

Minneapolis Somali Autism Spectrum Disorder Prevalence Project

Community Report 2013

Institute on Community Integration

UNIVERSITY OF MINNESOTA
Driven to DiscoverSM

Published December, 2013

Research & Training Center on Community Living (RTC), Institute on Community Integration (ICI)
University of Minnesota (U of M)

Authors: Amy Hewitt, *RTC, ICI, U of M*
Anab Gulaid, *RTC, ICI, U of M*
Kristin Hamre, *RTC, ICI, U of M*
Amy Esler, *Department of Pediatrics, U of M*
Judy Punyko, *Minnesota Department of Health*
Joe Reichle, *Department of Educational Psychology, U of M*
Michael Reiff, *Department of Pediatrics, U of M*

Graphic design: Connie Burkhart, *ICI, U of M*

Copy editors: Vicki Gaylord, *ICI, U of M*
Steve Baker, *College of Education and Human Development, U of M*
Steven Henneberry, *University Relations, U of M*

Technical assistance and funding was provided by the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and Autism Speaks, and managed through the Association of University Centers on Disability (AUCD). Additional financial support was contributed by the Minnesota Department of Health and the University of Minnesota's Institute on Community Integration.

The preparation of this report was supported by the National Institute on Disability Rehabilitation Research (NIDRR), U.S. Department of Education (Grant # H133B080005-09) awarded to Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

The opinions expressed are those of the authors and do not necessarily reflect those of the Research & Training Center on Community Living, Institute on Community Integration, University of Minnesota, or their funding sources.

The University of Minnesota is an equal opportunity educator and employer.

This document is available in alternate formats upon request. For alternate formats, contact —

Publications Office
Institute on Community Integration
University of Minnesota
109 Pattee Hall
150 Pillsbury Dr SE
Minneapolis, MN 55455

Tel: 612-624-4512
Email: icipub@umn.edu
Web: ici.umn.edu

The report can also be found at rtc.umn.edu/autism.

Recommended citation —

Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J. & Reiff, M. (2013). *Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

Contents

Executive summary p. 1

Project overview p. 2

- What is autism spectrum disorder (ASD)? **p. 2**
- Why do we need to know how many children have ASD? **p. 3**
- What was this project about? **p. 3**
- Why did this project focus on the Somali community? **p. 4**

What scientific method did this project use? p. 6

- What is prevalence? **p. 6**
- What is the ADDM Network method? **p. 7**
- What are advantages of using the ADDM Network method for this project? **p. 8**
- How have quality and accuracy been ensured? **p. 8**
- The role of the Somali community and advisory group **p. 9**

What did the project find? p. 10

- ASD prevalence in Minneapolis in 2010 **p. 10**
- Children with ASD and intellectual disability **p. 11**
- The average age when children were first diagnosed with ASD **p. 12**
- Where children with ASD were identified **p. 12**
- Limitations of this study **p. 12**

How should the information from this project be used by others? p. 13

Somali community perspective p. 14

- Parents and family members **p. 14**
- Professionals and community leaders **p. 14**

What information about ASD might be helpful? p. 15

- What do we know about the causes and risk factors for ASD? **p. 15**
- How can I tell if my child's development is on track? **p. 15**
- What resources are available in Minnesota if I think my child might have ASD? **p. 16**
- Treatments for conditions related to ASD **p. 19**
- How can I access medically necessary treatments of ASD? **p. 20**

Where can I get more information? p. 22

- Developmental milestones **p. 22**
- General information about ASD **p. 22**
- Local advocacy and information providers **p. 22**
- State agencies **p. 23**
- National resources **p. 23**
- Research **p. 24**

Who helped to make this project possible? p. 25

References p. 27



Executive summary

The Minneapolis Somali Autism Spectrum Disorder Prevalence Project was developed to determine if more Somali children aged 7-9 had autism spectrum disorder (ASD) than non-Somali children in Minneapolis in 2010. The project adopted the method used by the Centers for Disease Control and Prevention (CDC) to answer this question.

This project focused on comparing Somali and non-Somali children in Minneapolis to respond to community concerns about ASD in the Somali community. In 2008, Somali parents and others in Minneapolis expressed concerns to the Minnesota Department of Health (MDH) about what appeared to be more Somali children enrolled in Minneapolis Public Schools' preschool special education program for ASD as compared to the overall percentage of Somali children enrolled in the city's public schools. MDH shared the community's concerns and examined Minneapolis administrative data for preschool-age children enrolled in this program.

The Minneapolis Somali Autism Spectrum Disorder Prevalence Project is a next step to the MDH study. In October 2010, the Interagency Autism Coordinating Committee requested that federal agencies support additional ASD activities in Minneapolis. The CDC, the National Institutes of Health (NIH), and Autism Speaks funded the project and it was managed through the Association of University Centers on Disability (AUCD). The University of Minnesota's Institute on Community Integration and the Minnesota Department of Health provided additional funding. The project began in July 2011, and was completed in December 2013.

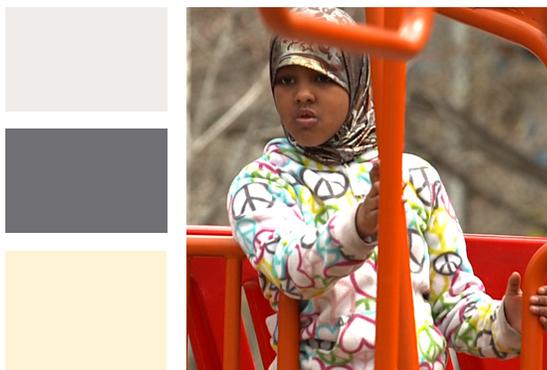
The key findings of this project include —

- The University of Minnesota estimates about 1 in 32 Somali children ages 7-9 years were identified as having ASD in Minneapolis in 2010.
- Somali and White children were about equally likely to be identified with 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 also have an intellectual disability than children with ASD in all other racial and ethnic groups in Minneapolis.
- The age at first ASD diagnosis was around 5 years for Somali, White, Black, and Hispanic children. This means that many children in Minneapolis are not being diagnosed as early as they could be.

This is the largest project to date that looked at the number and characteristics of Somali children with ASD in any U.S. community. However, these findings are limited to Minneapolis, and there are many challenges in identifying ASD in ethnically diverse groups. What we know for sure is that children and families living with ASD in Minneapolis continue to need support and that they are not being identified as early as they could be. These new findings can be used to make improvements so that all children in Minneapolis are identified and connected to appropriate services and supports as soon as possible. Future research can build upon these findings to understand how and why ASD affects Somali and non-Somali children and families differently.

It is important for parents and caregivers to act quickly whenever there is a concern about a child's development. Talk to the child's doctor right away — don't wait until the child starts school. Get help early.

More information can be found in the Community Report and online at <http://rtc.umn.edu/autism>.



Project overview

What is autism spectrum disorder (ASD)?

ASD is a developmental disability that can cause significant social, communication, and behavioral challenges. Symptoms of ASD appear in early childhood. It is usually a lifelong disorder, although symptoms change over time. People with ASD have a different way of understanding and reacting to people and events in their world. These differences are caused by the way their brains process information.

In the past, ASD was represented by three different diagnoses: 1) Autistic disorder, 2) Asperger disorder, and 3) Pervasive developmental disorder, not otherwise specified (PDD-NOS). These three diagnoses were recently combined into the one diagnosis of ASD. The term “spectrum” in ASD means that each person can be affected in different ways, and symptoms can range from mild to severe. People with ASD share some similar symptoms, such as problems with social interaction, problems with communication, and highly focused interests or repetitive activities. But, there are differences in how the symptoms affect a person’s functioning.¹

Diagnosis

At this time, there is no medical test, such as a blood test or brain scan, to diagnose ASD. Instead, it is diagnosed by qualified professionals who conduct comprehensive psychological and behavioral evaluations. These evaluations can include clinical observation, parental reports of developmental and health histories, psychological testing, and speech and language assessments. Also, neurologic and genetic testing can be used to rule out other disorders and to check for genetic or neurological problems that sometimes occur with ASD.²

A person with an ASD might —

- Not respond to his or her name by 12 months of age (e.g., appear to not hear).
- Not point at objects to show interest by 14 months of age (e.g., not point at an airplane flying over).
- Not play “pretend” games by 18 months of age (e.g., pretend to “feed” a doll).
- Avoid eye contact and want to be alone.
- Have trouble understanding other people’s feelings or talking about his or her own feelings.
- Have delayed speech and language skills (e.g., use words much later than siblings or peers or not use words to communicate).
- Repeat words or phrases over and over.
- Give unrelated answers to questions.
- Get upset by minor changes in routine (e.g., getting a new toothbrush).
- Have obsessive interests (e.g., have a very strong interest in trains that is difficult to interrupt).
- Flap his or her hands, rock his or her body, or spin in circles.
- Have unusual ways of playing with or using objects, such as spinning or lining them up repeatedly.
- Have unusual reactions to the way things sound, smell, taste, look, or feel.²

Why do we need to know how many children have ASD?

