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Disparities in Early Intervention Program Participation by Children With Autism Spectrum Disorder in a US Metropolitan Area, 2006 to 2016

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➕ **Supplemental content**

IMPORTANCE Multiple studies have shown the value of early interventions for autism spectrum disorder (ASD). In the US, the Early Intervention Program (EIP) is mandated by law (Part C of the Individuals With Disabilities Education Act [IDEA]) to provide services to all young children with delays or disabilities. However, the extent to which children with ASD participate in this key service system is unknown.

OBJECTIVES To evaluate EIP use by children with ASD from 2006 to 2016 and to describe the factors associated with EIP participation.

DESIGN, SETTING, AND PARTICIPANTS This cross-sectional study used repeated data collected from 2006 to 2016 by active ASD surveillance of the New York–New Jersey metropolitan area as reported in the New Jersey Autism Study. The New Jersey Autism Study identified 4050 children aged 8 years with ASD from 2006 to 2016. Demographic and clinical data were collected and participation in an EIP was assessed through active surveillance. Data were analyzed from June to December 2021.

EXPOSURE Sociodemographic factors associated with the outcome of EIP participation.

MAIN OUTCOMES AND MEASURES Participation in an EIP assessed at age 8 years. Demographic, ecological, and clinical factors, as well as temporal patterns, were examined by using standard and multilevel logistic regression models.

RESULTS Among 4050 children aged 8 years with ASD by active surveillance, 1887 (46.6%) received EIP services. Of these children, 3303 (81.6%) were boys; 1105 (27.3%) were Hispanic, 801 (19.8%) were non-Hispanic Black, 1816 (44.8%) were non-Hispanic White, and 328 (8.1%) were non-Hispanic other (included Alaska Native or American Indian and Asian or Pacific Islander). In adjusted regression models, non-Hispanic Black children with ASD had lower odds of EIP participation (adjusted odds ratio [AOR], 0.67; 95% CI, 0.54-0.84) compared with their non-Hispanic White peers, and children residing in affluent areas had higher odds of receiving EIP services (AOR, 1.71; 95% CI, 1.36-2.15) compared with children residing in underserved areas. Children with ASD born in 2008 had higher odds of EIP participation than children born in 1998 (AOR, 2.64; 95% CI, 2.07-3.36).

CONCLUSIONS AND RELEVANCE Early identification of ASD is an important public health priority and receipt of EIP services may improve ASD outcomes. Approximately half of the population of children aged 8 years with ASD received EIP services between 2006 and 2016, and EIP participation by children with ASD increased during the 10-year period. However, receipt of EIP services was marked by strong socioeconomic status– and race and ethnicity–based disparities. Universal ASD screening and additional strategies are needed to address disparities and to increase access to EIP services.

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Autism spectrum disorder (ASD) is one of the most prevalent and rapidly increasing developmental disorders.[1] In the US, approximately 2% to 4% of children have ASD.[2-4] Signs of ASD are evident by age 18 months, and the disorder can be reliably diagnosed by 24 months.[5,6] Early detection of ASD is a key step in receipt of early interventions,[7,8] and research suggests that early intervention leads to better outcomes.[9-11] The American Academy of Pediatrics and the US Department of Health and Human Services Interagency Autism Coordinating Committee have prioritized universal ASD screening to improve early identification and increase early intervention.[5,12,13]

In the US, the Individuals With Disabilities Education Act (IDEA) guarantees appropriate and free educational services to students with disabilities.[14] While Part B of IDEA is focused on providing preschool and special education services to school-aged children, Part C of IDEA is focused on infants and toddlers aged 0 to 36 months and mandates an early intervention program (EIP) for infants and toddlers with disabilities. All US states and territories maintain EIPs. Eligibility for an EIP and follow-through occur at the state level, usually through health or human services departments.[15] States vary in the definition of eligibility categories and services. For example, recent US Department of Education data showed a wide range of EIP participation, from 1% in Colorado to 11% in Massachusetts, with an average of 3.7% participation across the US.[15,16]

