

# A qualitative, cross-national analysis of the experiences of Somali parents raising children with and without autism

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## **WHY IS IT IMPORTANT TO UNDERSTAND FAMILIES' EXPERIENCES?**

Studies carried out in Sweden and the United States found that rates of autism are much higher among Somali children than non-Somali children. Researchers are debating whether the rate of autism increases for Somalis post-migration or autism is more likely to be diagnosed as such in North America than in Somalia. Nonetheless, Somali communities are affected by the belief that autism is prevalent and increasing in Somali families in North America. There are many Somali families raising a child with autism but little is known about the effects of autism on these families and how best to provide services to them.

## **WHAT WAS THIS STUDY ABOUT?**

The study examined the beliefs, views, and experiences of Somali families raising a child with or without autism (ASD) in Toronto and Minneapolis. The research looked at the impact of beliefs that rates of autism are high in Somali communities. Because different cultures have different views of disability and development, this study also examined Somali parents' beliefs and views of autism, mental health, disability, and child development. Finally, this research examined the similarities and differences in the experiences of these parents in Canada versus the United States, including their experiences with services and the possible effects on integration.

## **WHAT DID WE DO?**

The method of ethnographic fieldwork was used for this study. This included interviews with 22 parents of a child with ASD and 18 parents of a child without ASD, with equal numbers in Toronto and Minneapolis. We posed questions that explored Somali parents' perceptions of community issues in general, their beliefs regarding the increased incidence of ASD in the Somali communities in North America, perceptions of their children, perceptions of autism, disability, mental health and child development, perceptions about the service availability and accessibility, and potential psychosocial issues accompanying the perceived increased incidence of ASD. Informal interviews with Somali nurses, doctors, and social workers on the topic of ASD were also carried out in both Toronto and Minneapolis. In Minneapolis, we attended a Health Care and Human Services Finance hearing at the State Capitol Building where the Somali Parents Support Group, Somali parents, and ASD expert panelists presented information on the prevalence of autism in the Somali community. In addition, we attended meetings of the Minnesota State Autism Task Force. In Toronto, we attended monthly Somali parent support meetings. We analysed the outcomes and themes within transcripts of interviews and field notes in order to provide recommendations for future programs, identify gaps in the available literature, and develop recommendations for future research and practice.



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## WHAT DID WE LEARN?

The study found that many Somali families who do not have a child with autism have little awareness of the issue. Others had heard about autism and wanted to know the causes, but few asked about how the families were coping and how the community could help them. This may be due to the stigma associated with autism. The study found that in both Toronto and Minneapolis, parents of a child with autism are suffering. The stigma silences many of these parents who are afraid to acknowledge that their child may have autism. In their attempts to hide the problem, these parents become isolated. Isolation also occurs for parents of a child with autism who feel excluded by their communities. When these parents do seek resources for their children, many face barriers in getting the help they need. There are either long wait lists because the system is overwhelmed, or families' health insurance providers – whether Medical Assistance (MA) in the United States, Ontario Health Insurance Policy (OHIP) in Ontario, Canada, or private insurance – do not financially cover certain kinds of medically prescribed therapies. As a result, families who have a child with autism are struggling to pay for expensive treatments and therapies for their child. This affects these parents' economic well-being in both Canada and the United States.

Children on the autism spectrum can cause their parents both emotional and physical distress. Some parents discussed their experiences of life-threatening health issues due to the extreme stress they are under. Children with ASD frequently have difficulties sleeping and are unaware of the danger they can be to themselves or others. As a result, mothers and fathers sleep in front of their doors or stay up all night to prevent their child from letting his/herself out of the home. Others have put locks on all of their doors and windows. Families are getting evicted from their apartments because of the damage their child has caused to the building. The stress has led to separation and divorce among Somali mothers and fathers. Evident from the testimonies of parents is that the main problem is the lack of knowledge of autism and of the health, educational, political, and legal systems. Language is the biggest barrier to learning these systems and the result is that many mothers and fathers are unable to access the services they need for their children. For instance, one father I spoke with said, "I know over 100 parents myself who have a child with autism. Most of them do not get support from anywhere. Many are single mothers who don't drive or speak English and don't have fathers that can help."

The study found that social support embodied in parents support groups in both Minneapolis and Toronto helped parents to cope with raising their child and with getting access to and utilizing services. Somali mothers and fathers have come together and are advocating for their children and for policy changes. Parents who have turned to these groups have reconnected with a Somali community, getting the support they need, and are learning about the resources available to them. Through networking and education some parents have learned of therapies such as Applied Behavior Analysis (ABA), a behavioral intervention to improve socially significant behavior, and have seen improvements in their children. Some parents have even been trained in ABA themselves in order to help their children at home. Others have sent their children to speech pathologists, gastrointestinal specialists, and Defeat Autism Now (DAN) doctors. Through educating themselves, connecting with others, exchanging information, and listening to success stories, many parents have hope for their child's future. As one mother told me, "Parents need many different interventions for their child, but I have seen parents get their child back." Another mother said, "I go onto the computer and listen to stories of recovery. They give me hope."

The mothers and fathers are advocating for their children and policy changes at their school boards and in health care. Somali parents of children with autism travel long distances to get the care they need. They use transnational medical care and alternative therapies, traveling to different provinces (Canada), states (US) and to other countries.

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