

Understanding and awareness of autism among Somali parents living in the United Kingdom

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While much research has focused on attempting to clarify the numbers of autistic children in the Somali community, little attention has been given to the views and experiences of Somali parents of autistic children. The aim of the current study was to examine knowledge and awareness of autism (as well as typical and atypical development more broadly) among Somali parents of both autistic and non-autistic children.

32 Somali parents living in the UK took part in this research: 16 were parents of autistic children and 16 were parents of non-autistic children. All parents were interviewed by a researcher from the Somali community. As well as asking the parents about how children typically develop (e.g., how children's behaviour changes over time, what types of behaviour might be a cause for concern), we presented parents with vignettes (short stories) describing eight different children (e.g., children with possible autism, children with possible attention deficit hyperactivity disorder, children with possible developmental delay). For each vignette, parents were asked if the child's behaviour was similar to how other children of a similar age behave. If not, they were asked if they had a name for such behaviour and if they knew what might cause it. Finally, parents were asked how atypically developing children and their families might be perceived and supported by the Somali community.

We found that parents (of autistic and non-autistic children) commonly identified and labelled vignettes of autistic children, but experienced more difficulty labelling vignettes that described children with other forms of atypical development, sometimes mislabeling these children as autistic. This suggests that there is a need for greater support in recognising and identifying different types of atypical development in the Somali community (to mitigate the risk that the term 'autism' may take on its own meaning within the Somali community, becoming a euphemism for a range of developmental conditions).

Further analysis of our interviews identified key factors that either helped or hindered the inclusion of families with autistic children within the community. These include the Somali community's: (1) perceptions of disability, (2) beliefs about the causes of autism in the Western world and (3) strong reliance on religious beliefs in understanding and accepting an autism diagnosis.