We need to know how many children have ASD so that realistic plans in our communities can be made to support these children and their families. Some of the resources that are needed include therapists, specially trained teachers, diagnosticians, health care providers, and related service professionals who know and can use effective interventions. Understanding the number and characteristics of children who have ASD is also key to promoting awareness of ASD and identifying important clues for further research.

Families living with ASD have unique stresses.³ If communities and service systems are not prepared to meet the needs of children and adults with ASD, it takes a toll on all family members. Therapies are expensive and waiting lists are long. Many parents even report having to stop work to care for their child with ASD.⁴ Annual medical expenditures per child with an ASD range from \$2,100 to \$11,200. Additionally, we know that intensive behavioral interventions for a child with an ASD can cost from \$40,000 to \$60,000 per year and that the nonmedical costs of special education for a child with an ASD are about \$13,000 per year.⁵ Eventually, the cost to individual families extends into lost productivity and other financial problems for communities.

What was this project about?

The main focus of the Minneapolis Somali Autism Spectrum Disorder Prevalence Project at the University of Minnesota's Institute on Community Integration was to answer the question, "Is there a higher prevalence of ASD in Somali children who live in Minneapolis versus non-Somali children?" Research questions were later expanded to include —

- What was the prevalence of ASD among children aged 7 through 9 years in Minneapolis in 2010?
- Was the prevalence of ASD among Somali children aged 7 through 9 years significantly different from non-Somali children in 2010?
- Were children of Somali descent with ASD more likely to be identified by school data sources rather than clinic data sources when compared with children with ASD who were not of Somali descent?
- Were children of Somali descent more likely to have an ASD classification identified in existing health and school records than children who were not of Somali descent?
- Were children of Somali descent more likely to be classified with ASD at a later age than children not of Somali descent?
- Were children with ASD and of Somali descent more likely to have intellectual disability than children with ASD who were not of Somali descent?

Specifically, the project looked at information on children who were between the ages of 7 to 9 during the year 2010. At least one parent was required to have been a resident of Minneapolis in 2010.

Project activities included —

1. Review of school and medical records.
2. Review of the child's records by a clinician reviewer (such as a clinical psychologist) to determine if the child meets the ASD definition used in this project.
3. Community collaboration regarding the project and its importance.

This project was funded by the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and Autism Speaks, and it was managed through the Association of University Centers on Disability (AUCD). Additional funding was provided by the University of Minnesota and the Minnesota Department of Health. The project began in July 2011, and was completed in December 2013.

"I know a father who quit his job to help with his son with ASD. The family struggles with the added demands of his care."

~ Community advocate

Why did this project focus on the Somali community?



Intellectual and developmental disability and/or mental health problems may be considered taboo and carry stigma within the Somali community.⁹ In addition, the Somali language lacks words to describe different types of developmental and mental health issues, and this often leads to challenges in communication. For instance, there is no Somali word for autism,⁹ and there are only two words to describe the status of individual's mental health ("crazy" and "sane").⁹

“In our culture you are either sane or you are crazy, there is no gray area. So there is a fear that someone will call your child a name behind your back”
~Somali parent

Somali community in Minnesota

In the early 1990s, thousands of Somali refugees came to United States after civil war erupted in Somalia, a country located in the horn of Africa. Thousands of Somalis were resettled in Minnesota and were later joined by family members.⁶

According to the 2010 American Community Survey, Minnesota's Somali population is the largest in the United States. The number of people of Somali ancestry in the state is approximately 32,000, with an estimated 85,700 living all across the United States.⁷ The estimate includes both people born in Somalia and their descendants. Other states that have large Somali populations include Ohio with 12,300, Washington with 9,300, and California with 7,500.⁸

Many Somalis live throughout the Twin Cities metropolitan area and increasingly in smaller cities and towns in southern Minnesota. Strong resettlement, social service, and refugee assistance agencies, as well as a relatively good job market, are reasons why so many Somalis have made Minnesota their home.⁶

The Somali community in Minnesota has a younger mean age (25-years-old) compared with the general population of Minnesota (37-years-old). This community tends to live in multigenerational households and many within the Somali population are Sunni Muslims.⁷

ASD in Minneapolis

In 2008, Somali parents and others in the Twin Cities expressed concerns to the Minnesota Department of Health (MDH) about what appeared to be more Somali children, ages 3 through 4, enrolled in Minneapolis Public Schools (MPS) preschool special education program for ASD as compared to the overall percentage of Somali children enrolled in the city's public schools. The program is called the Early Childhood Special Education (ECSE) Citywide ASD Classroom Program.

MDH shared the community's concerns and agreed to re-examine Minneapolis administrative enrollment data for preschool-age children in the ECSE program. The results of this study were published in a report, *Autism Spectrum Disorders Among Preschool Children Participating in Minneapolis Public Schools Early Childhood Special Education Programs*. (<http://www.leg.state.mn.us/docs/2009/other/090520.pdf>) This report provided information on the rates of preschool special education program participation in MPS only. It did not attempt to measure the true occurrence of ASD in all children, and it did not attempt to identify possible causes or risk factors for ASD. Instead, the focus was on developing a better understanding of

reported differences in program participation rates among preschool-aged children enrolled in this MPS program.

The MDH 2009 study had three main findings —

1. The proportion of Somali children, ages 3 and 4, who participated in the ECSE ASD program was higher than for children of other races or ethnic backgrounds. This finding confirmed what families had observed. But it was not known whether the difference resulted because there was a truly higher rate of ASD among Somali children; there was better outreach about the program to Somali families compared to other children; non-Somali children accessed ASD services outside of the MPS more often than Somali children; or other reasons.
2. The proportion of preschool Asian and Native American children who participated in the ECSE ASD programs was strikingly low. Again, it was not known whether this was because Asian and Native American children had truly lower rates of ASD, whether there was less effective outreach to these children who were eligible for ASD special education services, whether they were accessing services outside of the school system, or due to other reasons.
3. Differences in participation rates between preschool Somali children and preschool children of other races and ethnic backgrounds decreased substantially over the three school years studied. It was not known whether Somali children improved over time and no longer needed services; whether more non-Somali children were being identified; or other reasons.

Following the release of the 2009 MDH report, advocates from the Somali community voiced concern and called for further research. In October 2010, Idil Abdull, a Somali mother and advocate, spoke at an Interagency Autism Coordinating Committee (IACC) meeting to express her continued concerns about the number of Somali children with ASD living in Minneapolis. In response, the CDC, NIH, and Autism Speaks provided technical assistance and funds to the University of Minnesota through the Association of University Centers on Disabilities, to estimate the number of children with ASD living in Minneapolis, and to examine whether ASD is more common among Somali children than non-Somali children. The Minnesota Department of Health and the University of Minnesota's Institute on Community Integration added additional funding and in-kind staff time to the project.

“We are hiding because of the insults; we want to hide our children from that. We want people familiar with our cultures to educate the community. Take the taboo out of (autism) through education. You know in our community you are either sane or crazy. Parents feel shame.”
~ Somali parent



What scientific method did this project use?

What is prevalence?

Prevalence is a scientific term describing the number of individuals with a disease or condition among a defined group of people at a specific period in time. For example, CDC estimated the prevalence of ASD among 8-year-olds in 2008 in Atlanta, Georgia, by counting all of the 8-year-olds in Atlanta who were identified with ASD, and then dividing that number by the total number of 8-year-olds living in Atlanta during 2008.¹¹ For this project we counted the number of 7- to 9-year-olds in 2010 who were identified with ASD and then divided that number by the total number of 7- to 9-year-olds in Minneapolis during 2010.

Estimating the prevalence of ASD at any given time is not simple. Some challenges are —

1. The changing definition of ASD, which means more or fewer people could be classified as having ASD over time.^{12,13}
2. The lack of a medical test for ASD, which means that diagnosis depends on observations of behavior and development.
3. The inability to identify all children with ASD in a given population. Prevalence estimates are intended to approximate the true rate of ASD, although every child may not be identified.



