

# Autism and the Somali Community – Report of Study

## Background

In 2008, Somali parents and others in the Twin Cities raised concerns about disproportionately high participation rates of Somali children in a preschool program for children receiving Autism Spectrum Disorder (ASD) special education services as compared to the overall percentage of Somali children in the city's public schools. The program, the Early Childhood Special Education (ECSE) Citywide ASD Classroom Program, is operated by the Minneapolis Public Schools (MPS).

The Minnesota Department of Health (MDH) shared the community's concerns about a possible elevation in ASD rates in Somali children and agreed to study the occurrence of ASD among preschool-age Somali children in Minneapolis. **This study did not attempt to identify possible causes or risk factors for ASD.**

## The Study

Minnesota does not have a public health surveillance system that will inform us about the actual occurrence – the *population prevalence* – of ASD in Minnesota, including in the Somali population. Therefore, the study involved analyzing special education data, known as *administrative prevalence*, about the number of children who are eligible to receive ASD services and are participating in ECSE programs. Administrative prevalence only tells us about who in the population is participating in the MPS ASD programs. It does not tell us about who in the population has ASD (population prevalence).

## What the Study Found

There were a number of significant scientific challenges in using administrative data to try to analyze this situation. Nonetheless, the study found that:

- Administrative prevalence of Somali children, ages 3 and 4, who participated in the MPS ECSE ASD programs was significantly higher than for children of other races or ethnic backgrounds. This is consistent with what families and others observed. Because of the study's limitations, it is not proof that more Somali children have autism than other children; however, it does raise an important question of why Somali children are participating in this program more than other children. In addition, it is not known whether this is because 1) there is truly a higher rate of autism among Somali children, 2) there is better outreach to Somali families compared to other children, 3) whether non-Somali children that are identified as having ASD use services outside of the school system, or 4) due to other reasons.
- Differences in administrative prevalence rates between preschool Somali children and preschool children of other races and ethnic backgrounds decreased markedly over the three year period. It is unclear if this is 1) an identification issue, 2) a change in parental awareness for the need for developmental screening, 3) whether Somali children improved over time and therefore no longer needed services, 4) whether more non-Somali children were being identified as needing services, or 5) there were other reasons.



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- The proportion of preschool Asian and Native American children, ages 3 and 4 participating in the ECSE ASD programs was strikingly low compared to other children. It is not known whether this is because 1) there are fewer Asian and Native American children who have ASD, 2) there is less effective outreach to these children, 3) they are using services outside of the school system, or 4) due to other reasons. This seemingly low prevalence rate among Asian and Native American children may artificially boost the comparative rate among Somali Children, distorting a true understanding of all groups involved.

Despite the limitations, the study represents an important step forward, providing information that will help guide future efforts to understand autism, both in the Somali community and in the larger population.

### Next steps

To better understand whether there is, indeed, a higher occurrence of ASD in Somali children as compared with non-Somali children, a wide range of skills, expertise, and knowledge of the community and environment is needed. Issues to be explored include:

- Exploring the feasibility of developing a population-based public health ASD surveillance system in Minnesota.
- Estimating administrative ASD prevalence for a larger geographic area in Minnesota and elsewhere in the country.
- Learning more about how children come into the system and whether there are cultural differences in how behavioral and developmental problems are addressed.
- Conducting additional analyses to address pending study questions.

While addressing these issues will assist in estimating the true prevalence of ASD in the Somali community and in Minnesota, MDH,

along with the Somali community and a wide range of partners, will continue work to:

- Improve access to culturally competent, care.
- Increase access to information about child development and available resources for children with special health care needs.
- Ensure that physicians and other providers have the right tools to diagnose and refer children with ASD to appropriate services.

### Ongoing opportunities

- MDH has convened representatives from the Minnesota Chapter of the American Academy of Pediatrics and members of the Somali Community to discuss issues related to culturally appropriate screening and medical diagnosis. These conversations continue.
- The University of Minnesota is applying for funds to study very early signs of autism that would be more bio-behavioral and valid cross-culturally.
- Minnesota is considering legislation establishing an Autism Spectrum Disorder Task Force charged with examining ways to improve services, service delivery, training of professionals, and education of parents and the public on autism.
- The *Somali and Autism* website is available through MDH to provide information and links to services for Somali families.
- The Interagency Autism Coordinating Committee, a federal government advisory panel, has released a blueprint for autism research to help fill the gaps between what we know about autism and what we need to do to help families.

### For more information

You can find the full report at:

<http://www.health.state.mn.us/ommh/projects/autism/index.cfm>

If you have questions please contact the Department of Health at 651-201-4754