

Prevalence and Disparities in the Detection of Autism without Intellectual Disability

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Abbreviations:

ADDM – Autism and Developmental Disabilities Monitoring Network

ASD – Autism Spectrum Disorder

CDC – Centers for Disease Control and Prevention

CI – Confidence Interval

ID – Intellectual Disability

IRB – Institutional Review Board

MHI – Median Household Income

NHB – Non-Hispanic Black

NHW – Non-Hispanic White

NJ – New Jersey

PR – Prevalence Ratio

SES – Socioeconomic status

SY – Surveillance year

Article Summary: From 2000-2016, ASD without ID increased 500% and ASD with ID increased 200%. Health disparities were evident in identification of ASD without ID.

What is known on this subject: At present, intellectual ability remains the best predictor of functional outcomes and classification of degree of impairment among children with ASD. Studies have shown that many children with ASD do not have ID.

What this study adds: This study evaluated time trends in ASD with and without ID from 2000-2016 from a population-based study in a large and diverse metropolitan area and evaluated trends by sociodemographic factors. Health disparities were identified in ASD identification.

Contributor's Statement

Dr. Shenouda conceptualized and designed the study, carried out the initial analyses, drafted the initial manuscript, and reviewed the revised manuscript.

Dr Barrett, conceptualized and designed the study, reviewed the study analyses, and critically reviewed the manuscript for important intellectual content.

Drs. Davidow, and Silenzio reviewed the study analyses, and critically reviewed the manuscript for important intellectual content.

Dr Halperin conceptualized and designed the study.

Ms. Sidwell and Ms. Lescott critically reviewed and revised the manuscript

Dr Zahorodny conceptualized and designed the study, supervised data collection, and critically reviewed the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Abstract

Background: Intellectual ability strongly predicts functional outcomes for children with Autism Spectrum Disorder (ASD). It is essential to classify ASD children with and without Intellectual Disability (ID) to aid etiological research, provide appropriate services, and inform evidence-based educational and health planning.

Methods: Using a cross-sectional study design, data from 2000-2016 active ASD surveillance among 8-year-olds residing in the New York-New Jersey Metropolitan Area between 2000 and 2016 were analyzed to determine ASD prevalence with and without ID. Multivariable Poisson regression models were used to identify sociodemographic trends for ASD with ID (ASD-I) and without ID (ASD-N).

Results: Active surveillance identified 4,661 8-year-old children with ASD. 1505 (32.3%) were ASD-I and 2764 (59.3%) were ASD-N. 3794 (81.4%) were male, 946 (20.3%) were Non-Hispanic Black (Black), 1230 (26.4%) were Hispanic, and 2114 (45.4%) were Non-Hispanic White (White). We observed 2-fold and 5-fold increases in the prevalence of ASD-I and ASD-N, respectively, from 2000-2016. Black children were 30% less likely to be identified with ASD-N compared to White children. Children residing in affluent areas were 80% more likely to be identified with ASD-N compared to children in underserved areas. A greater proportion of children with ASD-I resided in vulnerable areas compared to children with ASD-N. Males had higher prevalence compared to females regardless of ID status; however, male-to-female ratios were slightly lower among ASD-I cases compared to ASD-N cases.

Conclusion: 1-in-3 children with ASD had ID. Disparities in the identification of ASD without ID were observed among Black and Hispanic children as well as among children residing in underserved areas.

1 **Introduction**

2 Over the past decades, research has shown multifold increases in Autism Spectrum Disorder
3 (ASD) prevalence in the U.S ¹⁻⁴. While the Centers for Disease Control and Prevention (CDC)
4 estimated ASD prevalence at 0.6% in 2000, by 2018, estimates rose to 2.3% (1-in-44 8-year-old
5 children), surpassing Intellectual Disability (ID) as one of the most common neurodevelopmental
6 disorders among U.S. children ⁴⁻⁶. Heterogeneity of ASD expression presents a challenge for
7 research on etiology and interventions ^{7,8}. At present, intellectual ability represented by
8 intelligence quotient remains the best predictor of functional outcomes and classification of ASD
9 ^{9,10}. Prior to 2000, estimates suggested up to 75% of ASD children had ID. Recent studies report
10 that 30-40% of ASD children have ID indicating better identification of children with ASD
11 without ID ^{4,9-16}.

12
13 Research shows varying ASD prevalence patterns when intellectual ability is considered. For
14 example, while overall ASD prevalence estimates are considerably higher for males than
15 females, among individuals with ASD and ID, the sex difference is less pronounced ^{9,11,12,17}.
16 Similarly, recent findings indicate that the average lifetime costs to support individuals with
17 ASD varies by intellectual level with estimated lifetime costs of \$2.4 million for individuals with
18 ASD and ID versus \$1.4 million for ASD individuals without ID¹⁸. Consistent population-based
19 surveillance is needed to track prevalence trends, describe changes in ASD expression, provide
20 data for planning and allocation of resources and inform policy. Moreover, monitoring of ASD
21 trends with consideration of intellectual disability can provide useful information on overall in
22 population health and disparities as well as inform strategies for early ASD identification and
23 intervention.

24

1 Few studies have examined trends in ASD prevalence and intellectual ability referencing
2 demographic correlates such as race and socioeconomic status (SES). Given the evidence
3 demonstrating disparities in health and educational services, better understanding of the
4 prevalence of ASD and ID by sociodemographic factors is needed^{19,20}. For example, recent
5 analysis showed that Non-Hispanic Black children with ASD were less likely to participate in
6 Early Intervention Programs compared to Non-Hispanic White children²¹. Additionally, many
7 studies have documented disparities in early ASD identification among Hispanic and Non-
8 Hispanic Black children^{22,23}. Similarly, SES is associated with early identification and
9 services^{21,24,25}. Understanding the associations of ASD and intellectual ability can inform
10 recommendations and interventions provided by pediatricians, and to guide future policy
11 regarding ASD.

12
13 The current literature on the topic of ASD and ID has many limitations: some provide cross-
14 sectional reports at single time points¹², while others rely on administrative or clinical data
15 which could lead to underestimation and/or bias^{9,26-29}, others lack recent data^{14,30,31}, or use
16 homogeneous samples that are not generalizable to diverse populations^{32,33}. To address these
17 limitations, we used data from a population-based, active surveillance system to examine
18 intellectual ability among 8-year-old children with ASD in a diverse US metropolitan region,
19 from 2000-2016. We describe intellectual ability among children with ASD by sex,
20 race/ethnicity and SES and characterize temporal trends over this period.

21

1 **Methods**

2 Cross-sectional data from the New Jersey Autism Study (NJAS) which is part of the CDC -
3 Autism and Developmental Disabilities Monitoring (ADDM) Network were analyzed. ADDM is
4 a population-based active surveillance tracking ASD^{34,35}. The biannual ADDM surveillance
5 provides ASD prevalence estimates for birth cohorts, at age eight. New Jersey data for 2000,
6 2002, 2006, 2010, 2012, 2014 and 2016 (representing birth cohorts 1992, 1994, 1998, 2002,
7 2004, 2006 and 2008, respectively) were included in this analysis^{5,13,36-40}. Data from 2018
8 surveillance cycle were excluded here due to changes in the 2018 ADDM methodology⁴¹.

