

Impact of Sociodemographic Factors on the Access to Autism Spectrum Disorder (ASD) Related Services

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Abstract

Current research has consistently suggested disparities exist in ASD prevalence among children of different race/ethnicities and socioeconomic statuses. These disparities are largely due to inability of marginalized populations to access necessary resources, and in the case of race/ethnicity also stem from implicit bias and systemic racism in the healthcare system. To date, no work has comprehensively reviewed these studies to summarize and analyze their findings. Thus, this review will serve to fill that gap in current research. The following review includes twenty-five primary research studies published in the United States in 2005 or later. These studies evaluated a variety of different sociodemographic factors and the impact they had on accessing ASD related care, most often diagnosis and intervention. Overall, this paper found that children of minority races/ethnicities (particularly Black and Hispanic/Latino) as well children with low socioeconomic statuses consistently experienced more barriers in access to care for ASD related resources. As a result, these groups often have lower prevalence rates, later diagnoses, and lower utilization of intervention services. This review will guide future research to further understand and eventually diminish the disparities observed.

Keywords: Autism Spectrum Disorder, ASD, sociodemographic factors, socioeconomic factors, race, ethnicity, diagnosis, treatment, intervention, disparity

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Impact of Sociodemographic Factors on the Access to Autism Spectrum Disorder (ASD) Related Services

Previous research has examined the correlation between one or more given sociodemographic factors, but to date, there is no review to summarize the impact of these on both identification/diagnosis and treatment of ASD. This literature review will summarize and evaluate the findings of clinical research regarding the impact of sociodemographic factors (namely race/ethnicity and socioeconomic status) on the access to ASD related resources.

Etiology

Autism was first diagnosed as a discrete disorder in 1943 (Kanner, 1943) and was later described as its own diagnostic category in the 2000 Diagnostic and Statistic Manual of Mental Disorders IV Text Revision (DSM-IV-TR), from the American Psychiatric Association. The category included three separate, but largely overlapping conditions: Autistic Disorder, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS), and Asperger's Syndrome. These three disorders, along with Rett's Disorder and Childhood Disintegrative Disorder are all considered Pervasive Developmental Disorders under DSM-IV-TR.

Furthermore, American Psychiatric Association (2000) listed criteria for diagnosing Autistic Disorder as needing qualitative impairment in social interaction and communication, as well as restricted, repetitive patterns of behaviors and interests. Additionally, children needed to display delays or abnormal functioning in social interaction, language, or symbolic/imaginative play for diagnosis. The term PDD-NOS was first used in 1992 and is described by the American Psychiatric Association (2000) as having similar impairments to Autistic Disorder with criteria for other specific pervasive developmental disorders not met. It also includes late onset or atypical symptomatology of Autism. Asperger's Disorder is described in DSM-IV as having

impaired social interaction and repetitive behaviors, with no clinically significant delays in language or cognitive development.

Following the publishing of DSM-V in 2013, the categories were collapsed under the umbrella term Autism Spectrum Disorder (ASD). The criteria for an ASD diagnosis combines the above requirements for social or communication impairments with repetitive patterns of behavior and allows specification for presence of intellectual or language impairments. Because the transition to ASD was made rather recently, many of the articles reviewed in this paper considered Autistic Disorder, PDD-NOS, and Asperger's Disorder instead of ASD. For simplicity, the authors of this review will use the term Autism Spectrum Disorder (ASD) consistently.

According to the Center for Disease Control (2021), 1 in 54 children is diagnosed with ASD as of 2020, a marked increase from the 2016 prevalence rate of 1 in 59 children. While it is possible that there is a growing number of children who are afflicted with ASD, it is more likely that both the method of diagnosis and awareness of ASD are improving, resulting in the increased prevalence (CDC, 2021).

Screening and Diagnosis

The diagnosis of ASD can occur reliably around 2 years of age, with multiple studies reporting a 76% stability rate for diagnoses given before the age of 3 (Rondeau et al., 2011). Furthermore, there are multiple tools available for ASD screening, which is the first step of determining if a child has ASD. Screening tools include Communication and Symbolic Behavior Scales (CSBS), Parents' Evaluation of Developmental Status (PEDS), and Screening Tool for Autism in Toddlers and Young Children (STAT) (CDC, 2021). The most extensively studied is the Modified Checklist for Autism in Toddlers (M-CHAT). The M-CHAT is a written

questionnaire completed by parents, with a Follow-Up protocol used to clarify responses considered to indicate ASD (Khowaja et al. 2014).

Should a child screen positive with any of the aforementioned tests, immediate action is required. This most often includes more medical assessments and diagnostic tools. Diagnostic tests for ASD include Autism Diagnosis Interview- Revised (ADI-R), Autism Diagnostic Observation Schedule- Generic (ADOS-G), and Childhood Autism Rating Scale (CARS) (CDC, 2021). Any of these diagnostic tests, among others, may be used by a qualified healthcare or school professional to diagnose a child with ASD.

Early diagnosis has been noted as becoming more important as it allows early intervention therapies including Applied Behavioral Analysis (ABA), speech therapy, and sensory therapies, among others. It is currently accepted that starting these therapies early can result in decreased ASD symptom progression, as well as improved communication and social skill outcomes (Fennell et al. 2013). For example, data from Koegel (2000) showed that non-verbal children with ASD who began intervention in preschool years were more likely to become verbal than those who began intervention after 5 years old. Furthermore, the contrasting approach of “wait and see” before providing a diagnosis has been determined to have negative consequences in children with ASD (National Research Council, 2001).

Despite a plentitude of research suggesting diagnosis for ASD should be completed as early as possible to yield the best outcomes for the child, the age of diagnosis remains around 50-56 months. Less than half the children with ASD had an evaluation by age 3 (CDC, 2020). Thus, there is ample room for improvement in the method which ASD is currently detected and diagnosed.

Additionally, because the criteria for ASD can be subjective and hard to detect, children sometimes go undiagnosed or misdiagnosed with other conditions such as Attention Deficit Hyperactive Disorder (ADHD), emotional behavioral disorders, adjustment disorder, or conduct disorder (Kentrou et al., 2018). This can make it more difficult, and in some cases, nearly impossible, to obtain the necessary resources to help a child with ASD.

Delays in proper diagnosis and lack of treatment in children with ASD is largely contributed to a lack of access to Autism Spectrum Disorder related resources. These resources include pediatricians or qualified school staff capable of diagnosing a child with ASD, as well as required treatments and interventions for the child. These include but are not limited to therapy, prescription medication, and respite care.

Race/Ethnicity Terms

A variety of factors are known to influence an individual's access to healthcare. These include sociodemographic factors such as race or ethnicity. Throughout many of the works analyzed in this review, the terms "Black" and "African American" as well as "Hispanic" and "Latino" were used interchangeably. For the purposes of consistency, and in an effort to be as accurate as possible, the authors of this review have opted to use "Black" in all relevant instances. This is to insure inclusion of Black individuals descending from Caribbean regions instead of those only from the African continent, as indicated by research from Agyemang et al. (2005).

Additionally, research by the authors into the history of the term "Hispanic" (meaning Spanish speaking) found it often connotes elitism among the populations it is used to label (Noe-Bustamante et al., 2020). Also, because it refers to anyone from Spain or Spanish speaking regions of Latin America, it promotes Spanish heritage and a history of colonization (MacDonald, 2001). Despite this association, it has been used by the U.S. Census Bureau since

1980 (Simón, 2018), and therefore was prominently used in the studies detailed in this review. In a 2015 survey by the Pew Research Center, 51% of Hispanic/Latino individuals had no preference between the two terms while 32% preferred Hispanic and only 15% preferred Latino (Lopez et al., 2020), which refers directly to being from Latin America. Thus, to remain as accurate as possible to both the studies analyzed and the people being represented, the authors will consistently use Hispanic/Latino throughout the following review.

Other races frequently mentioned in studies included White, Asian, American Indian/Alaskan Native, Hawaiian/Pacific Islander (PI), Mixed Race, and not specified. White is used to refer to all individuals with origins in Europe, Middle East, or North Africa. Asian refers to anyone descending from the continent of Asia or the Indian subcontinent. Mixed race refers to anyone who identifies as being more than one of the listed races.

American Indian/Alaskan Native refers to any person having origins in North or South America. Most American Indians and Alaskan Natives prefer to refer to themselves as members of their tribe (Indian Country Today, 2016). However, this information was not made available in the studies analyzed, and therefore was not practical for use throughout this review. Furthermore, the U.S. Census Bureau (2018) uses American Indian and Alaskan Native (AIAN) and because the majority of the studies relied on Census data in some capacity, the authors opted to use this terminology to ensure consistency. AIAN is used most commonly in the review's tables, while the full term will be used elsewhere.

Race and ASD

In terms of race and ASD, there have been documented instances of bias in the ways healthcare professionals diagnose ASD. In the Netherlands, medical professionals were more likely to give a diagnosis of ASD to European children than non-European minorities, even when

their symptom presentation was very similar (Begeer et al., 2009). This may stem from a lack of familiarity with minorities due to underexposure during education, the environment of the health care professional, an implicit bias from the healthcare professional, or any combination of those factors. An implicit bias is defined as an unconscious association between a group and an attribute, such as seeing Black individuals as more violent or assuming Hispanic individuals are undocumented (Blair et al., 2011). Research into the presence of implicit biases in healthcare has determined there is an inverse relationship between level of implicit bias and quality of care (FitzGerald & Hurst 2017), specifically patient-provider interactions, treatment decisions, and patient health outcomes (Hall et al., 2015).

Often, the level of English proficiency is an identifying sociodemographic factor, much like race or ethnicity. It is closely tied with being of a minority race and has been documented as also providing a barrier to accessing ASD related services by research from both St. Amant et al. (2018) and Huerta & Lord (2013). St. Amant et al. (2018) found children with parents who spoke primarily English were more likely to have additional details within an individualized education plan (IEP), as well as more hours of direct services. Furthermore, Huerta & Lord (2013) found some diagnostic instruments may function differently for non-English speaking parents.

