

rtc on community living

Minneapolis Somali Autism
Spectrum Disorder Prevalence
Project

Community Providers Meeting

April 28, 2014

Acknowledgements

- Community advisors
- Community partners
 - MDE, DHS, Minneapolis Public Schools, charter schools, clinic sources
- AUCD, CDC, NIH and AS
- Project staff
- LEND Fellows

What Is Prevalence?



Minneapolis ASD Prevalence Project Overview

Overall Project Objectives

- Estimate ASD population prevalence for children ages 7 through 9 years with at least 1 parent a resident of Minneapolis in 2010
- Compare ASD prevalence by subgroup to assess differences in population prevalence
- Engage the Community
- Conduct Case Verification



Initial Research Question

“Is there a higher prevalence of autism in Somali versus non-Somali children who live in Minneapolis?”



Expanded Research Questions

- What was the **prevalence** of ASD among children aged 7 through 9 years 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 at school data sources** than clinic data **sources** 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?
- Did children with ASD of Somali descent have the **same degree of severity rated by the clinical reviewer** as children with ASD who are not of Somali descent?
- Did children with ASD of Somali descent have the same **distribution of ASD symptoms** noted in records as children with ASD who are not of Somali descent?

CDC ADDM Network Public Health ASD Surveillance Methodology

- A retrospective & records-based design
 - *Identify* children meeting age & residency criteria from multiple sources
 - *Abstract* information from records that contain “triggers”
 - Detailed descriptions of behaviors, developmental delays, co-occurring conditions; ASD & other eval results; evaluator’s summary diagnosis
 - *Review* records using standardized coding scheme based on DSM-IV-TR to determine a child’s surveillance ASD status

Screen health and special education records at multiple data sources in the community



Abstract information in records
(such as behaviors related to ASD, co-occurring conditions, and test data)



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

ADDM Network

■ Current (2010 and 2012) ADDM Network Sites:

- Alabama, Arizona, Arkansas, Colorado, Georgia/CDC, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, Wisconsin

■ Data Gathering/Reporting Cycle

- 2010 data released
 - 1/68 children have ASD (14.7/1,000)
 - 31% have ID
 - Proportion varied by race/ethnicity (48% black non Hispanic, 38% Hispanic and 25% non Hispanic white)
 - Non-Hispanic white children 30% more likely to have ASD than non-Hispanic black; and 50% more likely than Hispanic
 - Median age of diagnosis 53 months (4.4 years)

Eligibility Criteria

Population

- Ages 7 through 9 in 2010 (born between 2001 through 2003)
- One parent/custodial guardian a resident of the City of Minneapolis in 2010
- 12,329 Total 7-9 year olds who met criteria
 - 4,336 White
 - 4,319 Black (non Somali)
 - 1,176 Hispanic
 - 1,007 Somali
 - 900 Asian/Pacific Islander
 - 375 Native American

Rationale

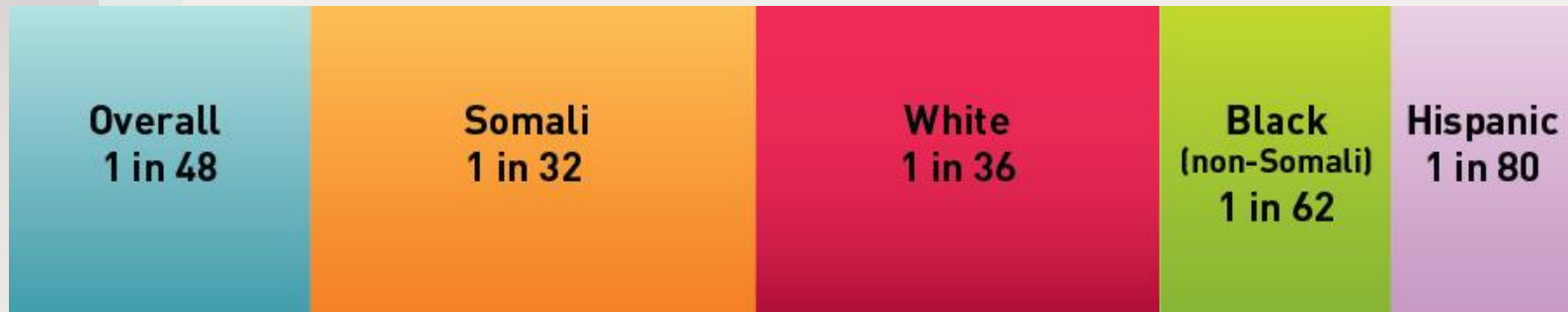
- Base population requirement: 10,000-15,000 children
- Age range with age 8 as the midpoint
- 2010 U.S. Census data

Limitations

- Minneapolis only
 - Cannot be generalized
 - Other age groups in Minneapolis
 - Other calendar years
 - Other MN communities
 - US or internationally
- Did not have 100% case ascertainment so likely an underestimate
- No information on causation
- Relies on educational administrative data without confirmation of diagnosis

