Autism Spectrum Disorder Prevalence Project
Minneapolis, Minnesota

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WELCOME
TO
Minnesota

- Somali population is largest in U.S.
- Early 1990's at time of civil war
- Strong settlement, social services, refugee support agencies, job market
- Somali mean age 25 yrs compared to general population 37 yrs
- Multigenerational households

Community concerns around ASD

- Ongoing concerns about rates of Somali children with ASD
  - Educators: Early intervention, K-12
  - Professional advocates: PACER, Arc
  - Somali community and families
  - Receiving local and some national attention.

Minnesota Department Of Health Investigation

- **ASD Prevalence Somali children > non-Somali** school years, program types
- **Somali: non-Somali** ASD ratios ranged from **2-7 times** greater for Somali children but differences decreased rapidly over the 3 school years
- ASD for Asian, Native American children **strikingly low**

Minneapolis ASD Prevalence Project Overview

- **Overall Project Objectives**
  - Estimate ASD prevalence for children in Minneapolis ages 7-9 in 2010
  - Compare ASD prevalence by subgroup to assess differences in population prevalence
  - Provide quantitative and qualitative data
  - Conduct Case Verification
  - **Engage the Community*****

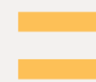
Primary Research Question

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

What Is Prevalence?

Number of 7- to 9-year-olds with ASD in Minneapolis

Total number of 7- to 9-year-olds in Minneapolis



PREVALENCE

as defined in this project

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?
- What was the **experience** of Somali families around ASD?

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

Minneapolis Surveillance Data Sources

ADDM 2008 Surveillance

9 sites: education and health sources

6 sites: health sources

Minnesota 2010 Surveillance

Education and health sources

** ADDM sites with health only access tend to have lower ASD prevalence estimates, suggesting the importance of including school records in ASD surveillance.*

Study Population

MPS children ages 7-9 in 2010

- One parent/custodial guardian a resident of Minneapolis in 2010
- 12,329 total children
  - 4,336 White
  - 4,319 Black (non Somali)
  - 1,176 Hispanic
  - 1,007 Somali
  - 900 Asian/Pacific Islander
  - 375 Native American

Quantitative Findings To Date

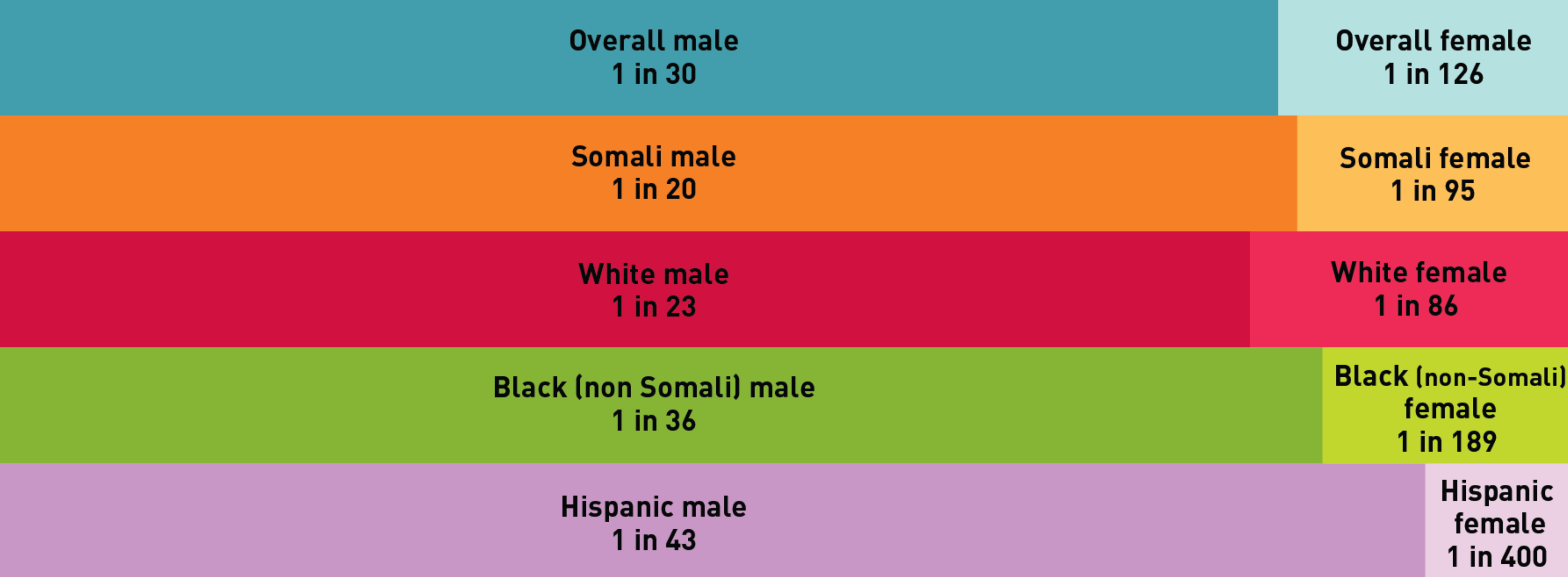
Prevalence Of ASD Among Children Aged 7 Through 9 In 2010 by Race and Ethnicity