Socioeconomic Status

Research has also long documented that low socioeconomic status is associated with a poor quality of healthcare, seeking healthcare less often, and using healthcare only in an emergency (Franks et al., 1993). Thus, socioeconomic status also directly affects access to healthcare resources, particularly for those who are at or below the poverty level. Poverty level is a term that can be used to identify both poverty thresholds and poverty guidelines. Poverty thresholds are a specified dollar amount considered to be the minimum level of resources

necessary to meet the basic needs of a family unit (U.S. Census Bureau, 2019). These thresholds vary by number of adults and children in the household, but do not vary by state (Lee, 2018). Poverty guidelines are simpler variants of poverty thresholds. These guidelines do not vary by number of adults or children in the household, but do differ by state. Poverty thresholds are issued by the U.S. Census Bureau and poverty guidelines by the Department of Health and Human Services. The poverty threshold is the number that defines what poverty is and poverty guidelines define what income levels should qualify for welfare benefits. In this review, when the phrase “federal poverty level” is used, poverty guidelines are being referred to, as per the U.S. Department of Health & Human Services (2021).

Medicaid status is determined by poverty guidelines from the federal poverty level, which differ by age. For children under 6 or pregnant women, they qualify for Medicaid with family income that is up to 133% of the federal poverty level. Children from ages 6-18 are eligible for Medicaid provided that their family income is at or below 100% of the federal poverty level (Committee on the Consequences of Uninsurance, 2002). The Children’s Health Insurance Program (CHIP) expands upon Medicaid (U.S. Centers for Medicare & Medicaid Services, n.d.). It gives insurance to children whose family may not qualify for Medicaid, but cannot afford private insurance. This coverage differs by state and may cover pregnant women (U.S. Centers for Medicare & Medicaid Services, n.d.).

Because the poverty guidelines vary by state, the Medicaid income requirements are thus relative to each state. For example, California’s specific program of Medicaid is called Medi-Cal. This program has over 90 specific categories to determine if one is eligible for aid (World Institute on Disability, n.d.). Eligibility for public insurance also is impacted by disability. For example, in Medi-Cal all medically necessary behavioral health treatment for those under 21

with ASD will be covered (California Department of Health Care Services, 2020). Even though Medicaid is correlated with federal poverty level, it must be recognized that for children with ASD or other similar disabilities, income qualifications may differ. Families may be able to make more than the typical Medicaid eligible family, and still receive Medicaid benefits for their child. In 2017, about half of the children in the US with special needs were covered by Medicaid and CHIP (Musumeci, 2019).

Furthermore, the two factors of socioeconomic status and race/ethnicity are incredibly intertwined as well. According to the U.S. Census Bureau (2020), poverty rates of Non-Hispanic White individuals have remained around 10% or lower since 1975. However, minorities, particularly Black and Hispanic individuals, face much higher poverty rates. In 2019, 18.8% of Black individuals were impoverished while the same was true for 15.7% of Hispanic individuals. Asian populations in the United States had higher poverty levels than White populations for the last several decades but in 2019 had 7.3% of their population in poverty, equivalent to that of White populations.

The ability to see healthcare professionals, particularly specialists, relies heavily on an individual's insurance and economic status. When considering that minorities have higher poverty rates than White populations in the United States, the intersectionality of demographic and socioeconomic factors becomes critical for healthcare access.

Objective

The following literature review will summarize and evaluate the findings of current primary research based in the United States to determine the impact of race/ethnicity and socioeconomic status on access to ASD related resources. Access to these resources is most commonly measured in terms of diagnoses (prevalence, age, etc) and treatment or interventions

(type, number of hours received, etc). Through its findings, this review will provide a guide for future research on this topic and allow progress to be made toward minimizing any disparities in access to ASD related resources.

Methods

Six databases were selected for the review: Education Resources Information Center (ERIC), SagePub, PsychInfo, PLOS One, PubMed Central (PMC), and BioMed Central (BMC). These databases were chosen based on their ability to provide open access to peer-reviewed research in the medical, and more specifically, psychological and sociological fields. These databases drew from a variety of different journals, including *Pediatrics*, the *Journal of Child Psychology and Psychiatry*, the *Journal of Autism and Developmental Disorders*, the *Journal of Special Education*, *Autism*, and the *Journal of the American Academy of Child and Adolescent Psychiatry*, among others.

After making database selections, general searches were made within these databases using keywords like *Autism* or *ASD*, *socioeconomic* or *sociodemographic*, *race* or *ethnicity*, and *treatment* or *diagnosis*, as well as their variations (e.g *socioeconomic* and *socioeconomic status*). Later searches were expanded to include terms like *accessibility*, *access* and *disparities*. These searches allowed accumulation of over 100 sources.

The title and abstract of these sources were then scanned by the authors to determine relevance to the review. Sources that met the inclusion criteria, primary research in the United States comparing multiple categories of the one or more sociodemographic factors (e.g. race, income) published in 2005 or later, were added to a spreadsheet by the authors. Sources published before 2005 were not included as the authors chose a 15 year time frame from the

initial search date (November 2020) to include only the most current findings. Prior to submission, another search was completed to ensure all relevant studies were included.

Primary research was required in order for this review to evaluate what is currently known in this particular area of study. Therefore, all other types of work were excluded and a focus was placed on sources looking at multiple races, socioeconomic statuses, etc. in order to facilitate comparisons between studies. The United States was chosen as the geographical focus as a means of limiting the scope, and for its relevance to the authors.

Bibliometric information about each source was compiled and initially added to one of two tables, depending on if the source focused more on race or economic status in its findings. However, as the authors continued to make more notes regarding research method and conclusion, a large overlap was found between the two subject areas and thus the tables were combined.

Findings were then further categorized by source in a series of tables focusing on different factors associated with race/ethnicity or socioeconomic status. For race, these included age of diagnosis or first treatment, prevalence rates, odds/risk ratios, utilization of care, and misdiagnoses. Race categories included White, Black, Hispanic/Latino, Asian, American Indian and Alaskan Native (AIAN), Hawaiian/Pacific Islander, Mixed, and Not specified. Language was evaluated by some sources and was generalized into Primarily English Speaking and Primarily Other Language Speaking categories for comparison. Some of the tables did not have any results pertaining to a given race or language category so the category was excluded from that table. Additionally, the authors recognize that more specific racial categories would lend themselves to more detailed analysis (e.g. mixed race does not specify what races, many relied

only on mother's race/ethnicity). However, the review was limited to the categories presented within the studies.

Socioeconomic status tables included parental education, insurance, poverty level and income. These were the four most common topics discussed in regards to socioeconomic status. The tables were broken down this way to lend for simple comparison between a variety of sources. Poverty level and income are similar categories, however, they were included separately in the tables and results section. Many studies discussed income solely in the context of proximity to the poverty line and thus these sources were analyzed separately. The categories of low, middle and high incomes and parental education levels were relative to each source. Some sources included these three categories specifically and in the other cases the authors manufactured these categories for easier comparison. The way the three categories (low, middle and high) were separated are listed in the respective tables.

Using the gathered information from each source, the authors then synthesized findings regarding the impact of the given sociodemographic factor on access to ASD related resources, using the tables to facilitate organization and comprehension by the reader.

Results

Table 1 serves as a literature review grid, which includes bibliometric data (authors, year published, journal, etc) from the studies included in this review. It is organized by chronological order. It also includes some brief information specifically relevant to this review: diagnoses used, insurance, determination of socioeconomic status, and races studied.

The studies included in this review were published from 2005 to 2020. They include a variety of sample sizes, ranging from 115 children in studies localized to a city or metropolitan area all the way to 13,272,573 children in larger scale studies. Furthermore, the ages of children

included in these studies range from 2 years old to 21 years old, though many of the studies focused on school-aged children, or more specifically 8 year olds. This is due to the availability of data from sources like the Autism and Developmental Disabilities Monitoring (ADDM) Network.

Of the twenty-five studies included in this review, ten had a national scale, another ten studied a specific state, and the remaining five focused on specific cities, counties, or metropolitan areas. Four of the state-level studies analyzed data from California, and many of the national studies also used California data as a reference, due to its previously discussed Medi-Cal program. The results of each of the studies in regards to race/ethnicity and socioeconomic status will be discussed further.

Race/Ethnicity

Age at Diagnosis/Age at First use of Services by Race

Table 2 illustrates the relationship between age at diagnosis or age at first use of services and race or primary language spoken. Seven studies analyzed this factor. The column headers indicate the race or language being compared while the left-most column indicates which source is being discussed. Within each square on the table, the mean age or general trend is detailed, including any caveats (e.g. U.S. born vs foreign born, or ages of evaluation vs diagnosis). Mandell et al. (2005), Wiggins et al. (2006), Becerra et al. (2014), Fountain et al. (2011), and Jo et al. (2015) looked at the age a child was first diagnosed with ASD. The remaining two studies analyzed the age at which they first visited a health professional with ASD related concerns (Mandell et al., 2006) and the mean age of first accessing classroom services (Nguyen et al., 2006).

One source, by Mandell et al. (2005), determined there was no significant difference in the age of diagnosis across all the races/ethnicities studied. However, the remaining six sources identified the same general trend: White children are diagnosed earlier than children of minorities, particularly Hispanic/Latino and Black children. Fountain, et al. (2011) suggested this trend is diminishing over time.

Conversely, the delay in diagnosis of Black and Hispanic/Latino children did not seem to carry over to the age at which a child first enters services. Nguyen et al. (2016) found that both Black children and Hispanic children entered classroom based programs at notably earlier ages than both White and Asian children.

Another factor altering age of diagnosis, in addition to race/ethnicity is the primary language spoken, which is closely associated with being foreign born. Because this was not a direct focus of this review, only two sources of the seven considered language as a variable. The first, by Nguyen et al. (2016), found that children from families that primarily speak English entered services, on average, almost three months earlier than children from families that primarily speak a different language. The second, by Jo et al. (2015), only divided their sample of Hispanic children into English and non-English speaking categories. They determined that Hispanic-Other language speaking children had lower percentages of later diagnoses across all severities, as well as with and without intellectual disabilities.

Becerra et al. (2014) did not evaluate primary language spoken, but they did consider nativity, or whether or not the mother was foreign born. Being foreign born makes having a primary language other than English much more likely. Their research found that foreign born White children had a later average diagnosis than those born in the United States, while the opposite was true for Black children. Hispanic, Asian, and Pacific Islander/Hawaiian races were

evaluated together and it was determined they were diagnosed at the same age on average, regardless of country of nativity.