9
10 ADDM ascertainment method is a two-phase process³⁵. In phase I, educational and clinical
11 records of children satisfying birth year and residency criteria were reviewed. Records for
12 children showing at least one specific, pre-determined, ASD indicator were abstracted³⁵. In phase
13 II, using standard procedures, expert clinician reviewers, identified and characterized ASD cases.
14 ASD case definition was satisfied if behaviors documented in professional evaluations reflected
15 the DSM-IV-TR ASD criteria (Supplemental Figure 1). Beginning with the 2014 ASD
16 surveillance cycle, the ADDM Network also included a case definition based on DSM-5 criteria
17 in addition to the case definition based on DSM-IV-TR criteria used from 2000-2012. Since
18 ADDM network identified minimal differences in ASD prevalence using DSM-IV-TR and
19 DSM-5 criteria³⁸, to remain consistent across the study period, the DSM-IV-TR surveillance case
20 definition was used in this analysis.

21

1 Across all surveillance cycles, the methodology, ASD case definition and surveillance region
2 remained constant. The study was approved by the Institutional Review Board (IRB) of Rutgers
3 University – New Jersey Medical School.

4 5 *Population and Setting*

6 The surveillance region included four counties (Essex, Hudson, Ocean and Union) representing
7 approximately 25% of the total New Jersey (8-year-old) population. The region is within the
8 New York-New Jersey Metropolitan Area, the most populous metropolis and encompasses a
9 diverse population (approximately, 40-42% Non-Hispanic White, 22-27% Non-Hispanic Black
10 and 25-32% Hispanic). Each surveillance cycle included approximately 30,000 children.

11 Population denominators were obtained from the National Center for Health Statistics vintage
12 2019 bridged-race postcensal data⁴² (Supplemental Table 1).

13 14 *Outcome variable*

15 The study included two case definitions: ASD-I and ASD-N. ASD-I included children with ID as
16 defined by an IQ score ≤ 70 . ASD-N was defined as IQ score >70 and included children with
17 borderline, average and above average IQ. By convention and for research purposes, ID is
18 traditionally defined according to IQ test scores^{4,15,26,38}. Case definitions reflected the most
19 recent IQ score in each child's record. Across all cycles, 4,661 children were identified with
20 ASD; 81% (n=3,762) had documented IQ scores.

21
22 Records of children with missing IQ test data (n=899) were reviewed to classify children as
23 ASD-I or ASD-N. When IQ test findings were unavailable, ASD-I was determined based on: 1)

1 documented cognitive delay, deficit, or impairment by a professional (n=181), 2) attempted
2 administration of an IQ test that was discontinued due to non-testable status (n=117), or 3) a
3 special education classification of Cognitive Impairment (n=5) at school. Conversely, ASD-N
4 was determined for children without IQ scores based on: 1) special education classification of
5 Speech-only deficit (n=9), 2) documentation of age-appropriate cognitive skills and/or average or
6 higher academic skills by standardized performance tests (n=95), or 3) ASD cases classified by
7 the surveillance with mild impairment and no indication of special education services (n=91).
8 Following this enhanced classification, 398 ASD cases (9%) had undetermined intellectual
9 ability and were excluded from further analysis.

10

11 *Demographic variables*

12 Sex and race/ethnicity data were obtained from individual records and birth certificates. Race
13 and ethnicity was categorized for Non-Hispanic White (White), Non-Hispanic Black (Black) and
14 Hispanic. SES was based on Median Household Income (MHI) at the census tract level and
15 categorized as a 3-level variable based on MHI tertiles for all census tracts in New Jersey,
16 namely: Low-SES (MHI \leq \$57,933), Mid-SES (MHI = \$57,934-\$87,313) and High-SES (MHI >
17 \$87,313).

18

19 Additional SES indicators were considered, including the social vulnerability index (SVI) and
20 the poverty rate, to assess whether different aspects of wealth were also associated with ASD-I
21 and ASD-N. SVI is a CDC-developed multifactorial index representing 15 demographic factors
22 grouped into four themes. The overall index (scaled 0-1, with 1 representing highest
23 vulnerability) combines all four themes: 1) traditional SES factors; 2) household composition

1 and disability; 3) minority status and language; 4) housing type and transportation. SVI was
2 categorized as a 3-level variable based on all census tracts in New Jersey. Geographic areas with
3 20% or greater poverty rates were classified as ‘poverty areas’ and areas with less than 20%
4 poverty rates as ‘non-poverty areas’ consistent with US Census classification⁴³.

6 *Data Analysis*

7 ASD prevalence was estimated overall and by intellectual ability status (ASD-I and ASD-N) in
8 each of the seven cycles (2000-2016). Wilson score method was used to compute 95%
9 confidence intervals (CI). ASD prevalence was evaluated by sex, race/ethnicity, and SES.
10 Descriptive statistics and Pearson chi-square tests were used to characterize differences between
11 children with ASD-I and ASD-N. Prevalence ratio (PR) and 95% CI were calculated to compare
12 prevalence estimates overall and by sex and race/ethnicity from 2000-2016. Analyses examining
13 SES were restricted to surveillance cycles 2010-2016 as comparable SES data from 2000-2006
14 were not available. Multivariable Poisson regression was used to analyze trends in ASD rates
15 over time allowing for overdispersion; the log of the population was treated as an offset. Models
16 were stratified by ASD type (ASD-I/ASD-N) and were adjusted for sex, race/ethnicity, SES, and
17 birth year across 2010-2016 surveillance cycles. In sensitivity analyses, we refit models
18 employing the stricter definition of ASD-I and ASD-N, based on IQ scores only. Statistical
19 analyses were performed using SAS 9.4.

21 **Results:**

22 From 2000-2016, 4,661 children satisfied the ASD case definition. ASD prevalence estimates
23 increased 3-fold from 9.6 per 1,000 (95%CI: 8.5-10.7) in 2000 to 31.8 per 1,000 (95%CI: 30.0-

1 33.8) in 2016. During the same period, ASD-I increased 2-fold, from 2.9 per 1,000 (95%CI: 3.6-
2 5.0) to 7.3 per 1,000 (95%CI: 7.6-9.6) while ASD-N increased approximately 5-fold, from 3.8
3 per 1,000 (95%CI: 3.3-4.7) in 2000 to 18.9 per 1,000 (95% CI: 19.2-22.3) in 2016 (Figure 1 &
4 Table 1).

5
6 The majority of ASD cases (n=2,764; 59%) satisfied the definition of ASD-N, while 32%
7 (n=1,505) met the definition of ASD-I. Among ASD-N cases with IQ scores, 33% (n=879) had
8 borderline IQ (71-84). ASD-N represented 57% of ASD cases in 2000 as compared to 72% in
9 2016.

