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SHORT REPORT

Prevalence of autism spectrum disorder in a large, diverse metropolitan area: Variation by sociodemographic factors

Josephine Shenouda[1,2] | Emily Barrett[1,3] | Amy L. Davidow[4] | William Halperin[1] | Vincent M. B. Silenzio[5] | Walter Zahorodny[2]

[1]Department of Biostatistics and Epidemiology, Rutgers – School of Public Health, Piscataway, New Jersey, USA
[2]Department of Pediatrics, Rutgers – New Jersey Medical School, Newark, New Jersey, USA
[3]Environmental and Occupational Health Sciences Institute, Rutgers School of Public Health, Piscataway, New Jersey, USA
[4]Department of Biostatistics, New York University School of Global Public Health, New York, NY, USA
[5]Department of Urban-Global Public Health, Rutgers School of Public Health, Piscataway, New Jersey, USA

Correspondence
Josephine Shenouda, 185 South Orange Ave F-511, Newark, NJ 07103, USA.
Email: shenoujo@njms.rutgers.edu

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Abstract
Autism spectrum disorder (ASD) prevalence estimates have varied by region. In this study, ASD prevalence, based on active case finding from multiple sources, was determined at the county and school district levels in the New Jersey metropolitan area. Among children born in 2008, residing in a four-county area and enrolled in public school in 2016, ASD prevalence was estimated to be 36 per 1000, but was significantly higher in one region—54 per 1000 and greater than 70 per 1000, in multiple school districts. Significant variation in ASD prevalence by race/ethnicity, socioeconomic status (SES), and school district size was identified. Highest prevalence was in mid-SES communities, contrary to expectation. Prevalence among Hispanic children was lower than expected, indicating a disparity in identification. Comprehensive surveillance should provide estimates at the county and town levels to appreciate ASD trends, identify disparities in detection or treatment, and explore factors influencing change in prevalence.

Lay Summary: We found autism prevalence to be 3.6% in New Jersey overall, but higher in one region (5.4%) and in multiple areas approaching 7.0%. We identified significant variation in autism spectrum disorder (ASD) prevalence by race/ethnicity, socioeconomic status (SES) and school district size. Mapping prevalence in smaller, well-specified, regions may be useful to better understand the true scope of ASD, disparities in ASD detection and the factors impacting ASD prevalence estimation.

KEYWORDS
ASD, autism, epidemiology, prevalence

BACKGROUND

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by social communication impairments in combination with restricted interests and/or repetitive behaviors (American Psychiatric Association, 2013). The most recent reports suggest autism prevalence affects approximately 2% of United States (US) children and indicates that ASD prevalence has increased 200% since 2000 (ADDM-CDC, 2007a, 2007b; Fombonne, 2018; Maenner et al., 2020), making ASD one of the most common childhood developmental disorders (Van Naarden Braun et al., 2015).

In the United States, ASD prevalence has been estimated by three different systems: the National Survey of Children's Health (NSCH), the National Health Interview Survey (NHIS), and the Autism and Developmental Disabilities Monitoring (ADDM) network. NSCH and NHIS provide national estimates based on parent report. The ADDM Network tracks ASD through an active, biannual, population-based multistate US surveillance system (Kogan et al., 2018; Rice et al., 2007; Zablotsky et al., 2015). One of the advantages of ADDM Network surveillance is the ability to identify undiagnosed ASD cases, compared to NSCH and NHIS systems. Since 2000, ADDM Network ASD prevalence estimates have risen three-fold—from 6.7 per 1000 (95% CI: 6.3–7.0) in

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2000, to 18.5 per 1000 (95% CI: 18.0–19.1) in 2016 (ADDM-CDC, 2007b; Maenner et al., 2020). Differences in ASD prevalence across US sites have been noted consistently (ADDM-CDC, 2007a, 2007b, 2009, 2012; Baio et al., 2018; Maenner et al., 2020), but not investigated.

