

Meeting of the Interagency Autism Coordinating Committee

April 4, 2023; 10:00 a.m. - 5:00 p.m. ET



Susan A. Daniels, Ph.D.

Acting HHS National Autism Coordinator
Director, Office of Autism Research Coordination, NIMH
And Executive Secretary, IACC

Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health (NIMH)
And Chair, IACC

Welcome and Announcements



Susan A. Daniels, Ph.D.

Acting HHS National Autism Coordinator
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

Virtual Meeting Etiquette



- Please keep microphones off unless you are speaking
- You are welcome to turn your cameras on when you are, speaking but may leave them off if you prefer.
- During discussion, please keep your comments brief (~1-2 minutes) to enable other members to have a turn speaking
- For Committee members that would like a comment read aloud:
 - Please send the text of your comment via Zoom chat function to the OARC Staff Member who is using the Zoom screen name “SEND COMMENTS HERE”
 - When it is your turn to be recognized, the OARC staff member will read your comment to the group.
 - Mr. Steven Isaacson from the OARC team will be reading member comments sent through the Zoom chat.
- Closed captioning is available in Zoom for Committee members and on Videocast for members of the viewing public.



New Data from the Autism and Developmental Disabilities Monitoring (ADDMM) Network

Kelly Shaw, PhD

Surveillance Team Lead
(Acting)

Matthew Maenner, PhD

Branch Chief

Child Development and Disability Branch

Division of Human Development and Disability

National Center on Birth Defects and Developmental Disabilities

**Early Identification of Autism Spectrum Disorder
Among Children Aged 4 Years — Autism and
Developmental Disabilities Monitoring Network,
11 Sites, United States, 2020**

**Prevalence and Characteristics of Autism Spectrum
Disorder Among Children Aged 8 Years —
Autism and Developmental Disabilities Monitoring
Network, 11 Sites, United States, 2020**

ADDM Modernization: 1 year faster, more efficient

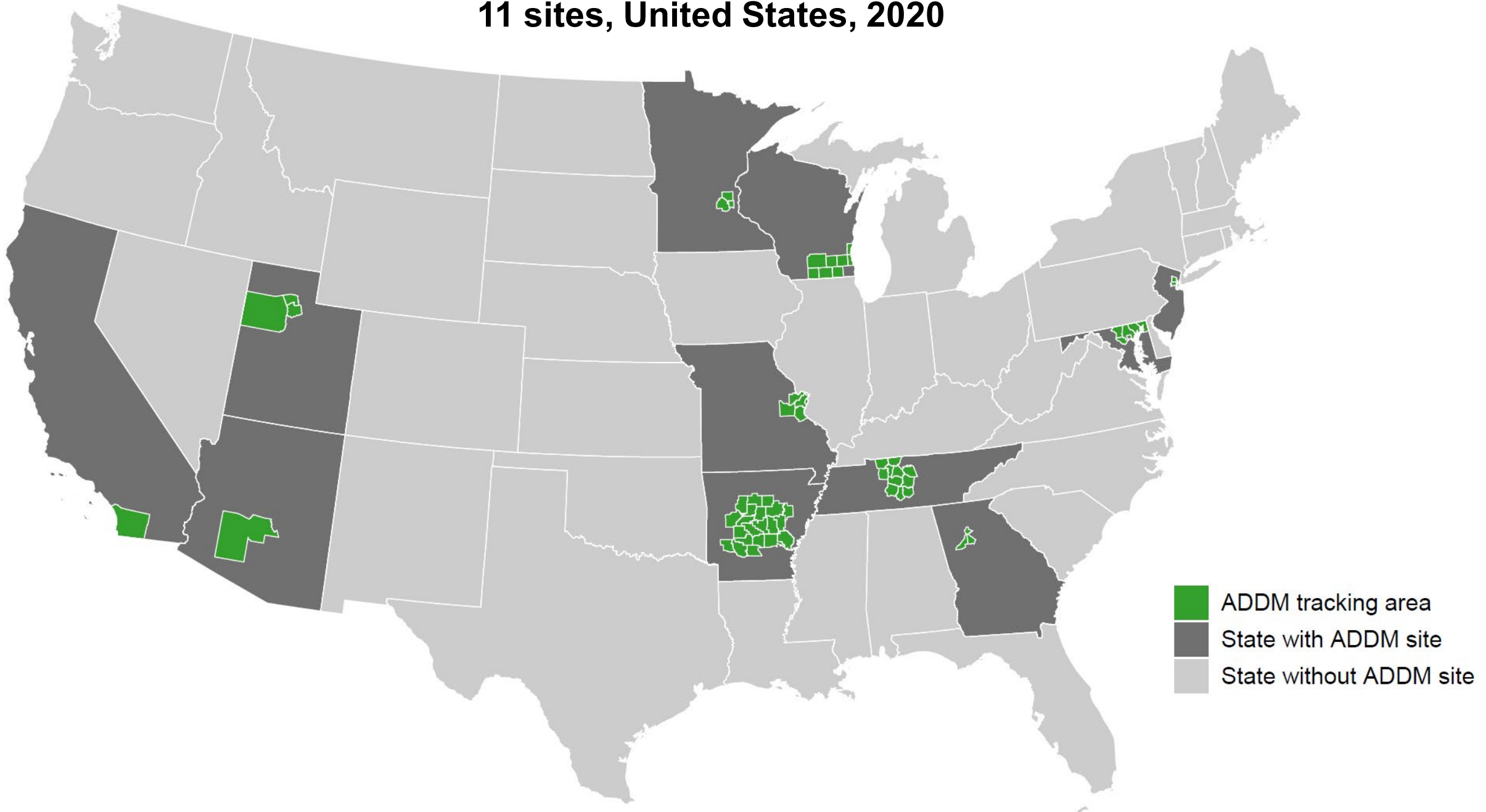
	Surveillance Year	Month / Year of Publication
Adopted new methods	2014	April 2018 (age 8 only)
	2016	March 2020
	2018	December 2021
	2020	March 2023

Additionally, starting with 2018 surveillance year:

- All sites track children aged 4 and 8 years
- 5 sites follow-up adolescents (age 16)

Autism and Developmental Disabilities Monitoring Network

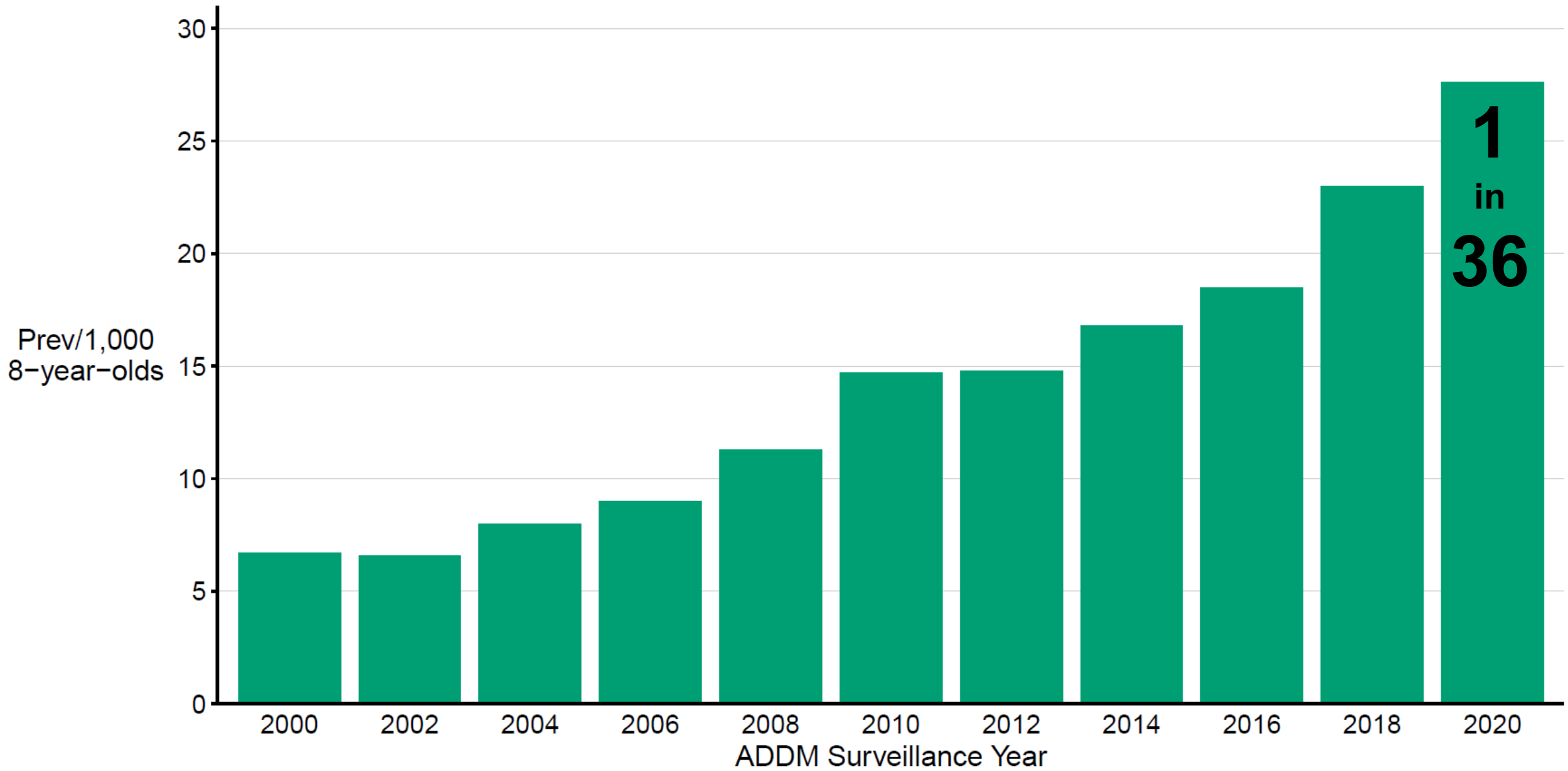
11 sites, United States, 2020

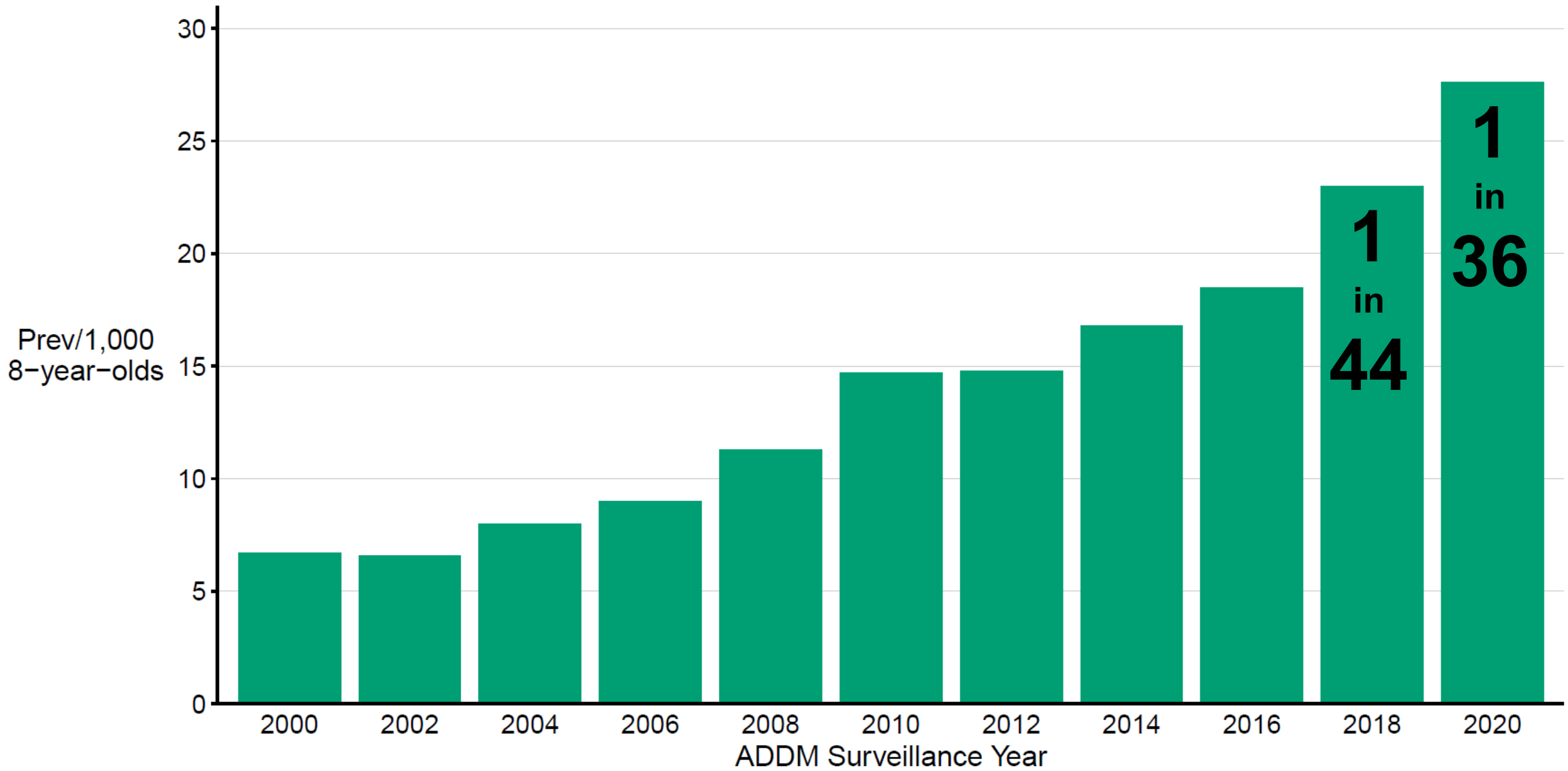


Case definition for ASD surveillance

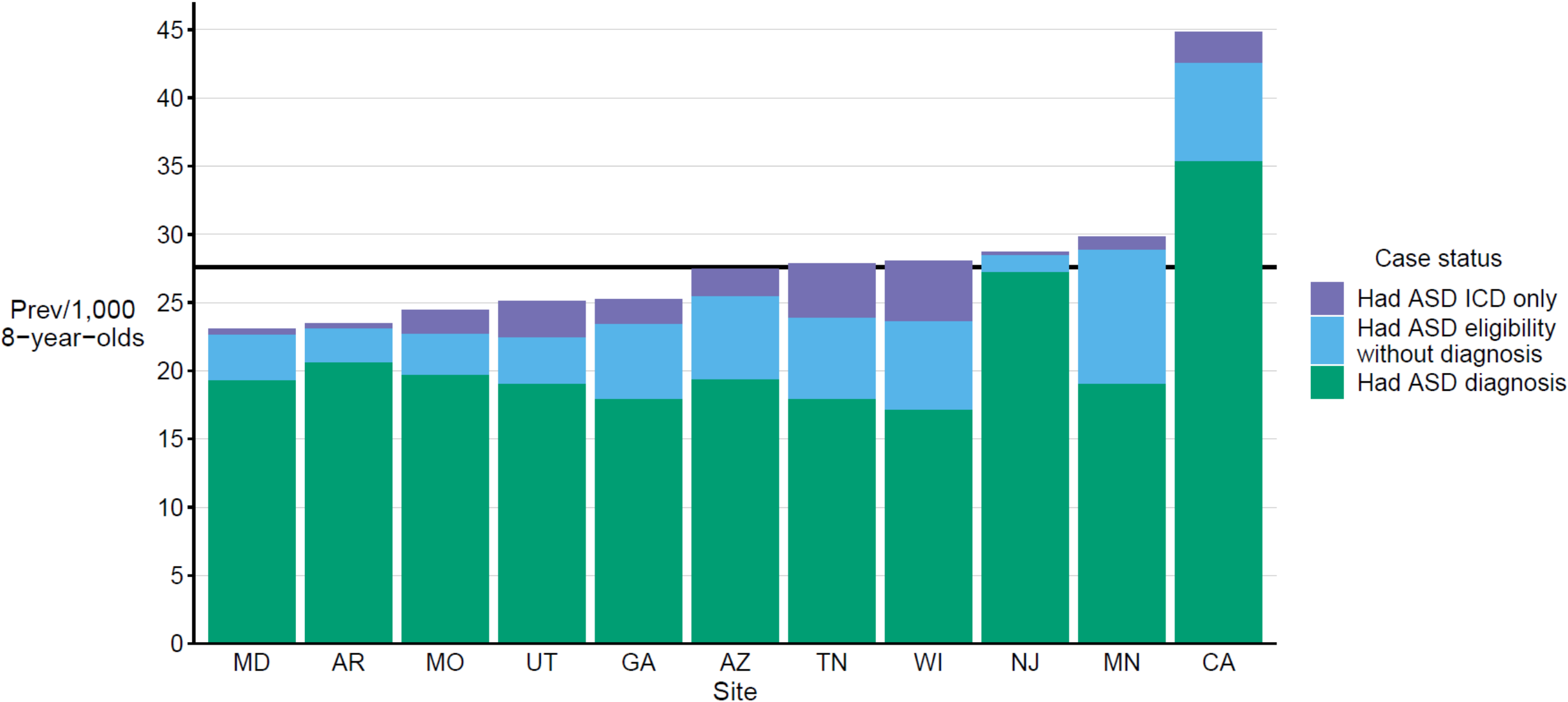
Child has documentation of ever receiving:

