



# Community testing practices for autism within the autism and developmental disabilities monitoring network

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## Abstract

**Background:** No data exist at the population level on what tests are used to aid in the diagnosis of autism spectrum disorder in community practice.

**Objectives:** To describe autism spectrum disorder testing practices to inform autism spectrum disorder identification efforts.

**Methods:** Data are from the Autism and Developmental Disabilities Monitoring Network, a multi-site surveillance system reporting prevalence estimates and characteristics of 8-year-old children with autism spectrum disorder. Percentages of children with autism spectrum disorder who received any autism spectrum disorder test or a 'gold standard' test were calculated by site, sex, race, median household income, and intellectual ability status. Risk ratios were calculated to compare group differences.

**Results:** Of 5058 8-year-old children with autism spectrum disorder across 11 sites, 3236 (64.0%) had a record of any autism spectrum disorder test and 2136 (42.2%) had a 'gold standard' ADOS or ADI-R test. Overall, 115 children (2.3%) had both the ADOS and ADI-R in their records. Differences persisted across race, median household income, and intellectual ability status. Asian/Pacific Islander children had the highest percent receiving any ASD test (71.8%; other groups range: 57.4–66.0%) and White children had the highest percent receiving 'gold standard' tests (46.4%; other groups range: 35.6–43.2%). Children in low-income neighbourhoods had a lower percent of any test (62.5%) and 'gold standard' tests (39.4%) compared to medium (70.2% and 47.5%, respectively) and high (69.6% and 46.8%, respectively) income neighbourhoods. Children with intellectual disability had a lower percent of any ASD test (81.7%) and 'gold standard' tests (52.6%) compared to children without intellectual disability (84.0% and 57.6%, respectively).

**Conclusions:** Autism spectrum disorder testing practices vary widely by site and differ by race and presence of co-occurring intellectual disability, suggesting opportunities to standardise and/or improve autism spectrum disorder identification practices.

## KEYWORDS

ADI-R, ADOS, autism spectrum disorder, diagnosis, gold standard, public health surveillance

## 1 | BACKGROUND

Autism spectrum disorder (ASD) is characterised by impairments in social communication and restricted or repetitive behaviours.<sup>1</sup> Diagnosis is based on evaluating a child's behaviour and development. No definitive diagnostic test or biomarker exists, but the 'gold standard' in ASD diagnosis is considered to be an evaluation by a multidisciplinary clinical team and is often, but not always, supported by an ASD test.<sup>2</sup> The Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R) are tests with high sensitivity and specificity<sup>3,4</sup> and, when used together, can increase diagnostic validity and reliability.<sup>5,6</sup> These tests themselves have been referenced in research and promotional materials as 'gold standard' ASD tests.<sup>7-11</sup> Information about ASD test use in community practice is lacking. This report aims to describe ASD testing practices to inform ASD identification efforts.

## 2 | METHODS

### 2.1 | Study design and sample

Data are from the Autism and Developmental Disabilities Monitoring (ADDM) Network, a multi-site surveillance system reporting prevalence estimates and characteristics of 8-year-old children with ASD. Children were identified with ASD if they resided in the surveillance area in 2018 and had a written diagnostic statement from a qualified professional, autism special education classification, or ASD International Classification of Diseases (ICD) code in health or education records.<sup>12</sup> All ADDM Network sites had access to records for medical service providers that evaluate children with developmental disabilities; Missouri and Wisconsin were the only two sites that did not have complete access to education records.<sup>12</sup>

### 2.2 | Sociodemographic variables

Race was categorised as White, Black, Hispanic, Asian/Pacific Islander (A/PI), American Indian/Alaskan Native (AI/AN), Multiracial, and Unknown. Sex was categorised as male and female. Median household income (MHI) was categorised as population weighted census-tract level tertiles. Intellectual disability (ID) was based on intelligence quotient (IQ) which included a score  $\leq 70$  or a qualified professional's statement of ID on the child's most recent IQ test.