The sex ratio estimate is one of the most consistent epidemiologic findings on ASD. Across multiple epidemiological investigations, a 4:1 (male/female) sex ratio is disclosed (ADDM-CDC, 2007a, 2009; Baio, 2012; Baio et al., 2018). Regarding the distribution of ASD by race/ethnicity, the most recent ADDM report indicated that prevalence estimates might be equalizing across race and ethnicity, though disparities remain (ADDM-CDC, 2007a, 2007b; Baio et al., 2018; Maenner et al., 2020). While multiple studies reported a positive association between SES and ASD prevalence, between 2000 and 2010 (Durkin & Yeargin-Allsopp, 2018; Durkin et al., 2010; Nevison & Parker, 2020; Thomas et al.,) Recent studies suggest that the association may be shifting (Nevison & Parker, 2020; Winter et al., 2020).

The distribution of factors contributing to ASD prevalence variation locally has been examined utilizing available (federal and state) administrative data by multiple studies (Maenner & Durkin, 2010; Mandell et al., 2010; Mandell & Palmer, 2005; Palmer et al., 2010; Shattuck, 2006). However, ASD prevalence estimates derived from administrative data often underestimate ASD prevalence and/or provide information reflecting only some sectors of the total population. For example, it has been shown that reliance on (autism) special education classification underestimates ASD prevalence (Baio et al., 2018). For example, across ADDM sites, autism special education classification ranges from 36.5% to 75% (Baio et al., 2018). More local or granular analyses of ASD prevalence information established by active surveillance may inform the understanding of ASD patterns overall and are likely to inform the allocation of resources to individuals with ASD. Additionally, understanding local variations in autism prevalence allows us to consider and control for multiple factors that are often cited as sources of variations in ASD prevalence estimates, including different methodologies, different regional policies and to some extent level of awareness and access to services (Broder-Fingert et al., 2018; Fombonne, 2018). Furthermore, data from epicenters of ASD may lead to understanding future trends in ASD prevalence and/or lead to innovative strategies for addressing the increase in ASD prevalence estimates.

This study determined ASD prevalence in a diverse and populous US region in New Jersey at the county and school district level and examined ASD prevalence variation in relation to sex, race, socioeconomic status (SES) and school district size. The main objectives were to: (1) describe variation in ASD prevalence in New Jersey using population-based data from an active ASD surveillance system and (2) examine sociodemographic factors related to ASD prevalence.

METHODS

Study design

Cross-sectional data from active, multiple source, (ADDM Network) ASD monitoring of 8-year-old, born in 2008 and residing in the New Jersey surveillance region in 2016, was utilized. Data were from population-based surveillance for ASD, developed by the CDC–National Center on Birth Defects and Developmental Disabilities (NCBDDD). Surveillance was conducted in Essex, Hudson, Ocean, and Union counties, a region consisting of 76 populous and diverse urban and suburban school districts (Supplemental Figure 1). Two districts did not participate and data from these districts were excluded. The counties differed in their race, SES, and district size profiles (Table 1).

The ADDM methodology has been extensively described elsewhere, but briefly it is an active surveillance method, using a two-phase approach to ASD ascertainment, using standard case identification procedures and standard DSM-specified ASD criteria (ADDM-CDC, 2007a, 2007b, 2012; Avchen et al., 2011; Baio, 2012; Baio et al., 2018; Christensen et al., 2016; Maenner et al., 2020). In phase 1, records from hospital-based developmental centers and special education records were reviewed for all children meeting age (born in 2008) and residency criteria, in 2016. Complete records of children showing one or more specific, predetermined, ASD indicators in professional evaluations conducted for educational services or clinical diagnosis or care, were comprehensively abstracted. Information contained in professional evaluations by community providers (e.g., psychologists, MD developmental specialists, speech and language pathologists, social workers, occupational, and physical therapists) was reviewed by trained researchers. ASD indicators included ASD diagnosis, autism special education classification information and/or documented indication of one or more specific ASD-associated behaviors such as “poor, variable or no eye contact,” “inability to form peer relationships,” and “preference for solo play,” among others. Information from comprehensive evaluations was compiled into a deidentified, chronological record, from birth to age eight, for each individual child.

