
Minnesota Autism Developmental Disabilities Monitoring Network

# Autism Prevalence Data: 2021 findings and how to use them

January 26, 2022

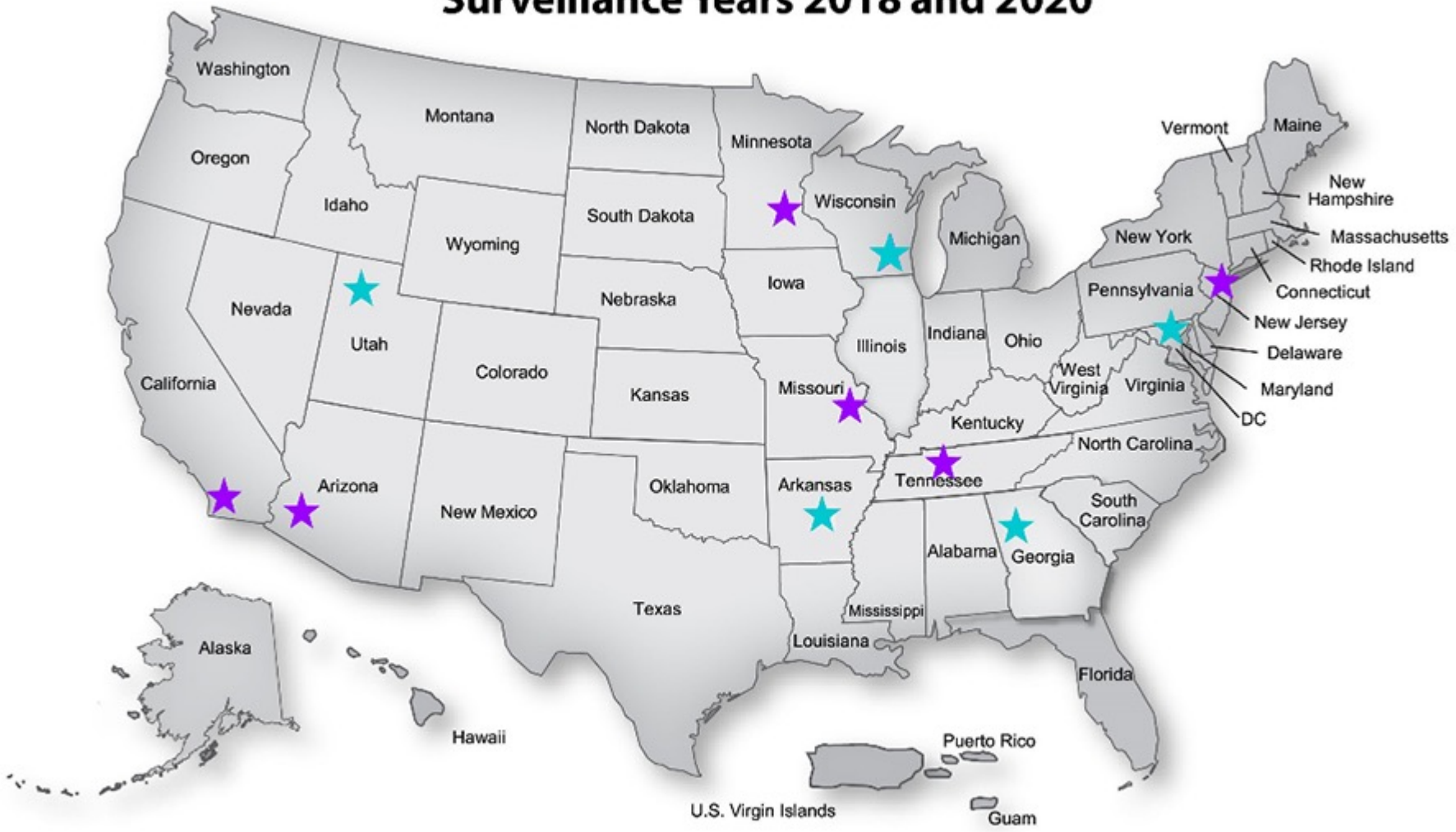
University of Minnesota
Driven to Discover®

# Autism Developmental Disabilities Monitoring (ADDM) Network

## ADDM is the largest, ongoing tracking system for ASD in the U.S.

- Describes population of children with ASD in communities in the U.S.
- Compares how common ASD is in different parts of the country.
- Provides information on age of identification.
- Identifies trends in ASD occurrence over time.

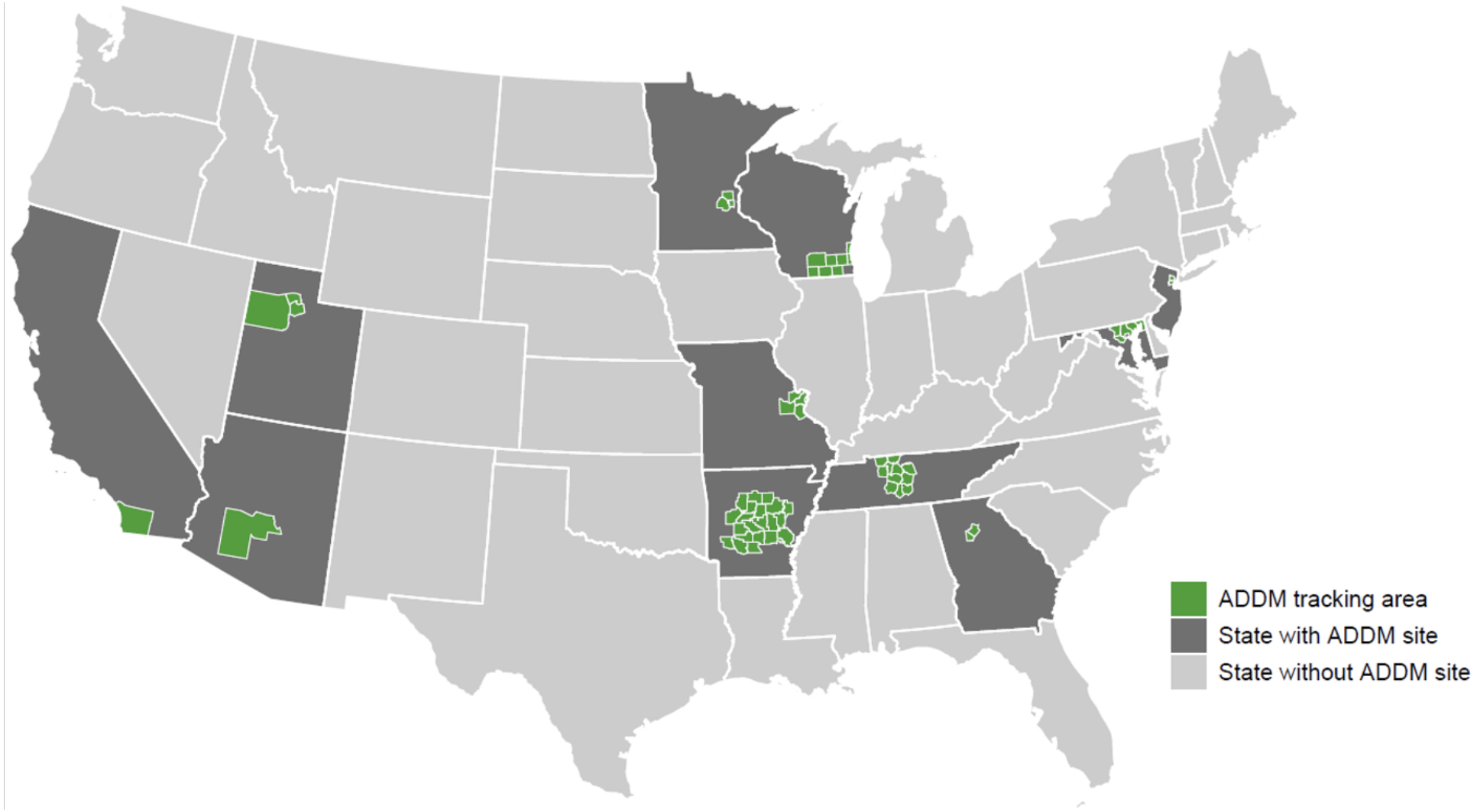
# Autism and Developmental Disabilities Monitoring (ADDM) Network Sites, Surveillance Years 2018 and 2020




Tracking Autism among 4- and 8-year-olds

Tracking Autism among 4- and 8-year-olds AND Follow-up of 16-year-olds

# Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



# New Methods in SY2018
# ADDM Ascertainment and ASD Case Definition

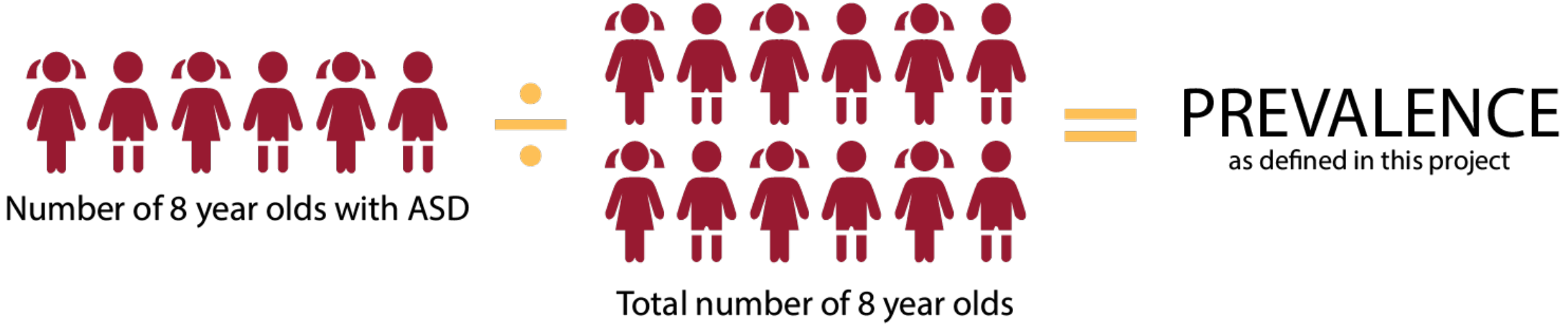
Records that included various billing codes from the *International Classification of Disease, Ninth Revision* (ICD-9) or *International Classification of Diseases, Tenth Revision* (ICD-10) or special education eligibility codes were requested from health and education sources. Children ages 4 or 8 who had a parent or guardian who lived in one of the surveillance areas during 2018 were classified as having ASD or suspected ASD if they met the below criteria.