- 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

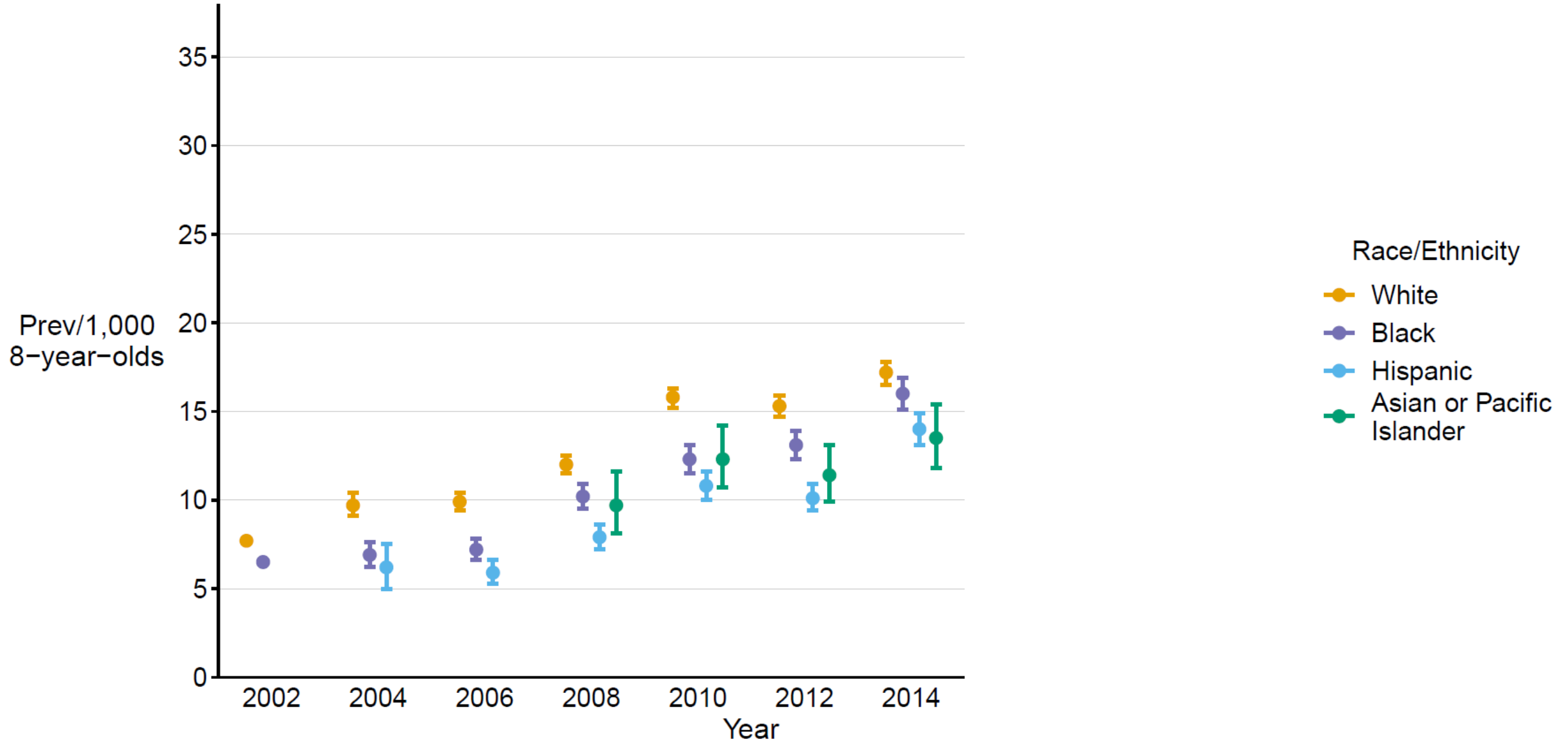




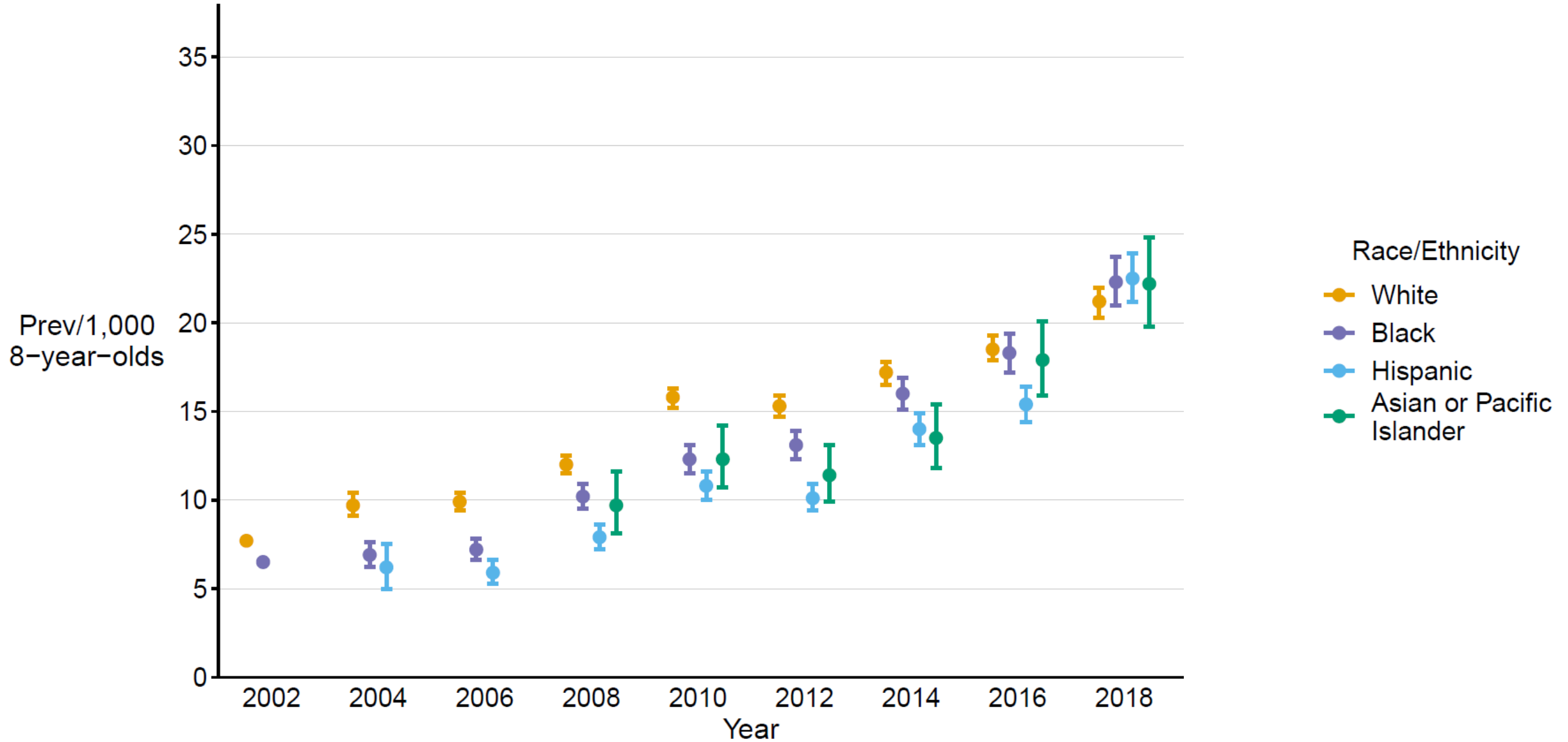
There is variability in practices across ADDM communities



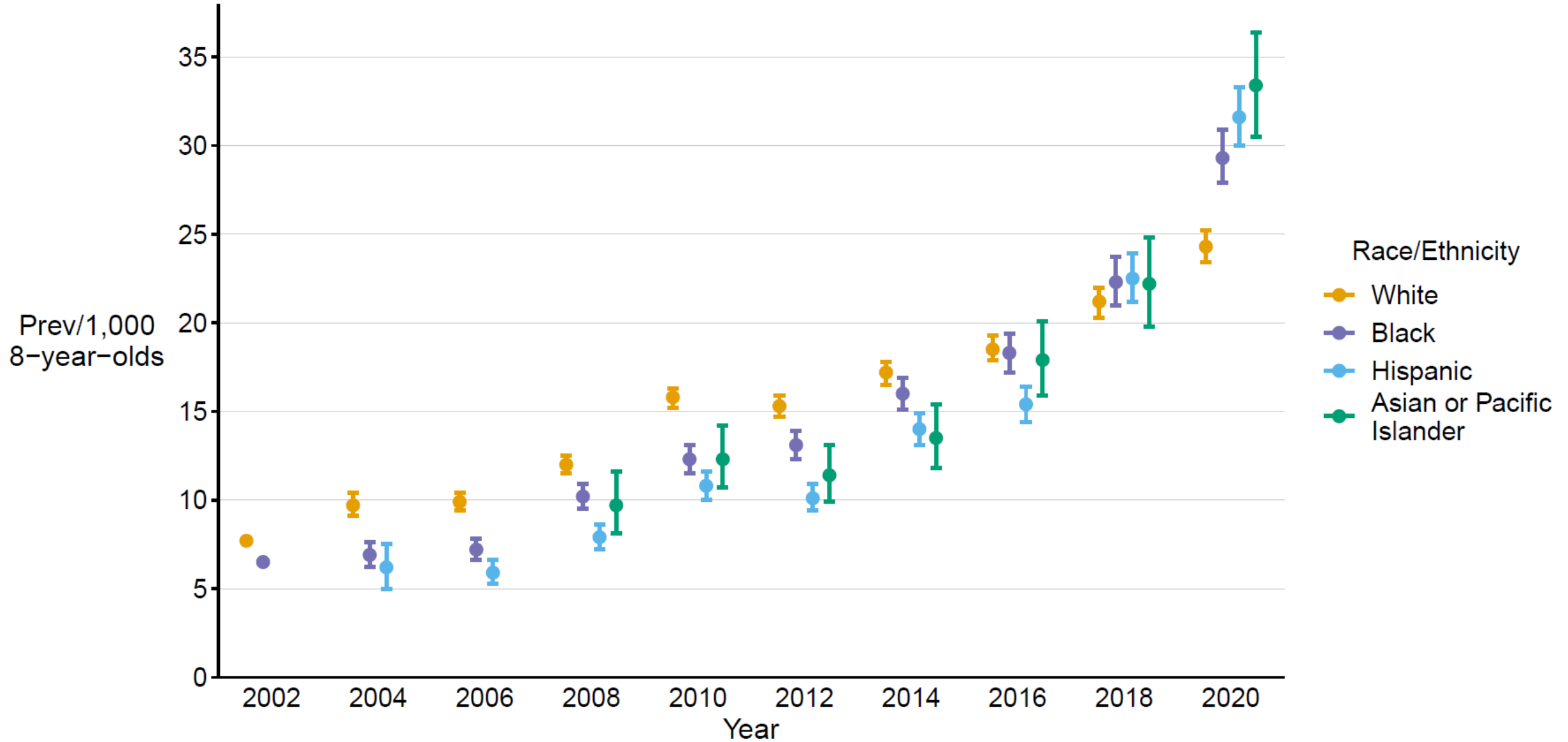
Patterns by race/ethnicity have changed for children aged 8 years



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

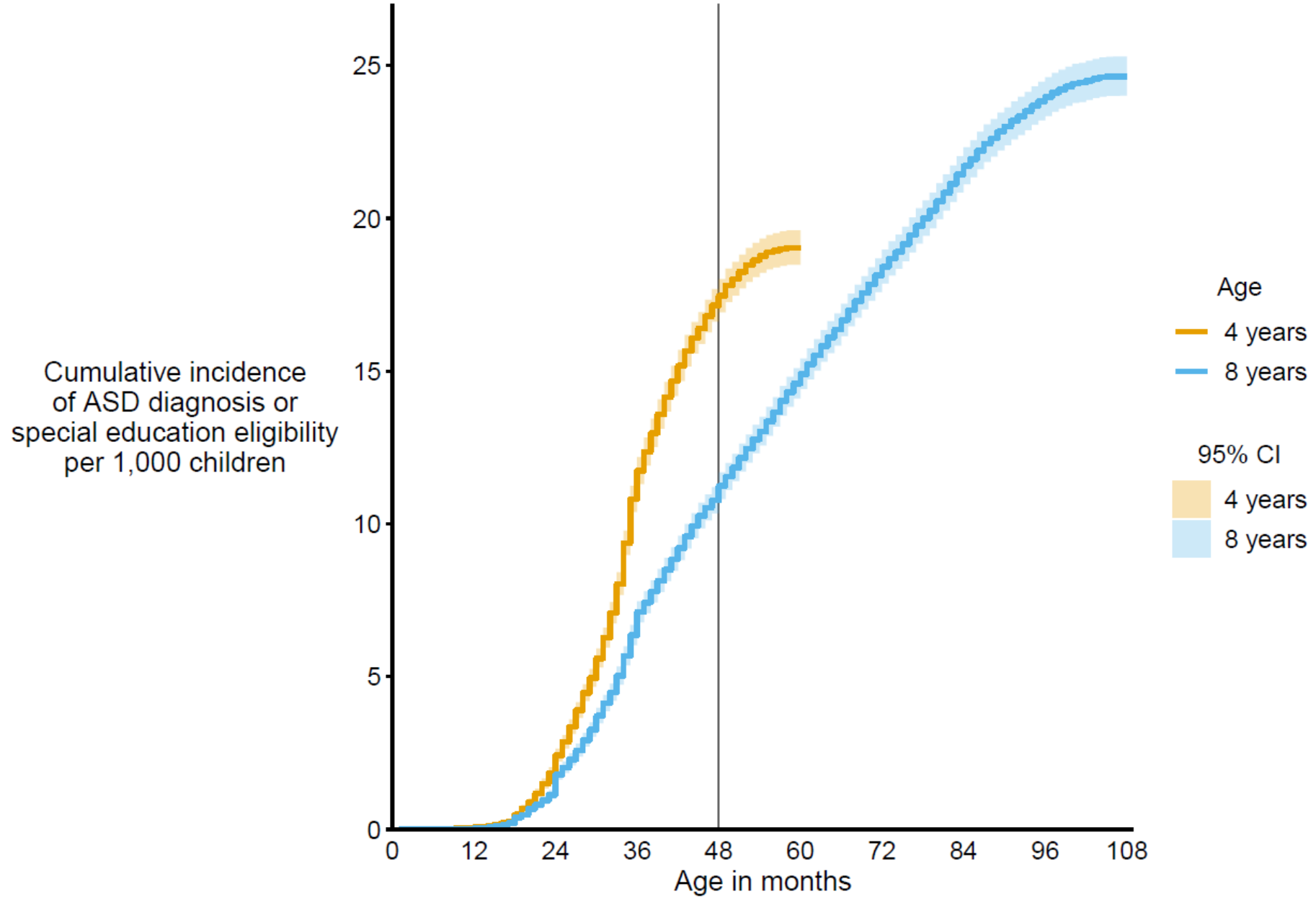


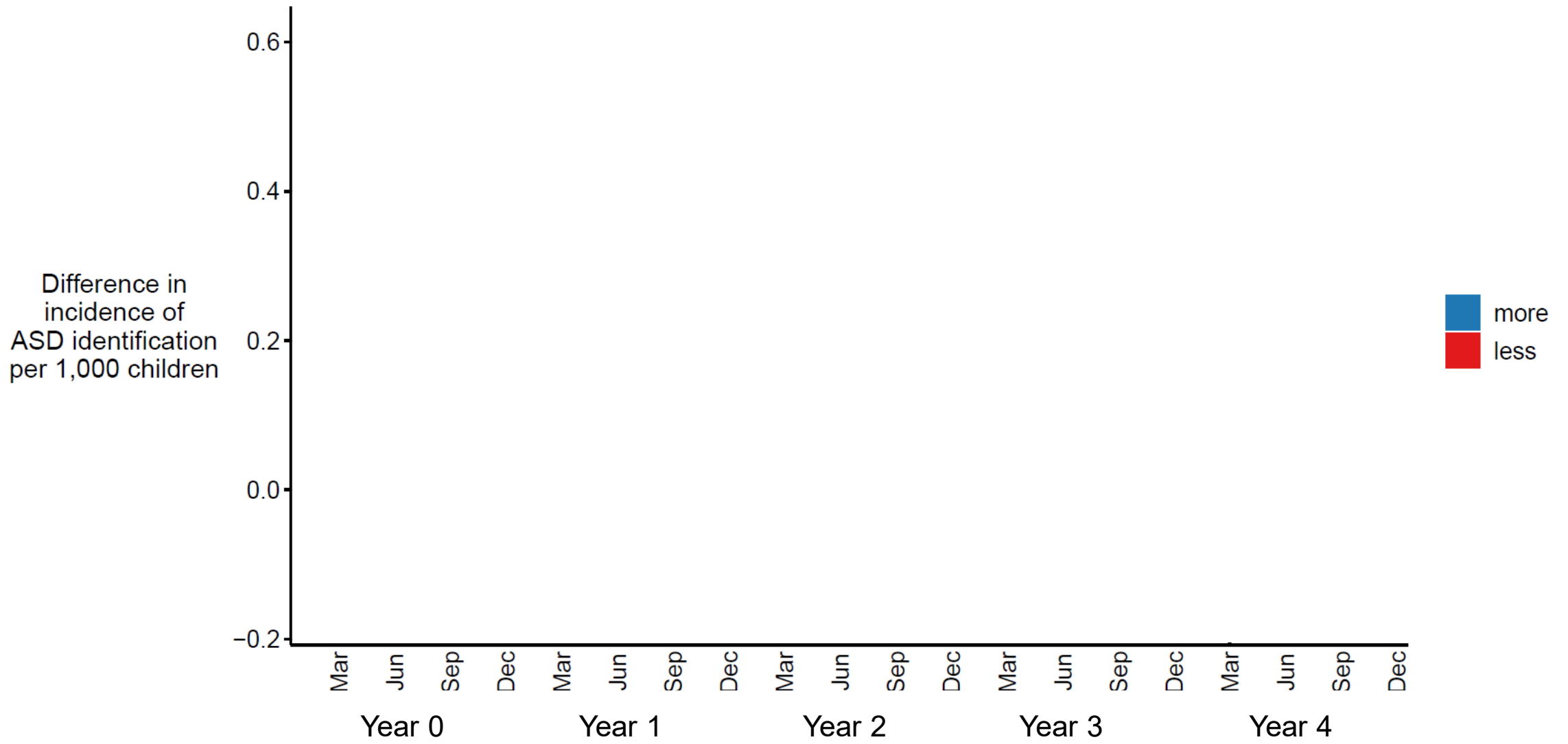
Patterns by race/ethnicity have changed for children aged 8 years



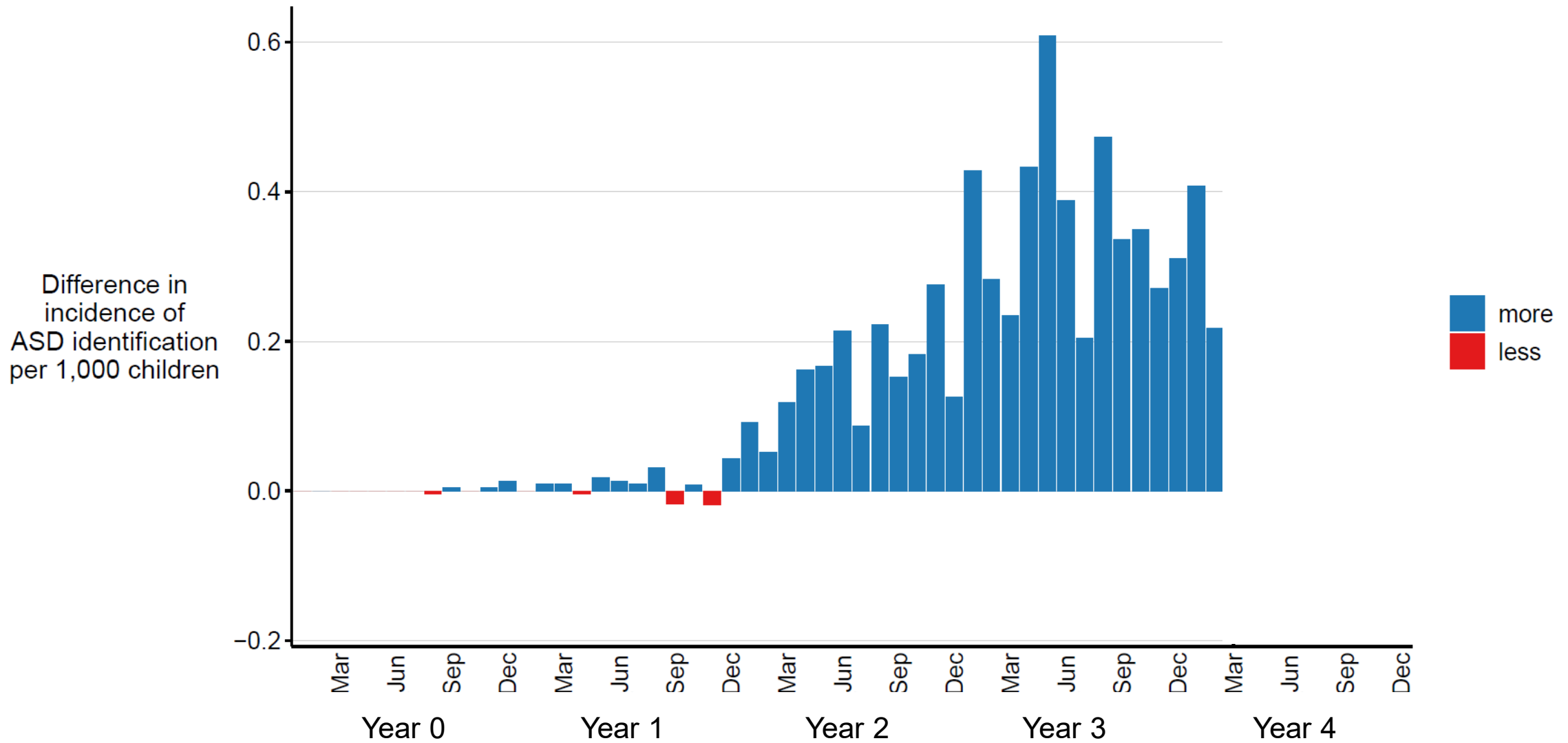
Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years

