

# Tracking Autism Prevalence in the Autism and Developmental Disabilities Monitoring (ADDM) Network

**Matthew Maenner, PhD**

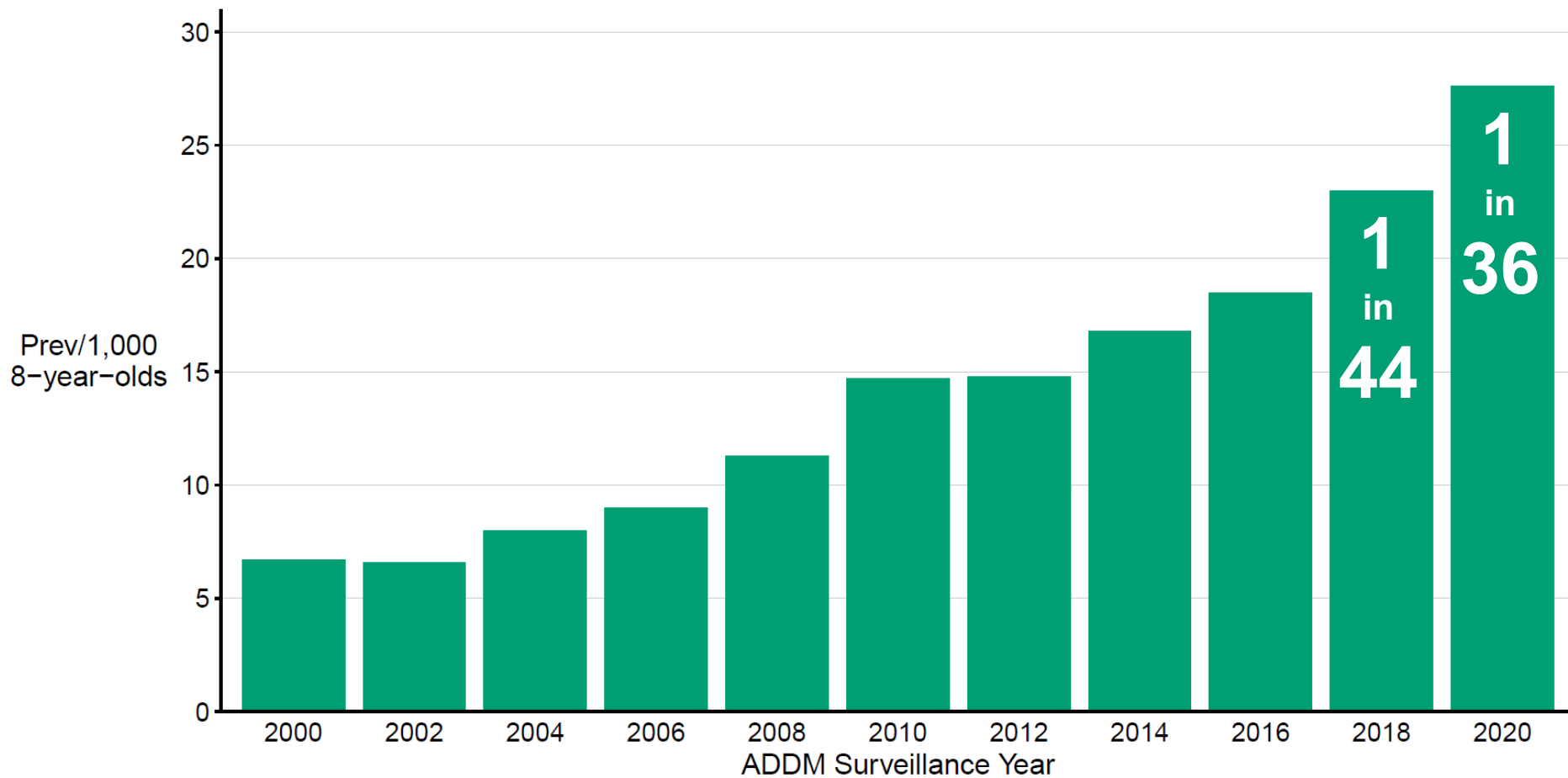
**Chief, Child Development and Disability Branch**

**Division of Human Development and Disability**

**National Center on Birth Defects and Developmental Disabilities**

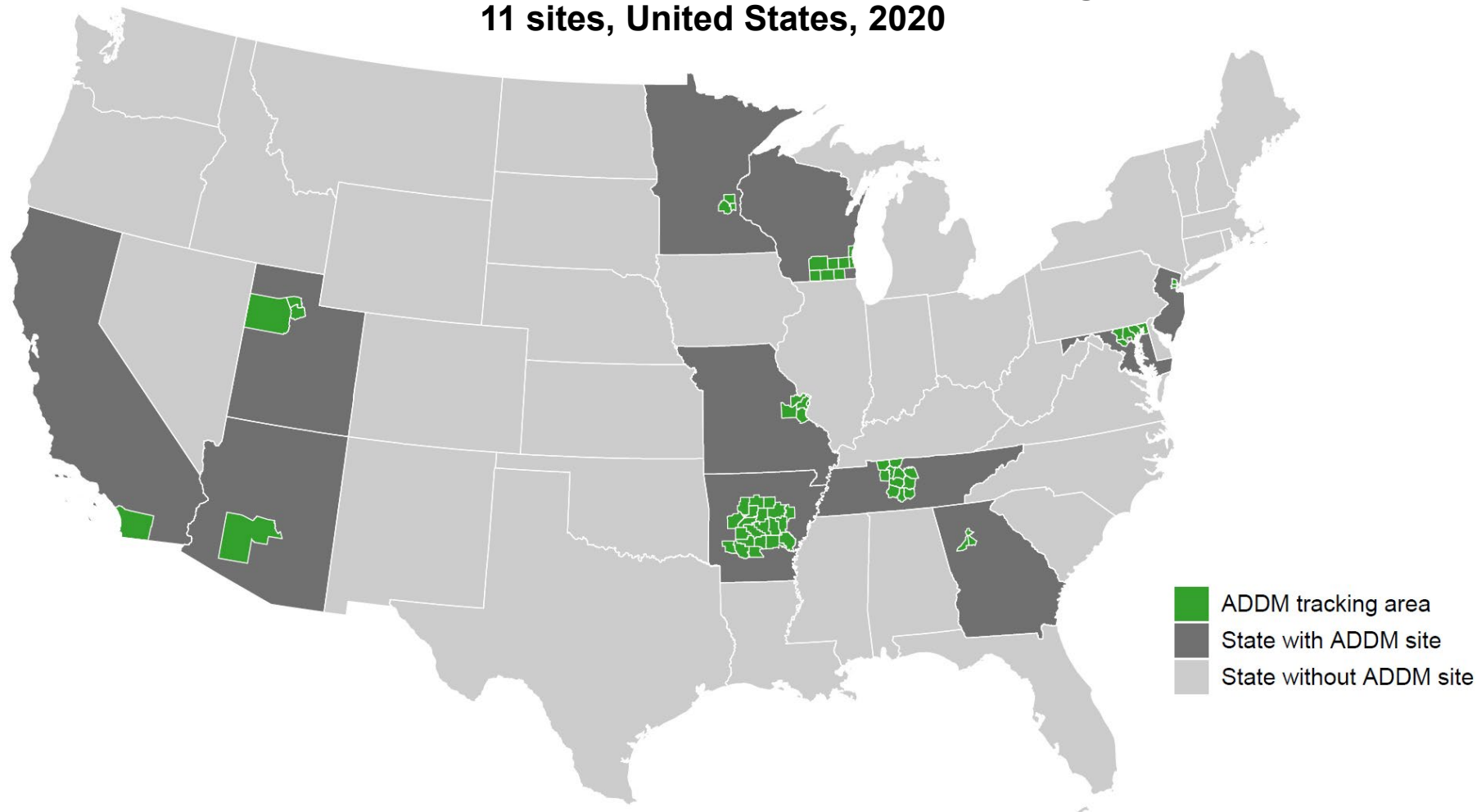
**Centers for Disease Control and Prevention**

