

Ethiopia: educating everyone about autism

Ethiopia might have as many as 500 000 children on the autism spectrum. Meeting their many needs is a huge challenge. But educating health extension workers, parents, teachers, medical professionals, and the general public, as well as the children themselves, promises a brighter future. Adrian Burton reports.

“Education is the most powerful weapon which you can use to change the world” (Nelson Mandela, Johannesburg, July 16, 2003). Mandela’s weapon is currently being wielded in Ethiopia in attempts to improve the lives of autistic children and, thereby, those of their families. It’s been drawn in a multipronged attack on the lack of awareness in the country regarding this neurodevelopmental condition (unfortunately even among health professionals), the stigma surrounding it, the enormous rate of underdiagnosis, the lack of specialists who can recommend appropriate treatment, support, and care (eg, speech therapy, support with social interactions and communication, support with behaviour and learning, and care to promote physical and mental health), and the frighteningly small number of schools that can teach these children with special needs. It’s a battle against tough odds, but there are some very determined warriors on the front line.

No one really knows how many Ethiopian children are affected by an autism spectrum disorder, but with approximately 44 million Ethiopians younger than 14 years, and no reason to think the burden should be smaller than in high-income countries, the commonly cited figure of 500 000 might not be unrealistic. Ask their parents what their most pressing unmet needs are, and nearly half will include medical care provided by professionals in their list. Part of the problem has been a historic lack of awareness about autism among the country’s health-care community. They themselves cite that it was only in 2003, with the start of postgraduate training in psychiatry at Addis Ababa University,

that the condition began to become better known. Since then, the country has been busy increasing its number of psychiatrists, under whose remit autism falls in Ethiopia: there might now be 60 professionals at work. But being aware of a disorder is one thing, and being able to accurately diagnose it is another: even now, Ethiopia has only two specialist child psychiatrists. There is a growing number of Master’s degree-level psychologists in the country, but none are trained in child mental health or neurodevelopmental conditions. And although there have been more than 460 psychiatric nurses helping to run 57 small psychiatric units across the country, none were trained in such conditions either, nor is it known how many still work in the sector. Furthermore, specialist medical services (still with no culturally adapted tool available to help diagnose autism) are largely restricted to Addis Ababa, even though 80% of the country’s population is rural. The upshot is that, for most autistic children, just getting a diagnosis can be impossible.

Certainly, the national government is fighting back against the country’s burden of mental illness (under which autism falls in Ethiopia)—which outstrips HIV/AIDS in terms of the number of people affected—by integrating mental health services into its existing primary care structure via its National Mental Health Strategy. Since 2012, moves have been made to educate primary health-care workers regarding mental health disorders. But the Strategy makes no specific mention of neurodevelopmental disorders. “Mental health research in Ethiopia has, until very recently, focused on common and severe mental disorders; there has been almost none on child mental

health problems”, explains Fikirte Girma, assistant professor of psychiatry (Addis Ababa University, Addis Ababa, Ethiopia). “Once integration of mental health into the primary health-care structure becomes successful, users of the service are expected to be from all age groups, including children. Our experience from the two child and adolescent psychiatric clinics in the country shows that the second most common cases (next to epilepsy, a condition also treated by psychiatrists in Ethiopia) are neurodevelopmental disorders, including autism spectrum disorders. This on its own will force policy makers to prioritise the condition.”

The pressing need for health workers able to identify autism and other neurodevelopmental disorders has been the focus of the Health Education and Training+ (HEAT+) project, launched in 2012. Since 2010, the Ethiopian Federal Ministries of Health and Education and the Open University (UK) have been developing a curriculum to upgrade the training of Ethiopia’s army of 40 000 health extension workers. Mostly women, these workers (about two for every 5000 people in each district) receive basic training to provide health education (hygiene, contraception, etc) to, and identify health problems in, the communities they serve. “This upgrade provided these workers with mental health training for the first time: how to detect mental health and child development problems, how to support people with these conditions, and how to raise mental health awareness in the community”, explains Rosa Hoekstra, now Lecturer in Psychology at King’s College, London (UK). “But feedback indicated there was interest for further



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For more on the worldwide prevalence of autism see *Autism Research* 2012; 5: 160–79

For more on the unmet needs of caregivers of Ethiopian autistic children see *BMC Health Services Research* 2016; 16: 152

For more on the challenges to improving autism services in Ethiopia see *Global Mental Health* 2016; 3: e21

For more on Ethiopia’s National Mental Health Strategy see <http://www.centreforglobalmentalhealth.org/sites/www.centreforglobalmentalhealth.org/files/uploads/documents/ETHIOP-2.pdf>

For the **HEAT+ videos** visit <http://www.open.edu/openlearnworks/mod/oucontent/view.php?id=51898>