Because most children are diagnosed with ASD after age 36 months, many children never receive EIP services.[2,17] Most children with ASD present with early developmental delays (DDs) and would qualify for EIP services because eligibility for services does not require an ASD diagnosis. To our knowledge, no epidemiologic studies to date have investigated the proportion of children with ASD participating in an EIP or examined demographic variations in EIP use. Moreover, there are no federal- or state-level sources reporting on EIP participation by children with ASD.[18] The Centers for Disease Control and Prevention's (CDC's) Autism and Developmental Disabilities Monitoring (ADDM) Network has shown that only 43.6% of children with ASD receive professional evaluations by age 36 months.[2,17] The remainder are not identified until after age 3 years, thereby missing the potential benefits of EIP. Interventions at younger ages can lead to improvement in ASD prognosis.[9,19,20] In addition, participation in EIP services may lead to earlier ASD diagnosis and access to additional services.[21]

Given the lack of empirical evidence on EIP use by the increasing number of children with a diagnosis of ASD in the US, in this cross-sectional study we examined EIP participation among children with ASD who were identified through active population-based surveillance. We evaluated the demographic and clinical factors that may be related to EIP participation. We also examined EIP participation patterns in a large, diverse, metropolitan area during the most recent decade.

Methods

Study Design

The analysis used repeated cross-sectional data from the New Jersey Autism Study, a population-based active surveillance

Key Points

Questions To what extent do children with autism spectrum disorder (ASD) participate in early intervention programs (EIPs) as mandated by the Individuals With Disabilities Education Act EIP, and are there differences among participants?

Findings In this cross-sectional study of 4050 children with ASD, identified by active surveillance by age 8 years, 1887 children used EIP services. Children from underserved (low socioeconomic status and racial and ethnic minority) communities were less likely to receive EIP services.

Meaning The findings suggest that the EIP system is underused by children with ASD from underserved communities and that cultural and socioeconomic barriers to early identification and EIP use can be identified and addressed through outreach and distribution of information.

system for the following surveillance years: 2006, 2010, 2012, 2014, and 2016. The New Jersey Autism Study is part of the CDC's ADDM Network, the largest US ASD tracking system, which has been tracking ASD prevalence among 8-year-old children since 2000.[2,17,22-26] The study was approved by the Institutional Review Board of Rutgers New Jersey Medical School, which also waived informed consent because public health investigations are allowed to be conducted under waiver of informed consent. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

Population and Setting

The study included children aged 8 years at the time of surveillance (2006, 2010, 2012, 2014, and 2016), representing cohorts born in 1998, 2002, 2004, 2006, and 2008, respectively. Participants resided in 4 New Jersey counties (Essex, Hudson, Ocean, and Union) during the surveillance year (**Figure 1**). Each cohort included approximately 30 000 children aged 8 years, representing 25% of the total state population of 8-year-old children. Denominators were obtained from the National Center for Health Statistics[28] (eTable 1 in the Supplement). Throughout the cycles, the population consisted of approximately 30% to 32% children who were Hispanic, 22% to 23% who were non-Hispanic Black, 41% to 43% who were non-Hispanic White, and 5% to 6% who were non-Hispanic other (which included Alaska Native or American Indian and Asian or Pacific Islander children).

In phase 1 of the surveillance, medical and special education records were retrospectively reviewed for all children who met the residency and birth year criteria and were either participating in special education services or had 1 or more surveillance-specific *International Classification of Diseases, Ninth Revision* codes[26]; approximately 15% of the study population satisfied phase 1 criteria. Information from individuals with 1 or more predetermined (autism-specific) triggers (eTable 2 in the Supplement) was abstracted into a chronologically organized file for each child. In phase 2, expert clinician-reviewers used a standard ASD surveillance case definition and study procedures to identify children