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

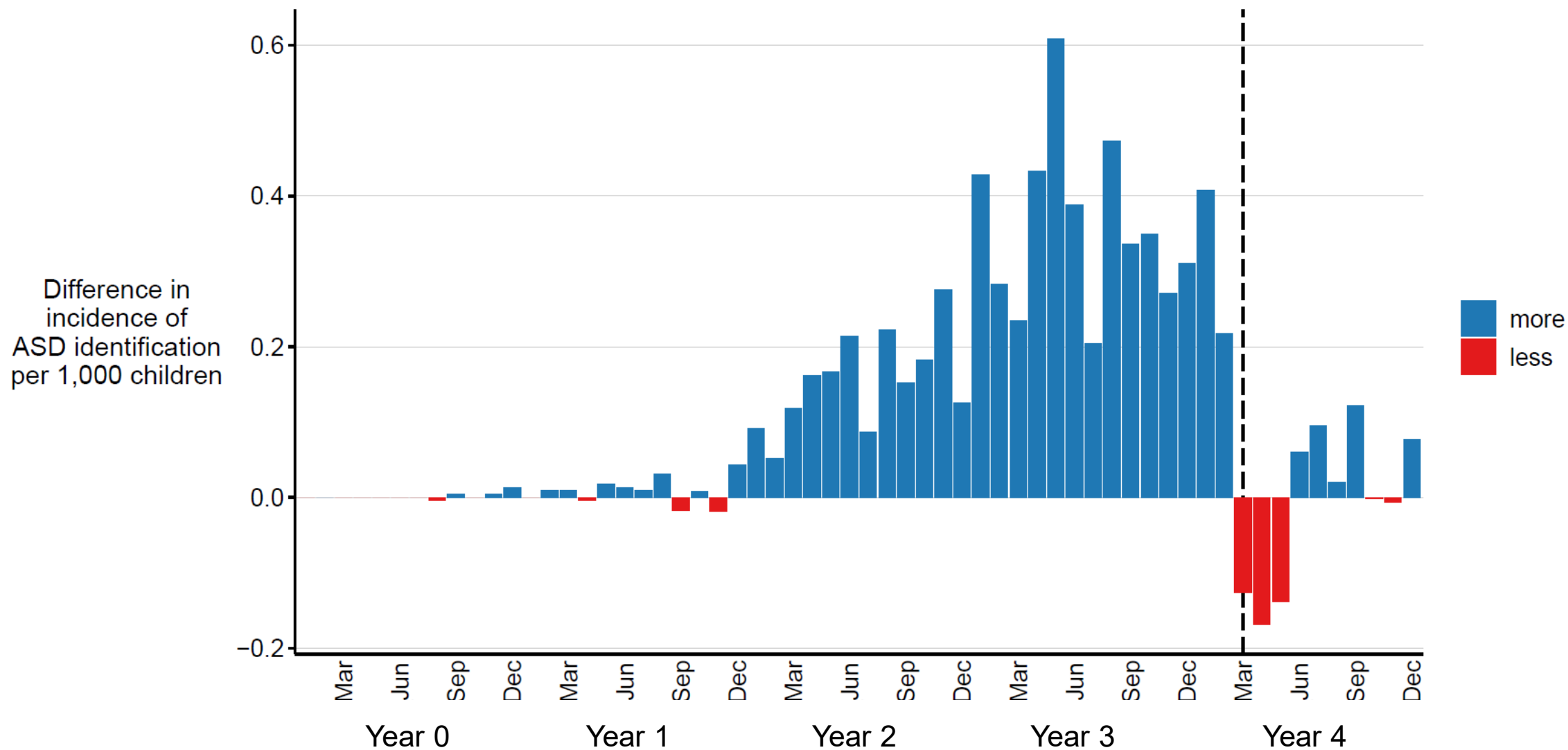




There were **increases** in early autism detection prior to the COVID-19 pandemic



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



ADDM Website

Autism and Developmental Disabilities Monitoring (ADDM) Network

[Print](#)

The Autism and Developmental Disabilities Monitoring (ADDM) Network is a program funded by CDC to collect data to better understand the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities living in different areas of the United States.

ADDM Network goals are to:

- Describe the population of children with ASD,
- Compare how common ASD is in different areas of the country,
- Measure progress in early ASD identification,
- Identify changes in ASD occurrence over time, and
- Understand the impact of ASD and related conditions in US communities.

[ADDM Network fact sheet](#)



Community Report

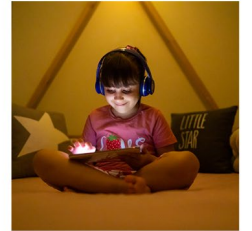
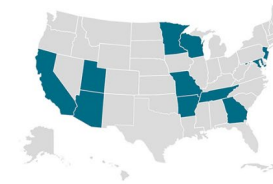


Easy-read summaries

ADDM Network Sites
Arizona, Arkansas,
California, Georgia,
Maryland, Minnesota,
Missouri, New Jersey,
Tennessee, Utah,
and Wisconsin

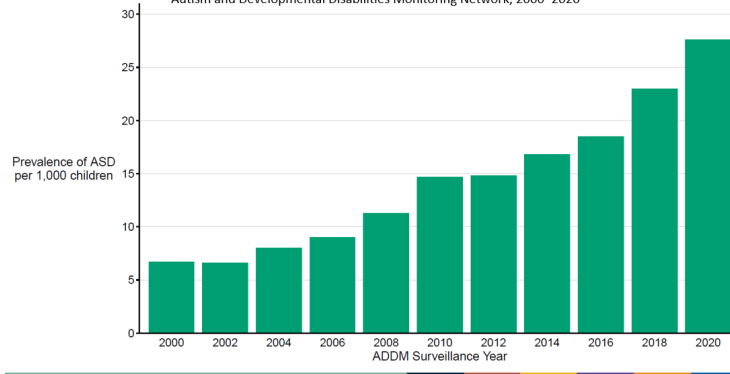
Collect Information

To learn about what age children with autism are being identified and the impact of COVID-19 on autism identification



Slides with visualizations

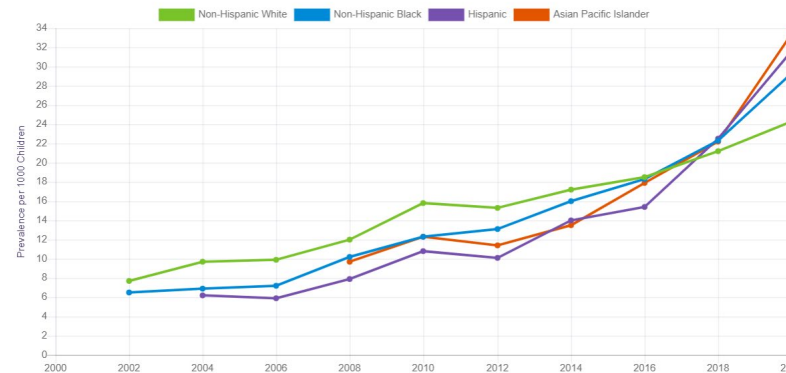
Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by surveillance year
Autism and Developmental Disabilities Monitoring Network, 2000–2020



Data visualization tool

Prevalence Estimates by Race/Ethnicity

Show ADDM prevalence estimates* by race/ethnicity for:



Invited commentary in STAT News

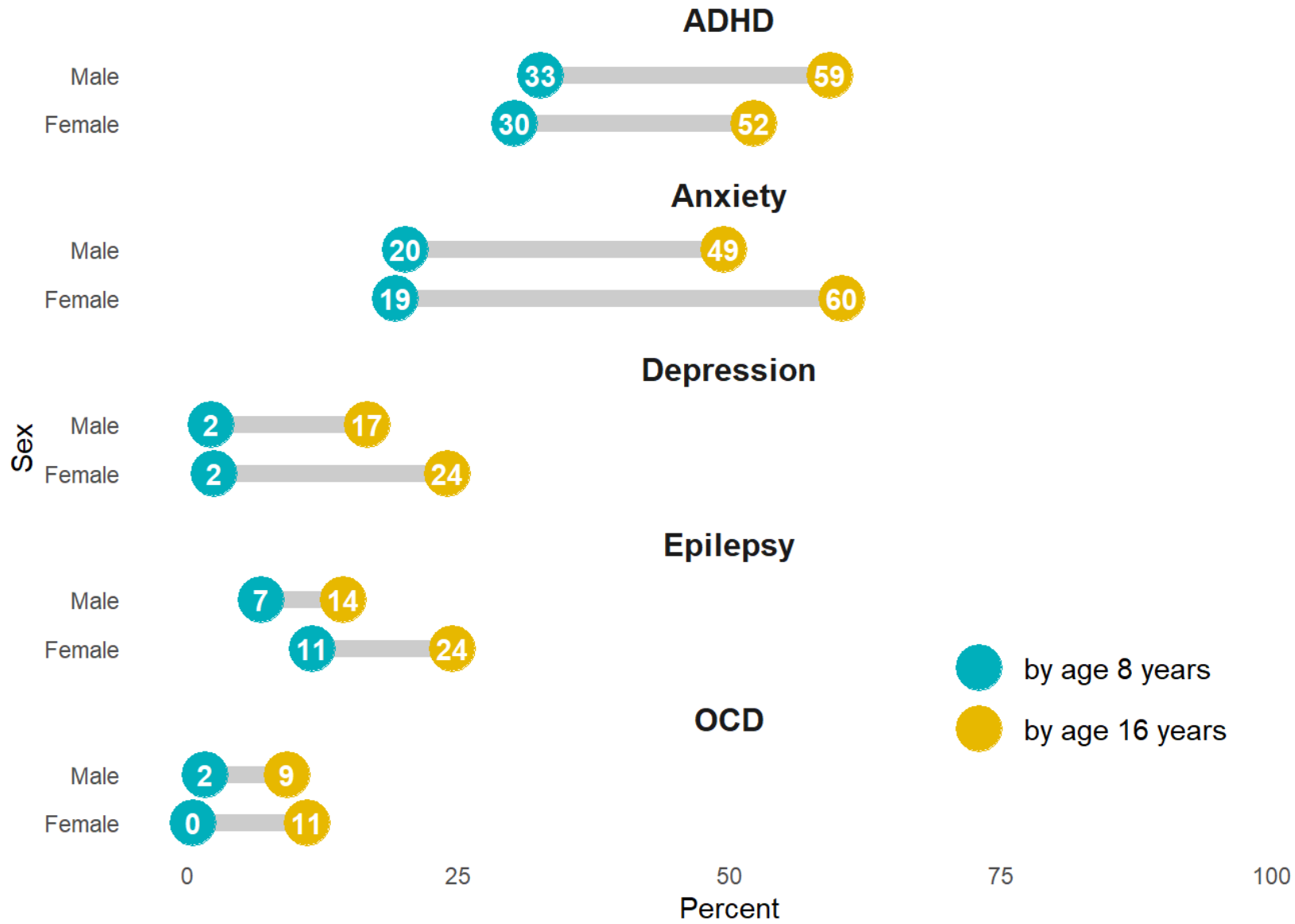
FIRST OPINION

**There is no epidemic of autism.
It's an epidemic of need**

By John Elder Robison and Dena Gassner March 23, 2023

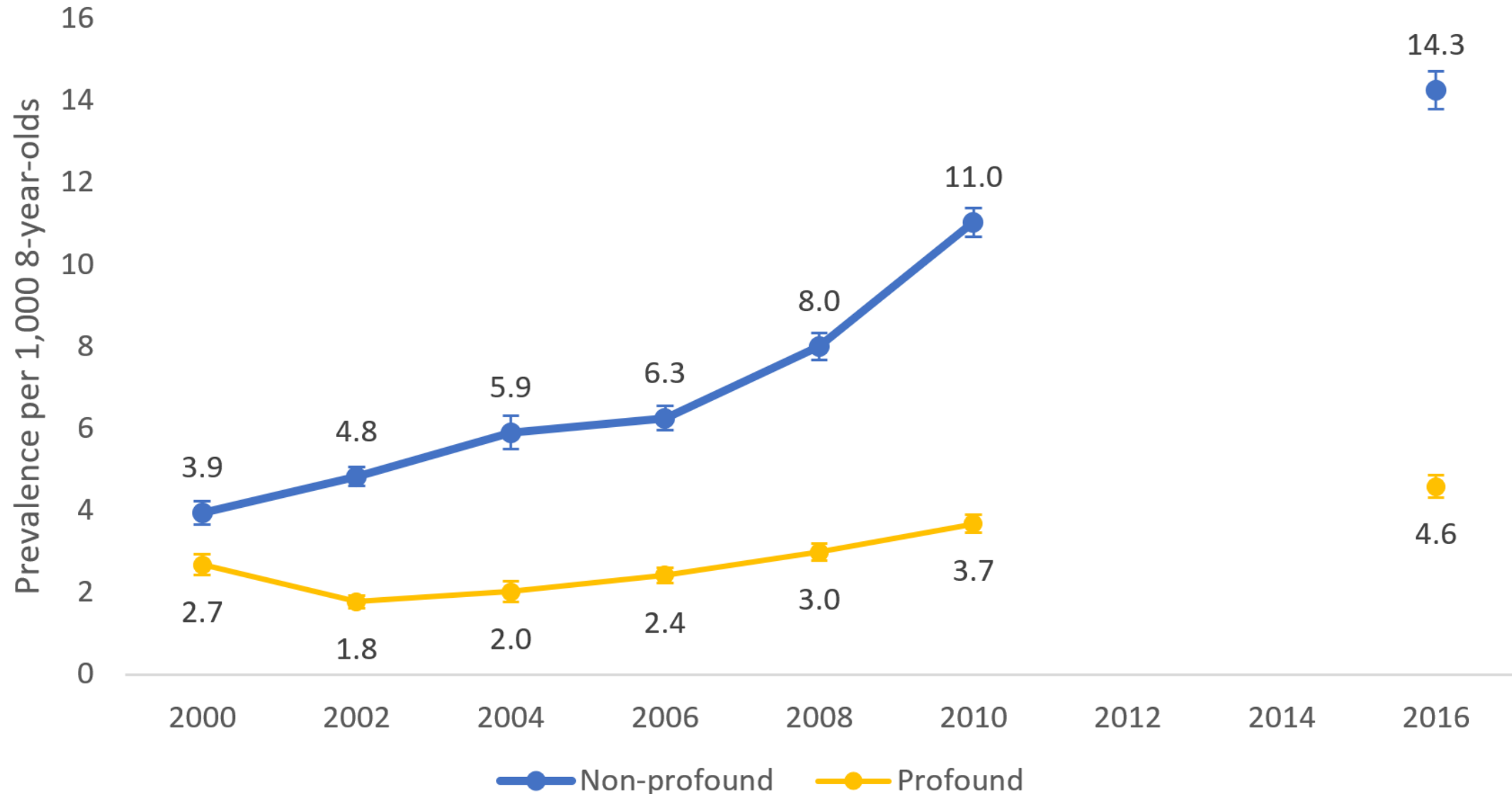
Recent and Upcoming ADDM findings

First adolescent follow-up study

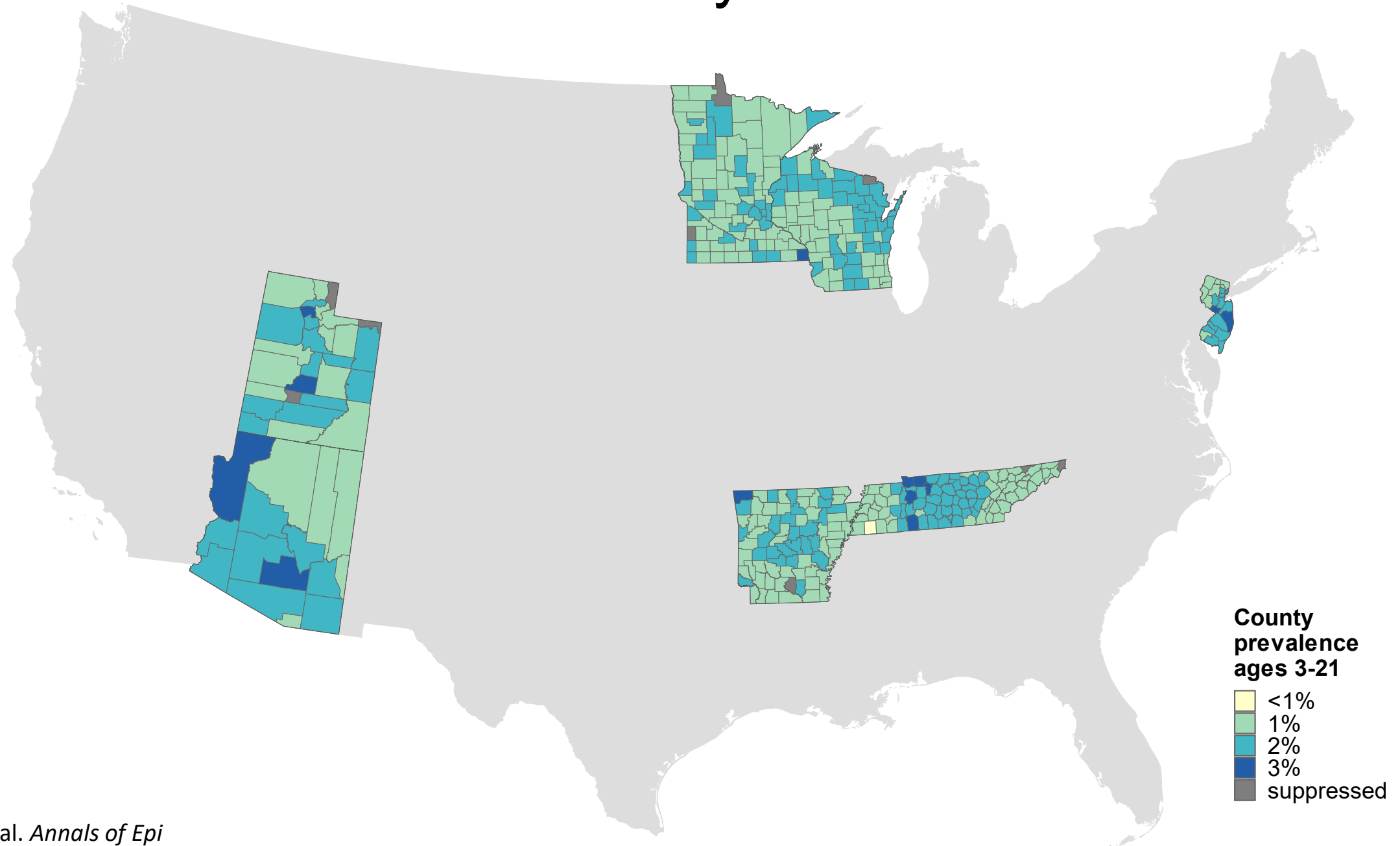


First population prevalence estimates of "Profound" Autism

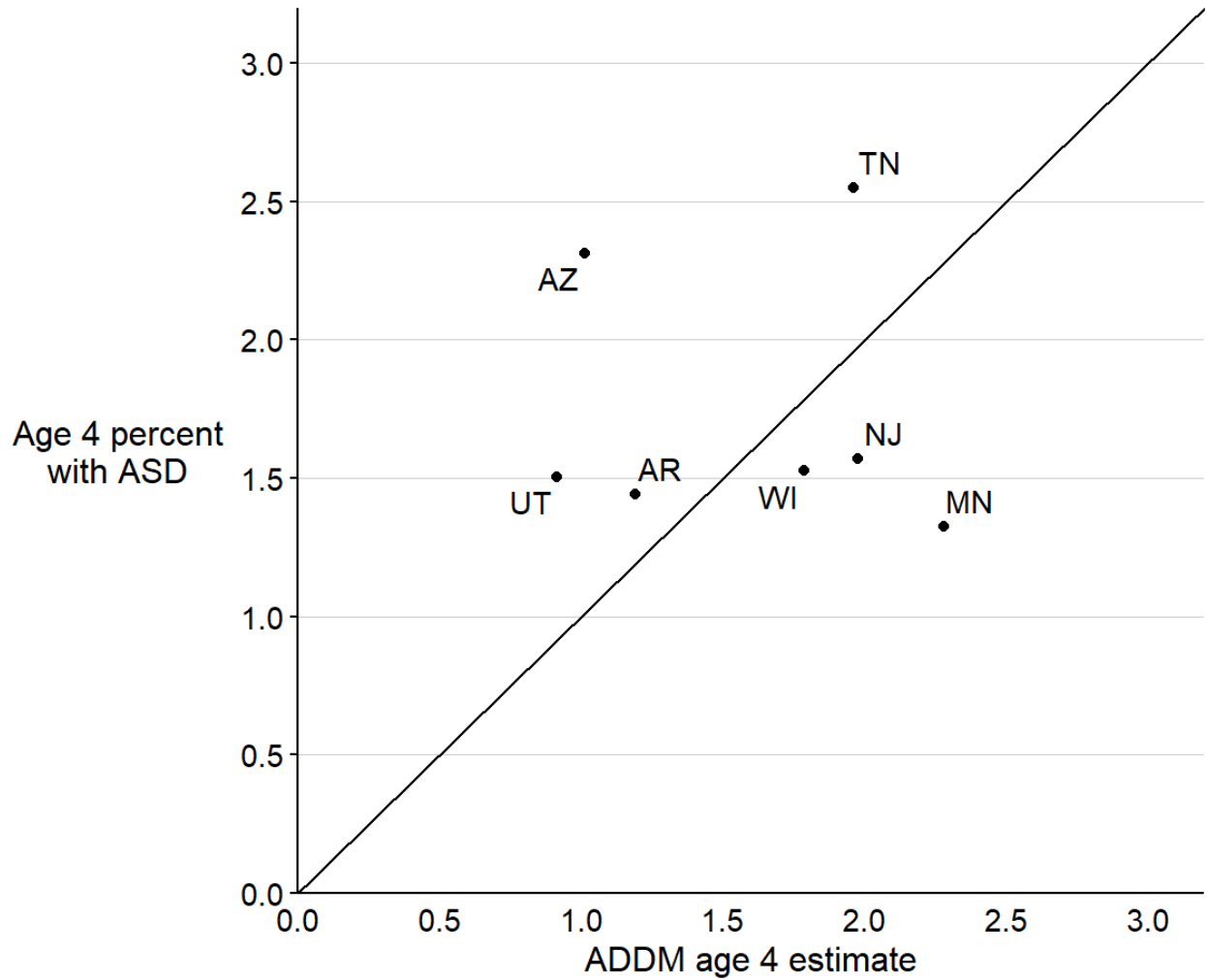
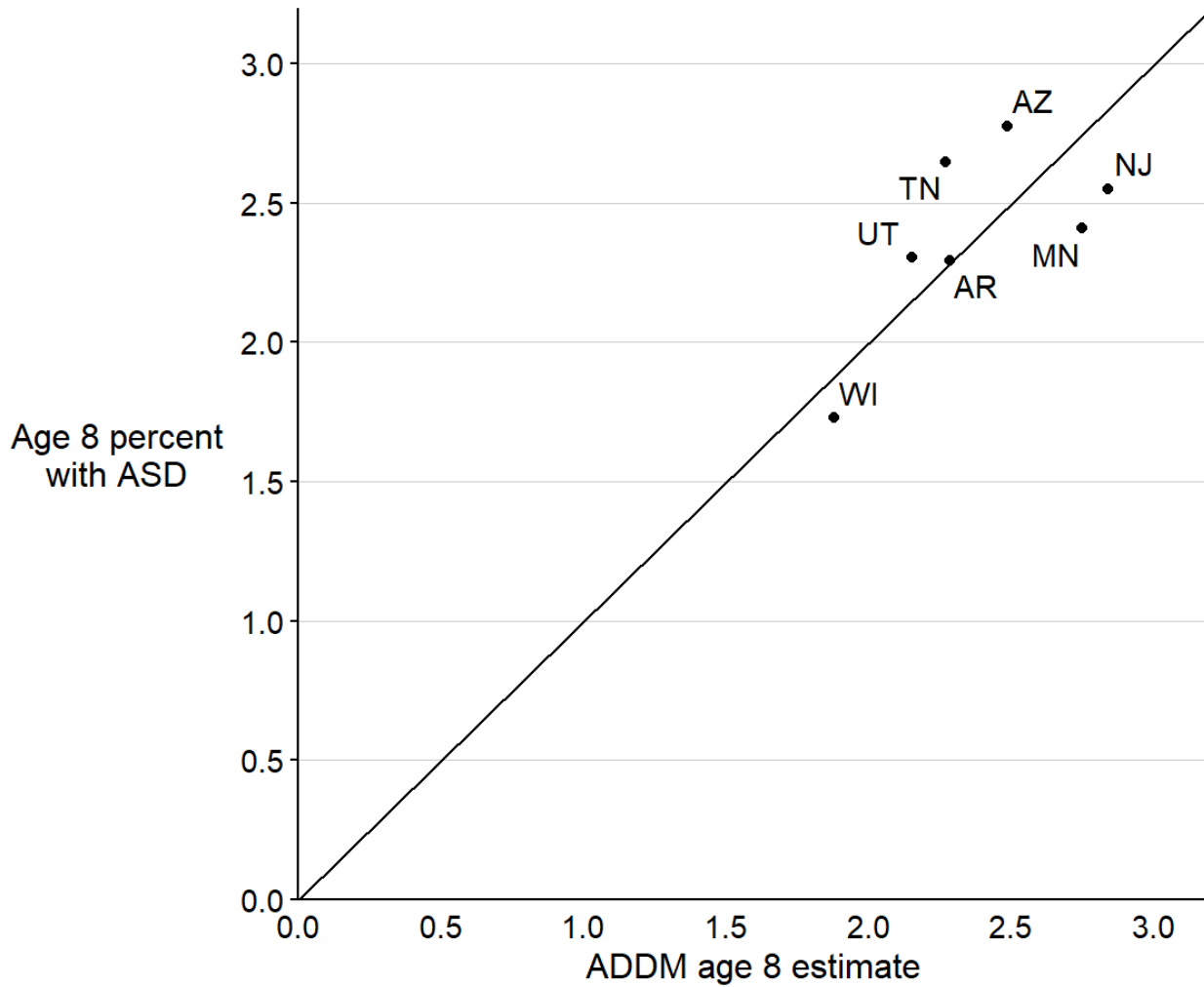
~27% of 8-year-old children with ASD with IQ < 50 or non- or minimally verbal



First statewide county-level ASD estimates



Statewide county-level ASD surveillance pilot



Acknowledgements: 2020 ADDM Investigators and Co-authors

Esther Amoakohene (CDC)

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Matthew Maenner (CDC)

Dedria McArthur (CDC)

Mary Patrick (CDC)

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Kelly Shaw (CDC)

Anita Washington (CDC)

Susan Williams (CDC)

For more information, contact CDC

1-800-CDC-INFO (232-4636)

TTY: 1-888-232-6348 www.cdc.gov

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Zachary Warren (TN)

Walter Zahorodny (NJ)

And many record abstractors, data managers, communications specialists, and project staff.

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

Contact: addm@cdc.gov



Break



National Autism Coordinator Update

IACC Full Committee Meeting
April 4, 2023

Susan Daniels, Ph.D.

Acting HHS National Autism Coordinator
Office of the NIMH Director
National Institute of Mental Health



White House and Autism Awareness Month Updates

- White House Updates
- United Nations (UN)
- Office of Autism Research Coordination (OARC)
- Indian Health Service (IHS)
- National Institute of Environmental Health Sciences (NIEHS)

White House Updates

- During Black History Month (February), White House released a [Fact Sheet on the Biden-Harris Administration's Work to Support Black Disabled Americans](#).
- Across the whole of the federal government, agencies are examining their policies and programs for disparities that have made it difficult for Black Americans and people with disabilities to thrive in their communities – at work, at school, and at home.
- Topics covered in the fact sheet include employment, financial empowerment, access to disability benefits, education, housing, family support, and healthcare.
- Read more [here](#).



White House Updates, cont.

- On March 31st, President Biden issued a proclamation on World Autism Awareness Day, 2023, renewing the Administration's commitment to equal rights, inclusion, and support for people on the autism spectrum.
- The proclamation highlighted issues where the Administration has made strides, including home and community-based services, housing, employment, education, safety & law enforcement, healthcare, and global human rights.
- Read [full proclamation here](#).



MARCH 31, 2023

A Proclamation on World Autism Awareness Day, 2023

[BRIEFING ROOM](#) [PRESIDENTIAL ACTIONS](#)

There is no one way to be autistic – each individual with autism experiences it differently – but together, autistic people make industries, communities, and our Nation stronger. Today, we celebrate the achievements of neurodiverse people everywhere and champion the equal rights and dignity of all those living on the autism spectrum.

Here in the United States, more than 5.4 million adults are autistic, and 1 in every 44 children has been diagnosed with autism. Yet this developmental disability is still misunderstood. Autistic people continue to face obstacles when seeking employment, health care, education, and housing, and the immense contributions of people with autism are often overlooked. We owe it

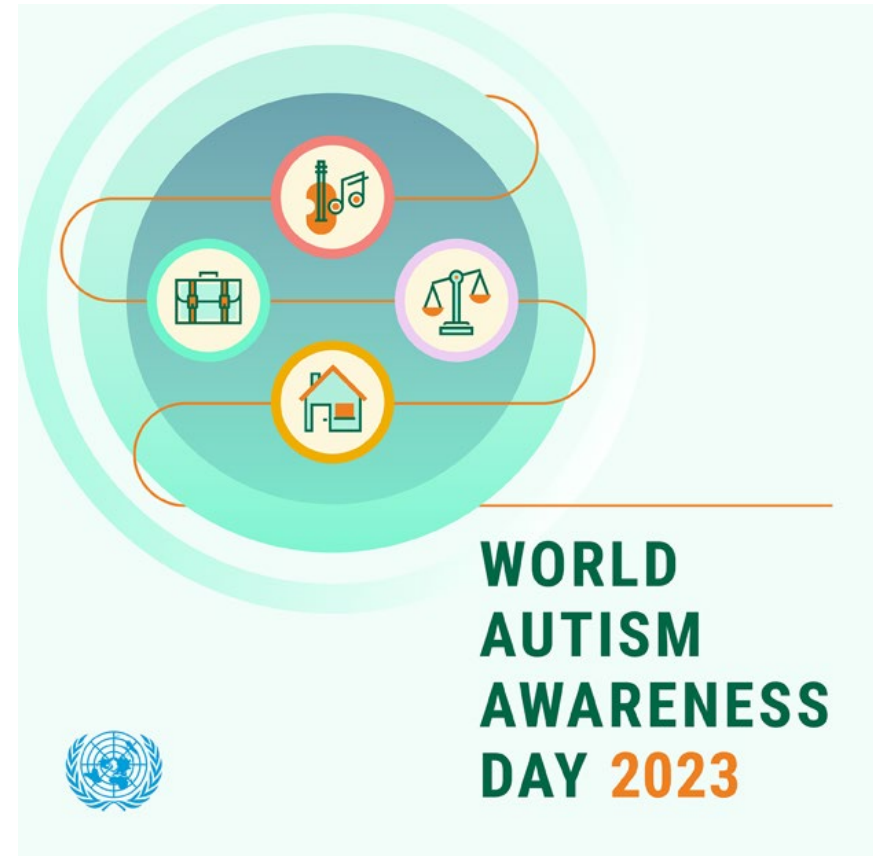
National Autism Coordinator Update

April is Autism Awareness Month

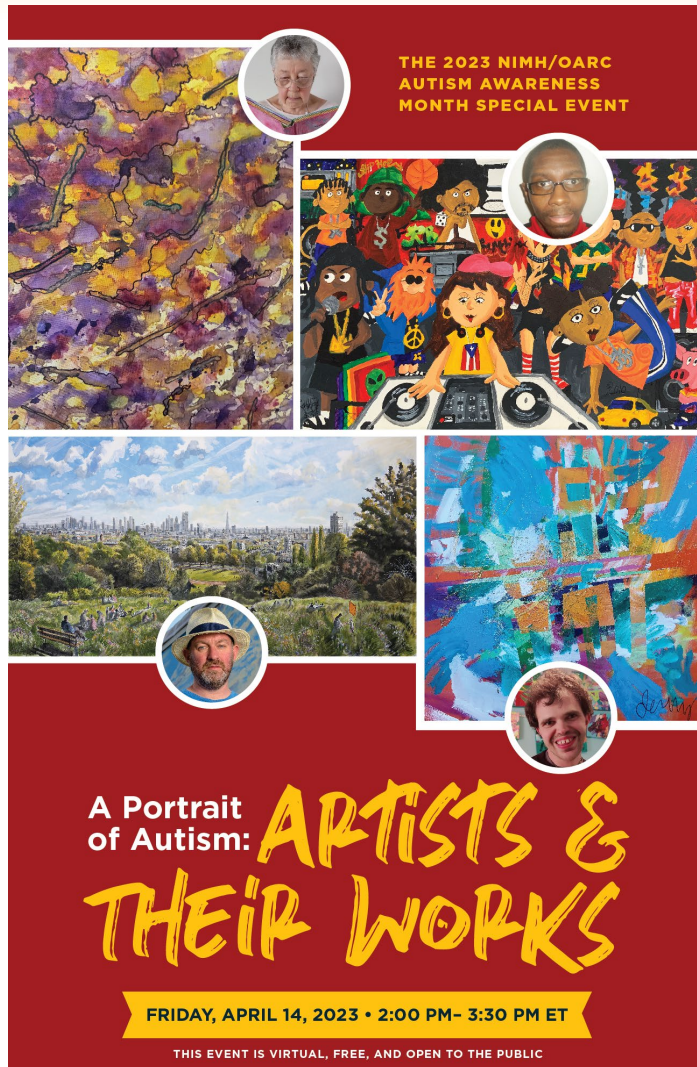


United Nations ([UN](#))

- On March 28th, UN Secretary General António Guterres issued a statement to mark World Autism Awareness Day, focused on building inclusive environments. Read [full statement here](#).
- The UN observed World Autism Awareness Day (April 2nd) with a global virtual event on the theme “Transformation: Toward a Neuro-Inclusive World for All”
- This year’s event will specifically explore the contributions autistic people make at home, at work, in the arts and in policymaking. It will also shed light on how the transformation in the narrative around neurodiversity can continue to be furthered in order to overcome barriers, improve the lives of autistic people everywhere and achieve the Sustainable Development Goals.
- For more information: <https://www.un.org/en/observances/autism-day>.



NIMH/OARC Autism Awareness Month Special Event



A Portrait of Autism: Artists and Their Works

- Friday, April 14, 2023, 2:00-3:30pm
- Event will feature interviews with 4 autistic artists
 - Sheila Benedis
 - Ronaldo Byrd
 - David Downes
 - Jeremy Sicile-Kira
- The event is virtual, free, and open to the public
- More details can be found on the event page on the IACC website:
<https://iacc.hhs.gov/meetings/autism-events/2023/april14/portrait-of-autism.shtml>


Indian Health Service ([IHS](#))

- In celebration of Autism Awareness Month, IHS will host a webinar titled “American Indian/Alaska Native Parents of Children with Autism Panel” on April 12, 2023, at 12 pm EST. The purpose of this webinar is to provide American Indian/Alaska Native (AI/AN) parents the opportunity to share their stories as parents of children with Autism. Additional information can be found [here](#).
- On April 27, 2023 at 2 pm EST, IHS will be hosting a webinar titled “The Importance of Screening for Autism Spectrum Disorder and Use of the M-CHAT.” This webinar will focus on developing providers’ skills in the early identification of ASD markers, understanding of ASD-specific screening tools, with an in-depth discussion on the Modified Checklist for Autism in Toddlers (M-CHAT) and utilizing ASD screening tools in clinics. Additional information can be found [here](#).



National Institute of Environmental Health Sciences ([NIEHS](#))

- On April 20, 2023 from 1:00-2:00 pm EST, NIEHS will be hosting a special virtual event for World Autism Awareness Month titled “Identifying Early Brain Markers in Infancy in Autism and Associated Developmental Disabilities.” This event will feature Dr. Mark Shen Ph.D. from the University of North Carolina at Chapel Hill.
- For more information, including registration, please visit the [event webpage](#).



NIH National Institute of Environmental Health Sciences

WORLD AUTISM MONTH

Brought to you by the Division of Extramural Research and Training Autism Program

Thursday, April 20, 2023 • 1:00-2:00 p.m.

Virtual Presentation

Identifying Early Brain Markers in Infancy in Autism and Associated Developmental Disabilities

Mark D. Shen, Ph.D.
Assistant Professor
University of North Carolina at Chapel Hill

Host: Cindy P. Lawler, Ph.D.

To register for this virtual event:
<http://bit.ly/3JEK7ep>

Individuals with disabilities who need accommodation to participate in this event should contact Astrid Haugen at 984-287-3266 or haugen@niehs.nih.gov. TTY users should contact the Federal TTY Relay Service at 800-877-8339. Requests should be made at least 5 business days in advance of the event.

National Institutes of Health • U.S. Department of Health and Human Services

National Autism Coordinator Update

Visit Our Autism Awareness Month Page!



The screenshot shows the IACC website's Autism Awareness Month 2023 page. The header includes the U.S. Department of Health & Human Services logo, the IACC logo (Interagency Autism Coordinating Committee), and navigation links for Get IACC Updates, Public Comments, and Contact. A search bar is also present. The main navigation menu includes Home, About IACC, About OARC, News, Meetings, Publications, Funding, and Resources. The page content features a banner with three photos of meetings and a sidebar with a 'Meetings' menu. The main content area has a breadcrumb trail: IACC Home > Meetings > Autism Awareness Month, followed by social media icons. Below this is a graphic of colorful hands and the title 'Autism Awareness Month 2023'. The text below the graphic reads: 'In celebration of Autism Awareness Month, the Office of Autism Research Coordination (OARC)/National Institute of Mental Health (NIMH) honors the contribution of people on the autism spectrum and the autism community to our nation and the world. We join the United Nations and the U.S. government in recognizing the needs of people on the autism spectrum and their families. Our office recognizes the need for supporting, understanding, accepting, including, and empowering of people on the autism spectrum. Throughout the month of April, we will be updating this page with the latest news and events.'

U.S. Department of Health & Human Services

Get IACC Updates | Public Comments | Contact

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

Search IACC Website Search

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Meetings

- IACC Meetings
- Autism Events
- Autism Awareness Month**
- Annual Observances
- Working Group Meetings
- Subcommittee Meetings
- Videos
- Public Comments

IACC Home > Meetings > Autism Awareness Month

✉ f t



Autism Awareness Month 2023

In celebration of Autism Awareness Month, the Office of Autism Research Coordination (OARC)/National Institute of Mental Health (NIMH) honors the contribution of people on the autism spectrum and the autism community to our nation and the world. We join the United Nations and the U.S. government in recognizing the needs of people on the autism spectrum and their families. Our office recognizes the need for supporting, understanding, accepting, including, and empowering of people on the autism spectrum. Throughout the month of April, we will be updating this page with the latest news and events.