| ASD case definition | Suspected ASD case definition |
|---|---|
| Child has documentation of ever receiving:<br>1) a written ASD diagnosis by a qualified professional,<br>2) a special education classification of autism, OR<br>3) an ASD ICD code obtained from administrative or billing information | **(4-year-old only)**<br>Child does not meet criteria of full case definition but there is a qualified examiner's diagnostic statement that the child is suspected of having ASD |

# Previous Methods, 2000-2016 ADDM Ascertainment and ASD Case Definition

# New Methods SY2018

# Prevalence


Number of 8 year olds with ASD
Total number of 8 year olds
PREVALENCE
as defined in this project

# “What is the prevalence of ASD for 8-year-old children?”

# ADDM findings

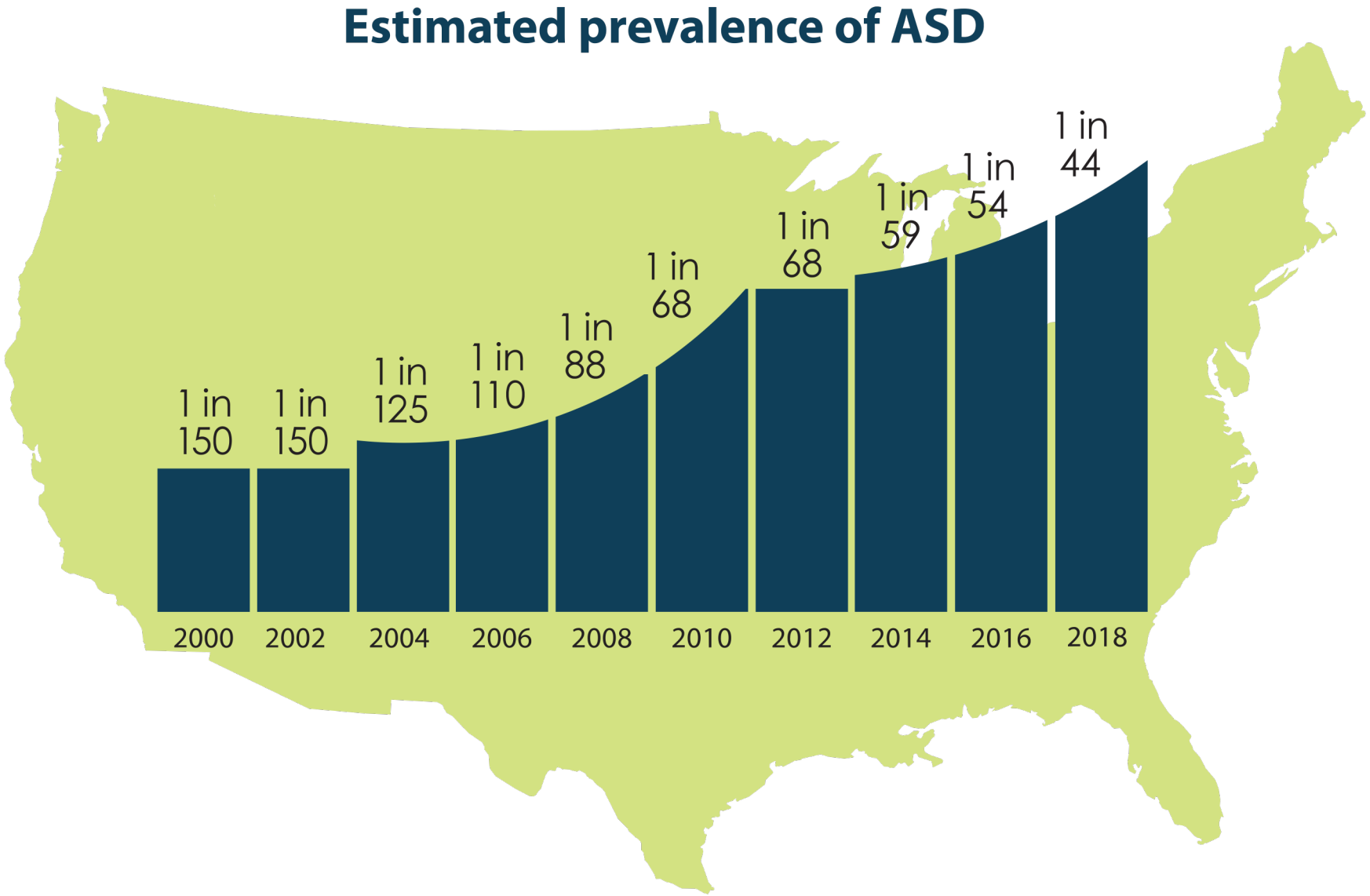
**2.3%**

is the average percentage identified with ASD

**1 in 44**

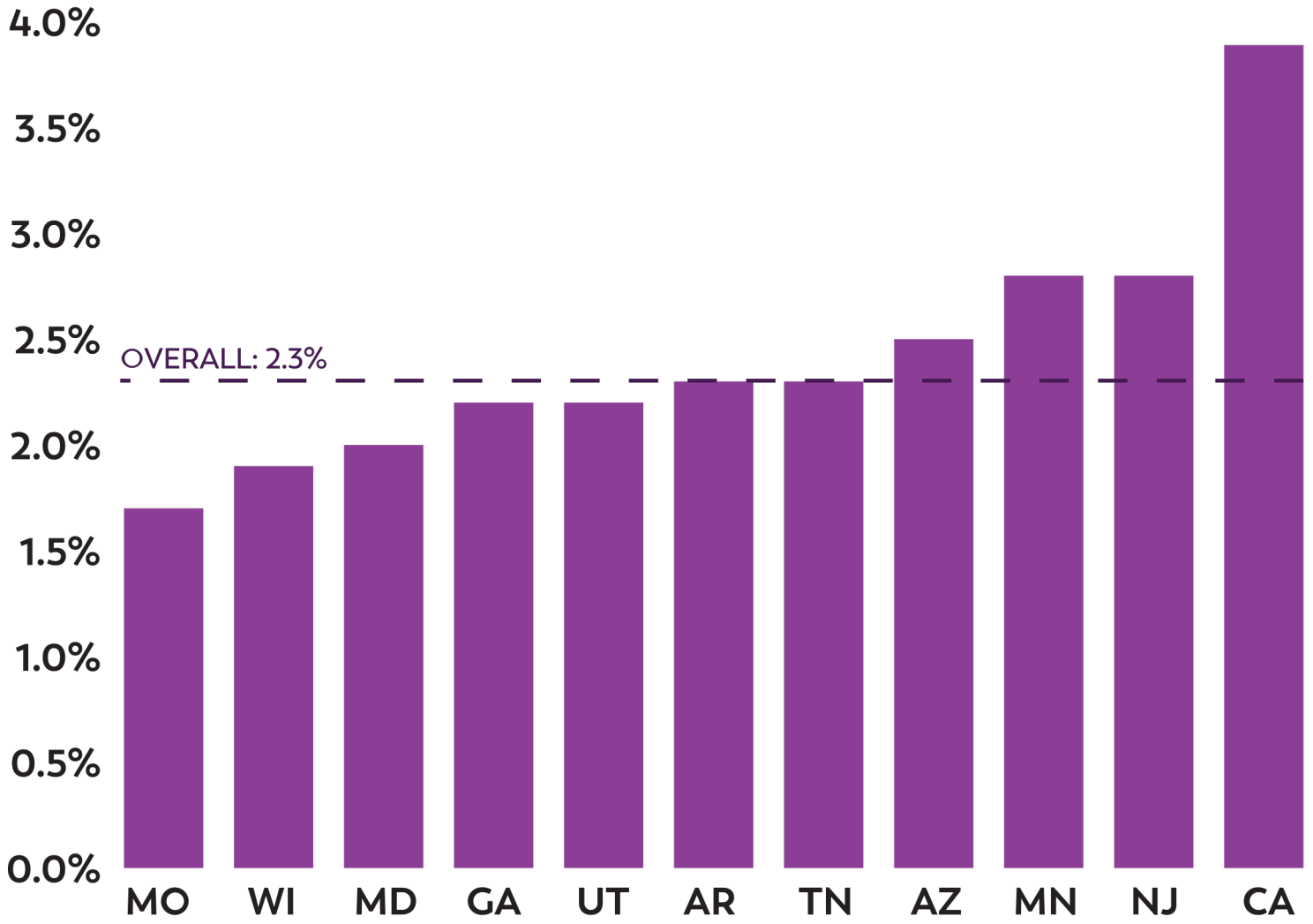
8-year-old children were identified with ASD in the ADDM Network

