

# Autism Prevalence in the District of Columbia (DC):

*How Many Autistic Children Live in DC?*





# DC Autism Collaborative (DC-AC)

- **Goal:** Develop and advocate for solutions that will increase early and equitable access to high-quality ASD diagnosis, treatment, and coordinated care, thus improving child and family outcomes.
- **Structure:**
  - Public-private **working group** (e.g., advocacy groups, health and education providers, government agencies)
    - **Subgroups targeting different needs**
  - **Family Advisory Group**
- **Resources** available on website (English, Spanish, Amharic)



[www.childrensnational.org/DC-AC](http://www.childrensnational.org/DC-AC)

# Why is Autism Data Important?

- Determines policy, resources, and other decisions
- Shows patterns over time and needs or inequities
- Informs advocacy efforts





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

**Matthew Maenner, PhD**

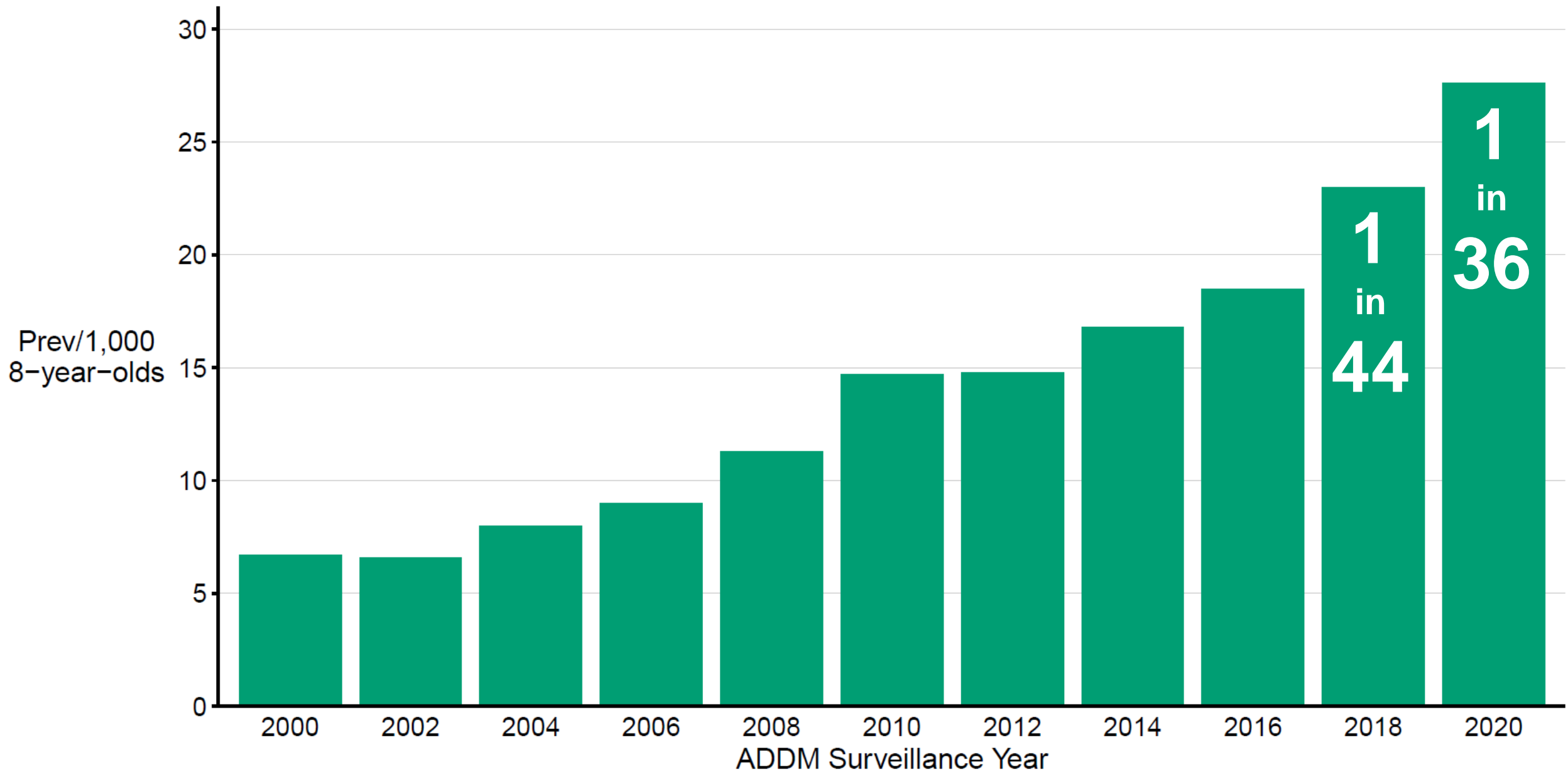
**Chief, Child Development and Disability Branch**

**Division of Human Development and Disability**

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

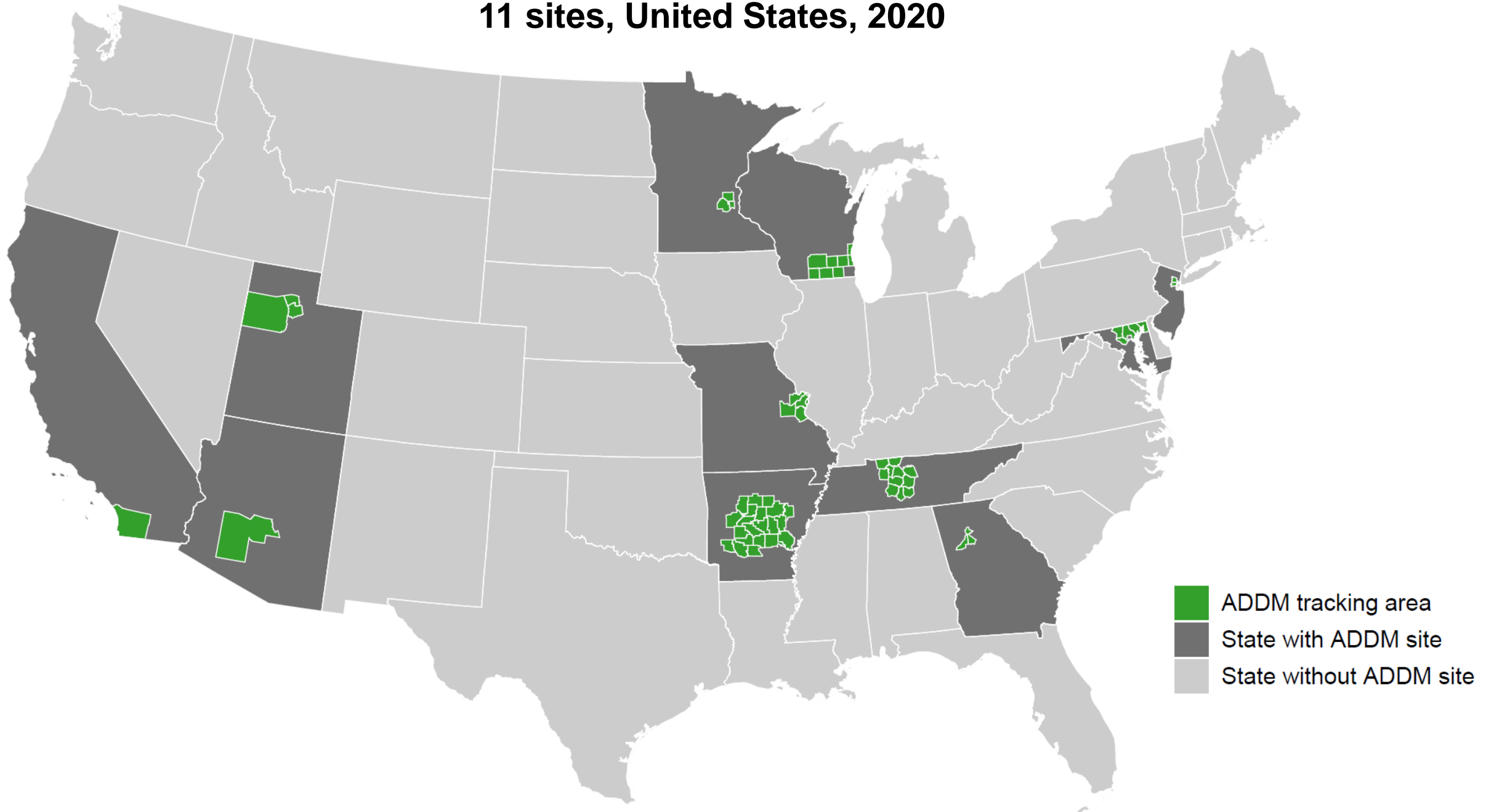
**Centers for Disease Control and Prevention**