'Gold standard' tests were defined as the ADOS and ADI-R based on alignment with clinical diagnoses in ASD research<sup>3,4</sup> and the similar levels of accuracy to the current diagnostic 'gold standard' that requires a multi-disciplinary team.<sup>5,6</sup> Additional tests include the Autism Spectrum Rating Scales (ASRS), Childhood Autism Rating Scale (CARS), Gilliam Autism Rating Scale (GARS),

### Synopsis

#### Study question

How many children diagnosed with autism spectrum disorder have autism spectrum disorder tests in their health or education records?

#### What is already known

Diagnosing autism spectrum disorder is based on evaluating a child's behaviour and development. There is no definitive diagnostic test or biomarker to diagnose autism spectrum disorder, but diagnosis can be supported by an autism spectrum disorder test.

#### What this study adds

Information on autism spectrum disorder testing practices to standardise and improve autism spectrum disorder identification to ensure all children with autism spectrum disorder are identified and receive the services and support they need.

Social Responsiveness Scale (SRS), and Other (Asperger Syndrome Diagnostic Scale (ASDS), Gilliam Asperger's Disorder Scale (GADS), and Krug Asperger's Disorder Index (KADI)). All test versions were collapsed into a single category.

### 2.3 | Statistical analysis

Percentages of children with ASD who received any ASD test or a 'gold standard' test were calculated by site, sex, race, MHI, and ID status. Risk ratios (RR) were used to compare group differences by calculating the ratio of the number of tests received by one group divided by the total number of members in that group to the number of tests received by a second group divided by the total number of members in that second group. AI/AN ( $n=39$ ), multiracial ( $n=209$ ), unknown race ( $n=49$ ), and unknown sex ( $n=2$ ) were excluded from stratified statistical analyses. R version 4.3.1 (R Foundation) was used for all analyses.

### 2.4 | Ethics approval

All sites functioned as public health authorities under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local institutional review board, privacy, and confidentiality requirements under 45 CFR 46.<sup>13</sup>

**TABLE 1** Percent of children with autism spectrum disorder who have recorded autism spectrum disorder tests by site and selected characteristics – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018.

Site/Characteristic	Children with ASD		
	No.	With	With
		Any ASD Test	ADOS or ADI-R
No. (%)	No. (%)	No. (%)	
<b>Site</b>			
Arizona	331	299 (90.3)	158 (47.7)
Arkansas	353	255 (72.2)	199 (56.4)
California	586	515 (87.9)	294 (50.2)
Georgia	514	350 (68.1)	168 (32.7)
Maryland	423	206 (48.7)	188 (44.4)
Minnesota	277	240 (86.6)	219 (79.1)
Missouri	405	298 (73.6)	198 (48.9)
New Jersey	491	116 (23.6)	70 (14.3)
Tennessee	573	388 (67.7)	281 (49.0)
Utah	548	270 (49.3)	166 (30.3)
Wisconsin	557	299 (53.7)	195 (35.0)
Total	5058	3236 (64.0)	2136 (42.2)
<b>Sex<sup>a</sup></b>			
Male	4111	2651 (64.5)	1743 (42.4)
Female	945	584 (61.8)	392 (41.5)
<b>Race/Ethnicity</b>			
White	2407	1573 (65.3)	1116 (46.4)
Black	1041	598 (57.4)	371 (35.6)
Hispanic	1019	673 (66.0)	399 (39.2)
Asian/Pacific Islander	294	211 (71.8)	127 (43.2)
Multiracial	209	133 (63.6)	94 (45.0)
American Indian/ Alaskan Native	39	24 (61.5)	16 (41.0)
Unknown	49	24 (49.0)	13 (26.5)
<b>Median household income tertile</b>			
Low	1723	1076 (62.5)	678 (39.3)
Medium	1713	1203 (70.2)	813 (47.5)
High	1356	944 (69.6)	635 (46.8)
<b>Co-occurring intellectual disability</b>			
No intellectual disability	1948	1636 (84.0)	1122 (57.6)
Intellectual disability	1059	865 (81.7)	557 (52.6)
Unknown	2051	735 (35.8)	457 (22.3)

Abbreviations: ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule; ASD, autism spectrum disorder.

<sup>a</sup>Excludes 2 children of unknown sex.