For more on the **mhGAP programme** see http://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/

For more on the **situation of special needs education in Ethiopia** see <http://www.cmpethiopia.org/content/download/2267/9609/file/ESDP%20V%20FINAL.pdf>

For more on the **Nia Foundation and Joy Centre** see http://www.ethioautism.org/Joy/Autism_in_Ethiopia.html

For more on the **ReachAnother Foundation's schools project** see <http://reachanother.org/autism-schools/>

training in child mental health and developmental disorders, so the HEAT+ project team, consisting of academics and psychiatrists from Ethiopia and the UK, developed a mental health pocket guide and filmed five short training scenarios modelling health workers interviewing mothers of children with autism or intellectual disability. These scenarios help teach skills in early detection, supportive counselling, and problem solving. The response has been very positive, and these materials are now reportedly used more widely, including in the training of nurses and primary health-care staff."

But given the resources available, what can parents actually do with a diagnosis if they get one? "As part of the WHO mhGAP programme, we are now piloting a package designed to educate parents of children with autism and other developmental disorders regarding misbeliefs about these conditions", says Chiara Servili (Technical Officer, Focal Point for Child and Adolescent Mental Health at WHO). "[The package also] addresses parental guilt, strengthens caregiver skills for engaging children and interacting through play, promotes communication, and [shows how to] deal with challenging behaviour. Delivered by non-mental health specialists via three home visits and eight sessions to groups of about six parents, using appropriate materials to help them remember the most important messages, we think this could help families understand and deal better with the challenges that autism and other developmental disorders bring. We hope to know the results soon." "The plan would then be to scale this up across Ethiopia" adds Andy Shih, Senior Vice President of Public Health and Inclusion with the New York-based NGO Autism Speaks, which helped fund and promote the package.

A full three quarters of parents, however, cite the provision of appropriate education for their children among their most pressing unmet

needs. Although a 2005 government report suggested that there were 285 schools across the country with special needs classes (their facilities, it was admitted, ranged from "very poor" to "satisfactory" and none were autism-specific), a recent Federal Ministry of Education document suggests that only 4% of children in Ethiopia with special needs of any kind receive primary schooling. Ambitious plans are being developed to strengthen special needs provision in state schools by training personnel to support teachers; however, the latest government document again makes no explicit mention of autism. Two NGOs have, however, established specialised schools. The Nia Foundation's Joy Centre in Addis Ababa, founded in 2003 by Zemi Yenus (a mother who could find no school willing to take her own autistic son) was the first. It has since expanded to provide for the educational needs of around 80 children. But it's not just children Yenus wants to educate, it's everyone. She campaigns tirelessly on the radio, in the press, and through speaking events to raise public awareness about autism to help lift the stigma surrounding the disorder in Ethiopia (where it is often believed to be caused by curses or sins), and to "pull the attention of decision makers into [adopting] relevant and appropriate policy and strategic measures", she explains. Furthermore, the Foundation has developed a centre for the professional diagnosis and assessment of autism, and has become an important source of counselling. "We now have a record of more than 1000 children from all parts of the country diagnosed on the autism spectrum and with other developmental disorders", says Yenus, "[and have provided] counselling for more than 3500 family members, [all] the direct result of our efforts in awareness creation and education on the issues."

The ReachAnother Foundation's schools also provides autism-specific education, now reaching beyond the

capital. The Nehemiah Autism Center (founded in 2010) in Addis Ababa now has roughly 60 children, the Bethel Adama Center for Autism (founded in 2015) in Adama has 20 and is growing, and the Bright Autism Center (founded in May 2016) in Hawassa has taken its first handful of children.

"Nehemiah Autism Centre educates and trains autistic children and prepares them for inclusive education [ie, to be able to attend normal schools]", explains Getaneh Abera, educational director and senior specialist in autism at the Center. "Our ultimate goal is to enable them to live without support or with minimal support, and be productive citizens according to their ability. We have developed an appropriate and comprehensive curriculum with evidence-based assessment mechanisms [that includes] self-help, communication and speech, sensory integration, physical and cognitive skills. Our teachers have psychology and teaching backgrounds, but they get continuous training in teaching autistic children."

With colleagues in the Hawassa University Psychology Department and University of Dilla Special Education Department, "our centres have also produced a series of videos to educate parents who might then set up self-help groups, and to train our own school staff", says Marinus Koning, Founder of ReachAnother (Bend, OR, USA). "But we also want to help educate trainee teachers, psychologists, and medical professionals about autism. We are working with Hawassa University so that their students visit us to get practical experience of our children's problems."

"Education and training, developed with and by Ethiopians, for Ethiopia, is key to so much here", concludes Hoekstra, "and there are so many people willing to learn and to teach about autism in the country. Little by little I'm sure Mandela's words can be proved right again."

Adrian Burton