May 10, 2024



# Autism and Developmental Disabilities Monitoring Network

## 11 sites, United States, 2020



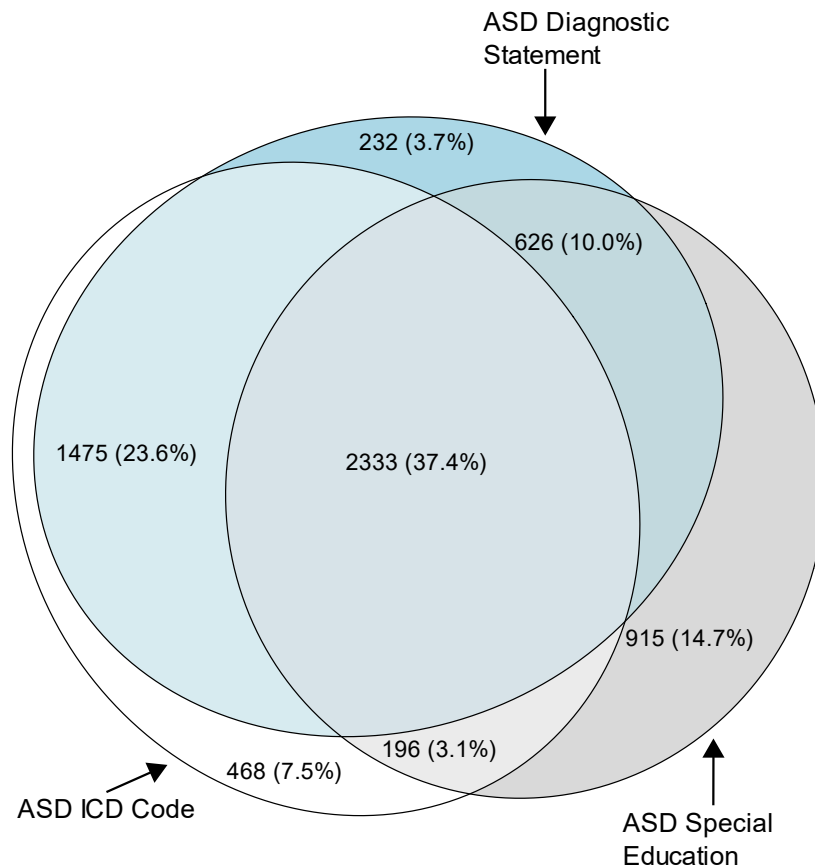
## Case definition for ASD surveillance

Child has documentation of ever receiving:

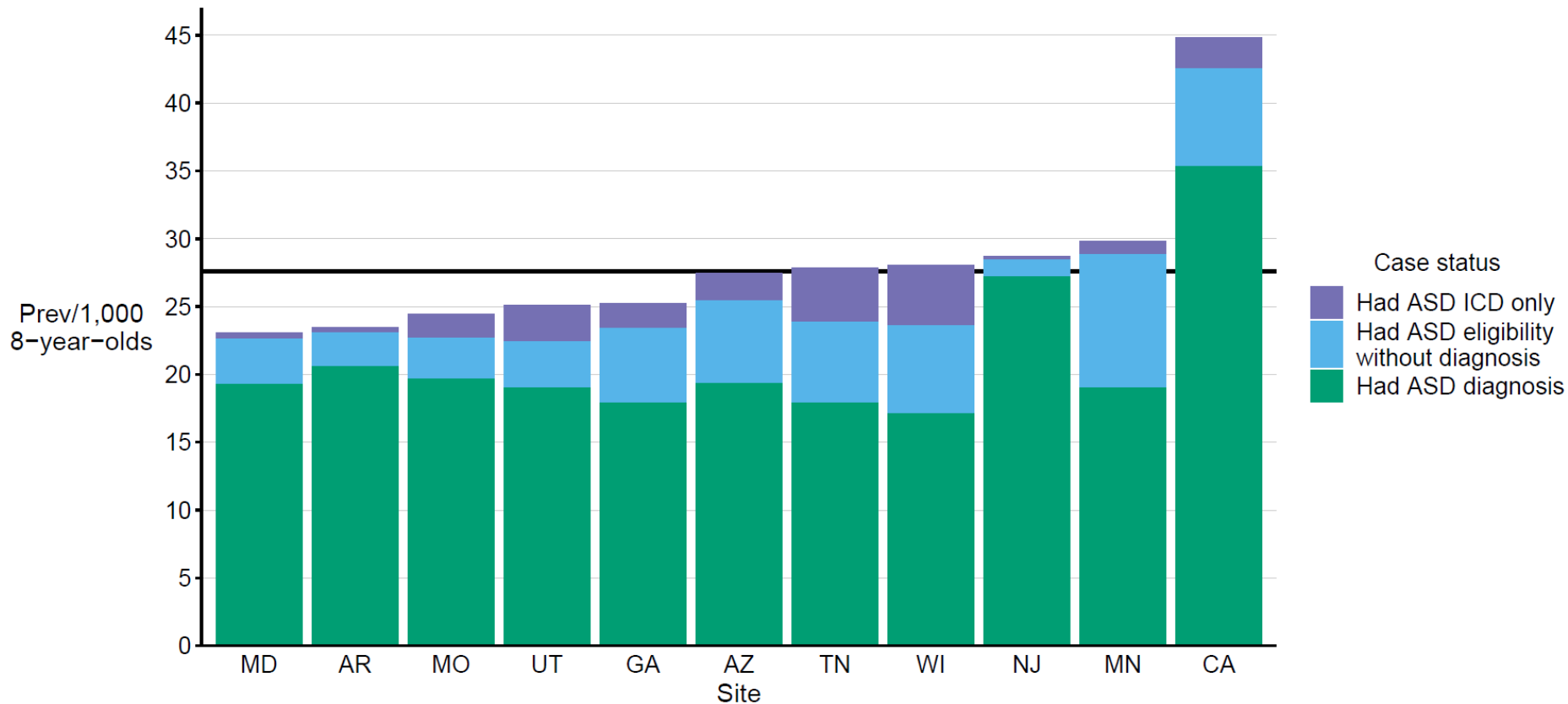
- 1) a written ASD diagnosis by a qualified professional,
- 2) a special education classification of autism, OR
- 3) an ASD ICD code obtained from administrative or billing information