Check the IACC website for more information and a list of events

<https://iacc.hhs.gov/meetings/autism-awareness-month/2023/>

Check out the April 2023 edition of the OARC Newsletter

OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

Please enjoy OARC's quarterly newsletter, which includes Autism Awareness Month activities, recent events, news, and publications.

Autism Awareness Month



A Proclamation on World Autism Awareness Day, 2023

In honor of World Autism Awareness Day, President Joseph R. Biden released a proclamation to recognize the achievements of neurodiverse people and to reiterate his

Administration's commitment to supporting the equal rights and dignity of all those on the autism spectrum. President Biden highlights recent achievements in the autism field, including support for home- and community-based services, the reauthorization of Kevin and Avonte's Law, and boosting employment opportunities.

- The OARC Newsletter provides updates on autism news from around the community.
- The April 2023 newsletter highlights Autism Awareness Month activities, federal agency updates, and more.
- To subscribe, visit: <https://iacc.hhs.gov/about-iacc/subscribe/>



U.N. Secretary-General Statement for World Autism Awareness Day

Federal Activities

- Interagency Committee for Disability Research (ICDR)
- National Council on Disability (NCD)
- Federal Partners in Transition (FPT)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- NIH/NICHHD Workshop: Ableism in Medicine and Clinical Research Workshop
- **Additional Committees** (no new updates since previous IACC meeting):
 - RAISE Family Caregiving Advisory Council (FCAC)
 - Federal Communication Commission Disability Advisory Committee (DAC)
 - President's Committee for People with Intellectual Disabilities (PCPID)
 - National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)

Interagency Committee on Disability Research ([ICDR](#))

Managed by the Administration for Community Living

- All-federal committee established to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
 - On March 22, 2023, ICDR held a Lunch & Learn Webinar on “[COVID-19 Data on Individuals with Intellectual and Developmental Disabilities](#).” The webinar featured Emma Plourde, Public Health Analyst from the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, and William Haltermann III, Program Specialist, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. HHS issued a [final report](#) on this topic in July 2021.

National Autism Coordinator Update
National Council on Disability ([NCD](#))

- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- Recent activities include:
 - NCD recently held their quarterly business meeting on February 16th, 2023, [agenda](#).
 - NCD issued a Notice of Funding Opportunity (Closed March 22, 2023) titled “[The Absence of People with Disabilities in Clinical Trials](#).” The awardee will prepare a final report to provide recommendations and promising practices to increase inclusion of people with disabilities in clinical trials.
 - On March 23, 2023 NCD issued an [update](#) on its [Health Equity Framework](#) published last year

National Autism Coordinator Update

National Council on Disability ([NCD](#)), cont.

- [National Indian Council on Aging](#), in collaboration with NCD, recently released a toolkit — “[Understanding Disabilities: In American Indian & Alaska Native Communities](#)” to share resources and recommendations on disability services and protections for Tribal Nations.
- View the publication [here](#).



National Autism Coordinator Update

Federal Partners in Transition ([FPT](#))

Managed by the U.S. Department of Labor

- All-federal workgroup formed in 2005 to facilitate exchange of information between federal agencies on transition-related issues for youth with disabilities.
- Recent activities include:
 - The FPT held a General Committee meeting on March 16th and is continuing development of a new Federal Youth Transition Plan.

National Autism Coordinator Update
Interdepartmental Serious Mental Illness Coordinating
Committee ([ISMICC](#))

**Managed by the Substance Abuse and Mental Health
Services Administration**

- Federal advisory committee charged with addressing issues related to serious mental illness (SMI) and serious emotional disturbance (SED). At times, this overlaps with autism or disabilities.
- Recent activities include:
 - The ISMICC met on March 14th. The agenda included a look ahead at the future meeting planning for the ISMICC, working group updates, and a presentation from Brandon Staglin, President of One Mind, on “The One Mind Initiative: Social Innovation for Better Mental Health.” [The full agenda and link are here.](#)

NIH/NICHD Workshop: Ableism in Medicine and Clinical Research Workshop

- From April 27-28, 2023, NICHD will host a two-day, virtual workshop focused on awareness and research opportunities to mitigate the impact of Ableism in both clinical care and the biomedical and behavioral research enterprise. This workshop is intended to inform future research areas in this complex area of public health.
- This event is co-sponsored by the National Center for Medical Rehabilitation Research at the Eunice Kennedy Shriver National Institute of Child Health and Human Development in collaboration with the NIH Medical Rehabilitation Coordinating Committee.
- For more information, including registration, please visit the [event webpage](#).



National Autism Coordinator Update

Additional Committees

No new activities since the previous IACC meeting

- **RAISE Family Caregiving Advisory Council ([FCAC](#))**
 - No new updates, details on a 2023 meeting are forthcoming.
- **Disability Advisory Committee ([DAC](#))**
 - No new updates since the November 1, 2022 meeting. The DAC will meet again this year in 2023 with new membership.
- **President's Committee for People with Intellectual Disabilities ([PCPID](#))**
 - No new updates since the July 28, 2022 meeting.
- **National Advisory Committee on Individuals with Disabilities and Disasters ([NACIDD](#))**
 - No new updates since the August 4, 2022 joint [meeting with National Advisory Committee on Seniors and Disasters \(NACSD\)](#).

National Autism Coordinator Update

Non-Governmental Activities

- Autism Science Foundation 10th Annual Day of Learning
- Kennedy Krieger Research Institute: Neurodiversity in the Workplace Conference
- AJ Drexel Autism Research Institute: National Autism Indicators Report Explores Autistic Individuals' Use of Medicaid Across the Lifespan
- INSAR 2023 Annual Meeting

National Autism Coordinator Update
ASF 10th Annual Day of Learning

- On March 30, 2023, the Autism Science Foundation held its 10th **Annual Day of Learning**.
- Featured talks by researchers & clinicians about important topics in autism research.
- More information and forthcoming event videos can be accessed on the ASF [event page](#).



Kennedy Krieger Research Institute: Neurodiversity in the Workplace Conference

- From March 22-24, **Kennedy Krieger Research Institute** hosted a conference in DC that brought together employers, stakeholders and policymakers who are committed to improving employment outcomes for the neurodiverse workforce.
- More information can be found [here](#).



National Autism Coordinator Update

AJ Drexel Autism Research Institute: National Autism Indicators Report Explores Autistic Individuals' Use of Medicaid Across the Lifespan

- In the latest edition of the National Autism Indicators Report series titled “Introduction to Medicaid and Autism,” researchers at Drexel University’s [A.J. Drexel Autism Institute](#) explore how autistic individuals use Medicaid and how their service use changes across the lifespan – from infants to older adults – using data from the Centers for Medicaid and Medicare Services (CMS) from 2008-2016.
- This is the first report in the Autism Institutes’ new Policy Insight series of National Autism Indicators Reports.
- For more information, including an [at-a-glance edition](#) of the report, please [visit here](#).



National Autism Coordinator Update

INSAR 2023 Annual Meeting

- From May 3-6, 2023, the International Society for Autism Research (INSAR) will be hosting their annual scientific meeting in-person in Stockholm, Sweden. This meeting aims to exchange and disseminate new scientific progress among autism scientists and their trainees from around the world.
- For more information, including registration, please visit the [event webpage](#).



IACC Committee Business

IACC Full Committee Meeting
April 4, 2023



Susan A. Daniels, Ph.D.

Acting HHS National Autism Coordinator

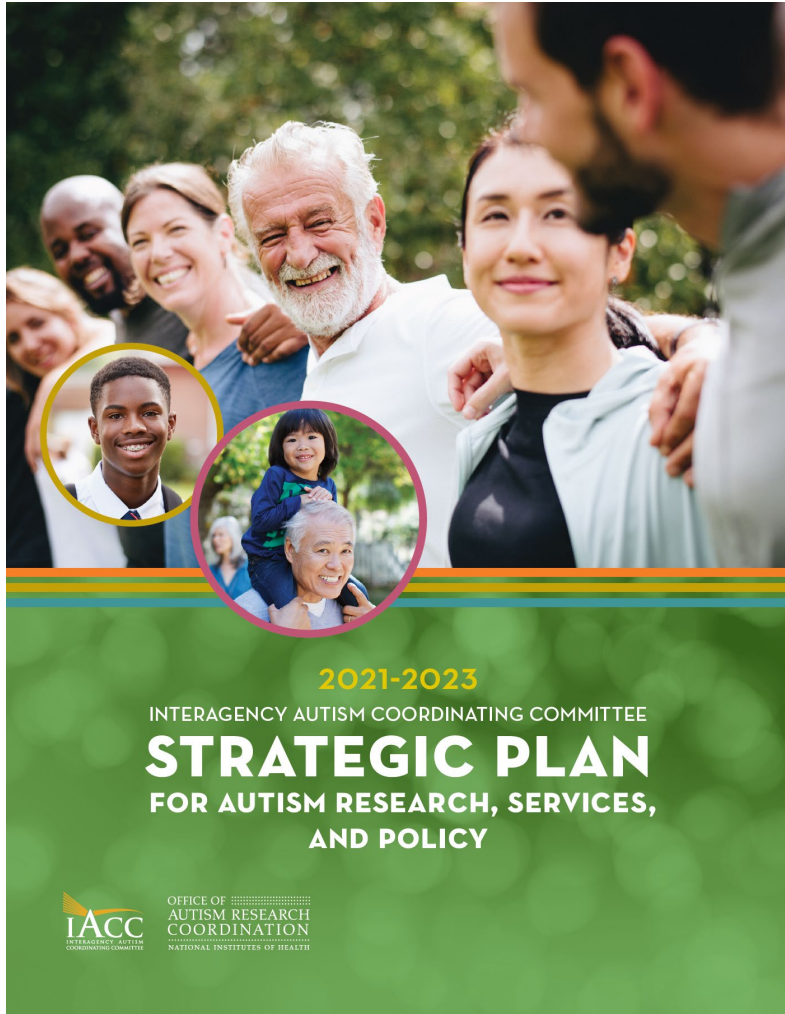
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

Committee Business Overview



- 2021-2023 IACC Strategic Plan update
- IACC Health Outcome Working Group report
- *2021 IACC Summary of Advances* update
- *2022 IACC Summary of Advances* update
- *2023 IACC Summary of Advances* discussion

2021-2023 IACC Strategic Plan: Status Update



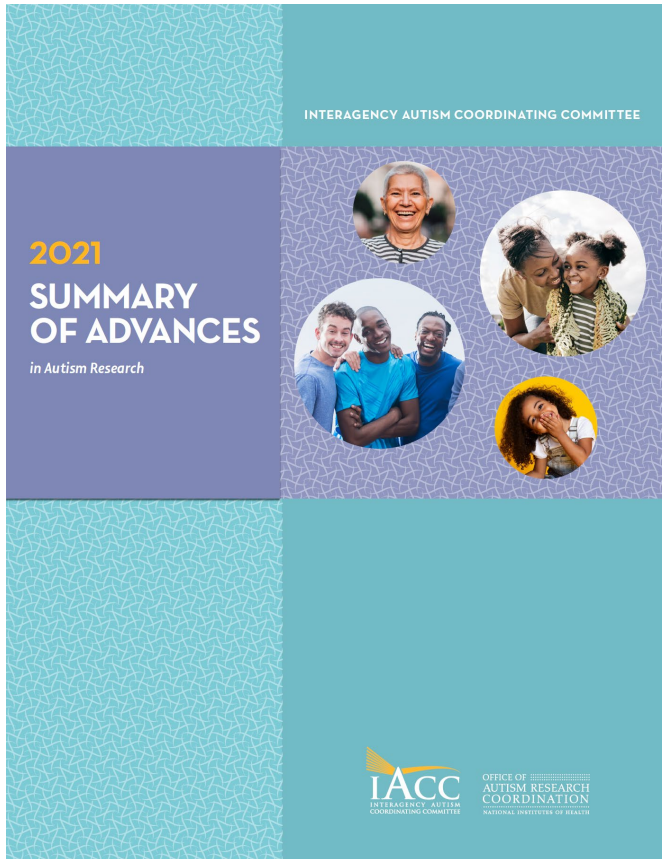
- The IACC voted to approve the *IACC Strategic Plan* at the January 2023 Full Committee Meeting
- OARC is currently preparing the approved Plan for publication in May 2023
- The *Strategic Plan* will be published on the IACC website, distributed via the IACC mailing list, and transmitted to Congress and the President (as required by the Autism CARES Act of 2019)
- An accessible easy-read version will also be released

Health Outcomes Working Group Report



- The report will be a continuation of the work of the IACC Health Outcomes Working Group, which held 2 workshops in September 2018 and May 2019
- OARC will work on revising the report in Spring and Summer 2023
- IACC members will have a chance to review and approve the report
- A status update will be provided at the October IACC Meeting

2021 IACC Summary of Advances: Available Now!



- Required by the Autism CARES Act of 2019
- Provides lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Includes articles addressing all 7 topic areas of the *IACC Strategic Plan*
- The full Report can be found here:
https://iacc.hhs.gov/publications/summary-of-advances/2021/summary_of_advances_2021.pdf
- OARC has also prepared an easy-read version of the 2021 Summary of Advances: https://iacc.hhs.gov/publications/summary-of-advances/2021/summary_of_advances_2021_easy_read.pdf

Status of the **2022** IACC Summary of Advances



- ✓ IACC members nominate articles (October 2022-January 2023)
- ✓ IACC members discuss nominations at committee meeting (January 2023)
- ✓ IACC members vote on top 20 articles (February-March 2023)
- OARC prepares article summaries and draft publication (March-May 2023)
- IACC members preview and comment on draft (Spring 2023)
- OARC prepares final publication (Summer 2023)

2023 IACC Summary of Advances Process



- ❑ IACC members nominate articles (January 2023 – January 2024)
- ❑ **TODAY:** IACC members discuss nominations at committee meetings (April 2023 - January 2024)
- ❑ IACC members vote on top 20 articles (January 2024)
- ❑ OARC prepares article summaries and draft publication (Winter-Spring 2024)
- ❑ IACC members preview/comment on draft (Spring 2024)
- ❑ OARC prepares final publication (Spring 2024)

Summary of Advances discussion guidelines



- Goal of today's discussion: review the list of 20 nominated articles to appear on the ballot
- Selected articles should represent **significant advances or progress** in understanding of autism, across the 7 topic areas of the *IACC Strategic Plan*
- During the discussion:
 - Are there nominated articles you find particularly noteworthy?
 - Are there any articles that should potentially be removed, including any in the following categories?
 - Study too preliminary
 - Small sample size
 - Review article
 - Commentary
 - Workgroup recommendations



2023 Summary of Advances Nominations



Question 1: Screening and Diagnosis



- Dahl et al. Differential Performance of Social Communication Questionnaire Items in African American/Black vs. White Children. *J Autism Dev Disord*.
- Engelhard et al. Predictive Value of Early Autism Detection Models Based on Electronic Health Record Data Collected Before Age 1 Year. *JAMA Netw Open*.
- Pham et al. Examination of the impact of the Get SET Early program on equitable access to care within the screen-evaluate-treat chain in toddlers with autism spectrum disorder. *Autism*.
- Pierce et al. Level of Attention to Motherese Speech as an Early Marker of Autism Spectrum Disorder. *JAMA Netw Open*.

Question 2: Biology



- Bozhilova et al. Profiles of autism characteristics in thirteen genetic syndromes: a machine learning approach. *Mol Autism*.
- Mattern et al. Sex differences in social and emotional insight in youth with and without autism. *Mol Autism*.

Question 3: Genetic and Environmental Factors



(There were no nominations covering Question 3 topics from January-March 2023)

Question 4: Interventions



- Guthrie et al. The earlier the better: An RCT of treatment timing effects for toddlers on the autism spectrum. *Autism*.

Question 5: Services and Supports



- Hinkle and Lerman. Preparing Law Enforcement Officers to Engage Successfully with Individuals with Autism Spectrum Disorder: An Evaluation of a Performance-Based Approach. *J Autism Dev Disord*.
- Ishler et al. Barriers to service and unmet need among autistic adolescents and young adults. *Autism*.
- Liu et al. Racial and Ethnic Disparities in Geographic Access to Autism Resources Across the US. *JAMA Netw Open*.

Question 6: Lifespan



- Charlton et al. Predictors of sleep quality for autistic people across adulthood. *Autism Res.*
- Kopp et al. Girls With Social and/or Attention Deficit Re-Examined in Young Adulthood: Prospective Study of Diagnostic Stability, Daily Life Functioning and Social Situation. *J Atten Disord.*
- Torenvliet et al. A longitudinal study on cognitive aging in autism. *Psychiatry Res.*
- Warreman et al. Psychological, behavioural and biological factors associated with gastrointestinal symptoms in autistic adults and adults with autistic traits. *Autism.*

Question 7: Infrastructure and Prevalence



- Casseus et al. Prevalence and treatment of mental, behavioral, and developmental disorders in children with co-occurring autism spectrum disorder and attention-deficit/hyperactivity disorder: A population-based study. *Autism Res.*
- Hughes et al. Adolescents With Autism Spectrum Disorder: Diagnostic Patterns, Co-occurring Conditions, and Transition Planning. *J Adolesc Health.*
- Maenner et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ.*

Question 7: Infrastructure and Prevalence



- Shaw et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ.*
- Shaw et al. Statewide county-level autism spectrum disorder prevalence estimates-seven U.S. states, 2018. *Ann Epidemiol.*
- Shenouda et al. Prevalence and Disparities in the Detection of Autism Without Intellectual Disability. *Pediatrics.*

2023 IACC Summary of Advances: Next Steps



- Continue to send article nominations to OARC
- New nominations will be discussed at the October IACC meeting

Lunch Break



Public Comment Session



Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health
(NIMH) and Chair, IACC

Susan A. Daniels, Ph.D.

Acting HHS National Autism Coordinator
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

Oral Public Comments



- Geraldine Dawson, Ph.D.
- Miya Asato, M.D.
- Anthony Tucci, LL.M., Esq.
- Christopher Banks, M.B.A., M.S.
- Idil Abdull
- Mariam Egal

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/april4/public_comments.pdf

Summary of Written Public Comments



38 written public comments were submitted on topics below by the following individuals:

Research and Service Needs, Resources, and Policy Implications - 28 comments

- Hilary Martin
- JL Angell
- Kevin Hintzman
- Robert Hackl-Blumstein
- Marylyle McCue
- Tosha Brothers
- Elizabeth Carey
- Sameena Flinner
- Charlotte and Trudy Dier-Chacon
- Megan Hrach
- Emily DeFour
- Megan McLaughlin
- Kim-Loi Mergenthaler
- George Sumner
- Whitney Geertsen
- Julia Simko
- Natalie Dowd
- Shannon Shea
- Algernon Lutwak
- M Horowitz
- Christina Capella
- Tim J Klaas
- River Bradley
- Christine Preimesberger
- Kate Seader
- Steven Bruce
- Jane Horn, MA, MSW
- Donna Murray, PhD, CCC-SLP

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/april4/public_comments.pdf

Summary of Written Public Comments



38 written public comments were submitted on topics below by the following individuals:

Research, Services, and Supports for Adults with Autism - 4 comments

- Pamela Alston
- Daniele Colozzi
- Kaitlin Walker
- Nicole Corrado

Mental Health Research, Services, and Treatment - 2 comments

- Anna Lauber
- Jeffrey Slater

The Role of the IACC and the Federal Government - 1 comment

- Larkin Taylor-Parker, Autistic Self Advocacy Network

Employment - 1 comment

- Bob Steinkamp

Inclusion of Autistic Perspectives in Research - 1 comment

- AJ Cho

Concern About Medical Practices- 1 comment

- Eileen Nicole Simon, R.N., Ph.D.