“One of the biggest problems I am seeing now is parents’ lack of understanding of services available to their children such as transitional programs and after school programs (families of older children with disabilities don’t access these services). Parents are also isolating their children; you will see parents busy stopping their children to interact with other children in public places.... Some of these parents’ children are not diagnosed and they do not want people to know.” ~ Somali parent

Different ways of estimating the prevalence of children with ASD

Method	What Is It?	Advantages and disadvantages
Population screening and evaluation	Screening and evaluating a sample of all children in a population.	Can provide high accuracy, but can be costly and time-consuming, and might reflect bias based on who participates.
National surveys	Collecting information via standardized instruments such as telephone interviews or self-completed questionnaires.	Is representative of national characteristics but might reflect bias based on who participates and how ASD is defined and reported.
Registries	Collecting information on children and families who voluntarily include themselves on a list of people affected by ASD.	Relatively low cost, but time-consuming and includes only individuals with a clear diagnosis and families who know about the registry and are willing to be on the list.
Administrative data	Looking at service records from Medicare and agencies such as the U.S. Department of Education.	Relatively low cost, but underestimates prevalence because not all children with ASD are receiving services for ASD.
Systematic record review (ADDM Network method used in this project)	Reviewing health and special education records to identify children with ASD behaviors.	Cost-effectively provides estimate of the prevalence of ASD from large communities and identifies children who might not have a clear ASD diagnosis already. Also uses multiple sources of data collection to identify children served through schools and/or clinics. However, it relies on the quality and quantity of information in records.

Source: 14,15

What is the ADDM Network method?

The Autism and Developmental Disabilities Monitoring (ADDM) Network method was developed by CDC and is used to track the number and characteristics of children with ASD and other developmental disabilities in diverse communities across the United States. The ADDM Network has used the same method to track the number and characteristics of children with ASD for over a decade. The Minneapolis Somali Autism Spectrum Disorder Prevalence Project adopted the ADDM Network method for this project. The ADDM Network method uses the following two-stage, records-based approach^{16,17}—

1. Screening and abstraction of records

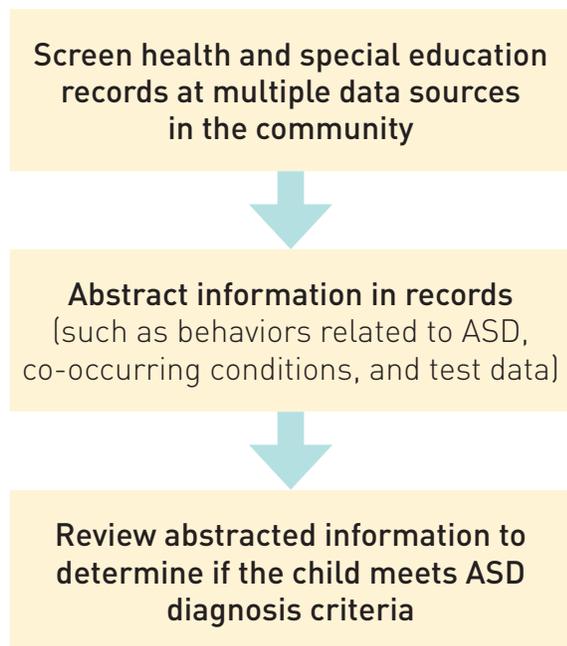
- Records are reviewed at multiple sources that educate, diagnose, treat, and provide services to children with developmental disabilities. Record review at multiple sources ensures as complete a count as possible of children with ASD. For example, a source may be a school or a pediatric clinic. All service records are reviewed and abstracted the same way.

Reviewing and abstracting records with the same criteria ensures prevalence is estimated similarly for all children.

2. Clinician review of records

- A panel of clinicians with expertise in identifying and assessing ASD reviewed abstracted information from service records using the *Diagnostic and Statistical Manual of Mental Disorders, (Fourth Revision, Text Revision)* definition of ASD. Clinicians determined whether the identified children met the definition of ASD used in this project and the ADDM Network. All service records were evaluated the same way. Evaluating records with the same criteria ensures prevalence is estimated similarly for all children.
- Record review does not rely solely on the presence of an ASD diagnosis, but also includes review of records for children who have behaviors consistent with ASD, even if they do not have a prior diagnosis.^{16,17}

The ADDM Network method



What are advantages of using the ADDM Network method for this project?

Data collected using the ADDM Network method can help explain if certain groups are more likely to be identified with ASD than others. Data collected using this method are also ideal for this type of project since data come from multiple sources in the community. For example, if a child was not being seen at a local clinic, that child could still be included in this project if they were receiving special education services at a local school. In addition, a child's ASD status does not depend on ASD tests or diagnoses, which can be delayed or overlooked, particularly among children from different cultures. Using the ADDM Network method, this project was able to estimate the number of children with an ASD diagnosis or ASD school eligibility, as well as the number of children with documented behaviors that indicate they have ASD but who have not yet been identified by a community provider, using the same method for all children. Lastly, the ADDM Network method requires many steps to ensure quality and precision, which can help ensure that the project results are accurate and unbiased.

How have quality and accuracy been ensured?

The Minneapolis Somali Autism Spectrum Disorder Prevalence Project undertook many steps to ensure quality and accuracy, including —

- Preparing a detailed proposal, which was reviewed by a team of experts.
- Obtaining approval from the Institutional Review Board (IRB) for the study.
- Hiring and training qualified individuals as a part of research and community teams.
- Developing partnerships with and gaining access to health and special education sources that provide data.
- Developing partnerships and engaging with the community as much as possible.
- Collecting data from health and special education sources.
- Checking data for quality and accuracy.
- Conducting and verifying detailed analyses by multiple agencies.

The standard criteria used as part of the ADDM Network method ensures that all records are evaluated and reviewed the same way and all children are defined as having ASD using the same definition.

CDC, NIH, and Autism Speaks monitored the project to ensure its quality and to make sure activities followed the methods agreed upon by the funders. The project coordinator had weekly meetings with a CDC project officer and weekly updates were sent to CDC, NIH, and Autism Speaks. The project leadership team, which included the project director, the project coordinator, and the Somali community leadership liaison, also had monthly calls with all the funders. For this project, CDC staff also monitored some of the data collection in Minneapolis and ensure reliability among abstractors and clinician reviewers. For instance, CDC conducted a site visit in November 2012 to review the study progress and to monitor study methods. During this site visit, CDC leadership met with project staff, attended a community advisory meeting, spoke with members of the Somali community, visited several health and special education partners, and reviewed the data collection process. CDC also verified the data analyses and findings.

The role of the Somali community and advisory group

This project involved the Somali community and other advisors in active roles related to communication and community access. Additionally, the questions included in this project expand beyond those that are reported in ADDM Network prevalence reports.

Community advisory group

University of Minnesota researchers made significant outreach efforts to engage the Somali community in this project. A community advisory group was established and provided important information on cultural issues that encouraged understanding of and participation in the project. The advisory group included Somali parents, advocates, health care professionals, and other individuals who care deeply about the community and results of this project. The community advisory group was established in July 2011 and met in October 2011, April 2012, August 2012, November 2012, February 2013, and December 2013. Members are listed on page 25.

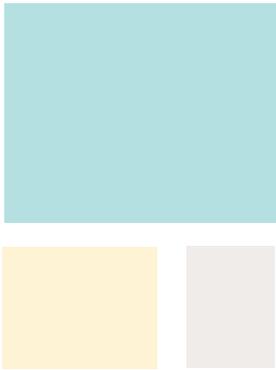
Community facilitators and liaison

Somali community facilitators were hired to be part of the project and work directly with the Somali community. The community facilitators made sure families and community leaders understood the goals and steps of the project from beginning to end. They also assisted with outreach to Somali media and the community at-large. The project was introduced at community meetings, mosques, Somali-run television and radio shows, Somali newspapers, and websites, as well as through informal community gatherings. In addition, the research team included a Somali community leadership liaison who served as a bridge between the community advisory group, the community facilitators, and the research team. This person attended research team meetings and shadowed some of the data collection process. Also, a person of Somali descent worked on the data collection process and coordinated communication efforts, which resulted in the development of this report as well as several additional communication tools and strategies designed to communicate the

results in a way that is useful for Somali community members. Such tools and strategies include specific outreach to Somali-run media, Somali leaders and advocates; the development of podcasts about ASD and current services and supports; as well as distribution of translated versions of the CDC's "Learn the Signs Act Early" brochure and booklet are available at rtc.umn.edu/autism.

“ What I hear from Somali families is that the children that are born here are the ones with ASD, not the ones born in African refugee camps. They said [nearly all of them], they rarely or never see ASD in Africa.”

