause a very strong genetic taint on the family,” Hoekstra says, essentially “replacing one stigma with another”. One major lesson is the importance of working with local beliefs – and that’s true anywhere in the world. “The fact that many African people believe that autism is caused by a curse or spirits, I don’t think that’s culturally any more unusual than some people saying that autism is caused by vaccinations or by particular diets, or by particular heavy metals,” De Vries says. “They’re all cultural beliefs, in a way.”

Yenus says the programmes seem to work best when experts solicit the opinions of parents like her – and wishes they would do so more often. “There should be no research about us without us,” she says. “Even though we are not psychiatrists, we are not doctors, we are doing the work. We have the knowledge as well.”

Yenus is using that knowledge to expand her centre’s reach. She has begun training teachers in 15 mainstream schools in and around Addis Ababa to help them provide inclusive education for children with autism. And last year, the Ethiopian government gave her permission to build another school for children with autism, on the outskirts of Addis Ababa. The new school, which Yenus calls her “Autism Centre of Excellence”, is set to accommodate roughly 400 children. She is still raising money but helped to lay the building’s cornerstone in March. She says the facility will be equipped with dedicated treatment rooms, as well as long-term living quarters for children in the direst need of help. » Source: Spectrum, Why autism remains hidden in Africa, 12 décembre 2017: www.spectrumnews.org/features/deep-dive/autism-remains-hidden-africa/.

Spectrum, 21 novembre 2017:

«Hidden at home:

One important barrier is stigma. Many caregivers of children with autism in Ethiopia say they are worried about other people finding out about their child's condition. Some parents feel the need to keep their child hidden at home.

Many caregivers provide spiritual explanations for their child's condition — for example, attributing autism or developmental delays to a curse on the family or a punishment from God. Spiritual explanations for autism are by no means unique to Ethiopia, but acknowledging them is key to understanding the treatment parents seek.

Perhaps more unique to a low-income setting such as Ethiopia are the severe unmet needs of families. The country has a population of 99 million people, of which 50 percent are children. But there are only two state-funded child mental health clinics where a formal diagnosis can be made. Both clinics are in Addis Ababa — inaccessible to most Ethiopians, who reside in dispersed rural communities⁶. The few autism schools that exist each have long waiting lists, meaning that most children with autism are without appropriate education. The vast majority of children with autism remain undiagnosed, with no access to intervention or appropriate education.

In 2003, the Ethiopian government launched the Health Extension Program to address the severe shortage in health services. Through this program, more than 40,000 community health workers received basic health training and were subsequently deployed throughout the country. The program has had some notable successes, including a marked increase in childhood vaccination rates and an increased uptake in the use of bed nets to prevent malaria.

But an evaluation of the program highlighted some gaps in training. Most importantly in the context of our work, the initial program did not include any training on mental health and developmental conditions.

At that time, we developed materials for the Health and Education Training (HEAT) program, which the government launched in 2011. Upon completion of the one-year program, community health workers gain a more senior title and a small pay raise.

The program provides the workers with two weeks of training in mental health, including some limited coverage of developmental conditions. In 2012, our team surveyed more than 100 workers from the first enrolled group. The workers were generally positive about the training but said they still felt ill-equipped to address developmental conditions⁷.

In response to those results, we produced five short videos illustrating how to identify developmental conditions and how to provide support to families. We also produced a mental health 'pocket guide' — an introduction to mental health, including sections dedicated to developmental conditions. Workers who completed the program, and particularly those who received the videos and pocket guide, have fewer negative beliefs about children with autism than workers who did not receive the training. They also are less likely to want to maintain a social distance from families with a child who has autism.

These findings suggest that brief training in mental health and developmental conditions has a positive effect on beliefs and attitudes toward children with autism and their families. The

HEAT study materials are open educational resources and free to be used or adapted for use elsewhere. » Source: Spectrum, How to address autism in Ethiopia and other low-income nations, 21 novembre 2017: www.spectrumnews.org/opinion/viewpoint/address-autism-ethiopia-low-income-nations/.

Waganesh A. Zeleke et al., 7 septembre 2017:

« *Autism has begun to attract both media and research attention across many developing countries. In Ethiopia, where there is limited attention to diagnostic processes and therapeutic interventions for children, the treatment for autism is widely misunderstood. This study examines the available behavioral and educational interventions currently implemented for children with autism in the Ethiopian capital of Addis Ababa, which is considered a progressive area of treatment in Africa. Survey data were collected from 80 helping professionals that included teachers, special needs educators, counselors, therapeutic care workers, and social workers. Results indicated that children with autism spectrum disorders (ASDs) who were enrolled in intervention programs received primarily (daily living) skill-based interventions delivered on an ad hoc basis rather than structured social, behavioral, and educational interventions. The children were underserved due to a dearth of available professionals, low number of training facilities, and inadequate resources for family support. Results also highlighted the need for preservice and in-service educators' training as well as the need to document and evaluate the types of strategies that are used in schools and agencies for children with ASDs in Ethiopia.* » Source: Waganesh A. Zeleke et al., Autism service providers report: Behavioral and educational interventions used in Ethiopia, 7 septembre 2017: www.tandfonline.com/doi/full/10.1080/21683603.2016.1278568?scroll=top&needAccess=true.