Finally, severity may also influence age of diagnosis and age at first accessing services. This variable is analyzed in work by Jo et al. (2015), which found that White children were more likely than Black children to have later diagnoses of mild/moderate ASD, as well as ASD with no intellectual disability. However, White children had a noticeably lower rate of late diagnosis for ASD that was considered severe or accompanied by intellectual disability.

Prevalence Rates by Race

Table 3 illustrates the relationship between ASD prevalence rates and race/ethnicity or primary language spoken. The column headers indicate the race/ethnicity or language being compared while the left-most column indicates which source is being discussed. Within each square on the table, the mean prevalence, general trend, or percentage is detailed. These boxes also include any caveats like whether the prevalence differs based on ASD severity or socioeconomic status.

Eleven studies, depicted in Table 3, used prevalence rates/ratios of ASD diagnosis in their analysis of access to ASD related services and were included in the table. Most of these studies only analyzed White, Black, Hispanic/Latino, or Asian populations. Only four sources of these eleven considered American Indian and Alaskan Native (AIAN) children and only two considered Hawaiian/Pacific Islander or multiracial categories. An additional two sources also considered language spoken. All articles except McGrath, et al. (2020) found that White children have the highest prevalence of ASD or are the least underrepresented. Minorities had different prevalence rates or levels of underrepresentation depending on the time and scale of the study completed.

For Black children, the prevalence rate was almost always lower than that of White children. In fact, the results from Travers et al. (2014) indicate this disparity actually increased between the years 2000 and 2007. The only source that directly conflicts this is the previously mentioned work by McGrath et al. (2020), which found that school districts with the highest rates of ASD had 2-4% more Black students and 5-6% fewer White students. More specifically, in districts with low ASD rates, an average of 80.93% of the district was White while 3.5% was Black. In districts with high ASD rates, 74.33% of the population was White while 7.6% was Black, on average. Additionally, the study by Morrier & Hess (2010) found that Black students were over-identified in 6.12% of states. However, White children were found to be overrepresented in 20% of states, therefore indicating the racial disparity still exists.

A similar trend of underrepresentation can be seen for Hispanic/Latino children as well. Hispanic/Latino children consistently have lower prevalence rates in all studies but the previously mentioned New York study. However, they are also underidentified in a greater number of states than Black children. Morrier & Hess (2010) found Hispanic/Latino children were not overrepresented in any states and were underrepresented in the vast majority of them (85.42%). Also of note, Jo et al. (2015), found Hispanic children from primarily English speaking homes had a much higher prevalence rate of mild/moderate ASD when compared to Hispanic children from other language speaking homes. In fact, the prevalence rate for mild/moderate ASD in English speaking Hispanic children (0.0127) was closer to that of White children (0.0139) than Black children (0.0084). However, this trend was not replicated in the study by McGrath et al. (2020), which evaluated English Language Learner status and found it was not a significant predictor of ASD prevalence.

Prevalence rates in other populations, including Asian, American Indian and Alaskan Native, Hawaiian/Pacific Islander, and Multiracial varied based on the study. Prevalence rates of ASD in Asian children were found to be higher than the prevalence rate of White children in 4 studies, and lower in 3 studies. American Indian and Alaskan Native children had prevalence rates lower than that of White children or were underrepresented in many states, which was reflected in Hawaiian/Pacific Islander populations as well. Multiracial children were found to be underidentified in only 13 states and overidentified in 5 (Travers & Krezmien, 2018). Contrastingly, Mcgrath et al. (2020) found school districts in New York with the highest rates of ASD had less than 1% more multiracial students.

Odds/Risk Ratios by Race

Table 4 explains the relationship between odds/risk ratios of being diagnosed with ASD and race/ethnicity. Of the four studies that analyzed odds or risk ratios, none looked at the impact of primary language spoken and thus those columns were not included in this table. The column headers indicate the race or language being compared while the left-most column indicates which source is being discussed. The boxes within the table indicate the odds or risk ratios of receiving an ASD diagnosis. White children were most commonly used as the reference group and given a risk or odd ratio of one. A number greater than one indicates a higher risk or odds of ASD, while a number less than one indicates the opposite. Details regarding presence of intellectual disability, as well as U.S. born vs foreign born were also included for clarity.

Typically, White, U.S. born children were used as the reference and assigned a ratio of one. Becerra et al. (2014), and Bhasin & Schendel (2007) both determined Black children had a higher risk of ASD diagnosis. The former study considered children of both U.S. and foreign born mothers, with children of foreign born mothers having an even higher risk of ASD

diagnosis. The latter considered ASD with and without mental retardation (MR) and found Black children had a much higher risk of ASD with MR. Becerra et al. (2014), also considered Hispanic/Latino children and Asian children. Both had a higher risk of ASD diagnosis than White children, especially when born in the United States.

Contradicting these two sources, Mandell et al. (2009) found Black, Hispanic/Latino, and “Other” races had a lower risk than White children of diagnosis of ASD, both with and without intellectual disability (ID). Asian children had a lower risk of ASD with ID diagnosis but higher risk of ASD with no ID.

Finally, Pinborough-Zimmerman et al. (2011), used minorities as the reference and found White children had much higher risks of being diagnosed with ASD only or ID only, with no association between race/ethnicity and a diagnosis of both ASD and ID.

The findings of studies that used risk or odds ratios are therefore split, with some determining minorities have a higher risk of being diagnosed with ASD and others finding the opposite. There is however, some consensus that presence of MR or ID increases the odds of diagnosis.

Utilization of Services by Race

Table 5 illustrates the relationship between race or primary language and utilization of services, in the form of odds ratios. The column headers indicate the race or language being compared while the left-most column indicates which source is being discussed. The boxes include odds ratios, with White children being used as the standardized odds of one, for comparison. As before, odds ratio values of greater than one indicate the given group has higher odds of utilizing a particular type of service, etc. Odds ratios of less than one indicate the opposite. Additionally, the treatment being used or the exact barrier to accessing care is

described within the boxes. Four studies are featured in this table. Thomas et al. (2007), and Liptak et al. (2008) both indicated Black and Hispanic/Latino families had consistently lower utilization of services than White families.

Thomas et al. (2007) evaluated odds of using different medical services, such as a psychologist, or a particular manner of treatment and grouped Black and Hispanic/Latino children together into one minority group. Liptak et al. (2008) utilized a survey to determine the odds of a family having difficulty receiving services for their child with ASD. This source found Hispanic/Latino families had much higher odds of problems while obtaining care, leading to lower odds of preventative care or obtaining acute care in a timely fashion. Black families with a child with ASD had lower odds than White families of having problems getting care from a specialist. Otherwise, they displayed similar trends as Hispanic families, with issues getting acute or preventative care for their child.

Nguyen et al. (2016) found that maternal race/ethnicity was not associated with hours of services a family received for their child per week. However, they did determine a trend of marginal statistical significance: those who primarily speak English were more likely to receive more than or equal to 25 hours of service per week while those who primarily speak another language were more likely to receive less than 15 hours of service. This trend is supported by the findings of Zuckerman et al. (2017) which found children from Hispanic Limited English proficient homes had higher odds than Hispanic English proficient or White children of having less therapy, unmet therapy needs, or utilizing prescriptions.

Misdiagnoses by Race

Table 6 illustrates the relationship between race/ethnicity and receiving misdiagnoses related to ASD. The column headers indicate the race or language being compared while the

left-most column indicates which source is being discussed. The boxes include percentages or odds ratios, with White children once again being used as the standard for comparison with an odds ratio of one. Two sources are featured in this table, discussing misdiagnoses as they relate to ASD. They differed however, in that Mandell et al. (2006) evaluated children who were initially misdiagnosed and later determined to have ASD while Khowaja et al. (2014) studied children who were initially diagnosed with ASD, some of which were found to have been false diagnoses on follow up visits.

Mandell, et al. (2006) found that White children had a much higher prevalence of ASD diagnosis on first visit while Black children had the lowest prevalence of all race/ethnicities. Hispanic/Latino, Asian, and American Indian/Alaskan Native were grouped together as “Other” and on average, half were diagnosed with ASD on their first visit, falling between White and Black children. Additionally, Black children were more likely to receive an adjustment or conduct disorder than White children, while the “Other” group was more likely to receive an adjustment disorder but less likely to receive a conduct disorder. All minorities had higher odds of receiving a diagnosis other than ASD on the first visit when compared to White children.

Khowaja et al. (2014) determined minority children were much more likely to initially screen positive for ASD when compared to White children, then less likely to screen positive on a subsequent follow-up visit. Additionally, racial minorities were less likely to complete follow-up visits, which is related to the utilization of services discussed previously.

Overall, both the articles reviewed identified that minorities are more likely to be misdiagnosed than White children, whether that diagnosis should actually be ASD or something else.

Socioeconomic Status

Impact of Parental Education on Access to ASD-related Care

Eleven of the twenty-five sources in this review discussed the impact of parental education on access to ASD related care. Data for these results appears in Table 7 and are broken down according to three categories: low, middle and high educational attainment. The method of determining educational attainment is also listed (parental, paternal or maternal). The consensus among the sources is that there is an association between families with higher educational attainment and earlier and better access to ASD diagnostics and care.

Several sources asserted that ASD is found at an increased prevalence and with higher odds of diagnosis when parental education is high. Mandell et al. (2009) found that mothers with at least some college education had the greatest odds for having a child diagnosed with Autism Spectrum Disorder. Children from mothers with at least a high school diploma or equivalent also had higher odds of diagnosis than those whose mothers did not graduate high school. Liptak et al. (2008) found from a national survey that the prevalence of ASD in children from parents with at least some education beyond high school was the highest. These percentages were higher than those in the general population which suggests a link between access to ASD diagnosis and parental education.

Winter et al. (2020) found that the prevalence of ASD and its association with maternal education has changed over time. In 1992, the prevalence of ASD from mothers with some college education was the highest; however, by 2016, it became the lowest. In 2016, less than high school educated and high school educated mothers had children with similar prevalence, both higher than those with at least some college education. In a similar comparison, King & Bearman (2011) reported results from 1992 to 2000. In both 1992 and 2000, it was found that

areas with higher percentages of adults with bachelor's degrees or higher had greater odds of ASD diagnoses. However, the gap between the high and low educational attainment categories was diminished during this period. The odds risks in 2000 were 0.0035 for the highest education group and 0.004 for the lowest education group.