~ Educator



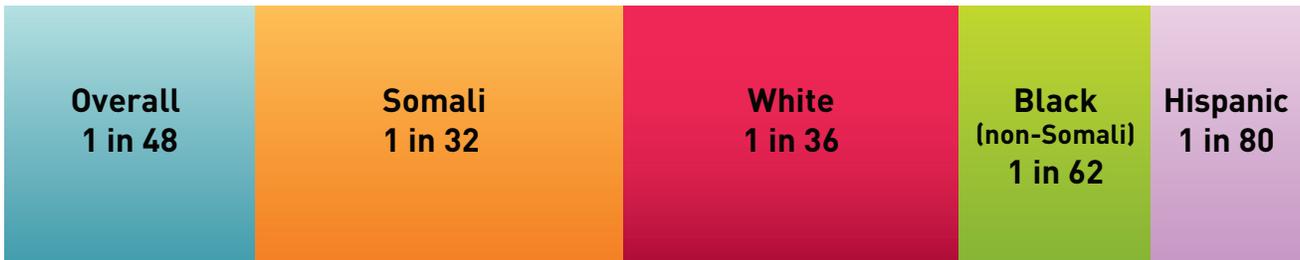
What did the project find?

ASD prevalence in Minneapolis in 2010

Number of 7- to 9-year-old children identified with ASD

The findings from this project are listed in this section along with the project limitations. The analyses were conducted by project staff at the U of M and the MDH. These findings were then independently verified by data analysts at the CDC.

By race and ethnicity



Race and ethnicity	Children with ASD identified/ Total population	Prevalence estimate (prevalence per 1,000 children)	95% Confidence interval*
Overall	255 of 12,329	1 in 48 (20.7 per 1,000)	18.3 – 23.4 per 1,000
Somali	31 of 1,007	1 in 32 (30.8 per 1,000)	21.6 – 43.8 per 1,000
White	120 of 4,336	1 in 36 (27.7 per 1,000)	23.1 – 33.1 per 1,000
Black (non-Somali)	53 of 3,312	1 in 62 (16 per 1,000)	12.2 – 20.9 per 1,000
Hispanic	30 of 2,399	1 in 80 (12.5 per 1,000)	8.7 – 17.9 per 1,000

Note: We are unable to report on Asian/Pacific Islanders and Native Americans due to their low numbers.

* 95% confidence interval is the range in which an estimate is likely to fall.

By gender

Overall male 1 in 30	Overall female 1 in 126
Somali male 1 in 20	Somali female 1 in 95
White male 1 in 23	White female 1 in 86
Black (non Somali) male 1 in 36	Black (non-Somali) female 1 in 189
Hispanic male 1 in 43	Hispanic female 1 in 400

- About 1 in 32 Somali children aged 7-9 years in 2010 was identified as having ASD in Minneapolis. Somali and White children were about equally likely to be identified with ASD in Minneapolis. Somali and White children were more likely to be identified with ASD than Black and Hispanic children in Minneapolis.
- The ASD estimates from Minneapolis are higher than most other communities where CDC has counted ASD, especially for Somali and White children. However, it is difficult to compare the estimates in Minneapolis with the estimates from CDC’s tracking system because they come from different points in time. Also, CDC’s overall estimate is an average based on 14 diverse communities across the United States whereas these estimates are based on only one urban community.
- It is unknown why Somali and White children were more likely to be identified with ASD than Black and Hispanic children in Minneapolis. This project was not designed to answer such questions, so future research is needed.
- The numbers of Native American and Asian children were so low in this project that meaningful conclusions could not be drawn about these children.
- Males were more likely to be identified in having ASD than females in all racial and ethnic groups in Minneapolis.

Children with ASD and intellectual disability

The percentage of children with ASD who also had a diagnosis of intellectual disability (ID) was identified through evaluations in records that included an Intelligence Quotient (IQ) score. Not all children had this information available in their education or clinic records. This information was available for 72% of the children identified with ASD. Children with ASD and ID were defined as those who had an IQ score less than 70.

Children with ASD who were identified as having ID

	Percentage of children with ID	Percentage of children missing IQ scores
Overall	33%	28%
Somali	100%	35%
White	20%	26%
Black (non-Somali)	30%	19%
Hispanic	22%	40%

- Somali children with ASD were more likely to also have ID than children with ASD in all other racial and ethnic groups in Minneapolis.
- It is unknown why Somali children with ASD were more likely to have ID than other children with ASD.
- It is important to note that information about whether or not a child had ID was not available for all children.

The average age when children were first diagnosed with ASD

Individuals with an ASD may play, learn, speak, and act differently than other people. Professionals gather information about the children through observation, interview, and tests in order to diagnose them with ASD.

	Average age in years	Age range in years
Overall	4.9	1.4 – 9.7
Somali	5.3	2.0 – 9.1
White	4.8	1.4 – 9.7
Black (non-Somali)	5.1	2.0 – 9.5
Hispanic	4.5	1.8 – 9.3

- The average age of the first ASD diagnosis for 7- to -9-year-old children in Minneapolis was around 5 years for Somali, White, Black (non-Somali), and Hispanic children. This means that many children in Minneapolis are not being diagnosed as early as they could be.
- Children with ASD can be reliably diagnosed around 2 years of age. Further research must be done to understand why children with ASD, especially those who also have intellectual disability, are not getting diagnosed earlier in Minneapolis.

Where children with ASD were identified

Service records were reviewed to help with identifying children with ASD. For the 255 children identified as having ASD, evaluations were found in either education or health records or both.

	School and health records	Health records only	School records only
Overall	36%	22%	42%
Somali	48%	10%	42%
White	38%	28%	33%
Black (non-Somali)	28%	11%	60%
Hispanic	33%	13%	53%

- White, Black (non-Somali), and Hispanic children were about as equally likely as Somali children to be identified at school and health sources.

Limitations of this study

To date, this is the largest project to look at the number and characteristics of Somali children with ASD in any U.S. community. However, these findings are limited to Minneapolis and there are challenges in identifying ASD in ethnically diverse groups. These findings tell us that there are differences in the number and characteristics of children with ASD across certain racial and ethnic groups in Minneapolis. The findings do not tell us why these differences exist. These findings support the need for additional research on why and how ASD affects Somali and non-Somali children and families differently.



How should the information from this project be used by others?

There are many children and families living with ASD in Minneapolis who continue to need services and supports. The information learned in this project is useful to families, service providers, clinicians, policymakers, advocates, and researchers. It can be used in many ways to improve policy, practices, and services and it can inform future research.

■ Families can use this information to —

- Understand more about ASD among children in Minneapolis, including which children are more likely to be identified with ASD and at what age they are likely to be diagnosed.
- Increase awareness and understanding of ASD among family and friends. There are materials to help parents monitor a child's development that have been translated into Somali. Several short videos were also developed to help teach the Somali community about ASD and ASD resources. These materials can be found at rtc.umn.edu/autism.
- Start a discussion with their child's doctor, their local early intervention program, or their local school, particularly if there is a concern about their child's development.
- Talk with local community leaders about promoting early identification of all young children with developmental problems.

■ Service providers and clinicians can use this information to —

- Plan and coordinate service delivery in Minneapolis.
- Promote early identification efforts in Minneapolis. Children with ASD can be reliably diagnosed as early as 2 years of age. Children with ASD in Minneapolis are diagnosed around 5 years of age. This finding can help service

providers and clinicians understand where improvements are needed so that all children in Minneapolis are identified and connected to appropriate services and supports as soon as possible.

■ Policymakers and advocates can use this information to —

- Promote awareness of ASD and bring the community together to address the growing needs of families living with ASD in Minneapolis.
- Develop policies and promote early identification and equity in access to services and supports so that all children have access to evaluations and services when they need them.
- Serve as the impetus for the creation of a task force or commission focused on the coordination of ASD activities in Minneapolis.

■ Researchers can use this information to —

- Inform future research projects, such as —
 - » Looking at why Somali children are more likely to have ASD and ID than other children with ASD.
 - » Understanding why and how ASD affects Somali and non-Somali children differently.
 - » Exploring how experiences during pregnancy and early childhood among ethnically diverse communities impact child development.
- Serve as an impetus for the creation of an ASD community research consortium in Minneapolis and Minnesota.
- Identify how tools used to screen and diagnose children with developmental disabilities take into account cultural differences.



Somali community perspective

During this project, it was important to hear from community members about how ASD affects families, particularly in the Somali community. Advisors were invited to take part in a focused discussion. The discussion was organized into two groups, one representing parents, and the other representing professionals and community leaders. Several key themes emerged from those discussions.