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/april4/public_comments.pdf

Break



Why Understanding the Impact of Racism and Discrimination Matters in Autism Research

Brian Boyd, PhD & Jill Locke, PhD

Presentation Overview

01

Discuss relevant terms and how racism operates in US society

02

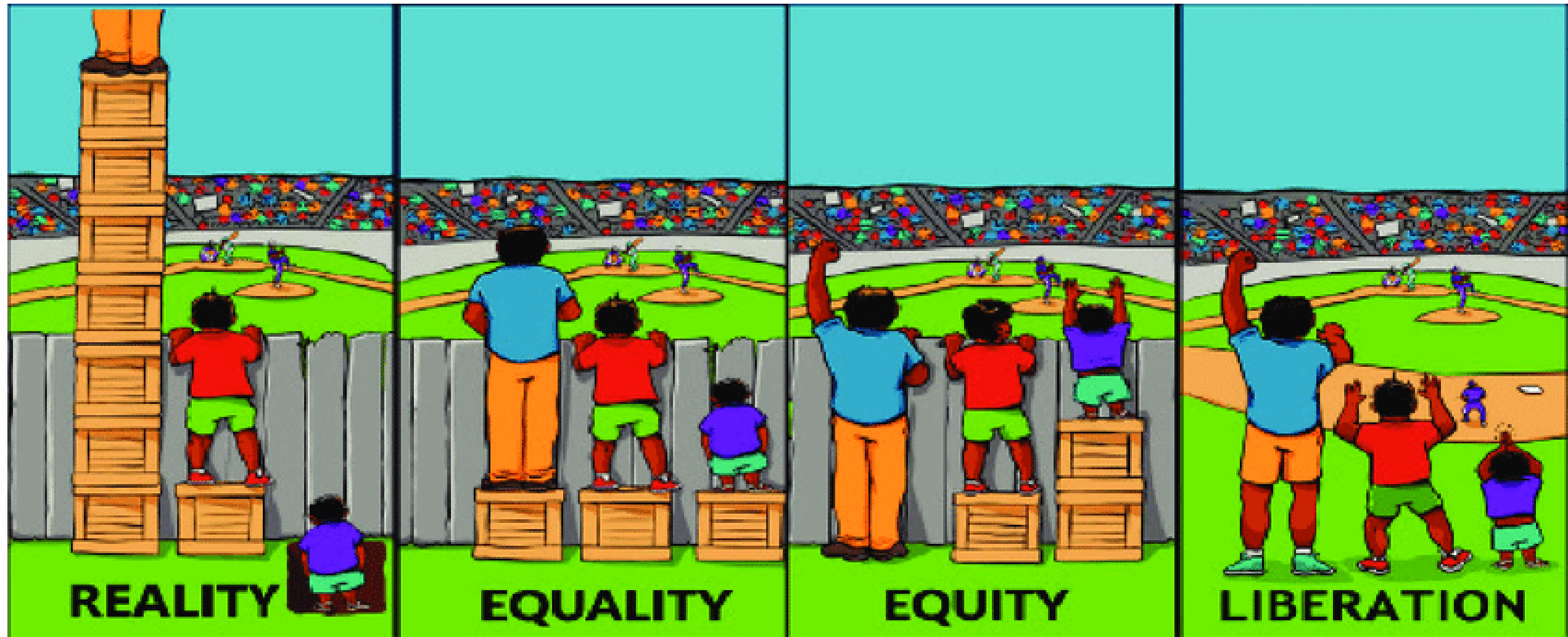
Provide examples of racism's impact on autistic people of color

03

Describe community-powered solutions to address these issues

04

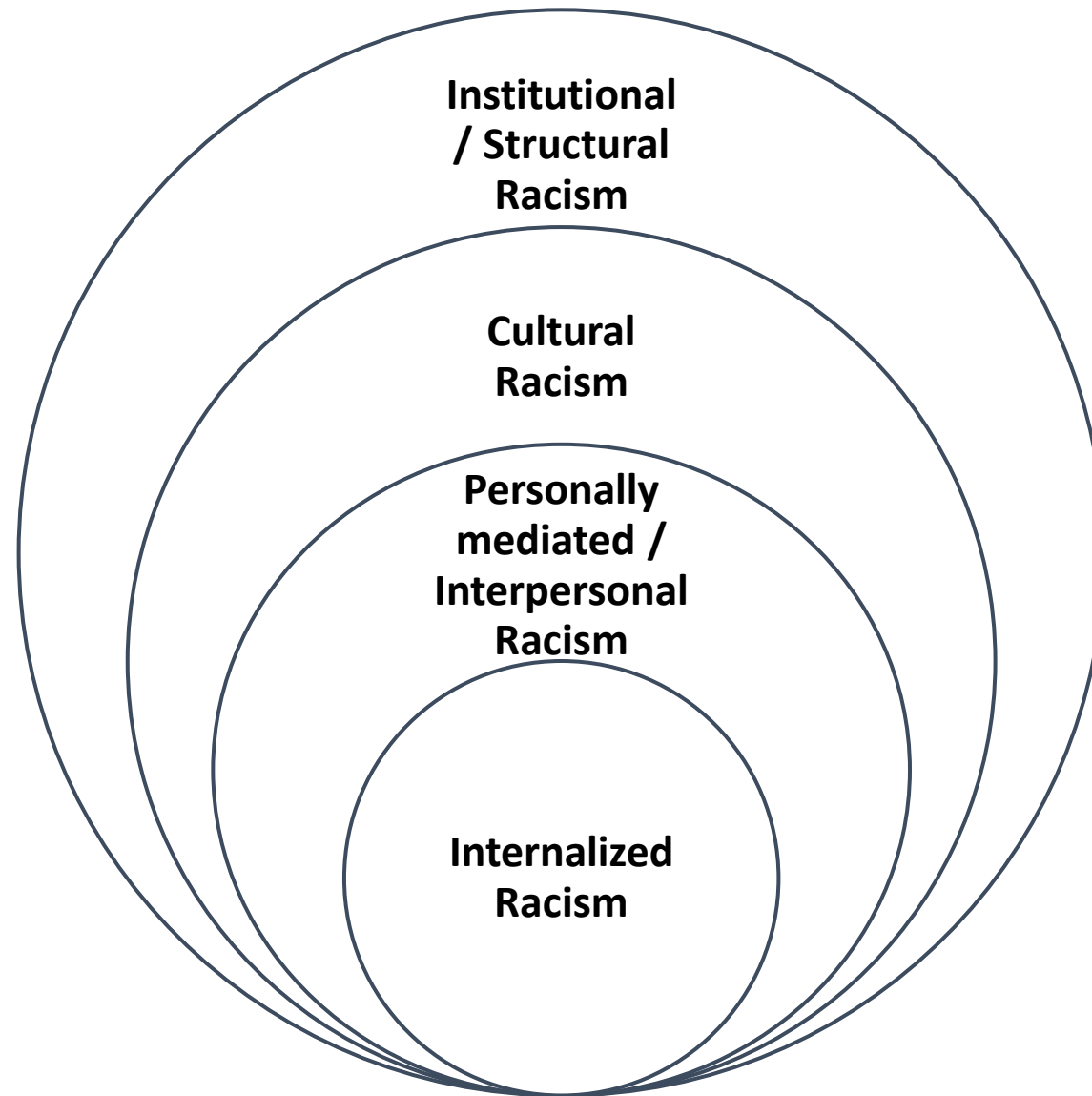
Identify potential next steps and directions



How Racism Operates in Society

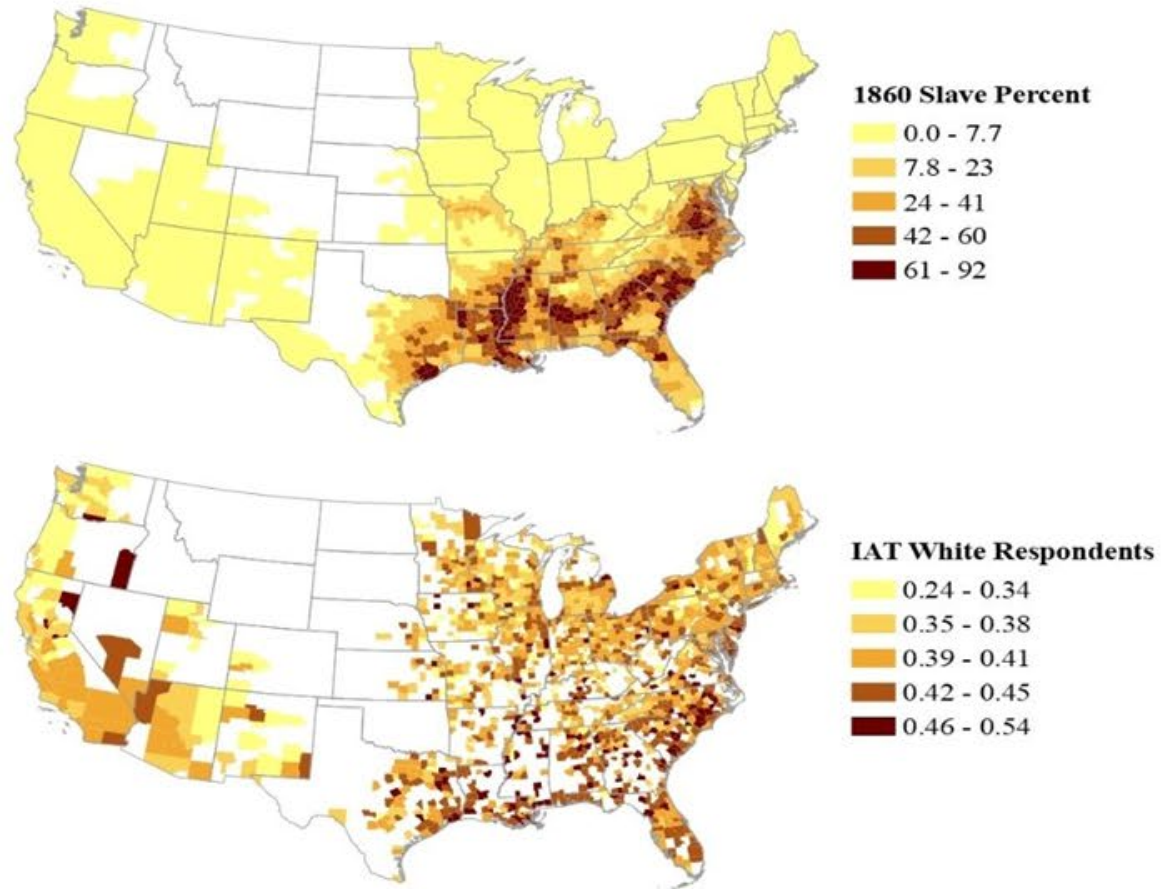


Jones, C. P. (2000). Levels of racism: a theoretic framework and a gardener's tale. *American journal of public health*, 90(8), 1212.

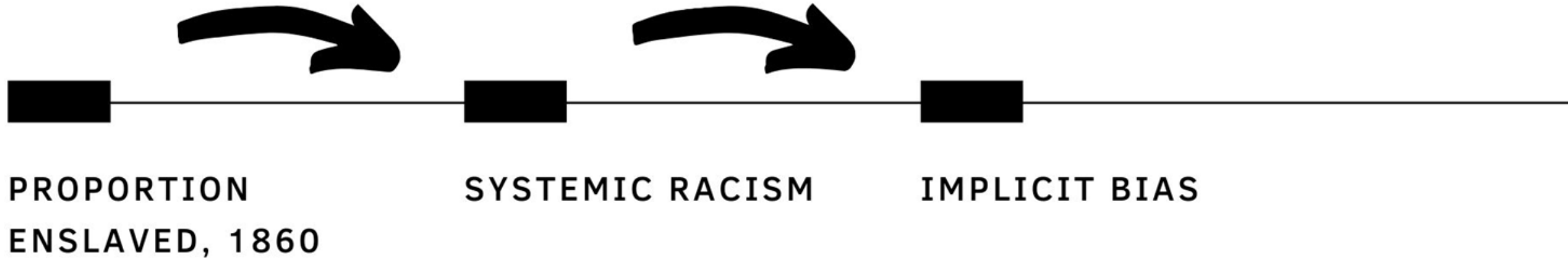


Association between enslaved population and implicit bias

Payne, Vuletich, & Brown-Iannuzzi, 2019



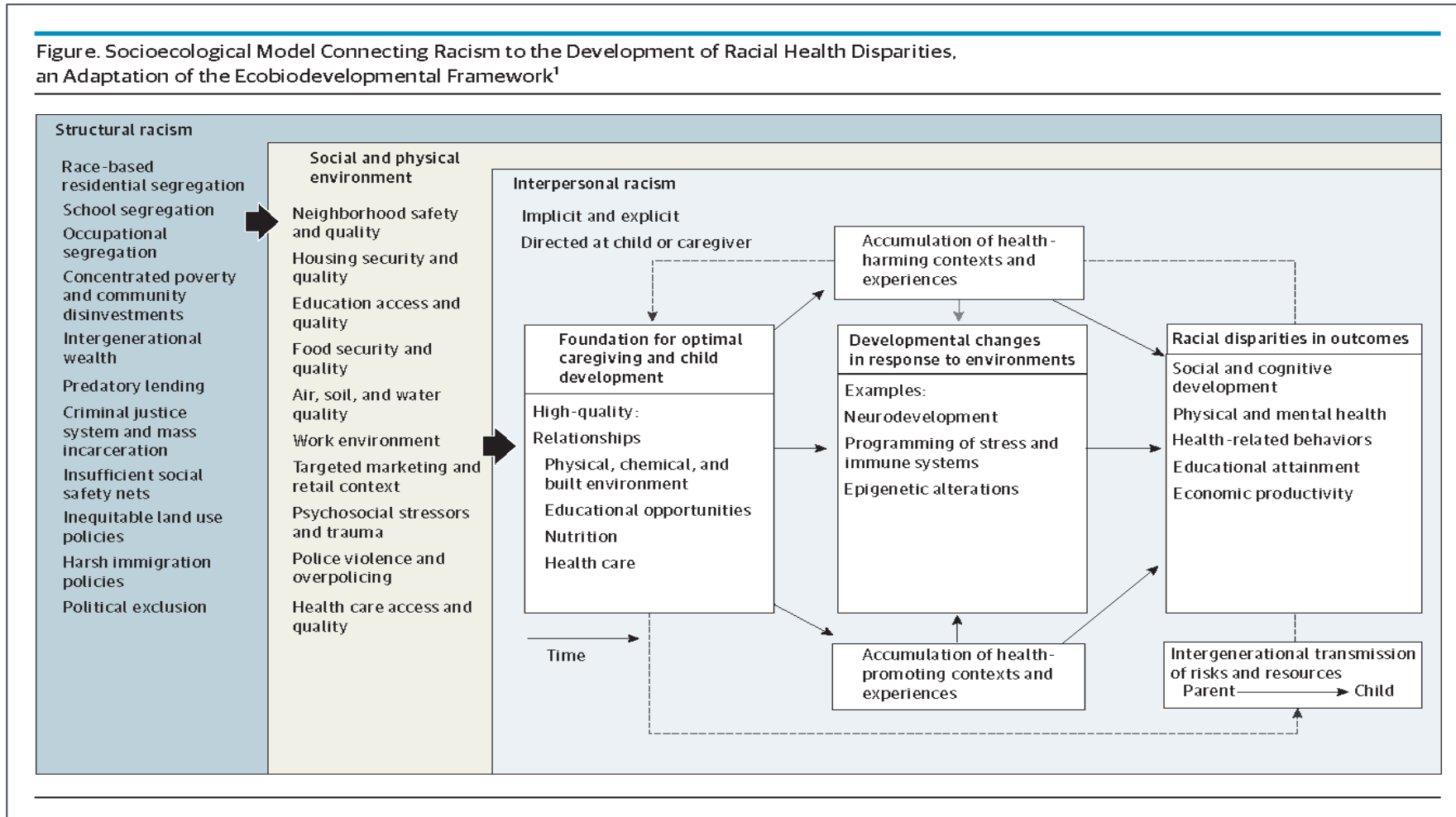
Systemic racism links historical racism to today's implicit bias



- Segregation
- Disparity in poverty
- Disparity in mobility

Structural Racism in Pediatric Healthcare

Figure. Socioecological Model Connecting Racism to the Development of Racial Health Disparities, an Adaptation of the Ecobiodevelopmental Framework¹



Sloven, Natalie, and Nia Heard-Garris. "Structural racism and pediatric health—a call for research to confront the origins of racial disparities in health." *JAMA pediatrics* 176.1 (2022): 13-15.

Intersection of
Race and Class
in the U.S.

60%

OF AMERICAN INDIAN, BLACK
AND LATINE CHILDREN LIVE IN
LOW-INCOME HOUSEHOLDS
COMPARED TO

30%

OF WHITE AND ASIAN
CHILDREN

Low income racially
minoritized children
are more likely to live
in and attend lower-
resourced, racially
segregated
neighborhoods and
schools

"Concentrated
disadvantage"

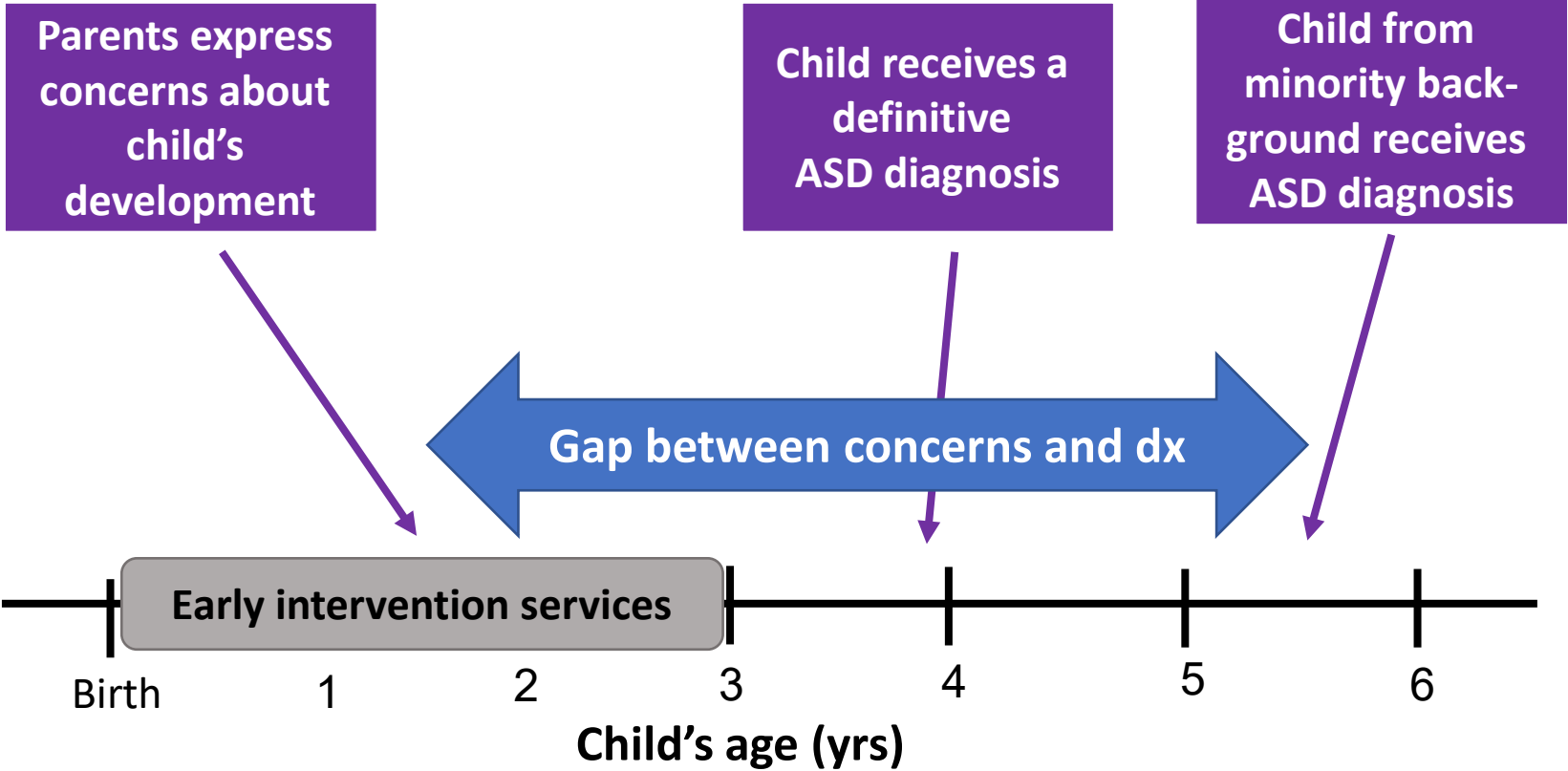
How Does Racism and
Discrimination Impact Autistic
People of Color?

