

DISPARITIES IN AUTISM DIAGNOSIS

DISPARITIES IN AUTISM DIAGNOSIS FOR CHILDREN: IMPACT OF RACE, GENDER,  
AND SES

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work] *and* perfecting *and* bringing it to full completion in you.” We did it honey, and I give God all the glory, honor, and praise.

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## ABSTRACT

### DISPARITIES IN AUTISM DIAGNOSIS FOR CHILDREN: IMPACT OF RACE, GENDER, AND SES

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Autism Spectrum Disorder or autism is a neurodevelopmental disorder affecting one in 36 children (Hodges et al., 2020). Diagnostic rates of autism have increased with boys being diagnosed at rates more than 3 times greater than girls (CDC, 2023). One of the critical impacts to autism is the timing of the diagnosis. According to Landa (2008) screening for autism can begin as early as 12 months, but the mean age of diagnosis falls between 51 and 53 months (Kilmer & Boykin, 2022). The disparity between screening and confirmation of autism diagnosis could lead to delays in children meeting their developmental milestones or eliminate the gap where early intervention can improve outcomes for impacted children. Research has shown a recent reversal in diagnostic rates, with non-White children being diagnosed more often than white children (Maenner et. al. 2023). Understanding the disparities in diagnosis and how they impact care could lead to improvements in screening and confirming diagnosis. The results of the study showed boys were diagnosed with autism more often than girls and at an earlier age.



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Black children were diagnosed more often than any other race. Socio-economic status/federal poverty level (SES/FPL) was the most significant predictor of diagnostic rates in the study.

*Keywords:* autism, diagnosis, gender, race, SES/FPL

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## CHAPTER ONE: DISPARITIES IN AUTISM DIAGNOSIS FOR CHILDREN: IMPACT OF RACE, GENDER, AND SES

Autism Spectrum Disorder (autism) is a neurodevelopmental disorder characterized by (a) deficits in communication and social interactions, and (b) the presence of repetitive behaviors such as hand and arm flapping, or preoccupation of narrow interests (Hodges et al., 2020). These behaviors can range from normal and typical childhood behaviors to diminished intellectual capacity (Rapin & Tuchman, 2008). Based on the current version of the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition Text Revision (DSM-5-TR, American Psychiatric Association, 2022), autism spectrum disorder is defined by meeting five diagnostic criteria, as follows:

(a); persistent deficits in social communication and social interactions, which must meet the three accompanying deficits for this criterion (b); restricted, repetitive behaviors, interests or activities and at least two out of four behaviors for this criterion (c); symptoms present during the early developmental period (d); the symptoms cause clinically significant impairment in social occupations, or other important areas of current functions; and, (e) disturbances cannot be explained or diagnosed using a diagnosis of intellectual developmental disorder, intellectual disability or global developmental delay (American Psychiatric Association, 2022, pp 56-58).

### **Autism Diagnosis and Identification Process**

According to the Centers for Disease Control and Prevention (CDC, 2023), one in 36 children are diagnosed with autism, with boys diagnosed almost 4 times as likely than girls. In comparison, in the 1960's and 1970's the rates of autism were two in 1,000 (Fombonne, 2018). The rates of autism and diagnosis are irrespective of race, ethnicity, or SES. Early signs of

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autism can subtly appear before the age of two and persist over time. These symptoms can be the avoidance of social interactions, ignoring a parent or guardian calling the child by his or her name, and an increasing preoccupation with a specific item or the item's function (Kennedy Krieger Institute, 2013; Center for Autism and Related Disorders, n.d.).

Early identification of autism requires collaboration between parents, caregivers, and the child's pediatrician to monitor the child's behavior for symptoms of autism (Landa, 2008). In most cases, parents spend the most time with the child. During this period, their accounts of the child's behaviors become one of the earliest methods of identifying autism (Landa, 2008). This method leads to the parental interview and allows the appropriate medical professional to develop a monitoring process of the symptoms.

The symptoms of autism may change overtime or beyond the child's first year of birth. It becomes important to not only monitor the behavioral symptoms of autism, but also atypical developmental behaviors for the child's age (Lord & Luyster, 2006). According to Kilmer and Boykin (2022), by the time a child has reached age two, continuous symptoms are observable to confirm an autism diagnosis. This takes place through the collaboration of experts which may include a pediatrician, psychologist, and any other medical expert qualified to administer the appropriate examinations to confirm the diagnosis (Landa, 2008). Clinical screening for autism can begin as early as 12 months. If a diagnosis is suspected at the 12-month mark but not confirmed, repeat screenings can take place at three-, six-, and twelve-months intervals (Wieckowski et al., 2021). Khozaei et al. (2020) noted the early detection of autism and the increase of confirmed cases of autism warrant universal screening in children. In cases where early screening for autism is conducted, whether there is a positive diagnosis of autism or not, some children and families may benefit from an Early Intervention Program (EIP) (Landa,

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2008). An EIP is a program designed for preschool aged and younger children to help them develop their physical, thinking, communication, social, and emotional skills alongside children of their same age (National Institutes of Health [NIH], 2017). The EIP is not guaranteed to reduce the behavioral symptoms related to autism, but to provide an opportunity for children to meet their developmental milestones. The EIP can begin in the preschool age and be conducted for at least 20 hours per week (Landa, 2008). The effectiveness of an EIP is greater the younger the child is and has been shown to improve the developmental performance of a child living with autism (Khozaei et al., 2020). Children eligible for an EIP can be referred by their primary care physician to a local community provider or self-refer their child to a Part C provider under the Individuals with Disabilities Education Act (IDEA) Services if the parents believe their child(ren) has autism or other developmental problems (CDC, 2020).