# ADDM Network



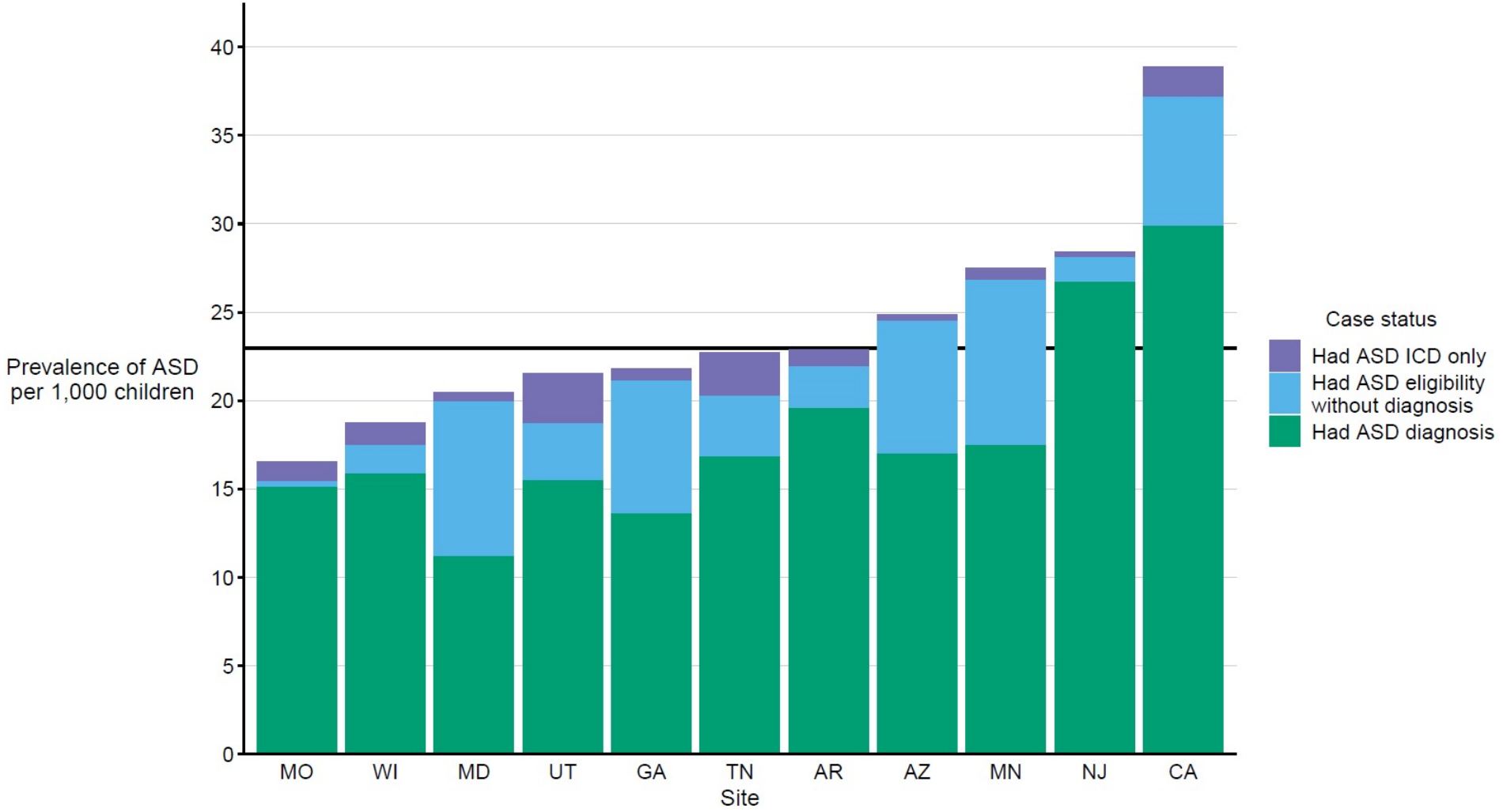
# Percentage of 8-year-old children

identified with ASD by ADDM Network Site



**Prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by identification type and site**

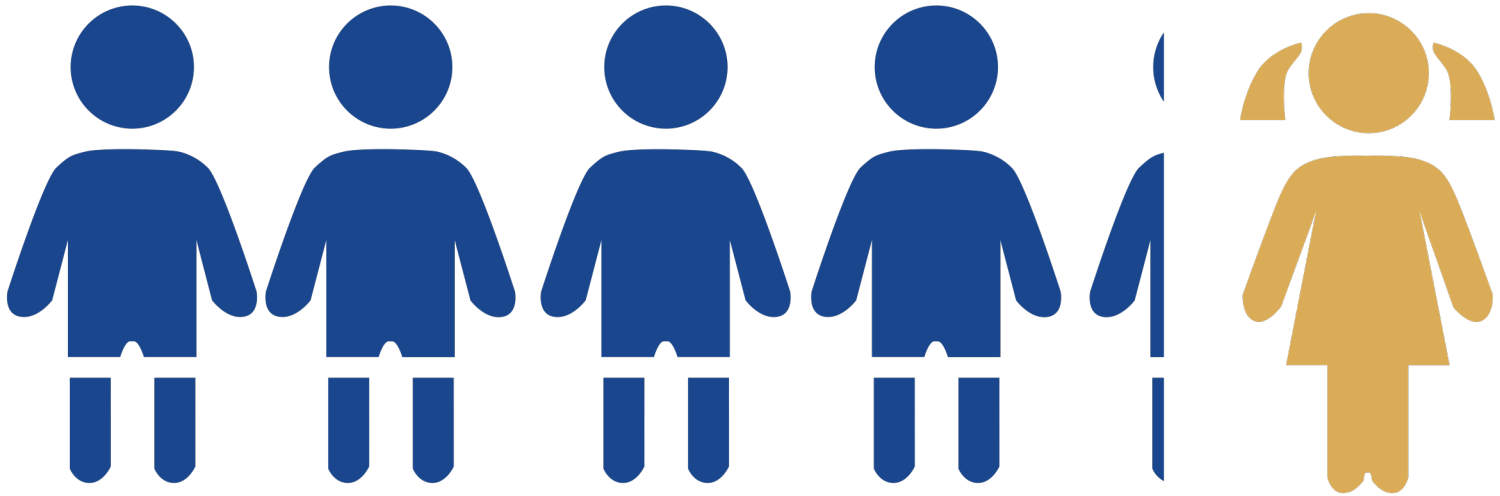
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018




* Horizontal line is the overall Autism and Developmental Disabilities Monitoring Network prevalence of 23.0 per 1,000 children aged 8 years. Children with documented ASD statements could also have ASD classifications in special education or ASD ICD codes.

# ADDM: ASD in boys vs. girls

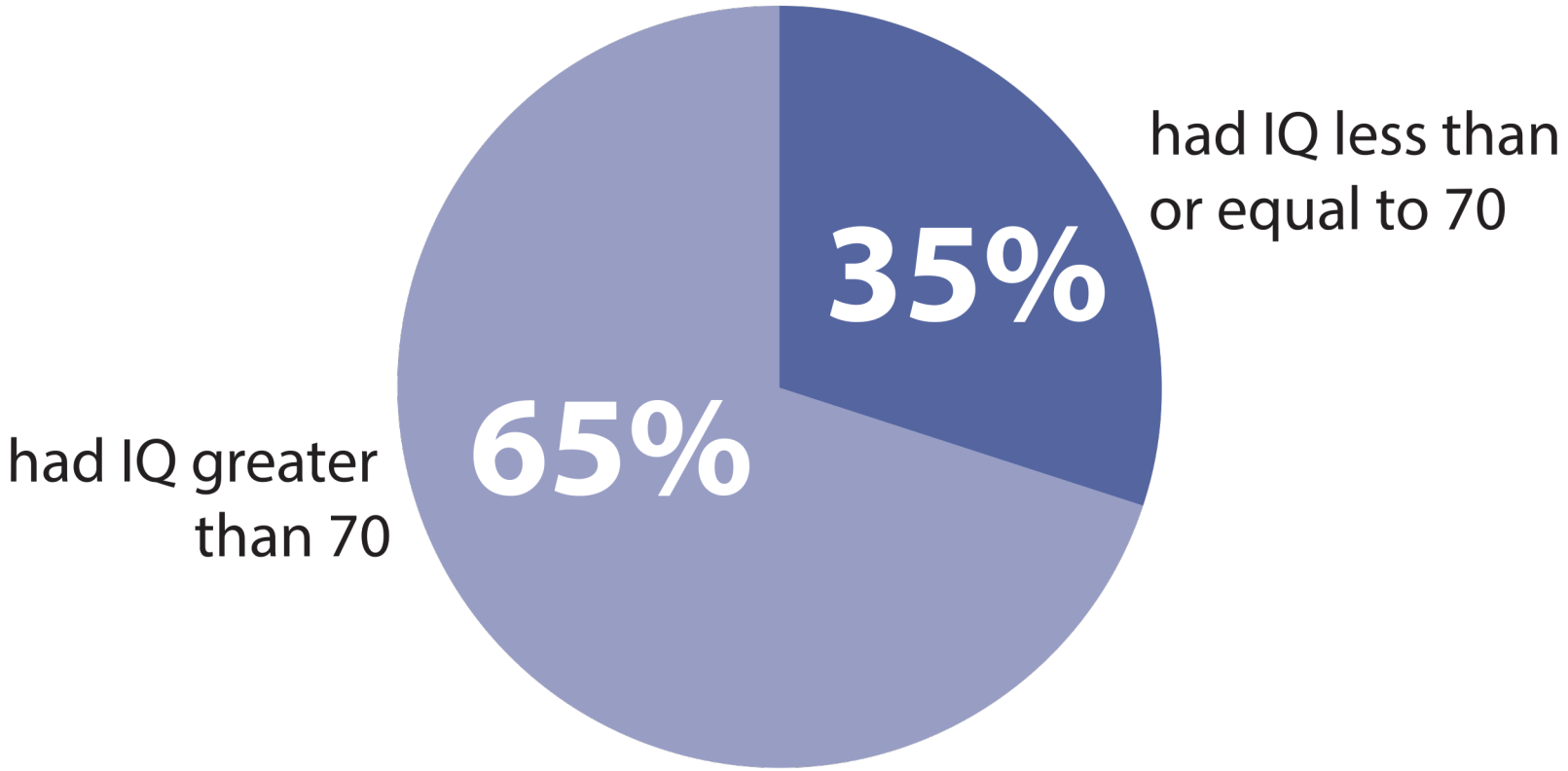
**Boys were 4.2 times more likely** to be identified with ASD than girls



