

## Public involvement and collaboration in a NIHR CLAHRC West research project:

### Project title: Autism in Somali Migrants: Exploring families' perceptions and experiences of diagnosis and services

This exploratory project was conducted in partnership between the University of Bristol, NIHR CLAHRC West and Autism Independence (AI), a community based group that supports members of the Somali community who are affected by autism. The aim of this collaborative approach was to inform preliminary recommendations for services and further research.

High rates of autism in children of Somali migrants mean that they have greater needs in relation to autism services. The Somali population in Bristol is large at about 10,000 people, and the number of families affected by autism is rising. Not much is known about their needs including; experiences of getting a diagnosis, barriers to care, and culture specific aspects of care. The project therefore aimed to gather information about the needs of this group in order to provide high quality services that this often marginalised population requires.

The NIHR CLAHRC West researchers Sabi Redwood (SR) and Fiona Fox (FF) adopted a community-based participatory research approach. This is based on principles of community engagement and empowerment, mutual respect and co-learning, as well as commitments to action and improvement. This way of working attempts to reduce health inequalities in potentially marginalised groups with few material and social resources to draw on, so that services can be adapted to meet needs. The topic of this project was identified as important by community members and early ideas and plans were discussed at a community meeting with parents.

The project was done in partnership with AI, whose aim is to raise awareness of autism, and to educate and empower affected people and their families, especially those with no or little previous knowledge about autism and those with limited access to services. Members of AI were involved in all aspects of the research, from deciding research questions and the conduct of the research, developing recommendations on the basis of the findings, and dissemination.



The approach, project plan and methods were negotiated between researchers and members of AI over several face-to-face meetings at a local community centre, telephone conversations and email exchanges. The founder and director of AI, Nura Aabe (NA), led the negotiations, providing 'cultural brokerage' not just between the White European

background of the researchers and the local Somali community, but also mediating between AI's members' enthusiasm for quick action and improvement, and the slower pace required for research processes. Research materials, including information flyers, and the interview schedule were developed and produced in English and Somali through collaboration with NA and the research team.

Due to the project context and its exploratory and collaborative nature, a qualitative, interview-based approach was chosen. Parents were invited to participate in the project via NA, who initially posted an invitation on a WhatsApp group for AI. Nine families expressed an interest and took part in interviews. After initial interviews the project group agreed that NA should directly contact some additional specific families to request their participation and six more parents agreed to take part.

The interview questions were developed by the research team at two meetings with members of AI, and then refined through a practice interview. Interviews were conducted by NA and FF, with NA providing ongoing translation where participants chose to speak in Somali. Typed up transcripts of the interviews were checked against the audio recording by NA, who added to and edited sections spoken in Somali.



After the first three interviews both FF and NA worked together to analyse the information collected. The themes and codes identified were discussed with the steering group, and FF then analysed the remaining interviews based on the agreed structure. Findings from the project have been written up, and there are plans to hold a community meeting in the next few months to share the findings and seek feedback.



For more information about this project contact Fiona Fox email [f.fox@bristol.ac.uk](mailto:f.fox@bristol.ac.uk). Autism Independence has a website <http://www.autism-independence.org/> or contact Nura Aabe email [hello@autism-independence.org](mailto:hello@autism-independence.org).

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