# Euler diagram of different types of autism spectrum disorder identification among children aged 8 years with autism spectrum disorder (N=6,245)

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020

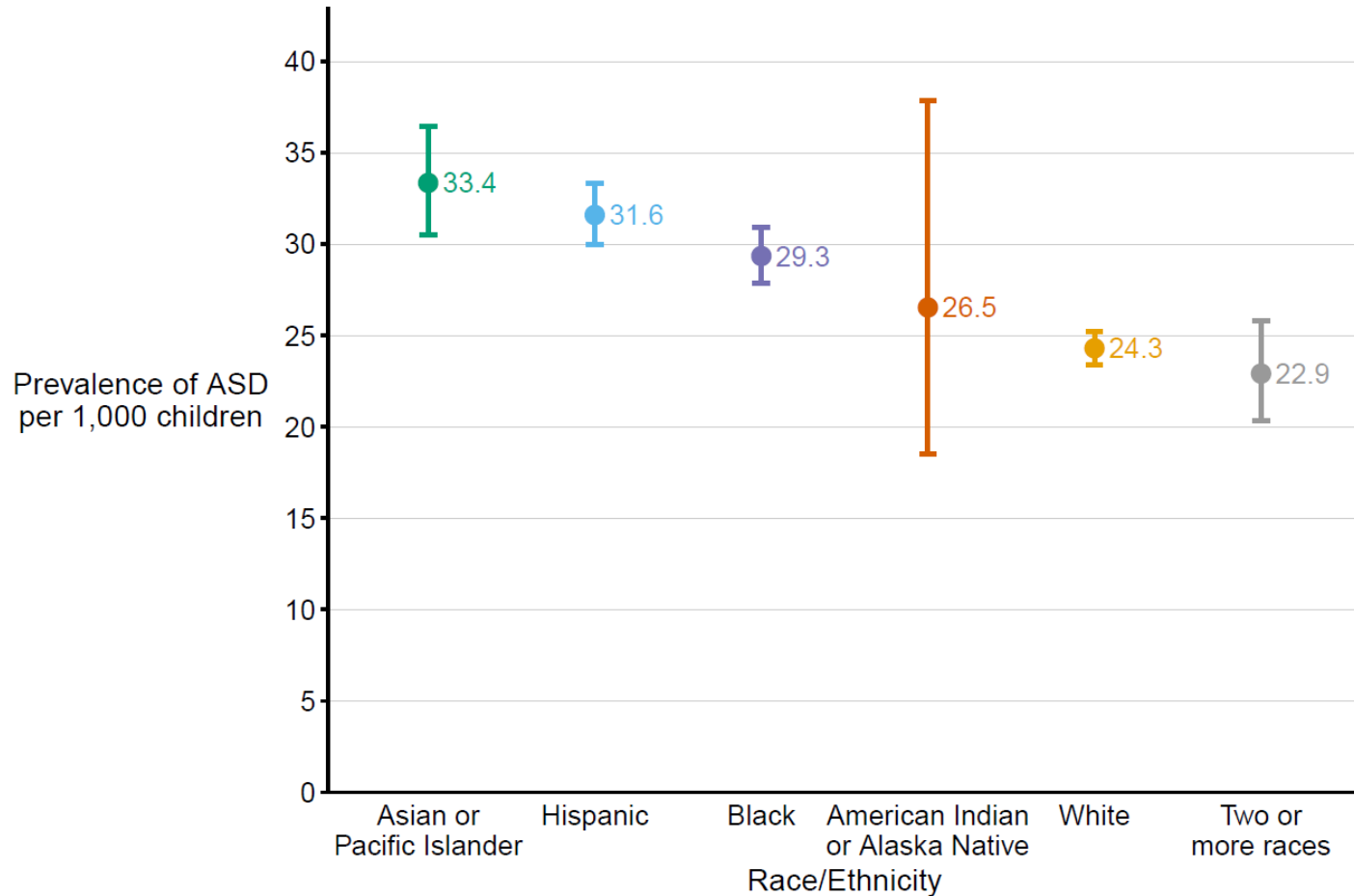


# There is variability in practices across ADDM