



CLAHRCBITE

Brokering Innovation Through Evidence

November 2017

Working with the Bristol Somali community to improve outcomes for children with autism



The number of children and adults affected by autism is rising, especially among migrant communities. Children whose parents have migrated from Somalia to western countries, including the UK, appear to be at greater risk of developing autism.

Autism affects social interaction, communication and behaviour. The needs and experiences of Somali families with children with autism aren't well understood. Many families don't engage with health or social services.

We worked in partnership with Autism Independence (AI), a community group that supports Somali families affected by autism. AI is led by Nura Aabe. Nura came from Somalia to the UK aged eight, and has a child with autism. She campaigns for wider awareness of the issues surrounding autism in the Somali community.

This project explored:

- how autism is seen and understood in the Somali community
- how parents find out that their child has autism
- their experiences of health and social care
- how health and social care services can best support these families



What we found

Four themes emerged from the interviews with 12 mothers and three fathers: My child is different; Perceptions of autism; Navigating the system; Support. Here are some highlights.

Perceptions of autism

There is no Somali word for autism, so many parents were confused when they were told that their child had it. They hadn't heard of it before and their child didn't show physical signs of disability. Mental illness can be viewed negatively in the Somali community, so some parents hid their child and delayed seeking help.

Members of their community often advised parents that their child would improve, telling them not to worry or seek help from doctors. Some parents hoped that their child might 'grow out' of autism, or might not have it at all.

Navigating the system

While their child was being assessed, parents often felt confused by the different professionals involved and the many appointments they were given.

When they were told that their child had autism, parents were shocked or sad.

Some didn't believe it. They wanted a better explanation and more information in Somali. Even those with fluent English found it hard to understand some of the words used. They said that an interpreter should always be available.

Support

Some parents were supported to get help by social, education and health staff. Regular communication with school or nursery was especially helpful.

Others felt unsupported and wanted more help with speech and respite care at weekends. Some parents suggested that a Somali link worker, who understood autism, could help them find services.

How we shared our research

The team have raised awareness of these issues through: a presentation to the All Party Parliamentary Group on Autism; national and international performances of the play 'Yusuf Can't Talk'; presentations at academic and community events; media appearances including local and national radio, television, interviews with Buzzfeed and a TED X talk.

Read the paper

"It was like walking without knowing where I was going": A qualitative study of autism in a UK Somali migrant community

Fiona Fox, Nura Aabe, Katrina Turner, Sabi Redwood, Dheeraj Rai. Journal of Autism and Developmental Disorders
bit.ly/somaliautism

Find out more

clahrc-west.nihr.ac.uk/somaliautism/

www.autism-independence.org

What is NIHR CLAHRC West?

NIHR CLAHRC West works with partner organisations, including the NHS, local authorities and universities, to conduct applied health research and implement research evidence, to improve health and healthcare across the West.

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