In phase 2, clinician reviewers satisfying specialized CDC training and reliability criteria, used standardized scoring and case definition procedures to confirm ASD cases. The ASD case definition was satisfied if (1) behaviors documented in abstracted professional evaluations met the DSM-5 criteria as specified by the surveillance case definition and/or (2) if abstracted information disclosed an ASD diagnosis by age 8-years.

Assessment of ASD prevalence

Records of 5453 (8-year-old) children were reviewed. Information from 2520 children was abstracted,

TABLE 1 Distribution of sex, race/ethnicity, socioeconomic status, and school district size (overall and by county) in the surveillance region for 8-year old children in 2016

	NJAS surveillance region		Distribution of demographic and ecological factors by county								
			Essex		Hudson		Ocean		Union		*p*-value
Category	Pop.	%	Pop.	%	Pop.	%	Pop.	%	Pop.	%	
Sex											0.35
Female	12,837	49.2	4163	48.5	2959	49.9	2304	48.9	3412	49.7	
Male	13,246	50.8	4413	51.5	2974	50.1	2403	51.1	3456	50.3	
Race/ethnicity											<0.001
White, non-Hispanic	8835	33.9	2292	26.7	1045	17.6	3209	68.2	2289	33.3	
Black, non-Hispanic	5317	20.4	3053	35.6	697	11.7	218	4.6	1350	19.7	
Hispanic	9860	37.8	2520	29.4	3568	60.1	1042	22.1	2731	39.8	
SES											<0.001
Low (<$45,000)	8482	32.5	4405	51.4	933	15.7	969	20.6	2175	31.7	
Mid ($45,000–$100,000)	12,811	49.1	1718	20.0	4851	81.8	3735	79.3	2507	36.5	
High (>$100,000)	4809	18.4	2459	28.7	150	2.5	–	–	2191	31.9	
School district size											<0.001
Small (<250 students)	4357	16.7	699	8.2	691	11.6	1427	30.3	1540	22.4	
Medium (250–999 students)	13,918	53.4	5153	60.1	3162	53.3	2210	47.0	3393	49.4	
Large (>999 students)	7810	29.9	2724	31.8	2080	35.1	1070	22.7	1936	28.2	
Total	26,083		8576		5932		4707		6868		

Note: SES is based on U.S Census 2016 American Community Survey Median Household Income by County Subdivision equivalent to school districts. *p*-value for differences between counties.

Abbreviations: NJAS, New Jersey autism study; Pop, population based on NJ Department of Education public school enrollment data for 2016–2017 school year; SES, socioeconomic status.

consequent to a documented (ASD) indicator, in one or more professional evaluation. One thousand and thirty-six children satisfied the surveillance ASD case definition. Ninety-four confirmed ASD cases did not attend a public school in 2016 and were excluded from analysis, yielding 942 ASD children enrolled in public school. The study denominator—26,083 individuals included all 8-year-olds attending public school in the surveillance counties, in 2016 (NJ Department of Education, 2017). ASD prevalence was estimated at the district and county levels.

Estimates were based on population denominators obtained from New Jersey Department of Education (NJ DOE) public school enrollment data (26,083 8-year-old children) (NJ Department of Education, 2017). Population denominators obtained from the National Center for Health Statistics (NCHS) vintage 2018 postcensal estimates for the surveillance region were obtained at the county level to estimate the number of 8-year-old children not enrolled in public school (33,031 8-year-old children) (National Center for Health Statistics 2018). We estimate that 6948 (21%) children of the birth cohort were not enrolled in a public school in 2016. Since NCHS does not provide district level population estimates, public school enrollment information, was used to estimate the denominator on behalf of ASD prevalence determination at the district and county level.

Demographic and ecological variables

Data reflecting demographic and ecological factors potentially related to ASD prevalence, including sex and race/ethnicity were abstracted. Race was categorized as White (Non-Hispanic), Black (Non-Hispanic), and Hispanic. Race and ethnicity information was obtained from medical and educational sources and supplemented with information from birth certificates when source data on race and ethnicity was missing. Ecological factors assessed included: SES and school district size. SES by county was determined by averaging median household income (MHI) across the school districts within each county. MHI was defined at the district level, based on 2016 intercensal 5-year estimates and served as the proxy for SES. MHI estimates ranged from $33,025 to $190,625, with a median of $73,596 (SD: $35,171) among districts. SES was categorized as low SES (MHI < $45,000), mid SES (MHI $45,000–$100,000), and high SES (MHI > $100,000) (US Census, 2016).