Parents and family members

Parents reported that ASD is “taboo” within the Somali community and many feel shame if their child is given the ASD label. This can lead to the diagnosis being hidden from the community. This is partially due to a significant cultural stigma found within the Somali community that may be rooted in religious and cultural beliefs. In addition, it is often difficult to explain the diagnosis of ASD to family members because they do not understand what ASD is.

It was also reported that parents are often unsure of where to go for support and how to advocate for their child in school and clinic settings. Some parents reported the spread of potential of misinformation about the causes of ASD, which leads to avoidance of the measles, mumps, and rubella (MMR) vaccine. There is also confusion about whether ASD can be “cured” and what treatments are available.

Parents shared stories about the challenges of having a child diagnosed with ASD, such as having to stop work or school to tend to their child’s needs, increased stress, and lack of sleep. At the same time, parents described joys and strengths they have gained through the process of parenting a child with ASD, such as gaining patience and strength, becoming a more considerate person, experiencing an unimaginable level of love, and becoming more educated.

Professionals and community leaders

Community leaders and professionals, which included service providers, educators, and community advocates, reported similar perceptions of the effects of ASD within the Somali community. They perceive a significant impact on Somali mothers, including isolation and stigma from the rest of the community. Challenges that were identified by the providers include long waiting periods for diagnosis, obtaining late diagnosis after the child has entered school, lack of knowledge and information, and a belief that children may outgrow ASD. Many providers reported knowing families who took their child back to Somalia to get healed. In general, the providers and leaders indicated that Somali families are not being reached and are often unaware of what services and funding are available for their children with ASD.

Key concerns

The following key concerns emerged during the discussions with the two groups —

- There is a wide perception in the community that Somali children with ASD have more severe symptoms compared to non-Somalis.
- There is a wide belief that ASD did not exist in Somalia and that children who have ASD were born abroad.
- There is concern that many people in the Somali community are not getting their children vaccinated because of the fear of the unknown. In particular, parents are fearful of MMR vaccines.
- The community needs answers about the cause and prevalence of ASD.
- The community needs more targeted outreach to break down stigma, and access early intervention and treatment.



What information about ASD might be helpful?

What do we know about the causes and risk factors for ASD?

Most scientists who study ASD believe that there is no single cause. Research has shown that —

- Both genetic and non-genetic factors play a role in whether or not a person will have ASD.
- Children who have a sibling with ASD are at a higher risk of having ASD.
- Children born to older parents also are at a higher risk of having ASD.
- ASD tend to occur more often among people who have certain genetic or chromosomal conditions. About 10% of children with ASD also have been identified as having Down syndrome, fragile X syndrome, tuberous sclerosis, or other genetic and chromosomal disorders.
- When taken during pregnancy, the prescription drugs Valproic acid and Thalidomide have been linked with a higher risk of ASD.
- A small percentage of children who are born prematurely or with low birth weight are at a greater risk for having ASD.

How can I tell if my child’s development is on track?

There are many resources for parents interested in tracking their child’s development. First and foremost, your child should have a consistent primary care provider (e.g., pediatrician, nurse) whom you trust and feel comfortable talking with. The American Academy of Pediatrics¹⁸ recommends seeing your pediatrician for well-child checks on a regular schedule. Visits can include physical measurements, patient history, hearing and vision screenings, behavioral assessments, and planned procedures (screenings and other tests). It is recommended that screening measures for general developmental concerns be given at well-checks at 9, 18, 24, and 30 months. At 18 and 24 months, screening specific to ASD is strongly recommended for *all* children. Further developmental evaluation is required whenever a child fails to meet any of the following milestones: babbling by 12 months; gesturing (e.g., pointing, waving bye-bye) by 12 months; single words by 16 months; two-word spontaneous (not just repeating what was just said) phrases by 24 months; or loss of any language or social skills at any age.

Interagency Autism Coordinating Committee

ASD is one of few conditions that has a federal advisory committee tasked with coordinating all efforts within the Department of Health and Human Services concerning ASD. The Interagency Autism Coordinating Committee is key to helping us answer the questions that remain about ASD. For more information, please visit iacc.hhs.gov.

“I have seen my child make tremendous gains when her specific needs were matched to the services she received. What works for one child does not work for another.”
~ Somali parent

Recommended schedule for well-child checks

3 to 5 days
1 month
2 months
4 months
6 months
9 months
12 months
15 months
18 months
24 months
30 months
3 years
4 years
And once every year thereafter for an annual health supervision visit that includes a physical exam as well as a developmental, behavioral, and learning assessment.

There also are several online resources for tracking your child's development and for identifying signs of ASD and other developmental disorders —

- **Help Me Grow Minnesota**
<http://helpmegrowmn.org>
- **Baby Development Tracker**
www.parents.com/baby/baby-development-tracker/
- **Learn the Signs. Act Early**
www.cdc.gov/Actearly
- **Developmental Milestones Checklist**
www.cdc.gov/Milestones
- **Questions and Answers about Developmental Milestones**
www.med.umich.edu/yourchild/topics/devmile.htm

What resources are available in Minnesota if I think my child might have ASD?

First, you should talk to your child's healthcare provider, who should have checklists with questions for you to answer to see whether your child is showing risk signs for ASD. However, even if the checklists do not clearly show concerns, *you should still pursue an evaluation for ASD if you OR your healthcare provider have concerns.* In many cases, simply the presence of parent or healthcare professional concerns about ASD is a good indicator that ASD or another developmental disorder might be present, and further intervention is needed.¹⁴

Your child's school district is another good resource for seeking further evaluation or services. If your child is a preschooler or toddler, **Minnesota's Help Me Grow** program is a good resource that can connect you with your local Early Intervention program. You also can contact Help Me Grow to talk to an early childhood specialist about your child's development.

Early intervention services

Minnesota Public Education

■ Help Me Grow

Services are free of charge.

» Infant and Toddler Intervention

For children from birth through 2 years of age and their families. Services will vary based on the child's and family's needs.

www.parentsknow.state.mn.us/parentsknow/age1_2/HelpMeGrow_SpecialNeeds/WhatisHelpMeGrow/index.html

» Preschool Special Education

For children 3 through 5 who have a disability and are eligible for preschool special education services that are individually tailored to meet the unique learning needs of each child.

www.parentsknow.state.mn.us/parentsknow/age3_5/HelpMeGrow_SpecialNeeds/WhatisHelpMeGrow/index.html?selectedTab=Overview

Audio and print content is available in Hmong, Somali, Spanish and English. Phone: 1-866-693-GROW (4769).

If your child is school age, you should also bring your concerns to your healthcare provider, and the school system is again a good place to find further evaluation and interventions. In the public schools, parents can request a special education evaluation at any time. If your child does not already receive special education, the first step would be to talk to his/her teacher about your concerns. Your teacher may be able to work with you to connect with the special education referral team and determine what, if any, assessments should be considered. If you want to request a special education evaluation directly, you need to do so in writing, to your child's school. For more information —

■ **Special Education**

Services are free of charge.

» *Local School District Special Education Services*

An Individualized Education Program (IEP) is designed with parents to provide free appropriate public education for eligible individuals birth to 21 years with ASD and other disabilities. Contact your local school district's special education director for information.

<http://w20.education.state.mn.us/WebsiteContent/SpecEdDirectors.jsp>

Diagnosis and assessment

There are specialty clinics for ASD in the Minnesota/Twin Cities area. Some insurance providers require that children receive a diagnosis from a licensed psychologist or medical doctor before they will cover intervention services in the community. Contact your insurance provider for specific guidance.

■ **Autism Spectrum Disorder Clinic**

University of Minnesota/Amplatz Children's Hospital
717 Delaware Street SE, Suite 340
Minneapolis, MN 55414
612-625-3617

www.umphysicians.org/Clinics/autism-spectrum-and-neurodevelopmental-disorders-clinic/

■ **Children's Hospitals and Clinics of Minnesota**

Multiple locations
www.childrensmn.org

■ **Fraser Child and Family Center**

2400 W 64th St
Minneapolis, MN 55423
612-769-7222
www.fraser.org

■ **Gillette Children's Hospital**

Multiple locations
www.gillettechildrens.org

■ **Mayo Clinic**

200 First Street SW
Rochester, MN 55905
www.mayoclinic.com

■ **Park Nicollet Alexander Center for Child Development**

8455 Flying Cloud Drive, Suite 205
Eden Prairie, MN 55344
952-993-7600
www.parknicollet.com/specialtycenters/alexander-center

■ **Rosenberg Center**

1935 County Road B2, Suite 100
Roseville, MN 55113
651-636-4155
www.rosenbergcenter.com

■ **St David's Center**

Main Campus
3395 Plymouth Road
Minnetonka, MN 55305
952-939-0396
www.stdavids.net

Intensive intervention providers

Interventions using a comprehensive behavioral approach have the strongest evidence for improving outcomes for children with ASD.²⁰ These interventions typically involve a full-time program of therapy individualized to your child's needs either within your home or a specialized center. Another common term for these types of therapies is applied behavior analysis (ABA).