Figure 1. New Jersey Autism Study Surveillance Process, 2006 to 2016
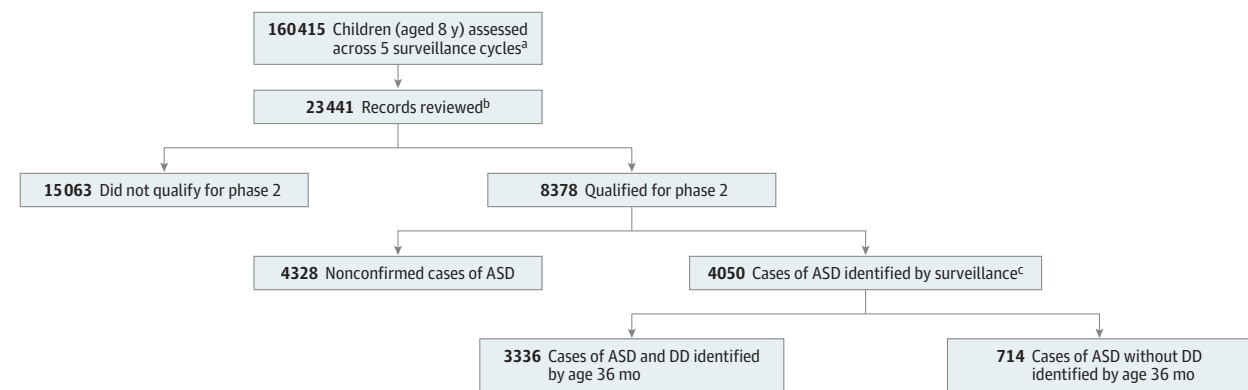
ASD indicates autism spectrum disorder; DD, developmental delay identified before age 36 months.

[a] Population denominators were obtained from the National Center for Health Statistics.

[b] Approximately 15% of the population qualified for phase 1 of the study based on residency, birth year, receipt of services through special education services in the surveillance year, having 1 or more surveillance-specific *International Classification of Diseases, Ninth Revision* codes, or some combination of these factors.

[c] Diagnoses of ASD were confirmed by an active surveillance standard case definition based on criteria in the *Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition, Text Revision).*[27]

with ASD. The surveillance definition was satisfied if behaviors documented in professional evaluations reflected ASD criteria specified in the *Diagnostic and Statistical Manual of Mental Disorders (Fourth edition, Text Revision).*[27] The surveillance system abstracts information for children qualifying for phase 2, including EIPs and preschool disabilities (PSD) services.

Study Variables

The main outcome variable was EIP participation (yes or no). Multiple factors were assessed to evaluate EIP participation by children with ASD. Demographic factors included sex and race and ethnicity. Race and ethnicity were based on information found in each child's record and categorized based on US Census reporting guidelines: Hispanic, non-Hispanic Black (Black), non-Hispanic White (White), and non-Hispanic other (other, which included Alaska Native or American Indian and Asian or Pacific Islander).

Ecological factors included proxies of socioeconomic status (SES), including median household income (MHI), poverty rates, and Social Vulnerability Index (SVI). Median household income and poverty rates at the census tract level were obtained from the US Census.[29-32] Median household income and poverty rates were not available for the 2006 cycle; therefore, 2010 census data were used for 2006. The study's primary SES variable was based on MHI tertiles for all census tracts: low SES (MHI, ≤\$57 933), mid SES (MHI, \$57 934-\$87 313), and high SES (MHI, >\$87 313). Areas with 20% or greater poverty rate were classified as poverty areas, and areas with less than 20% poverty rate were classified as nonpoverty areas.[33] Recognizing that social factors, including household composition and English language fluency, might affect EIP participation, we included the SVI as an additional SES proxy. The SVI is a multifactorial index developed by the CDC based on 15 socioeconomic and demographic factors grouped

into 4 themes: economic, household composition and disability, minority status and language, housing type and transportation.[34] Data on the SVI were available at the census tract level for 2010, 2014, and 2016.[34] Tertile ranks within the SVI were constructed for all census tracts: low vulnerability (0 to 33rd percentile), mid vulnerability (34th to 66th percentile), and high vulnerability (67th to 100th percentile). In New Jersey, EIP services are organized and provided at the county level. Because EIP use may vary by county, we adjusted our analysis at the county level.

Intellectual ability, degree of impairment due to ASD, and DD were included in analyses to examine variation based on these factors. Intellectual ability was classified as a 2-level variable (ASD without intellectual disability [IQ, >70] vs ASD with intellectual disability [IQ, ≤70]), based on the most recent documented IQ test score in the individual's record. Surveillance expert reviewers classified degree of impairment due to ASD as mild, moderate, or severe based on review of all information and reflecting the individual's need for services. Developmental delay was identified from indication of any DD before age 36 months. In addition, we analyzed differences among children with ASD receiving and not receiving EIP services with regard to documentation of ASD diagnosis, proportion diagnosed with ASD by age 48 months, and participation in PSD and special education services.