District size was defined as small (<250), medium (250 to 999), or large (>999), according to the number of 8-year-olds in the district. District size categorization was based on enrollment data from the National Center for Education (NCES) (Gray et al., 2013).

Data analysis

Prevalence estimates were based on the number of confirmed ASD cases in public school, identified by surveillance, divided by the total population of public school enrolled 8-year-old children. Wilson score method was used to calculate 95% confidence intervals for prevalence estimates and prevalence ratios (PRs). Pearson chi-square and Fisher exact tests were used to compare distributions across counties. Prevalence rate ratios and 95% confidence intervals at the county level and overall surveillance region were assessed by sex (reference: female), race/ethnicity, SES (reference: low SES), and school district size (reference: small district size). Sociodemographic analysis at the school district level was not included due to small sample sizes.

This study was approved by the Institutional Review Board (IRB) of Rutgers University—New Jersey Medical School and ASD surveillance was conducted under waiver of informed consent, consistent with public health investigation standards.

RESULTS

Description and characteristics of the surveillance region

The surveillance region was densely populated, entirely urban and suburban, racially and ethnically diverse, with White (Non-Hispanic), Black (Non-Hispanic), and Hispanic children comprising 33.9%, 20.4%, and 37.8% of the population, respectively (Table 1). The distribution of race/ethnicity, SES, and school district size varied across the four counties ($p < 0.001$) (Table 1).

Table 2 describes the characteristics of children identified with ASD at the county level. Overall, 767 children (81.4%) were diagnosed with ASD by a community provider such as a Developmental Pediatrician or a Pediatric Neurologist, and 175 children (18.6%) did not have an ASD diagnosis but met the surveillance case definition for ASD. ASD diagnosis by a community provider was highest in Hudson County (90.1%) and lowest in Union County (73.8%) ($p = 0.0003$).

In general, while most children identified with ASD received special education services through their local public school system in 2016 (94.1%), only 40.7% (n = 485) of children with ASD were educated under the Autism (special education) classification and special education classification varied by county. Hudson County had the highest Autism classification (66.9%) and Ocean County had the lowest classification (35.7%) ($p < 0.0001$). Among children with ASD with documented intelligence quotient (IQ) data, 74.8% (n = 541) children did not have IQ in the intellectual disability range. Intellectual ability also differed by county. In Ocean County, 88.4% of children with IQ data had IQ scores above 70, while in Essex County 69.4% had IQ scores above 70 ($p < 0.0001$).

ASD prevalence comparisons at the county level

Overall, ASD prevalence was 36 per 1000 (95% CI: 34–38) in the combined four-county surveillance region (Table 2). ASD prevalence estimates varied by county, sex, race/ethnicity, SES, and school district size. ASD prevalence estimates for Hudson County were lowest and highest in Ocean County (Table 3). Across the region, ASD prevalence was consistently (4.0–4.8 times) higher

TABLE 2 Characteristics (overall and by county) in the surveillance region for 8-year old children in 2016

			Distribution of demographic and ecological factors by county								
	NJAS surveillance region		Essex		Hudson		Ocean		Union		p-value
Category	Pop.	%	Pop.	%	Pop.	%	Pop.	%	Pop.	%	
ASD community classification											
ASD diagnosis	767	81.4	230	79.9	163	90.1	211	83.7	163	73.8	0.0003
Autism special education classification	485	40.7	184	63.9	121	66.9	90	35.7	90	40.7	<0.0001
ASD diagnosis and autism classification	478	40.7	177	61.5	121	66.9	90	35.7	90	40.7	<0.0001
Special education											
Receiving school services	886	94.1	279	96.9	177	97.8	226	89.7	204	92.3	0.0004
Intellectual ability (n = 736)											<0.0001
IQ ≤ 70	182	25.2	64	30.6	53	36.3	23	11.6	42	24.7	
IQ > 70	541	74.8	145	69.4	93	63.7	175	88.4	128	75.3	
Number with IQ data	723	76.8	209	72.6	146	80.7	198	78.6	170	77.0	0.18

Note: p-value for differences between counties.
Abbreviations: ASD, autism spectrum disorder; IQ, intelligence quotient; NJAS, New Jersey autism study.