10

11 *Comparison by sociodemographic factors*

12 Males had higher overall ASD prevalence estimates compared to females across all birth cohorts,
13 ranging from 3.6 to 4.1 male-to-female ratio (MFR) across the 16-year period. Prevalence was
14 higher among males regardless of ID status (Figures 2a&2d); however, the MFR was higher
15 among ASD-N, compared to ASD-I, cases. ASD-N prevalence estimates for males increased 5.2-
16 fold (PR = 5.2; 95% CI: 4.2-6.4), while estimates for ASD-I males increased 2.1-fold (PR = 2.1;
17 95% CI: 1.6-2.5). Similar increases were observed among females with ASD-N (PR = 5.8; 95%
18 CI: 3.5-9.3) and ASD-I (PR = 1.8; 95% CI: 1.2-2.8).

19

20 ASD-I and ASD-N estimates varied by race/ethnicity. Increases in ASD-I and ASD-N were
21 evident across all races/ethnicities between 2000-2016, with the greatest increase observed
22 among Black (PR = 5.0; 95% CI: 3.1-8.1) and Hispanic (PR = 9.3; 95% CI: 5.6-15.4) children

1 with ASD-N. By 2016, across all races/ethnicities, ASD-N estimates were higher than ASD-I
2 estimates (Figures 2b&2e).
3
4 ASD-I and ASD-N estimates varied by SES. ASD-N prevalence estimates were lower among
5 children residing in Low-SES compared to High-SES areas (Figure 2f). From 2010-2016,
6 estimates for ASD-N were stable for children residing in High-SES areas but increased 1.9-fold
7 (95% CI: 1.5-2.3) and 1.6-fold (95% CI: 1.3-1.7) among children residing in Low and Mid-SES
8 areas, respectively. Estimates for ASD-I also increased significantly for children residing in
9 Low-SES areas (Table 1). Results using alternative SES metrics were similar. Among ASD-I
10 children, 31% resided in poverty areas, compared to 15% of ASD-N children. Similarly, 68% of
11 ASD-I children resided in SVI-designated highly-vulnerable areas, compared to 38% of ASD-N
12 children (Table 2).

14 *Multivariable Regression*

15 In multivariable regression analyses, ASD-N was twice as prevalent as ASD-I (adjusted Rate
16 Ratio (ARR) = 2.1, 95% CI:1.8-2.5). The male-to-female ratio (MF-ARR) was higher among
17 individuals with ASD-N (MF-ARR=4.4, 95% CI:3.8-5.3) than ASD-I cases (MF-ARR = 3.9,
18 95% CI:3.3-4.7). Differences by race/ethnicity were evident. While Black (ARR = 2.1, 95%
19 CI:1.7-2.5) and Hispanic (ARR = 1.7, 95% CI:1.4-2.1) children were more likely to be identified
20 with ASD-I, compared to White children, Black children were 30% less likely to be identified
21 with ASD-N compared to White children. Among ASD-I cases there were no differences by
22 SES; however, children residing in High-SES (ARR = 1.8, 95% CI:1.5-2.2) and Mid-SES (ARR
23 = 2.0, 95% CI:1.7-2.3) areas were more likely to have ASD-N compared to children from Low-

1 SES areas. An increase in identification of ASD-N by birth cohort was observed. Children born
2 in 2008 were 80% more likely to be identified with ASD-N compared to children born in 2002.
3 Similarly, there was a 40% increase in ASD-I identification over time. Sensitivity analyses using
4 a narrower case definition of ASD-I and ASD-N, based solely on IQ scores, yielded similar
5 results (Table 3).

6

7 **Discussion:**

8 From 2000-2016, we observed a 500% increase in the prevalence of ASD without ID and a
9 200% increase in the prevalence of ASD with ID, using consistent, population-based active
10 surveillance in a diverse and populous region. ASD prevalence increased across all sex,
11 race/ethnicity and SES subgroups and the greatest increases were seen among children without
12 intellectual impairment. These findings are consistent with prior studies^{4,12-14}. While earlier
13 studies reported that a large proportion of children with ASD had ID, more recent findings
14 suggest the reverse, namely that most children with ASD have intellectual ability in the non-
15 disabled range. In this study, 57% of ASD cases did not have ID in 2000 versus 72% in 2016, a
16 trend likely explained by better recognition of ASD among children with average intellectual
17 ability. Adjusting for various factors and time trends, for every child identified with ASD-I, two
18 children with ASD-N were identified.

19

20 Consistent with previous findings, the male-to-female ratio was 3.9 among children with ASD-I;
21 slightly lower than the male-to-female ratio of 4.4 among children with ASD-N. We anticipated
22 a considerably lower sex ratio in the ASD-I group based on recent research⁴⁴. The high sex ratio
23 has been consistently observed in ASD populations and has been attributed to possible clinical

1 differences between males and females and under identification and/or ascertainment bias in
2 identifying females with ASD. This analysis shows possible under-identification of females with
3 ASD regardless of ID status as the sex ratio among ASD-I children is 4:1.

4
5 By 2016, ASD-N was higher than ASD-I among all races which suggests better identification
6 and increased identification of children with ASD-N. However, our findings underscore the
7 persistent sociodemographic disparities in the identification of ASD-N. Black children had lower
8 estimates of ASD-N compared to White children, suggesting likely under-identification or
9 misdiagnosis of Black children. Multiple studies have reported racial disparities in ASD
10 identification^{23,45-48}, disparities that may be driven by under-identification or mis-diagnosis of
11 children with ASD-N⁴⁹. Under-identification may result in loss of access to services. Universal
12 ASD screening at routine pediatric visits is needed to better identify children with moderate to
13 mild forms of ASD. Pediatricians are in an ideal position to address diagnostic inequalities. By
14 36-months, a child has typically seen a pediatrician at multiple well-child visits, and use of
15 effective screeners to monitor child development can lead to earlier identification and the
16 initiation of appropriate services at earlier ages. Cultural barriers may also impact ASD
17 identification and targeted, culturally-sensitive parent-focused education may increase ASD
18 knowledge and awareness as well as community acceptance, potentially reducing disparities in
19 the utilization of services⁵⁰⁻⁵².

20
21 Our findings demonstrate significant health disparities in ASD particularly in relation to SES.
22 From 2010-2016, ASD-N prevalence was higher in affluent areas compared to disadvantaged
23 areas, indicating probable under-identification of children with ASD-N in disadvantaged areas.

1 Many U.S studies have shown a positive SES gradient in relation to ASD prevalence. This SES
2 relationship remains when intellectual ability is considered. Additionally, our findings indicate
3 that a greater proportion of children with ASD-I reside in underserved, highly vulnerable
4 communities, where they likely have diminished access to care and services. The SES-based
5 differential among ASD-I children shows the need for additional effort to improve the early
6 detection and linkage to services especially in socially disadvantaged communities.

7
8 As identification of ASD-N improves, particularly among Black and Hispanic children,
9 continued increases in ASD prevalence are likely. With up to 72% of the ASD population having
10 borderline or average intellectual ability, emphasis should be placed on early screening, early
11 identification, and early intervention to promote optimal functional outcomes. Studies have
12 shown improved outcomes with early intense interventions⁵³⁻⁵⁶, and this may be particularly true
13 in ASD children without ID⁵⁷. Moreover, research has shown gains in intellectual and adaptive
14 functioning with intense intervention at younger ages, in general⁵³.

