

BEYOND THE SILENCE: RAISING A CHILD WITH AUTISM

By Sarah Nakasenge

Autism is one of those conditions that many people struggle to relate to and it is often difficult to detect in a child's early development. In many families, the realisation that something may be different comes only when a child is about two-and-a-half years old. By then, parents may have noticed delayed speech, limited eye contact or repetitive behaviour, but lack the knowledge to understand what these signs mean or where to seek help.

It is against this backdrop of uncertainty and delayed recognition that April was chosen to raise awareness on autism. World Autism Awareness Day is marked on April 2 to call for greater understanding, acceptance and inclusion of people living with autism and their families. In Uganda, awareness is growing through conversations in the media, schools and health facilities. Even so, progress remains slow and many families continue to navigate diagnosis, stigma and limited support largely on their own.

UNDERSTANDING AUTISM

Autism is a neurodevelopmental condition characterised by two key areas, according to Dr Caroline Nerima, a developmental paediatrician and paediatric neurodisability specialist at Nsambya Hospital. These areas are persistent deficits in social communication and interaction, as well as restricted or repetitive patterns of behaviour, interests or activities.

"To meet the diagnostic criteria, a child must show all features under social communication and interaction and at least some features under restricted and repetitive behaviour," Dr Nerima explains.

Some children with autism may prefer to be alone, have difficulty maintaining conversations or show limited use of gestures such as pointing. Others may not maintain eye contact or respond to social cues such as smiling back. Sensory sensitivities are common, including discomfort with loud sounds. Repetitive behaviours may include playing with the same object

repeatedly or fixating on items such as sticks, sand or leaves.

Autism is classified according to the level of support a child requires, Dr Nerima explains.

At level one, a child needs minimal support and may mainly require help initiating social interactions.

At level two, the child requires substantial support as repetitive behaviours and communication challenges interfere with daily functioning.

At level three, the child requires very substantial support due to severe challenges in social communication and behaviour, often needing constant assistance.

Early intervention, Dr Nerima emphasises, can significantly improve outcomes. When children receive consistent support between the ages of three and five, they can make remarkable progress and sometimes move from higher to lower support needs over time.

Globally, autism is diagnosed more frequently in boys than in girls at a ratio of about four to one. However,



Dr Caroline Nerima

girls are often under-diagnosed because their symptoms may be subtler and emerge later, particularly in social situations where they may struggle silently.



Teachers and children of Teens and Tots Neuro Development Centre and Integrated School marching to mark World Autism Day

IN NUMBERS

- The Uganda Bureau of Statistics (2014 National Population and Housing Census) estimated autism prevalence at 70 per 10,000 people.
- More recent analyses by organisations such as Save the Children and Autism Uganda suggest this has risen to 88 per 10,000, attributed to population growth and increased awareness.

CULTURE, STIGMA AND PERCEPTION

Autism is understood differently across societies. Sarah Kisitu Kasule, a special needs education specialist, parent and proprietor of a school for children with autism, explains that cultural interpretation shapes how families respond.

"In some communities, autism is associated with shame, spiritual causes or poor parenting," she

- The central region has the highest estimated number of individuals with autism, followed by the eastern, western, and northern regions.
- The national estimate of people living with autism is approximately 388,000.
- Boys are more likely to be diagnosed with autism than girls.
- Research indicates advanced maternal age as a potential risk factor: Mothers aged 30-35 face a higher risk.
- Mothers aged 40 and above face an even greater likelihood.

says. "In others, there is growing acceptance once people understand the condition."

This is supported by practitioners at Teens and Tots Neuro Development Centre and Integrated School, who note that community attitudes vary widely depending on awareness and

Continued on page 24

EARLY DIAGNOSIS, INTERVENTION CAN IMPROVE OUTCOMES

From page 23

exposure to accurate information.

Studies in Uganda show that autism is often interpreted through cultural or spiritual lenses, with some families initially seeking help from religious or traditional healers. Health experts report that stigma remains deeply rooted, with autism sometimes viewed as an embarrassment or supernatural affliction.

“All these perspectives intersect and shape how people with autism are treated in society,” Kisitu says.

PREVALENCE AND POSSIBLE CAUSES

Kisitu notes that genetic factors, poor maternal nutrition, lack of antenatal care, birth complications such as infections or prolonged labour and environmental factors after birth may contribute. However, despite extensive research, no single factor has been identified as the cause.