Statistical Analysis

Data were analyzed from June through December 2021. The proportion of children with ASD who were receiving EIP services throughout surveillance cycles, from 2006 to 2016, was assessed. We evaluated differences between children with ASD who did and did not receive EIP services by using Pearson χ^2 tests. Standard and multilevel models were fit to examine multiple factors associated with EIP participation, and adjusted odds ratios (AORs) and 95% CIs were estimated. Because chil-

Table 1. Distribution of Sociodemographic Factors Among Children With ASD Who Received and Did Not
Receive EIP Services and Among Children With ASD and DD Identified Before Age 36 Months

	No. (%)			
Characteristic	Total (N = 4050)	Received EIP (n = 1887)	Did not receive EIP (n = 2163)	Children with ASD and DD who received EIP (n = 1814)[a]
Sex				
Boys	3303 (81.6)	1530 (81.1)	1773 (82.0)	1473 (81.2)
Girls	747 (18.4)	357 (18.9)	390 (18.0)	341 (18.8)
Race and ethnicity				
Hispanic	1105 (27.3)	500 (26.5)	605 (28.0)	482 (26.6)
Non-Hispanic Black	801 (19.8)	347 (18.4)	454 (21.0)	332 (18.3)
Non-Hispanic White	1816 (44.8)	892 (47.3)	924 (42.7)	863 (47.6)
Non-Hispanic other[b]	328 (8.1)	148 (7.8)	180 (8.3)	137 (7.6)
Socioeconomic status[c]				
Low	1843 (45.5)	769 (40.8)	1074 (49.7)	738 (40.7)
Mid	1297 (32.0)	635 (33.7)	662 (30.6)	612 (33.7)
High	910 (22.5)	483 (25.6)	427 (19.7)	464 (25.6)
New Jersey county				
Essex	1241 (30.6)	584 (30.9)	657 (30.4)	563 (31.0)
Hudson	812 (20.0)	329 (17.4)	483 (22.3)	312 (17.2)
Ocean	1006 (24.8)	462 (24.5)	544 (25.2)	446 (24.6)
Union	991 (24.5)	512 (27.1)	479 (22.2)	493 (27.2)
Birth cohort, y				
1998	532 (13.1)	209 (11.1)	323 (14.9)	204 (11.2)
2002	696 (17.2)	296 (15.7)	400 (18.5)	286 (15.8)
2004	803 (19.8)	371 (19.7)	432 (20.0)	353 (19.5)
2006	964 (23.8)	426 (22.6)	538 (24.9)	409 (22.6)
2008	1055 (26.0)	585 (31.0)	470 (21.7)	562 (31.0)

Abbreviations: ASD, autism spectrum disorder; EIP, early intervention program; DD, developmental delay.

[a] Children with DD identified before age 36 months are more likely to be identified early with ASD and receive EIP.[35]

[b] Includes Asian or Pacific Islander and American Indian or Alaska Native.

[c] Based on median household income at the census tract level. Data were obtained from the US Census.

dren with diagnoses of ASD and DD before age 36 months would be more likely to be eligible for EIP services than children with a diagnosis of ASD without DD before age 36 months,[35] we restricted our models to children with ASD and DD before age 36 months (n = 3336) in our primary analysis. We refit the models using the full cohort without restriction to those with a diagnosis of DD before age 36 months. Covariates were selected a priori: birth cohort year, intellectual ability, degree of impairment, sex, race and ethnicity, SES (MHI), and county of residence. We estimated 4 models: model 1, adjusted for birth cohort year only; model 2, adjusted for birth cohort year and clinical factors; model 3, adjusted for birth cohort year, clinical factors, and demographic factors; and model 4 (multilevel model), adjusted for all prior factors plus ecological factors. This sequence of model staging was based on a priori expectations of the likely association with EIP participation each factor would have in the model (ranging from highest to lowest association). Autism spectrum disorder prevalence was estimated for each surveillance cycle, and 95% CIs were computed using the Wilson score method. We used a significance level of 2-sided $P < .05$ for all reported outcomes. Statistical analyses were performed using SAS, version 9.4 (SAS Institute Inc) and R, version 4.1.3 (R Foundation for Statistical Computing).