Other sources found that there was a connection between parental education and diagnoses of ASD with other disabilities/degrees of impairment. For example, Pinborough-Zimmerman et al. (2011) found that the odds of having a child with ASD-only or both ASD and an intellectual disability were higher for children of mothers with more than 13 years of education. Compared to those with 12-13 years of education, children of mothers with less than 12 years of education had about the same odds of an ASD only diagnosis and much higher odds of both an ASD and intellectual disability diagnosis. This shows that higher educated mothers are most likely to have their child diagnosed with ASD in the absence of an intellectual disability. Similar results were found by Bhasin & Schendel (2007). This article found that there is more than two times the odds of a child being diagnosed with ASD without mental retardation when the mother has 16 or more years of education. In both of these findings, children from mothers with higher educational attainment had greater odds of being diagnosed with ASD without the presence of mental retardation or another intellectual disability.

Some studies also discussed correlations with the location of ascertainment based on parental education. Bhasin & Schendel (2007) and Dickerson et al. (2017) found little to no correlation between maternal education and the ascertainment location for their child. A different study by Durkin et al. (2017) found that in areas with a lower percentage of adults with a bachelor's degree, the ascertainment amounts were lower. In areas with the highest percentages of adults with a bachelor's degree, it was most likely that children's ASD ascertainments were

done in health only or in both health and school settings. This shows that areas with higher educational attainment may have better access to healthcare. Typically, a diagnosis from a health resource shows that the diagnosis was achieved at an earlier age (Dickerson et al., 2017). Thus, being diagnosed from a healthcare setting only or from both healthcare related and school settings is indicative of better access to care.

Two sources focused on the quality and type of ASD resources in connection to parental education. Thomas et al. (2007) found that parents with a college degree had much greater odds of using resources such as neurologist, Picture Exchange Communication System (PECS) or hippotherapy. Nguyen et al (2016) discussed the correlation between maternal education and hours of intervention services per week. Children of mothers with a bachelor's degree were more likely to have less than 25 hours a week of classroom-based services, but more likely to have 15 to 24 hours of service. There was no correlation found between maternal education and individual-based services.

Impact of Insurance on Access to ASD-related Care

Seven of the sources addressed in this review discussed the impact of insurance on ASD related care. These results are summarized in Table 8. Three of the column headings address the different types of insurance coverages compared: private, public or uninsured. The last column of the table lists the specific types of insurances compared specific to each study. The overall results of these studies were mixed.

While all studies addressed public insurance, two of the studies addressed Medi-Cal specifically. The first, Winter et al. (2020), compared the prevalence of ASD between children with and without Medi-Cal from 1992 to 2016. In 1992, the Medi-Cal group had a prevalence of 0.002 and the non-Medi-Cal group had a prevalence of 0.004. In 2016, however, the prevalence

for both groups had increased but the trends were nearly identical at 0.012 and 0.01 respectively. The other source that analyzed Medi-Cal coverage was by King & Bearman (2011). This source compared data from 1992 and 2000. In 1992, the odds of being diagnosed with ASD while on Medi-Cal were lower than the odds for patients with other insurances. In 2000, however, the odds were very similar. Both of these sources show that the diagnostic gap due to insurance differences may be diminishing over time.

Four different sources looked at the effect on ASD related resources when there are insurance differences. Mandell et al. (2006) analyzed Medicaid eligibility for at least one year compared to Medicaid eligibility for less than one year. It was found that it was over three times as likely for a patient who was Medicaid eligible for more than a year to be diagnosed with a disorder other than ASD (ADHD, conduct and adjustment disorders). Another source, by Nguyen et al. (2016) found a correlation between public insurance and hours of intervention services. Those on public insurance were found to be more likely to receive less than 15 hours of service per week in comparison to 25 or more hours. Thomas et al. (2007) found that when children with ASD were covered by public insurances they had much greater odds of using medically necessary and therapeutic services than those with private insurance. In addition, children without medical insurance had much higher odds of using a case manager than those with insurance. Liptak et al. (2008) found similar results: children on public insurance are less likely to have had problems with preventive care. They are also more likely to receive prescription medications.

One source found different results than the rest. Jo et al. (2015) claimed in their findings that a child's health insurance was not statistically significant in the timing of ASD diagnosis. This study took privately, publicly, and uninsured individuals into account.

Impact of Relation to Poverty Level on Access to ASD related Care

Seven sources of the twenty-five analyzed in the review discussed links between poverty levels and ASD related care. These results are summarized in Table 9. The studies that addressed relation to poverty level had two different methods of comparison. Some looked at the percent of people who live below the poverty line and compared them to those not in poverty. The other sources looked at three categories: people below, near/at, or above the poverty level. This is indicated by the headers of the table. The methods of the source for determining the comparison by poverty level is also listed. Overall, these studies found that poverty is strongly correlated with access to care.

Some of the studies addressed the differences in diagnostic age based on poverty levels. Mandell, Novak & Zubritsky (2005) concluded that children from families near the poverty line received an ASD diagnosis 0.9 years later than those above the poverty line. Those from families below the poverty line received diagnoses 0.2 years later. According to Jo et al. (2015), when children lived in households that had an income less than 200% of the federal poverty level they were 1.44 times more likely to have a later ASD diagnosis. Fountain, King & Bearman (2011), however, did not find a correlation between age of diagnosis and poverty status.

Pinborough-Zimmerman et al. (2011) discussed the odds of being diagnosed with ASD as well as other disabilities. It found that those under the poverty line were less likely to have ASD diagnoses and more likely to be diagnosed with an intellectual disability than those above the poverty line. Liptak et al. (2011) discussed access to services in depth. It was found that those living near or below the poverty line had much higher odds of having difficulty in getting care from a specialist. It was also concluded that these groups had much higher odds of not having a personal doctor or nurse for their child compared to those above the poverty line.

Durkin et al. (2017) found differences in ascertainment of ASD based on poverty level. In this study it was asserted that when people live in areas where 20% or more of the population is in poverty, they are more likely to be diagnosed in school. They are least likely to be diagnosed in health only resources. Opposing results were found by Dickerson et al. (2017). This study found that areas with high percentages of families below the poverty line had higher odds of being diagnosed through healthcare rather than in schools. This opposes a lot of typical findings. This study also asserted that areas with high poverty rates had lower prevalences of ASD diagnoses.

Impact of Income on Access to ASD-related Care

Eight studies addressed income and the correlation with access to ASD related care. The results are summarized in Table 10. Similar to Table 7, these results were divided into three categories: low, middle and high incomes. The “Income Categories” column details the amounts that quantify each income category. Most results show that highest income groups are more likely to have better access to care and higher ASD prevalences.

Three studies highlight the differences in ASD resources based on income. Thomas, Ellis et al. (2007) found that children from families with highest incomes were much more likely to visit a developmental pediatrician and more likely to undergo speech language therapy. Two other sources evaluate differences in ASD ascertainment. Dickerson et al. (2017) discovered that in areas with median income above the 75th percentile, ASD diagnoses were mostly ascertained in a combination of school and healthcare settings. Bhasin & Schendel (2007) found that healthcare only, as well as school and healthcare resources combined, were where the majority of children from higher income families were diagnosed. Both of these sources also found that ASD prevalence was positively associated with income.

Some studies focused solely on the prevalence rate of ASD in connection to income. Durkin et al. (2010) found that prevalence of ASD was positively associated with income. According to McGrath, Bonuck & Mann (2020), school districts in New York with more economically disadvantaged students had greater prevalences of ASD. This contrasts most sources.

The rest of the studies discussed the odds of being diagnosed with ASD based on income. Thomas et al. (2011) found that the highest income category had two times the odds of being diagnosed with ASD than the lowest category and that the two factors were positively associated. Palmer et al. (2010) found that the risk of ASD diagnosis was higher in areas with household incomes above the median level. It was also found that the chance of having a learning or intellectual disability was lower in these higher income areas. Similar results were found by Pinborough-Zimmerman et al. (2011). In this study it was concluded that higher incomes were associated with higher ASD odds. In addition, the odds of an ASD diagnosis with an intellectual disability were highest in the low income categories.

Discussion

The connection between sociodemographic factors and access to healthcare is well documented, but relatively few studies have taken the initiative to try to quantify the disparity for children with Autism Spectrum Disorder. The current review considered 25 such studies from the last 16 years and identified that the disparity is wide-reaching and multifaceted. That being said, the studies used were often limited in their means of analyzing race/ethnicity and socioeconomic status.

The first and most prominent limitation of all studies discussing ASD in any capacity is that the data relies entirely on children who have already been diagnosed as having ASD. An

unknown amount of children in any given sociodemographic category are undiagnosed and thus our awareness of the disparity in access to care can never be entirely comprehensive. Because these children do not even have a diagnosis, they are facing the largest disparity of all. The only way to approximate said disparity is to look at the prevalence of adults diagnosed with ASD, which according to the CDC (2017) is approximately 0.36% of American adults. Thus, this 0.36% of the population went their entire childhood without being diagnosed or accessing ASD related resources. While this statistic approaches the amount of children who are not identified as having ASD it still does not include individuals who go their entire lifetime without accessing ASD related resources due to never being diagnosed.

However, this limitation is not the fault of any of the completed studies, but rather part of a larger systemic issue in lack of access to ASD related resources to which this review hopes to draw attention. In the following sections, we will more fully address how race/ethnicity and socioeconomic status contribute to this issue.

Additionally, some studies in this review lacked information important for determining the value, like the year(s) the study was conducted. As shown in Table 1, the study by Khowaja et al. (2014) includes the sample size (11,845 children) and scale (national) but does not specify the time frame over which the study took place. Thus, the authors of this review are unable to determine how recently the research was completed, and by extent, how relevant it is to the field. Furthermore, it was the only source considered in this review that looked at the relationship between a particular diagnostic tool and accuracy of ASD diagnoses, and so the specific results found could not be verified with other sources. That being said, Khowaja et al. (2014) did report the same trend found in many other reviewed studies: minorities face more barriers to ASD

related care. Additionally, the study had a relatively large sample size on a national scale, and was published in 2014 and so its findings should still be considered.