TABLE 3 Autism spectrum disorder prevalence at the county level in New Jersey among 8-year old children (overall and by sex, race/ethnicity, socioeconomic status, and school district size) in 2016

Region	NJAS surveillance region		ASD prevalence per 1000 children by county								
			Essex county		Hudson county		Ocean county		Union county		*p*-value
Category	ASD cases	Prevalence (95% CI)	ASD cases	Prevalence (95% CI)	ASD cases	Prevalence (95% CI)	ASD cases	Prevalence (95% CI)	ASD cases	Prevalence (95% CI)	
Sex											
Female	180	14 (12–16)	53	13 (10–17)	37	13 (9–17)	51	22 (17–29)	39	11 (8–16)	0.003
Male	762	58 (54–62)	235	53 (47–60)	144	48 (41–57)	201	84 (73–95)	182	53 (46–61)	<0.0001
Race/ethnicity											
White, non-Hispanic	402	46 (41–50)	75	33 (26–41)	39	37 (27–51)	198	62 (54–71)	90	39 (32–48)	<0.0001
Black, non-Hispanic	181	34 (29–39)	102	33 (28–40)	30	43 (30–61)	10	46 (25–82)	39	29 (21–39)	0.29
Hispanic	272	28 (25–31)	89	35 (29–43)	79	22 (18–28)	29	28 (19–40)	75	27 (22–34)	0.02
SES											
Low SES (<$45,000)	285	34 (30–38)	157	36 (31–42)	13	14 (08–24)	41	42 (31–57)	74	34 (27–43)	0.003
Mid SES ($45,000–$100,000)	521	41 (37–44)	67	39 (31–49)	162	33 (29–39)	211	56 (50–64)	81	32 (26–40)	<0.0001
High SES (>$100,000)	136	28 (24–33)	64	26 (20–33)	6	40 (18–85)	–	–	66	30 (24–38)	0.62
School district size											
Small (<250 students)	147	34 (29–40)	19	27 (17–42)	23	33 (22–49)	65	46 (36–58)	40	26 (19–35)	0.02
Medium (250–999 students)	447	32 (29–35)	150	29 (25–34)	73	23 (18–29)	109	49 (41–59)	115	34 (28–41)	<0.0001
Large (>999 students)	348	45 (40–49)	119	44 (37–52)	85	41 (33–50)	78	73 (59–90)	66	34 (27–43)	<0.0001
Total	942	36 (34–38)	288	34 (30–38)	181	31 (26–35)	252	54 (47–60)	221	32 (28–37)	<0.0001

Note: ASD cases are based on DSM 5 ASD case definition using ADDM methodology. Population denominators are based on public school enrollment in 2016–2017 school year. Prevalence per 1000 8-year old children. 95% Confidence interval based on Wilson score method. SES is based on US Census 2016 American Community Survey Median Household Income by County Subdivision equivalent to school districts. No cases were identified in Ocean County in the high-SES category. *p*-value for differences between counties.

Abbreviations: ASD, autism spectrum disorder; CI, confidence interval; NJAS, New Jersey autism study; SES, socioeconomic status.

among male children, compared to female children (Table 4). Ocean County had higher ASD prevalence across all subgroups, except for Hispanic children (Table 3).

Comparisons by race/ethnicity, SES, and school district size

Race and ethnicity-based differences were observed, across counties. Hispanic children had significantly lower identified ASD prevalence compared to White (Non-Hispanic) children (PR = 0.6; 95% CI: 0.5–0.7; $p < 0.001$). ASD prevalence estimates were 30%–60% lower among Hispanic children in three of four counties (Table 4). Mid SES districts had significantly higher ASD prevalence (PR = 1.2; 95% CI: 1.1–1.4; $p = 0.01$) compared to low- and high-SES districts (PR = 0.8; 95% CI: 0.7–1.0; $p = 0.09$; Table 4). School district size was consistently and positively associated with ASD prevalence estimates (PR = 1.3; 95% CI: 1.1–1.6; $p = 0.004$) (Table 4). This difference was observed across counties and yielded ASD estimates ranging from 1.2 to 1.6 times higher in large districts, compared to small districts.