15
16 *Strengths and Limitations*

17 This was a population-based study using a standard ASD case definition, in a well-defined,
18 diverse region that utilized an active case-finding methodology, independent of ASD diagnosis.
19 ASD case definition, region and methodology were consistent across all surveillance cycles. IQ
20 data were available for 81% of cases and upon further review we determined intellectual ability
21 for 91% of cases. Importantly, the study population was highly diverse and included large
22 numbers of Hispanic and Black children, allowing us to generate accurate estimates for these
23 understudied groups. While many studies have reported on ASD and ID at a single time point,

1 we examined patterns in ASD prevalence over a 16-year period. In addition, New Jersey is an
2 autism epicenter and may be an indicator of future ASD trends in the US.

3
4 Several limitations are acknowledged, including the broad categorization of ASD into two types,
5 ASD-I and ASD-N. A substantial proportion of ASD-N cases had borderline IQ and these
6 children likely experience significant challenges. Additionally, the age of IQ testing was not
7 included in the analysis and ID was defined based on IQ scores without consideration to adaptive
8 scores. While the surveillance region included four urban/suburban counties encompassing a
9 large diverse metropolitan population, the observed findings may not be representative of ASD
10 prevalence across the US. The ADDM surveillance method uses information from health and
11 educational records, and ascertainment bias cannot be ruled out as some children lacked
12 documented IQ scores.

13
14 **Conclusion:**

15 We observed that 2-in-3 children with ASD do not have co-occurring ID indicating increased
16 identification of ASD without ID among all demographic subgroups from 2000-2016. However,
17 our findings underscore the likely presence of health disparities in ASD without ID identification
18 especially among disadvantaged children. ASD is a major public health concern and prevalence
19 estimates are likely to continue to rise as disparities are reduced and ASD identification is
20 improved. Since ASD is a complex heterogeneous disorder, it is important to further study ASD
21 in relation to intellectual ability to understand etiology and to inform effective interventions and
22 appropriate services as well as aid in educational and health planning at the community level, as
23 the needs for children with ASD and ID differ from the needs of children with ASD without ID.

1 Furthermore, tracking ASD trends from diverse populations can identify health disparities and
2 provide vital information on shifts in community health over time. Future work should focus on
3 addressing health disparities in the identification of ASD through the expansion of screening
4 programs and improved linkage to care.

5

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19 **References:**

- 20 1. Chiarotti F, Venerosi A. Epidemiology of Autism Spectrum Disorders: A Review of Worldwide
21 Prevalence Estimates Since 2014. *Brain Sci.* 2020;10(5).
- 22 2. Davidovitch M, Hemo B, Manning-Courtney P, Fombonne E. Prevalence and incidence of autism
23 spectrum disorder in an Israeli population. *J Autism Dev Disord.* 2013;43(4):785-793.
- 24 3. Fombonne E. Editorial: The rising prevalence of autism. *J Child Psychol Psychiatry.*
25 2018;59(7):717-720.
- 26 4. Maenner MJ, Shaw KA, Bakian AV, et al. Prevalence and Characteristics of Autism Spectrum
27 Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring
28 Network, 11 Sites, United States, 2018. *MMWR Surveill Summ.* 2021;70(11):1-16.
- 29 5. ADDM-CDC. Prevalence of autism spectrum disorders--autism and developmental disabilities
30 monitoring network, six sites, United States, 2000. *MMWR Surveill Summ.* 2007;56(1):1-11.
- 31 6. Patrick ME, Shaw KA, Dietz PM, et al. Prevalence of intellectual disability among eight-year-old
32 children from selected communities in the United States, 2014. *Disabil Health J.*
33 2021;14(2):101023.
- 34 7. Amaral DG, Anderson GM, Bailey A, et al. Gaps in Current Autism Research: The Thoughts of the
35 Autism Research Editorial Board and Associate Editors. *Autism Res.* 2019;12(5):700-714.

- 1 8. Russell G, Mandy W, Elliott D, White R, Pittwood T, Ford T. Selection bias on intellectual ability in
2 autism research: a cross-sectional review and meta-analysis. *Mol Autism*. 2019;10:9.
- 3 9. Duvall SW, Huang-Storms L, Presmanes Hill A, Myers J, Fombonne E. No Sex Differences in
4 Cognitive Ability in Young Children with Autism Spectrum Disorder. *J Autism Dev Disord*.
5 2020;50(5):1770-1785.
- 6 10. Newschaffer CJ, Croen LA, Daniels J, et al. The epidemiology of autism spectrum disorders.
7 *Annual review of public health*. 2007;28:235-258.
- 8 11. Fombonne E. Epidemiological trends in rates of autism. *Mol Psychiatry*. 2002;7 Suppl 2:S4-6.
- 9 12. Katusic MZ, Myers SM, Weaver AL, Voigt RG. IQ in Autism Spectrum Disorder: A Population-
10 Based Birth Cohort Study. *Pediatrics*. 2021.
- 11 13. Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children
12 Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United
13 States, 2016. *MMWR Surveill Summ*. 2020;69(4):1-12.
- 14 14. Van Naarden Braun K, Christensen D, Doernberg N, et al. Trends in the prevalence of autism
15 spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment,
16 metropolitan atlanta, 1991-2010. *PLoS One*. 2015;10(4):e0124120.
- 17 15. Srivastava AK, Schwartz CE. Intellectual disability and autism spectrum disorders: causal genes
18 and molecular mechanisms. *Neurosci Biobehav Rev*. 2014;46 Pt 2:161-174.
- 19 16. Blumberg SJ, Bramlett MD, Kogan MD, Schieve LA, Jones JR, Lu MC. Changes in prevalence of
20 parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011-2012. *Natl*
21 *Health Stat Report*. 2013(65):1-11, 11 p following 11.
- 22 17. Lord C, Brugha TS, Charman T, et al. Autism spectrum disorder. *Nat Rev Dis Primers*. 2020;6(1):5.
- 23 18. Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United
24 Kingdom and the United States. *JAMA pediatrics*. 2014;168(8):721-728.
- 25 19. Aylward BS, Gal-Szabo DE, Taraman S. Racial, Ethnic, and Sociodemographic Disparities in
26 Diagnosis of Children with Autism Spectrum Disorder. *J Dev Behav Pediatr*. 2021.
- 27 20. Benevides TW, Carretta HJ, Rust G, Shea L. Racial and ethnic disparities in benefits eligibility and
28 spending among adults on the autism spectrum: A cohort study using the Medicare Medicaid
29 Linked Enrollees Analytic Data Source. *PLoS One*. 2021;16(5):e0251353.
- 30 21. Shenouda J, Barrett E, Davidow AL, et al. Disparities in Early Intervention Program participation
31 by children with Autism Spectrum Disorder in a US Metropolitan Area: 2006-2016. 2022;Under
32 Review.
- 33 22. Shenouda J, Barrett E, Davidow AL, Halperin W, Silenzio VMB, Zahorodny W. Prevalence of
34 autism spectrum disorder in a large, diverse metropolitan area: Variation by sociodemographic
35 factors. *Autism Res*. 2022;15(1):146-155.
- 36 23. Wiggins LD, Durkin M, Esler A, et al. Disparities in Documented Diagnoses of Autism Spectrum
37 Disorder Based on Demographic, Individual, and Service Factors. *Autism Res*. 2020;13(3):464-
38 473.
- 39 24. Durkin MS, Maenner MJ, Baio J, et al. Autism Spectrum Disorder Among US Children (2002-
40 2010): Socioeconomic, Racial, and Ethnic Disparities. *American journal of public health*.
41 2017;107(11):1818-1826.
- 42 25. Durkin MS, Maenner MJ, Meaney FJ, et al. Socioeconomic inequality in the prevalence of autism
43 spectrum disorder: evidence from a U.S. cross-sectional study. *PLoS One*. 2010;5(7):e11551.
- 44 26. Charman T, Pickles A, Simonoff E, Chandler S, Loucas T, Baird G. IQ in children with autism
45 spectrum disorders: data from the Special Needs and Autism Project (SNAP). *Psychol Med*.
46 2011;41(3):619-627.