The same occurs with the study by Nguyen et al. (2016), which also lacks a year. While Khowaja et al. (2014) had a sample size of nearly twelve thousand, Nguyen et al. (2016) only studied 696 families and was localized in California. Additionally, the main findings of Nguyen et al. (2016) concluded Black and Hispanic children, as well as those from families who do not primarily speak English, accessed services at earlier ages on average. This contrasts the findings of many of the other studies reviewed. When considering all of these aspects of the study together, the findings of Nguyen et al. (2016) ultimately need to be further verified before they can provide additional value.

Along a similar theme, three studies within this review also did not specify the exact number of participants. Palmer et al. (2010) referenced their sample size as 1184 Texan school districts. The authors of this review looked at population data for Texas for the years studied (2004-2005) and found that the number of participants was about 14,000 children with ASD, from a cohort of approximately 3.5 million. Similarly, McGrath et al. (2020) referenced their sample size as 895 school districts in New York. The authors used population data from the New York State Education Department (2017) to determine there were 2,629,970 total students enrolled in the 2016-2017 school year, 37,435 of which were diagnosed with ASD. Dickerson et al. (2017) referenced their sample size as being 2489 census tracts, from the national ADDM surveillance network. According to the U.S. Census Bureau (2019), a census tract has a population between 1,200 and 8,000 people. Therefore, the Dickerson et al. (2017) sample was roughly 3,000,000 at the least, and anywhere up to roughly 20,000,000. While all three studies

failed to specify their actual sample size, all samples are very large, allowing them to still be valuable to the review overall.

Race/Ethnicity

In the current review, the following racial categories were used for analysis: White, Black, Hispanic/Latino Asian, American Indian/Alaskan Native, Hawaiian/Pacific Islander, Mixed Race, and Not Specified. These categories are notably broad, and based on the categories used most often in the studies reviewed. As a result, subtleties in the disparity faced by minorities may be generalized or completely overlooked. For example, none of the 25 studies evaluated looked specifically at Arabic populations, instead including them in the White racial category during analysis, since census data does the same. This lack does not just occur in this collection of studies, but is actually prevalent throughout the field of healthcare. Research on Arab Americans and immigrant Arabs is so scarce that Al Khatib (2017) reported only three empirical studies focused on disability of any kind in Arab American children. Thus, considering these Arab children White for the purposes of research into inequality does them a disservice by allowing their access to healthcare resources to go relatively unknown.

Furthermore, while there is a chance Arabic children may access healthcare resources associated with ASD at the same or similar rates as other White populations, the sources that compared primary language spoken found that in general a primary language other than English served as a barrier to accessing care. These results are supported by the findings of St. Amant et al. (2018) and Huerta & Lord (2013), indicating that language is a large barrier to accessing ASD related resources, especially diagnostic and intervention services. Thus, children of Arabic-speaking immigrants are more likely to experience that barrier.

The example of Arabic children being grouped together with other White populations is not the only overgeneralization noted over the course of this review. All Asian populations being analyzed together also may result in misrepresentation of access to care. Only one of the studies analyzed, by Becerra et al. (2014), subcategorized the race category of “Asian” into several ethnicities. They then found significant differences in access to care among the ethnicities. For example, prevalence rates for children of mothers born in China were found to be 48.9 per 10,000 births while the rate for children of mothers born in Vietnam was found to be 92.8 per 10,000 births. The mean prevalence for all children of Foreign-born Asian mothers was found to be 64.1 per 10,000 births, relatively close to the US-born White prevalence of 62.5 per 10,000. Thus, by looking at the prevalence for all children of Foreign-born Asian mothers, the disparity for children of mothers born in China, as well as the relatively high prevalence for children of mothers born in Vietnam are both overlooked.

The ability of these results to be generalized is limited, because Becerra et al. (2014) is the only source to have analyzed these ethnicities. However, their findings suggest there may be a confounding factor besides race and foreign-language that creates a barrier to access to ASD related resources, such as culture.

Another limitation in the race/ethnicity analysis of these studies is that of the Mixed Race and Other categories. Only four of the sources used multiracial as a category which highlights the fact that the other twenty sources generalized the race/ethnicity of any child determined to have more than one race. However, using the mixed race category also presents its own issue. At no point did any of the four sources using a mixed race category (2+ races, multiracial, etc) include the races of the children placed in this category. Leaving this variable unknown limits the ability to practically address the disparity.

The categories were also determined most often by maternal ethnicity only. While there is a practical necessity for this, as paternal information is not always available, it is possible children were considered to be one race when they should have been included in a Mixed Race category. Thus, for the studies that utilized this category, it is most likely underrepresented and very vague which minimizes the reliability of the findings.

Similarly, many studies utilized a racial category titled “Other or Not Specified”. Some studies would then use “Other” in their analysis and merge many minorities into one category for comparison. For example, Pinborough-Zimmerman et al. (2011) combined Black, Hispanic/Latino, Asian, American Indian/Alaskan Native, and Hawaiian/Pacific Islander categories into “Other” and compared them to White children. This almost undoubtedly resulted in the misrepresentation of at least one of those minority categories in their access to care for ASD related resources. As a result, the generalizability of these findings are incredibly limited, as it combines the averages, much like the previously discussed example for Asian populations and results in a misrepresentation of a specific group’s access to care.

Additionally, only four sources analyzed primary language, two of which only looked at English and Spanish. The impact of primary language spoken had mixed results on access to ASD related resources. Nguyen et al. (2016) found other primary languages resulted in a slightly later age of access to care in classrooms and marginally higher odds of receiving less than 15 hours of service per week. Contrastingly, McGrath et al. (2020) found English Language Learner status did not statistically predict the prevalence of ASD in a given area. For Hispanic/Latino populations, primarily speaking another language, was associated with higher unmet service needs (Zuckerman et al., 2017), lower prevalence rates of mild/moderate ASD, and less frequent late diagnoses (Jo et al., 2015). The less frequent late diagnoses appear to be promising;

however, when combined with the notably lower prevalence rates for “Other” language speakers, this statistic most likely indicates large portions of that population are going completely undiagnosed until adulthood or throughout their lifetime.

Also of note, most of these studies only offered their surveys or conducted interviews in English or Spanish. Thus, populations without a proficiency in either of these languages were completely overlooked, which limited the ability to accurately determine the degree to which language serves as a barrier to ASD related services. Overall, the impact of language on access to care is still unclear and should be analyzed more in the future to better determine methods of minimizing what disparity may exist.

Despite the various limitations discussed, the majority of sources did indicate relatively consistent findings: Access to care for ASD related resources is generally more limited for minorities, particularly Black and Hispanic/Latino children. The results that did not directly support this trend may actually be indicating a larger disparity: no diagnosis, rather than a late diagnosis. For example, Nguyen et al. (2016) found White children access services later than minority children. Jo et al. (2015) found White children had the higher percentage of late diagnoses for mild/moderate ASD and ASD with no intellectual disability.

While these findings initially suggest White children are facing a larger disparity in access to ASD related resources, they may in fact be indicating a complete lack of diagnosis in higher functioning minority children. To elaborate, high-functioning children with ASD (those lacking a cognitive delay) often receive later diagnoses and thus access ASD-related services later (Sheldrick et al., 2017). This would skew the average age of accessing services higher or result in a higher amount of late diagnoses, much like what is seen in the results from Nguyen et al. (2016) and Jo et al. (2015), respectively, for White children. Because neither study found

those same results for children of minorities, it can be inferred that some high functioning minority children with ASD may be going undiagnosed.

This could possibly be accounted for by different cultural responses to children with special needs, particularly those who are considered high functioning, or the aforementioned tendency to utilize other resources prior to medical professionals. However, systemic racism is also undoubtedly contributing to this disparity.

Systemic Racism

Systemic racism is defined as the system and structures that have processes that disadvantage individuals of color. The United States healthcare system is shaped from centuries of slavery and white oppression, which in turn continues to restrict access to adequate healthcare (Feagin & Bennefield 2013). Furthermore, perceived racism has been found to result in delaying or forgoing care due to lack of trust and/or poor doctor communication (Rhee et al. 2019). Sue & Sue (2008) expand on alternatives sought by minorities when delaying or forgoing care from a healthcare professional.

They found Black Americans more likely to seek recommendations from their support system (friends, family) before reaching out to professionals, while Asian Americans are more likely to address the so-called problem independently and reach out to professionals only when unable to manage any longer (Sue & Sue, 2008). Hispanic/Latino families may turn to healers or try nontraditional treatments before reaching out to professionals (Sue & Sue, 2008). These choices likely stem from a combination of mistrust of healthcare professionals, as well as various cultural beliefs and stigmas surrounding disabilities and mental illness. (Mandell & Novak 2005).

Altogether, research has consistently indicated minorities are more likely than White families to utilize other alternatives prior to reaching out to medical professionals (Dyches et al., 2004; Sue & Sue, 2008). This likely explains part of why Thomas et al. (2007) and Liptak et al. (2008) found Black and Hispanic/Latino families to have consistently lower utilization of ASD related services when compared to White families.

Ultimately, lack of trust is a documented issue many minorities experience with their healthcare professionals, which in turn makes them more likely to rely on other cultural solutions. This then makes them less likely to seek necessary care in a timely fashion, contributing to negative healthcare outcomes, and continuing to drive mistrust of healthcare professionals (Kennedy et al., 2021). One direct example contributing to mistrust was seen in research by Mandell et al. (2006), which found minority children with ASD more likely to be diagnosed with a condition other than ASD on their first visit. Black children in particular were more likely to get conduct and adjustment disorder diagnoses, which carry negative connotations in classroom settings (Mandell et al. 2006). This indicates minorities are less likely to get adequate care (i.e proper diagnosis) from their healthcare professional, leading to dissatisfaction and perpetuating generational mistrust.

Overall, systemic racism in the United States has consistently placed minorities at a disadvantage in accessing necessary resources, including healthcare, but extending to socioeconomic mobility as well (Kearney, 2006). Put simply, systemic oppression and discrimination resulted in limited choices for minorities in terms of education and occupation, driving high poverty rates and unemployment (Kearney, 2006). According to the U.S. Census Bureau (2020), poverty rates for Black and Hispanic individuals are about twice as high as White

populations. This should be kept in mind as the connection between access to ASD related resources and socioeconomic status is discussed further.