June 6, 2024



# Autism and Developmental Disabilities Monitoring Network

11 sites, United States, 2020



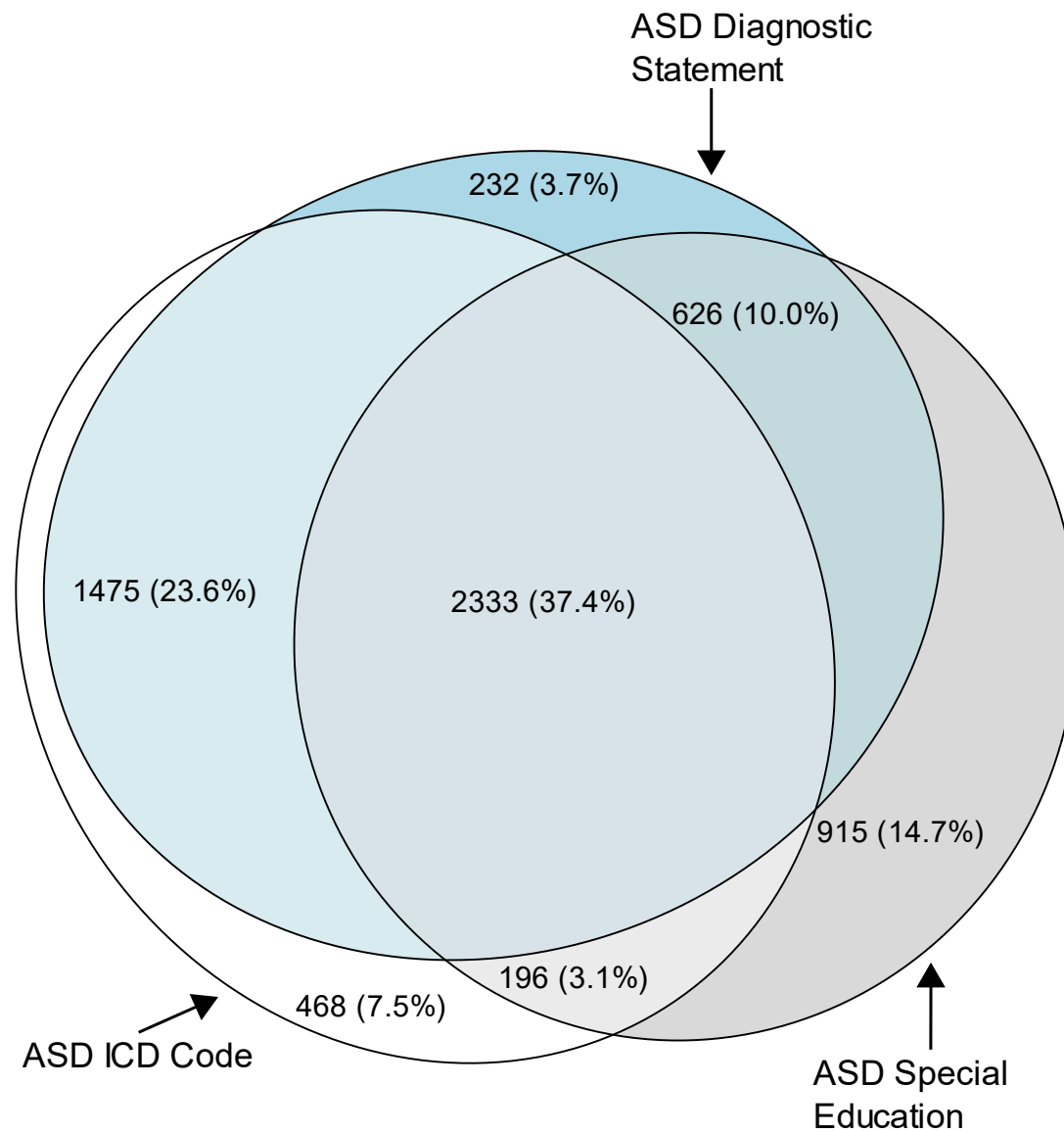
## Case definition for ASD surveillance

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

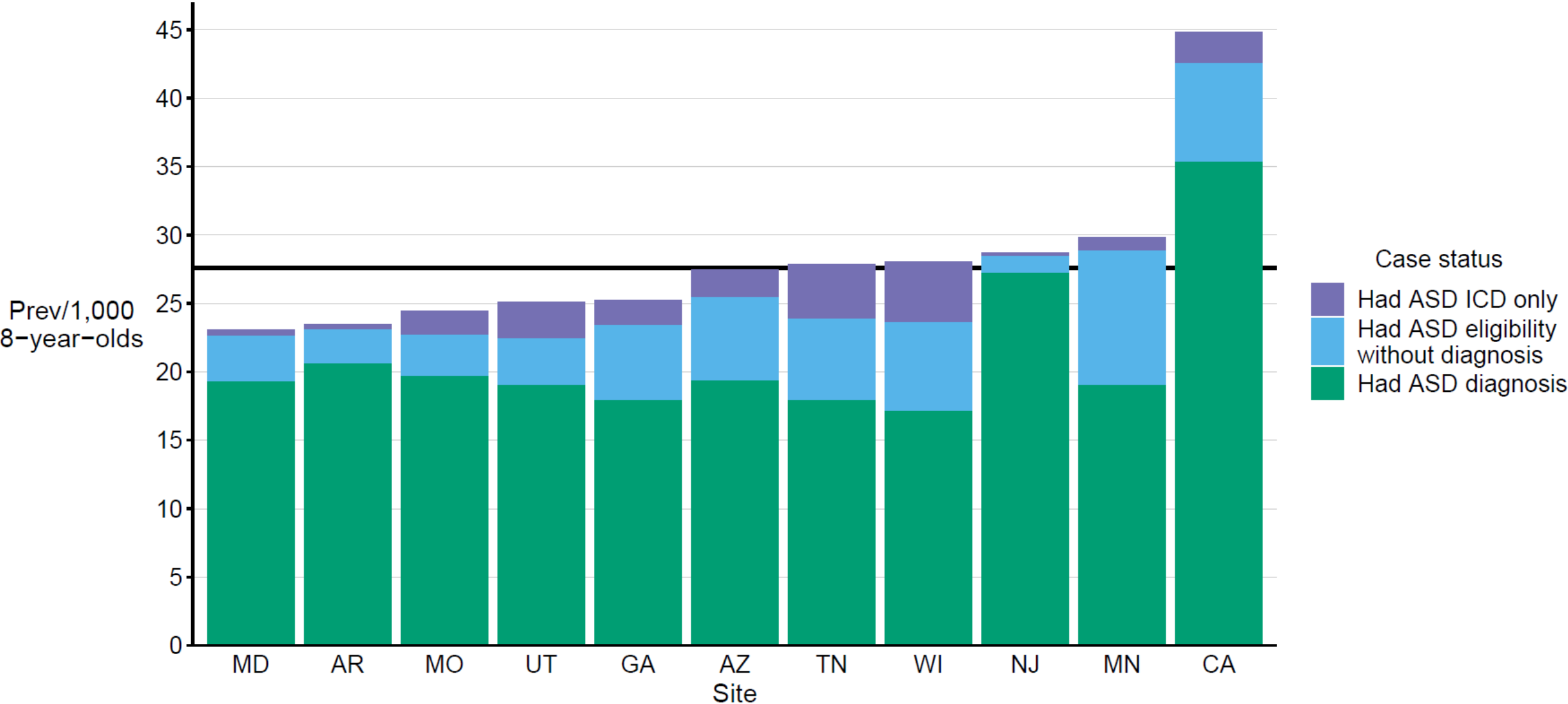
# Euler diagram of different types of autism spectrum disorder identification among children aged 8 years with autism spectrum disorder (N=6,245)