Results

A total of 4050 children aged 8 years satisfied the ASD surveillance case definition throughout the cycles, 2006 to 2016.

Of these 4050 children, 3303 (81.6%) were boys, and 747 (18.4%) were girls; 1105 (27.3%) were Hispanic, 801 (19.8%) were non-Hispanic Black, 1816 (44.8%) were non-Hispanic White, and 328 (8.1%) were non-Hispanic other children. Prevalence of ASD ranged from 17.5 per 1000 children (95% CI, 16.0-19.0 per 1000 children) in 2006 to 31.8 per 1000 children (95% CI, 30.0-33.8 per 1000 children) in 2016, an 82% increase. Among children with ASD, 3336 (82.4%) had a documented diagnosis of DD identified before age 36 months; among those, 1814 (54.4%) received EIP services (Part C of IDEA). Among the 4050 children with ASD with or without DD identified before age 36 months, 1887 (46.6%) received EIP services. A stepwise increase in the use of EIP services was evident between 2006 and 2016, from 209 of 532 children with ASD (39.3%) born in 1998 to 585 of 1055 (55.5%) born in 2008, a 16.2 percentage point difference (**Table 1**).

Boys and girls with ASD were equally likely to receive EIP services. Socioeconomic status appears to have been a factor in EIP participation. Children residing in high and mid SES census tracts were more likely to receive EIP than children residing in low SES census tracts (Table 1). An increase in EIP participation with increasing SES status was observed (**Figure 2**C). Overall, 779 of the 4050 children with ASD (19.3%) resided in areas designated as poverty areas[33]; 320 of those (41.1%) participated in EIP compared with 1560 of the 3252 children (48.0%) residing in nonpoverty areas. Poverty areas are classified by the US Census as areas with greater than 20% of the population below the poverty rate. Similar patterns in EIP participation were observed when SVI was examined. Overall, children with ASD residing in highly vulnerable areas were less
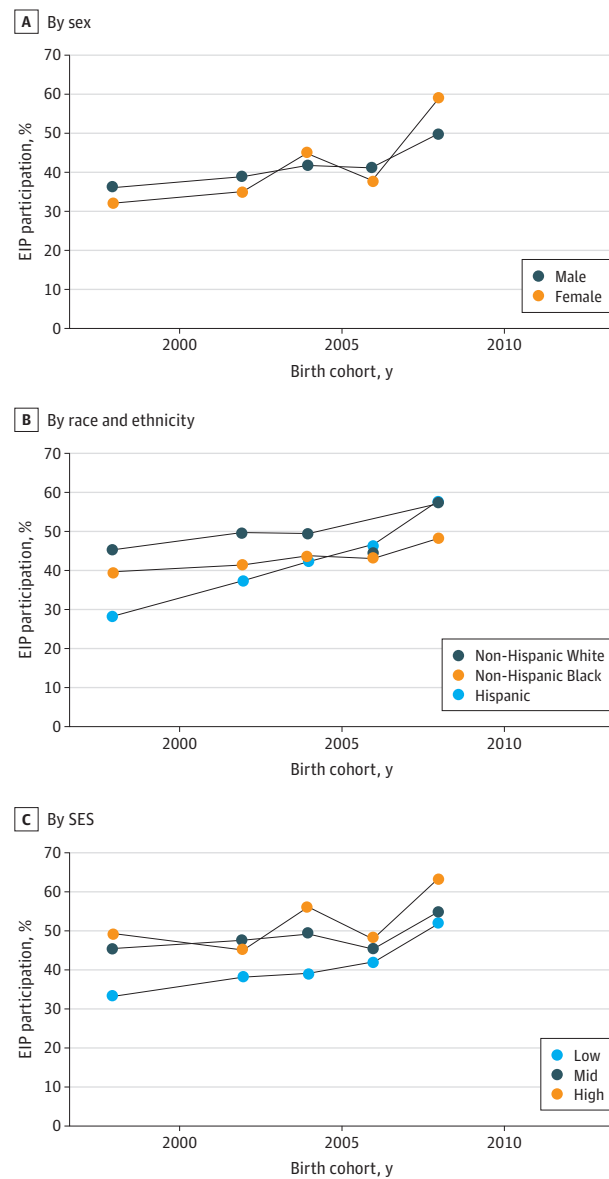
Participation in an EIP by different sociodemographic subgroups from 2006 to 2016 is shown. SES indicates socioeconomic status.