- 1 27. Howard J, Copeland JN, Gifford EJ, et al. Brief Report: Classifying Rates of Students with Autism
2 and Intellectual Disability in North Carolina: Roles of Race and Economic Disadvantage. *J Autism*
3 *Dev Disord.* 2021;51(1):307-314.
- 4 28. Kim ET, Franz L, Fannin DK, Howard J, Maslow G. Educational classifications of autism spectrum
5 disorder and intellectual disability among school-aged children in North Carolina: Associations
6 with race, rurality, and resource availability. *Autism Res.* 2021;14(5):1046-1060.
- 7 29. Polyak A, Kubina RM, Girirajan S. Comorbidity of intellectual disability confounds ascertainment
8 of autism: implications for genetic diagnosis. *American journal of medical genetics Part B,*
9 *Neuropsychiatric genetics : the official publication of the International Society of Psychiatric*
10 *Genetics.* 2015;168(7):600-608.
- 11 30. Bhasin TK, Schendel D. Sociodemographic risk factors for autism in a US metropolitan area. *J*
12 *Autism Dev Disord.* 2007;37(4):667-677.
- 13 31. Delobel-Ayoub M, Ehlinger V, Klapouszczak D, et al. Socioeconomic Disparities and Prevalence of
14 Autism Spectrum Disorders and Intellectual Disability. *PLoS One.* 2015;10(11):e0141964.
- 15 32. Dunn K, Rydzewska E, Fleming M, Cooper SA. Prevalence of mental health conditions, sensory
16 impairments and physical disability in people with co-occurring intellectual disabilities and
17 autism compared with other people: a cross-sectional total population study in Scotland. *BMJ*
18 *open.* 2020;10(4):e035280.
- 19 33. Xie S, Heuvelman H, Magnusson C, et al. Prevalence of Autism Spectrum Disorders with and
20 without Intellectual Disability by Gestational Age at Birth in the Stockholm Youth Cohort: a
21 Register Linkage Study. *Paediatr Perinat Epidemiol.* 2017;31(6):586-594.
- 22 34. Centers for Disease Control and Prevention. Autism Spectrum Disorder (ASD). 2021;
23 <http://medbox.iiab.me/modules/en-cdc/www.cdc.gov/ncbddd/autism/research.html>. Accessed
24 4/6/2021, 2021.
- 25 35. Rice CE, Baio J, Van Naarden Braun K, et al. A public health collaboration for the surveillance of
26 autism spectrum disorders. *Paediatr Perinat Epidemiol.* 2007;21(2):179-190.
- 27 36. ADDM-CDC. Prevalence of autism spectrum disorders--autism and developmental disabilities
28 monitoring network, 14 sites, United States, 2002. *MMWR Surveill Summ.* 2007;56(1):12-28.
- 29 37. ADDM-CDC. Prevalence of autism spectrum disorders--Autism and Developmental Disabilities
30 Monitoring Network, 14 sites, United States, 2008. *MMWR Surveill Summ.* 2012;61(3):1-19.
- 31 38. Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children
32 Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United
33 States, 2014. *MMWR Surveill Summ.* 2018;67(6):1-23.
- 34 39. Christensen DL, Baio J, Van Naarden Braun K, et al. Prevalence and Characteristics of Autism
35 Spectrum Disorder Among Children Aged 8 Years--Autism and Developmental Disabilities
36 Monitoring Network, 11 Sites, United States, 2012. *MMWR Surveill Summ.* 2016;65(3):1-23.
- 37 40. Zahorodny W, Shenouda J, Howell S, Rosato NS, Peng B, Mehta U. Increasing autism prevalence
38 in metropolitan New Jersey. *Autism.* 2014;18(2):117-126.
- 39 41. Maenner MJ, Graves SJ, Peacock G, Honein MA, Boyle CA, Dietz PM. Comparison of 2 Case
40 Definitions for Ascertaining the Prevalence of Autism Spectrum Disorder Among 8-Year-Old
41 Children. *Am J Epidemiol.* 2021;190(10):2198-2207.
- 42 42. Bridged-Race Population Estimates, United States July 1st resident population by state, county,
43 age, sex, bridged-race, and Hispanic origin. Compiled from 1990-1999 bridged-race intercensal
44 population estimates (released by NCHS on 7/26/2004); revised bridged-race 2000-2009
45 intercensal population estimates (released by NCHS on 10/26/2012); and bridged-race Vintage
46 2019 (2010-2019) postcensal population estimates (released by NCHS on 6/25/2019). CDC
47 WONDER Online Database; 2019. Accessed Accessed at [http://wonder.cdc.gov/bridged-race-](http://wonder.cdc.gov/bridged-race-v2018.html)
48 [v2018.html](http://wonder.cdc.gov/bridged-race-v2018.html) on Jul 24, 2021 1:14:32 PM.