According to Khowaja et al. (2017), research on two-tiered screening, investigators point to the high rates of false positive diagnosis with an initial screening. In instances where a second screening at a predetermined interval was scheduled, some children were discovered to not have a diagnosis of autism after screening two, highlighting the importance of multiple screenings. The CDC (2018) recommends developmental monitoring between parents, caregivers, and extended family, as well as educational personnel along with the medical providers to monitor a child's progress as they grow. Developmental monitoring in conjunction with screenings, gives those with the most access to the child, the necessary tools on which specific behaviors should be monitored, and at which age to ensure the child is meeting his or her developmental milestones in comparison to children their age. Working together, these tools become a resource in detecting autism (CDC, 2018).

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### **The Impact of Social Cultural Variables on Early Autism Identification: Race, Gender, SES**

#### **Race**

With the increasing rates of autism nationally, available data shows the impact and the importance of early screening. Of equal importance is examining race and its relationship to autism diagnoses.

**Black Children.** According to the CDC Community Report on Autism for North Carolina (CDC, 2018), autism diagnosis among White children is 1.6 times more likely than Black children and 1.4 times more likely than Hispanic children, and Black/African American children were more likely to be identified with autism than Hispanic children (ADDM, n.d.). In some instances, Black children are misdiagnosed with psychiatric disorder, and autism is not diagnosed until much later if at all compared to White and Hispanic children (Jones & Mandell, 2020). Researchers suggest one of the disparities in autism among race and Black /African American children is an absence of Black autism researchers at all levels and the absence of Black trainees which includes "scientists, practitioners, and researchers at the doctoral, postdoctoral and junior faculty levels" (Jones & Mandell, 2020).

Jones and Mandell (2020) believe hiring and developing Black trainees will close the gap between missed and delayed autism diagnoses in the Black community. There is concern about how Black parents report or underreport the symptoms of autism. Past studies (Donohue et al., 2017) suggest Black parents, underreported, or did not report autism concerns or specific behaviors associated with autism such as speech, repetitive, social, or restrictive behaviors, while at the same time reporting other concerns of behaviors unrelated to autism. Donahue et al. (2017) further highlighted the gap in reporting of autism behaviors. In their study, White parents were four times more likely to report typical autistic related behaviors, while Black parents failed to

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report symptoms of autism which has been a contributing factor in the disparity gap of autism diagnosis among Black children (Donohue et al., 2017). The sample size was relatively small ( $n = 174$ ) divided across two sites: Atlanta and Connecticut.

According to Constantino et al. (2020), the gap in diagnosis among Black children is varied, but large enough for concern. In this study which consisted of Black/African American children only ( $n = 584$ ), parents and children across four sites shared their experiences in how an autism diagnosis was made. Parents stated their concerns about autism behaviors were ignored, but the average age of first reported symptoms three years before a formal diagnosis. When appointments were made, there was a delay in appointments because of the shortage of qualified professionals to make a diagnosis, also leading to a higher wait time during the appointment. An Intellectual Disability (ID) diagnosis among these participants was twice as high as the national average, which could lead to inability to meet developmental milestones, and worsen the impact of an autism diagnosis.

**Latino Children.** Latino and Hispanic children are also diagnosed later than the national average (2.5 years later) or receive a diagnosis when symptoms of autism have become most severe (Zuckerman et al., 2014). According to research conducted among Latino parents ( $n = 33$ ), from both urban and rural areas, barriers to autism diagnosis are for several reasons including stigma of autism within the culture, lack of resources in Spanish, and parents' education related to autism and the symptoms for monitoring. Of the parents included in the study, most were born in Mexico and had less than a high school education (Zuckerman et al., 2014). Researchers noted the themes of lack of parent and community information on autism, the negative perception of a mental or disability diagnosis in Latino culture, and the traditional masculine view of Latino males, and their expectations as barriers to autism diagnosis. These

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themes were uncovered through a qualitative study, including responses that families in Mexican communities would hide a child with a disability because culturally the child would be considered an embarrassment. Qualitative data also suggests fathers would have less involvement with the child if autism or a diagnosis were given, and fathers would choose not to have any more children out of fear of having another child with a disability (Zuckerman et al., 2014). Three years later in a follow up study (Zuckerman et al., 2017), researchers increased the sample size of families ( $n = 352$ ) with half of participants being Latino, to examine the disparities in diagnosis and treatment of Latino children to non-Latino white families. Access to material in Spanish and limited English were noted as barriers to care. In fact, the results show Latino families with limited English proficiency (85%) and Latino families with English proficiency (72%) reporting parents having knowledge of autism as the biggest barrier (Zuckerman et al., 2017). The process to a diagnosis and trusting doctors were the next biggest concern of Latino parents, and sheds light on the concern of resources being present. A lack of bilingual doctors and bicultural staff are reasons the Latino families did not trust the doctors and medical staff. In the absence of bilingual doctors and staff, Latino families were not able to culturally identify with the diagnosis of autism or its symptoms or know the signs to look for.