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



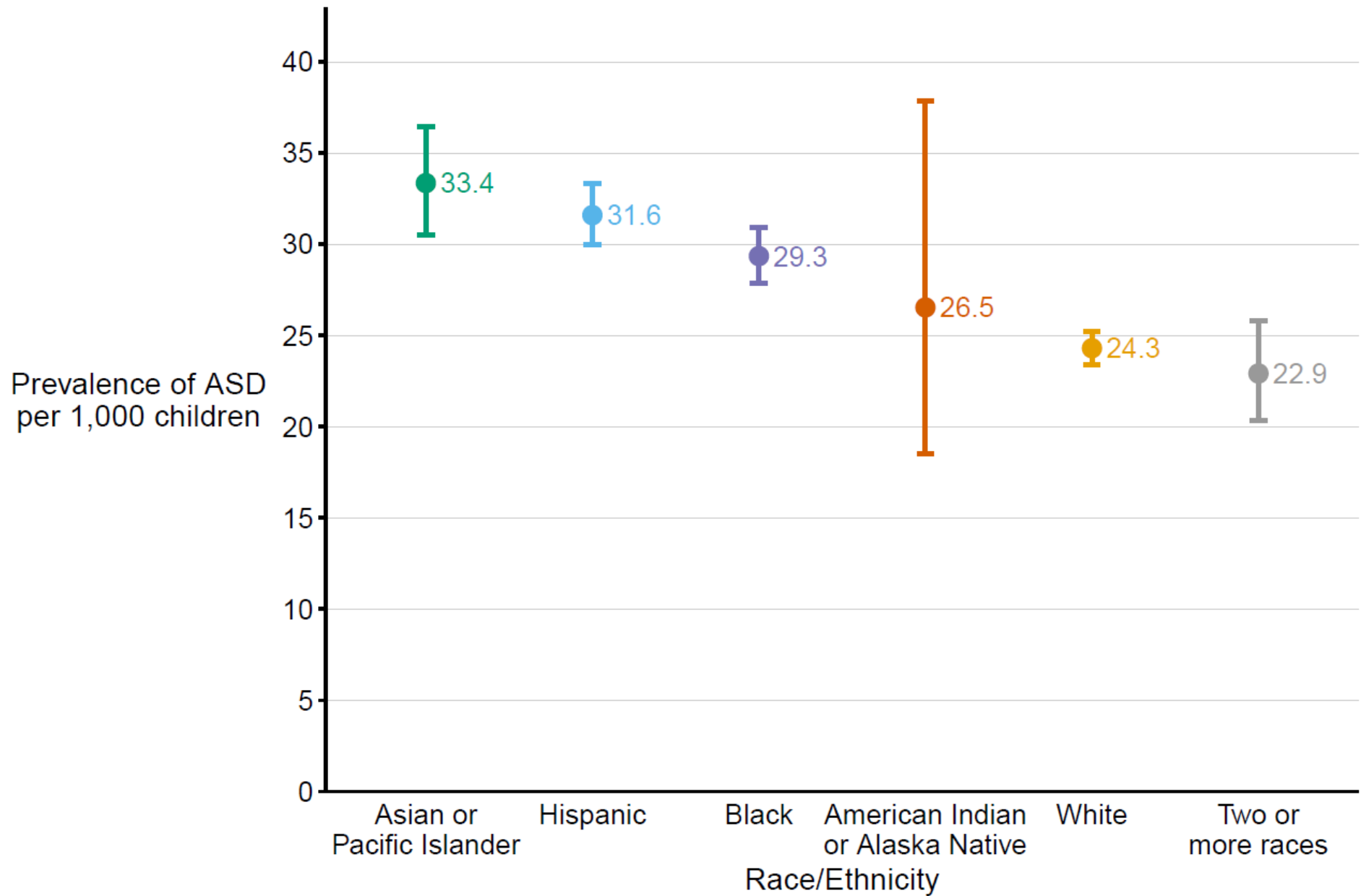


# There is variability in practices across ADDM communities

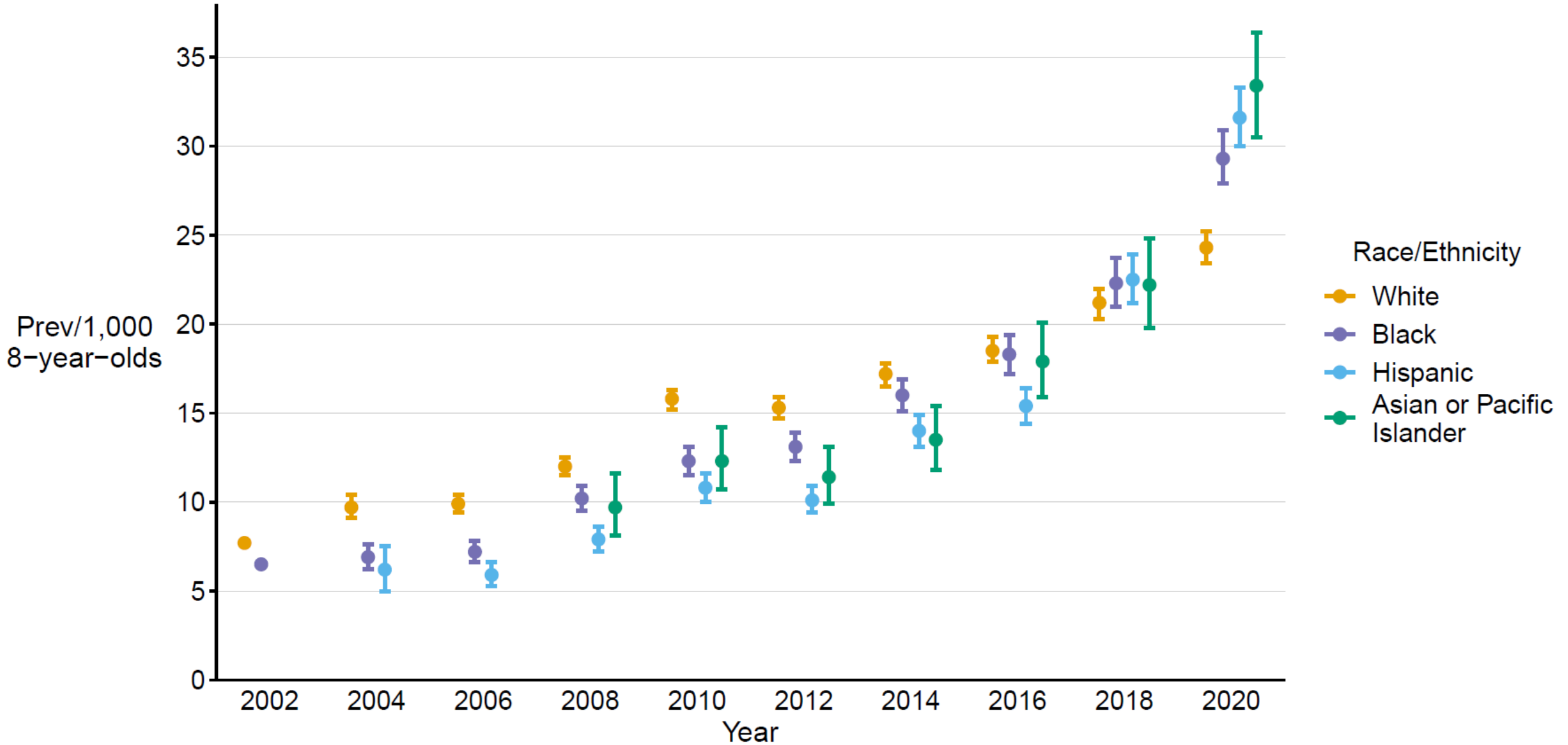


# Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by race/ethnicity

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

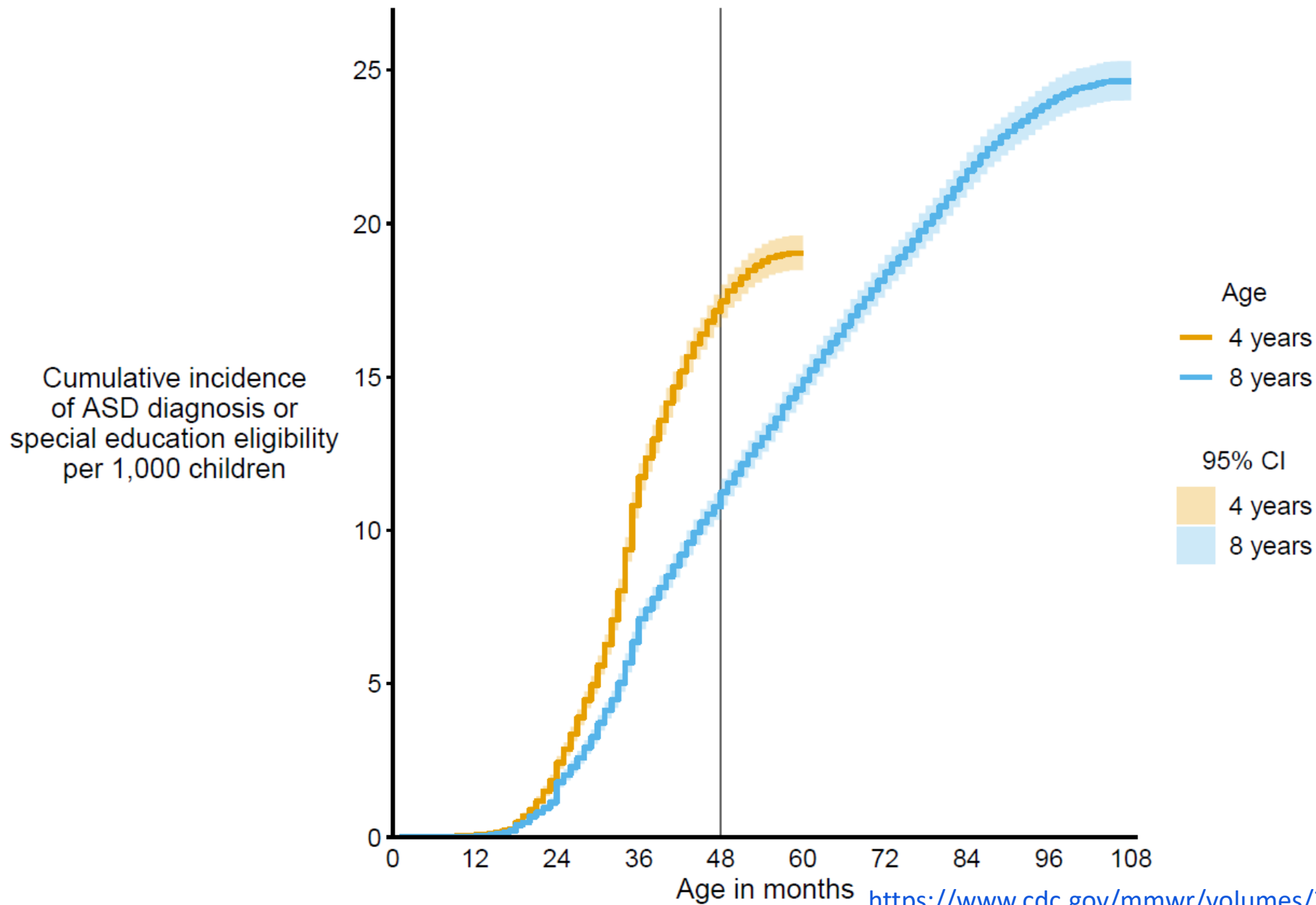


# Patterns by race/ethnicity have changed for children aged 8 years



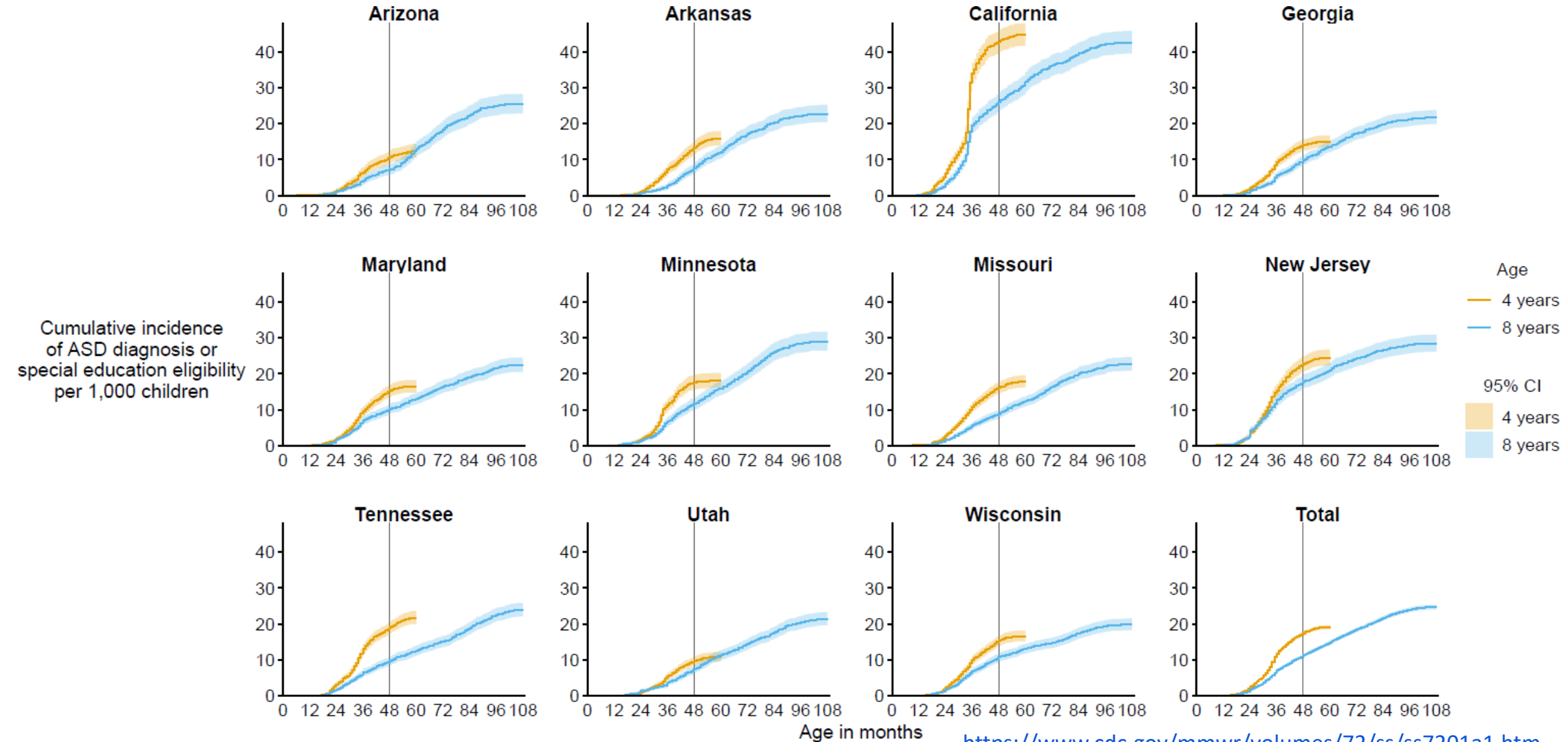
# Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years