- 1 43. Bishaw A, Benson C, Shirider E, Glassman B. Changes in Poverty Rates and Poverty Areas Over
2 Time: 2005 to 2019. 2020; REPORT NUMBER ACSBR/20-
3 08:<https://www.census.gov/library/publications/2020/acs/acsbr20-08.html>. Accessed
4 November 8, 2021.
- 5 44. Posserud MB, Skretting Solberg B, Engeland A, Haavik J, Klungsøyr K. Male to female ratios in
6 autism spectrum disorders by age, intellectual disability and attention-deficit/hyperactivity
7 disorder. *Acta psychiatrica Scandinavica*. 2021.
- 8 45. Barger B, Benevides T, Risz S, et al. Race/ethnic inequities in conjoint monitoring and screening
9 for U.S. children 3 and under: Disparities in Monitoring and Screening. *Disabil Health J*.
10 2021;101179.
- 11 46. Mandell DS, Ittenbach RF, Levy SE, Pinto-Martin JA. Disparities in diagnoses received prior to a
12 diagnosis of autism spectrum disorder. *J Autism Dev Disord*. 2007;37(9):1795-1802.
- 13 47. Yuan J, Li M, Lu ZK. Racial/Ethnic Disparities in the Prevalence and Trends of Autism Spectrum
14 Disorder in US Children and Adolescents. *JAMA Netw Open*. 2021;4(3):e210771.
- 15 48. Fombonne E, Zuckerman KE. Clinical Profiles of Black and White Children Referred for Autism
16 Diagnosis. *J Autism Dev Disord*. 2021.
- 17 49. Jarquin VG, Wiggins LD, Schieve LA, Van Naarden-Braun K. Racial disparities in community
18 identification of autism spectrum disorders over time; Metropolitan Atlanta, Georgia, 2000-
19 2006. *J Dev Behav Pediatr*. 2011;32(3):179-187.
- 20 50. Gordillo ML, Chu A, Long K. Mothers' Adjustment to Autism: Exploring the Roles of Autism
21 Knowledge and Culture. *J Pediatr Psychol*. 2020;45(8):877-886.
- 22 51. Kang-Yi CD, Grinker RR, Mandell DS. Korean culture and autism spectrum disorders. *J Autism Dev*
23 *Disord*. 2013;43(3):503-520.
- 24 52. Samadi SA. Parental Beliefs and Feelings about Autism Spectrum Disorder in Iran. *Int J Environ*
25 *Res Public Health*. 2020;17(3).
- 26 53. Dawson G, Rogers S, Munson J, et al. Randomized, controlled trial of an intervention for toddlers
27 with autism: the Early Start Denver Model. *Pediatrics*. 2010;125(1):e17-23.
- 28 54. Kasari C, Gulsrud AC, Wong C, Kwon S, Locke J. Randomized controlled caregiver mediated joint
29 engagement intervention for toddlers with autism. *J Autism Dev Disord*. 2010;40(9):1045-1056.
- 30 55. Nahmias AS, Pellecchia M, Stahmer AC, Mandell DS. Effectiveness of community-based early
31 intervention for children with autism spectrum disorder: a meta-analysis. *J Child Psychol*
32 *Psychiatry*. 2019;60(11):1200-1209.
- 33 56. Tsang LPM, How CH, Yeleswarapu SP, Wong CM. Autism spectrum disorder: early identification
34 and management in primary care. *Singapore Med J*. 2019;60(7):324-328.
- 35 57. Anderson DK, Liang JW, Lord C. Predicting young adult outcome among more and less
36 cognitively able individuals with autism spectrum disorders. *J Child Psychol Psychiatry*.
37 2014;55(5):485-494.

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Table 1. ASD with ID (ASD-I) and ASD without ID (ASD-N) prevalence ratio in New Jersey overall and by sex, race/ethnicity, 2000-2016 and SES 2010-2016.

	Prevalence Ratio (95% CI)	
	ASD-I 2016:2000	ASD-N 2016:2000
Overall	2.0 (1.6, 2.5)	5.3 (4.4, 6.4)
Sex		
Male	2.1 (1.6, 2.7)	5.2 (4.2, 6.4)
Female	1.8 (1.2, 2.8)	5.8 (3.5, 9.3)
Race/Ethnicity		
Non-Hispanic White	1.5 (1.0, 2.2)	4.2 (3.3, 5.4)
Non-Hispanic Black	2.0 (1.4, 2.8)	5.0 (3.1, 8.1)
Hispanic	2.8 (1.8, 4.3)	9.3 (5.6, 15.4)
*SES (MHI)		
Low SES	1.4 (1.1, 1.7)	1.9 (1.5, 2.3)
Mid SES	1.4 (1.0, 2.0)	1.6 (1.3, 2.0)
High SES	0.7 (0.5-1.2)	1.0 (0.8-1.3)

Abbreviations: ASD-I = ASD and intellectual disability; ASD-N = ASD without intellectual disability; CI = confidence interval; ID = Intellectual Disability; MHI = Median household income; SES = socioeconomic status
 *Prevalence ratio compares prevalence estimates between 2016 to 2000 except for SES category comparing 2016 to 2010 for ASD-I and ASD-N cases

Table 2. Sociodemographic characteristics of children with ASD with ID (ASD-I) and ASD without ID (ASD-N).

	ASD-I		ASD-N		P value
	n	%	n	%	
Overall	2560		1196		
Sex					0.001
Male	944	79	2120	83	
Female	242	21	440	17	
Race/Ethnicity					<0.001
Non-Hispanic White	329	28	1367	53	
Non-Hispanic Black	387	32	364	14	
Hispanic	373	31	639	25	
SES¹ (MHI)					<0.001
Low SES	770	64	956	37	
Mid SES	274	23	875	34	
High SES	152	13	729	29	
SES² (Poverty)					<0.001
Poverty Area	325	31	331	15	
Non-Poverty Area	732	69	1861	85	
SES³ (SVI)					
High Vulnerability	720	68	835	38	
Mid Vulnerability	191	18	678	31	
Low Vulnerability	147	14	680	31	

Abbreviations: ASD = Autism Spectrum Disorder; ASD-I = ASD and intellectual disability; ASD-N = ASD without intellectual disability; ID = Intellectual Disability; MHI = Median Household Income; SES = Socioeconomic Status; SVI = Social Vulnerability Scale

Table 3. Multivariable Poisson regression model stratified by ASD type (ASD-I/ASD-N) and adjusted for sociodemographic factors, 2010-2016 and sensitivity analysis using the narrower ASD type case definition based on IQ scores.

ASD Type	Based on enhanced ASD-I/ASD-N Study case definition (n= 4263)		Based on IQ scores ASD-I/ASD-N Study case definition (n = 3762)	
	Model 1 ¹	Model 2 ²	Model 3 ³	Model 4 ⁴
	ASD-I	ASD-N	ASD-I	ASD-N
Sex				
Female	Reference	Reference	Reference	Reference
Male	3.9 (3.3-4.7)	4.4 (3.8-5.3)	3.8 (3.2-4.6)	4.5 (3.8-5.4)
Race/Ethnicity				
White	Reference	Reference	Reference	Reference
Black	2.1 (1.7-2.5)	0.7 (0.5-0.8)	2.3 (1.9-2.9)	0.7 (0.6-0.9)
Hispanic	1.7 (1.4-2.1)	0.8 (0.7-1.0)	1.8 (1.5-2.2)	0.9 (0.8-1.1)
SES				
Low	Reference	Reference	Reference	Reference
Mid	1.0 (0.9-1.2)	2.0 (1.7-2.3)	1.0 (0.9-1.2)	2.0 (1.7-2.3)
High	0.8 (0.6-1.0)	1.8 (1.5-2.2)	0.8 (0.6-1.0)	1.9 (1.6-2.3)
Birth Year				
2002	Reference	Reference	Reference	Reference
2004	1.3 (1.0-1.5)	1.2 (1.0-1.5)	1.1 (0.9-1.4)	1.1 (0.9-1.4)
2006	1.5 (1.2-1.8)	1.6 (1.4-2.0)	1.6 (1.3-2.0)	1.6 (1.3-1.9)
2008	1.4 (1.1-1.7)	1.8 (1.5-2.2)	1.5 (1.2-1.9)	1.7 (1.4-2.1)

Abbreviations: ASD = Autism Spectrum Disorder; ASD-I = ASD and Intellectual Disability;

ASD-N = ASD and no Intellectual Disability; IQ = Intelligence Quotient; SES = Socioeconomic Status

1 Model 1 evaluated rate ratio for ASD-I (enhanced study case definition) adjusted for sociodemographic factors, from 2010-2016 surveillance cycles.