# ADDM: Estimated prevalence by race and ethnicity

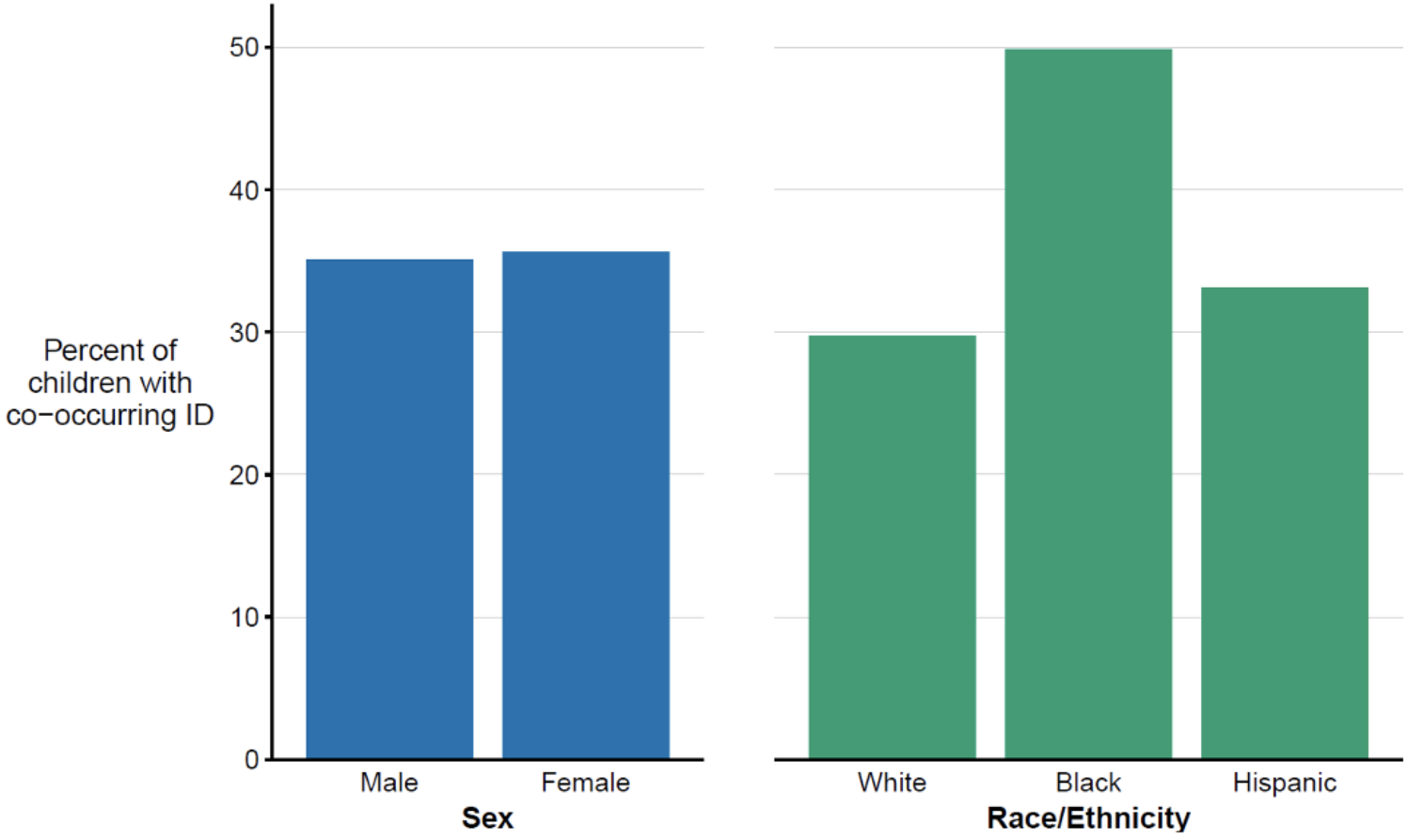
# ADDM: Percentage with co-occurring intellectual disability

**Among children identified with ASD who had intelligence quotient (IQ) scores available (59.5%)**



# Percent of children aged 8 years with autism spectrum disorder with co-occurring intellectual disability*, by sex and race/ethnicity

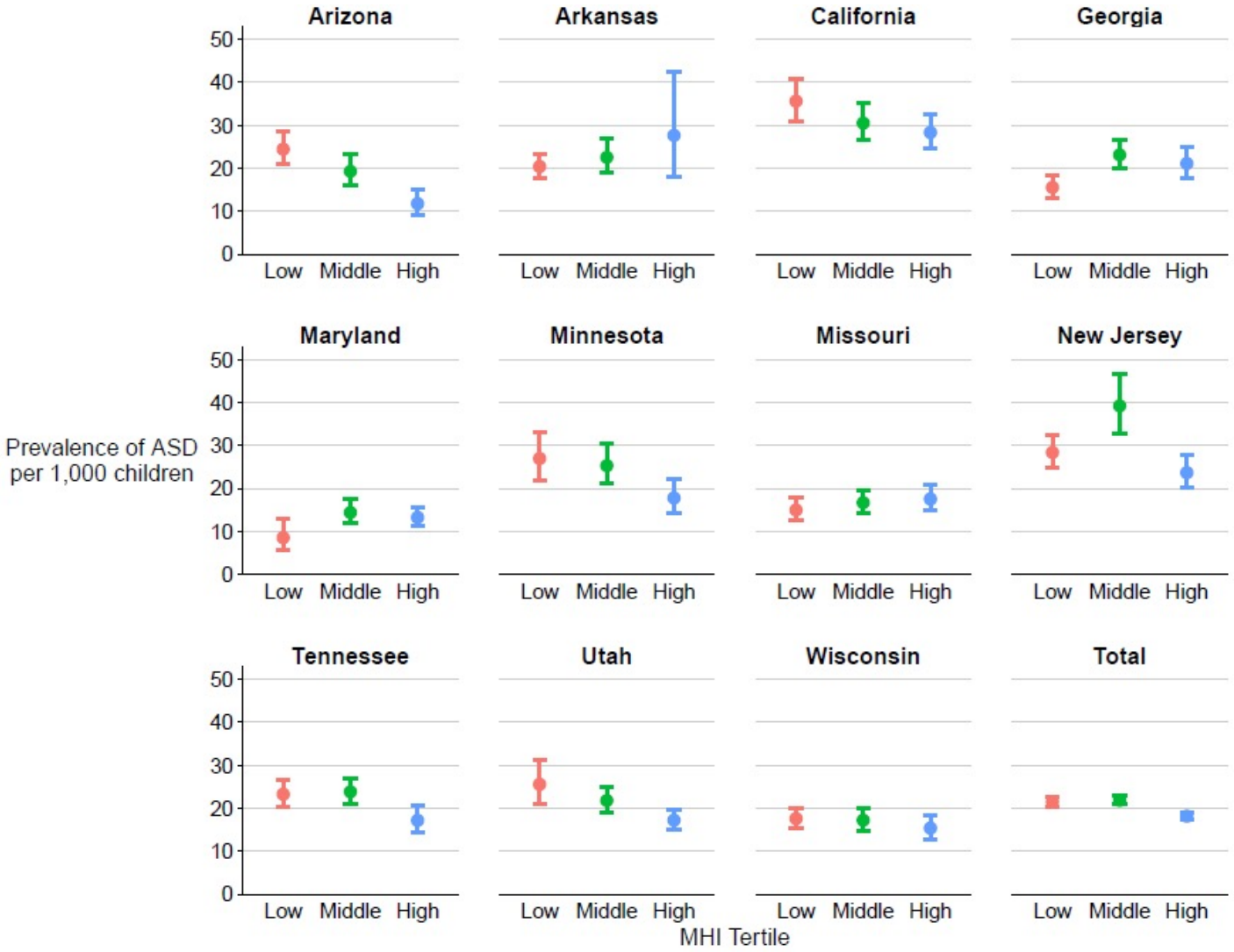
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018




* IQ score ≤70 or examiner statement of intellectual disability in a comprehensive evaluation

# Prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by median household income tertile and site†

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018

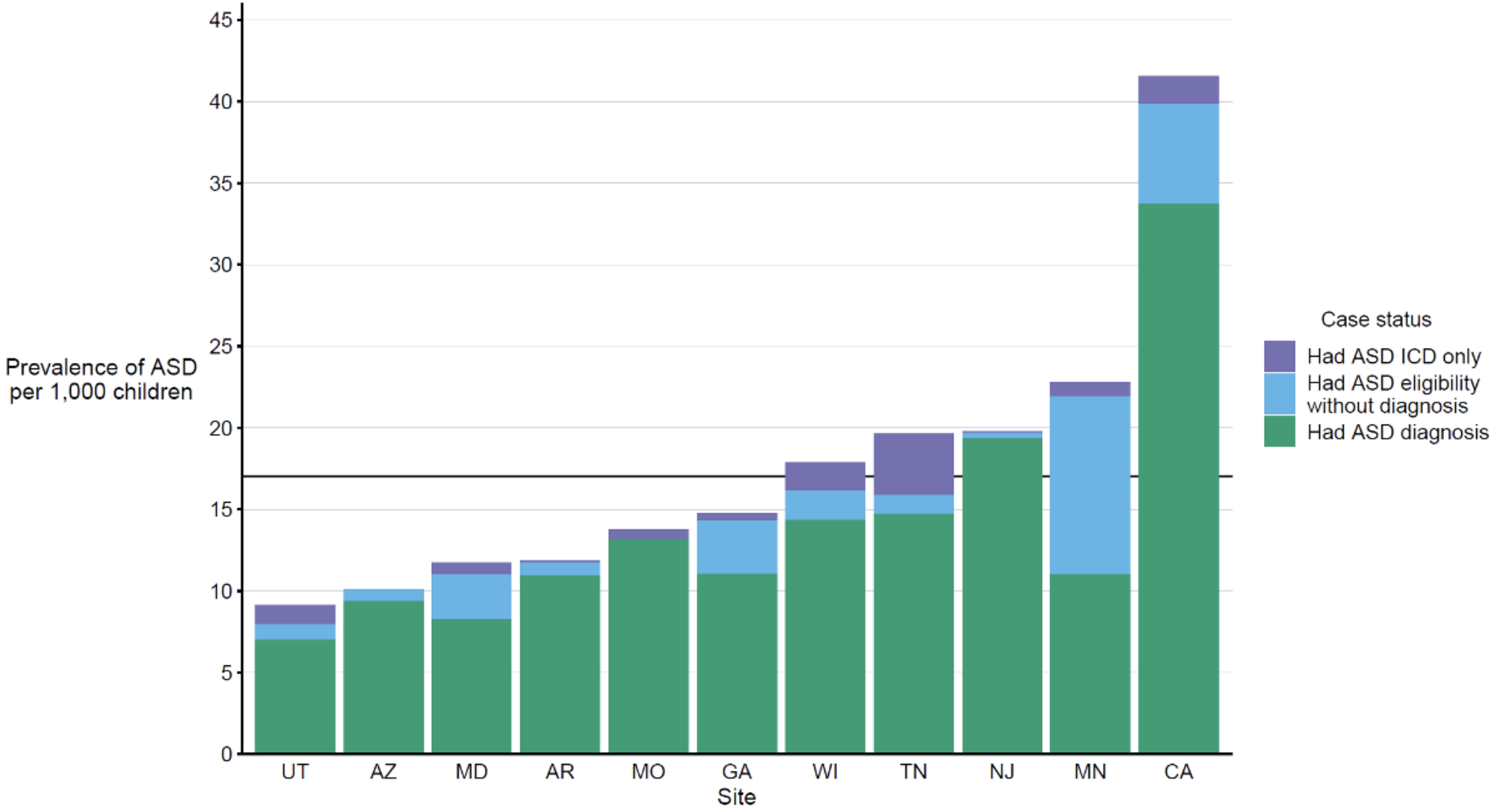



* Dots are the point estimates and horizontal lines are the 95% confidence intervals.

†Cochran Armitage test of trend results for association between socioeconomic status tertile and ASD prevalence, by site and overall: Arizona (p<0.001), Arkansas (p = 0.17), California (p = 0.03), Georgia (p = 0.01), Maryland (p = 0.21), Minnesota (p = 0.01), Missouri (p = 0.21), New Jersey (p = 0.15), Tennessee (p = 0.02), Utah (p<0.001), and Wisconsin (p = 0.27); all sites (p<0.001).

# “What is the prevalence of ASD for 4-year-old children?

# ADDM: Estimated prevalence per 1,000 children by type of ASD identification and site, 4-year-olds




* Horizontal line is the overall Autism and Developmental Disabilities Monitoring Network prevalence of 17.0 per 1,000 children aged 4 years. Children with documented ASD statements could also have ASD classifications in special education or ASD ICD codes.

# ADDM findings, 4-year-olds

**1.7%**

is the average percentage identified with ASD

**1 in 59**

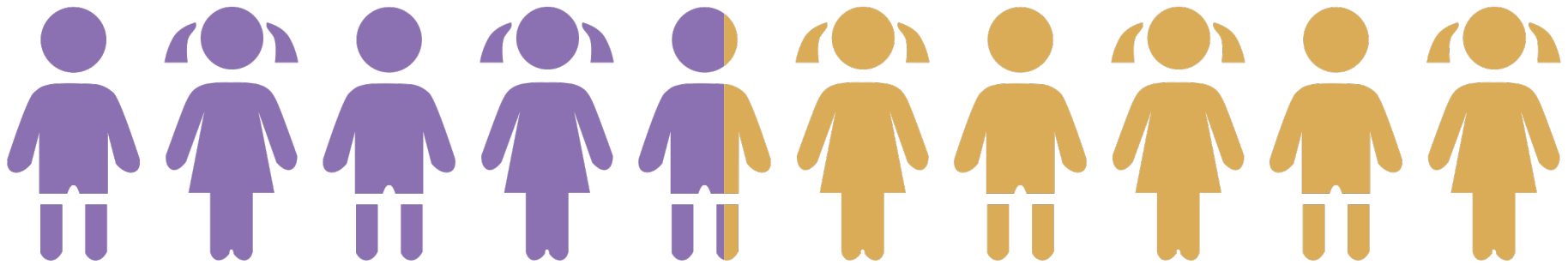
4-year-old children were identified with ASD in the ADDM Network