### 3 | RESULTS

Of 5058 total 8-year-old children with ASD, 3236 (64.0%) had a record of any ASD test and 2136 (42.2%) had a 'gold standard' test (Table 1). The percentage of children with any ASD test ranged from

23.6% (New Jersey) to 90.3% (Arizona); percentages of 'gold standard' tests ranged from 14.3% (New Jersey) to 79.1% (Minnesota). The ADOS was the most common test at eight sites, while the ASRS was most common in three. New Jersey had the highest ADI-R use (9.4%; Figure 1). Overall, 115 children (2.3%) had both the ADOS and ADI-R in their records. In addition, the percent of ADOS tests that used the most recent version (the ADOS-2) ranged from 57.3% in Tennessee to 95.5% in Missouri (Table S1).

Some differences in race were observed. A/PI children had the highest percent receiving any ASD test at 71.8%. White and Black children received fewer ASD tests than A/PI children (65.3%, RR 0.91, 95% confidence interval (CI) 0.84, 0.98 and 57.4%, RR 0.80, 95% CI (0.73, 0.87), respectively, Table 2), though White children received more ASD tests than Black children (RR 1.14, 95% CI 1.07, 1.21) and Black children received fewer ASD tests than Hispanic (66.0%) children (RR 0.87, 95% CI 0.81, 0.93). White children had the highest percent receiving 'gold standard' tests at 46.6%. White children received more 'gold standard' tests than Black (35.6%, RR 1.30, 95% CI 1.19, 1.43) and Hispanic (39.2%, RR 1.18, 95% CI 1.08, 1.29) children. Black children received fewer 'gold standard' tests than A/PI children (43.2%, RR 0.83, 95% CI 0.71, 0.96).

Children in low MHI neighbourhoods had a lower percent of any test (62.5%) and 'gold standard' tests (39.4%) compared to medium (70.2%, RR 0.89, 95% CI 0.85, 0.93 and 47.5%, RR 0.83, 95% CI 0.77, 0.90, respectively) and high (69.6%, RR 0.90, 95% CI 0.85, 0.94 and 46.8%, RR 0.84, 95% CI 0.77, 0.91, respectively) MHIs. Most sites followed the overall pattern of differences in the percentage of any ASD test and 'gold standard' tests for race (Table S2) and MHI (Table S3). No sex differences were observed.