CDC Prevalence Rates

“ Interpretation: ...For the first time among children aged 8 years, the prevalence of ASD was lower among White children than among other racial and ethnic groups, reversing the direction of racial and ethnic differences in ASD prevalence observed in the past. Black children with ASD were still more likely than White children with ASD to have a co-occurring intellectual disability.”

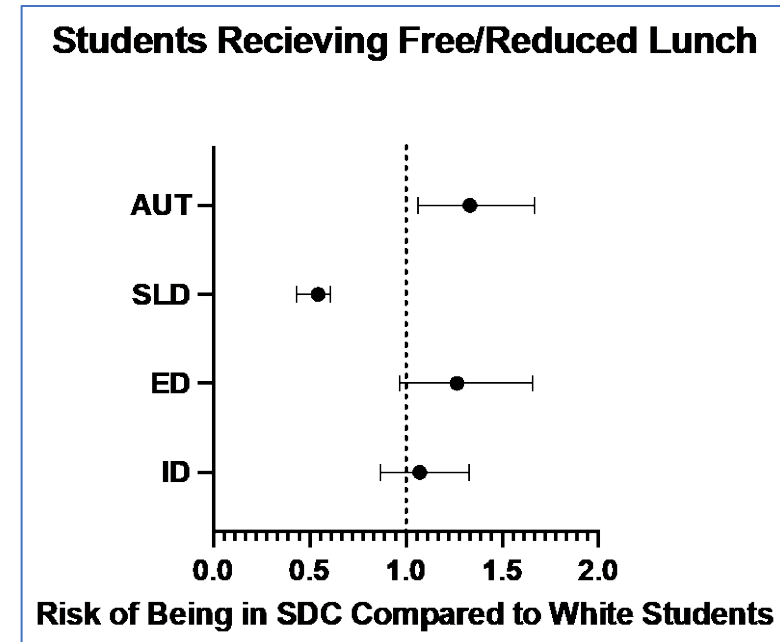
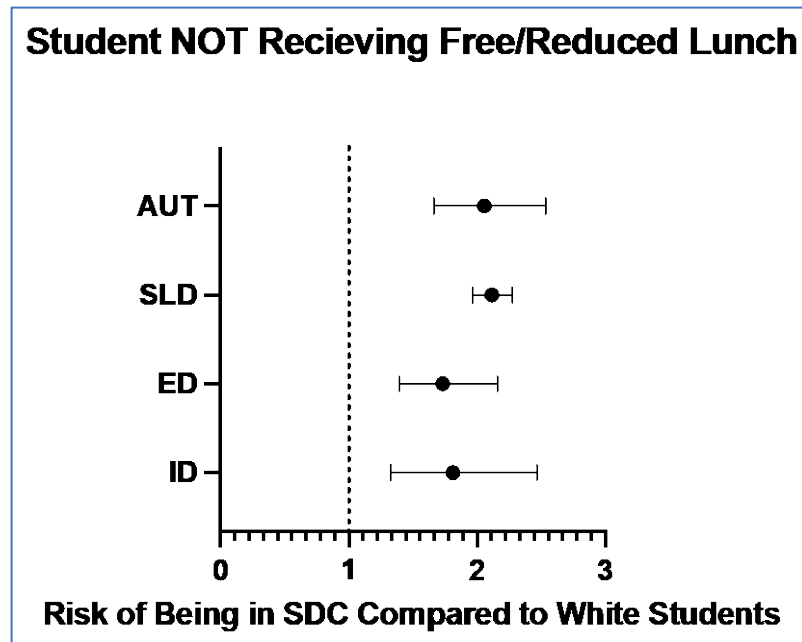


Autism Detection: Diagnostic Timeline



Slide courtesy of Wendy Stone, Ph.D.

Disparities in Classroom Placement for Black Autistic Students: Is it Structural Racism?



Social Relationships in Schools

Figure 1. Group differences in the number of friendship nominations.

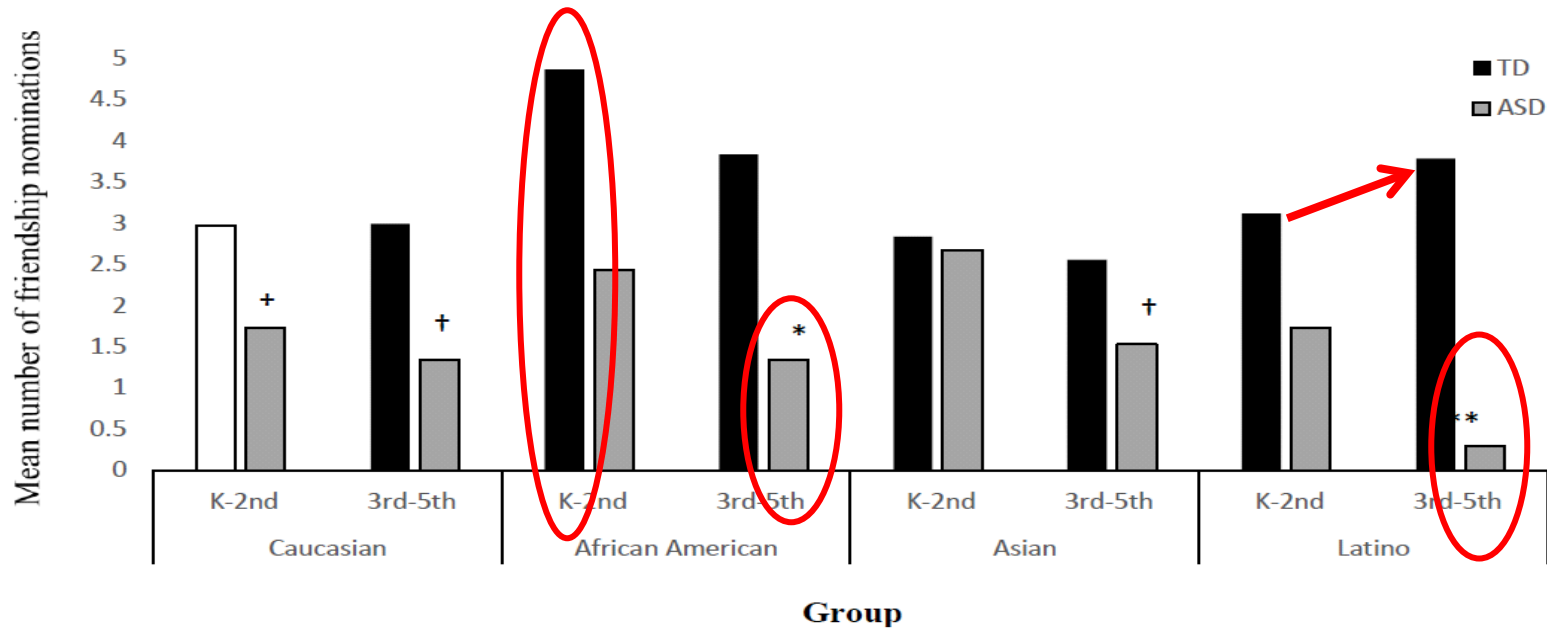
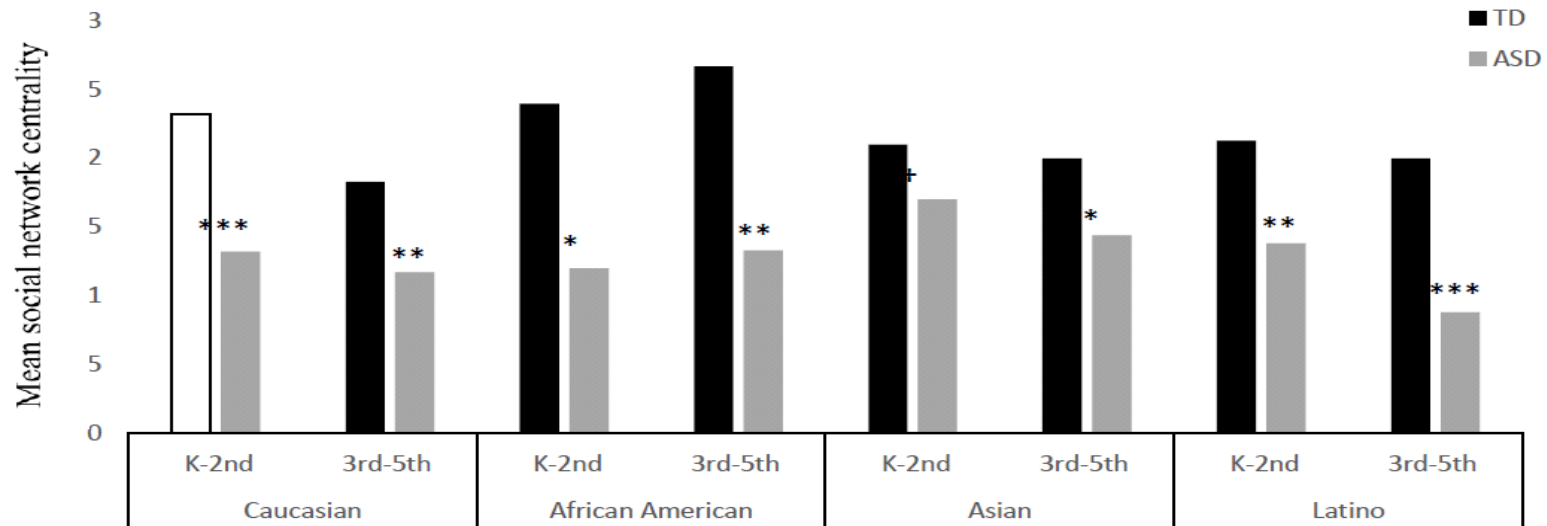


Figure 2. Group differences in social network centrality.



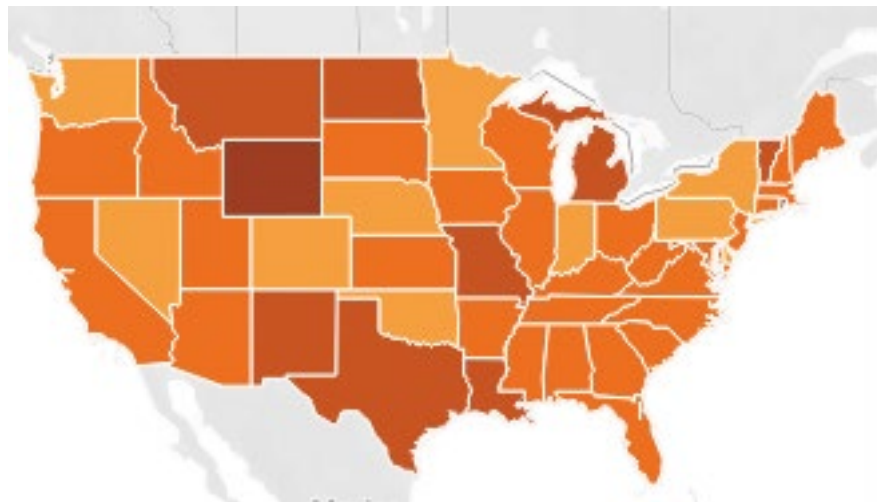
Azad, G., Locke, J., Kasari, C., & Mandell, D (2014). Ethnicity, disability and grade: Social relationships for children with autism spectrum disorders. *Journal of Abnormal Child Psychology*

Preliminary Data: School-based Research Participants by Race/Ethnicity

	Autistic Youth	Teachers	Paraeducators
American Indian/Alaska Native	1%	0%	0%
Asian	9%	4%	5%
Black or African American	14%	6%	29%
White	60%	84%	58%
Other	6%	1%	2%
More than 1, including white	8%	4%	4%
More than 1, not including white	1%	0%	1%
White, not Hispanic/Latina/o/x/Mexican/Spanish Origin	55%	81%	56%
Hispanic/Latina/o/x/Mexican/Spanish Origin	21%	8%	11%

Massive Infusion of Support for Title 1 Districts and for Special Education

IDEA funding



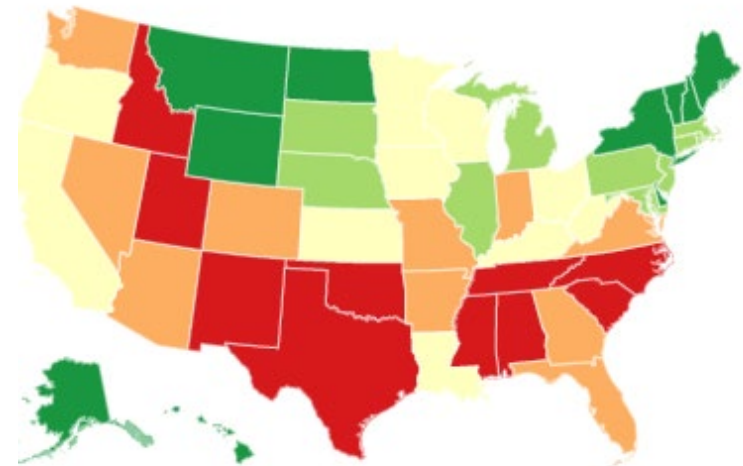
Average IDEA grant am..



1,090

3,537

Title 1 funding



\$1,110

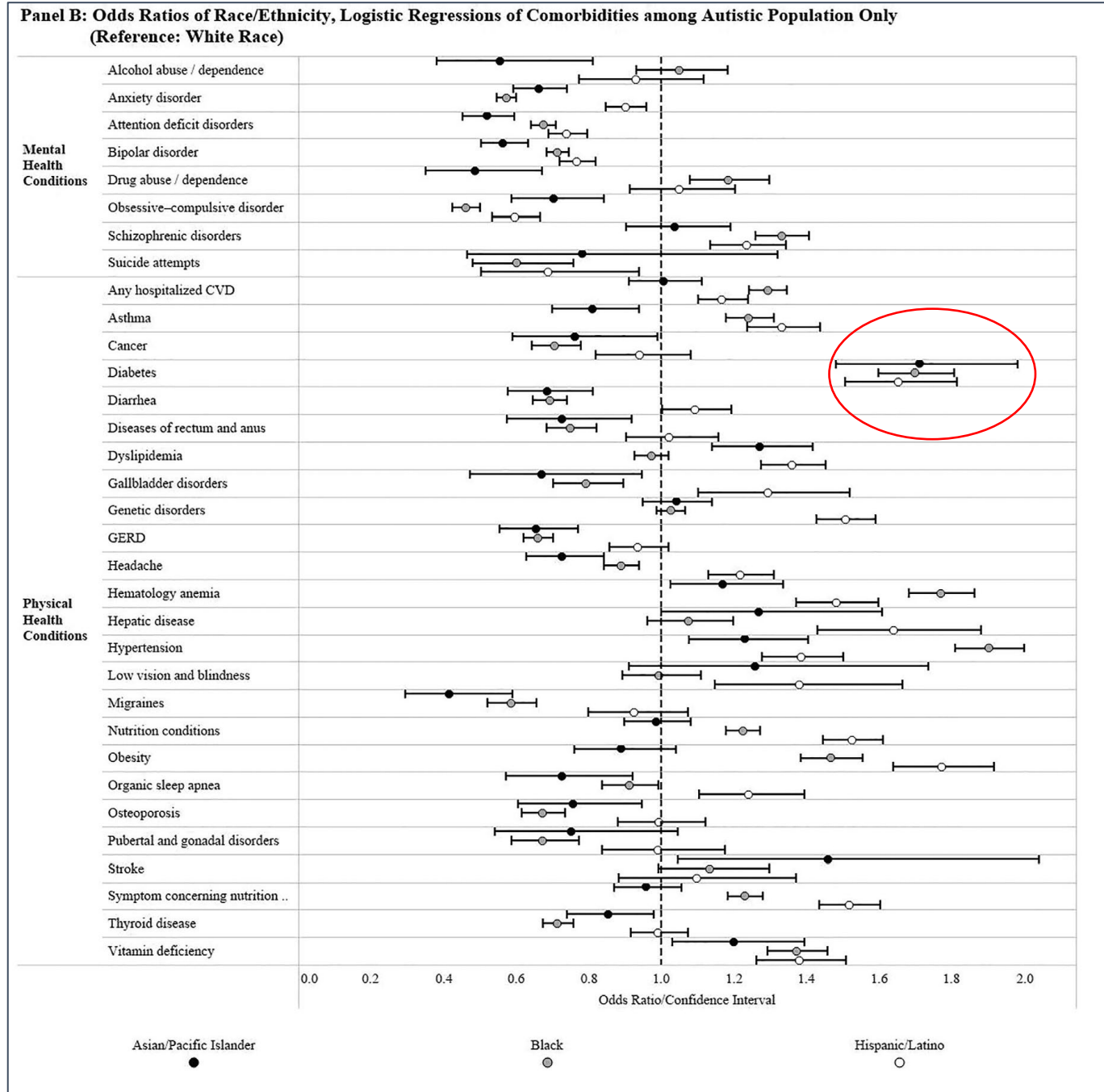
\$1,317

\$1,500

\$1,771

Co-occurring Mental & Physical Health Conditions for Autistic POC

Schott, W., Tao, S., & Shea, L. (2022). Co-occurring conditions and racial-ethnic disparities: Medicaid enrolled adults on the autism spectrum. *Autism Research, 15*(1), 70-85.



Examination of Race and Autism Intersectionality Among African American/Black Young Adults

Amber Davis , Marjorie Solomon, and Harolyn Belcher

Published Online: 13 Dec 2022 | <https://doi.org/10.1089/aut.2021.0091>

 [Sections](#)  [View article](#)

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Abstract

Background: African American/Black (AA/B) young adults with diagnoses of autism spectrum disorders rarely are studied in a way that acknowledges both their racial identity and their autism diagnosis. Little is known about intersectional oppression in the lives of these young adults. Early adulthood is a time when a young people of color may come to terms with a society that may not treat them fairly and equally due to their race. Autistic AA/B young adults may be even more vulnerable to stress and psychological disempowerment due to the added impact of negative experiences of being Black and having an autism diagnosis.

Methods: Thirty-two autistic and 30 non-autistic AA/B young adults took part in an online survey examining risk factors of everyday discrimination, perceived stress and potential protective factors of psychological empowerment, and Black identity. Differences in score measures for the autistic and non-autistic samples were examined along with the predictors of perceived stress assessed. Frequencies of intersectional discrimination experiences were also examined.