There are a number of organizations in Minnesota that provide ABA services, designed to support a child in learning new skills and behaviors and reducing unwanted behaviors —

ABA providers in Twin Cities area

- **Autism Matters**
11606 Wayzata Blvd
Minnetonka, MN 55305
952-544-0349
www.autismmatters.net
- **Behavioral Dimensions, Inc.**
7010 Highway 7
St Louis Park, MN 55426
952-814-0207
behavioraldimensions.com
- **Behavior Therapy Solutions**
700 Commerce Dr, Suite 260
Woodbury, MN 55125
651-328-6280
www.btsofmn.org
- **Fraser Child and Family Center**
2400 W 64th St
Minneapolis, MN 55423
612-769-7222
www.fraser.org
- **Helena Center**
5301 E River Rd #110
Fridley, MN 55421
763-432-3926
www.minnesotautismtherapy.com
- **Holland Center**
10273 Yellow Circle Dr
Minnetonka, MN 55343
952-401-9359
www.hollandcenter.com

- **Lazarus Project**
3021 Harbor Lane N, Suite LL105
Plymouth, MN 55447
www.lazarusprojectmn.org
- **LIFE Midwest: Lovaas Institute**
2925 Dean Parkway, Suite 300
Minneapolis, MN 55416
612-925-8365
www.lovaas.com
- **Minnesota Early Autism Project (MEAP)**
7242 Forestview Line N
Maple Grove, MN 55369
763-425-0792
www.meapkids.org
- **Minnesota Autism Center**
5710 Baker Rd
Minnetonka, MN
952-767-4200
www.mnautism.org
- **Partners in Excellence**
7380 France Ave, Suite 100
Edina, MN 55435
952-358-6220
www.partnersmn.com

ABA providers in greater Minnesota

- **Behavioral Dimensions, Inc.**
7010 Highway 7
St Louis Park, MN 55426
952-814-0207
behavioraldimensions.com
- **Minnesota Autism Center**
3380 Northern Valley Plane NE
Rochester, MN
507-923-4000
www.mnautism.org
- **Rochester Autism Center**
3640 9th St NW
Rochester, MN 55901
507-424-3234
www.rcautism.com

Social skills groups

Social skill difficulties are common for children with ASD. Social skills groups can significantly improve social competence and social skill development.^{20,21} Often, these groups focus on recognizing common (spoken and unspoken) social cues and learning skills like holding a conversation, negotiating play with peers, handling difficult situations, and even more advanced adult skills like job interviews and dating. Many children receiving special education will attend a social skills group as part of their educational intervention plan at school. There also are social skills groups available in the community in the Twin Cities —

- **Autism Society of Minnesota**
651-647-1083
ausm.org
- **Fraser Child and Family Center**
612-861-1688
fraser.org
- **Rosenberg Center**
651-636-4155
www.rosenbergcenter.com
- **University of Minnesota
Autism Spectrum Disorder Clinic**
Contact Desirae Rambeck at 612-624-0171
- **West Metro Learning Connections**
www.wmlc.biz/our-services/social-skills-therapy

“The children are very hyperactive, some are uncontrollable, run everywhere, and stay awake 24/7.”
~ Community advocate

Treatments for conditions related to ASD

Many children with ASD have difficulties with speech/language development, attention, behavior, motor coordination, and/or mood.²²⁻²⁶ Some children also have dietary issues due to limited diets or food sensitivities.²⁷ Many children also have sleep problems.^{28,29} These are often referred to as “related conditions,” and the following therapies are often used to address them²⁰ —

- Speech/language therapy
- Occupational therapy
- Physical therapy
- Individual and/or family counseling
- Family consultation to address problem behaviors in the home

The following websites may include resources for these therapies and others in Minnesota —

- **Autism Society of Minnesota**
www.ausm.org (downloadable resource guide)
- **Autism Speaks, Minnesota resources**
www.autismspeaks.org/resource-guide/state/MN

Are there any medications to treat ASD?

There is no medication for ASD itself, but medications can help the frequent co-existing symptoms of attention-deficit/hyperactivity disorder (ADHD), sleep problems, behavioral outbursts, mood regulation, anxiety or depression. Families should consult closely with their healthcare provider when considering medication treatments. A referral to a healthcare provider specializing in developmental and behavioral disabilities (e.g. developmental behavioral pediatrician or psychiatrist) may be warranted.

Are there dietary and nutritional interventions that might help with ASD symptoms?

Gluten free, casein free diet (GFCF)

Many families of children with ASD are interested in dietary and nutritional interventions that may help with some of their child's symptoms. The GFCF diet has received a lot of attention due to reports

that removing gluten (a protein found in barley, rye, wheat, and sometimes oats) and casein (a protein found in dairy products) from a child's diet can be helpful in reducing some symptoms of ASD or associated behavior problems. The theory behind this diet is that some children with ASD absorb nutrients differently, and this affects their brain function. So far, research on the GFCF diet has not supported it as an effective intervention for ASD symptoms, but more research is needed. Children who clearly show behavioral or physical symptoms after eating gluten or casein may benefit from this diet. Consultation with a dietitian or healthcare provider is strongly recommended for the healthy application of a GFCF diet. This may be especially true for children who are picky eaters.

Multivitamins

Again, due to the concern that children with ASD might absorb nutrients differently, vitamin and supplement interventions are sometimes recommended. Present research does not support the use of megadoses of vitamins, such as taking vitamin B-12 shots, but taking a general multi-vitamin or probiotics is sometimes recommended. This is especially the case for children who are picky eaters and have a restricted diet.

The role of vitamin D in ASD also has been a subject of investigation. There is very limited evidence suggesting that vitamin D deficiency prenatally or in early childhood may be an environmental trigger for ASD in individuals genetically predisposed for ASD. However, researchers emphasize the need for further research before verifying a relationship between vitamin D and ASD.³⁰

Other interventions

There is a large number of biomedical or complementary/alternative treatments available for children with ASD. Unfortunately, these treatments have not yet been scientifically proven as effective. Many parents opt to try some of these treatments to see if they have any specific benefit to their children. Parents are strongly recommended to consult with their healthcare provider to make sure of any potentially harmful effects that may result or that may interact with their child's other treatments. For more information on complementary/alternative treatments for ASD, see <http://takingcharge.csh.umn.edu/conditions/autism-spectrum-disorders>

How can I access medically necessary treatments of ASD?

Medically necessary treatment for children with ASD may be available through public health insurance. Medical Assistance (MA) and MinnesotaCare are public health care programs for eligible people who live in Minnesota. You may apply for these programs in either of these ways —

1. Complete a Minnesota Health Care Programs Application at <https://edocs.dhs.state.mn.us/Ifserver/Public/DHS-3417-ENG>, or
2. Apply online at, "ApplyMN" www.applyminnesota.com

Apply as soon as possible. It can take up to two months for your application to be reviewed.

If you need help filling out the application or have questions about the Minnesota Health Care Programs, you can contact the MHCP Member Helpdesk, 651-431-2670 or toll free at 800-657-3739. The Member Helpdesk can answer questions and can connect you with other services available such as application agents to help you fill out the application. Please indicate if you need language assistance. Interpreter services are available upon request.

In Minnesota, there currently is no separate, specific or single county, medical, or human services program for children with ASD. In 2013, the Minnesota Legislature approved a new benefit specifically intended for children with ASD. That benefit will be available no earlier than March of 2014, and upon federal approval. While the new autism intensive intervention benefit is being developed, children with ASD may continue to have access to —

- Speech therapy
- Occupational therapy
- Physical Therapy
- Children's Therapeutic Services and Supports (CTSS)

CTSS is available in managed care and fee-for-service for children from birth through age 20 with a range of emotional difficulties including ASD. Some CTSS providers currently provide behavioral interventions such as applied behavior analysis (ABA) to children including those with ASD under "skills training" services. CTSS services also include

psychotherapy and skills training services for individuals, groups, and families. If you have public health insurance (Medical Assistance) and want to contact an eligible Children's Therapeutic Services and Supports (CTSS) provider for services, information is available at www.dhs.state.mn.us/ctssproviders.