Socioeconomic Status

Socioeconomic status has been known to impact or predict health and mortality (Sweeney, 2015). Even though the link between healthcare access and SES has been established, the correlation between ASD specific care and SES has not been as well documented. This review has found that socioeconomic status does indeed impact access to ASD related care to some extent. In the category of socioeconomic status, this review looked at parental education, insurance, poverty level and income. These were all established as notable determinants in access to ASD related care. Access to care is a broad term, however, this focus was purposefully left broad because of the gaps in research on the topic. For example, there are not enough studies specifically on age of diagnosis or hours of service as they relate to socioeconomic status to warrant a review into such specific aspects of care. While most of the studies found some correlation between socioeconomic factors and ASD related care, the results varied from source to source. Collectively, it was found that children from families with lower socioeconomic statuses had poorer access to care for ASD. This typically included later diagnoses, lack of diagnosis, or less likelihood to use available resources.

A few sources did not fully explain their methodologies and results had to be interpolated by the authors of this review. For example, the source by Durkin et al. (2010) did not quantify the range for their tertiles. In this source there were tertiles created for three different groups: percent above the poverty level, percent with bachelor's degrees, and median household income. Because the ranges weren't quantified, the comparison to other sources is limited. Similar issues arose with the source by McGrath, Bonuck & Mann (2020). The results found that schools with

economic disadvantages had higher ASD prevalences. This source contrasted most others, but it never explained the qualifications for economic disadvantage which limited its findings for this review.

Differences in diagnosis prevalence and odds are particularly troubling because there is no biological explanation for this. While there are programs in place (Medicaid, welfare, etc.) there is still a strong difference in prevalence of ASD among those from different socioeconomic backgrounds. Many sources also found results that showed lower SES was correlated with higher levels of school-only ascertainment than healthcare ascertainment. School-only ascertainment is associated with later ages of diagnosis. Higher quantities of school-only ascertainment in those of lower socioeconomic status also suggests they face a disparity in accessing healthcare professionals, thus receiving a diagnosis only once their child reaches school age. This implication is supported by Liptak et al. (2011): people living below the poverty line were much less likely to have a personal doctor or nurse.

Longitudinal studies by King & Bearman (2011) and Winter et al. (2020) concluded that the gaps in socioeconomic statuses may be declining over time. The latter study is one of the most recent studies addressing the socioeconomic impact of ASD-related care, and thus may indicate the trend of future studies. Another recent and related study (Mcmaughan, Oloruntoba, & Smith, 2020) discussed the gap between SES and healthcare access in general. According to this research, people from lower socioeconomic backgrounds are disproportionately affected with more barriers in access to healthcare. This impact goes beyond just ASD related care; it can lead to worse healthcare outcomes and premature death in these populations (Mcmaughan, Oloruntoba, & Smith, 2020).

Another study (Arpey, Gaglioti & Rosenbaum, 2017) reflects a two fold bias; people from lower socioeconomic backgrounds perceived their own healthcare as inferior and saw their physician's as likely to look down on them. So not only may there be a bias in the physician's themselves, but the individuals receiving care may also perpetuate biases. These biases need to be addressed.

Medicaid was one of the factors assessed that was shown to result in poorer access to ASD related care than those with private insurances. It has been found that expansions in state Medicaid programs have resulted in less uninsured individuals and lower mortality rates and better access to care (Sommers et al. 2012).

Limitations of Review

This review also has various limitations, the first being the scale of studies used. In our scope, we included only studies conducted in the United States and published within the last sixteen years. This left us with a variety of studies that focused on broader sociodemographic factors, namely race/ethnicity, or socioeconomic tertiles. Thus, in this review we were unable to fully consider other possible confounding variables, like language, culture, or specific geographic location (i.e. city, community type).

Another limitation by the authors in this review was in the comparison of sources that discussed relation to poverty level. As mentioned in the introduction, poverty level has more than one meaning and the amounts could be different based on this meaning. It seemed that three of eight sources that discussed poverty level were using poverty guidelines and the other five used poverty thresholds. Thus, the data presented was simplified for comparison purposes. If the focus of this study was solely based on an individual's relation to poverty level and its impact on access to care, the differences in poverty threshold and guidelines would have been discussed in

greater detail. This would lead to more specific comparison and less generalized data. However, the general trends elucidated by this review would remain the same, allowing this review to still hold value.

Conclusions

Overall, most of the sources reviewed came to the same general consensus: minorities and those with lower socioeconomic status typically had more barriers when accessing care for ASD related resources. This results in later age of diagnosis, lower prevalence rates, and lower utilization of services, a clear disparity that must be addressed.

More recent data, from 2018 US surveillance found the gap between prevalence rates of ASD for Black and White children to be narrowing, which is promising (Constantino et al. 2020). However, in order to properly address this disparity in all of its facets, more research needs to be done.

Future Research

Research should continue along the same vein as many of the studies included in this review, in order to continue validating the results. In addition to national studies, smaller geographical studies should also be conducted as the dynamics of one city, county, or region, may result in different impacts on access to ASD related resources and therefore require a different solution.

Regarding race/ethnicity, research needs to continue more inclusively. Rather than just conducting surveys in English or Spanish, translators should be used to provide surveys or conduct interviews in a wider variety of languages. Additionally, the use of “other” race categories in analysis should be discontinued, as it overgeneralizes the study results and makes it difficult to determine how best to minimize any found disparity. Rather than using a term like

Asian or Hispanic/Latino, more studies should conduct analyses based on specific countries of origin before grouping ethnic groups together. This would help minimize overgeneralizations like that seen in the Chinese vs Vietnamese sample from Becerra et al. (2014).

In terms of socioeconomic status, more precise studies should be done. Many of the studies used umbrella categories (such as tertiles) to quantify socioeconomic status. While large scale studies help to find trends, smaller scale and highly analytical studies would be beneficial as well. These studies could focus more specifically on individuals in order to address any confounding factors that may contribute to differences in access to care (race/ethnicity, location, etc.).

Research into the next step for reducing this multifaceted disparity is also required. Studies must be completed to determine how to best help a given demographic, since one blanket solution would be largely ineffective.

Solutions

A variety of solutions could be applied to minimize the current disparity affecting both minority and low socioeconomic status populations. However, more research, like that described above, should be completed in order to fully understand who is impacted and how best to help them.

First, health professionals must be exposed to more than just vignettes of White children with ASD during their training. They should also be educated more on cultural competency to better create a trusting relationship with previously marginalized populations. Over time, this will work to reduce the generational mistrust minorities often have with health professionals while also making the health professional more likely to recognize possibly differing signs of ASD in children (DeWeerd, 2012). Currently, only 19% of children with ASD have been

diagnosed directly due to flagging by their pediatricians (Khowaja et al. 2014). Thus, there is ample room for improvement.

Beyond this, all school professionals should have a standardized education on the early signs of ASD in diverse populations. This would help reduce the diagnosis gap between those of different socioeconomic backgrounds; many people have trouble affording frequent physician appointments and better diagnostics in school would ensure equitable diagnoses. This would also contribute to the reduction of the misdiagnoses, as found by Mandell et al. (2006) and Khowaja et al. (2014). By ensuring all school professionals are familiar with ASD, instead of just school psychologists, nurses, or special needs teachers, it is more likely that children who would have otherwise slipped through the system undetected will be diagnosed.

An ASD education campaign should also be more widely implemented in order to reach parents who are unfamiliar with the disorder, or who may not have the means of accessing a healthcare professional unless absolutely necessary. Currently in place is the US Centers for Disease Control and Prevention “Learn the Signs, Act Early” campaign. Studies into the impact of this campaign have found it to be educational but lacking in terms of significance or providing direct outreach for parents in need (Raspa et al., 2014). Furthermore, clear disparities in access to ASD related resources persist (Constantino et al., 2020).

A supplemental informational campaign could take the form of informational brochures, given to the parent in their primary language at time of childbirth, or at an early pediatrician visit. Additionally, information posters could be placed at community centers, churches, or other common gathering places. These informational documents should include common signs of ASD, including delayed speech, lack of eye contact, or self-stimulating behaviors, as well as who

to reach out to should the parent have concerns. Steps towards universal screening for all children should also be taken.

One important consideration for improved access to care for those of low socioeconomic status would be for hospitals and other medical groups to create initiatives to reach out to communities with major social barriers in the way of their healthcare. This should start with screening and information to these communities, followed by assistance in helping individuals navigate the healthcare system. Healthcare systems should be aligning themselves with the local communities to meet their specific needs (Bhatt & Bathija, 2018). Another consideration to improve this equitable access to care would be expansion of public insurances. This may eliminate some of the barriers established by one's socioeconomic status. Throughout this review, the impact of insurance on access to care was highlighted. It has been found that expansions to state Medicaid programs result in less uninsured individuals, lower mortality rates and better access to care (Sommers et al. 2012).

Ultimately, the above listed ideas would work to reduce the disparity minorities and low socioeconomic status populations face when accessing resources required for ASD diagnosis and treatment. However, this disparity extends to all aspects of the United States healthcare system, and even farther into the systemic lack of support for marginalized populations. In order to truly make sure all children with ASD have access to the resources they need for the best possible life, steps must be taken by the United States government to provide more equal access to healthcare and generally more support for the people who need it most.

References

- Agyemang, C., Bhopal, R., & Bruijnzeels, M. (2005, December 1). *Negro, Black, Black African, African Caribbean, African American or what? Labelling African origin populations in the health arena in the 21st century*. *Journal of Epidemiology & Community Health*.
<https://jech.bmj.com/content/59/12/1014>.
- Alsayyari, H. (2017). Perceptions of Arab American Mothers of Children with Autism Spectrum Disorder: An Exploratory Study. *Special Education and Teaching Commons*.
<https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-017-0179-8?report=reader>
- American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders* (4th ed., Text Revision). Washington, DC.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed., Text Revision). Washington, DC.
- Arpey, N. C., Gaglioti, A. H., & Rosenbaum, M. E. (2017). How Socioeconomic Status Affects Patient Perceptions of Health Care: A Qualitative Study. *Journal of Primary Care & Community Health*, 8(3), 169-175. doi:10.1177/2150131917697439
- Becerra, T., von Ehrenstein, O., Heck, J., Arah, O., Jeste, S., Rodriguez, M., & Ritz, B. (2014). Autism Spectrum Disorders and Race, Ethnicity, and Nativity: A Population-Based Study. *PEDIATRICS*, 134(1). <https://doi.org/10.1542/peds.2013-3928d>
- Begeer, S., Bouk, S. E., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2008). Underdiagnosis and Referral Bias of Autism in Ethnic Minorities. *Journal of Autism and Developmental Disorders*, 39(1), 142–148. <https://doi.org/10.1007/s10803-008-0611-5> .

