



Update on the Minneapolis Somali ASD Prevalence Project

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Background

- ❑ **2008**— Community concerns about what appeared to be more Somali children enrolled in Minneapolis public preschool special education program for children with ASD

- ❑ **March 2009**—Report from Minnesota Department of Health suggesting that Somali children participated in ASD public pre-school programs much more than other children
 - Racial and ethnic differences in administrative prevalence decreased over the three years examined
 - Administrative prevalence estimates for Asian and Native American children were very low compared to other children

- ❑ **October 2010**—Request from IACC that federal agencies support additional ASD activities in Minneapolis

- ❑ **July 2011**—Start of the Minneapolis Somali ASD Prevalence Project

Autism and Developmental Disabilities Monitoring (ADDM) Network Method

- Multisource, records-based surveillance methodology

Screen health and education records
(multiple data sources) in community

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graph TD; A[Screen health and education records (multiple data sources) in community] --> B[Abstract information in records (e.g., behaviors related to ASD, co-occurring conditions, and test data)]; B --> C[Review abstracted information to determine if the child meets ASD surveillance criteria];
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Abstract information in records
(e.g., behaviors related to ASD, co-occurring conditions, and test data)

Review abstracted information to
determine if the child meets ASD
surveillance criteria

Advantages of Using the ADDM Method in Minneapolis

1. Population-based rather than administrative-based
2. Gathers information on ASD status, clinical characteristics, co-occurring conditions, and age of diagnosis
3. Collects information from multiple sources (i.e., school and health sources)
4. Does not rely on previous ASD diagnosis
5. Collects information the same way using the same criteria for all children
6. Can be implemented in diverse communities with emerging concerns
7. Requires community partnerships that can continue to grow and develop

Key Project Findings

Based on children who were 7-9 years old and living in Minneapolis in 2010:



- ❑ Somali and White children were about *equally likely* to be identified with ASD. Somali and White children were more likely to be identified with ASD than Black and Hispanic children.
- ❑ Somali children with ASD were much more likely to have intellectual disability than children with ASD in other racial and ethnic groups.
- ❑ The average age of diagnosis among Somali children was about the same as White, Black and Hispanic children –about 5 years old.

Conclusion

- ❑ Largest project to date looking at number and characteristics of Somali children with ASD in any US community
 - Findings are limited to Minneapolis
 - Challenges in identifying ASD in racially/ethnically diverse groups

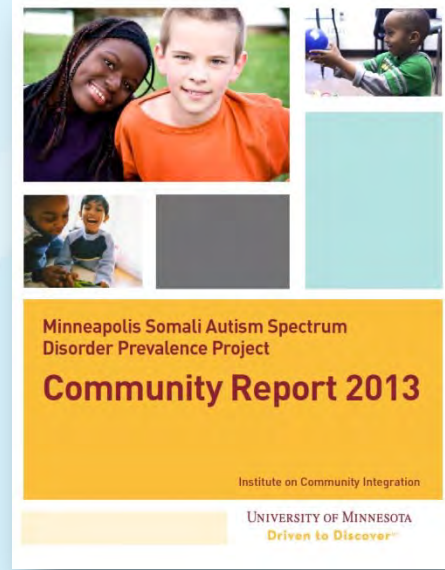
- ❑ Estimates are high but not unprecedented
 - Cannot make direct comparisons to CDC's ADDM Network data because of differences in person, place, and time (e.g., the last ADDM reporting period was 2008 and the Minneapolis reporting period was 2010)

- ❑ Children and families living in Minneapolis continue to need support, and they are not being identified as early as they could be
 - Findings can be used to make improvements (early identification efforts, service planning, etc.)
 - Future research can build upon findings to understand how and why ASD affects Somali and non-Somali children differently

Data Release Efforts

Proactive data dissemination

- Development and distribution of Community Report, Somali Parent One-Pager (English/Somali), videos/podcasts in Somali, project website
- Interviews with local and national media (i.e., Start Tribune, Associated Press, New York Times, etc.)
- Interviews (radio, TV, print) with Somali media
- Tweets and Facebook postings



Community engagement

- In-person meetings with project partners and with Somali Advisory on day of data release
- Presentation to Somali Health Coalition
- Outreach to MN Congresspeople
- Meetings with leaders of local mosques
- And it continues...



There are many Somali and non-Somali children with autism spectrum disorder. Make sure your child and family get the help they need.

What is autism spectrum disorder (ASD)?
ASD is a brain disorder that affects how a person thinks, communicates, and interacts with others in different ways. Most signs of ASD appear in early childhood. Children with ASD play, learn, speak, and act differently than other children. ASD is a lifelong condition, but symptoms may change and improve over time.

