

HEALTH & BEAUTY

YOUR WELLNESS GUIDE

A MOTHER'S TALE ON RAISING AUTISTIC CHILD

In 2014, Kulusum Naigaga's son was diagnosed with autism spectrum disorder and attention deficit hyperactivity disorder. She refused to let the conditions to ruin her son's life. In her book, *Tread the Journey*, the mother, wife, pharmacist, entrepreneur, philanthropist and founder of Neurodiversity Community Outreach Uganda Ltd shares lessons for parents on how to bring the best out of children with special needs, writes **Ritah Mukasa**

At three years old, Naigaga's firstborn child, Aizat, was diagnosed with autism and attention deficit hyperactivity disorder (ADHD).

He was not hitting milestones as expected. Aizat could barely talk and had restricted habits, inattentiveness, hyperactivity and impulsiveness.

This went on for months until Naigaga accepted her son's condition and vowed to do whatever was in her means to support him fully. It paid off. "Today, my son attends a

mainstream school and is doing well," she says.

Aizat is 11 years old, going to Primary Five, which is unusual for many children living with autism and ADHD.

Every time Aizat enters a new class, Naigaga sits down with his new teachers and discusses how to support him. At home, he has become independent and does everything by himself.

Naigaga thanks her husband, Mustafa Ahmad, whom she calls a strong pillar

in the family.

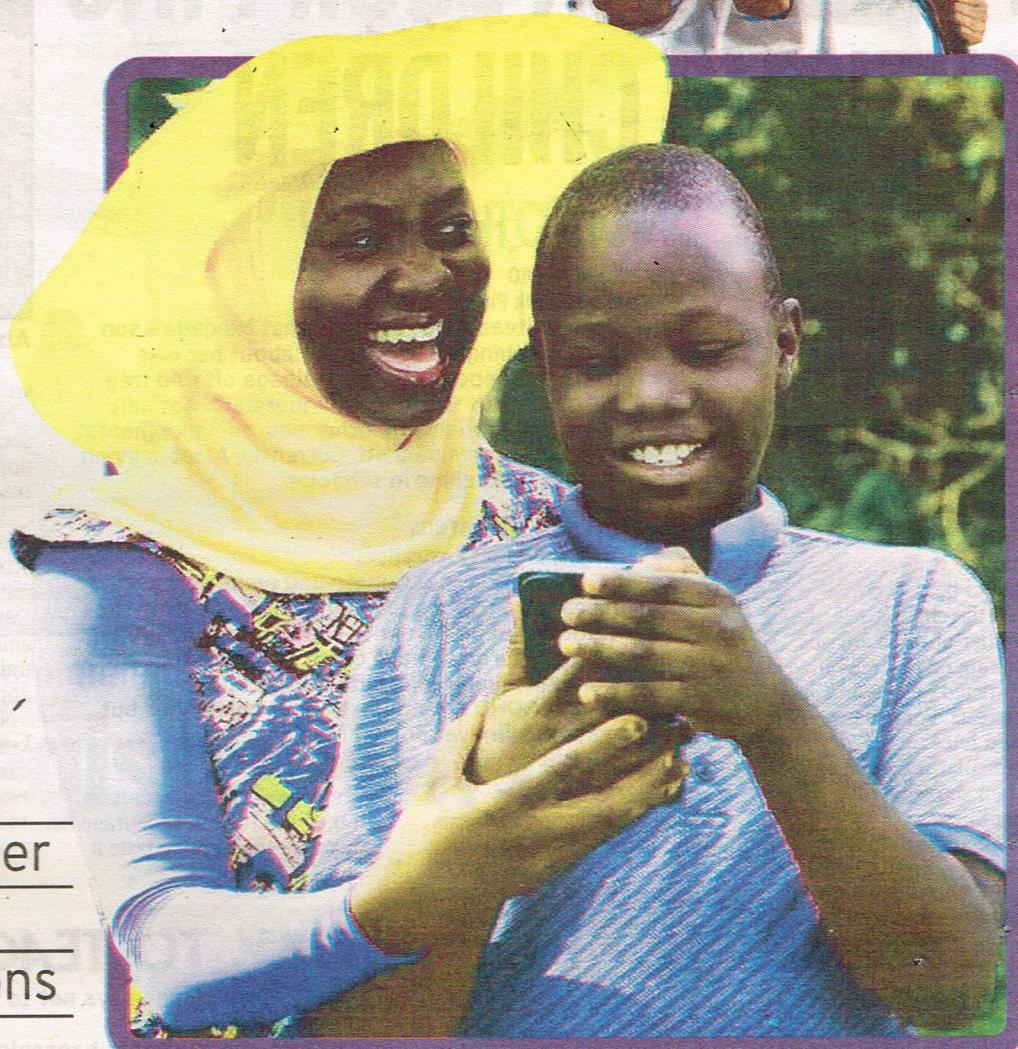
"He is very supportive and positive-minded. He has never blamed me as some men do to the mothers of their special needs children," Naigaga says.