ASD prevalence at the school district level

ASD prevalence estimates ranged from 8 to 108 per 1000, at the district level ($p < 0.0001$). Thirteen of seventy-four school districts (18%) showed ASD prevalence greater than 50 per 1000.

Among the four largest school districts (age 8 enrollment >1000), ASD prevalence was highest in Toms River (Ocean County), 73 per 1000 (95% CI: 5.9–9.0).

DISCUSSION

Our findings are consistent with prior ADDM reports and other epidemiologic studies showing wide variation in ASD prevalence across geographic regions. This study demonstrates that significant variation in ASD prevalence is also present at the local level. Variation in ASD prevalence across countries is likely the result of using different methods to estimate ASD prevalence (Chiarotti & Venerosi, 2020; Fombonne, 2018). In contrast, the ADDM Network employs a standard and consistent ascertainment method. Observed inter-state variation in ASD prevalence in the ADDM Network

TABLE 4 Prevalence ratio of ASD prevalence by sex, race/ethnicity, socioeconomic status, and school district size

	NJAS surveillance region			ASD prevalence ratio in each county in the surveillance region: Essex			Hudson			Ocean			Union		
Category	**PR**	**95% CI**	***p*-value**	**PR**	**95% CI**	***p*-value**	**PR**	**95% CI**	***p*-value**	**PR**	**95% CI**	***p*-value**	**PR**	**95% CI**	***p*-value**
Sex															
Female (reference)															
Male	4.3	3.6–5.1	<0.001	4.4	3.2–5.9	<0.001	4.0	2.8–5.8	<0.001	4.0	2.9–5.5	<0.001	4.8	3.4–6.8	<0.001
Race/ethnicity															
BNH:WNH	0.7	0.6–0.9	0.001	1.0	0.8–1.4	0.90	1.2	0.7–1.9	0.55	0.7	0.4–1.4	0.34	0.7	0.5–1.1	0.10
Hisp:WNH	0.6	0.5–0.7	<0.001	1.1	0.8–1.5	0.62	0.6	0.4–0.9	0.01	0.4	0.3–0.6	<0.001	0.7	0.5–0.9	0.02
BNH: Hisp	0.8	0.7–1.0	0.03	1.1	0.8–1.4	0.70	0.5	0.3–0.8	0.01	0.6	0.3–1.2	0.16	0.9	0.6–1.4	0.79
SES															
Low (<$45,000) (reference)															
Mid ($45,000–$100,000)	1.2	1.1–1.4	0.01	1.1	0.8–1.5	0.53	2.4	1.4–4.3	0.01	1.4	1.0–1.9	0.08	0.9	0.7–1.3	0.74
High (>$100,000)	0.8	0.7–1.0	0.09	0.7	0.5–1.0	0.03	2.9	1.1–7.9	0.02	-	-	-	0.9	0.6–1.2	0.47
School district size															
Small (<250 students) (reference)															
Medium (250–999 students)	1.0	0.8–1.1	0.60	1.1	0.7–1.7	0.78	0.7	0.4–1.1	0.12	1.1	0.8–1.5	0.60	1.3	0.9–1.9	0.14
Large (>999 students)	1.3	1.1–1.6	0.01	1.6	1.0–2.7	0.05	1.2	0.8–2.0	0.37	1.6	1.2–2.3	0.01	1.3	0.9–2.0	0.17

Note: *p*-value <0.05 represents significant difference in prevalence between groups.
Abbreviations: ASD, autism spectrum disorder; BNH, Black, non-Hispanic; CI, confidence interval; Hisp, Hispanic; NJAS, New Jersey autism study; PR, prevalence ration; SES, socioeconomic status; WNH, White, non-Hispanic.

may be a function of differences in policy, awareness and/or access to professional services (Broder-Fingert et al., 2018; Fombonne, 2018; Pinborough-Zimmerman et al., 2010). Within New Jersey; however, the observed variations are not likely to be due to differences in policy or awareness but may reflect differences in utilization of services or access to care and should be considered, systematically.