### **Gender**

The prevalence rate of autism is 3.8 times more likely for boys than girls (43.0 versus 11.4 per 1,000; Maenner, 2023). Girls also often receive an autism diagnosis even later if there is no concern for intellectual disabilities (Hiller et al., 2015; Loomes et al., 2017). Gender bias is cited as one of the reasons girls often receive a diagnosis significantly later than in boys, but researchers also believe diagnostic screening is biased against girls, leading to missed diagnosis (Loomes et al., 2017). More than 50 studies were examined leading to the discovery of

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inadequate measures or measures that were not well established being used to make an autism diagnosis. A second discovery was among forty of the studies which showed a failure to demonstrate if the participants represented a national population before making claims of the findings (Loomes et al., 2017). To provide answers as to why there is disparity in autism diagnosis between boys and girls, Postorino et al. (2015) conducted a longitudinal study of preschool children ( $n = 60$ ), between 2-0 and 5.4 years of age, ( $M = 3.55$ ). Participants were assessed using the ADOS-G when the study was conducted in 2015. For background information, we must note the current version, the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2), the US standard of diagnosing autism, was released in 2012, three years before the study was conducted.

Using outdated instruments in some cases can lead to under or over identification among the participants being assessed, and results should be interpreted with caution. There were no noted differences in behavior of the children that would explain the disparity in diagnosis among girls. Gender, time, and parental stress were all factors ruled out as contributing factors to missed diagnosis in girls. In a later study Ratto et al. (2018) introduced the theory of camouflaging as a barrier to girls receiving an autism diagnosis. The theory of camouflaging suggests girls face pressure to fit into societal norms, gender expectations set by parents and society, as well as the ability to have strong social and communication abilities. To meet these standards, girls with autism will camouflage or mask their traits that could lead to an autism diagnosis. The researchers noted one way this was identified was through the gap in symptoms reported by the parents versus the symptoms of impairments identified by the clinicians who could make the diagnosis. When girls are camouflaging their behavior, current measures used to identify autism in boys and girls may not identify autism in girls.



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To understand functional differences among preschoolers who were diagnosed with autism, Craig et al. (2020) investigated to see which variables would be different between male and female children in the study ( $n = 114$ ) age ( $M = 4.5$ ,  $M = 4.2$  females). All participants were assessed using the ADOS-2, and the Psychoeducational Profile-Third Edition (PEP-3).

Researchers noted ID in 93.5% of the cases in male children and 91.2% of the cases in female children, noting each group shared similarities of symptoms and the severity. Differences were related to motor skills with females having significantly stronger fine motor skills than males, but males displayed more developed gross motor skills. The researchers were able to determine that lower performance on the PEP-3 predicted ADOS-2 performance in male children. Craig et al. (2020) found that female children, show a weaker relationship between fine motor skills, communication skills and social affect, while fine motor skills in male children was a predictor of social affect.

### **Socioeconomic Status**

Socioeconomic status (SES) is the place where a person falls along an economic scale which correlates with overall quality of life, wellbeing, income, occupation, homeownership, ethnicity and in some cases social standing (Majumder, 2021; Noël, 2018). SES is a stable and consistent predictor of lifespan development and outcomes, and can be measured at societal, community, neighborhood, and individual levels (APA, 2015; APA, 2017). Within SES, the “big 3” variables are family income, parental educational attainment, and parental occupation, which are combined to give the best overall picture of SES (National Center for Education Statistics, 2013). SES may have an impact on parents understanding of the symptoms of autism, testing for autism, and understanding of resources to care for a child who may be diagnosed with autism (Zuckerman et al., 2015). Previous research on SES and autism has focused on the neighborhood

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and its impact on the community. In neighborhoods with insufficient resources and disorganization, stress and fewer resources are negatively impacting health and wellbeing (King & Bearman, 2011).

Further review of the literature has shown a correlation between higher SES and autism diagnosis, while the opposite is true of children from lower SES backgrounds. Compared to children of higher SES, Children of lower SES were diagnosed often 3-4 times later in the same period compared to higher SES children (Durkin et al., 2017). Recent research has shown greater maternal education and access to healthcare increases the likelihood of autism diagnosis (Aylward et al., 2021). The general hypothesis is that mothers who are more educated about the early symptoms of autism will be more conscious of observing their children earlier in life and for the early signs that could lead to a diagnosis of autism. When the earlier diagnosis is made, parents are able to take advantage of an early intervention plan to ensure their children meet developmental milestones (Aylward et al., 2021).

Researchers have indicated that, in the state of California, the gap is closing between racial disparities in diagnoses regardless of SES. Kilmer and Boykin (2022) looked at the pattern of autism diagnosis in California between the years 1992-2018. Reviewing all birth records for this period ( $n = 13, 272, 573$ ) among children (ages 3–6-year-old) researchers noticed two trends. First, White children among higher SES families were diagnosed more frequently than other racial groups and SES backgrounds. In addition, the rates of autism diagnosis had a 612% increase between 1998-2018 (Winter et al., 2020). By the time the study concluded in 2018, SES no longer led to faster diagnosis among the highest SES families. In fact, diagnosed cases of autism were higher among Black and Hispanic children of lower SES backgrounds, than they were of White children. This significant change in diagnoses in California is attributed to the

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widespread knowledge and resources of the increased prevalence of autism and the importance of early diagnosis (Winter et al., 2020). Since 2009, the California Senate committee on Autism and Related disorders has worked to implement universal screening for autism at well-child visits. This came about after the 2006 recommendation by the American Academy of Pediatrics. Part of the initiatives included improving cultural competency by ensuring social services workers were bilingual and bicultural when interacting with nonwhite families. Additionally, the Senate committee conducted hearings to purposely ensure all children had access to regional centers specializing in autism. These initiatives combined contributed to more diagnosis and the expansion of care to all children irrespective of race (Winter et al., 2020).