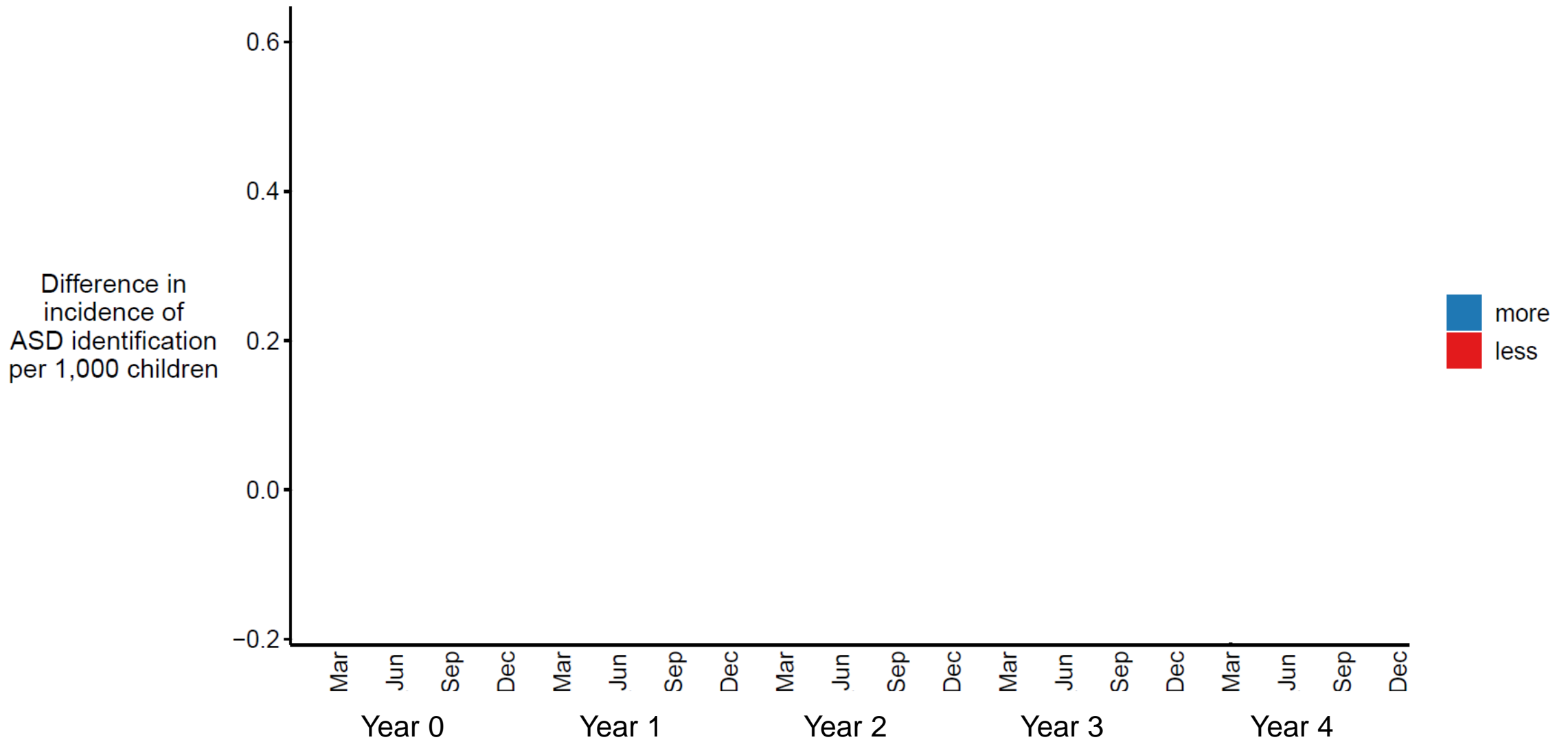
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020



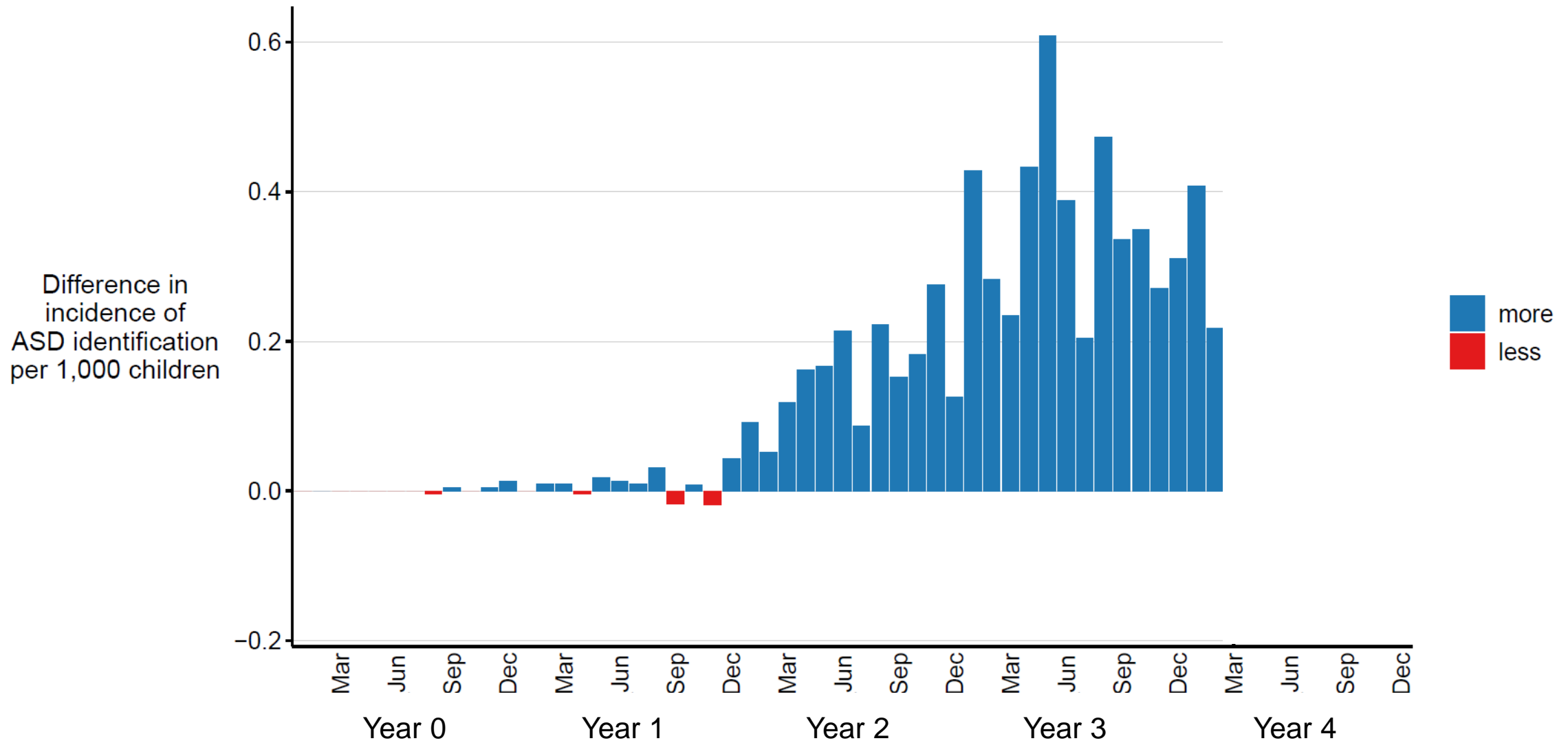
# Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years, by site