likely to participate in EIP compared with their peers residing in less vulnerable areas (eTable 3 in the Supplement). Differences associated with race and ethnicity were also evident. White children with ASD were more likely than their Black and Hispanic peers to receive EIP services (Table 1). In addition, we observed substantial variation in EIP use at the county level. Union County had the highest proportion of children with ASD receiving EIP services (512 of 991 [51.7%]), and Hudson County had the lowest proportion (329 of 812 [40.5%]) (Table 1).

Children with more severe impairment due to ASD (as classified by the surveillance expert reviewers) and level of intellectual disability or both were more likely to receive EIP ser-

vices (Table 2). Children who received EIP services were more likely to have a documented ASD diagnosis and to receive the diagnosis of ASD earlier than children who did not receive EIP services even after demographic and clinical factors were controlled for. Furthermore, 2667 of 4050 children with ASD (65.9%) received PSD services (Part B of IDEA); however, among the 1887 children participating in EIP (Part C of IDEA), 1661 (88.0%) received PSD services compared with 1006 (46.5%) receiving PSD services among the 2163 children with ASD who did not participate in EIPs. Similar patterns were observed when we evaluated autism special education eligibility and participation in special education services in general (Table 2).

Demographic, ecological, and clinical factors, as well as temporal patterns, were examined by using standard and multilevel logistic regression models. Analyses were restricted to children with ASD and DD identified before age 36 months (3336 [82.4%]) (Table 3). Estimates for individual factors were largely stable across the 4 models. In the fully adjusted multilevel model (model 4), Black children (AOR, 0.67; 95% CI, 0.54-0.84) and Hispanic children (AOR, 0.77; 95% CI, 0.63-0.94) had lower odds of EIP participation compared with their White peers. Similarly, children residing in high SES areas (AOR, 1.71; 95% CI, 1.36-2.15) and middle SES areas (AOR, 1.50; 95% CI, 1.25-1.81) had higher odds of EIP participation than children residing in low SES areas. A child with ASD and DD identified before age 36 months who were born in 2008 had 2.64 greater odds (95% CI, 2.07-3.36 greater odds) of participating in an EIP than a child born in 1998. Results of secondary models using the full sample of 4050 children (without regard to diagnosis of DD before age 36 months) had patterns similar to those of the primary models (eTable 4 in the Supplement).

Discussion

To our knowledge, this is the first population-based study to document receipt of EIP services by children with ASD in a large diverse US metropolitan area and the first to assess variation in EIP participation by demographic, clinical, and temporal factors. Only 46.6% of the children with ASD in the study population received EIP services; however, the number and proportion of children with ASD receiving EIP increased during the 10-year period. When adjustments for covariates were made, children born in 2008 had 2.64 greater odds of receiving EIP compared with children born in 1998, suggesting greater use of EIPs over time by children with ASD in the study region. The findings revealed inequalities in EIP participation based on race and ethnicity and SES. With only 46.6% of the children with ASD receiving EIP services and large demographic disparities in EIP participation, these findings suggest that substantial changes are needed to improve identification of ASD and to increase EIP participation by children with ASD from low SES and racial and ethnic minority communities.

Our findings are consistent with prior studies showing socioeconomic and racial and ethnic disparities with regard to ASD identification and intervention.[35-39] After accounting for multiple clinical and ecological factors, we observed that Black and Hispanic children had significantly lower odds (AORs,

Table 2. Differences in Clinical and Service Factors Among 4050 Children With ASD Who Received and Did Not Receive EIP