Although what is clear is that early diagnosis and intervention can significantly improve outcomes for children on the autism spectrum.

THE COST OF LATE DIAGNOSIS

In Uganda, autism diagnosis often happens after the optimal window for early intervention. According to the World Health Organisation, intervention in the first three years of life significantly improves developmental outcomes.

A United Nations Children’s Fund and Ministry of Health report shows that most Ugandan children with developmental disorders are identified late due to limited services and low awareness. Similar trends are observed across sub-Saharan Africa where shortages of specialists



Sarah Kasule (fourth-right) and some of the members of the consortium during the celebration of the world Autism Day at Kati Kati Grounds

and persistent stigma remain major barriers. Delayed diagnosis limits access to behavioural and communication therapies which are most effective when started early.

THE IMPACT OF EARLY INTERVENTION

Despite challenges, progress is possible. Kisitu’s son was diagnosed with severe autism at the age of two. Through early and consistent intervention, he gradually improved.

“Today I can move with him in public. He communicates using a few words and gestures,” she says.

Margaret Hope Serugyendo from Wakiso district shares a similar journey.

Drawing on techniques she had observed in Kenya, her son Joshua learned to attend church, accompany his sister to school and master toilet use by the age of seven.

“One day he started sounding numbers,” she recalls. “We counted together. I will never forget that moment.”

These stories show that consistent intervention works even in low-resource settings.

LIVING AFTER DIAGNOSIS

Dr Nerima emphasises that while autism has no cure, structured support and patience can result in significant improvement.

“See the child before the diagnosis. The child should not be overshadowed by the condition,” she advises. Routine and predictability are essential. Sudden changes can distress autistic children, so new experiences should be introduced gradually.

Parents are cautioned against unverified treatments that exploit desperation. Support groups, counselling and caregiver education are vital. Caring for a child with autism can be emotionally and financially demanding and caregiver burnout is common.

Interventions such as play therapy, music therapy, sensory activities, physical exercise and social skills training are beneficial.

Dr Nerima also highlights pet therapy, noting improved engagement in children who interact with animals.

Some children may have nutritional

deficiencies due to restricted diets. Supplements may help, but only under medical supervision. Dietary adjustments may also support behaviour management.

Most importantly, children with autism should not be hidden or isolated. Inclusion in everyday life helps social development.

A SYSTEM UNDER PRESSURE

According to Sarah Bugoosi Kibooli, Commissioner for Special Needs and Inclusive Education at the Ministry of Education and Sports, special needs schools are increasing, particularly in central Uganda. Inclusive education policies exist, but access remains unequal.

A UNICEF report estimated that only about 2% of children with autism were enrolled in school due to high costs, limited personnel and low awareness. Services remain concentrated in urban areas while rural communities are underserved.

The Ministry acknowledges progress but cites limited funding, inadequate teaching staff and insufficient learning materials as key barriers. Increased investment in inclusive education and teacher training remains critical.

LOOKING AHEAD

Experts call for stronger awareness campaigns, early screening and accessible services. “If we diagnose early and intervene early, we reduce stigma and improve lives,” Kisitu says. Dr Nerima urges government investment in diagnostic centres, subsidised therapy and support.

For parents like Kisitu and Serugyendo, autism is not just a diagnosis. It is a daily negotiation with systems still learning how

MYTHS AND FACTS ABOUT AUTISM

Misinformation is a major obstacle. Kisitu outlines common myths and facts about autism:

Myth: Autism is caused by bad parenting or lack of love.

Fact: Autism is a neurological condition and has nothing to do with parenting style or affection.

Myth: Autism can be cured.

Fact: There is no cure but therapy and support can improve functioning and quality of life.

Myth: All autistic individuals are the same.

Fact: Autism is a spectrum and each individual has unique strengths and challenges.

Myth: Autistic people lack empathy.

Fact: Many autistic individuals feel deep empathy but may struggle to express it.

Myth: Autism only affects children.

Fact: Autism is lifelong and continues into adulthood.

Myth: Vaccines cause autism.

Fact: Extensive scientific research has found no link between vaccines and autism.

Myth: Autistic people cannot live fulfilling lives.

Fact: With appropriate support many live independent, meaningful and productive lives.

to respond. Their stories reflect resilience, love and the possibility of change.