Results: Autistic AA/B participants reported significantly less everyday discriminatory experiences than non-autistic AA/B participants, whereas perceived stress was not significantly different between the two groups. The majority of non-autistic AA/B participants endorsed race as their prime source of experiences of discrimination, whereas autistic AA/B participants also cited being autistic as a major contributor to reports of discrimination. Although the autistic group had significantly lower reports of self-determination, they reported higher on the Black identity, private regard scale, pertaining to feelings about group membership, which can be considered a protective factor. There is heterogeneity in reasons for discriminatory experiences for autistic AA/B young adults whereby some of the participants (12%–30%) endorsed race + disability as dual reasons for experiencing regular discrimination.

Conclusions: Mental health clinicians and other direct service providers working with autistic AA/B young adults should understand that intersecting identities of race and disability may be at play when they are working with these individuals, and that treatment should consider these factors.



Structural
Inequities Lead to
Differences in...

Access

Outcomes

Experiences

Community Partnered Research: A Bridge Over Troubled Waters

CPR Example

Parents Taking Action: Adapting a Peer-to-Peer Program for Parents Raising Black Children With Autism

Sarah Dababnah, Wendy E. Shaia, Irang Kim, and Sandy Magaña

Abstract

We report on the adaptation and delivery of a peer-led, 14-session manualized program, Parents Taking Action, among parents raising Black children with autism in low-income neighborhoods. We engaged a community advisory group made up of parents and grandparents of Black children with autism, a Black self-advocate, clinicians, and other stakeholders to culturally adapt the intervention. Three Parent Leaders delivered the program to seven Black mothers of children with autism. We collected and analyzed quantitative and qualitative data on intervention implementation. Our study revealed key participation barriers and facilitators facing families of Black children with autism, particularly financial and other material burdens, which can inform efforts to better serve parents experiencing the effects of poverty and racism.

SHARP Framework

Structural Oppression

Historical Context of Community

Analysis of Provider's Role

Reciprocity in Provider-Client Relationship

Power Dynamics

Health Equity is defined as

- “the state in which **everyone** has the **opportunity** to attain **full health potential**, and **no one is disadvantaged** from achieving this potential because of social position or any other socially defined circumstance.”

National Academies of Science, Engineering, and Medicine, Health and Medicine Division, Board on Population Health and Public Health Practice & Committee on Community-Based Solutions to Promote Health Equity in the United States (2017)

Racial Equity is defined as

- a process of **eliminating racial disparities** and **improving outcomes for everyone**
- It is the intentional and continual practice of changing policies, practices, systems, and structures by prioritizing measurable change in the lives of people of color

Scaling up Community Solutions

- Researchers support communities in the development of inherently culturally grounded interventions
- Practice-based interventions may be feasibly and meaningfully be implemented in every-day practice
- Culturally grounded interventions that are developed for and by Black communities may ultimately have a better chance of being used and sustained than those developed in university-based research settings
- Interventions that emerge from practice may have an advantage compared to university-developed interventions, in that much of the work of fitting the treatment to the setting has already been done, so the intervention is more appropriate and relevant to the community
- Practice-based research increases the likelihood that resulting interventions will be more culturally relevant, tailored, and actionable than if they were developed in a laboratory or university-based setting

Potential Next Steps

Disentangle and unpack the impact of race/ethnicity in research trials

Involve autistic self-advocates of color in research to better understand intersectionality

Develop and evaluate culturally responsive interventions and antiracist programs for racially minoritized autistic individuals and families

Increase workforce diversity (e.g., among research teams, between provider/client)

Fund existing systems & change policies that contribute to inequities

Need funding and mechanisms beyond single investigator R01s to address health and racial equity in autism

Acknowledgements



Beza Ayalew



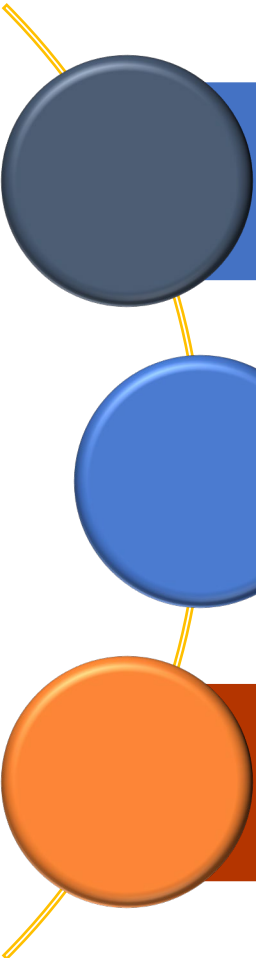
David Mandell, ScD

Racial and Ethnic Disparities in healthy weight and culturally tailored interventions to address them

Sandy Magaña, PhD, MSW
Professor, Steve Hicks School of Social Work
University of Texas at Austin



Overview



Importance of exploring racial and ethnic disparities in health outcomes for autistic children and adults

Why should culturally tailored interventions be funded?

Examples from PODER study

The image features a white background with several abstract geometric elements. In the top left, there are two vertical yellow dashed lines. To their right is a solid blue circle. Further right, a green line forms a right-angled corner pointing towards the top right. In the top right corner, a portion of a yellow circle is visible. On the left side, a green square outline is partially shown. Below it, a series of yellow dashed lines forms a curved path. The right side of the image is dominated by a large, solid orange semi-circle. Centered within this orange area is the text "Disparities in Health Outcomes" in a black, sans-serif font.

Disparities in Health Outcomes

Research on disparities and equity in autism

Has examined (but more research is needed)

- Disparities and differences in diagnosis
- Disparities in specialty services
- Disparities in health care

As more research is focused on health outcomes among autistic adults and children

- We need to explore whether there are racial and ethnic disparities in these outcomes
- What contributes to them
- How to address these disparities



**Healthy Weight
Research Network**

**Children with
Autism Spectrum Disorder
& Developmental Disabilities**

Funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health Services (HHS) under the Healthy Weight Research Network (UT4MC41898).

Racial Ethnic Disparities in Obesity and Overweight Status among Boys with Autism Spectrum Disorder

Sandy Magaña, PhD, MSW, Misha Eliasziw, PhD, April
Bowling, MA, ScD, and Aviva Must, PhD

Method

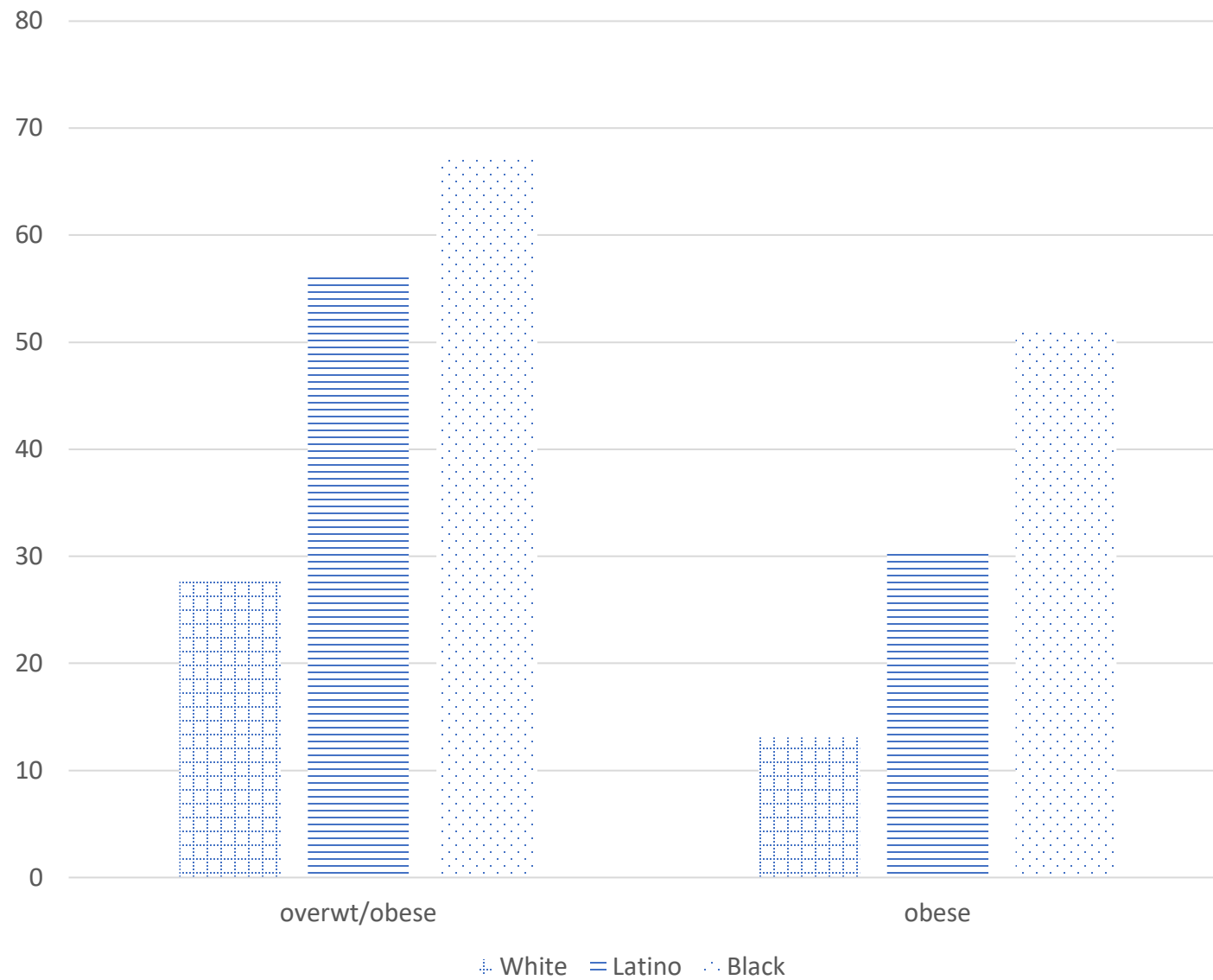
- Sample
 - Baseline data from the Adolescent Brain Cognitive Development (ABCD) Study
 - Multistage probability sample
 - Sampled children between the ages of 9 and 10
 - We selected only boys (due to small n of girls with ASD) and only those whose parent and son were of the same racial and ethnic category
 - Total n=273, 187 non-Latino White, 40 Latino and 46 non-Latino Black

Mean Comparisons



Ethnicity Race	Latino (n = 40)	Non-Latino White alone (n = 187)	Non-Latino Black alone (n = 46)	P-value
BMI	20.4 (1.1)	18.4 (0.5)	23.2 (1.1)	< 0.001
BMIz	1.03 (0.25)	0.45 (0.11)	1.31 (0.24)	0.003

Levels of overweight/obesity and obesity by racial/ethnic category



**PODER: Promoting
Obesity prevention
among Latinx children
with Developmental
disabilities and families
through Engaged
Research**

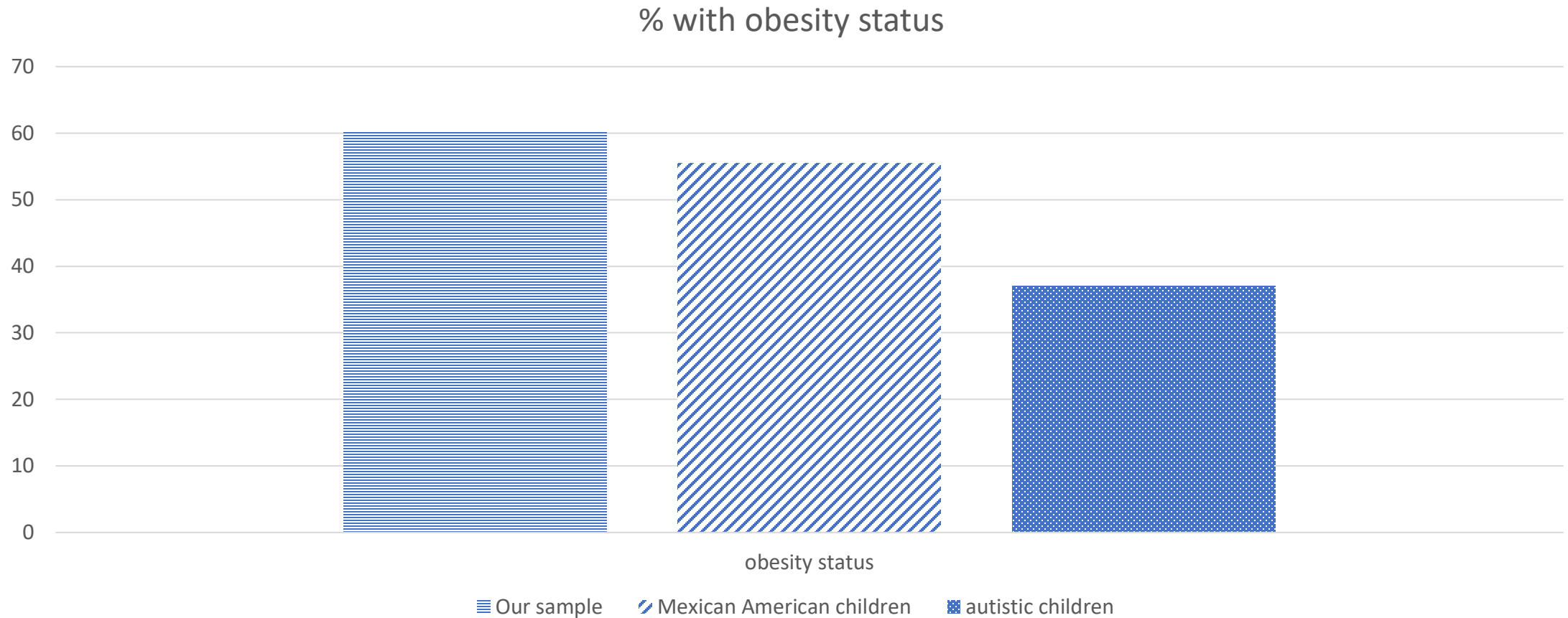
PIs: S. Magaña, Y. Suarez-Balcazar, M. Mirza, S.
Vanegas, D. Parra Medina, V. Errisuriz



PODER

*Funded by: Administration for Community Living (ACL),
National Institute on Disability, Independent Living,
and Rehabilitation Research (NIDILRR)
Grant #90DPHF0005-01-00.*

Rates of obesity in our sample compared to other groups



Parenting diet and physical activity strategies

- We found that
 - controlling parenting diet strategies was associated with lower body mass index (BMI) percentile—the opposite of what is in the literature
 - Monitoring parenting physical activity strategies was associated with higher levels of BMI percentile
- Findings may be related to children with IDD, Latino culture or a combination



The image features a white background with several abstract geometric elements. In the top left, there are two vertical yellow dashed lines. To their right is a solid blue circle. Further right is a green L-shaped line. In the top right corner, a yellow circle is partially visible. On the left side, there is a green square outline. In the bottom left, a yellow dashed line forms a curved path. A large orange semi-circle occupies the right half of the image, containing the text 'Culturally tailoring Interventions' in a black, sans-serif font.

Culturally tailoring
Interventions

To what extent are people of color underrepresented in autism intervention research?

- In a review of published autism intervention studies Steinbrenner and colleagues (2022), found that out of 1013 articles
 - Only 25% reported any data on race and ethnicity
 - There was slight increase in reporting overtime
 - In the studies that did report, 64.8% were White, 9.4 were Latino, 7.7% were Black and 6.5% were Asian

**Why are people
of color
underrepresented
in autism
intervention
research?**

Mistrust of Healthcare Providers and Researchers

Conducted in unfamiliar settings

Sites may be far away from BIPOC communities

Can't take time off work

May have other caregiving responsibilities

fast and reliable internet may be required

Non-English speakers often excluded

Not yet diagnosed

Cultural adaptations in mental health interventions

- Meta-analysis of cultural adaptations (Griner & Smith, 2006; Rathod et al., 2018) found
 - Moderate to large effects for culturally adapted interventions
 - Those conducted in clients' native language were twice as effective as those in English
 - Interventions tailored for specific groups were 4 times more effective than those provided to all groups



Cultural Adaptation Process

The process is iterative and updating the intervention is continual based on feedback

Circle diagram divided into 6 numbered wedges of different colors, each labeled with a step of the Cultural Adaptation Process.



Best Practices in Developing or Adapting Culturally Tailored Interventions

- Involve Stakeholders
- Consider using peer-based recruitment and delivery methods
- Create/adapt/translate materials for the specific group
 - Ensure content is relevant and salient to group
- Ensure accessibility and reduce effort and barriers
- Consider using the Ecological Validity Framework



PODER Familiar



PODER



What is the PODER Familiar Program?

PODER Familiar is designed to promote the health and wellbeing of mothers of children with IDD and their children.




Including 10-individual remote sessions



3 Multi-Family Gatherings





Pilot study under way now

- Developed using data from cross-sectional study and family input
- Pre- and post-evaluations conducted by grad students

After second pilot study- second iteration

- Revised based on pilot results and focus groups
 - Randomized control trial
- 

Questions?

Contact Sandy Magaña

smagana@austin.utexas.edu



blackfeathers.org



DR. CRYSTAL HERNANDEZ

Autism Mom, Advocate, & Ally
Cherokee Citizen & Latina
Tribal Disabilities Expert
Mental Health Administrator &
Psychologist

CHPSYD@GMAIL.COM



Break



Round Robin Updates



Susan A. Daniels, Ph.D.

Acting HHS National Autism Coordinator

Director, Office of Autism Research Coordination, NIMH

and Executive Secretary, IACC

Closing Remarks

Susan A. Daniels, Ph.D.

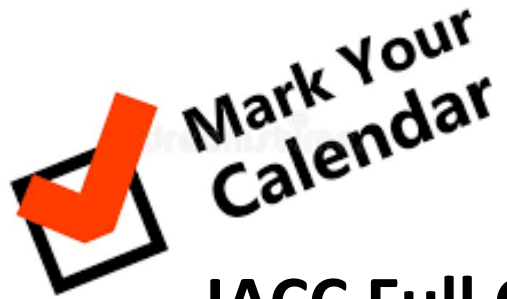
Acting HHS National Autism Coordinator
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

Shelli Avenevoli, Ph.D.

Deputy Director, NIMH



Next IACC Meeting



IACC Full Committee Meeting (virtual or hybrid)

October 11, 2023

Check the IACC Website for meeting information and updates.

<https://iacc.hhs.gov>

Thank you to the OARC Staff and Meeting Support Team!



Susan Daniels, Ph.D.
Acting National Autism
Coordinator, HHS
Director, OARC



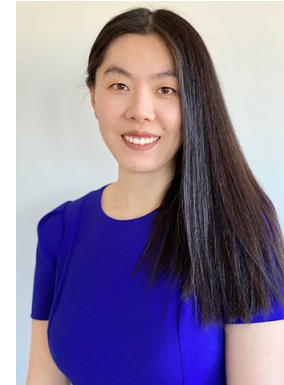
Oni Celestin, Ph.D.
Science Policy Analyst



Katrina Ferrara, Ph.D.
Science Policy Analyst



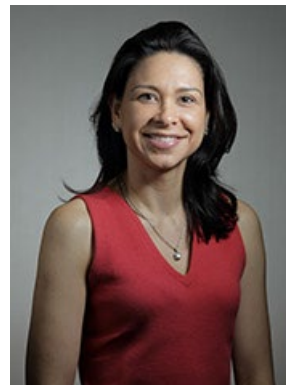
Steven Isaacson, B.A.
Policy Analyst



Tianlu Ma, Ph.D.
Science Policy Analyst



Rebecca Martin, M.P.H.
Public Health Analyst



Angelice Mitrakas, B.A.
Management Analyst



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Science Policy Analyst



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