The most up to date research related to autism diagnostic rates comes from the Autism and Developmental Disabilities Monitoring Network (ADDM). This research shows a recent reversal in racial disparities in diagnoses within eleven states participating in the ADDM (Maenner et al., 2023). According to Maenner et al. (2023), in 2020 children 8 years of age, Black children (29.3%), Hispanic children (31.6%), and Asian/Pacific Islander children (33.4%) were all diagnosed more often than White children (22.9%). The results show, 50.8% of Black children, 34.9% of Hispanic children, and 41.5% of Asian/Pacific Islander children with co-occurring intellectual disability. Those children with autism and intellectual disabilities were diagnosed with autism at an earlier age (3.7 years) than children in the study without intellectual disabilities (4.5 years). Rates of autism diagnosis had also increased 1% in girls for the first time since the first report in 2002 (Maenner et al., 2023). The first gap in autism diagnoses among Black and White children closing was noted in 2014. By 2020 rates of diagnoses among Black and Hispanic children had risen a minimum of 30%. In the same period, diagnostic rates among White children were only 14.6% higher from 2018 to 2020. The data represents a drastic change

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in direction of diagnoses and recognizes early identification to be by the age of 4 years of age to measure progress of children between 4-8 years of age from comparable upbringing and neighborhoods across the network (Maenner et al., 2023).

### **Purpose of the Present Study**

This study aims to investigate further the social cultural factors specifically, race, gender, and SES, which contribute to the disparity in autism diagnosis and age of diagnosis. Based on the current literature, my research questions and hypotheses are as follows:

**Research Question 1.** Do diagnostic rates differ across gender?

*H<sub>0</sub>*: There will be no difference in diagnostic rates among boys or girls.

*H<sub>1</sub>*: There will be a significant difference in diagnosis of autism, with boys receiving more diagnosis than girls.

**Research Question 2.** Does gender of the child account for differences in age of diagnosis?

*H<sub>0</sub>*: There will be no difference in age of diagnosis between boys or girls.

*H<sub>1</sub>*: The mean age of diagnosis for boys will be greater than girls.

**Research Question 3.** Does race of the child contribute to the disparity in diagnosis of autism among White, Black, and Hispanic children?

*H<sub>0</sub>*: Race will have no impact on diagnosis of autism between White, Black, and Hispanic children.

*H<sub>1</sub>*: Disparities of autism will be evident among races, with White children accounting for more diagnoses than Black and Hispanic children, and Black children receiving more autism diagnoses than Hispanic children.

**Research Question 4.** Does SES have an impact on diagnosis of autism?

*H<sub>0</sub>*: Diagnosis of autism is not impacted by SES.

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*H1:* Children of higher SES will be diagnosed more often than children from lower SES.

### **National Survey of Children's Health**

#### **Methods**

##### **Participants**

The participants included in the study totaled 225,443 of which 1,042 were excluded from the analysis due to missing data. A total of 6,368 participants across eleven states were identified as having autism. Girls identified with autism totaled 1,332 and boys identified with autism totaled 5,036. Children with two or more races totaled 751, American Indian/Alaskan Native children totaled 29, Asian/Pacific Islander children totaled 476, Black children totaled 419, Hispanic children totaled 778, White children totaled 3921 (see Table 1 for participant characteristics).

##### **Materials**

Beginning June 2016 and concluding January 2022, The United States Census Bureau dispersed 300,00 screener questionnaires (NSCH-S1 see Appendix A) to households with children. The questionnaires were initially sent by US mail and email. One of the purposes of the questionnaire is to collect data on the health and well-being of children, their families, and their local communities and to identify the prevalence of special healthcare needs (The United States Census Bureau, 2022). The households included were identified from the Census' Master Address File (MAF). The MAF is used for demographic data collection operations and for specific collection of data that includes addresses shared by children under the age of 18. Addresses confirmed to have children under the age of 18 are assigned to a specific confirmation category. Addresses and household with unconfirmed children or children under the age of 18 were also categorized separately for additional confirmation using the American Community

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Survey (ACS) (The United States Census Bureau, 2022). The ACS is administered by the Census and represents the primary source for the collection of population and housing data across the US.

The initial screener consisted of 44 multiple choice and fill-in-the-blank response questions, divided into two sections. Section one confirmed if there were children in the home, the primary language spoken, and if the home was rented or owned. The next section is related to the demographics and health of the children and included items such as first name, age, and gender (The United States Census Bureau, 2022). Based on the responses included on the screener questionnaire one of three possible topical questionnaires were mailed for completion, for one randomly selected child in the home. As an incentive to complete the questionnaire a \$5 bill was included with the initial questionnaire mailed. The number of completed screener questionnaires returned totaled 106,000 or 40.3%. Of this number 62,010 were complete and eligible for the topical questionnaire to be mailed to collect data on health issues faced by children in the United States. Of the 62,010 topical questionnaires, a total of 50,892 were completed (The United States Census Bureau, 2022).

### **Procedure**

As part of the NSCH data collection, a topical questionnaire was issued based on the age of the randomly selected child. Questionnaire NSCH-T1 was issued for children aged 0-5 years (see Appendix B), NSCH-T2 was issued for a child aged 6-11 years (see Appendix C), and NSCH-T3 for a child between 12-17 years (see Appendix D). The raw data from the three completed questionnaires went through a data cleaning process. During this process incomplete, invalid, or duplicated data and responses were removed through a multi-step and repeat process to ensure valid data remained. Once this process was completed, the remaining raw data went

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through standardization process. This allows the data to be transformed into variables that can be analyzed using SPSS version 29.