What was the Minneapolis Somali ASD Prevalence Project about?
Many Somali parents and others expressed a concern that there appeared to be more Somali children with ASD than other children. The University of Minnesota led a project to see how many children ages 7- to 9-year-old in Minneapolis have ASD. The project looked at Somali and non-Somali children.

What did this project find?

- About 1 in 33 Somali children ages 7-9 years in 2010 was identified as having ASD in Minneapolis. Somali and White children were more likely to be identified with ASD than Black and Hispanic children.
- Somali children with ASD were more likely to have an intellectual disability than children in other racial and ethnic groups in Minneapolis.
- The age at first ASD diagnosis was around 5 years for Somali, White, Black, and Hispanic children.

Why is this project important?

- Somali parents can use project findings to raise awareness of ASD among their family and friends.
- Educators, health care providers, and Somali advocates can use findings to promote early identification efforts and also encourage families to connect to services and supports as soon as possible.
- Researchers can use project findings to look at how and why ASD affects children differently.

What can I do if I think my child might have ASD?

- Talk to an educator or doctor about your concerns. Don't wait. Getting help early is important for your child.
- If your child is 5 years old or younger, call the **Help Me Grow Program** at 1-866-624-7310. Services are free to all children. It does not matter where your child was born.
- If your child is older than 5, contact your local school district's Special Education Director. More information is available at <http://www.mn.gov/education> or <http://www.mn.gov/education>.
- Ask a doctor who helps children and families with ASD. They are there to support you.

What should I do if I want to learn more about this project?
For more information about the project and how to request community resources at rtc.uminn.edu/autism, contact project staff: Anab Saleh, 612-624-0739, Kirstin Hamre, 612-625-7939 or autism@uminn.edu.

Institute on Community Integration
UNIVERSITY OF MINNESOTA
Driven to Discover™
rtc.uminn.edu/autism

Waxa jira carruur badan oo Soomaliyeed iyo Carruro kale oo badan oo qaba Cilladaha ootisamka (ASD) Ku dadaal in aad ilmahaaga iyo qoyskaaga u heshid kaalimo

Waxa maxay muhiimada muhiimada?

- Opayka Soomali waxa ay weli jira oo opayka muhiimada u dhexeysa kaarim in wax waligii galayso opayka kale iyo qaabka.
- Opayka muhiimada waxa ay kaalimo muhiimada, dalka muhiimada cilmuudka bayo, iyo Soomali u heshid kaalimo aay u dhigayso walidka aadi ay qaybka u dhexeysa waxa opayka u dhexeysa aay ugu badan inay ay dhacdo.
- Opayka muhiimada waxa ay u dhexeysa kaalimo muhiimada in ay baarano dhacdo ah iyo inay soo wariyo opayka muhiimada ASD u dhexeysa kaarim.

Maxaa samayn karaa haddii aan-umayyo in ilmahaaga ay qaba ASD?

- Waxa haddii dhacdo kaalimo muhiimada ama dhacdo muhiimada. Waxa ay inaad haddii dhacdo dhacdo ah wax muhiim.
- Opayka muhiimada ay jira kaarim aay ka ay wax waligii ama muhiimada **Help Me Grow**, 1-866-624-7310. Makuumidka waxa ay kaalimo muhiimada.
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Maxaa samayn karaa haddii aan-umayyo in ilmahaaga ay qaba ASD?

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Next Steps

- ❑ Translation of CDC's "Learn the Signs. Act Early" materials into Somali
 - Available on project website:
<http://rtc.umn.edu/autism/>
- ❑ Funding for the Somali Autism Community Engagement Project
- ❑ New ADDM Funding Opportunity Announcement (FOA)
- ❑ Opportunities through CDC's Study to Explore Early Development

**La soco
Marxaladaha Koboc
ee Cunuggaaga**



Koboca amminka hore ee cunuggaagu waa geeddi-socod. Adeegso khariiddada marxaladaha nolosha, si aad u ogaato waxyaabahaad mar walba eegayso.

habkaan ama nidaamkan sidaad ula socon laheyd ama ku ogan laheyd barbaarinta u dhaxeysa 0 to 4yrs

 Centers for Disease Control and Prevention
www.cdc.gov/ActEarly
1-800-CDC-INFO

Department of Health and Human Services
Centers for Disease Control and Prevention

Baro Astaamaha. Ammin horena ku Dhaqaaq.

Thank You!

Please visit the project website
to access project documents, tools, and resources:

<http://rtc.umn.edu/autism/>

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333

Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348

E-mail: cdcinfo@cdc.gov Web: www.cdc.gov