communities

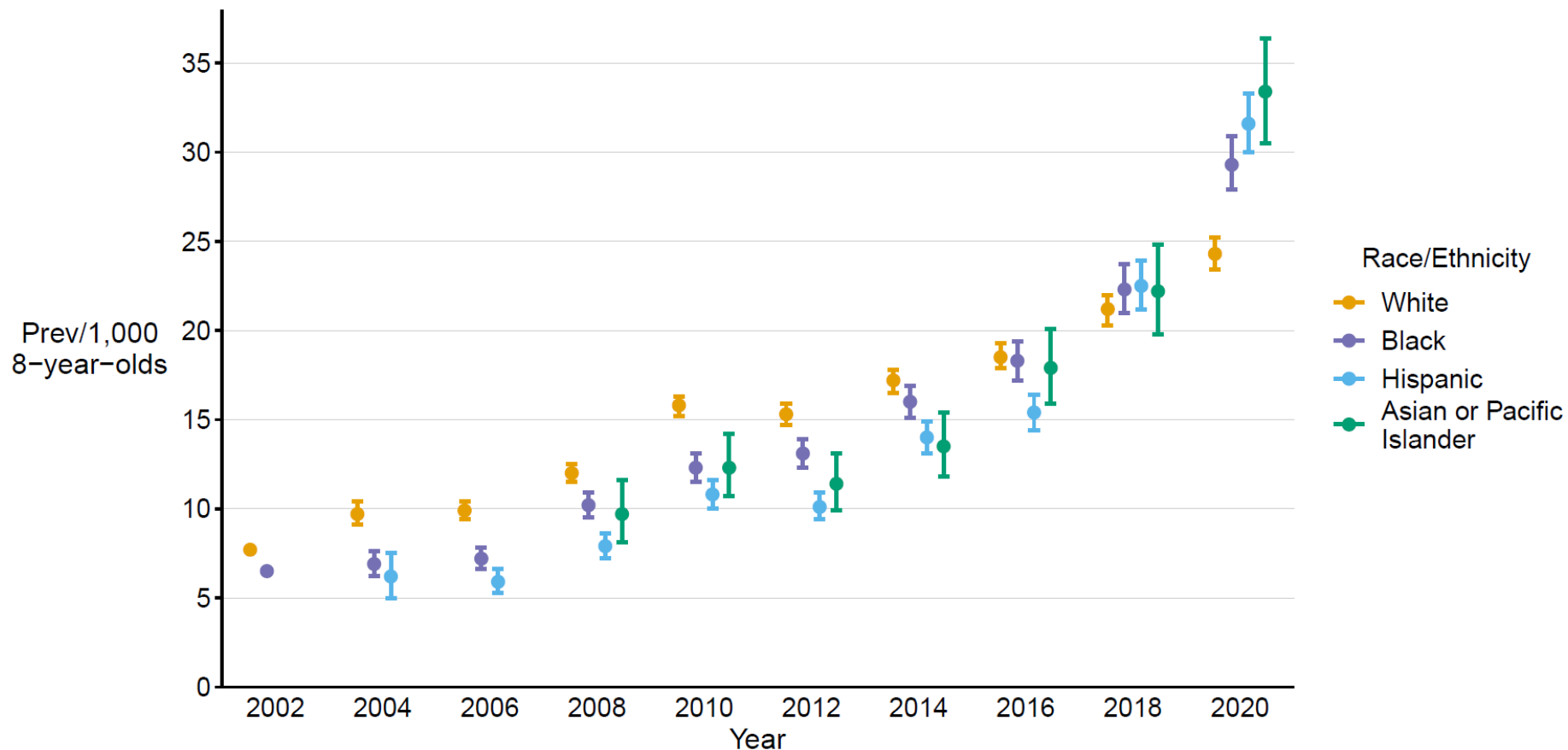


# Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by race/ethnicity

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020



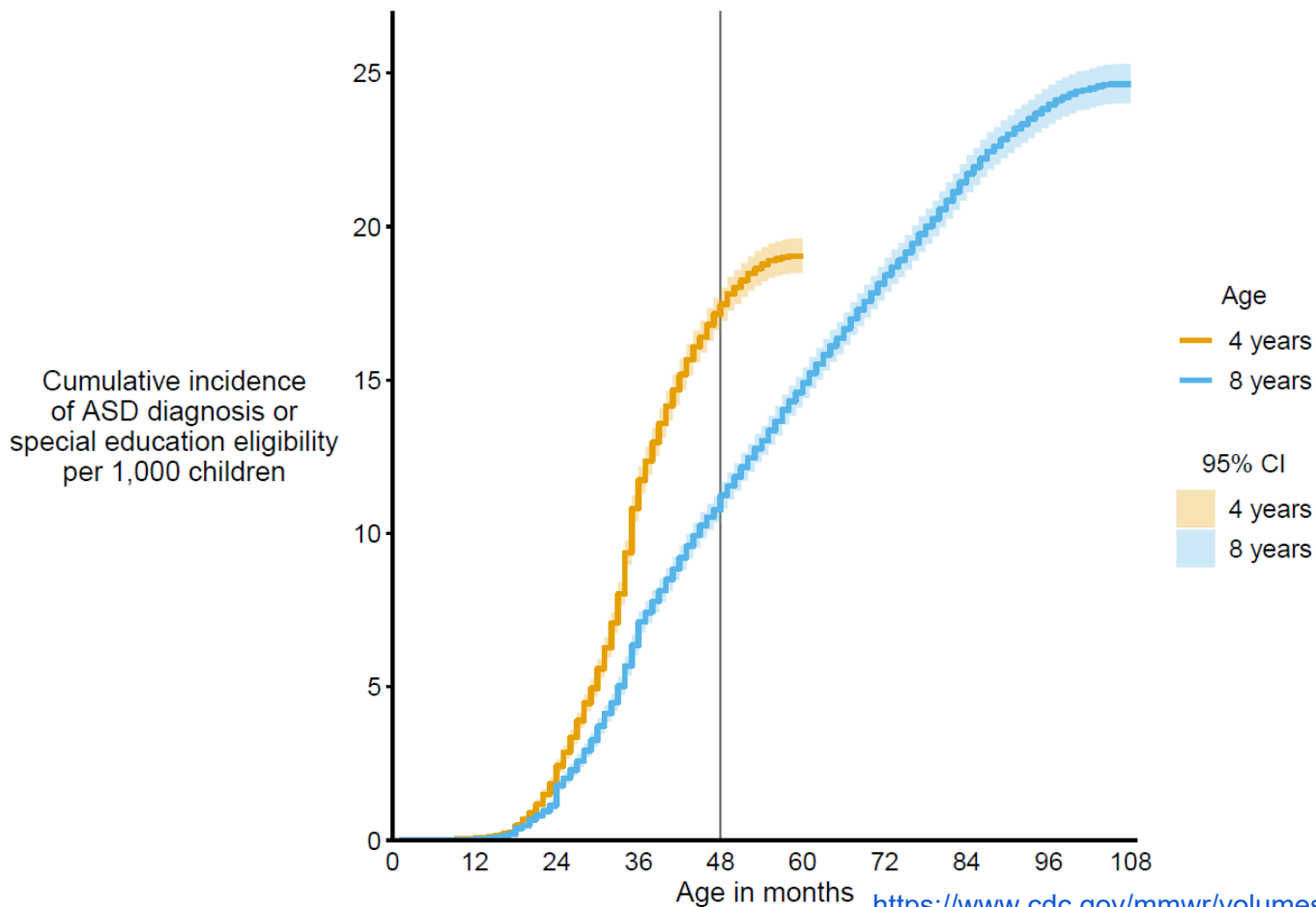
# Patterns by race/ethnicity have changed for children aged 8 years