A binary logistic regression model was used to investigate which participants received an autism diagnosis. Based on the outcome, participants were assigned to one of two groups. Group 1 yes, diagnosed with autism, or Group 2 no, not diagnosed with autism. Next, using a multiple regression analysis, the participants age at diagnosis was determined. Based on the determination of age, participants were assigned to one of six groups (see Table 1). Once this was completed, research was conducted to determine if race, gender, and SES were predictors of autism diagnosis. Specific questions used from the questionnaires for the data analysis were included as part of the review. The variables for investigating the relationship predictors of autism (see Table 4).

### Data Analysis

**Diagnostic rates.** Using IBM SPSS Statistics (Version 29.0.0.0) A binary logistic regression was performed to investigate the effects of gender, race/ethnicity, and SES on the likelihood of a child being diagnosed with autism. The reference category for “asdever” was 0. The total sample size included ( $N = 225,443$ ) participants, of which ( $n = 6368$ ) were identified with autism.

**Age of diagnosis.** Using IBM SPSS Statistics (Version 29.0.0.0), a 2 (Gender)  $\times$  4 (Race/Ethnicity)  $\times$  4 (Federal Poverty Level) factorial ANOVA was conducted with age of diagnosis identified as the dependent variable and gender, race/ethnicity, and federal poverty level identified as independent variables. All main effects, two-way interactions, and the three-way interaction were included in the ANOVA. Main effects of race/ethnicity and federal poverty level were evaluated using follow-up tests with Bonferroni correction.

## Results

### Gender, Race/Ethnicity, SES, and Autism Diagnostic Rates

A binary logistic regression was performed to investigate the effects of gender, race/ethnicity, and SES on the likelihood of a child being diagnosed with autism. The total sample size included ( $N = 225,443$ ) participants, of which ( $n = 6,368$ ) were identified with autism. The overall binary logistic model was significant  $\chi^2(7) = 2420.25, p < .001$ . The model explained 47% (Nagelkerke  $R^2$ ) of the variance of autism diagnostic rates, and correctly classified 97% of the identified cases where a child was diagnosed with autism. Of the three predictor variables, two were statistically significant, gender,  $\beta = -1.29, p < .001$ , and poverty level, Wald = 311.97,  $p < .001$ . Males were 2.75 times more likely to be diagnosed than females. Children living in level II poverty were diagnosed .90 (CI = .83 - .98) times less, children living in level III poverty were diagnosed .70 (CI = .64 - .75) times less, and children living at the lowest level of poverty, level IV were .54 (CI = .50-.59) times less likely to have a diagnosis than children who were not living below the federal poverty level (see Table 3).

### Gender, Race/Ethnicity, SES, and Age of Autism Diagnosis

A 2 (gender) x 4 (race/ethnicity) x 4 (SES/federal poverty level) factorial ANOVA with age of diagnosis as the dependent variable was used to investigate the effect of: gender, race/ethnicity, and SES/FPL on age of autism diagnosis. The ANOVA revealed that there was a statistically significant difference in age across gender,  $F(1,5837) = 9.45, p = .002$ , with females ( $M = 5.57$ ) identified 1.09 years later than males ( $M = 4.94$ ). The ANOVA also revealed that there was a statistically significant difference in age across race,  $F(3, 5865) = 30.51, p < .001$ . Post hoc tests revealed statistical significance between all races, with Black children diagnosed earlier ( $M = 4.32, SD = 2.81$ ), than Hispanic children ( $M = 4.45, SD = 3.00$ ), children of two or



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more races ( $M=4.63$ ,  $SD = 3.24$ ), and White children ( $M = 5.36$ ,  $SD = 3.45$ ) were diagnosed later than all other races. There were no statistically significant interactions between gender, and race/ethnicity for age of diagnosis,  $F(3, 5837) = 2.04$ ,  $p = .11$ , gender and SES,  $F(3, 5837) = .08$ ,  $p = .97$ , or between gender, race/ethnicity, and SES,  $F(9, 5837) = .54$ ,  $p = .84$  (see Table 4).

### Discussion

The discussion is organized into three sections. First, an overview and summary of study findings will be provided. Second, potential implications of the findings will be discussed. Finally, a review of study limitations and recommendations for future research will be provided.

#### Summary of Findings

**Diagnostic rates.** The results of the study suggest boys (4.32%) are being diagnosed with autism at a rate of 3 times that of girls (1.22%). Looking at race more specifically in the study, Black children were diagnosed more often than any other race, then Hispanic children, then children of two or more race, and White children were diagnosed with autism the least in the study. When investigating how gender, race/ethnicity, and SES impacted diagnostic rates, the results were surprising. Results of the study were statistically significant when looking at SES. The study included 4 categories for FPL. The lowest FPL is < 100% poverty, and the highest level is 400%+ above FPL. When looking at the results of SES the largest gap in a later diagnosis was made between FPL 2 and 3. The FPL assigned to a family is based on household size and the monthly income. Income below Level 1 of FPL indicates the household is not living in poverty based. Level 1-4 of the FPL indicates the household is living in poverty. The further a family classifies in poverty up to FPL 3, the more resources the household qualifies for. The FPL threshold between level 2-3 is greatest across all poverty levels and is correlated with a child

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receiving an autism diagnosis at a later age if they live in a household classified between FPL 2-3. There are minimum changes in terms of resources and services a household could receive between FPL 3-4. This indicates the services and resources provided at FPL 4 are not significantly higher than level 3. While there was a later autism diagnosis, is it significantly earlier than a diagnosis made between FPL 2-3.