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

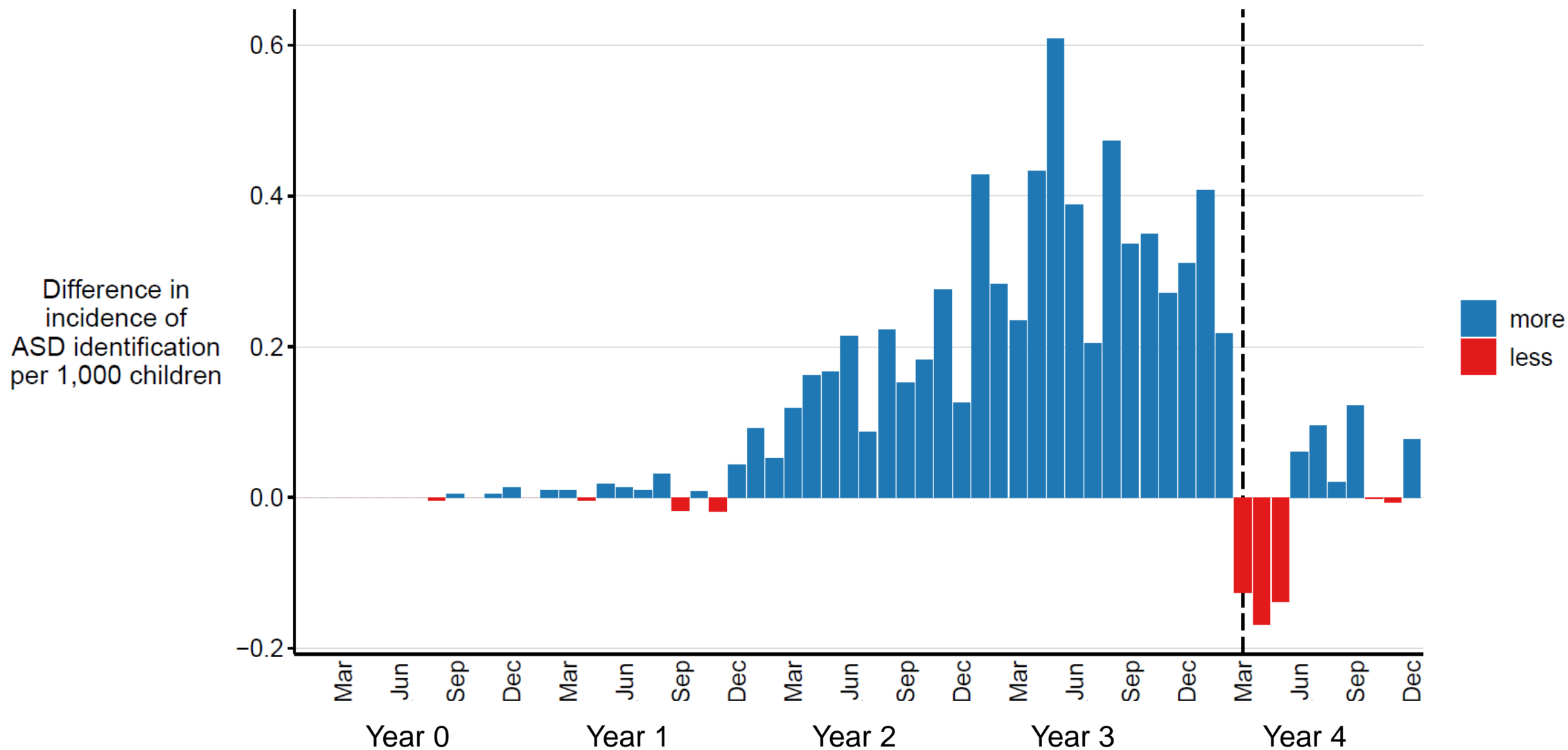




# There were **increases** in early autism detection prior to the COVID-19 pandemic

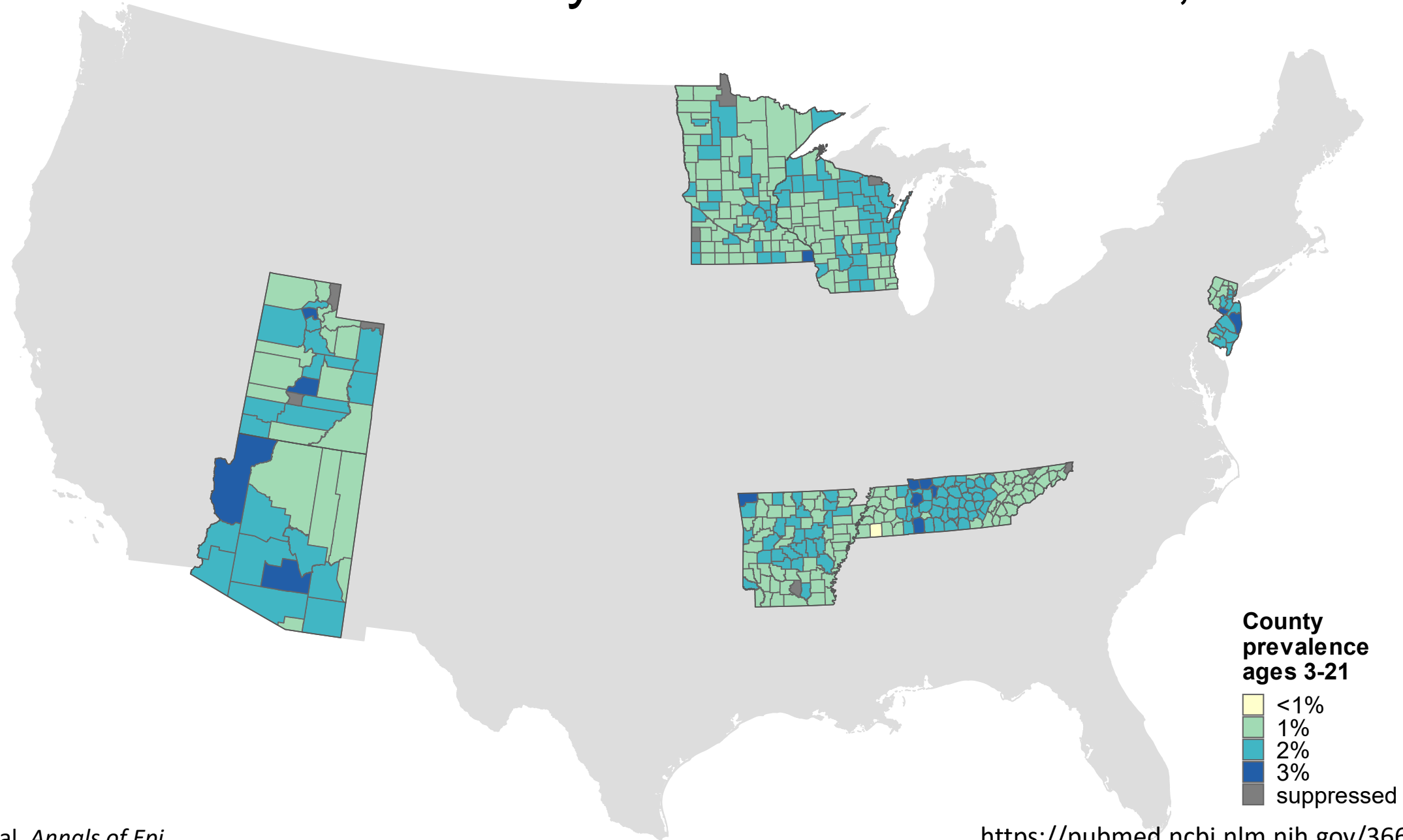


# Progress in early autism detection was **disrupted** during COVID-19 pandemic



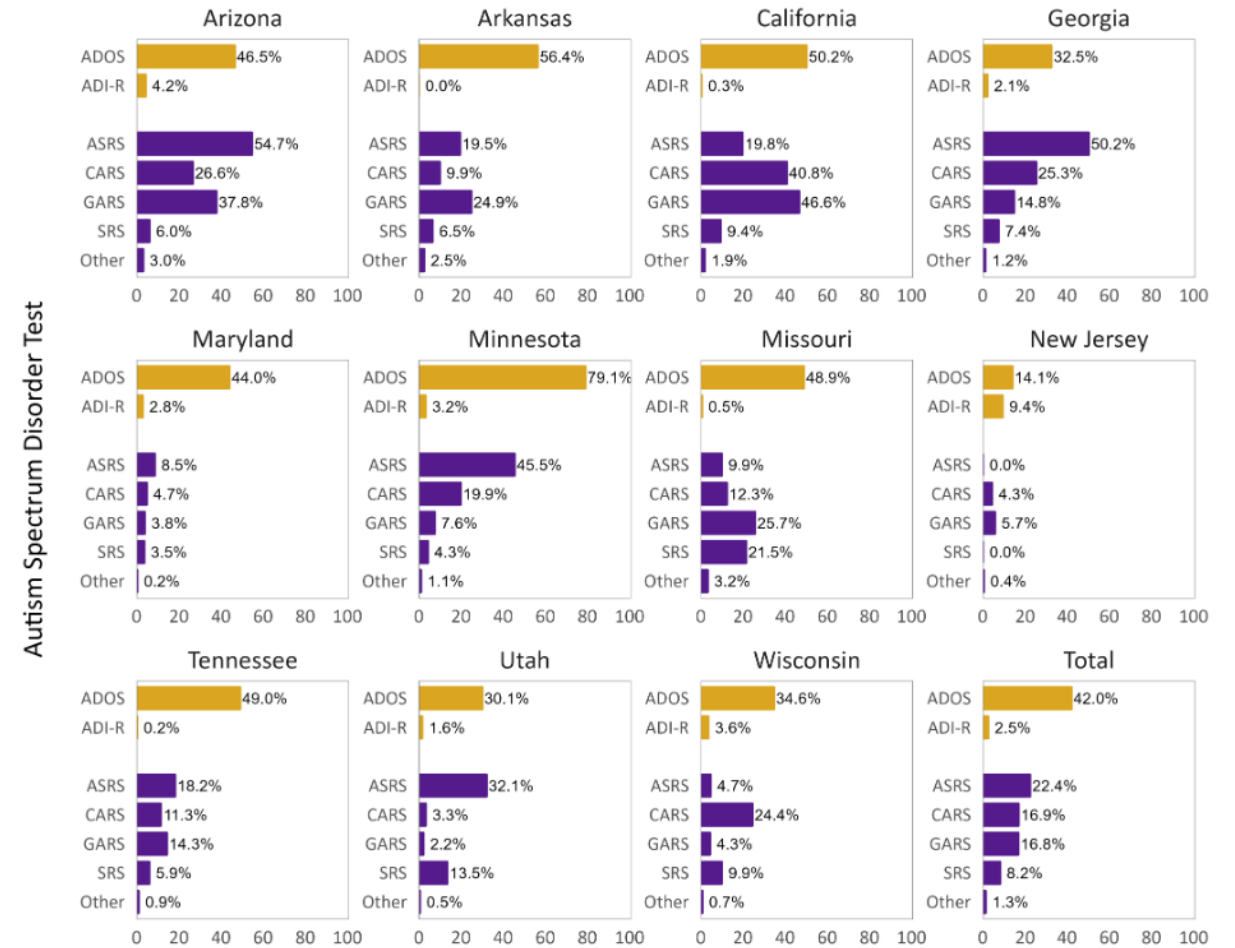


# Statewide county-level ASD estimates, 2018



Testing practices vary by community

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



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

"Gold Standard" Test  
■ Yes  
■ No

# Local Data for Action

DATA FOR ACTION

## Data for Action

### How can the ADDM Network Findings Be Used?

There are many children with ASD across the United States. The ADDM Network's information on the number and characteristics of children with ASD provides data for action. These findings can be used in local communities and nationwide to advance initiatives, policies, and research that help children with ASD.

#### The federal government is using this information to

- Guide research on ASD.
- ADDM Network findings have helped inform the Interagency Autism Coordinating Committee's Strategic Plan for ASD research (2).
- Inform and promote early identification efforts.
- ADDM Network findings on age of diagnosis of ASD support CDC's [Learn the Signs. Act Early](#) Program, which aims to improve early identification by promoting early childhood developmental monitoring by parents, childcare providers, and healthcare providers.

#### Service providers, such as healthcare organizations and school systems, can use this information to

- Promote early identification efforts for developmental concerns in children and help get those children diagnosed with ASD enroll in community-based support systems as soon as possible.
- CDC's [Learn the Signs. Act Early](#) Program offers free tools, including the [Milestone Tracker](#) app, that service providers can promote among parents to help

improve developmental monitoring, a critical step in the early identification of developmental delays.

- Plan for resource and service needs.
- Target outreach to communities with higher rates of ASD and those living in low-income neighborhoods.

#### Policymakers and community leaders can use this information to

- Promote awareness of ASD and bring the community together to address the growing needs of families with ASD.
- Develop policies that promote early identification and equal access to services and supports so that all children get the help they need.
- Serve as the basis for the creation of a task force or commission focused on the coordination of ASD activities in local communities.
- Assess current service needs following disruptions in evaluations and services during the COVID-19 pandemic.

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Specific examples regarding:

- Policy
- Services
- Planning

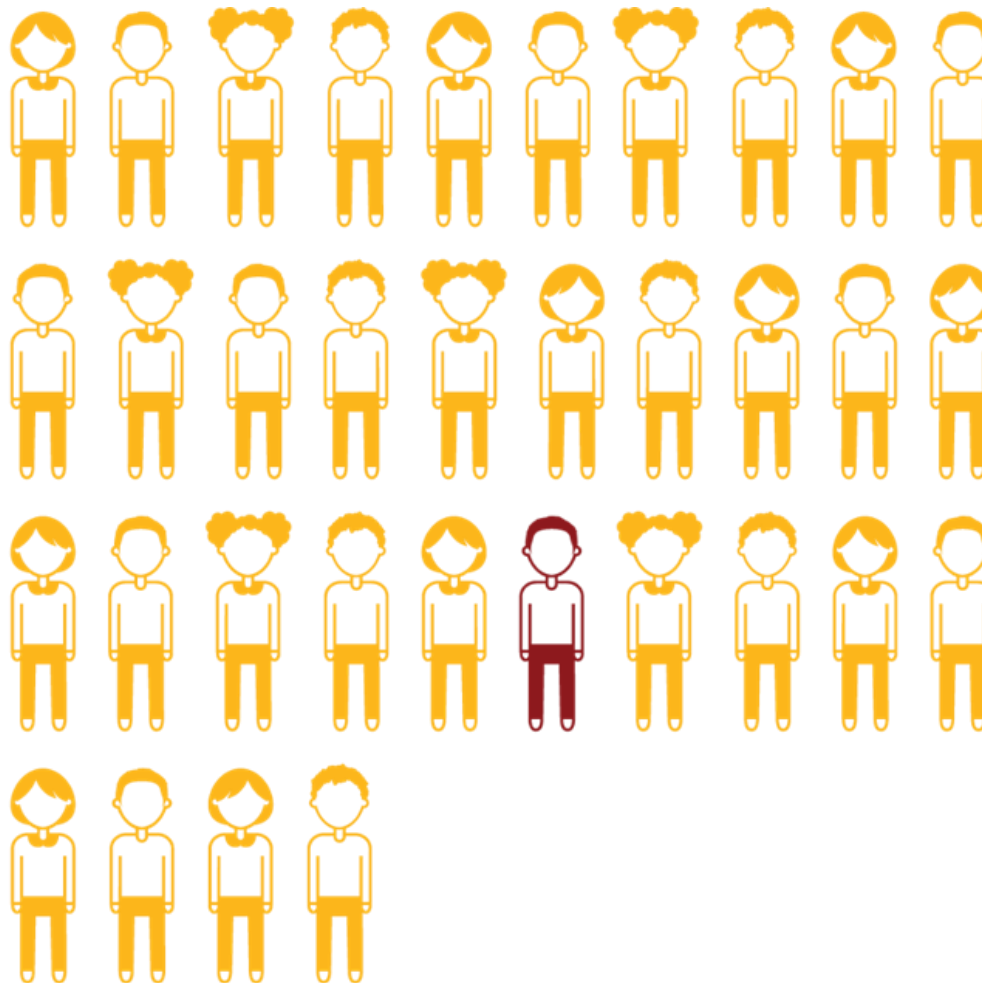


 **ADDMM**  
Minnesota Autism Developmental  
Disabilities Monitoring Network

# Autism Prevalence Minnesota

# 3.0%

is the average percentage  
identified with ASD



# 1 in 34

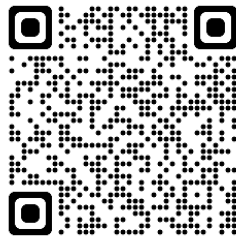
8-year-old children were  
identified with ASD in  
the ADDM Network







## Informing State Policy

- Early Intensive Developmental Behavior Intervention
- Direct Support Professional/PCA
- Autism Interagency Committee

The [MN Autism Resource Portal](#) is a complete resource guide!