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

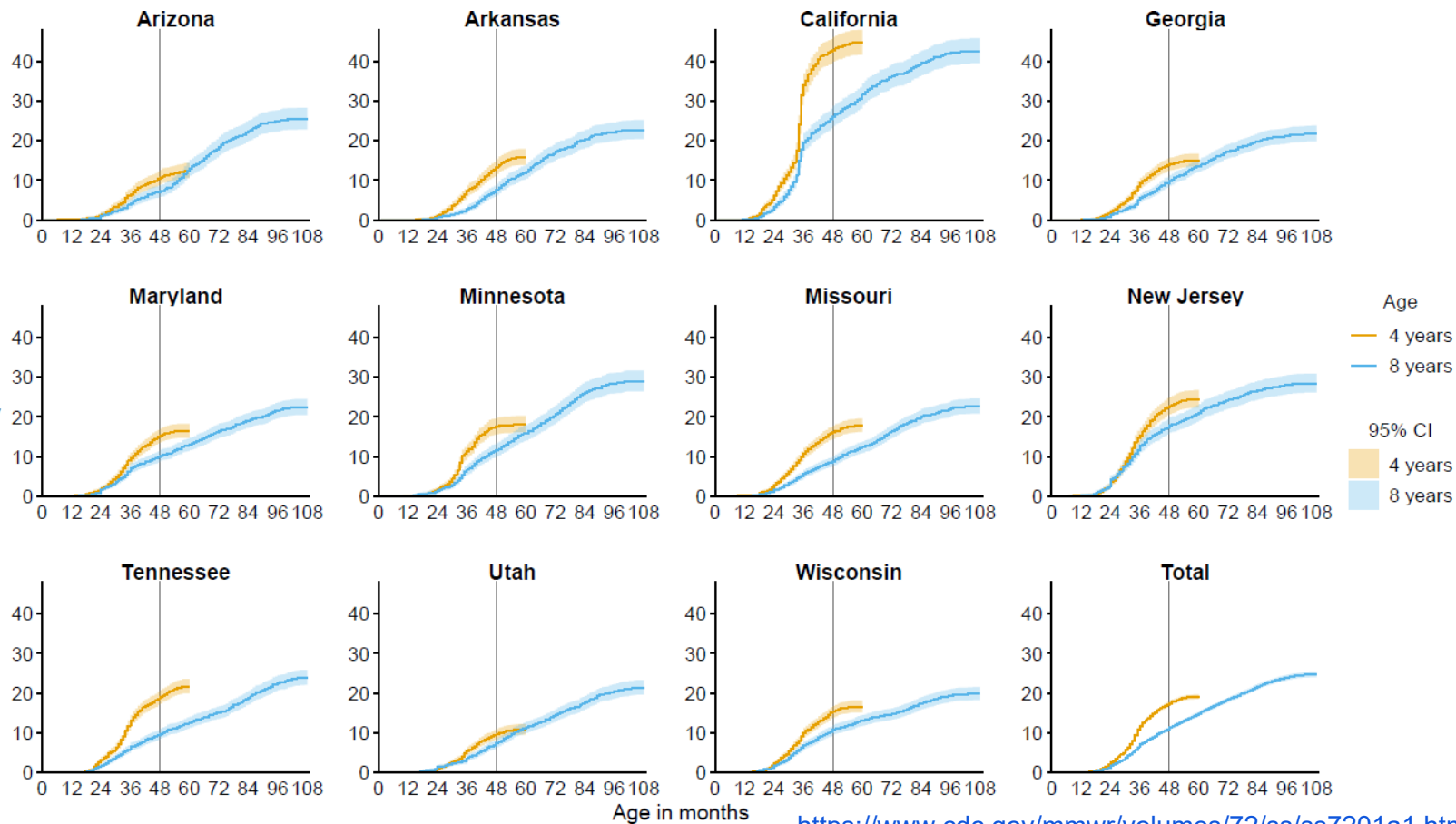
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020