Our examination of ASD prevalence at the county and school district levels confirms that ASD is not uniformly distributed, even within a region, and highlights counties and districts with higher than expected prevalence. For example, in Ocean County, over 5% of public students had ASD and nearly one in five districts in our surveillance region had ASD prevalence between 5% and 10%. We also found differences between counties in identification of ASD by a community provider. For example, while 90% of children in Hudson County had an ASD diagnosis, in Union County only 73.8% of children had a diagnosis. Furthermore, Ocean County had the highest proportion of children with ASD and IQ >70 suggesting better identification of children with ASD with borderline and average intellectual ability.

Even when utilizing a rigorous and standardized ascertainment method, in a region known for policies aiming to ensure access to high-quality educational resources (EducationWeek, 2019), significant variations in ASD identification, diagnosis and educational classification exist. Active surveillance in metro New Jersey indicated that 3.6% of (8-year-old) children in the public education system had ASD. By focusing "down" to the more granular county level, we were able to see that the identified rate of ASD ranged from approximately 3% in Hudson County, to 5% in Ocean County. Focusing still further "down"—to the district level, we recognized that many communities in our region, approximately one in five, including some of the largest, had ASD rates between 5% and 10%.

This study discloses an important and continuing disparity—Hispanic children with ASD are less likely to be identified than White, non-Hispanic peers. When we parsed the surveillance data at a more granular level, we detected meaningful county and district level differences in the identification of Hispanic children with ASD. Case identification by the active multiple source method depends on the quality and quantity of information in professional evaluations. If Black and/or Hispanic children received services less frequently, they might be less likely identified. That possibility is supported by recent studies showing that Hispanic children are less likely to receive occupational and physical therapy, compared to White, non-Hispanic children (Bilaver & Havlicek, 2019) and indicating that case-relevant information was more likely to be missing for Black, non-Hispanic, and Hispanic children than for White, non-Hispanic peers (Imm, 2019). Even in regions with high levels of awareness, support for and access to services, disparities in ASD identification may persist. If disparity is identified, local level information may lead to the provision of focused information and resource sharing with districts needing the most helps. Accurate specific information at the local level is likely to be most useful for planning and implementation.

Previous epidemiologic studies from New Jersey and the ADDM Network observed a significant and persisting stepwise association of SES and ASD prevalence, between 2000 and 2010 (Durkin et al., 2010; Durkin & Yeargin-Allsopp, 2018; Thomas et al., 2012). Surprisingly, in our (2016) population, ASD prevalence rates were highest among children from Mid SES communities. ASD prevalence estimates in high-SES communities were lower than in low-income communities, contrary to expectation. Our findings support the possibility of a shift away from the positive SES gradient for ASD observed from 2000 to 2010 and are consistent with recent ASD trend reports (Nevison & Zahorodny, 2019; Winter et al., 2020). Additional research and ongoing surveillance are necessary to clarify these observations and understand the drivers of the shift in ASD demographics. Previous studies based on administrative data have shown a relation between ASD identification and school district characteristics (Palmer et al., 2005). This study also found that higher rates of ASD were identified in large school districts. Multiple school districts in the New Jersey metro region had higher ASD prevalence compared to the average for the entire surveillance region and compared to the ADDM Network average for the period. Zero cases and sporadically higher than expected estimates would be predicted in small districts, as a function of small numbers. However, ASD rates were highest in some of the largest school districts. For example, in Newark, the largest urban district in New Jersey, identified ASD prevalence was 4.4%, while in Toms River, the largest suburban district, ASD prevalence was 7.1%. Larger districts may provide more services from a greater number of professionals or have additional resources for detection or care of ASD. It is possible that parents of children with learning or developmental disorders, including ASD, relocate from small districts to large districts, to maximize their children's educational attainment. Additional studies are needed to specify the impact of district size and the potential influence of in-migration on ASD prevalence. If large districts are better able to identify and serve children with ASD, it might be useful for small districts to consider consolidating special education services at a county or regional level or to facilitate ASD-specific training and education of staff in small sized districts.