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



Findings: ASD Prevalence

- 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.
- The ASD estimates from Minneapolis are **higher than most other communities where CDC has counted ASD, especially for Somali and White children**.

** *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.*

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%

Children With ASD and Intellectual Disability

- **Somali children with ASD were more likely to also have ID** than children with ASD in all other racial/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

	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 When Children Were First Diagnosed With ASD

- 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.

Community Findings
Qualitative Data

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

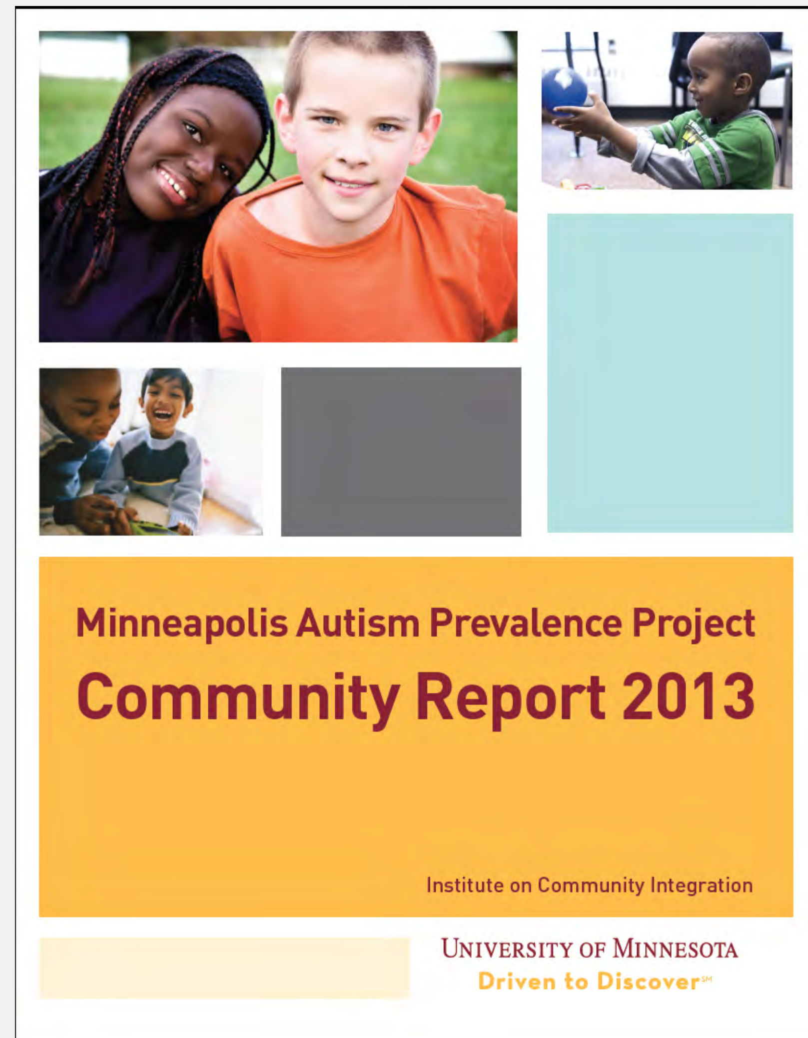
Somali Families Need Information and Access to Services

