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.

- 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.
Ongoing Opportunities
In response to the 2009 MDH report, these projects are being implemented:

- **Minneapolis Autism Prevalence Study**
  The Department is providing technical assistance to the University of Minnesota LEND – Leadership Education in Neurodevelopmental and Related Disabilities – program where a study of 7–9 year olds in Minneapolis is under way to estimate ASD prevalence. The study is funded by Centers for Disease Control and Prevention, National Institutes of Health, and Autism Speaks and seeks to determine whether there is a higher rate of autism among Somali children compared to non–Somali children.

- **Qualitative Study of Cultural Influences on Early Identification and Access to Services**
  In 2012, the legislature designated $200,000 for a study to shed light on how culture influences Somali parents’ understanding of the signs and symptoms of ASD and the treatment options they choose for their children with ASD. It may also help in understanding how culture influences providers and others in the community addressing ASD.

  In partnership with the University of Minnesota School of Public Health, SoLaHmo (Somali, Latino and Hmong Partnership for Health and Wellness) is using a community–based participatory research approach in which communities generate the questions that are most important to them. The 2014 results of this study may guide and inform program planners and policy makers in developing more culturally meaningful or relevant outreach, educational or training programs, and intervention programs for parents and their children.

- **Autism Spectrum Disorder Task Force**
  In 2011, the Minnesota Legislature established an Autism Spectrum Disorder Task Force charged with developing a statewide strategic plan that focuses on improving awareness, early diagnosis and intervention, and ensuring delivery of treatment and services for individuals diagnosed with: [http://www.lcc.leg.mn/asd/](http://www.lcc.leg.mn/asd/)

Assuring Services
MDH, along with the Somali community and a wide range of partners, is working 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.

Additional initiatives include:

- **Investing in Health and Early Learning for New Americans**
  MDH has convened representatives from the Minnesota Chapter of the American Academy of Pediatrics and members of the Somali community to reduce barriers new American Somali children face that prevent them from obtaining well-child care that can improve their path to school readiness. Several educational videos have been developed for the Somali community to address common child health topics.

- **Interagency Autism Coordinating Committee (IACC)**
  The IACC, 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, available at: [http://iacc.hhs.gov/strategic-plan/2012/IACC_2012_Strategic_Plan.pdf](http://iacc.hhs.gov/strategic-plan/2012/IACC_2012_Strategic_Plan.pdf)

For a copy of the full report or for more information contact: Children & Youth with Special Health Needs health.cyshn@state.mn.us 651-201-3650