- Bhasin, T. K., & Schendel, D. (2006). Sociodemographic Risk Factors for Autism in a US Metropolitan Area. *Journal of Autism and Developmental Disorders*, 37(4), 667-677.
doi:10.1007/s10803-006-0194-y
- Bhatt, J., & Bathija, P. (2018). Ensuring Access to Quality Health Care in Vulnerable Communities. *Academic Medicine*, 93(9), 1271-1275.
doi:10.1097/acm.0000000000002254
- Blair, I., Steiner, J., & Havranek, E. (2011). Unconscious (Implicit) Bias and Health Disparities: Where Do We Go From Here? *The Permanente Journal*, 15(2), 71–78.
- California Department of Health Care Services. (2020, June 16). Behavioral Health Treatment. Children with Autism Spectrum Disorder.
<https://www.dhcs.ca.gov/services/medi-cal/Pages/BehavioralHealthTreatment.aspx>.
- Centers for Disease Control and Prevention. (2020, March 26). *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016*. Centers for Disease Control and Prevention.
https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w.
- Centers for Disease Control and Prevention. (2021, January 12). *Autism Spectrum Disorder (ASD)*. Centers for Disease Control and Prevention.
<https://www.cdc.gov/ncbddd/autism/index.html>.
- Committee on the Consequences of Uninsurance, Board on Health Care Services, & Institute of Medicine. (2002). Overview of Public Health Insurance Programs. Health insurance is a family matter. essay, National Academy Press.

- Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., ... Geschwind, D. H. (2020). Timing of the Diagnosis of Autism in African American Children. *Pediatrics*, 146(3). <https://doi.org/10.1542/peds.2019-3629>
- DeWeerd, S. (2012). Culture: Diverse diagnostics. *Nature*, 491(7422). <https://doi.org/10.1038/491s18a>
- Dickerson, A. S., Rahbar, M. H., Pearson, D. A., Kirby, R. S., Bakian, A. V., Bilder, D. A., ... Wingate, M. S. (2016). Autism spectrum disorder reporting in lower socioeconomic neighborhoods. *Autism*, 21(4), 470-480. doi:10.1177/1362361316650091
- Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., ... Yeargin-Allsopp, M. (2017). Autism Spectrum Disorder Among US Children (2002–2010): Socioeconomic, Racial, and Ethnic Disparities. *American Journal of Public Health*, 107(11), 1818–1826. <https://doi.org/10.2105/ajph.2017.304032>
- Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuseppi, C., Nicholas, J. S., ... Schieve, L. A. (2010). Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study. *PLoS ONE*, 5(7). <https://doi.org/10.1371/journal.pone.0011551>
- Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34, 211–222.
- Erlangga, D., Suhrcke, M., Ali, S., & Bloor, K. (2019). The impact of public health insurance on health care utilisation, financial protection and health status in low- and middle-income countries: A systematic review. *Plos One*, 14(11). doi:10.1371/journal.pone.0225237

- Feagin, J., & Bennefield, Z. (2013). Systemic Racism. *Social Science & Medicine*.
<https://doi.org/10.4324/9781315880938>
- Fernell, E., Eriksson, M. & Gillberg, C. (2013). Early diagnosis of autism and impact on prognosis: a narrative review. *Clinical Epidemiology*, 5, 33–43.
<https://doi.org/10.2147/clep.s41714>
- FitzGerald, C. & Hurst, S. (2017). Implicit bias in healthcare professionals: a systematic review. *BMC Medical Ethics*, 18(1). <https://doi.org/10.1186/s12910-017-0179-8>
- Fountain, C., King, M. D., & Bearman, P. S. (2010). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *Journal of Epidemiology & Community Health*, 65(6), 503-510. doi:10.1136/jech.2009.104588
- Franks, P., Clancy, C., & Gold, M. (1993). Health Insurance and Mortality. *JAMA*, 270(6), 737.
<https://doi.org/10.1001/jama.1993.03510060083037>
- Kentrou, V., de Veld, D. M. J., Mataw, K. J. K., & Begeer, S. (2018). Delayed autism spectrum disorder recognition in children and adolescents previously diagnosed with attention-deficit/hyperactivity disorder. *Autism*, 23(4), 1065–1072.
<https://doi.org/10.1177/1362361318785171>
- Hall, W. J., Chapman, M. V., Lee, K. M., Merino, Y. M., Thomas, T. W., Payne, B. K., ... Coyne-Beasley, T. (2015). Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review. *American Journal of Public Health*, 105(12), 2588–2588. <https://doi.org/10.2105/ajph.2015.302903a>
- Huerta, M., & Lord, C. (2012). Diagnostic Evaluation of Autism Spectrum Disorders. *Pediatric Clinics of North America*, 59(1), 103–111. <https://doi.org/10.1016/j.pcl.2011.10.018>

- Indian Country Today Staff (2016, August 29). Native American vs. Indian. Indian Country Today. <https://indiancountrytoday.com/archive/native-american-vs-indian>.
- Jo, H., Schieve, L. A., Rice, C. E., Yeargin-Allsopp, M., Tian, L. H., Blumberg, S. J., . . . Boyle, C. A. (2015). Age at Autism Spectrum Disorder (ASD) Diagnosis by Race, Ethnicity, and Primary Household Language Among Children with Special Health Care Needs, United States, 2009–2010. *Maternal and Child Health Journal*, 19(8), 1687-1697.
doi:10.1007/s10995-015-1683-4
- Kearney, M. S. (2006). Intergenerational Mobility for Women and Minorities in the United States. In *The Future of Children* (Vol. 16, pp. 37–53). essay, Princeton University.
- Kearney, M. S. (2006). Intergenerational Mobility for Women and Minorities in the United States. *The Future of Children*, 16(2), 37–53. <https://doi.org/10.1353/foc.2006.0016>
- Kennedy, B., Mathis, C., & Woods, A. (2021). African Americans and Their Distrust of the Healthcare System: Remain an Issue in the 21st Century. *Journal of Cultural Diversity*, 14(2), 56–60. <https://doi.org/10.35455/brk1232021>
- Khowaja, M. K., Hazzard, A. P., & Robins, D. L. (2014). Sociodemographic Barriers to Early Detection of Autism: Screening and Evaluation Using the M-CHAT, M-CHAT-R, and Follow-Up. *Journal of Autism and Developmental Disorders*, 45(6), 1797-1808.
doi:10.1007/s10803-014-2339-8
- King, M. D., & Bearman, P. S. (2011). Socioeconomic Status and the Increased Prevalence of Autism in California. *American Sociological Review*, 76(2), 320-346.
doi:10.1177/0003122411399389
- Koegel, L. K. (2000). Interventions to facilitate communication in autism. *Journal of Autism and Developmental Disorders*, 30(5), 383–391. <https://doi.org/10.1023/a:1005539220932>

- Lee, A. (2018, March 25). U.S. Poverty Thresholds and Poverty Guidelines: What's the Difference? Population Reference Bureau.
<https://www.prb.org/insight/u-s-poverty-thresholds-and-poverty-guidelines-whats-the-difference/>.
- Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in Diagnosis and Access to Health Services for Children with Autism: Data from the National Survey of Children's Health. *Journal of Developmental & Behavioral Pediatrics, 29*(3), 152–160.
<https://doi.org/10.1097/dbp.0b013e318165c7a0>
- Lopez, M. H., Krogstad, J. M., & Passel, J. S. (2020, September 22). *Who is Hispanic?* Pew Research Center. <https://www.pewresearch.org/fact-tank/2020/09/15/who-is-hispanic/>.
- MacDonald, V.-M. (2001). Hispanic, Latino, Chicano, or “Other”? Deconstructing the Relationship between Historians and Hispanic-American Educational History. *History of Education Quarterly, 41*(3), 365–413. <https://doi.org/10.1111/j.1748-5959.2001.tb00093.x>
- Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2006). Disparities in Diagnoses Received Prior to a Diagnosis of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1795–1802.
<https://doi.org/10.1007/s10803-006-0314-8>
- Mandell, D. S., Novak, M. (2005). The role of culture in families’ treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*, 110–115.

- Mandell, D. S., Novak, M., & Zubritsky, C. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *PEDIATRICS*, *116*(6), 1480–1486.
<https://doi.org/10.1542/peds.2005-0185>
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., Diguseppi, C., Durkin, M. S., . . . Kirby, R. S. (2009). Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders. *American Journal of Public Health*, *99*(3), 493-498.
[doi:10.2105/ajph.2007.131243](https://doi.org/10.2105/ajph.2007.131243)
- Mcgrath, K., Bonuck, K., & Mann, M. (2020). Exploratory spatial analysis of autism rates in New York school districts: Role of sociodemographic and language differences. *Journal of Neurodevelopmental Disorders*, *12*(1). [doi:10.1186/s11689-020-09338-x](https://doi.org/10.1186/s11689-020-09338-x)
- Mcmaughan, D. J., Oloruntoba, O., & Smith, M. L. (2020). Socioeconomic Status and Access to Healthcare: Interrelated Drivers for Healthy Aging. *Frontiers in Public Health*, *8*.
[doi:10.3389/fpubh.2020.00231](https://doi.org/10.3389/fpubh.2020.00231)
- Morrier, M. J., & Hess, K. L. (2010). Ethnic Differences in Autism Eligibility in the United States Public Schools. *The Journal of Special Education*, *46*(1), 49–63.
<https://doi.org/10.1177/0022466910372137>
- Mudrak, B. Open Access Publishing: Five Myths. *American Journal Experts*.
- Musumeci, M. B. (2019). Medicaid's Role for Children with Special Health Care Needs. *Journal of Law, Medicine & Ethics*, *46*(4), 897–905.
<https://doi.org/10.1177/1073110518821987>
- National Research Council (US) Committee on Educational Interventions for Children with Autism. (2001). *Educating Children with Autism*. National Academies Press.
<https://doi.org/10.17226/10017>

New York State Education Department. (2017). 2017: NY STATE - Enrollment Data: NYSED Data Site. data.nysed.gov.