Aizat's father provides home, school and hospital needs without hesitation. In addition to buying play



Aizat loves toy cars

ASK THE DOCTORS
Why do my knuckles and wrists hurt in the morning?
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Naigaga shares lessons in raising a child with autism and ADHD in her book

Aizat (centre) with his siblings. He is going to Primary Five



items, he is a hands-on father with their three children.

HOW TO TELL
In her book, *Tread the Journey*, Naigaga delves into the signs, symptoms and management of autism

and ADHD.

Based on her experience, she cautions parents to pay attention to how their young ones behave, for example, avoiding eye contact, playing alone and not responding

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UGANDAN MOTHER TIPS PARENTS ON EQUIPPING AUTISTIC CHILDREN

From page 19

WHAT OTHERS SAY

NKONO YEEKO

Founder, Lark Phonics Academy

I was the headteacher at a school that Naigaga's son attended. One thing that stood out about her was her passion to support her son. Naigaga offered free training to our staff for them to understand not only her son but also autism and other neurodevelopmental disorders. Her efforts paid off. Currently, Aizat is living a great life and excelling in school.

MARK IVAN TURYAGENDA,

Principal, Bigstuff Productions

Naigaga offers a compassionate and empowering guide for families, caregivers and individuals navigating the complexities of neurodiversity experiences. As I reflect upon my own journey, I have come to realise that the stories of individuals living with autism spectrum disorder and ADHD are not just about challenges but also creativity, innovation and resilience.

SUPPORT IS CRITICAL

Naigaga calls upon parents and caregivers to be patient because children respond to the interventions differently. "Most importantly, create a safe and conducive environment for the child. This makes learning easier and effective," she says.

"Always observe how they react to things like paint of the room, bright light, clothing designs and food."

For foods they do not like, Naigaga suggests starting by tasting, then taking small bites or sips, followed by small portions.

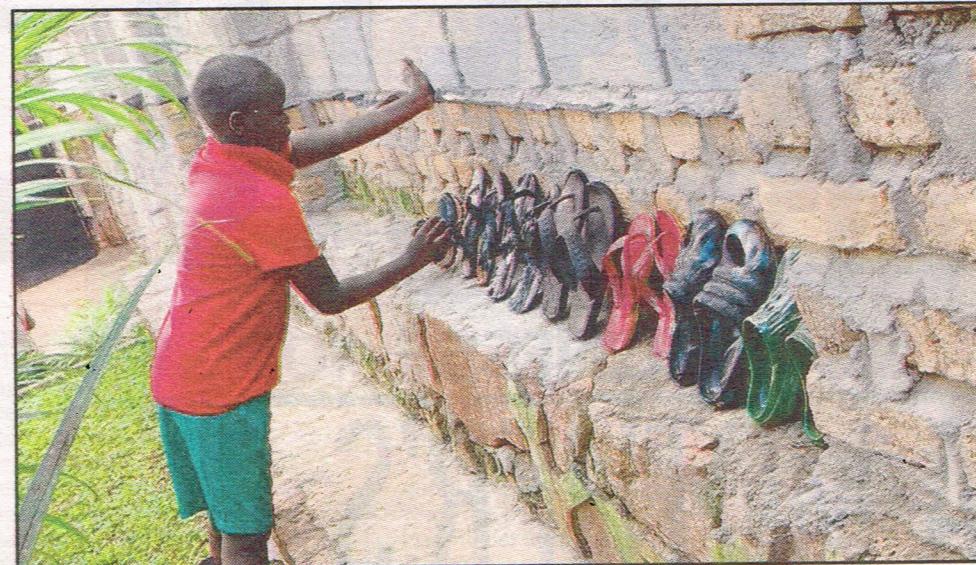
"You can convince them to taste with closed eyes as you

TALK TO TEACH

Kulsum Naigaga says not to watch TV in silence.