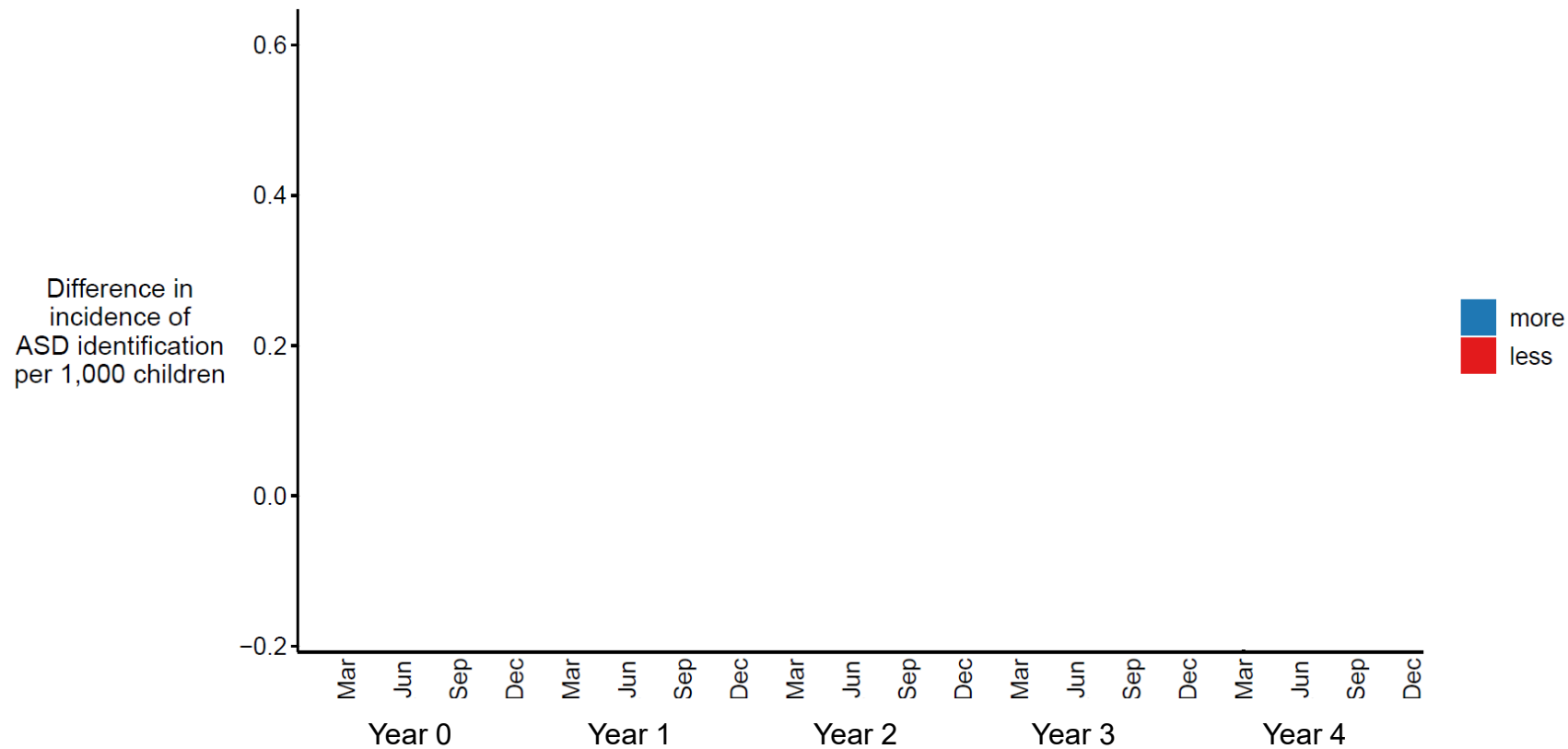


# Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years, by site

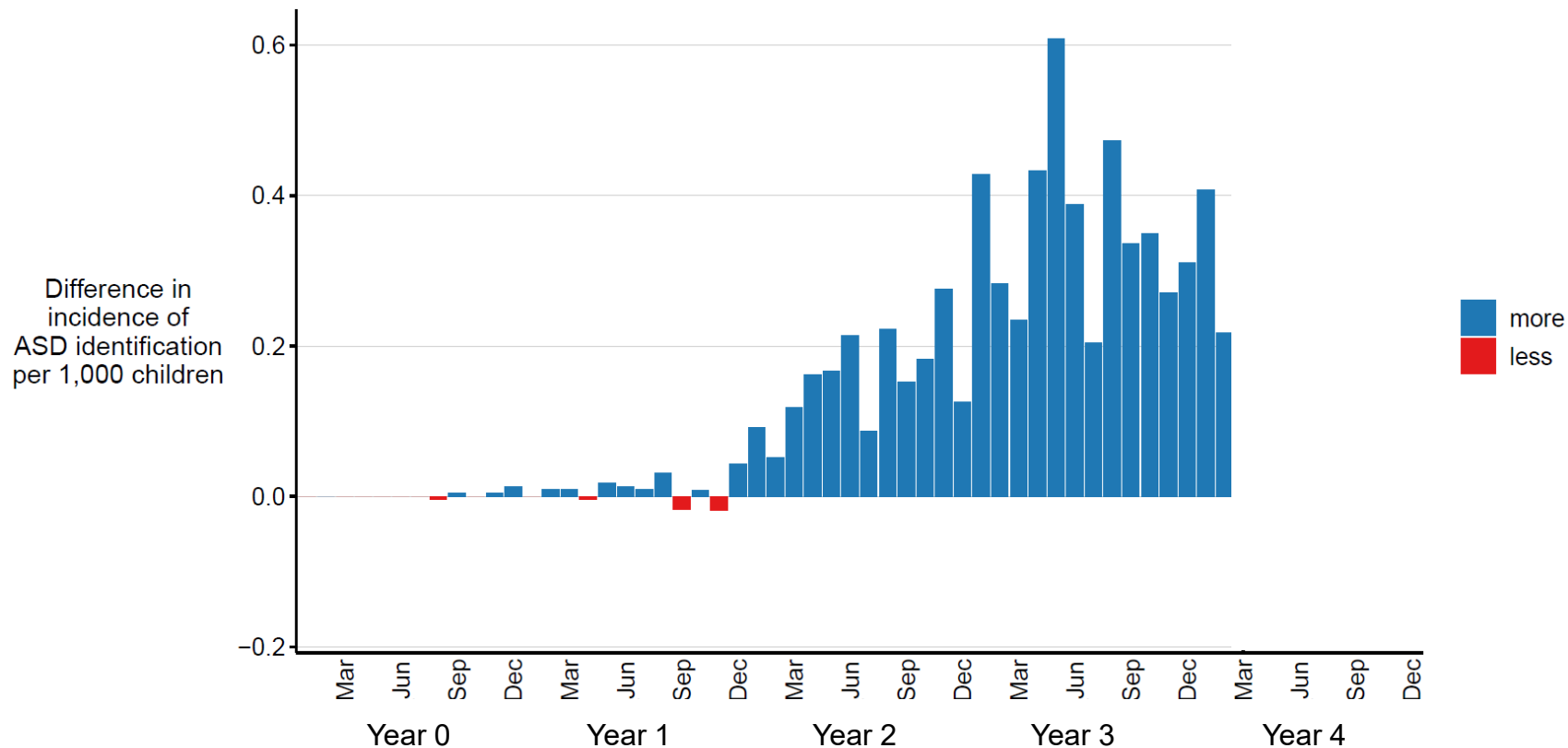
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020

Cumulative incidence of ASD diagnosis or special education eligibility per 1,000 children

