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Autism: tackling cultural barriers

Jun 13, 2010 12:00 AM| By

Early diagnosis hampered because rural kids are kept hidden, writes Sarah Groves



BUBBLE FUN: Speech therapist Nono Njongwe assesses a two-year-old Zulu child in a screening test to identify autism. Researchers are trying to establish the cultural appropriateness of such tests Picture: JACKIE CLAUSEN

Photograph by:

"White people go to the doctor. We do something else. We speak to our ancestors' " Jacob Zuma

Nhlanhla (not his real name) was 13 before anyone suspected he was autistic. He had no interest in the world around him, treated people as objects to be ignored, indulged in tantrums and aggression without remorse, repeated actions obsessively, and flapped his hands and rocked back and forth when upset.

Yet, although the KwaZulu-Natal teenager checked positive for many of the classic signs of autism, his mother did not want to have him diagnosed.

Nono Njongwe, who has worked as a speech therapist in a rural South African school and clinic, says autism is sometimes left undiagnosed because strange behaviour is often kept hidden.

"What you're fighting," she says, "is a belief system that says, 'White people go to the doctor. We do something else. We speak to our ancestors.' Many mothers feel guilty that their children are sick. They think it's because they skipped a ritual. And sometimes husbands blame their wives for producing children that aren't normal. So moms generally think that it's best just to avoid a diagnosis."

It was this realisation that led Njongwe to become involved in the South African arm of First Words autism research, a project based at Florida State University in the US that encourages autism screening in young children aged 18-36 months.

Because autism is a disorder that affects social communication and interaction, its negative effects can be lessened through therapy. But part of the tragedy of keeping autistic children hidden is that much of the success of this therapy depends on early intervention.

South African speech therapist Dr Nola Chambers, who did her doctoral research with First Words and is heading their SA research, says: "If you are able to diagnose and work with autistic children before the age of three, their chances of academic success and being able to communicate verbally are much greater. Unfortunately, many children in SA,

especially rural children, are not diagnosed until the age of seven, when parents try to get them into school."

Chambers, Njongwe and others are working to change this. Partnering with researchers from the universities of KwaZulu-Natal, Witwatersrand and Cape Town, as well as autism research experts from the US universities of Florida State and George Washington, they hope to raise autism awareness.

One of the challenges of diagnosing autism in SA is that it might look different in the US. "We know that autism exists in every culture, but we don't know if it looks the same in every culture," says Chambers. "It can't be diagnosed through laboratory tests, but only through observing behaviour. Various tools have been developed in the West to screen children for autism, and what we want to find out is if these tools are culturally appropriate."

Because Chambers is based in KwaZulu-Natal, the research will focus on the Zulu community and preliminary work has begun in Inchanga and areas surrounding Pietermaritzburg. Focus groups will be asked to give feedback on the cultural appropriateness of autism tests that have been translated into Zulu. For example, a classic test for autism is whether a child can look an adult in the eye, but is it appropriate in the Zulu culture to expect a child to look an adult in the eye?

Then a selection of Zulu children will be screened, through play, for possible signs of autism. Can the children point at a toy that excites them or do they take your hand, without looking at you, and place it on the toy? Do they interact through chatting or do they stare at you?

One of the purposes is to develop a database of normal behaviour among Zulu children, which can then be compared with autistic behaviour. "One of the tests in the US model involves offering a wind-up toy to a child," says Chambers. "A normal child would show the toy to their mom, play with it and then return it on request. But an autistic child would not show it, not return it and would fiddle obsessively with the moving parts. For children in the West, who have lots of wind-up toys, that's an appropriate test. But children in a rural community who have never seen a wind-up toy before may be so excited that all they want to do is fiddle with the moving parts. So that may not indicate autism in a rural community."

The hope is that the research will develop diagnostic tools that are culturally appropriate.

So what is autism, anyway?

Autism is a neuro-developmental disorder that affects communication, social interaction and imagination. It can be very mild, and manifest in children who are slow to speak or socially awkward, and it can be severe and manifest in children who never speak. It can be found in people with above average intellectual ability, such as Albert Einstein, or it can be accompanied by intellectual impairment.

People with autism struggle to understand other's thoughts and emotions, and they struggle to understand abstract expressions, such as, "I almost died."

According to Autism South Africa, autism affects one in 110 children and thus, on average, a child that will develop autism will be born every hour in South Africa.

There are special needs schools in South Africa that cater for children with autism. - **Sarah Groves**