Autism Developmental Disabilities Monitoring (ADDM) Network

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

- Describes population of children with ASD in communities in the U.S.
- Compares how common ASD is in different parts of the country.
- Provides information on age of identification.
- Identifies trends in ASD occurrence over time.
Autism and Developmental Disabilities Monitoring (ADDM) Network Sites, Surveillance Years 2018 and 2020

- Tracking Autism among 4- and 8-year-olds
- Tracking Autism among 4- and 8-year-olds AND Follow-up of 16-year-olds
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018
New Methods in SY2018
ADDM Ascertainment and ASD Case Definition

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

<table>
<thead>
<tr>
<th>ASD case definition</th>
<th>Suspected ASD case definition</th>
</tr>
</thead>
</table>
| 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 | *(4-year-old only)*  
Child does not meet criteria of full case definition but there is a qualified examiner’s diagnostic statement that the child is suspected of having ASD |
Previous Methods, 2000-2016
ADDM Ascertainment and ASD Case Definition

Community Partnerships are the Key

Step 1:
Sites identify places in the community that educate, diagnose, treat, or provide services to children with ASD.

Step 2:
Trained abstractors collect records of children with behaviors consistent with ASD.

Step 3:
Specialized clinicians review records to determine if the child meets the surveillance case criteria for ASD.

Step 4:
Scientists analyze information.

Step 5:
Findings return to the community to improve the care of children.
New Methods SY2018

Community Partnerships are the Key

**STEP 1:** Sites identify places in the community that educate, diagnose, treat, or provide services to children with ASD.

**STEP 2:** Trained abstractors review records and collect diagnostic/eligibility data.

**STEP 3:** Scientists analyze information.

**STEP 4:** Findings return to the community to improve the care of children.
Prevalence

\[
\text{Number of 8 year olds with ASD} \div \text{Total number of 8 year olds} = \text{PREVALENCE} \quad \text{as defined in this project}
\]
“What is the prevalence of ASD for 8-year-old children?”
ADDM findings

2.3% is the average percentage identified with ASD

1 in 44 8-year-old children were identified with ASD in the ADDM Network
ADDM Network

Estimated prevalence of ASD
Percentage of 8-year-old children identified with ASD by ADDM Network Site

OVERALL: 2.3%
Prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by identification type and site
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018

* Horizontal line is the overall Autism and Developmental Disabilities Monitoring Network prevalence of 23.0 per 1,000 children aged 8 years. Children with documented ASD statements could also have ASD classifications in special education or ASD ICD codes.
Boys were 4.2 times more likely to be identified with ASD than girls.
ADDM: Estimated prevalence by race and ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>21.2</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>22.3</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>22.5</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>22.2</td>
<td></td>
</tr>
</tbody>
</table>

**PREVALENCE OF ASD PER 1,000 CHILDREN**

- Male: 36.5
- Female: 8.8

- White: 21.2
- Black: 22.3
- Hispanic: 22.5
- Asian: 22.2
Among children identified with ASD who had intelligence quotient (IQ) scores available (59.5%)
Percent of children aged 8 years with autism spectrum disorder with co-occurring intellectual disability*, by sex and race/ethnicity

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

* IQ score ≤70 or examiner statement of intellectual disability in a comprehensive evaluation
Prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by median household income tertile and site†

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

* Dots are the point estimates and horizontal lines are the 95% confidence intervals.
† Cochran Armitage test of trend results for association between socioeconomic status tertile and ASD prevalence, by site and overall: Arizona (p<0.001), Arkansas (p = 0.17), California (p = 0.03), Georgia (p = 0.01), Maryland (p = 0.21), Minnesota (p = 0.01), Missouri (p = 0.21), New Jersey (p = 0.15), Tennessee (p = 0.02), Utah (p<0.001), and Wisconsin (p = 0.27); all sites (p<0.001).
What is the prevalence of ASD for 4-year-old children?
ADDM: Estimated prevalence per 1,000 children by type of ASD identification and site, 4-year-olds