"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."

Communication and Outreach: Resources and Tools

Community Report

- Executive Summary
- Project Overview
- What scientific methods did we use?
- What did we find?
- Community perspective
- How can information from this project be used by others?
- What are some important questions to answer?
- What additional information about autism might be helpful?
- Where can I get more information?
- Who helped make this project possible?
- References



Autism Awareness Materials

- http://rtc.umn.edu/autism/
- Podcasts (in Somali & Subtitled)
  - What is Autism or Autism Spectrum Disorders?
  - Parent story
  - Current Treatments
- One page summary
  - Findings
  - What is Autism
  - Who I should talk to

Learn the Signs Act Early

- Significant community outreach with Act Early
- Translated materials
- Built network of community delegates from diverse communities to spread the act early message.

Dissemination and Outreach Plans

- Meetings with partners and advisors
- Press release
- Somali community specific engagement activities
- Ongoing outreach events in Somali community
- Meet and work with health care clinics and providers, immigrant and refugee providers, state agencies, Somali advocates, and parents

Specific Somali Focused Strategies

- Compile Somali media contact List
- Conduct Interviews with Somali Media
  - Televisions
    - Somali TV MN
    - Somali Media TV
    - Somali Mai TV
  - Radios
    - KFAI African American Show
    - Somali Public radio
    - Somalida Maanta
    - BBC Somalia
    - Voice of America Somali
- Press
  - Soomalida Maanta
  - Warsan Times
- Internet sites
  - Mogodishu Times
  - Hiiraan Online
  - Bartamaha
  - African News Journal
- List Servs
  - eDemocaracy
  - Metro Refugee task force
- Outreach
  - Community leader meetings
  - Somali community events
  - Friday Mosque event or Sunday teaching event

What Families Can Do With the Results

- Learn more about the early signs of ASD
- Start a discussion with doctor or teacher
- Increase awareness about ASD in community
- Talk with local community leaders about need for better awareness, early identification and equity in access to care for all children

What Service Providers and Clinicians Can Do With the Results

- Promote early identification in Minneapolis
  - Identify where improvements are needed
  - Better know where outreach should be directed

- Coordinate service delivery in Minneapolis

What Policymakers and Advocates Can Do

- Promote awareness of ASD and bring the community together to address growing needs
- Develop policies and promote early identification and equity in access so that all children have access to evaluation and treatment
- Use as an impetus to the creation of a Minneapolis and/or Somali task force on ASD

What Researchers Can Do With the Results

- Inform future research projects
  - Case verification
  - Intervention related to assessment and diagnosis access
  - Access and equity in service delivery for Somali and Non-Somali children
  - Service outcome analyses for Somali and Non-Somali
- Use as an impetus for the creation of a community research consortium in Minneapolis

University of Minnesota Next Steps

- Continued community engagement
  - Post release activities
  - Begin conversations about the implications of findings
    - Systems needs (e.g. MDE, DHS, MDH)
    - Practice (e.g. assessment, diagnosis)
    - Research (e.g. on-going surveillance, beyond Mpls)
- Further Research
  - Additional analyses and technical report
  - Verification
  - ADDM site

Thank you!