

AUTISM IS AN UNRECOGNISED EPIDEMIC

[Vezi Silwanyana](#)



Teresa Hodge, right, teaches her preschool autism class at Bucknell Elementary School on Tuesday February 16, 2021 in Alexandria, VA. Fairfax County Public Schools reopened Tuesday for some students. (Photo by Matt McClain/The Washington Post via Getty Images)

Imagine not being able to verbally express your feelings and thoughts (being nonverbal), being highly sensitive to certain sounds, sights, tastes, smell or touch but unable to regulate sensory input or not fully understanding social cues?

This is the experience of many children and adults who have been diagnosed with [autism spectrum disorder](#) (ASD). Although autism presents itself in various ways, there are some characteristics that are common among most people.

This became our reality when our then two-year-old daughter, Inam, was diagnosed with autism in 2014.

The rise in cases of children diagnosed with autism has reached epidemic proportions in South Africa and the rest of the world. According to a 2020 report, one in 54 children are diagnosed with ASD in the United States, according to the Centres for Disease Control and Prevention's 2016 data.

Although these are American statistics it is fair to assume that it is a reasonable reflection of this global phenomenon.

Living with autism

Receiving an autism diagnosis is devastating for any parent. One goes through a plethora of emotions not knowing where to start seeking assistance, which healthcare practitioner to turn to or even consider what your child's future will look like. My husband and I consulted several doctors with the hope of finding an explanation for our daughter's speech regression, the flapping of hands

in front of her face, not making eye contact and involuntarily covering her ears, among other behaviours we observed.

ADVERTISING

I was relieved when we walked out of an autism school in 2015, having been promised the hope of her “recovery” if she were to undergo an intensive three-year therapy treatment programme. Six years later, although there has been a significant improvement in her speech, she has not recovered. We’ve come to realise that this is a lifelong, emotional journey that has no predetermined outcome. We also live in the hope that many children diagnosed with ASD go on to live independent, productive and fulfilling lives.

What is autism

ASD is a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviours. There is no known cause for the disorder — although there are speculations — nor is there a cure for it.

The autism diagnosis age and intensity of autism’s early signs vary widely. Some infants show hints in their first months. In others, behaviours become obvious as late as the age of two or three. The symptoms, according to the organisation [Autism Speaks](#), invariably include:

- Loss of previously acquired speech or social skills;
- Delayed language development;
- Persistent repetition of words or phrases;
- Avoidance of eye contact;
- Persistent preference for solitude;
- Difficulty understanding other people’s feelings;
- Resistance to minor changes in routine or surroundings;
- Restricted interests;
- Repetitive behaviours (flapping, rocking, spinning); and
- Unusual and intense reactions to sensory input.

Social ills and autism

In 2018, 10-year-old [Katlego Joja](#)’s body was found floating in a river in Mamelodi, Pretoria. [Nhlanhla Mnguni](#), a four-year-old in Klerksdorp, was found in a drain, murdered in 2014. In 2020, a 15-year-old girl was raped at a school for learners with special needs in Tembisa. Mxolisi Vilakazi, an 18-year-old boy from Orange Farm, was chained to a chair by his mother, who feared for his safety.

Although there is no correlation in these cases, there is one commonality — all the victims have or had autism. Why is this necessary to mention? Some individuals with autism have cognitive impairments, which make them susceptible to dangerous situations and, as seen in some of these cases, murder.

While the country battles with violence against women and children, it is imperative that we bring some awareness about people living with autism because they live at a higher risk of being victims of crimes.

Autism in the African context

Generally African culture has [long-established beliefs](#) about the causes of some disabilities. There are many, especially those outside of urban settings, who believe that disabilities are the result of witchcraft, sin or not following certain rituals correctly. The “strange behaviours” of individuals with autism are difficult to place in cultures that revere conformity.

Stories and images in the media of those with autism are usually of Caucasian or Asian people, so it is not seen as a common occurrence in African populations.

But, autism doesn't discriminate; it is not associated with a specific race, social or economic class.

The importance of autism awareness

An inescapable fact is that children with autism live in neighbourhoods that need to be educated about it. Shame, isolation, stigma and misconceptions are attached to the condition. This is understandable because there is little to no information publicly available, particularly those that are under-resourced in areas. This is the reason we formed the Inam Autism Advocacy Group. The objective is to create awareness about ASD, hoping that it will create a ripple effect in the way that individuals, communities, government and others respond to all matters relating to the treatment and education of children with autism.

The framework necessary to support children with autism is another deficient area. “No child should be left behind” and “inclusive education” are slogans that are regularly referred to in public and private schools. Children with autism, however, are left behind because education is not inclusive. The costs of autism specific education or therapy in private schools is extraordinarily high and there are only a few government schools available that cater for it. This is the reason we advocate for children with autism because no child should be left behind, regardless of their limitations.

For more information on the foundation visit www.inamfoundation.org.

Subscribe to the M&G

Thanks for enjoying the **Mail & Guardian**, we're proud of our 36 year history, throughout which we have delivered to readers the most important, unbiased stories in South Africa. Good journalism costs, though, and right from our very first edition we've relied on reader subscriptions to protect our independence.

Digital subscribers get access to all of our award-winning journalism, including premium features, as well as exclusive events, newsletters, webinars and the cryptic crossword. [Click here to find out how to join them and receive a 40% discount on our annual rate.](#)

[Vezi Silwanyana](#)

Vezi Silwanyana is co-founder of the Inam Autism Advocacy Group