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

1.7% is the average percentage identified with ASD

1 in 59 4-year-old children were identified with ASD in the ADDM Network
Age of Identification
ADDM: Median age at clinical diagnosis

50 months (4 years, 2 months)

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

Source: CDC, 2018
Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years

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

Cumulative incidence = Rate of identification over time

Cumulative incidence of ASD diagnosis or special education eligibility per 1,000 children
Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years, by site
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018
Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 years, by median household income tertile

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

Geographic area
» Cannot generalize to all of US
» Cannot generalize to any sub population

Small sample size
» Limits ability to detect real differences in sub populations
  • Race, ethnicity and linguistic background

Age of identification
» Includes 4- and 8-year-olds, not all age groups
Implications and Use of the Information

- Adult service system and shortage of providers
- Use data to inform policy
- Continue to work for early identification
- Eight year olds (in 2018) will be transition age soon
- More providers and behavioral supports for families
Misinterpretations of ADDM data:

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

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

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

4. We’re no longer seeing differences in prevalence by race/ethnicity
   1. Several states showed lower prevalence for Hispanic children
   2. Still seeing differences in proportion of Black children with co-occurring ID
For more information on ADDM national trends:
https://www.cdc.gov/ncbddd/autism/addm.html
Website

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

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MN-ADDM staff

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Susan Madden, Abstractor
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ICI Web Team
ICI Communications Team
QUESTIONS
International Collaboration for Diagnostic Evaluation of Autism (IDEA)
January 2022
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Cultural Diversity Career Advancement Program (C-CAP)

Purpose:

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

Audience:

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

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

### Trans-discipline model:
- Mentor works outside of the mentee’s field of focus

### Networking model:
- Less dependence on individual mentor

### Spot mentoring model:
- One-off spot meetings that are specific and focused

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Burgess et al., 2018
C-CAP survey results

- Students: 41%
- Researchers: 30%
- Faculty: 23%
- Other: 6%

$n = 79$
Areas of Interest Identified by Survey Respondents

- Identifying sources of research funding
- Developing international collaborations
- How to write a grant proposal
- Participant recruitment/community engagement
- Integrating research into a clinical/practice setting
- Identifying appropriate journals/manuscript preparation
- Developing research questions and protocols
C-CAP Activities

Develop a mentor training curriculum / resource site for mentoring

Develop tailored webinars for mentors and mentees

Match mentors with mentees

Hold networking meet and greet sessions year-round & at annual meeting
C-CAP at a Glance: Mentees and Mentors

• 28 mentees
  • Ecuador, India, Israel, Nepal, New Zealand, Pakistan, Qatar, Russia, Trinidad and Tobago, Turkey, and USA

• 18 mentors
  • Argentina, Belgium, India, Israel, Turkey, USA
Current Mentor Matching

- Areas of interest identified by mentees
- Geographical location
- Areas of expertise identified by mentors
C-CAP Activities to Date

- **May 2021**
  - Launch at INSAR

- **Sep. 2021**
  - Experiences in Mentoring

- **Jan. 2022**
  - Grant Writing Sessions

- **May 2022**
  - Meet and Greet INSAR
C-CAP Launch at INSAR 2021

• Keynote address: Dr. Vikram Patel (India)

• Speakers:
  • Drs. Waganesh Zeleke (Ethiopia)
  • Petrus De Vries (South Africa)
  • Alexia Rattazzi (Argentina)
  • Gauri Divan (India)
C-CAP Session on Mentoring
Measuring Success in C-CAP

- Increase number of ASD researchers from and in LMIC
- Increase number of researchers from underrepresented groups in HIC
- Increase number of global collaborations
How to Sign Up

Apply to be mentor/mentee here:
• https://www.autism-insar.org/page/CCAP

Email us with questions:
• culturaldiversitycommittee@autism-insar.org