

Exploring experiences of Autism among Somali families

Autism is a lifelong developmental disability affecting communication, social interaction and behaviour

Research has linked Autism to migration and suggests that migrants from Somalia may be at greater risk than other populations

We want to find out about the experiences of Somali families, living in Bristol, who have a child with autism and to understand how health and social care services can be best delivered to support them.

Community-based Participatory Research



Autism Independence

"It is my destiny to climb the highest"

- This exploratory study is being conducted in partnership with Autism Independence (AI)
- AI is a community based group that supports members of the Somali community who are affected by Autism.
- Members of AI are active partners, contributing to all aspects of the research

There is no Somali word for Autism (PPT 2, male)

To understand what it meant would have made so much difference (PPT 3, female)



Aims

To understand views about and perceptions of Autism in the local Somali community

To explore the process through which a child is identified as having autism

To understand the experiences and challenges of accessing & engaging with services

- **What:** 15 in-depth interviews with members of the Somali community who have a child with Autism
- **Who:** Interviews conducted by a CLAHRC West researcher and a member of AI, who interprets
- **Where:** Interviews take place in a community centre, are audio recorded and fully transcribed
- **How:** The qualitative data is being analysed using the Framework Method

Accessing Support

"apart from the services that I've received through school there are no other services out there that really support me in any direction"
(PPT 4, female)

Perceptions of Autism

"People with this kind of condition, I have never seen it before. A child who looks just like another child, who is healthy and strong, who just can't cope, can't talk or is out of control"
(PPT 2, male)

Emerging Findings

Children with Autism are Different

"I realised that something was wrong with her when went to nursery aged 3. That's when I understood she was different from my other children. If I had known that there was something wrong with her, I would have taken her to the doctor"
(PPT 1, female)

Navigating the System

"When you're new to a country, it's just impossible for you to find all the different services available. The reason that causes further delay to our children or accessing services is because you haven't got the capacity, or the ability, or the understanding to access services"
(PPT 3, female)

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