**Age of diagnosis.** This statistically significant difference in the study revealed more than a full year in age difference between when boys are diagnosed and when girls are diagnosed. With boys being diagnosed more often than girls, not surprisingly the mean age of diagnosis for boys ( $M = 4.9$ ) was earlier than that of girls ( $M = 5.6$ ). Looking at the mean age of diagnosis by race showed the recent reversal in trends with racially minoritized children being diagnosed more often than White children which has historically been the case. The age of diagnosis for Black children was ( $M = 4.3$ ) followed by Hispanic children ( $M = 4.5$ ), children of two or more races ( $M = 4.6$ ), and with White children being diagnosed latest ( $M = 5.4$ ).

### Interpretation of Findings

#### **Diagnostic rates.**

Despite the increase in awareness, diagnostic rates for autism have outpaced national efforts to increase early screening and a formal diagnosis. Racially minoritized children were diagnosed more often than White children in the results which shows some promise in terms of all children having access to screenings. In the study, SES or FPL contributed to lower diagnostic rates. Children living within levels 2-3 of FPL received fewer diagnoses irrespective of race. This may be due to limited access to providers who can screen for autism and make a formal diagnosis. In this case, those providers would be education based (school psychologists for example).

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In most cases for children living in poverty, their access to care is sometimes limited to public service providers who accept state insurance like Medicaid. From an educational perspective, there are other methods in place to close the gap and prevent fewer diagnoses. Screenings for autism can begin as early as preschool and can be conducted in such programs as Head Start centers, preschools and or daycare centers who are licensed through the state to provide childcare services to preschool aged children (Janiver et al., 2016). If this does not happen, parents in cooperation with the school can begin the process of screening a child for autism or an intellectual disability if the school determines the child meets district level criteria to be screened for autism. Because not all schools will have a school psychologist, the timing for screening may be delayed based on the availability of a school psychologist who is assigned to specific schools or to a specific region within a school district. In contrast parents and children who live above the poverty level may have access to private insurance that could provide parents with the ability to seek screenings on their own, outside of the school, and at much earlier times.

The results of the study showing boys being diagnosed more often than girls were unsurprising. Traditionally, autism has been viewed as a male defined disorder, and not solely based on boys/male demonstrating the outward behaviors which meet diagnostic criteria for an autism diagnosis. The 'Extreme Male Brain' hypothesis suggests male brains have a stronger drive for systemizing or operating as an input-operation-output, or developing systems operations based on rules. Researchers evaluated this theory and learned autistic males had brain sizes larger than females with autism, and larger than participants who were in a control group. In contrast, the same theory also suggests the brains of girls are motivated for empathizing which means to look at and confirm another person's emotions so they can respond appropriately (Baron-Cohen, 2002; Baron-Cohen et al., 2011).

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Contributing further to the delay in an autism diagnosis among girls is emerging research on Masking or the “Camouflage Hypothesis.” Dean et al. (2017) suggests girls tend to behave or follow typically developing behavior associated with other girls. Their IQ may be at or below the level of their peers, and they are in line with socializing and behaving like other girls. When screening based on gross motor skills, or more observable symptoms alone, when there are no outwardly visible behaviors in girls like hand flapping or preoccupation with an item or toy or leading another girl by hand but rarely or if all looking at her face, girls could be excluded from screening and testing. In some cases, girls tend to mimic the behaviors they see among girls, while masking or camouflaging social and repetitive behaviors to avoid drawing attention to themselves. If screenings do not take into consideration the practice of masking or camouflaging, this could lead to missed or later diagnoses in girls, which could negatively impact their developmental outcome.

This Camouflage Hypothesis remains an accurate way of describing one method girls are often not considered for screening simply based on grounds of their outer presentation. In contrast, boys are more readily assessed because their behaviors are more noticeable and pronounced, including hand flapping, and preoccupation with a specific item or toy (Dean et. al., 2017). Future research including age of diagnosis and symptoms which lead to screening for girls will help provide evidence for the need of educational training on how to screen boys and girls universally but with different criteria for boys and girls.

Considering the presentation of autism across boys and girls, these factors could be one of the reasons why autism has traditionally been considered a male oriented disorder. Screening measures often examine observable symptoms that are non-typical for boys to support a diagnosis for autism. However, the same measures are not designed to measure or uncover social

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constructs that may be used by girls who are trying to fit in and abide by the typical Western behavior that is expected of girls.

When reviewing the racial differences in the study, the results are likely explained by the continued efforts of states like California who created state level programs to ensure racially minoritized children received the same access to screening as White children (Winter et al., 2020). This could also be the fruits of the CDC and ADDM's labor in collecting data on autism, developmental disabilities, and conducting research to educate health professionals and the public. The Childrens Healthcare Act in 2000 allowed the National Institute of Health (NIH), through grants and other awards, to help the CDC create the ADDM, which in turn led to more autism awareness surrounding diagnostic rates. This in turn led to health professionals who are trained to screen and make an autism diagnosis which expanded access to screening for all children (Bilirakis, 2000).

### **Age of diagnosis.**

In this study, age of diagnosis varied based on race. Black children were diagnosed the earliest, then Hispanic Children, then children of two or more races, and White children were diagnosed less often. This is due to direct efforts to ensure racially minoritized children are receiving access to care the same as White children. In this case, this appears to be the efforts of educational professionals working together to identify children who should be screened for developmental disabilities with emphasis on screening children for autism. This could be due to the increase in prevalence of autism nationally or efforts to ensure racially minoritized children are now included in the screening for developmental disorders in general.