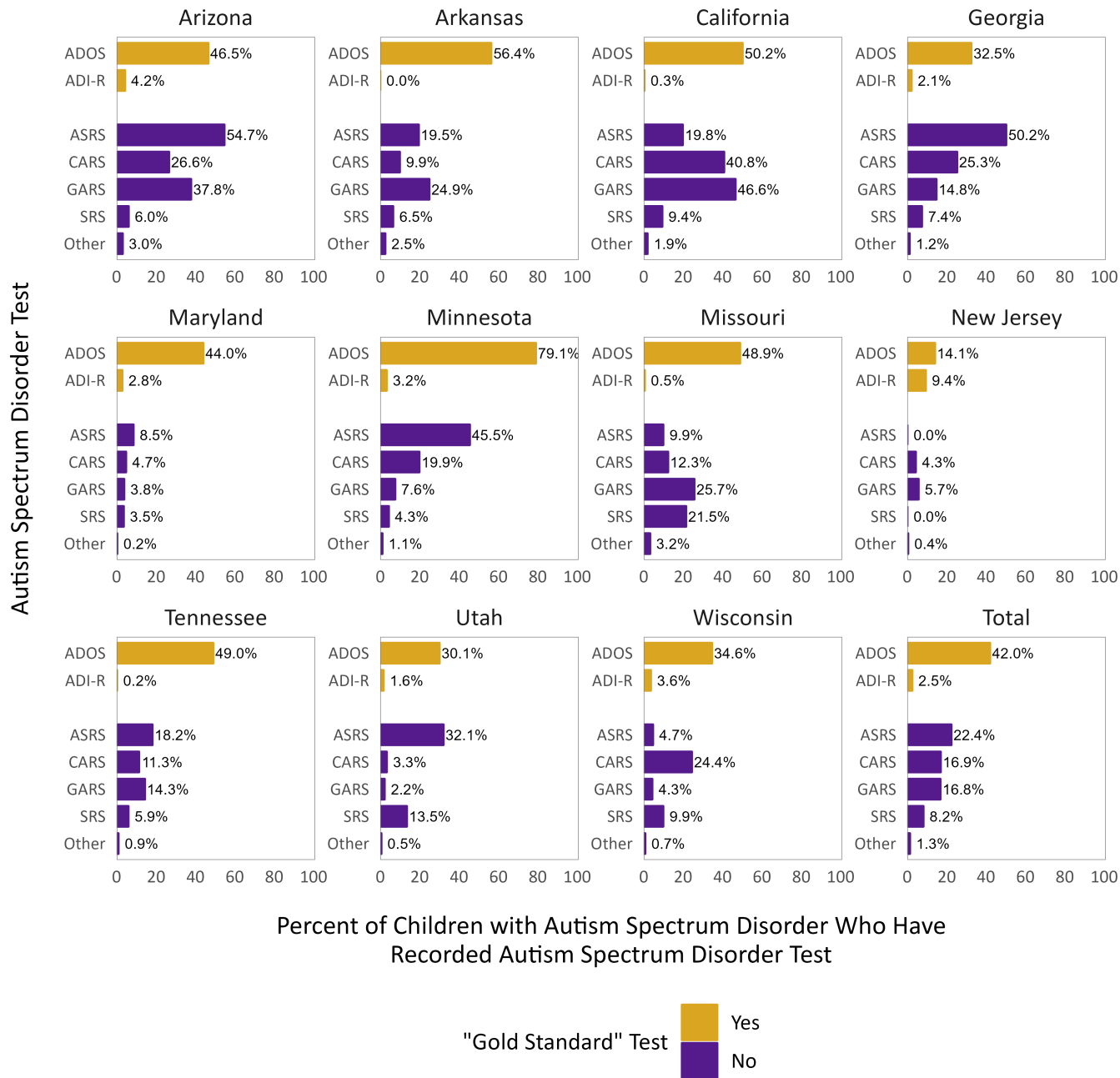
Children without ID had a higher percentage of 'gold standard' tests (57.6%) compared to children with ID (52.6%, RR 1.10, 95% CI 1.02, 1.17). Additionally, of those children who had an ADOS test in their records, 86.4% of those who had no ID received the most recent version of the ADOS (the ADOS-2) compared to 76.1% of children with ID (Table S1). Approximately 92% of children had detailed IQ data that allowed for intellectual ability level classification. Children with moderate ID (IQ < 50) had a similar percentage of 'gold standard' tests at 56.5% compared to 57.6% of children with no ID (IQ > 70), while those with mild ID (IQ 50–70) had a lower percent at 52.3% (Figure S1).

There were also differences in 'gold standard' tests by ASD identification location; of children whose ASD was identified at school only, 24.8% had a 'gold standard' test in their records compared to 39.5% identified at a clinical source only and 51.4% identified at both school and clinical sources (Figure S2).

## 4 | COMMENT

### 4.1 | Principal findings

Variability observed across communities could indicate differences in practices, resources, and/or state requirements. Less than half of children meeting the ADDM ASD case definition received a 'gold standard' test, presenting uncertainty about the generalizability of research



**FIGURE 1** Percent of children with autism spectrum disorder who have recorded autism spectrum disorder test by site – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018. ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule; ASD, autism spectrum disorder; ASRS, Autism Spectrum Rating Scales; CARS, Childhood Autism Rating Scale; GARS, Gilliam Autism Rating Scale; Other, Asperger Syndrome Diagnostic Scale, Gilliam Asperger's Disorder Scale, and Krug Asperger's Disorder Index; SRS, Social Responsiveness Scale.

requiring 'gold standard' tests to the population identified with ASD.<sup>14</sup> Lack of standardised ASD diagnostic practices could contribute to inequities in receiving services that require a diagnosis.

#### 4.2 | Strengths of the study

This is the first study to report on the use of ASD tests in community practice. Additionally, the study uses a large sample size ( $n=5058$ ) across 11 sites in the United States.

#### 4.3 | Limitations of the data

This analysis includes children within ADDM study areas with recorded ASD diagnostic statements, special education classification, or ICD codes; findings are not necessarily generalizable to other groups. ADDM abstracted ASD test information from health and education records, but results are dependent on the completeness and quality of data in those records. We were unable to examine whether tests were administered in combination at the same evaluation. Furthermore, ID was defined using ADDM's

**TABLE 2** Risk ratios of pairwise comparisons for children with autism spectrum disorder having a recorded autism spectrum disorder tests by selected characteristics – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018.