# Age of Identification

# ADDM: Median age at clinical diagnosis

**50 months** (4 years, 2 months)

**Of the children identified with ASD, 47%** had an evaluation recorded by age 36 months

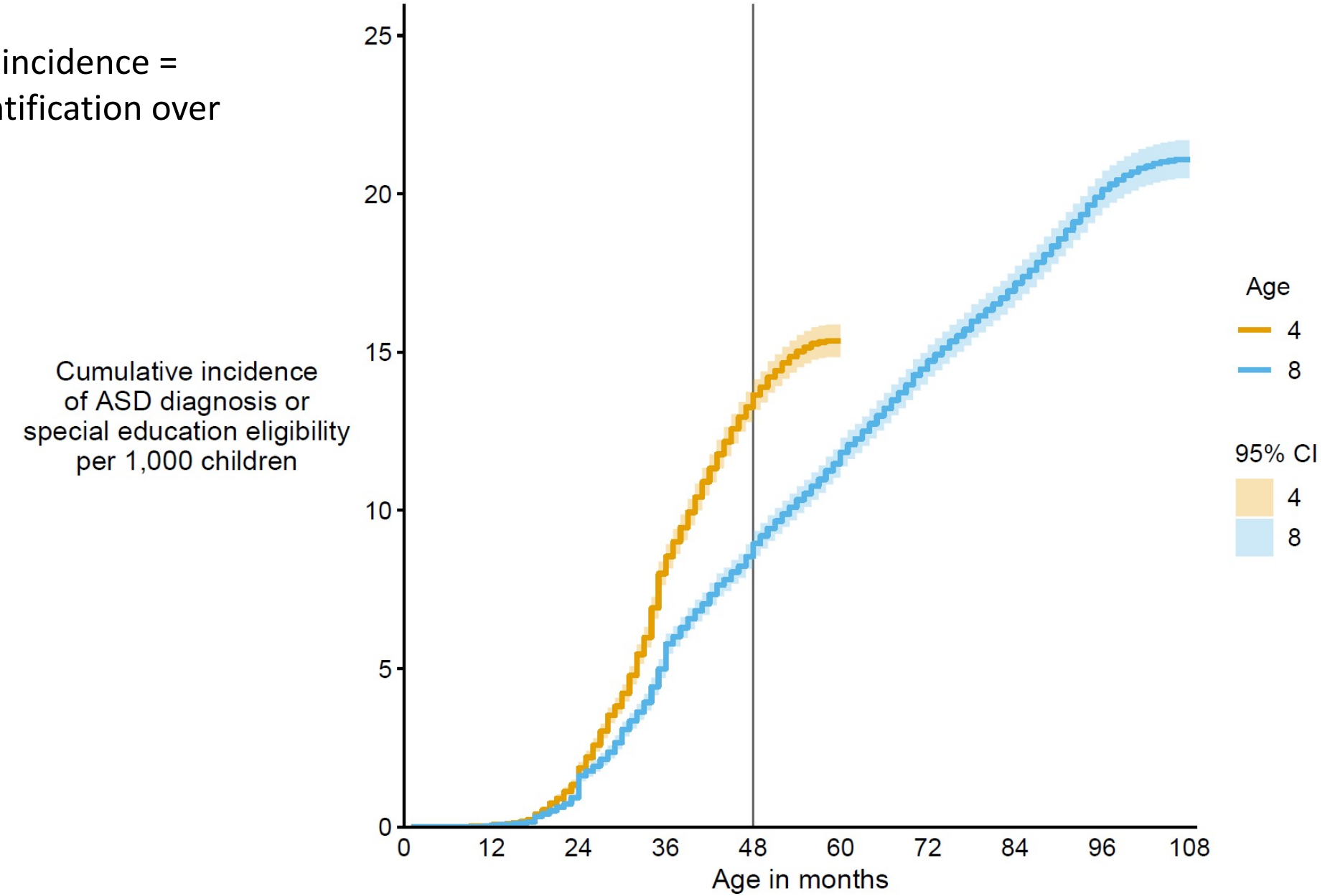


Source: CDC, 2018

# Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years

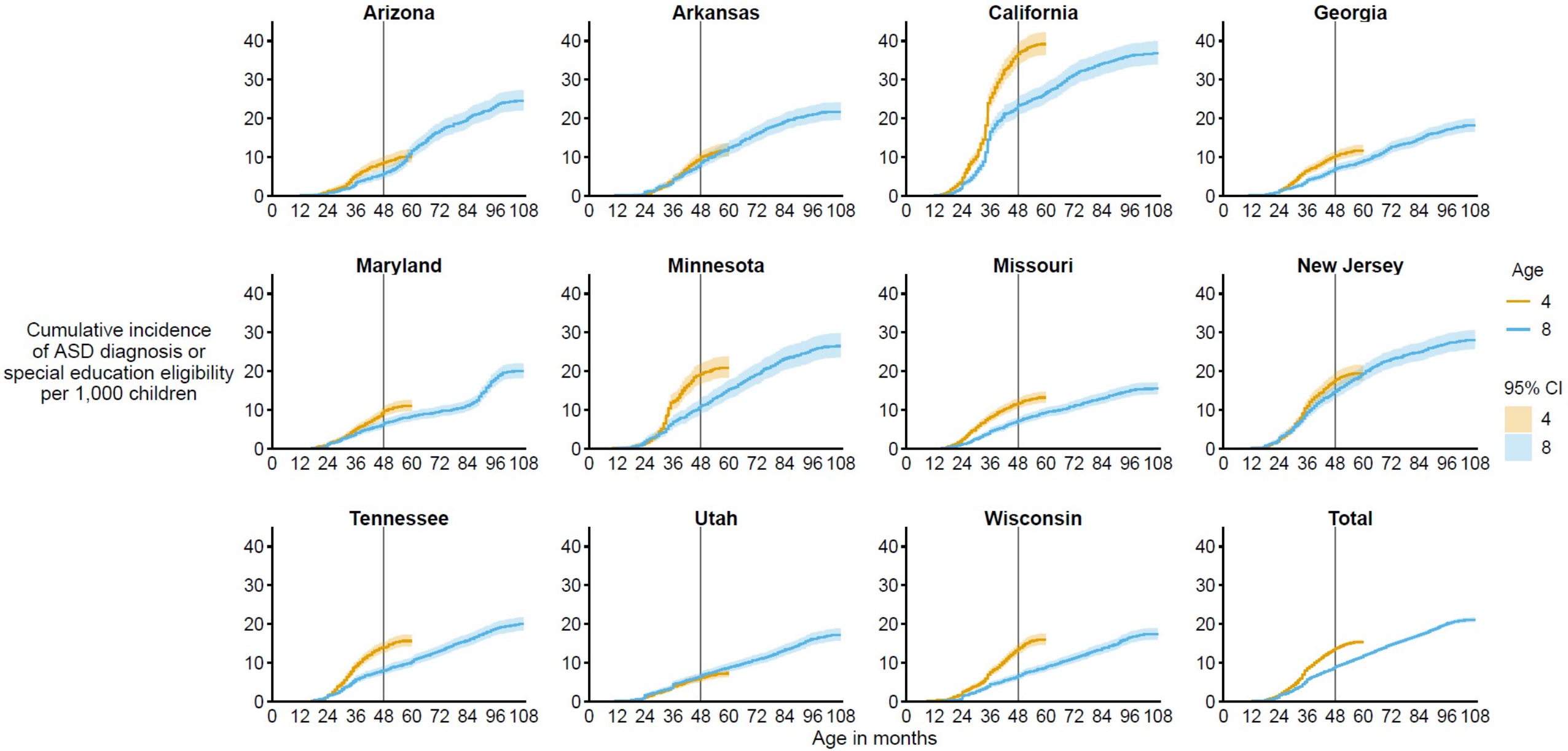
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018

Cumulative incidence = Rate of identification over time



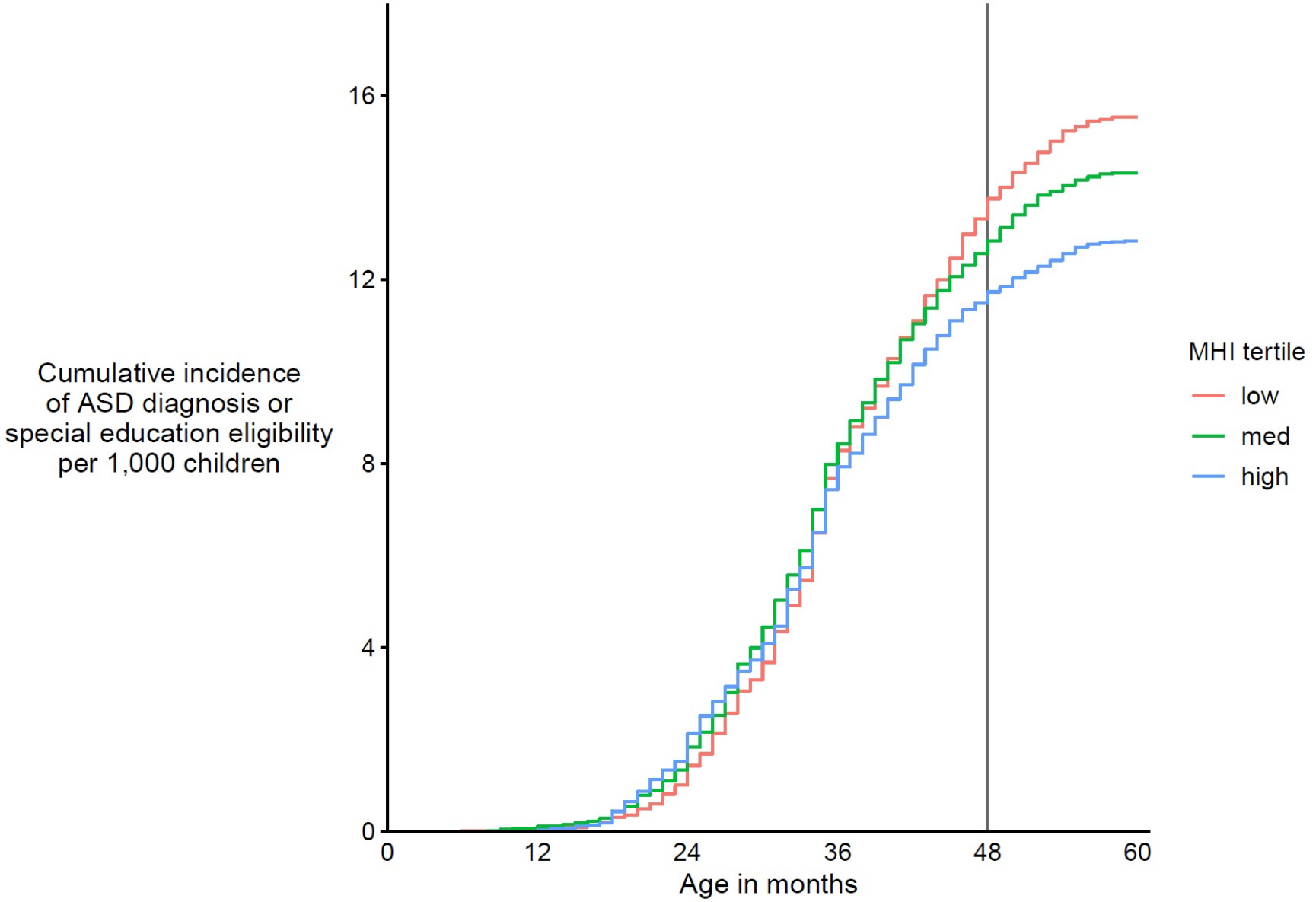
# Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years, by site

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



# Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 years, by median household income tertile