Living within the FPL significantly contributed to fewer diagnoses in the study. The greatest jump in contributing to fewer diagnoses in autism was between the 2<sup>nd</sup> and 3<sup>rd</sup> FPL.

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Hispanic children at these FPL levels were diagnosed the latest, then children of two or more races, then White children, and Black children showed the least distance in fewer diagnoses between the 2<sup>nd</sup> and 3<sup>rd</sup> FPL. Fewer diagnoses in age ranged from greater than 1 year in Hispanic children, to less than a year in difference among Black children. I suspect the disparities between ages are impacted by a level baseline as children fall further into poverty. Meaning all children tend to meet the same qualification for resources the further they are in poverty. Other differences between age of diagnosis can be explained by or attributed to lack of professional resources in health professionals for screening. As children are classified further in poverty, they lose access through no fault of their own to private resources which normally accompany private insurance.

In this study, the results show how poverty is correlated with fewer autism diagnoses, which can further impact a child's ability to meet developmental milestones including accessing services that could help mitigate negative health and poor or below grade level educational performance. Children who live in poverty must rely on free resources and screenings provided through their school system for identification. Further contributing to delay in diagnosis due to the poverty level, is the access of professionals within the school or district. While a child may be identified for screening by a teacher (including preschool teachers or daycare teachers), this referral then requires approval from a parent and the availability for a professional such as a school psychologist who is trained in conducting screening and testing for autism. These services will likely be based on availability and resources within the school or the district. An absence of qualified professionals in each school could lead to a longer wait period before a child could be screened for autism. This absence of measures that screen for symptoms that girls normally

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present with may contribute to the reasons girls are diagnosed later than boys or why sometimes a diagnosis is not made until adulthood.

### **Limitations and Future Directions**

This research unfortunately does not explain why there remains a large disparity among gender diagnosis for autism. Diemer et al. (2022) has shown that Black females are excluded from existing research on autism, despite this group being associated with cooccurring intellectual disabilities and lower school performance that raises a concern for screening. Future research would benefit from mixed methods studies which includes quantitative and qualitative data from girls. Emerging female adults will help provide valuable information to facilitate the development of screeners that can be given to parents and teachers as part of the screening process. There should also be an effort to specifically include racially minoritized girls who are more likely to be impacted by a later diagnosis of autism and a cooccurring disability. This group would benefit from research on ways to specifically close this gap as an intergroup of girls. Another opportunity for future research will be in the area of SES/FPL and how it impacts and access to autism screenings directing future research to educating communities living within the FPL across all races about autism, its symptoms and signs will need to become a priority. This research should include finding ways to educate the public on the places and timing for screening services to begin, such as when a child being old enough to attend Head Start centers and state licensed preschool and daycare centers. This research can help educate about the importance of early screening, and that their income does not mean they need to wait until; a child is enrolled in elementary school if they suspect their child needs a screening for autism or another neurodevelopmental disorder.

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Another limitation of this study is its broadness. As the study progressed, it became apparent through current research and the existing disparity, a better study would have been to focus on the disparity among girls solely, and with the possibility of a multiple regression analysis to look at one or more predictors and how they contribute to the autism diagnostic disparity rate among girls. A post hoc power analysis revealed enough participants in girls alone to conduct the analysis. Two, Maenner et. al. (2023) reminded researchers that since the first results were reported of autism diagnostic rates in 2002 through the ADDM, there has only been a 1% increase in girls being diagnosed versus boys, and 11.6% of the participants were showing autism diagnosis after autism had already been ruled out previously.

### **Conclusion**

As of 2021, the rates of autism have increased to 1 in 36 (Maenner et. al. 2023). By comparison, in 2004 the diagnostic rates for autism were 1 in 125 (Centers for Diseases Control and Prevention, 2023). The Centers for Disease Control and Prevention (CDC) as well as the U.S. Department Health and Human Services (HHS) are working to compile data annually on the diagnostic rates of autism across the nation. This is accomplished through the efforts of enlisting the US Census Bureau to send out questionnaires to household across the country to confirm if there are children and to then send follow up surveys for completion by mail, internet, or over the phone.

The collection of this information then trickles down to states who will also monitor and gather information on diagnostic rates to determine prevalence and resources needed to meet the increasing needs not only of children, but adults who have autism and a cooccurring intellectual disability.



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The collection efforts are streamlined and the information for research is easy to locate. As it stands, the diagnostic rates will continue to increase. More research and resources will be needed to ensure screening efforts take into consideration the growing immigrant population and the diversity of cultures, and ethnicities. Updated screeners and evaluations will need to uncover how idioms of expressions may replace or describe autism among different ethnic groups, and if there is a different expression for girls within the same ethnic group. Planning for better screening methods, for example, will ensure the disparities are actively worked towards being steadily reduced to a minimum. This will help to ensure children who need a screening for autism receive it regardless of their race, gender, or their family's SES, while expanding the providers and places where an autism diagnosis can be made.