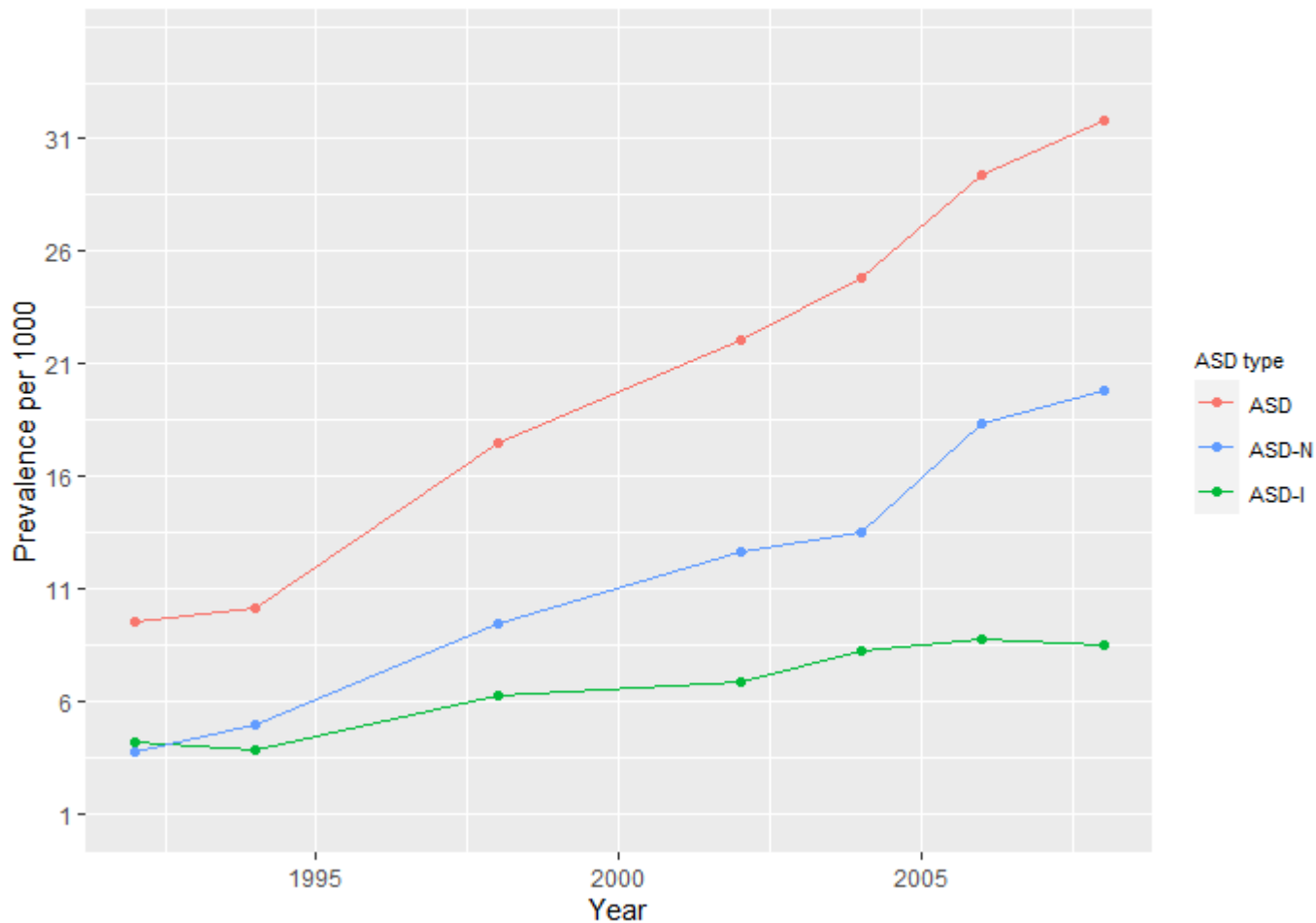
2 Model 2 evaluated rate ratio for ASD-N (enhanced study case definition) adjusted for sociodemographic factors, from 2010-2016 surveillance cycles.

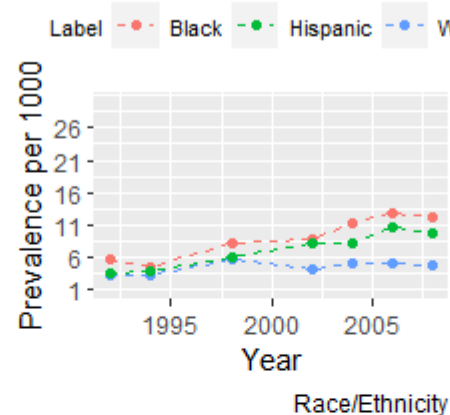
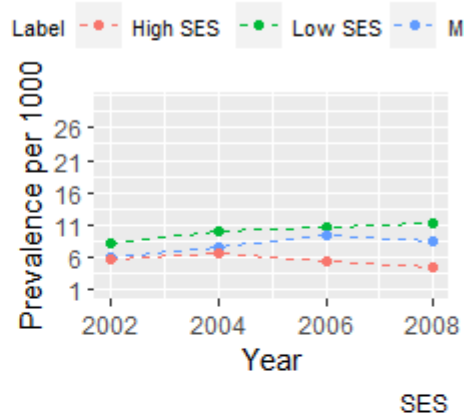
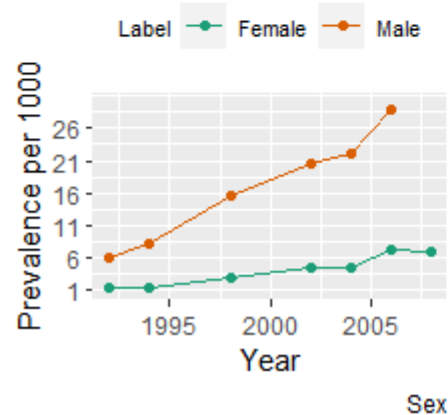
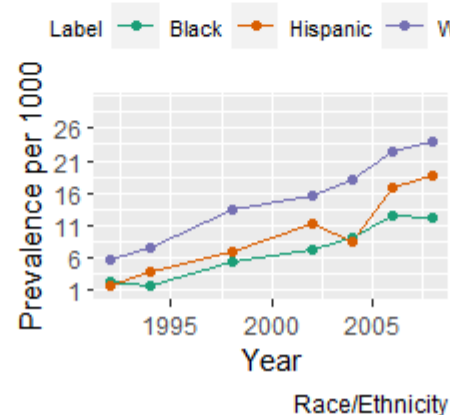
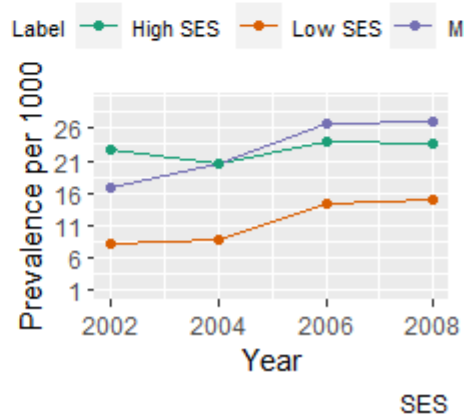
3 Model 3 (sensitivity analysis) evaluated rate ratio for ASD-I (IQ scores only) adjusted for sociodemographic factors, from 2010-2016 surveillance cycles.