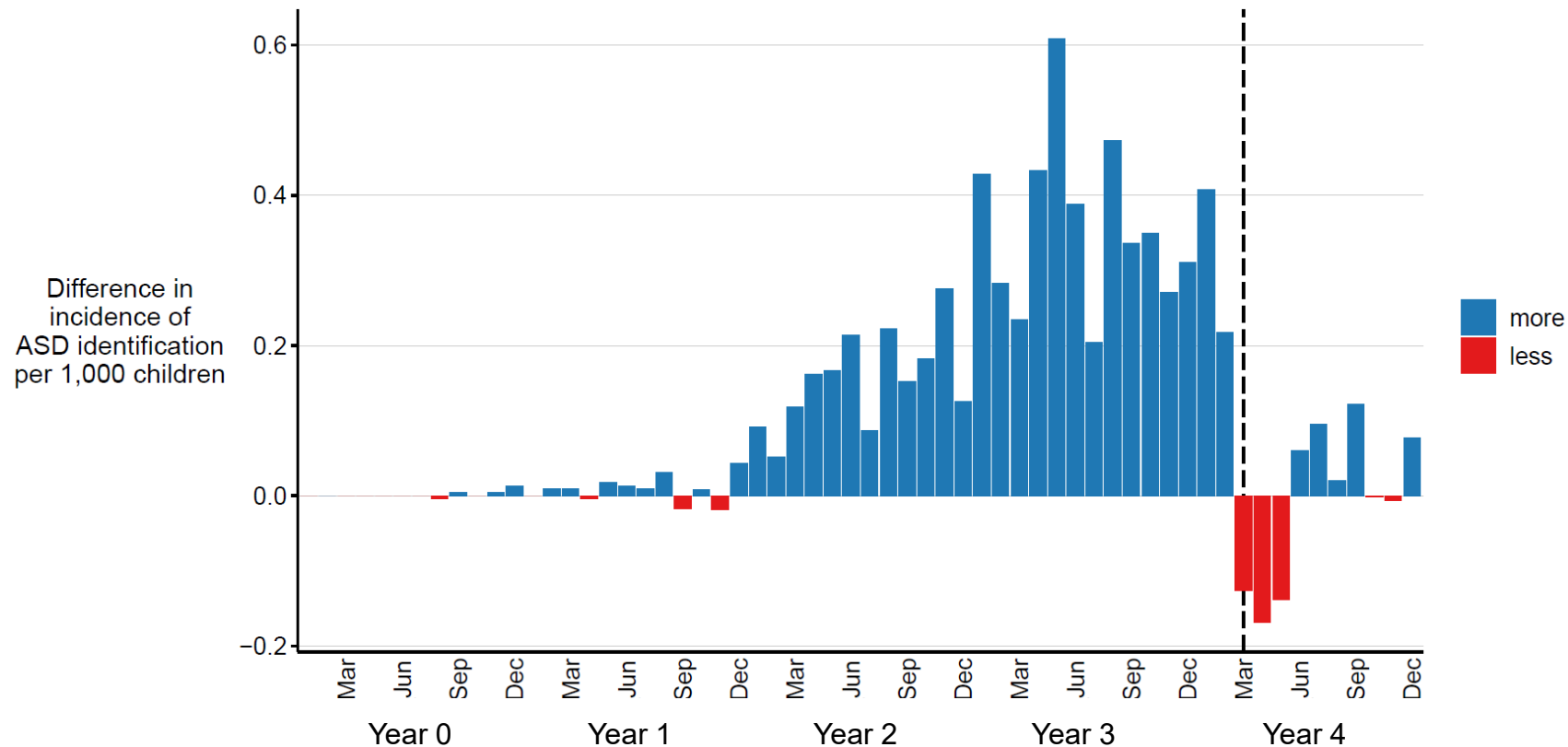




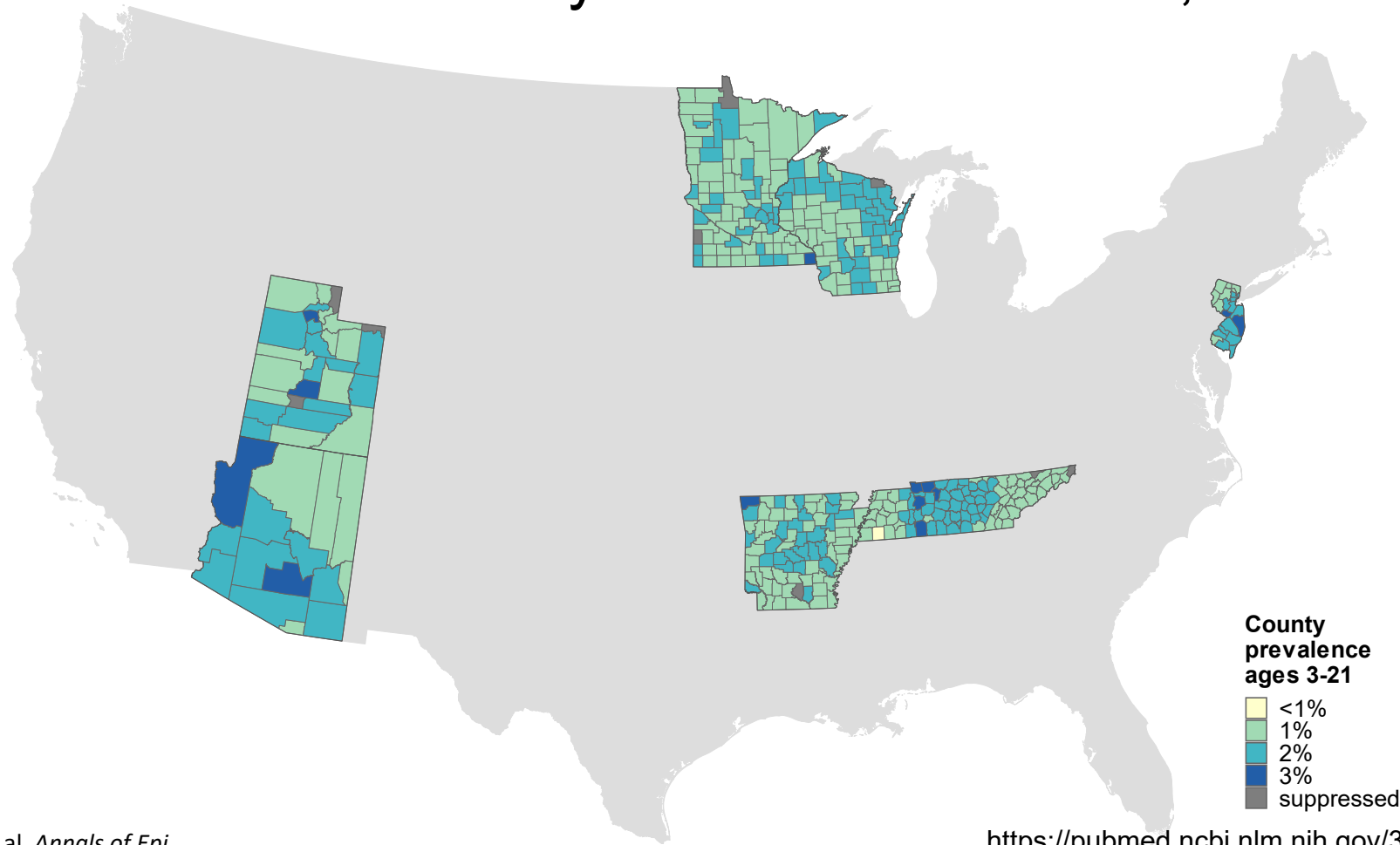
There were **increases** in early autism detection prior to the COVID-19 pandemic