Factor	No. (%)		
	Total (N = 4050)	Received EIP (n = 1887)	Did not receive EIP (n = 2163)
Intellectual ability, IQ			
>70	2487 (61.4)	1092 (57.9)	1395 (64.5)
≤70	1252 (30.9)	659 (34.9)	593 (27.4)
Unknown	311 (7.7)	136 (7.2)	175 (8.1)
Degree of impairment			
Mild	1678 (41.4)	683 (36.2)	995 (46.0)
Moderate	1460 (36.0)	681 (36.1)	779 (36.0)
Severe	912 (22.5)	523 (27.7)	389 (18.0)
ASD diagnosis documented[a]	3050 (75.3)	1480 (78.4)	1570 (72.6)
ASD diagnosis by age 48 mo	1521 (37.6)	1025 (54.3)	496 (22.9)
Special education services			
PSD services	2667 (65.9)	1661 (88.0)	1006 (46.5)
Autism eligibility	1842 (45.5)	968 (51.3)	874 (40.4)
Special education services under any eligibility	3586 (88.5)	1711 (90.7)	1875 (86.7)
Development			
DD identified before age 36 mo	3336 (82.4)	1814 (96.1)	1522 (70.4)
Social and/or language regression[b]	588 (14.5)	380 (20.1)	208 (9.6)

Abbreviations: ASD, autism spectrum disorder; DD, developmental delay; EIP, early intervention program; PSD, preschool disabilities services.

[a] A diagnosis of ASD refers to documentation of an ASD diagnosis conferred by a community professional for an ASD case that met the surveillance definition. On average, in New Jersey, 20% of cases identified by surveillance do not have an ASD diagnosis conferred by a community professional.[3]

[b] Regression refers to documented loss of social skills, speech and language skills, or both sets of skills as determined by professional evaluations.

Table 3. Standard and Multilevel Logistic Regression Models Examining the Odds of Receiving EIP Services Among 3336 Children With ASD and Developmental Delay Identified Before Age 36 Months[a]

Factor	Model 1, OR (95% CI)[b]	AOR (95% CI)		
		Model 2[b]	Model 3[b]	Model 4[c]
Birth cohort, y				
1998	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
2002	1.33 (1.04-1.70)	1.31 (1.02-1.67)	1.35 (1.06-1.74)	1.28 (0.99-1.65)
2004	1.55 (1.22-1.97)	1.59 (1.25-2.02)	1.65 (1.30-2.10)	1.58 (1.23-2.02)
2006	1.45 (1.16-1.84)	1.49 (1.19-1.88)	1.59 (1.26-2.02)	1.51 (1.18-1.92)
2008	2.51 (2.00-3.17)	2.62 (2.08-3.31)	2.79 (2.20-3.53)	2.64 (2.07-3.36)
Clinical factor				
Intellectual ability, IQ				
>70		1 [Reference]	1 [Reference]	1 [Reference]
≤70		1.04 (0.89-1.22)	1.18 (1.00-1.39)	1.27 (1.07-1.50)
Unknown		0.87 (0.66-1.13)	0.86 (0.66-1.13)	0.92 (0.70-1.22)
Degree of impairment				
Mild		1 [Reference]	1 [Reference]	1 [Reference]
Moderate		1.16 (0.99-1.37)	1.20 (1.01-1.41)	1.21 (1.03-1.44)
Severe		1.66 (1.37-2.01)	1.71 (1.41-2.08)	1.72 (1.41-2.10)
Sociodemographic factor				
Sex				
Female			1 [Reference]	1 [Reference]
Male			1.02 (0.85-1.21)	1.01 (0.84-1.22)
Race and ethnicity				
Hispanic			0.61 (0.51-0.72)	0.77 (0.63-0.94)
Non-Hispanic Black			0.55 (0.45-0.66)	0.67 (0.54-0.84)
Non-Hispanic White			1 [Reference]	1 [Reference]
Non-Hispanic other[d]			0.69 (0.52-0.91)	0.72 (0.55-0.96)
Ecological factor				
Socioeconomic status[e]				
Low				1 [Reference]
Mid				1.50 (1.25-1.81)
High				1.71 (1.36-2.15)

Abbreviations: AOR, adjusted odds ratio; ASD, autism spectrum disorder; EIP, early intervention program; OR, odds ratio.

[a] All logistic regression models were restricted to children with ASD and noted developmental delay identified before age 36 months.

[b] Models 1 to 3 are standard logistic regression models and were restricted to children with ASD and noted developmental delay identified before age 36 months.

[c] Model 4 is a multilevel model that accounts for ecological factors and socioeconomic status (at the census tract level) nested within the study counties.

[d] Includes Asian or Pacific Islander and American Indian or Alaska Native.