"Talk about what is happening to teach speech and language. Also, change the channels together to help improve their motor skills as well as attention and reasoning. You can also point to images on the TV and keep talking," she says.

"Do the same during bathtime. Train the child how to open and close the tap, soap the sponge and scrub their body. That is part of occupational therapy."



Aizat engages in all home chores. He has grown to do everything by himself

with eyes open," she says.

Naigaga advises covering sockets and keeping electrical appliances out of sight and reach.

"Do the same with pins, coins, beads, razor blades, scissors, needles, pesticides and other harmful products. Depending on their reasoning ability, you can gradually train the child to safely use appliances," she says.

Naigaga also advises keeping the learning environment free of clutter, switching off the TV or radio and putting the phone away. At school, she

advises educating teachers about the child's condition and how to support him.

PRIORITISE PLAY

A big part of Naigaga's book explores how play goes a long way in improving autism and ADHD.

"Start by creating time to play and do chores with your child. And during that course, imitate the child's words, movements and gestures.

You can also make different faces, clap rhythmically, tap objects, make interesting sounds, play with toys or sing as they

imitate you."

Naigaga recalls that when her son was between three and five years old, he loved playing with toy cars. So, she always got him such toys and included car games during playtime. However, Naigaga would make these games come towards the end of play. This was to motivate him to co-operate during activities since he looked forward to an exciting activity.

"If we started with car games, he would never want to stop and this would prevent him from exploring other games," she says.

At six to seven years, he moved on to drawing comic pictures. Naigaga ensured that before dinner, he had time to draw. Then, as he grew older, he fell in love with bicycle riding, and his father ensured Aizat's bike was in good condition.

In her book, Naigaga explores more pertinent topics, including how to prepare your child for adolescence, building the child's memory and dealing with challenging behaviour.

Tread the Journey is now available in major bookshops.



Naigaga trains her son to write

ABOUT AUTISM

Dr Sabrina Kitaka, a paediatrician, explains that autism is a lifelong neurodevelopmental condition that affects how a person interacts with the world. It leads to differences in social communication, behaviour and sensory processing.

"It is a spectrum, meaning it presents differently in everyone, with unique strengths and challenges. Key characteristics include difficulties with social communication and interaction, restricted or repetitive behaviours and interests and sensory sensitivities," she says.

Kitaka attributes the condition to multiple factors, noting that it is complex, with symptoms

that vary in severity from person to person. This variation suggests that both genetic and environmental factors may be involved.

According to data from the Uganda Bureau of Statistics (UBOS), the prevalence of autism in Uganda is estimated at 88 people per 10,000 (or 0.88%). Data from the 2014 census indicated a rate of 70 per 10,000, though some studies suggest slightly higher or lower figures.

The World Health Organisation estimates a global prevalence of 1 in 100 children (or 1%).

Kitaka says inconsistencies and variations in prevalence estimates are common due



INCONSISTENT DATA:
Dr Sabrina Kitaka

- methodologies, geographical locations and age groups studied, particularly in resource-limited settings like Uganda.

Dr Justus Byarugaba, a paediatric neurologist, says autism cases are on the rise. Due to limited awareness, some parents assume their children are merely experiencing delays, which often results in late diagnoses.

"Some of the cases I receive are referred very late," Byarugaba says.

Based on his experience, neither parental age nor regional background appears to be a significant factor.

"Maternal and paternal age are not factors, and neither is tribe. We receive people from all over the country," he explains.

Uganda has the highest number of individuals with autism, followed by the eastern region. The northern region is recorded as having the lowest numbers.

Kitaka notes that some research reports a prevalence rate of 1.2-1.3% (120-130 per 10,000) among children aged 2-9.

Efforts to effectively address the condition, she adds, have been hindered by a lack of awareness, limited numbers of specialised healthcare professionals and inadequate resources, factors that contribute to challenges in accurate diagnosis and reporting.

Byline: Jon Ssenyonyi | Photo: Rita Mukasa