The Minnesota Department of Human Services offers other services to help children with more severe disabilities including ASD live in the community and receive daily living and support. These services include —

- **Home and community based services (commonly called the "waiver")** provides services and supports to maintain children in their own homes instead of an institution.
- **Personal care assistance (PCA)** provides services to children who need help with day to-day activities to allow them to be more independent in their own home.
- **Family support grant** provides funding to prevent or delay the out-of-home placement of children with disabilities and promote family health and social well-being by facilitating access to family-centered services and supports.

A child may have to meet certain guidelines to be eligible for these programs and some programs have waiting lists. More information can be found at www.dhs.state.mn.us/dsdprograms or the Disability Linkage Line® (DLL) at 866-333-2466 (toll-free). Click on this link, "pathways to services for children with autism spectrum disorders (ASD)."



Where can I get more information?

Developmental milestones

- CDC Learn the Signs Act Early program**
 Resources about child development, developmental delays, examples of what to say to health care professionals, and tips about what to do if you have to wait for an appointment.
www.cdc.gov/ActEarly
 Somali version available at: rtc.umn.edu/autism

General information about ASD

- CDC Autism Information Center**
 Full range of resources for parents, educators, researchers, and practitioners. Information about developmental milestones.
www.cdc.gov/autism
- Autism Speaks**
 Information about ASD, research into its causes and treatments, free resources available to families and individuals, and efforts to raise awareness about the ASD.
www.autismspeaks.org
- American Academy of Pediatrics**
 Resources for parents and providers, including interviews with pediatricians, researchers, and parents.
www.aap.org/healthtopics/autism.cfm
- National Institutes on Health (NIH)**
 Recommended NIH resources for ASD including mental health, environment, communications, genetic, and neurological perspectives.
health.nih.gov/search_results.aspx?terms=Autism

Local advocacy and information providers

- The Arc Greater Twin Cities**
 Information and referral services, individual advocacy, family education, and benefit assistance.
www.arcgreatertwincities.org
- The Arc of Minnesota**
 Information on the human rights of people with intellectual and developmental disabilities, and supporting them to live in the community.
www.thearcofminnesota.org
- Autism Society of Minnesota**
 Education, advocacy, and support for families and people with ASD.
www.ausm.org
 Content is also available in Spanish, Hmong, Somali, Lebanese, Arabic, and Hebrew.
- Family Voices of Minnesota**
 Families of people with special healthcare needs helping others navigate the system.
<http://familyvoicesofminnesota.org>
 Content is also available in Spanish.
- PACER Center**
 Parent Advocacy Coalition for Educational Rights.
www.pacer.org
 Content is also available in Hmong, Somali, and Spanish.

State agencies

- **Help Me Grow**
 Infant and toddler early intervention and preschool special education.
education.state.mn.us/MDE/JustParent/EarlyLearnKReadi/HelpMeGrow/
 Content is also available in Hmong, Somali, and Spanish.
- **Minnesota Children with Special Health Needs**
 General ASD information.
www.health.state.mn.us/cyshn
 Content is also available in Hmong, Somali, and Spanish.
- **Minnesota Department of Human Services**
 Provides services to Minnesota’s most vulnerable residents.
www.dhs.state.mn.us
 Content is also available in Arabic, Hmong, Khmer, Lao, Oromo, Russian, Serbo-Croatian/Bosnian, Somali, Spanish, and Vietnamese.
- **New Americans Project, Vocational Rehabilitation Services**
 Provides vocational rehabilitation services to recent immigrants with disabilities. Services include help finding a job and keeping a job.
<http://mn.gov/deed/vrs>
- **Minnesota Department of Education**
 Provides support and technical assistance to local school districts to ensure a high quality education for Minnesota’s children and youth with disabilities.
<http://education.state.mn.us/MDE/index.html>

National resources

- **Association of Maternal and Child Health Programs**
 Home of the State Public Health Autism Resource Center, a comprehensive resource center for Title V programs and others interested in improving systems for children and youth with ASD and their families.
www.amchp.org/programsandtopics/CYSHCN/projects/spharc

- **Educating Children with Autism**
 Review of early intervention, preschool, and school programs designed for young children with ASD by the National Academy of Sciences.
www.nap.edu/books/0309072697/html/
- **Early Childhood Technical Assistance Center**
 Early Childhood Research and Resource Portal provides access to a variety of primary sources, research and reference materials.
ectacenter.org/topics/autism/autism.asp
- **National Autism Center**
 Provides information, promotes best practices, and offers comprehensive resources for families, practitioners, and communities.
www.nationalautismcenter.org
- **NIH-National Institute of Mental Health**
 Information about the process of diagnosing ASD and about treatment options, including medications used to help people with ASD.
www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml
- **National Professional Development Center on Autism Spectrum Disorders (NPDC-ASD)**
 A multi-university center (FPG Child Development Institute, M.I.N.D. Institute and Waisman Center) promoting use of evidence-based practice for children and adolescents with ASD.
autismpdc.fpg.unc.edu
- **The Pediatrician’s Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children**
 Treatments and interventions physicians use to treat ASD in this report from the American Academy of Pediatrics.
pediatrics.aappublications.org/cgi/content/full/107/5/e85
- **Operation Autism. A Resource Guide for Military Families**
 Directly supports U.S. military families touched by ASD. Sponsored and maintained by the Organization for Autism Research.
www.operationautisonline.org

Research

■ CDC Study to Explore Early Development (SEED)

Information about the largest study in the United States to help identify factors that might put children at risk for ASD and other developmental disabilities.

www.cdc.gov/SEED

■ Interactive Autism Network (IAN)

Online project that links the ASD community and researchers.

www.ianproject.org

■ Interagency Autism Coordinating Committee (IACC)

Information about the IACC and IACC approved Strategic Plan for Autism Research.

www.iacc.hhs.gov

■ Clinical Trials

A searchable database that provides patients, family members, and the public with information about current, ongoing clinical research studies.

www.clinicaltrials.gov or 301-496-4000

■ The Autism Science Foundation (ASF)

Information about the ASF, which provides funding to scientists and organizations conducting, facilitating, and promoting ASD research.

www.autismsciencefoundation.org
or 646-723-3978

■ NIH-National Institute on Deafness and Other Communication Disorders

Information about what ASD is, who is affected, how it influences communication, how speech and language problems are treated, and research to improve communication in children with ASD.

www.nidcd.nih.gov/health/voice/Pages/Communication-Problems-in-Children-with-Autism-Spectrum-Disorder.aspx

■ NIH-National Human Genome Research Institute

Information about ASD symptoms, diagnosis, treatment, inheritance, clinical research, and resources.

www.genome.gov/25522099

■ NIH-Eunice Kennedy Shriver National Institute of Child Health and Human Development

Information on what ASD is, treatment, prognosis, research, clinical trials, organizations and more.

www.nichd.nih.gov/health/topics/autism/conditioninfo/Pages/default.aspx

■ NIH-National Institute of Environmental Health Sciences

A list of links on health studies and clinical trials, research, general information, and information for educators.

www.niehs.nih.gov/health/topics/conditions/autism/index.cfm

■ NIH-National Institute of Mental Health

Information about ASD, also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. Links to publications, science news, meeting summaries and more.

www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml

■ NIH-National Institute of Neurological Disorders and Stroke

Information on what ASD is, treatment, prognosis, research, clinical trials, organizations and more.

www.ninds.nih.gov/disorders/autism/autism.htm

■ Organization for Autism Research (OAR)

Information about OAR's mission to apply research to the challenges of ASD and access their resources for families and providers.

www.ResearchAutism.org or 703-243-9710

■ Research and Training Center on Community Living at the University of Minnesota

Information on research, training, technical assistance, and dissemination about community living. Additional information about ASD and the Somali ASD Prevalence Project.

rtc.umn.edu/autism



Who helped to make this project possible?

This project was a collaborative effort among many dedicated and concerned community members; local, state, and national agencies; advocates; and project staff. Without their involvement this project would not have been possible, and we are thankful for their support and unwavering commitment.