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



# Limitations

ADDM
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## Geographic area

- Cannot generalize to all of US
- Cannot generalize to any sub population

## Small sample size

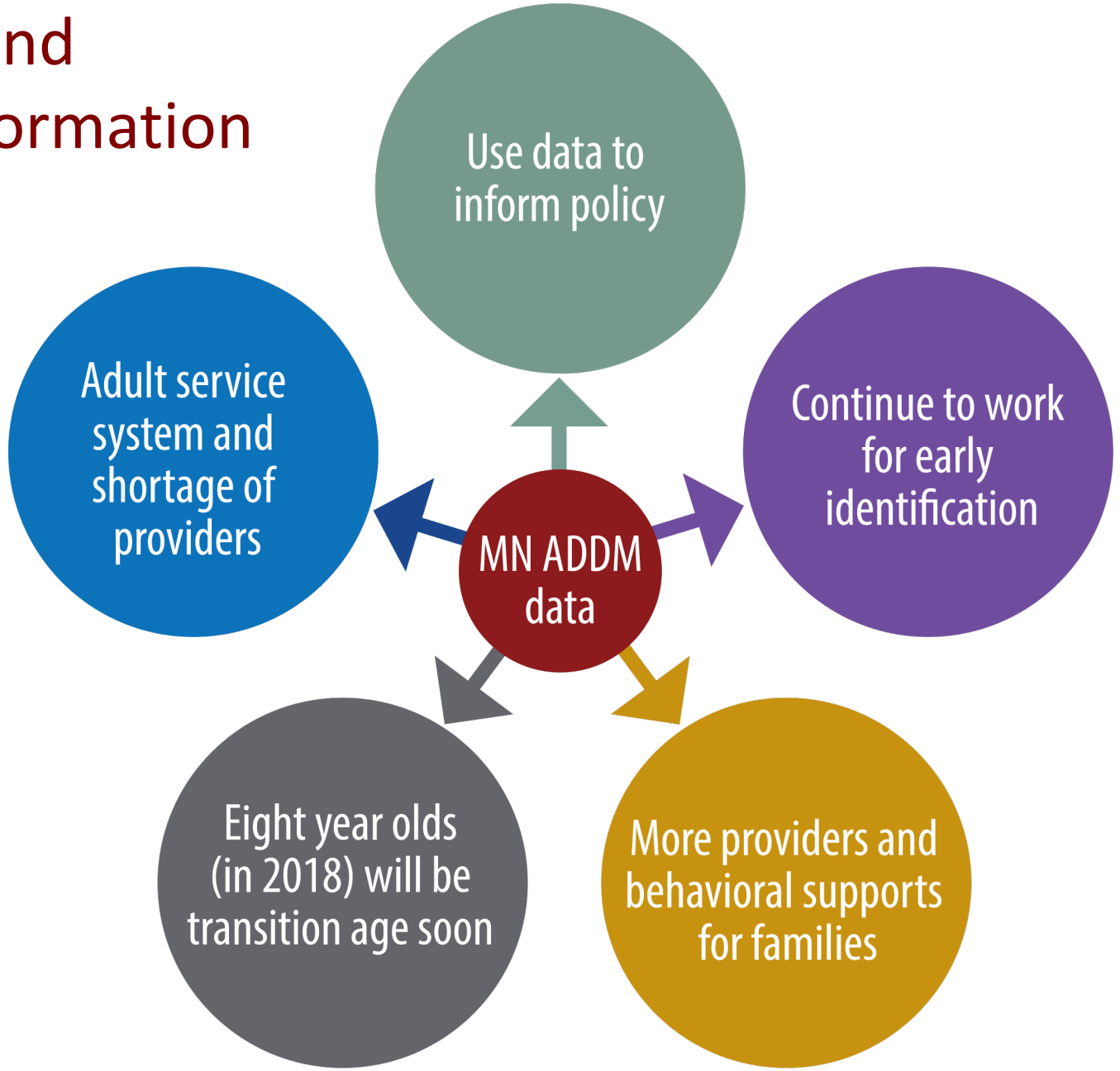
- Limits ability to detect real differences in sub populations
  - Race, ethnicity and linguistic background

## Age of identification

- Includes 4- and 8-year-olds, not all age groups

# Implications and Use of the Information

ADDM
Minnesota Autism Developmental Disabilities Monitoring Network



# Misinterpretations of ADDM data:

ADDM
Minnesota Autism Developmental Disabilities Monitoring Network

1. Prevalence is on the rise since SY2016, prevalence is up over 20%, etc.

2. 1 in 44 U.S. children have autism.
    1. Prevalence ranged from 1.7% in MO to 3.9% in CA
    2. Data represent 11 *communities* in the U.S.

3. With median age of diagnosis still over age 4, we have not made progress on early diagnosis.
    1. Cumulative incidence tells a more optimistic story
    2. 4-year-olds (born in 2014) were 50% more likely to receive an autism diagnosis or special education classification by 48 months of age compared to children born in 2010 (8-year-olds).
    3. We continue to diagnose people well into childhood and adulthood

4. We're no longer seeing differences in prevalence by race/ethnicity
    1. Several states showed lower prevalence for Hispanic children
    2. Still seeing differences in proportion of Black children with co-occurring ID


# ADDM Community Report

For more information on ADDM national trends:

https://www.cdc.gov/ncbddd/autism/addm.html

# Website

ADDM
Minnesota Autism Developmental Disabilities Monitoring Network

https://addm.umn.edu/

# ASD videos for the community
# https://ici.umn.edu/series/o2WnXdvkRSmCtAhblUdvqg

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Minnesota Autism Developmental Disabilities Monitoring Network

# 2018 ADDM Surveillance Summary Citations and Links


Maenner MJ, Shaw KA, Bakian AV, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ 2021, 70 (No. SS-11): 1-16.

Shaw KA, Maenner MJ, Bakian AV, et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ 2021, 70 (No. SS-10): 1-14.

# Acknowledgements

ADDM
Minnesota Autism Developmental Disabilities Monitoring Network

We would like to acknowledge and thank the following partners:

- CDC
- **State agencies**: MDH, MDE, DHS
- **Data partners**: Our educational and clinical partners

# MN-ADDM staff

ADDM
Minnesota Autism Developmental Disabilities Monitoring Network

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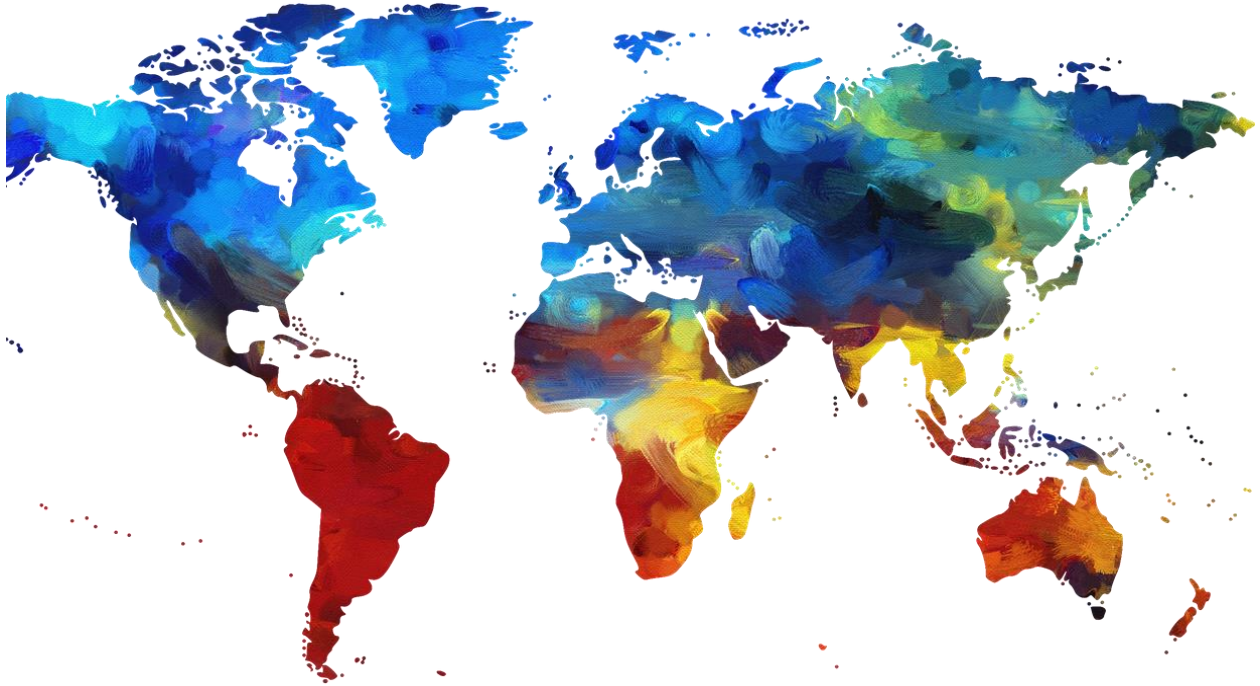
QUESTIONS



INSAR

International Society for Autism Research

CULTURAL DIVERSITY CAREER ADVANCEMENT PROGRAM (C-CAP)

# International Collaboration for Diagnostic Evaluation of Autism (IDEA) January 2022

# Cultural Diversity Committee Co-Chairs

Marshalyn Yeargin-Allsopp

Centers for Disease Control and Prevention

Sandra Vanegas

Texas State University

Gulnoza Yakubova

University of Maryland, College Park

Shoba S. Meera

National Institute of Mental Health and Neurosciences

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National Institute of Mental Health

# Cultural Diversity Committee
# C-CAP Committee

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Serene Habayeb

Children's National Hospital

Lisa Joseph

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# Cultural Diversity Career Advancement Program (C-CAP)

## Purpose:

- Grow the number of researchers among individuals from LMIC and historically underrepresented groups,
- Facilitate career development, and
- Improve quality of autism research using collaboration and mentorship as a model.

## Audience:

- Researchers at any stage of their career (early, mid, late) are eligible to join the program
  - Low- and middle-income countries (LMIC), and
  - Underrepresented groups in high income countries (HIC)

# Mentorship Models

## Classic model:

- Formal approach to mentoring, with one-on-one meetings; generally, both mentor and mentee are from the same field