# Progress in early autism detection was **disrupted** during COVID-19 pandemic



# Statewide county-level ASD estimates, 2018





## Autism Spectrum Disorder (ASD)

< Autism Spectrum Disorder (ASD) Home

### ABOUT 1 IN 36 CHILDREN

WERE IDENTIFIED WITH AUTISM SPECTRUM DISORDER  
AMONG A 2020 SAMPLE OF 8 YEAR OLDS FROM 11 US  
COMMUNITIES  
IN CDC'S ADDM NETWORK

#### ASD Data Visualization

Explore the information below to see autism spectrum disorder (ASD) prevalence estimates and demographic characteristics at the national, state, and community levels. Click on methodology to learn more about the data sources.

[Accessible versions of the data presented below are available.](#)

Includes state-based data from four sources:

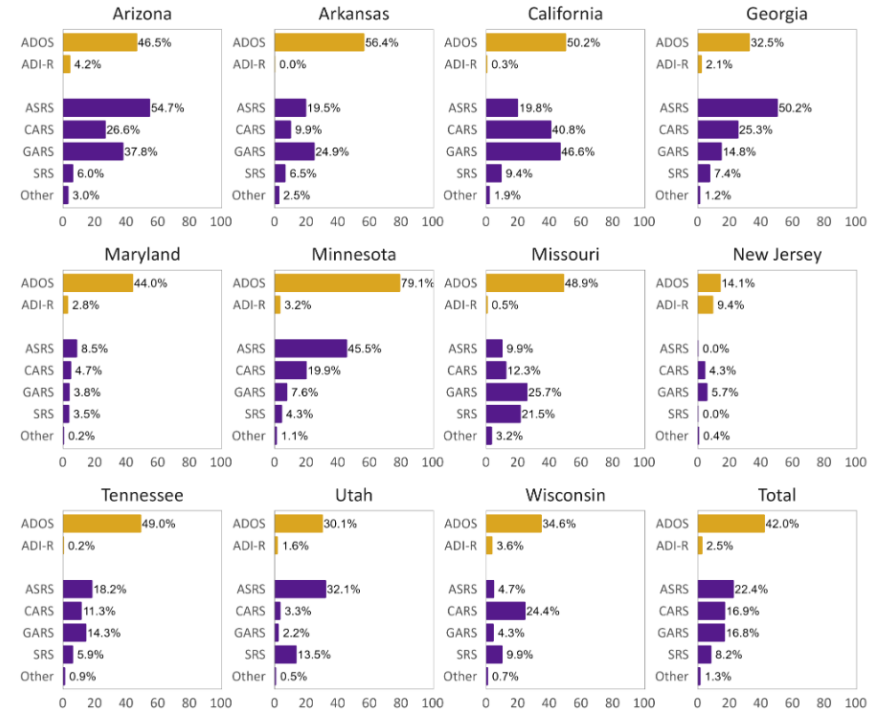
- ADDM
- Dept of Ed. Special Education
- Medicaid
- National Survey of Children's Health

- Brief description of methods
- Availability of data (states/years)
- Ability to download
- References to technical/methods documents

Testing practices vary by community

<50% of children identified as having ASD had documentation of a “gold standard” assessment.

Autism Spectrum Disorder Test



Percent of Children with Autism Spectrum Disorder Who Have Recorded Autism Spectrum Disorder Test

"Gold Standard" Test  
 Yes (Yellow)  
 No (Purple)



# Two older studies involving in-person assessment of autism status

➤ [Emerg Themes Epidemiol.](#) 2018 Aug 16;15:12. doi: 10.1186/s12982-018-0081-y. eCollection 2018.

## **Assessment of demographic and perinatal predictors of non-response and impact of non-response on measures of association in a population-based case control study: findings from the Georgia Study to Explore Early Development**

Laura A Schieve <sup>1</sup>, Shericka Harris <sup>1</sup>, Matthew J Maenner <sup>1</sup>, Aimee Alexander <sup>1</sup>, Nicole F Dowling <sup>1</sup>

Affiliations [+ expand](#)

PMID: 30147744 PMCID: [PMC6094575](#) DOI: [10.1186/s12982-018-0081-y](#)

- participation associated with demographic factors
- potentially addressable if characteristics of sampling frame are known

➤ [J Autism Dev Disord.](#) 2011 Feb;41(2):227-36. doi: 10.1007/s10803-010-1050-7.

## **Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders**

Rachel Nonkin Avchen <sup>1</sup>, Lisa D Wiggins, Owen Devine, Kim Van Naarden Braun, Catherine Rice, Nancy C Hobson, Diana Schendel, Marshalyne Yeargin-Allsopp

- conducted in a single place/time
- two-phase design with evaluation of screen-negative group

# Considerations for measuring autism prevalence

## Variation by

- **Calendar year**
- **Age of children**
- **Race/ethnicity, socioeconomic status**
- **Community**
  - Availability of services, providers, expertise
  - Policies or requirements
  - Evaluation/diagnostic practices
- **Combinations of the above**

## Challenges and trade-offs

- **Generalizability between communities, population subgroups, time periods**
- **Rigor of in-person assessment versus non-participation bias**
- **Comparability between assessment standards or different systems/processes**

For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 [cdc.gov](https://www.cdc.gov)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the U.S. Centers for Disease Control and Prevention.