Community advisory group members

- Idil Abdull, *Parent and Somali American Autism Foundation co-founder*
- Abdulirahem Adem, *MPS*
- Ismail Ahmed
- Dr. Osman M. Ahmed (Harare), *East Africa Health Project*
- Shelly Brandl, *Fraser*
- Barb Dalbec, *MDH*
- Kaltun Dubbe, *Parent*
- Mariam Egal, *Advocate*
- Saeed Fahia, *Confederation of Somali Community in Minnesota*
- Ann Fox, *MPS*
- Said Garaad, *MPS*
- Anne Harrington, *DHS*
- Farhan Hussein, *The Lighthouse Academy*
- Jennifer Daulman Johnson, *Arc GTC*
- Farhio Khalif, *The Farhio Khalif Show*
- Mohamed Mohamud, *Somali American Parent Association*
- Osob Mohamed
- Abdirashid Warsame, *Ubah Medical Academy*
- Ladan Yusuf, *Hennepin County*
- Hussein Samantar, *African Development Center*
- Hassan Samantar, *PACER Center, Inc.*

Community collaborators

- **School sources**
 - Minneapolis Public Schools
 - Participating charter schools
- **Clinic sources**
- **Community consultants**
 - Minnesota Department of Education
 - Minnesota Department of Administration

Funders

- Association of University Centers on Disability
- Centers for Disease Control and Prevention
- National Institutes of Health
- Minnesota Department of Health
- Minnesota Department of Human Services
- University of Minnesota
- Autism Speaks

Project staff and consultants

Investigators

- Amy Hewitt, *Principal Investigator, RTC, ICI, U of M*
- Joe Reichle, *Co-Principal Investigator, Department of Educational Psychology, U of M*
- Amy Esler, *Co-Principal Investigator, Department of Pediatrics, U of M*
- Michael Reiff, *Investigator, Department of Pediatrics, U of M*

Coordinators

- Anab A. Gulaid, *Communication Coordinator, RTC, ICI, U of M*

- Kristin Hamre, *Project Coordinator, RTC, ICI, U of M*
- Quannah Parker-McGowan, *GRA, RTC, ICI, U of M*

Abstractors

- Denise Bryan, *RTC, ICI, U of M*
- Anab A. Gulaid, *RTC, ICI, U of M*
- Jen Hall-Lande, *RTC, ICI, U of M*
- Susan Madden, *RTC, ICI, U of M*
- Kelly Nye-Lengerman, *RTC, ICI, U of M*
- Vicki Bondurant, *Independent Consultant*
- Andrew Intveld, *Independent Consultant*
- Tamara Teague Watson, *Independent Consultant*

Clinic Reviewers

- Monica DiRienzo, *Independent Consultant*
- Meredith Hepburn, *Independent Consultant*
- Nancy Hobson, *Independent Consultant*
- Andrea Hoog, *Independent Consultant*
- Judy Reaven, *Independent Consultant*
- Julie Rusyniak, *Independent Consultant*
- Walter Zahorodny, *Independent Consultant*

Information technology

- John Westerman, *RTC, ICI, U of M*
- Kristin Dean, *RTC, ICI, U of M*

Research consultants

- John Connett, *Division of Biostatistics, U of M*
- Judy Punyko, *Minnesota Department of Health*
- Sohoon Hong, Kristine Piescher, and Traci LaLiberte, *Minnesota Linking Information for Kids (Minn-LInK), U of M*

Community facilitators and liaisons

- Halima Abdulahi, *Community Facilitator*
- Amira Adawe, *Community Liaison*
- Hodan Hassan, *Community Facilitator*
- Istaahil Malin, *Community Facilitator*
- Nasro Mohamed, *Community Facilitator*
- Anab Guliad, *Community Facilitator*



References

1. American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, D.C.: Author.
2. CDC. *Screening and diagnosis*. Last modified May 13, 2010. Retrieved from <http://www.cdc.gov/ncbddd/autism/screening.html>
3. Schieve L.A., Boulet S.L., Kogan M.D., Yeargin-Allsopp M., Boyle C.A., Visser S.N., Blumberg S.J., & Rice C. (2011). Parenting aggravation and autism spectrum disorders: 2007 national survey of children's health. *Disability and Health Journal*, 4 (3), 143-52.
4. Kogan M.D., Strickland B.B., Blumberg S.J., Singh G.K., Perrin J.M., & van Dyck P.C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*, 122 (6):e 1149-58.
5. Amendah D., Grosse S.D., Peacock G., & Mandell D.S. (2010) The economic costs of autism: A review. In Amaral, D., Geschwind, D., & Dawson, G. (Eds.), *Autism spectrum disorders*. New York: Oxford University Press, Inc.
6. Kusow, A., & Bjork, S. (2007). *From Mogadishu to Dixon: The Somali diaspora in a global context*. Lawrenceville, N.J.: Africa World Press/The Red Sea Press, 2007. Retrieved from <http://academic.evergreen.edu/g/grossmaz/somali.html>
7. *Somalis in Minnesota: Common medical issues and cultural concerns of Somali patients*. Retrieved from <http://culturecareconnection.org/matters/diversity/somali.html>
8. Williams, C. (2011). *New census data: Minnesota Somali population grows*. *Star Tribune*. Retrieved from <http://www.startribune.com/132670583.html?refer=y>
9. Russell, S. (2009). Somalis deal with the reality and stigma of mental illness. *Minneapolis Bridgeland News*. Retrieved from <http://www.bridgelandnews.org/7912>
10. Antell, R. & Pierce, E. (2013). *No word For autism*. Retrieved from www.nowordforautism.com
11. Center for Disease Control (CDC). (2012). Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, United States, 2008. *Morbidity and Mortality Weekly Report*, 61 (3), 1-19.
12. Fombonne E. (2003). Epidemiologic surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism Developmental Disorders*, 33 (4), 365-82.
13. Rutter, M. (2005). Incidence of autism spectrum disorders: Changes over time and their meaning. *Acta Paediatr*, 94, 2-15.
14. Teutsch, S.M. & Churchill, R.E. (2000). *Principles and practice of public health surveillance: 2nd ed*. New York: Oxford University Press.
15. Van Naarden Braun, K., Pettygrove, S., Daniels, J., Miller, L., Nicholas, J., Baio, J., Schieve, L., Kirby, R.S., Washington, A., Brocksen, S., Rahbar, H., & Rice, C. (2002). *Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders*. Autism and Developmental Disabilities Monitoring Network, 14 sites, United States.
16. Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C. & Murphy, C. (2003). Prevalence of autism in a U.S. metropolitan area. *JAMA*, 298 (1), 49-55.

- 17.** Center for Disease Control (CDC). (2007). Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000. In: *Surveillance Summaries*, February 9, 2007. *Morbidity and Mortality Weekly Report*, 56 (No. SS-1), 1–11.
- 18.** Hagan, J. F., Shaw, J.S., & Duncan, P.M. (2008). *Bright futures: Guidelines for health supervision of infants, children, and adolescents*. Elk Grove Village, IL: American Academy of Pediatrics.
- 19.** Wetherby, A.M., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism Developmental Disorders*, 34 (5), 473–493.
- 20.** Wilczynski, S., Green, G., Ricciardi, J., Boyd, B., Hume, A., Ladd, M., & Rue, H. (2009). *National standards report: The national standards project: Addressing the need for evidence-based practice guidelines for autism spectrum disorders*. Randolph, MA: National Autism Center.
- 21.** McConnell, S.R. (2002). Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. *Journal of Autism Developmental Disorders*, 32 (5), 351–372.
- 22.** Leyfer, O.T., Folstein, S.E., Bacalman, S., Davis, N.O., Dinh, E., Morgan, J., Tager-Flusberg, T., & Lainhart, J.E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of Autism Developmental Disorders*, 36 (7), 849–861.
- 23.** Matson, M.L., Matson, J.L., & Beighley, J.S. (2011). Comorbidity of physical and motor problems in children with autism. *Research in Developmental Disabilities*, 32 (6), 2304–2308.
- 24.** Kanne, S.M., & Mazurek, M.O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism Developmental Disorders*, 41 (7), 926–937.
- 25.** Mazurek, M.O., Kanne, S.M., & Wodka, E. L. (2013). Physical aggression in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7 (3), 455–465.
- 26.** Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47 (8), 921–929.
- 27.** Schieve, L.A., Gonzalez, V., Boulet, S.L., Visser, S.N., Rice, C.E., Braun, K.V.N., & Boyle, C. A. (2012). Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006–2010. *Research in Developmental Disabilities*, 33 (2), 467–476.
- 28.** Gail Williams, P., Sears, L.L., & Allard, A. (2004). Sleep problems in children with autism. *Journal of Sleep Research*, 13 (3), 265–268.
- 29.** Malow, B.A., Crowe, C., Henderson, L., McGrew, S.G., Wang, L., Song, Y., & Stone, W.L. (2009). A sleep habits questionnaire for children with autism spectrum disorders. *Journal of Child Neurology*, 24 (1), 19–24.
- 30.** Kočovská, E., Fernell, E., Billstedt, E., Minnis, H., & Gillberg, C. (2012). Vitamin D and autism: Clinical review. *Research in Developmental Disabilities*, 33 (5), 1541–1550.