[e] Based on median household income at the census tract level obtained from the American Community Survey, US Census.[29-32]

0.67 and 0.77, respectively) of EIP participation than White children. We cannot pinpoint where in the "pipeline" these disparities emerged, but studies have suggested that every step in the ASD diagnostic process is important for intervention.[40] Socioeconomic status was an important determinant of EIP receipt, with children from affluent areas having greater odds of receiving EIP (AOR, 1.71) compared with children from underserved areas. The considerable disparities indicate that novel strategies, efforts, and policies are needed to expand ASD screening and to improve access to care, especially for children from low-income and racial and ethnic minority communities.

As expected, we observed that children with more severe ASD impairment, intellectual disability, or both were more likely to receive EIP services. That differential is understandable; however, toddlers (children aged 18-36 months) with mild ASD impairment and average IQ are also likely to benefit from early interventions and should lead us to approaches to identify children with ASD throughout the range of ability and impairment.[41]

This study's findings suggest multiple downstream benefits to EIP participation. Children with ASD who received EIP services were more likely to go on to receive IDEA Part B PSD services and special education services. Transitions from IDEA Part C to Part B services were successful; 88.0% of children who participated in EIP received PSD services compared with 46.5% of children who did not participate in EIP. Participation in EIP may provide families with additional opportunities to gather information and interact with community professionals, potentially leading to completed diagnostic referrals. This advantage can be surmised from our finding that children who participated in EIP were more likely to receive an early ASD diagnosis compared with peers who did not receive EIP services. Our findings are consistent with a recent analysis[21] showing that children who received EIP services were diagnosed 2 years earlier than their peers who did not participate in EIPs.

Multiple organizations and entities consider early identification of and intervention for ASD to be a public health priority.[5,12] Many studies have shown encouraging results regarding the usefulness of early interventions.[9,42,43] More rigorous studies are needed to evaluate long-term effects of EIP participation. Universal autism screening of toddler-age children is needed to identify those who are at risk and to provide appropriate care and services for affected persons with a range of impairment. Some studies[44] suggest that autism screening is lagging in the US compared with other developed countries. Our findings show that underserved areas should be particularly targeted for ASD screening initiatives. Early ASD screening, provision of EIP services to children with ASD, and comprehensive professional evaluation are vital steps. With autism prevalence estimates approaching 7% in some communities,[3] enhanced support for EIPs and improved access to clinical and educational services will be essential to address the increasing number of affected children and to reduce socioeconomic and race-based disparities in autism identification and care.

Strengths and Limitations

To our knowledge, this is the first population-based study to estimate the proportion of children with ASD who received EIP services and to examine demographic factors associated with receipt of those services. The ADDM method is considered the criterion standard strategy of active case finding. Strengths include the size and diversity of the surveillance population, access to educational and clinical information, ability to determine the number of undiagnosed cases of ASD satisfying the autism definition, comprehensive case-level information among 5 cohorts in a 10-year period, and consistent access to information from sources. The study region is within one of the most populous and diverse metropolitan areas in the US.

This study also has limitations. One limitation is the lack of information regarding EIP services, including age at initial receipt of EIP services and the intensity of services. Although some children receive EIP services by age 18 months, others may not have begun receiving services until they were nearly 3 years old, and EIP services are likely to vary by degree of impairment. In addition, we used multiple ecological variables as proxies for SES that do not reflect individual-level information. Furthermore, surveillance was conducted in 4 urban-suburban New Jersey counties representing approximately 25% of the total state population of 8-year-old children, and the findings may not be representative of the entire state or the US.

Conclusions

In a populous US metropolitan region with high levels of access to educational and health resources, this cross-sectional study's findings indicated that only 46.6% of children diagnosed with ASD through active surveillance at age 8 years received EIP services. The use of EIPs increased 16.2 percentage points during the 10-year study period. Socioeconomic status- and race-based disparities in EIP participation, a key early and universal resource, were observed. Universal and effective ASD screening may enhance early identification and help to redress disparities in detection and intervention. It is important to track service use among an increasing number of children with ASD, especially those from diverse regions, to identify the needs of the population and uncover health disparities as well as provide meaningful information on overall shifts in community health over time. Additional novel strategies and resources are needed to improve early evaluation and intervention for young children with ASD.

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