## Trans-discipline model:

- Mentor works outside of the mentee's field of focus

## Networking model:

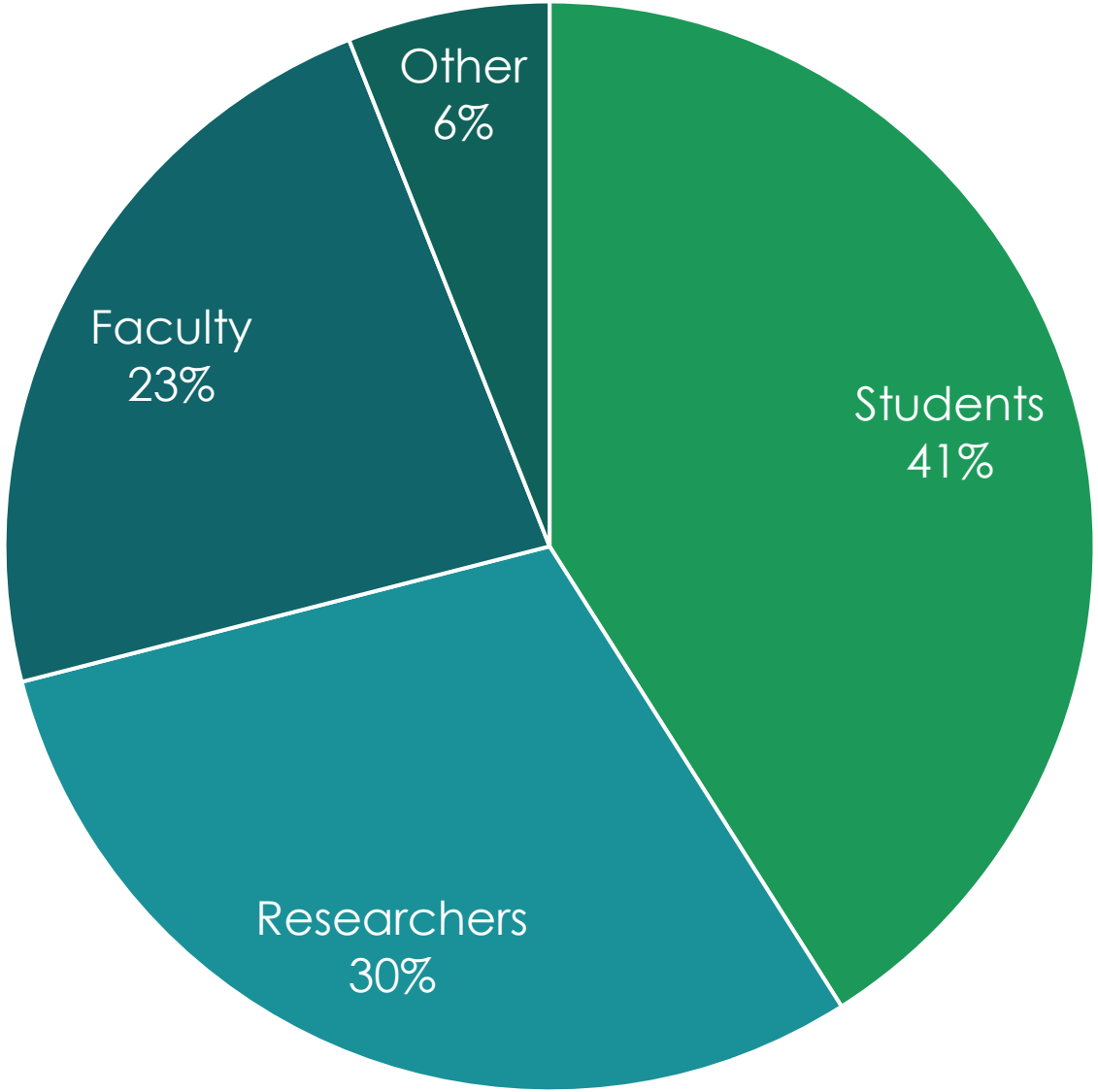
- Less dependence on individual mentor

## Spot mentoring model:

- One-off spot meetings that are specific and focused

Burgess et al., 2018

# C-CAP survey results




*n* = 79

# Areas of Interest Identified by Survey Respondents

Identifying sources of research funding

Developing international collaborations

How to write a grant proposal

Participant recruitment/community engagement

Integrating research into a clinical/practice setting

Identifying appropriate journals/ manuscript preparation

Developing research questions and protocols

# C-CAP Activities

Develop a mentor training curriculum / resource site for mentoring

Develop tailored webinars for mentors and mentees

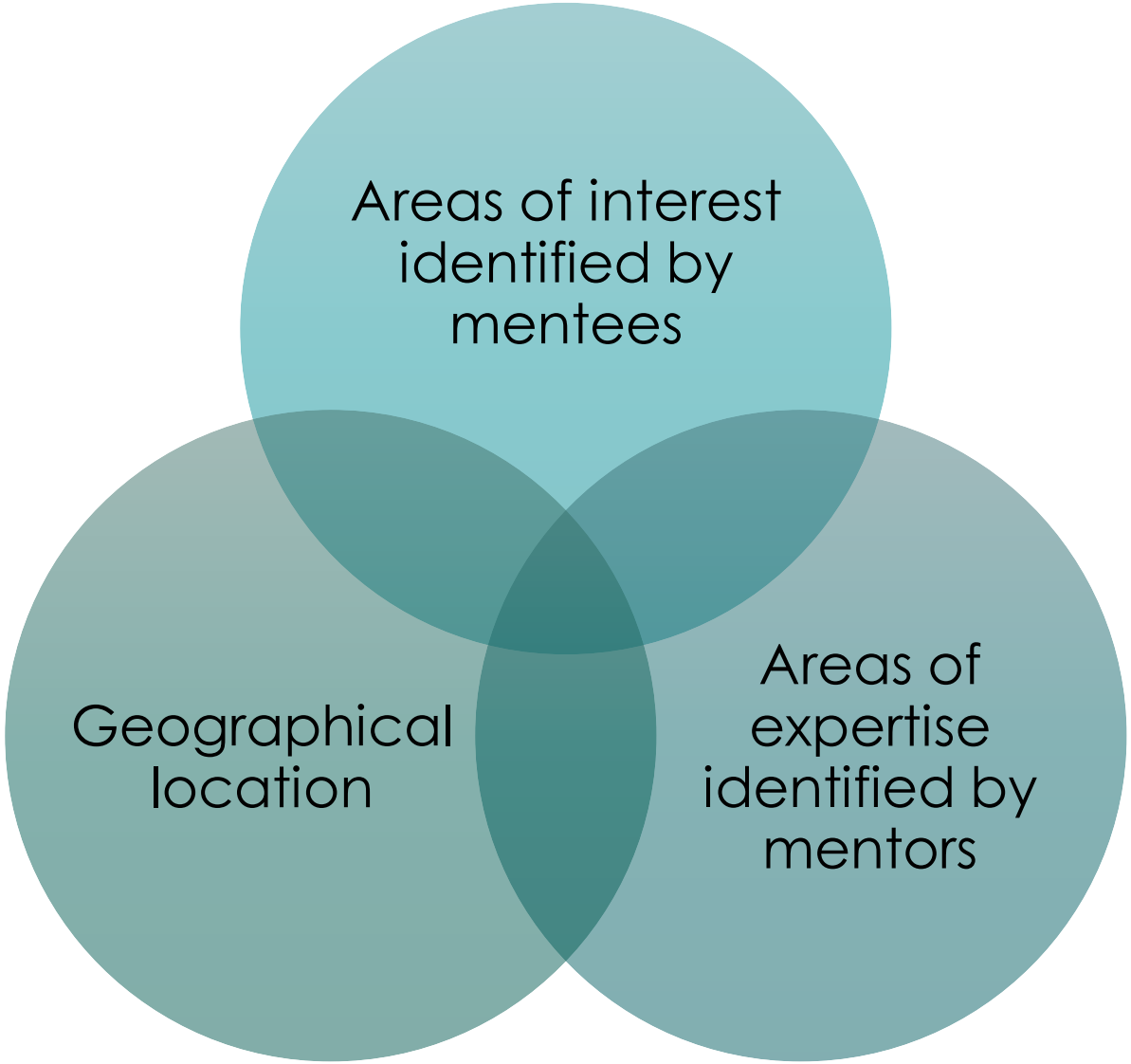
Match mentors with mentees

Hold networking meet and greet sessions year-round & at annual meeting


# C-CAP at a Glance: Mentees and Mentors

- 28 mentees
  - Ecuador, India, Israel, Nepal, New Zealand, Pakistan, Qatar, Russia, Trinidad and Tobago, Turkey, and USA
- 18 mentors
  - Argentina, Belgium, India, Israel, Turkey, USA

# Current Mentor Matching



# C-CAP Activities to Date

**May 2021**

Launch at INSAR

**Sep. 2021**

Experiences in Mentoring

**Jan. 2022**

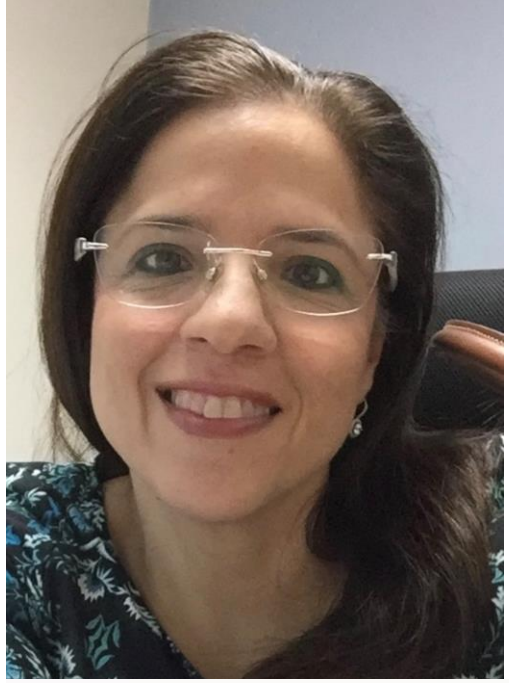
Grant Writing Sessions

**May 2022**

Meet and Greet INSAR

# C-CAP Launch at INSAR 2021

- Keynote address: Dr. Vikram Patel (India)
- Speakers:
  - Drs. Waganesh Zeleke (Ethiopia)
  - Petrus De Vries (South Africa)
  - Alexia Rattazzi (Argentina)
  - Gauri Divan (India)




# C-CAP Session on Mentoring

# Measuring Success in C-CAP

- Increase number of ASD researchers from and in LMIC
- Increase number of researchers from underrepresented groups in HIC
- Increase number of global collaborations

# How to Sign Up

## Apply to be mentor/mentee here:

- https://www.autism-insar.org/page/CCAP

## Email us with questions:

- culturaldiversitycommittee@autism-insar.org