Comparison	Children with ASD	
	With any ASD test	With ADOS or ADI-R
	RR (95% CI)	RR (95% CI)
<b>Sex<sup>a</sup></b>		
Male to Female	0.96 (0.91, 1.01)	0.98 (0.90, 1.06)
<b>Race/Ethnicity<sup>b</sup></b>		
White to Black	1.14 (1.07, 1.21)	1.30 (1.19, 1.43)
White to Hispanic	0.99 (0.94, 1.04)	1.18 (1.08, 1.29)
White to Asian/Pacific Islander	0.91 (0.84, 0.98)	1.07 (0.94, 1.23)
Black to Hispanic	0.87 (0.81, 0.93)	0.91 (0.81, 1.02)
Black to Asian/Pacific Islander	0.80 (0.73, 0.87)	0.83 (0.71, 0.96)
Asian/Pacific Islander to Hispanic	1.09 (1.00, 1.18)	1.10 (0.95, 1.28)
<b>Median household income tertile</b>		
Low to medium	0.89 (0.85, 0.93)	0.83 (0.77, 0.90)
Low to high	0.90 (0.85, 0.94)	0.84 (0.77, 0.91)
Medium to high	1.01 (0.96, 1.06)	1.01 (0.94, 1.09)
<b>Co-occurring intellectual disability</b>		
No intellectual disability to intellectual disability	1.03 (0.99, 1.06)	1.10 (1.02, 1.17)
No intellectual disability to unknown	2.34 (2.20, 2.49)	2.58 (2.36, 2.83)
Intellectual disability to unknown	2.28 (2.14, 2.43)	2.36 (2.14, 2.61)

Abbreviations: 95% CI, 95% confidence interval; ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule; ASD, autism spectrum disorder; RR, risk ratio.

<sup>a</sup>Excludes 2 children of unknown sex.

<sup>b</sup>Children of American Indian/Alaskan Native, multiracial, or unknown race excluded from statistical analysis due to small numbers or missing data.

surveillance case definition using only IQ rather than a clinical definition of ID that includes IQ and adaptive behaviour; however, previous analyses using ADDM data showed the inclusion of adaptive behaviour did not change overall findings.<sup>15</sup>

#### 4.4 | Interpretation

While no sex differences were observed, a higher percentage of White children received 'gold standard' tests than Black or Hispanic children.

Although ADOS results have not shown a race or sex bias,<sup>16</sup> there was an apparent racial disparity in who received tests in these communities. Additionally, children with ID and ASD had fewer of any ASD tests and 'gold standard' tests compared to children without ID. This could reflect preference for other ASD assessment methods for children with ID. It could also reflect racial and socio-economic disparities limiting access to testing; Black children and children in lower-MHI neighbourhoods with ASD received fewer tests but are more likely to have ID.<sup>15</sup> Furthermore, children in lower MHI neighbourhoods were less likely to receive tests despite having a higher prevalence of ASD in recent reports.<sup>12,17</sup>

## 5 | CONCLUSIONS

These data show that ASD testing practices vary widely by site and differ by race and presence of co-occurring ID, suggesting opportunities to standardise and/or improve ASD identification to ensure all children with ASD are identified and receive the services and support they need.

### AUTHOR CONTRIBUTIONS

Conceptualization: Shaw and Robinson Williams. Data curation: Shaw, Maenner, Zahorodny, DiRienzo, Grzybowski, Hall-Lande, Pas, Bakian, Lopez, Patrick and Shenouda. Formal analysis: Robinson Williams. Investigation: Robinson Williams. Methodology: Robinson Williams and Shaw. Supervision: Shaw. Validation: Amoakohene. Visualization: Robinson Williams. Writing—original draft: Robinson Williams. Writing—review and editing: Shaw, Maenner, Zahorodny, DiRienzo, Grzybowski, Hall-Lande, Pas, Bakian, Lopez, Patrick and Shenouda.

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### CONFLICT OF INTEREST STATEMENT

The authors report no conflicts of interest with respect to the research, authorship, and/or publication of this article.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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