

NEWS

# Studies highlight need to adapt autism tests for African cultures

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11 SEPTEMBER 2017

Some of the items on a common diagnostic test for autism may not translate well to African cultures, according to preliminary results from multiple teams. Two teams presented their unpublished results Friday at the **2017 Africa Regional International Meeting for Autism Research** in Stellenbosch, South Africa.

The teams are trying to adapt the autism test for use in South Africa and Tanzania and evaluate its cultural appropriateness. A third project reveals unique aspects of autism in Ethiopian children that traditional tests may miss. And a fourth effort aims to develop an open-source tool for autism screening and another for diagnosis that could be used in various low-income countries.

“Africa is so broad, there are so many different cultural contexts, and yet we are finding so many similarities,” says **Amina Abubakar**, research psychologist at the Wellcome Trust’s Kenya Medical Research Institute in Kilifi and lead researcher on the open-source project. “There is an opportunity for collaborative work for looking for common ground for how things can be moved forward.”

A billion people live in sub-Saharan Africa, and about half of them are children. It is unclear how many of the children have autism. That’s in part because none of the most widely used autism screening and diagnostic tests — which were developed in English — have been translated into languages people in the region understand. It is also unclear whether the items on those tests are appropriate for African cultures.

Translated tools and the open-source project are both critical, says **Petrus de Vries**, Sue Struengmann Professor of Child and Adolescent Psychiatry at the University of Cape Town in South Africa. “We have to have new ways to screen and diagnose, because we’ll never have enough therapists, we’ll never have a translation of the [tools] in every language on the African continent,” de Vries says. He led the South African project and works with Abubakar and others on the open-source effort.

## Fear of frogs:

In the South African study, de Vries and his colleagues translated the Autism Diagnostic Observation Schedule (ADOS), a gold-standard test for autism diagnosis, into Afrikaans, one of the country's 11 official languages. Afrikaans is used by about 77 percent of 'colored' people in the Western Cape province. (The term 'colored' is used in South Africa to refer to an ethnic group that was oppressed under apartheid; people in this group are typically descended from both Africans and Europeans.)

The researchers explored whether the translated test's phrasing and the associated activities and materials can be understood by 40 colored people who speak Afrikaans, have a child and have a low income. They also administered the translated test to the parents of seven children referred to a local clinic for autism diagnosis. They interviewed all of the participants to evaluate the comprehensibility and cultural appropriateness of the translated test.

The researchers identified 20 words on the test not universally understood by the participants. Most of these words describe emotions or feelings, such as cheerful, lonely and anxious.

The participants were familiar with most of the activities and materials used during the test. However, more than one-third of parents reported that their child would be afraid to play with a toy frog used for one of the items, because amphibians and reptiles are seen as scary in South Africa.

The parents also reported that some activities, such as blowing out candles on a birthday cake and singing the 'Happy Birthday' song, were unfamiliar to their children. And most boys would be reluctant to play with the baby doll used during the celebration.

The findings suggest that the Afrikaans version of the ADOS is mostly culturally appropriate, says **Lesia Smith**, a graduate student in de Vries's lab who presented the findings. But "examiners need to be mindful of administering the tool in a way that is sensitive to the community," she says. They should also consider adapting or removing items that might be unfamiliar to Afrikaans-speaking people.

## Tanzania translation:

Abubakar and her colleagues saw similar results in Tanzania with a translation of the ADOS into Kiswahili, the country's official language. The team interviewed 51 parents, teachers, social workers and clinicians about the test's activities and items.

Most participants reported they were familiar with the activities and materials — with a few exceptions. Although most participants could read, only four said they regularly spend time reading to their children — a task performed as part of a typical ADOS.

The participants also reported that a person's familiarity with birthday celebrations depends on income level.

"Most of the ADOS activities, when presented, were familiar to this urban, middle-class setting," Abubakar says.

In Ethiopia, **Rosa Hoekstra** of King's College London led a team that interviewed 15 people who have a child with autism, and nine clinicians who have experience with autism. The children in the study speak few or no words, and most have intellectual disability. The researchers asked the participants about the autism features most commonly seen in Ethiopian children with the condition.

The interviews reveal that caregivers are unlikely to report **repetitive behaviors** such as hand flapping and body rocking but do often report social difficulties and speech problems. Their primary concern is that they struggle to understand their child's needs, such as whether the child is hungry or feels ill.

## Common concerns:

The results also indicate that Ethiopian children with autism show all the usual hallmarks of autism, but with a cultural twist. For example, one child meticulously lines up shoes by the door of his home rather than repetitively lining up toys, which are uncommon in many parts of Ethiopia.

"There was no indication that the core symptoms of autism — the expression of those symptoms — differs markedly from reports in high-income Western countries," Hoekstra says. But cultural norms in Ethiopia may mean that standard English-language diagnostic tools will not pick up some autism features in Ethiopian children, she says.

The ADOS and other tools are costly and require extensive training for accurate results, but the translated versions are not yet ready for clinical use. The open-source project aims to fill this need by **developing tools** to screen for and diagnose autism.

As a first step, the researchers reviewed the literature to identify more than 30 tests for autism diagnosis. They created a spreadsheet containing all 200 items from these tests, and examined how they fit the core diagnostic criteria for the condition, as described in the current "Diagnostic and Statistical Manual of Mental Disorders."

The team is also interviewing autism experts worldwide to determine which items to use. They plan to then test the tools in several countries.

*For more reports from the 2017 Africa Regional International Meeting for Autism Research, please [click here](#).*