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**TABLE 1**

*Variables from the National Survey of Childrens Health Dataset used as Predictors of Disparities of Autism Diagnosis in Children.*

<i>Independent Variables</i>	<i>National Survey of Childrens Health</i>	<i>Values</i>
<b>Predictors</b>		
Gender	Gender of child	1 = Boy 2 = Girl
Race	Race of child	0 = White 1= Black or African American 2 = Hispanic 3 = Other/two or more races
Federal Poverty Level	Family income at or below FPL	1 = Less than 100% Poverty Level 2 = 100-199% Poverty Level 3 = 200-397% Poverty Level 4 = 400%+ Poverty Level
<b>Outcome Variables</b>		
Autism diagnosed	Current Diagnosis	1 =Y 2 = N
Age of diagnosis	Age	3-17

*Note.* FPL = Federal Poverty Level

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**TABLE 2**

*Participant Characteristics (N = 225,443)*

<u>Variable</u>	<u>Min</u>	<u>Max</u>	<u>M</u>	<u>SD</u>	<u>Skew</u>	<u>Kurt.</u>	<u>n</u>	<u>%</u>
Age (yrs.)	3	17	9.15	5.26	5.68	.005	224401	99.5
Survey Year								
2016							50212	22.3
2017							21599	9.6
2018							30530	45.4
2019							29433	58.5
2020							42777	77.4
2021							50892	22.6
Gender								
Male							116672	51.8
Female							108771	48.2
Child Ever Diagnosed with Autism								
Yes							6368	2.8
No							218033	96.7
Missing							1042	0.5
Race/Ethnicity								
White							153516	68.1
Other							29757	13.2
Hispanic/Latino							27855	12.4

## DISPARITIES IN AUTISM DIAGNOSIS

Black/African American	14315	6.3
Federal Poverty Level (Code)		
Less than 100% Poverty Level (1)	26366	11.7
100 – 199% Poverty Level (2)	36540	16.2
200 – 399% Poverty Level (3)	69243	30.7
400+ Poverty Level (4)	93294	41.4

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*Note.* Federal Poverty Level (FPL) is calculated based on the total income of the household and is compared to the Census Bureau's poverty thresholds. Poverty levels range from 1 at poverty level, to 4 highest level of poverty based on total income.

DISPARITIES IN AUTISM DIAGNOSIS

**TABLE 3**

*Logistic Regression Predicting the Likelihood of Autism Diagnosis based on Gender, Race/Ethnicity, and SES*

	$\beta$	SE	Wald	df	p.	Odds Ratio	95% CI for odds ratio	
							Lower	Upper
Child Gender-Female	-1.29	.031	1715.86	1	<.001	.28	.26	.29
White			1.661	3	.646			
Black	-.038	.052	.535	1	.465	.96	.87	1.07
Hispanic	-.030	.039	.577	1	.448	.97	.90	1.05
Other	-.040	.039	1.035	1	.309	.96	.89	1.04
Less than 100% Poverty			311.970	3	<.001			
Level (1)								
100-199% Federal	-.102	.043	5.666	1	.017	.90	.83	.98
Poverty Level (2)								
200-399% Federal	-.362	.040	81.62	1	<.001	.70	.64	.75
Poverty Level (3)								
400%+ Federal Poverty	-.610	.040	232.44	1	<.001	.54	.50	.59
Level (4)								
Constant	-2.73	.036	5816.18	1	<.001	.07		

*Note.* Family Poverty Ratio (FPL) - The family poverty ratio is calculated as the ratio of total family income to the family poverty threshold. The family poverty threshold is derived from the Census Bureau’s poverty threshold. Thresholds vary by family size and the number of related children under 18 years old. They do not vary across geographies, and the threshold levels are updated on the US Census Bureau website annually.

DISPARITIES IN AUTISM DIAGNOSIS

**TABLE 4**

*Tests of Between-Subjects Effects*

Dependent Variable: Age autism identified

Source	<i>SS</i>	<i>df</i>	<i>Mean Square</i>	<i>F</i>	<i>Sig.</i>	<i>Partial Eta Squared</i>
Corrected Model	1678.865 <sup>a</sup>	31	54.157	4.938	<.001	.026
Intercept	39993.602	1	39993.602	3646.927	<.001	.385
Child Sex	103.584	1	103.584	9.446	.002	.002
Child Race/Ethnicity	678.656	3	226.219	20.628	<.001	.010
Poverty Level	34.404	3	11.468	1.046	.371	.001
Child Sex by Child Race/Ethnicity	67.079	3	22.360	2.039	.106	.001
Child Sex by Poverty Level	2.723	3	.908	.083	.969	.000
Child Race/Ethnicity by Poverty Level	51.567	9	5.730	.522	.859	.001
Child Sex by Child Race/Ethnicity by Poverty Level	53.637	9	5.960	.543	.844	.001
Error	64010.791	5837	10.966			
Total	216665.000	5869				
Corrected Total	65689.657	5868				

a. R Squared = .026 (Adjusted R Squared = .020)

# DISPARITIES IN AUTISM DIAGNOSIS

## APPENDIX A

### National Survey of Children's Health screener questionnaire



NSCH-S1 Screener  
Questionnaire.pdf

# DISPARITIES IN AUTISM DIAGNOSIS

## APPENDIX B

### National Survey of Children's Health topical questionnaire ages 0-5 (NSCH-T1)



NSCH-T1 Topical  
questionnaire ages



# DISPARITIES IN AUTISM DIAGNOSIS

## APPENDIX C

### National Survey of Children's Health topical questionnaire ages 6-11 (NSCH-T2)



NSCH-T2 Topical  
Questionnaire ages

# DISPARITIES IN AUTISM DIAGNOSIS

## APPENDIX D

### National Survey of Children's Health topical questionnaire ages 12-17 (NSCH-T3)



NSCH-T3 Topical  
Questionnaire ages