Public schools are the primary source of interventions to students with autism. Overall, 94% of our total population received special education services in the study year, indicating the importance of the public education system to students with ASD. Four in ten (41%) ASD students were served under the Autism classification, suggesting that the actual scope of ASD is dramatically underrepresented by the Autism classification count. Similarly, while about 80% of surveillance identified ASD cases have an ASD diagnosis by age nine, that leaves one in five ASD children undiagnosed and potentially underserved. If ASD diagnosis is associated with more robust services, evidence from this active surveillance system indicates a general area for improvement as well as providing the method for identifying the groups that are most likely to benefit from targeted action.

Significant resources are needed to care for, educate, and support children with ASD. Effective planning and action are best served by accurate appreciation of the scope of a challenge. Aggregate estimates and general averages of ASD prevalence can obscure the useful information conveyed at the local level. ASD rates of 5% and higher were already evident in multiple New Jersey communities in 2016 and there is no reason to believe that similar rates of occurrence are not the case in other US metropolitan areas. Moreover, future autism estimates are likely to increase, as detection improves in underserved communities. The findings emphasize the need for increasing resources to and evidence-based planning of services to children with ASD and the enhancement of systems, which monitor the expression of ASD at the local level and seek to define the social determinants, which influence the identification and distribution of ASD (Krieger, 2011).

An important strength of this study was use of a rigorous, comprehensive, and validated method of active ascertainment in a diverse metropolitan Area. The active ascertainment method has multiple advantages, including detection of undiagnosed ASD cases, use of a standardized and reliable case definition based on DSM criteria and surveillance coverage of the total population, including children from under-represented populations. These ASD prevalence estimates were determined in the context of ongoing ASD monitoring by experienced investigators with access to information from multiple clinical and educational sources in a populous, diverse population.

Several limitations are acknowledged. The study denominators represent children attending public schools, only. Approximately 80% of children in the region attended public schools. ASD prevalence among nonpublic (private school and home schooled) students was not considered. Overestimation of ASD prevalence is possible among children enrolled in public school, as children in private schools and home-schooled, are less likely to have significant impairment in learning, requiring special education services. However, underestimation is also possible since our findings reveal disparities in the identification of Hispanic children. While ASD prevalence estimates where stratified by sociodemographic factors, this study did not examine whether SES and race-based differences exist across public and nonpublic school students. SES and school district size are ecological factors and do not reflect individual-level information. As in many epidemiological studies, residual confounding is possible, given that SES and school district size are broad categories. Surveillance was conducted in only four urban-suburban New Jersey counties representing approximately 25% of the total state population. No rural area was included, and findings may not be representative of the entire state. Additional sources of ascertainment bias cannot be ruled out. The ADDM active ascertainment method relies on access to a wide range of information from multiple sources and the completeness of existing information. Incomplete records due to socioeconomic and/or race/ethnic disparities may have led to underestimation of ASD, in some districts. However, these ASD estimates may still understate actual ASD prevalence. There are children with ASD who first come to attention after age eight and, therefore, would not be identified. Additionally, it is likely that SES and/or race and ethnicity-based disparities in ASD identification, in parts of our region, led to underestimation of ASD. Finally, a considerable limitation of this study is the sample size. Small sample sizes may produce higher prevalence estimates (Fombonne, 2002). There were several small sample sizes when the data was further stratified by race/ethnicity and SES.

The findings suggest that the true scope of ASD may be under-represented by extant national and state estimates. If ASD rates of 4%–7% were recorded in the NJ-NY area, it is possible that similar levels might be detected in other US metro regions. Exclusive reliance on Autism classification or ASD diagnosis data may bias the appreciation of ASD prevalence on individual districts or regions. Additional research is needed to identify specific systemic or local conditions or practices that contribute to the use of health or education resources and, in turn, may affect the estimation of ASD prevalence.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

ORCID

Josephine Shenouda https://orcid.org/0000-0003-2279-9549

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