- The portal was created with input from caregivers, advocates, educators, professionals, & others.
- [Contact us](#) 
- [Like us on Facebook](#) 
- [Event request form](#) 
- [Event calendar](#) 



# Portal Postcard

## MN Autism Resource Portal Postcard



**m1 MINNESOTA**  
AUTISM RESOURCE PORTAL

**mn.gov/autism**

Access the **MN Autism Resource Portal** website anytime, anywhere, for trusted information on healthcare, education, services, and more!

**mn.gov/autism**

facebook.com/mnautismportal

The postcard features a central image of a computer monitor displaying the MN Autism Resource Portal website. To the left, a smartphone and a tablet also show the website's interface. The text describes the portal as a source for trusted information on healthcare, education, services, and more. The URL [mn.gov/autism](https://mn.gov/autism) is prominently displayed, along with the Facebook page [facebook.com/mnautismportal](https://facebook.com/mnautismportal).



**Pathway to autism spectrum disorder (ASD) services & supports**  
*Helping you access the right supports, at the right time*

**mn.gov/autism**

Questions? Email us:  
**ASD.DHS@state.mn.us**

Next steps:  
Pathway to services and supports for a child recently identified with ASD

**1** First steps: pathway to learning, playing and growing

**2**

**3** Overview of medical identification and educational determination of ASD

**4** Next stage: Pathway to transition and long-term services and supports

The postcard features a QR code in the top left corner that links to [mn.gov/autism](https://mn.gov/autism). A winding road graphic with four numbered markers (1, 2, 3, 4) illustrates the pathway to services and supports. The markers are: 1. First steps: pathway to learning, playing and growing; 2. (unlabeled); 3. Overview of medical identification and educational determination of ASD; 4. Next stage: Pathway to transition and long-term services and supports. The text also includes the email address [ASD.DHS@state.mn.us](mailto:ASD.DHS@state.mn.us) for questions.



A young girl with braided hair, wearing a colorful striped hoodie, is reaching out towards a woman. The woman is wearing a grey hijab and a black jacket, and she is smiling while clapping her hands. The background is plain white.

Early Identification



Minnesota Autism Developmental  
Disabilities Monitoring network



# MN Act Early Parent Connector Project

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- Connect ADDM data to community needs
- Innovative ways for outreach (cultural festivals, mosques, cultural child care, organizations, Open Streets, etc.)
- Share Act Early materials with families with young children.
- Culturally sensitive view of child development.
- Promote access early screening and early intervention community
- Built parent leaders and normalized disability/delays in community.

We are @ Franklin Ave Open street

Thank you



UNIVERSITY OF MINNESOTA

**Driven to Discover<sup>SM</sup>**



# Selected DHCF Data on Children With Autism Spectrum Disorder or Intellectual Disability Diagnoses

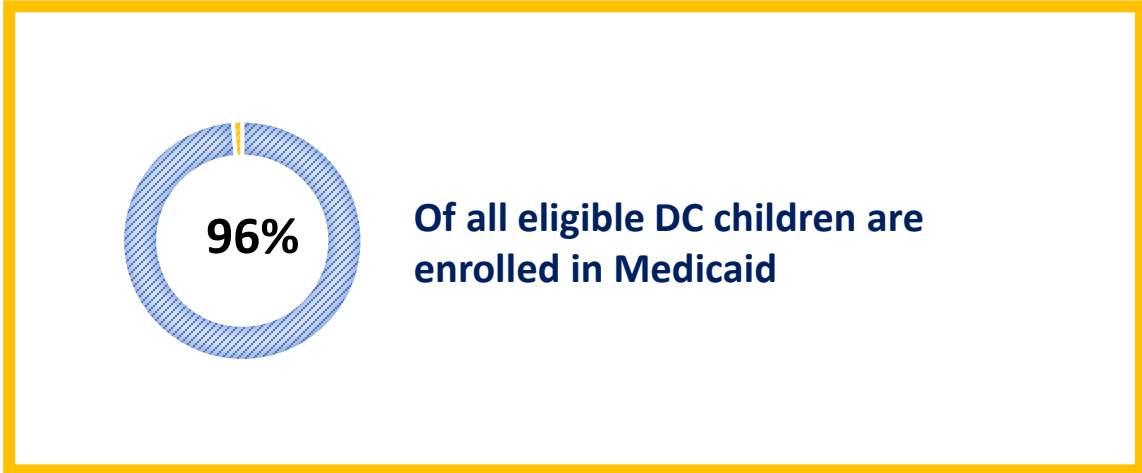
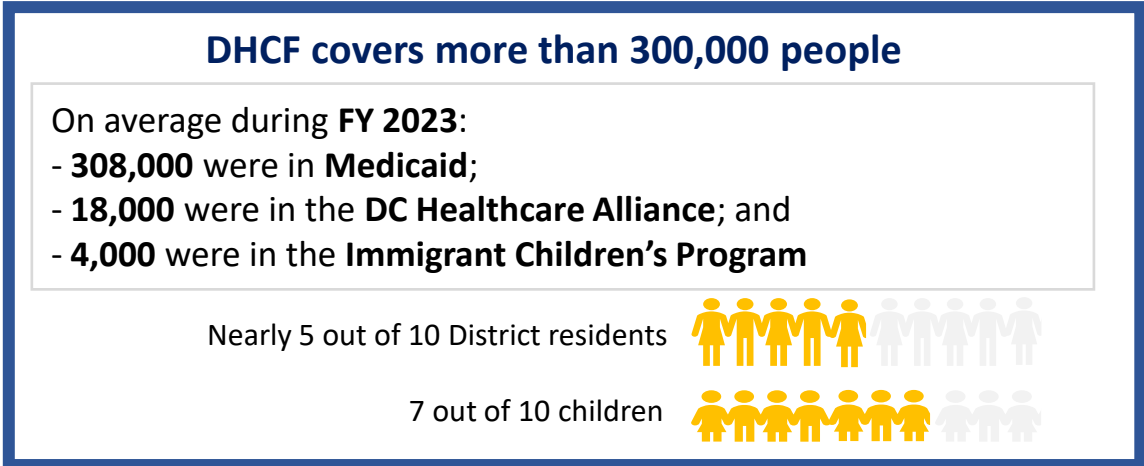
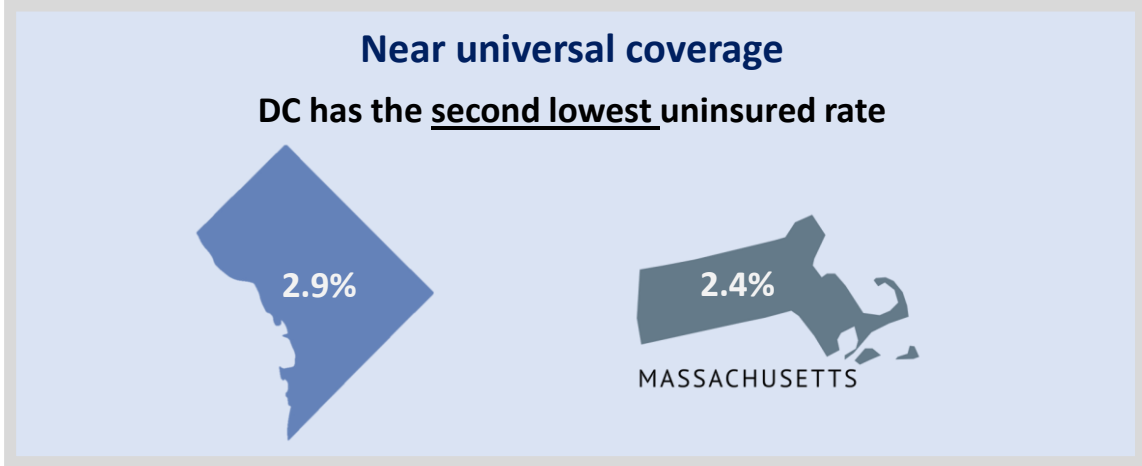
April Grady

Director, Data Analytics and Research Administration  
District of Columbia Department of Health Care Finance (DHCF)

June 6, 2024



# Medicaid and Other DHCF Programs Cover Nearly Half of All Residents and 70% of Children in the District



- ### Most children with Medicaid are in managed care
- Managed care program**
    - Approximately 90% of Medicaid children
    - Plans: Amerigroup DC; AmeriHealth Caritas DC; HSCSN; MedStar Family Choice
  - Fee-for-service program**
    - Approximately 10% of Medicaid children
    - Includes those with: disabilities; foster care or adoption assistance; justice involvement (DYRS)
- Examples of Medicaid provider types serving children in MCPs and FFS:** FQHCs (e.g., Unity, Mary’s Center, Community of Hope); facility-based (e.g., Children’s National, Howard University, Georgetown); physician and other practice groups

Source: Population and demographic estimates are from the U.S. Census Bureau’s the 2022 ACS 1-Year [Data Tables](#); DHCF Medicaid Management Information System (MMIS) data extracted in January 2024; Haley et al., “Insurance Rose Among Children and Parents in 2019,” Urban Institute, July 2021.