Findings

Prevalence Of ASD Among Children Aged 7 Through 9 In 2010 by Race and Ethnicity

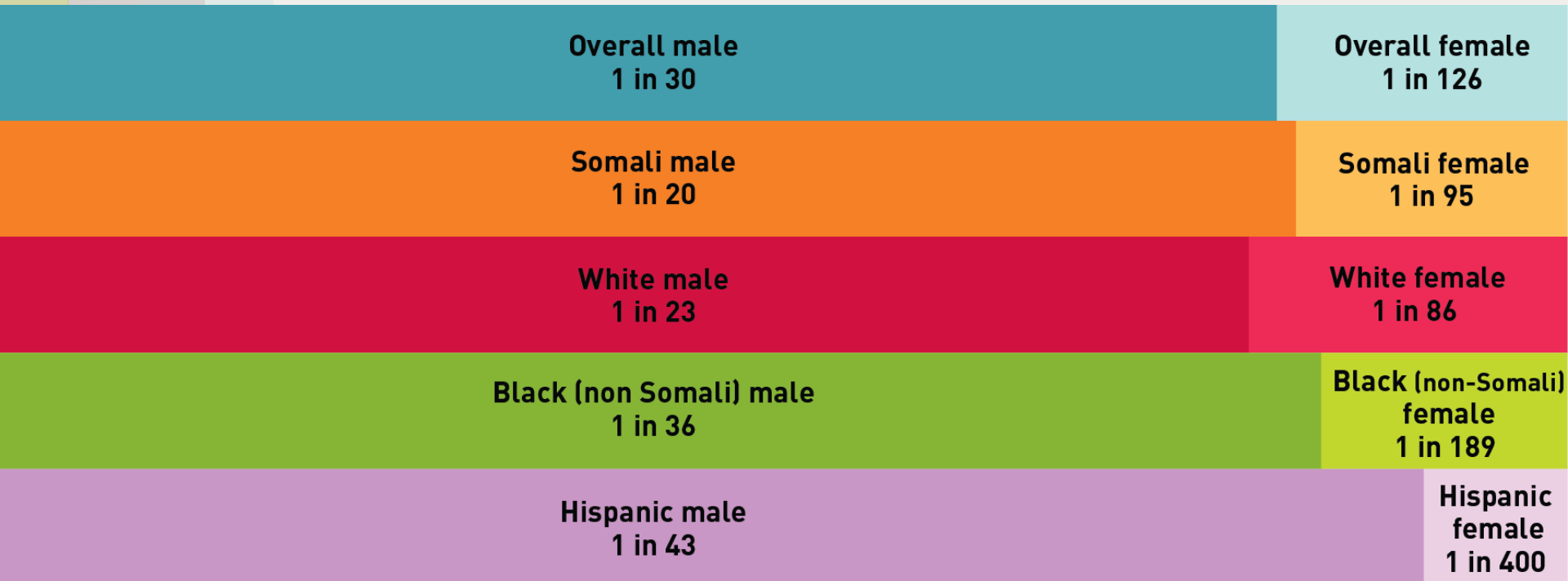


Race and ethnicity	Children with ASD identified/ Total population	Prevalence estimate (prevalence per 1,000 children)	95% Confidence interval*
Overall	255 of 12,329	1 in 48 (20.7 per 1,000)	18.3 – 23.4 per 1,000
Somali	31 of 1,007	1 in 32 (30.8 per 1,000)	21.6 – 43.8 per 1,000
White	120 of 4,336	1 in 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.

Prevalence Male and Female



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%

The Average Age When Children Were First Diagnosed 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

Where Children With ASD Were Identified

	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%

Community Findings

Stigma of IDD, Autism, Mental Health

- No words for autism
- Regarding mental health only “crazy” and “sane”

“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

“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

“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

Somali Families Need Information and Access to Services

“Unless parents know the different areas that the therapist can work on with their children and follow through they will not get what they need. Parents should be able to easily follow the program. Evaluate their child’s progress and should tell the therapist to move to the next goal.”

Families and Community Want “Cause” Answer

“The most tragic thing I am seeing is that a lot of moms are holding off on vaccines, especially MMR. We are a story-telling community, and so they hear not to do it. It seems like every parent is against immunization. The risk is not only ASD, but we are also exposing our kids to more illnesses. If you get fever or rubella, it only takes one bad fever to put a kid in to a coma.”

■ Vaccination

- MMR vaccination decline in MN
- Strong belief and advocacy
 - Divided community with different opinions and beliefs about ASD
- Families and professionals
- No cure, no cause

Communication and Outreach: Resources and Tools YOU Can Use

Autism Awareness Materials

- <http://rtc.umn.edu/autism/>
- Podcasts (in Somali & Subtitled)
 - [What is Autism or Autism Spectrum Disorders?](#)
 - [Parent story](#)
 - [Current Treatments](#)
- Learn the Signs Act Early (Translated Materials)
 - [Brochure](#)
 - [Booklet](#)
- [One page summary](#)
 - Findings
 - What is Autism
 - Who I should talk to



For More Information

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