4 Model 4 (sensitivity analysis) evaluated rate ratio for ASD-N (IQ scores only) adjusted for sociodemographic factors, from 2010-2016 surveillance cycles.

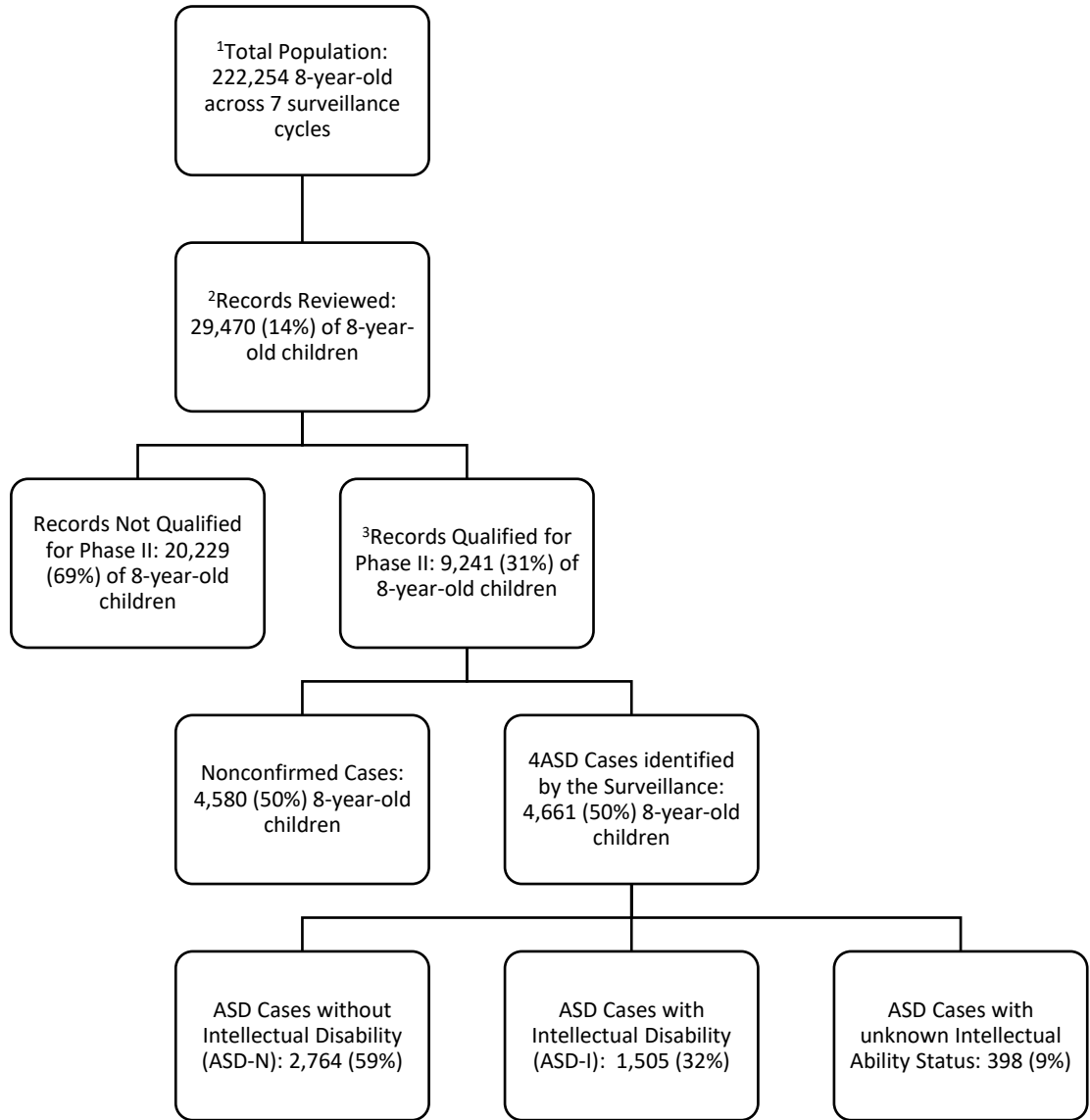
Figure 1. ASD prevalence estimates per 1,000 8-year-old children in New Jersey overall and by Intellectual Ability

2000-2016



a ASD-I
2000-2016**b** ASD-I
2000-2016**c** ASD-I
2010-2016**d** ASD-N
2000-2016**e** ASD-N
2000-2016**f** ASD-N
2010-2016

Supplemental Figure 1. New Jersey Autism Study Surveillance Process, 2000-2016



Abbreviations: ASD = Autism Spectrum Disorder; ASD-I = ASD with Intellectual Disability; ASD-N = ASD without Intellectual Disability

¹Population denominators were obtained from the National Center for Health Statistics (NCHS)

²Approximately 14% of the population qualify for phase I of the study based on residency, birth year, receipt of services through special education services in the surveillance year and/or having one or more surveillance specific International Classification of Diseases, Ninth Revision (ICD-9) codes

³Records qualifying for Phase II, had at least one surveillance indicator of ASD

⁴ASD cases are confirmed based on active surveillance standard case definition based on DSM-IV-TR criteria.

Supplemental Table 1. Population denominators for 8-year-olds residing in the surveillance area during the surveillance year (by cycle).

Surveillance Cycle	2000		2002		2006		2010		2012		2014		2016	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Overall	30,851		30,988		30,475		31,559		32,433		32,803		33,145	
Sex														
Male	15,797	51	15,941	51	15,471	51	16,034	51	16,614	51	16,721	51	16,903	51
Female	15,054	49	15,047	49	15,004	49	15,525	49	15,819	49	16,082	49	16,242	49
Race/Ethnicity														
White, Non-Hispanic	13,059	42	13,246	43	13,167	41	13,577	43	13,706	42	13,579	41	13,269	40
Black, Non-Hispanic	8,421	27	8,228	27	7,933	22	7,387	23	7,120	22	7,132	22	7,186	22
Hispanic	7,750	25	7,880	25	7,780	31	8,965	28	9,746	30	10,173	31	10,619	32
SES (MHI tertiles)														
Low SES	-	-	-	-	-	-	16196	51	16493	51	16335	50	14719	44
Mid SES	-	-	-	-	-	-	7700	24	7333	23	7767	24	9249	28
High SES	-	-	-	-	-	-	5933	19	6745	21	6782	21	7740	23

Abbreviations: SES = Socioeconomic Status

Population denominators obtained from National Health Center for Statistics vintage 2019 bridged-race postcensal data