# EPSDT Medicaid Benefit for Children

## Early and Periodic Screening, Diagnostic, and Treatment



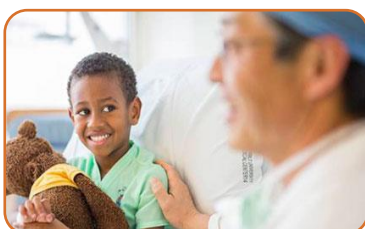
### Access

- State duty to inform families of benefit and services their children are entitled to and provide assistance so that children can receive the services they need



### Screenings and Education

- Assessments (and documentation) of physical, developmental and behavioral health in pediatric primary care visits
- Health education and counseling to parents



### Diagnosis and Treatment

- When screenings/visits uncover health concerns, EPSDT requires coverage of services needed to diagnose and treat the concerns
- Medically necessary services must be covered as long as they fall in the federal categories of Medicaid services, and regardless of whether they are in the individual State's Medicaid Plan



# DHCF Data Reflects Children Diagnosed with Autism Spectrum Disorder During a Visit with a Health Care Provider



## DC Department of Health Care Finance (DHCF) data

- When beneficiaries receive health services covered by Medicaid or other DHCF programs, their provider bills for the care by submitting a claim for payment; the claim is a record of services delivered and includes diagnosis codes indicating the health conditions that were present or treated
- In addition to claims, DHCF obtains demographic information when individuals enroll in coverage; external sources of data (e.g., from other DC agencies) may also be linked to obtain a more complete picture of the population with DHCF coverage

## Data and methods for information presented today

- Analyzed DHCF paid claims data to identify beneficiaries with an autism spectrum disorder (ASD) diagnosis (ICD-10 F84.0-F84.1, F84.4-F84.9; ICD-9 299.0) or intellectual disability (ID) diagnosis (ICD-10 F70-F79; ICD-9 299.8-299.9, 317-319)
- Unless noted otherwise, diagnosis (Dx) and utilization statistics reflect claims in the past year (e.g., for an individual enrolled in October 2021, which is the first month of FY 2022, claims from November 2020 through October 2021 are included in the analysis)
- Due to rounding, the sum of average monthly numbers may differ slightly across tables





# Summary of DHCF Data on Children Diagnosed with Autism Spectrum Disorder and/or Intellectual Disability



## Population size

- Approximately 2% of the FY 2022 DHCF population under age 21 had an ASD and/or ID diagnosis in the past year (~2,000 DHCF-enrolled children), largely reflecting ASD
- The percentage of DHCF beneficiaries under age 21 with a past year diagnosis of ASD/ID has increased, from 1.6% for those enrolled in FY 2018 to 1.9% for those enrolled in FY 2022

## Demographic characteristics

- Compared to DHCF children without an ASD/ID diagnosis, those with ASD/ID are more concentrated in age groups 3-5, 6-9, and 10-14
- More likely to be male
- More likely to be African American
- No more/less likely to live in certain wards compared to other DHCF children

## Service use and co-occurring conditions

- Some of the most common services include speech/language/communication and other therapies
- Top co-occurring conditions include other neurodevelopmental diagnoses such as speech/language disorders and attention deficit hyperactivity disorder



# Nearly 2% of the FY 2022 DHCF Population Under Age 21 Had an ASD and/or ID Diagnosis on 2+ Claims in the Past Year, Largely Reflecting ASD



**Average Monthly DHCF Beneficiaries Under 21 by ASD/ID Dx Combinations in Past Year, FY 2022**

	Number	Percent
<b>Dx ASD/ID on 0 claims past yr</b>	<b>102,013</b>	<b>97.7%</b>
<b>Dx ASD/ID on 1 claim past yr</b>	<b>367</b>	<b>0.4%</b>
<b>Dx ASD/ID on 2+ claims past yr</b>	<b>2,023</b>	<b>1.9%</b>
<b>Dx ASD on 0 claims past yr</b>	<b>408</b>	<b>0.4%</b>
Dx ID on 2+ claims past yr	408	0.4%
<b>Dx ASD on 1 claim past yr</b>	<b>10</b>	<b>0.0%</b>
Dx ID on 1 claim past yr	2	0.0%
Dx ID on 2+ claims past yr	8	0.0%
<b>Dx ASD on 2+ claims past yr</b>	<b>1,604</b>	<b>1.5%</b>
Dx ID on 0 claims past yr	1,530	1.5%
Dx ID on 1 claim past yr	25	0.0%
Dx ID on 2+ claims past yr	49	0.0%
<b>Grand Total</b>	<b>104,402</b>	<b>100.0%</b>



# Share of DHCF Children With ASD/ID Diagnosis Has Increased and Varies Depending on Number of Claims Required and the Lookback Period



- For beneficiaries under age 21 enrolled in FY 2022:
  - 2.3% had a diagnosis of ASD or ID on at least 1 claim in the past year (2,389 individuals)
  - 1.9% had a diagnosis of ASD or ID on 2+ claims in the past year (2,023 individuals)
  - 2.8% had a diagnosis of ASD or ID on 2+ claims when the lookback period is increased to 5 years (2,934 individuals)
- The share of beneficiaries under age 21 with a diagnosis of ASD or ID on 2+ claims in the past year increased from 1.6% for those enrolled in FY 2018 to 1.9% for those enrolled in FY 2022

**Table 1. Average Monthly DHCF Beneficiaries Under 21 by ASD/ID Dx in Past 1-5 Years and Number of Claims with Dx, FYs 2018-2022**

Number of beneficiaries	FY2018					FY2019					FY2020					FY2021					FY2022				
	FY2018	FY2019	FY2020	FY2021	FY2022	FY2018	FY2019	FY2020	FY2021	FY2022	FY2018	FY2019	FY2020	FY2021	FY2022	FY2018	FY2019	FY2020	FY2021	FY2022	FY2018	FY2019	FY2020	FY2021	FY2022
<b>Dx ASD/ID on 0 claims past 5 yr</b>	93,501	94,776	94,448	97,932	101,040	93,501	94,776	94,448	97,932	101,040	97.3%	97.1%	97.0%	97.0%	96.8%	93,501	94,776	94,448	97,932	101,040	97.3%	97.1%	97.0%	97.0%	96.8%
Dx ASD/ID on 0 claims past yr	93,501	94,776	94,448	97,932	101,040	93,501	94,776	94,448	97,932	101,040	0.3%	0.3%	0.3%	0.3%	0.2%	93,501	94,776	94,448	97,932	101,040	0.3%	0.3%	0.3%	0.3%	0.2%
<b>Dx ASD/ID on 1 claim past 5 yr</b>	398	408	405	402	429	398	408	405	402	429	0.4%	0.4%	0.4%	0.4%	0.4%	398	408	405	402	429	0.4%	0.4%	0.4%	0.4%	0.4%
Dx ASD/ID on 0 claims past yr	245	275	264	259	255	245	275	264	259	255	0.2%	0.1%	0.1%	0.1%	0.2%	245	275	264	259	255	0.2%	0.1%	0.1%	0.1%	0.2%
Dx ASD/ID on 1 claim past yr	153	133	141	143	174	153	133	141	143	174	0.1%	0.1%	0.1%	0.2%	0.2%	153	133	141	143	174	0.1%	0.1%	0.1%	0.2%	0.2%
<b>Dx ASD/ID on 2+ claims past 5 yr</b>	2,198	2,399	2,518	2,659	2,934	2,198	2,399	2,518	2,659	2,934	2.3%	2.5%	2.6%	2.6%	2.8%	2,198	2,399	2,518	2,659	2,934	2.3%	2.5%	2.6%	2.6%	2.8%
Dx ASD/ID on 0 claims past yr	538	606	633	743	719	538	606	633	743	719	0.6%	0.6%	0.7%	0.7%	0.7%	538	606	633	743	719	0.6%	0.6%	0.7%	0.7%	0.7%
Dx ASD/ID on 1 claim past yr	110	131	137	182	192	110	131	137	182	192	0.1%	0.1%	0.1%	0.2%	0.2%	110	131	137	182	192	0.1%	0.1%	0.1%	0.2%	0.2%
Dx ASD/ID on 2+ claims past yr	1,550	1,662	1,748	1,734	2,023	1,550	1,662	1,748	1,734	2,023	1.6%	1.7%	1.8%	1.7%	1.9%	1,550	1,662	1,748	1,734	2,023	1.6%	1.7%	1.8%	1.7%	1.9%
<b>Grand Total</b>	96,097	97,583	97,371	100,993	104,403	96,097	97,583	97,371	100,993	104,403	100.0%	100.0%	100.0%	100.0%	100.0%	96,097	97,583	97,371	100,993	104,403	100.0%	100.0%	100.0%	100.0%	100.0%



# Some Demographic Characteristics of DHCF Children With an ASD/ID Diagnosis Differ From Those With No Diagnosis



- Compared to DHCF beneficiaries under 21 **without** ASD/ID on 2+ claims in the past year, those **with** ASD/ID on 2+ claims are more likely to be:
  - Enrolled in Medicaid versus locally funded Alliance/ICP coverage
  - In age groups of 3-5, 6-9, and 10-14
  - Male
  - African American
  - Differences by ward (a unit that divides the District into 8 geographic areas) were not substantial

Table 3. Average Monthly DHCF Beneficiaries Under 21 by ASD/ID Dx in Past Year and Age Group, FY 2022

<u>Number of beneficiaries</u>			
	FY2022		Grand Total
	Dx ASD/ID on 0-1 claims past yr	Dx ASD/ID on 2+ claims past yr	
Age 0	4,733		4,733
Age 01-2	9,834	75	9,909
Age 03-5	16,345	375	16,720
Age 06-9	21,434	518	21,952
Age 10-14	25,456	629	26,085
Age 15-18	16,620	318	16,938
Age 19-20	7,957	109	8,066
<b>Grand Total</b>	<b>102,379</b>	<b>2,024</b>	<b>104,403</b>
<u>Percent of beneficiaries</u>			
	FY2022		Grand Total
	Dx ASD/ID on 0-1 claims past yr	Dx ASD/ID on 2+ claims past yr	
Age 0	5%	0%	5%
Age 01-2	10%	4%	9%
Age 03-5	16%	19%	16%
Age 06-9	21%	26%	21%
Age 10-14	25%	31%	25%
Age 15-18	16%	16%	16%
Age 19-20	8%	5%	8%
<b>Grand Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>



# Relatively Few DHCF Children With an ASD/ID Diagnosis Use Inpatient Services and the Most Common Procedures Include Various Therapies



**Table 7. Average Monthly DHCF Beneficiaries Under 21 with ASD/ID Dx in Past Year by Claim Type for Any (Not Limited to ASD/ID) Service Used, FY 2022**

**Note:** Population reflects beneficiaries with ASD/ID diagnosis on 2+ claims in past year.

Categories cannot be summed to obtain unduplicated beneficiary counts because individuals may appear in more than one category.

<b>Number of beneficiaries</b>	
<b>Claim Type</b>	<b>FY2022</b>
Other (e.g., physician, other practitioner, outpatient hospital, clinic, etc.)	2,019
Pharmacy (RX)	1,257
Dental	1,168
Laboratory and Xray	673
Medical Supply (DME)	351
Inpatient or Nursing Facility	44
<b>Grand Total</b>	<b>2,023</b>
<b>Percent of beneficiaries</b>	
<b>Claim Type</b>	<b>FY2022</b>
Other (e.g., physician, other practitioner, outpatient hospital, clinic, etc.)	99.8%
Pharmacy (RX)	62.1%
Dental	57.7%
Laboratory and Xray	33.3%
Medical Supply (DME)	17.4%
Inpatient or Nursing Facility	2.2%
<b>Grand Total</b>	<b>100.0%</b>



# Relatively Few DHCF Children With an ASD/ID Diagnosis Use Inpatient Services and the Most Common Procedures Include Various Therapies (cont.)



**Table 8. Average Monthly DHCF Beneficiaries Under 21 with ASD/ID Dx in Past Year by Claim Type and Procedure/Drug for Any (Not Limited to ASD/ID) Service Used, FY 2022**

**Note:** Population reflects beneficiaries with ASD/ID diagnosis on 2+ claims in past year.

Categories cannot be summed to obtain unduplicated beneficiary counts because individuals may appear in more than one category.

