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Fighting autism spectrum disorder: A mother's story

In Summary

When Grace Lyimo learnt about plans to kill her autistic son, she embarked on a mission to educate society on the little known disorder.



Children who are labelled as cursed, possessed and bewitched by their communities are put at risk because of a disorder unknown to many.

Misinformation about autism in Tanzania is rampant, with families opting for witchdoctors and faith healers over medical science, say local advocates.

Grace Lyimo, executive director of Connects Autism Tanzania, has spent the past two decades attempting to change the cultural narrative around Autism Spectrum Disorder — a range of neurodevelopmental disorders that manifest during childhood.

Children with autism struggle to express themselves physically and verbally. The disorder affects communication abilities, social interaction and includes repetitive and rigid behaviours.

Lyimo says there is a lack of awareness about autism in Tanzania, despite

affecting approximately one per cent of the global population.

“The majority of people, they still think it’s a curse,” she says. “Some people think you have to pray.”

Lyimo’s son Erick, 23, was diagnosed with autism at the age of three in Arusha. “Before that, I thought there was something wrong, but I didn’t know what,” she says.

Lyimo says community members assumed Erick was bewitched and wanted to keep him separated from other children, even preventing him from taking the local school bus.

“He was beaten up, he was abused, they called him dumb,” Lyimo says. “I lost all my friends. They thought the house was cursed.”

Raising awareness

In 2010, Lyimo’s family faced a turning point when a group of local boys planned to kill Erick. She says a neighbour’s warning saved his life.

Lyimo decided to host town meetings to tell people about autism so that they would better understand the disorder — a move that ultimately allowed Erick to become integrated into the wider community.

“We went house to house, shop to shop, to explain what autism looks like,” she says. “He was no longer a victim there.”

Lyimo continues to educate people about autism through her advocacy group Connects Autism Tanzania, based in Moshi. But the difficulties Erick has faced are all too common for other children, she says.

Lyimo adds that she has encountered extreme cases where children with autism are left chained indoors, isolated from their families.

“Early intervention matters a lot, they should be in the school, in the community.”

Dr Karim Manji, a pediatrician based in Dar es Salaam, agrees that early intervention is essential.

Once a week he holds a training seminar for families to educate them about ways to improve their children’s communication skills and social interaction.

Manji’s clinic has more than 50 patients with autism, and though he generally operates a private practice, Manji offers autism services for free.

“There are many children not identified,” he says. “It’s probably just the tip of the iceberg.”

There aren't reliable statistics on the number of autistic children in Tanzania, he says. U.S. statistics suggest that one in 88 children at the age of eight will fall on the autism disorder spectrum. Boys are also four times more likely to have the disorder compared to girls.

Manji says clinics and centres have collectively identified more than 400 children with autism in six Tanzanian regions. But he assumes there are countless more children across the country.

"People should consider all the children who can't communicate, or speak, they should be assessed," he says.

He echoes Lyimo's concerns about the association between witchcraft and the disorder.

Need for early diagnosis

"People think the child needs to go to spiritual healing," he says, adding that this belief crosses all religious denominations.

He adds that while there are several government-run schools for children with special needs, standards at the schools vary greatly and not all are equipped to handle autistic students.

"You would think these children are worse than prisoners," he says, adding that classrooms offer little stimulation. "They're just dumped there."

Families often can't afford to send children to private schools, which can cost around Sh4 million per year, Manji says.

He adds that while access to services is improving, it's not enough. Early diagnosis needs to be made a priority, he says.

"The brain is still malleable," he says. "Once a child grows up with the same behaviours fixed in his head, it's difficult to change."

He says both parents need to be involved in a child's development to ensure the best outcomes.

"These are special children," he says, adding that he urges parents to look at their children as individuals.

One of the barriers to diagnosing autism is that there isn't a formal test doctors can use specifically designed for Tanzania. For the past two years, Manji has been working with a team from the University of Georgia to change this. The test would include interviews with a child's parents as well as observational assessments to make a more informed diagnosis.

“Even among pediatricians and general physicians, they don’t know autism,” Manji says.

Tanzania’s future doctors aren’t exposed to the disorder in medical school, he adds, which creates a gap in knowledge on the front line of health care. Manji trains medical residents about autism but says there isn’t a formal recognition of the disorder in the curriculum.

Kerri Elliott, director of programmes at Connects Autism Tanzania, says early intervention involves some form of speech therapy, occupational therapy, physical therapy and behaviour intervention therapy.

But there aren’t enough therapists who specialise in these treatments, leaving families without options, she adds.

“We recently went to one district and did a stigma study, and a lot of families don’t know where to go and are scared to ask,” she says. “There are lot of families that have ended up taking their children to witchdoctors.”

Treated like an animal

“There was one little boy in Arusha who was cemented into a room ... and given food like an animal. In a lot of those cases, neighbours will report it and they will try to help in some instances.”

She adds that autistic children are sometimes isolated because parents are confused and scared, or alternatively it’s an attempt to keep children safe.

“There are some families where children have been killed,” she says.

“One family had three children with autism and ... they had a local shop. People stopped shopping there because they saw the children there. The family ended up having to relocate the shop and the mother and father had to separate to survive financially.”

She says there are complex factors preventing children from accessing services. “There are very few services for them to even go to,” she says.

Brenda Shuma runs the Gabriella Rehabilitation Centre in Moshi, which offers a class for autistic children.

“Most of them are unable to fit in normal schools,” she says. “Most of them are left out.”

Shuma, who is an occupational therapist, hopes to see more funding for vocational programmes, where autistic adults can learn trades and skills. Her centre also offers training programmes for caregivers who may want to learn more about the disorder.

Shuma says the stigma around autism is slowly decreasing as people become more aware of the disorder.

“The community has a lot of misinformation about them,” she says. “But they have a lot of potential.”

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<http://www.thecitizen.co.tz/magazine/soundliving/Fighting-autism-spectrum-disorder--A-mother-s-story/-/1843780/2852060/-/ejfi8u/-/index.html>