Number of beneficiaries	
Claim Type and Procedure/Drug	FY2022
<b>Other (e.g., physician, other practitioner, outpatient hospital, clinic, etc.)</b>	
TREATMENT OF SPEECH, LANGUAGE, VOICE, COMMUNICATION, AND/OR AUDITORY PROCESSING DISORDER (INCLUDES AURAL REHABILITATION); GROUP, TWO OR MORE INDIVIDUALS: Procedure - CPT/HCPCS 92508	1,026
TREATMENT OF SPEECH, LANGUAGE, VOICE, COMMUNICATION, AND/ OR AUDITORY PROCESSING DISORDER; INDIVIDUAL: Procedure - CPT/HCPCS 92507	1,022
ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 20-29 MINUTES: Procedure - CPT/HCPCS 99213	973
THERAPEUTIC ACTIVITIES, DIRECT (ONE-ON-ONE) PATIENT CONTACT (USE OF DYNAMIC ACTIVITIES TO IMPROVE FUNCTIONAL PERFORMANCE), EACH 15 MINUTES: Procedure - CPT/HCPCS 97530	872
NON-EMERGENCY TRANSPORTATION; TRIP ENCOUNTER (PER ONE-WAY TRIP): Procedure - CPT/HCPCS T2003	828
THERAPEUTIC PROCEDURE(S), GROUP (2 OR MORE INDIVIDUALS): Procedure - CPT/HCPCS 97150	701
ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 30-39 MINUTES: Procedure - CPT/HCPCS 99214	698
ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 10-19 MINUTES: Procedure - CPT/HCPCS 99212	620
INFECTIOUS AGENT DETECTION BY NUCLEIC ACID (DNA OR RNA); SEVERE ACUTE RESPIRATORY SYNDROME CORONAVIRUS 2 (SARS-COV-2) (CORONAVIRUS DISEASE [COVID-19]), AMPLIFIED PROBE TECHNIQUE: Procedure - CPT/HCPCS 87635	568
BRIEF EMOTIONAL OR BEHAVIORAL ASSESSMENT: Procedure - CPT/HCPCS 96127	553
EMERGENCY DEPARTMENT VISIT WITH LOW LEVEL OF MEDICAL DECISION MAKING: Procedure - CPT/HCPCS 99283	492
Established patient periodic preventive medicine examination, age 5 through 11 years: Procedure - CPT/HCPCS 99393	490
SCREENING TEST OF VISUAL ACUITY, QUANTITATIVE, BILATERAL: Procedure - CPT/HCPCS 99173	422
SCREENING TEST, PURE TONE, AIR ONLY: Procedure - CPT/HCPCS 92551	406
IMMUNIZATION ADMINISTRATION THROUGH 18 YEARS OF AGE VIA ANY ROUTE OF ADMINISTRATION, WITH COUNSELING BY PH	381
IMMUNIZATION ADMINISTRATION (INCLUDES PERCUTANEOUS, INTRADERMAL, SUBCUTANEOUS, OR INTRAMUSCULAR INJECTI	378
ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 40-54 MINUTES: Procedure - CPT/HCPCS 99215	371
BEHAVIORAL HEALTH COUNSELING AND THERAPY, PER 15 MINUTES: Procedure - CPT/HCPCS H0004	369



# Some of the Most Common Co-Occurring Diagnoses Include Neurodevelopmental Disorders Other Than ASD/ID



**Table 10. Average Monthly DHCF Beneficiaries Under 21 with ASD/ID Dx in Past Year by Other Diagnoses in Past Year, FY 2022**

**Note:** Population reflects beneficiaries with ASD/ID diagnosis on 2+ claims in past year.

Categories are based on the Clinical Classifications Software Refined (CCSR) for ICD-10-CM

Diagnoses from the Agency for Healthcare Research and Quality (AHRQ). The CCSR groups

diagnoses into 21 body systems that generally follow the ICD-10-CM diagnosis codebook

chapters, with a further breakout into additional detailed categories shown here that reflect

several hundred clinically meaningful groupings.

Number of beneficiaries				
DiagnosisLongDescription	DiagnosisCode	CCSR Body System	CCSR Detailed Category	FY2022
AUTISTIC DISORDER	F84.0	Mental, behavioral and	Neurodevelopmental di	1,606
ENCOUNTER FOR IMMUNIZATION	Z23	Factors influencing heal	Exposure, encounters, s	836
ENCOUNTER FOR ROUTINE CHILD HEALTH EXAMINATION WITHOUT ABNORMAL FINDING	Z00.129	Factors influencing heal	Medical examination/ev	569
ENCOUNTER FOR ROUTINE CHILD HEALTH EXAMINATION WITH ABNORMAL FINDINGS	Z00.121	Factors influencing heal	Medical examination/ev	532
CONTACT WITH AND (SUSPECTED) EXPOSURE TO COVID-19	Z20.822	Factors influencing heal	Exposure, encounters, s	508
MILD INTELLECTUAL DISABILITIES	F70	Mental, behavioral and	Neurodevelopmental di	387
UNSPECIFIED LACK OF EXPECTED NORMAL PHYSIOLOGICAL DEVELOPMENT IN CHILD	R62.50	Symptoms, signs and ab	Other general signs and	371
DEVELOPMENTAL DISORDER OF SPEECH AND LANGUAGE, UNSPECIFIED	F80.9	Mental, behavioral and	Neurodevelopmental di	319
MIXED RECEPTIVE-EXPRESSIVE LANGUAGE DISORDER	F80.2	Mental, behavioral and	Neurodevelopmental di	266
CONTACT WITH AND (SUSPECTED) EXPOSURE TO OTHER VIRAL COMMUNICABLE DISEA	Z20.828	Factors influencing heal	Exposure, encounters, s	257
DEVELOPMENTAL DISORDER OF SCHOLASTIC SKILLS, UNSPECIFIED	F81.9	Mental, behavioral and	Neurodevelopmental di	245
2019 NOVEL CORONAVIRUS (COVID-19)	U07.1	Certain infectious and p	COVID-19	222
DIETARY COUNSELING AND SURVEILLANCE	Z71.3	Factors influencing heal	Other specified encount	219
UNSPECIFIED URINARY INCONTINENCE	R32	Diseases of the genitou	Urinary incontinence	190
ATTENTION-DEFICIT HYPERACTIVITY DISORDER, UNSPECIFIED TYPE	F90.9	Mental, behavioral and	Neurodevelopmental di	186
ATTENTION-DEFICIT HYPERACTIVITY DISORDER, COMBINED TYPE	F90.2	Mental, behavioral and	Neurodevelopmental di	181
OTHER DISORDERS OF PSYCHOLOGICAL DEVELOPMENT	F88	Mental, behavioral and	Neurodevelopmental di	176



# Office of the State Superintendent of Education

*IDEA Part B Educational Data*

**Chandi Wagner**

**June 6, 2024**



# IDEA Special Education Part B (Ages 3-22)

OSSE oversees the implementation of Part B of the Individuals with Disabilities Education Act (IDEA), including the provision of a free appropriate public education (FAPE) by local education agencies (LEAs) for students ages 3 to 22.

In school year 2022-23, **2,241 students with autism received services**, out of 97,059 enrolled students, or 2.3%

- Students may be found eligible for IDEA services through a primary eligibility of autism, or autism may be one of multiple disabilities through which the student qualifies.

Included in OSSE Part B Data	Excluded from OSSE Part B Data
Students in DC Public and Public Charter Schools	Students who continue to receive Part C services through an IFSP
Students in a non-public placement	Students who are otherwise enrolled in private schools
Students who are parentally placed in private school and received speech services through DCPS	

# Takeaways



- We may be **under-diagnosing/under-identifying** autistic children in DC.
- However, we **do not yet know the true prevalence**.
- We **do not know how well these data capture children with autism** in part given that we do not know how much overlap there is in these datasets.
- We **have not yet explored differences** based on race, ethnicity, sex, or Ward.

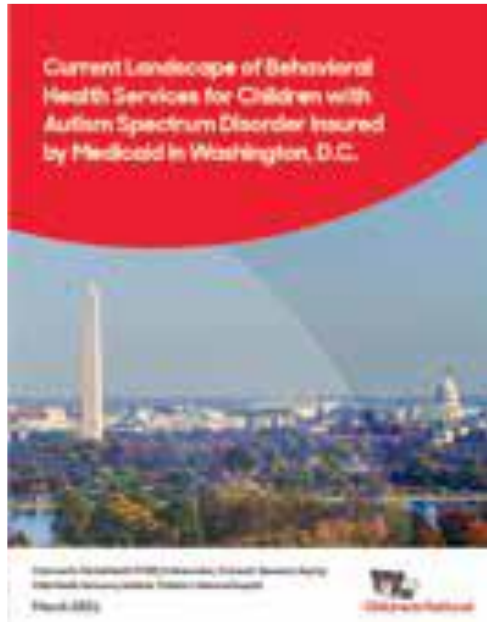
National: 1:36

DC: 1:65 (medical dx) &

1:58 (edu classification)

# Next Steps

- **Share** information widely
- Establish a **data tracking system** that could link health and education data



## How Many Autistic Children (0-21 years) Live in the District of Columbia (DC)?



Autism or [autism spectrum disorder \(ASD\)](#) is a neurodevelopmental disorder that may be associated with social, communication, and behavioral challenges. Autistic individuals may communicate, interact, behave, and learn in ways that are different from people without autism.

### WHY IS IT IMPORTANT TO KNOW HOW MANY AUTISTIC CHILDREN LIVE IN DC?



This information is used to determine policy, resource allocation, and other decisions, such as which programs and services may be most needed. If children are not accurately counted, children may not get their fair share of money to fund needed services.



Data also shows patterns over time and needs or inequities based on factors, such as race, sex, and Ward. This information can then be used to address any concerning trends.



Knowing more about the prevalence of autism in DC (and information gaps) can inform advocacy efforts to ensure that autistic children in DC get the recognition and resources they need.

### AUTISM IN NUMBERS:

[National prevalence of autism:](#)



It is estimated that **1 in 36** children (2.8%) in the US have autism<sup>1</sup> but prevalence varies widely across communities

Two separate data sources suggest the following information about children with autism in DC:



Approximately 70%<sup>4</sup> of children in DC are insured through Medicaid.

1.5% of those children (~1 in 65) had a medical diagnosis of ASD in fiscal year (FY) 22<sup>2</sup>



Public Schools in DC Education Data (includes both DC Public Schools and DC Public Charter schools, covering approximately 85% of all DC children):

1.7% of children (~1 in 58) had an Individualized Education Program (IEP) under the classification of autism in school year 2021-2022<sup>3</sup>



<sup>1</sup> Source: <https://www.cdc.gov/ncbddd/autism/data.html>

<sup>2</sup> Data provided by DC DHCF includes DC Medicaid beneficiaries under age 21 enrolled in FY 2022 with a diagnosis of ASD on 2+ claims in the past year (1,604/104,402 individuals)

<sup>3</sup> Data provided by OSSE based on children with Individualized Education Program classification code of autism (2022\_Q77D - 1613 of 94,532)

<sup>4</sup> Source: [American Community Survey \(ACS\) data](https://data.census.gov/table?q=population%20by%20age&g=040XX00US11) <https://data.census.gov/table?q=population%20by%20age&g=040XX00US11>

Thank you for joining!