<https://data.nysed.gov/enrollment.php?year=2017&state=yes>.

Nguyen, C. T., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K. (2016).

Sociodemographic Disparities in Intervention Service Utilization in Families of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 46(12), 3729-3738. doi:10.1007/s10803-016-2913-3

Noe-Bustamante, L., Mora, L., & Lopez, M. H. (2020, October 2). *Latinx Used by Just 3% of U.S. Hispanics. About One-in-Four Have Heard of It*. Pew Research Center's Hispanic Trends Project.

<https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/>.

Palmer, R. F., Walker, T., Mandell, D., Bayles, B., & Miller, C. S. (2010). Explaining Low Rates of Autism Among Hispanic Schoolchildren in Texas. *American Journal of Public Health*, 100(2), 270–272. <https://doi.org/10.2105/ajph.2008.150565>

Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbone, P. S., Nangle, B. E., . . . McMahon, W. M. (2011). Sociodemographic risk factors associated with autism spectrum disorders and intellectual disability. *Autism Research*, 4(6), 438-448. doi:10.1002/aur.224

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., . . . Wolf, R. B. (2015). Examining Parents' Experiences and Information Needs Regarding Early Identification of Developmental Delays. *Journal of Developmental & Behavioral Pediatrics*, 36(8), 575–585. <https://doi.org/10.1097/dbp.0000000000000205>

- Rhee, T. G., Marottoli, R. A., Van Ness, P. H., & Levy, B. R. (2019). Impact of Perceived Racism on Healthcare Access Among Older Minority Adults. *American Journal of Preventive Medicine*, 56(4), 580–585. <https://doi.org/10.1016/j.amepre.2018.10.010>
- Rondeau, E., Klein, L. S., Masse, A., Bodeau, N., Cohen, D., & Guilé, J.-M. (2010). Is Pervasive Developmental Disorder Not Otherwise Specified Less Stable Than Autistic Disorder? A Meta-Analysis. *Journal of Autism and Developmental Disorders*, 41(9), 1267–1276. <https://doi.org/10.1007/s10803-010-1155-z>
- Sheldrick, R. C., Maye, M. P., & Carter, A. S. (2017). Age at First Identification of Autism Spectrum Disorder: An Analysis of Two US Surveys. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(4), 313–320. <https://doi.org/10.1016/j.jaac.2017.01.012>
- Simón, Y. (2018, September 14). *Hispanic vs. Latino vs. Latinx: A Brief History of How These Words Originated*. Remezcla. <https://remezcla.com/features/culture/latino-vs-hispanic-vs-latinx-how-these-words-originated/>.
- Sommers, B. D., Baicker, K., & Epstein, A. M. (2012). Mortality and Access to Care among Adults after State Medicaid Expansions. *New England Journal of Medicine*, 367(11), 1025–1034. <https://doi.org/10.1056/nejmsa1202099>
- St. Amant, H. G., Schragger, S. M., Peña-Ricardo, C., Williams, M. E., & Vanderbilt, D. L. (2017). Language Barriers Impact Access to Services for Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 48(2), 333–340. <https://doi.org/10.1007/s10803-017-3330-y>

Sue, D. W., Sue, D. (2008). *Counseling the culturally diverse: Theory and practice* (5th ed.). Hoboken, NJ: John Wiley.

Sweeney, M. (2015, September). Stop Skipping Class: Why socioeconomic status (SES) matters. Retrieved from

<https://www.apa.org/pi/ses/resources/indicator/2015/09/socioeconomic-status>

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to Care for Autism-Related Services. *Journal of Autism and Developmental Disorders*, 37(10), 1902–1912. <https://doi.org/10.1007/s10803-006-0323-7>

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2011). The association of autism diagnosis with socioeconomic status. *Autism*, 16(2), 201–213. <https://doi.org/10.1177/1362361311413397>

Travers, J. C., Krezmien, M. P., Mulcahy, C., & Tincani, M. (2012). Racial Disparity in Administrative Autism Identification Across the United States During 2000 and 2007. *The Journal of Special Education*, 48(3), 155–166. <https://doi.org/10.1177/0022466912454014>

Travers, J., & Krezmien, M. (2018). Racial Disparities in Autism Identification in the United States During 2014. *Exceptional Children*, 84(4), 403-419. [doi:10.1177/0014402918771337](https://doi.org/10.1177/0014402918771337)

U.S. Census Bureau (2018, February 23). *Intergovernmental Affairs: Tribal Affairs- American Indian and Alaska Native (AIAN)*. The United States Census Bureau. <https://www.census.gov/about/cong-gov-affairs/intergovernmental-affairs/tribal-aian/about.html>.

U.S. Centers for Medicare & Medicaid Services. Children's Health Insurance Program (CHIP) - HealthCare.gov Glossary. HealthCare.gov.

<https://www.healthcare.gov/glossary/childrens-health-insurance-program-chip/>.

U.S. Department of Health & Human Services. (2021, February 3). 2021 Poverty Guidelines. Office of the Assistant Secretary for Planning and Evaluation.

<https://aspe.hhs.gov/2021-poverty-guidelines>.

US Census Bureau. (2019, September 16). Glossary. The United States Census Bureau.

https://www.census.gov/programs-surveys/geography/about/glossary.html#par_textimage_13.

Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the Time Between First Evaluation and First Autism Spectrum Diagnosis in a Population-based Sample. *Journal of Developmental & Behavioral Pediatrics*, 27(Supplement 2).

<https://doi.org/10.1097/00004703-200604002-00005>

Winter, A. S., Fountain, C., Cheslack-Postava, K., & Bearman, P. S. (2020). The social patterning of autism diagnoses reversed in California between 1992 and 2018. *Proceedings of the National Academy of Sciences*, 117(48), 30295-30302.

doi:10.1073/pnas.2015762117

Wolff, S. (2004). The history of autism. *European Child & Adolescent Psychiatry*, 13(4).

<https://doi.org/10.1007/s00787-004-0363-5>

Woolhandler, S., & Himmelstein, D. U. (2017). The Relationship of Health Insurance and Mortality: Is Lack of Insurance Deadly? *Annals of Internal Medicine*, 167(6), 424.

doi:10.7326/m17-1403

Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families. *Pediatrics*, *139*(5). <https://doi.org/10.1542/peds.2016-3010>

Tables

Table 1

Literature Review Grid, chronological order

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/ Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Factors Associated with Age of Diagnosis Among Children With Autism Spectrum Disorders	Mandell, D., Novak, M., & Zubritsky, C.	2005	Pediatrics	969 children	2004	2-21 yrs	Pennsylvania	Survey of caregivers of children with Autism	Autism, Asperger's PDD-NOS	Public, private	Comparison to poverty level	White, Black, Asian/PI, Latino, AIAN
Disparities in Diagnoses Received Prior to a Diagnosis of Autism Spectrum Disorder	Mandell, D., Ittenbach, R., Levy, S., & Pinto-Martin, J.	2006	J Autism Dev Disord ^a	406 children	1993-1999	3-10 yrs	Philadelphia, Pennsylvania	Medicaid reimbursed mental health claims	Autistic disorder ADHD, conduct, adjustment & cognitive disorders	Medicaid eligible	Medicaid eligibility	AIAN, Asian, Black, Latino, White, other ^b .
Examination of the Time Between First Evaluation and First Autism Spectrum Diagnosis in a Population-based Sample	Wiggins, L., Baio, J., & Rice, C.	2006	Developmental & behavioral pediatrics	115 children	2000	8 yrs	5-county Metropolitan Atlanta area	Population based surveillance system at CDC	ASD, PDD-NOS Asperger's. With/without MR	-	-	White, Black, not-stated, other ^c
Access to Care for Autism-Related Services	Thomas, K., Ellis, A., McLaurin, C., Daniels, J., & Morrissey, J.	2007	Journal of Autism & Developmental disorders	383 children	2003-2005	< 12 yrs	North Carolina	Telephone/ in-person surveys. UNC Research Center ^d	ASD	Public, private, none	education, income, insurance	White, Black, Hispanic, other

^aJournal of Autism and Developmental Disorders. ^b Only Black, White, & other were used as categories for analysis. ^cAsian-PI, Hispanic, American Indian. ^dNeurodevelopmental Disorders Research Subject Registry, University of North Carolina at Chapel Hill (UNC).

Table 1 (cont.)

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/ Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Sociodemographic Risk Factors for Autism in a US Metropolitan Area	Bhasin, T., & Schendel, D.	2007	Journal of Autism & Developmental Disorders	1201 children	1996	3-10 yrs	Atlanta, Georgia	MADDSP ^a & birth certificate data	Autism/MR, Autism/no MR	-	mother's education, mother's age & median family income level	White, Black
Disparities in Diagnosis and Access to Health services for Children with Autism: Data from the National Survey of Children's Health	Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G.	2008	Journal of Developmental & behavioral pediatrics	495 children	2003-2004	< 17 yrs	National	National survey of children's health. Parent reports	ASD	Medicaid, private, no insurance	income, education, insurance	White, Latino, Black
Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders	Mandell, D., Wiggins, L., Carpenter, L., Daniels, J., DiGuiseppi, C., Durkin, M., Giarelli, E., Morrier, M., Nicholas, J., Pinto-Martin, J., Shattuck, P., Thomas, K., Yeargin-Allsopp, M., & Kirby, R.	2009	American Journal of Public Health	2568 children	2002	8 yrs	14 National Sites ^b	ADDM network surveillance data & birth certificate data	ASD	-	Maternal education	AIAN; Asian; Black; Hispanic; native Hawaiian/PI White; other/multiracial; not stated
Ethnic Differences in Autism Eligibility in the United States Public Schools	Morrier, M., & Hess, K.	2010	The Journal of Special Education ^c	295,945 children	2007-2008	3-21 yrs	National	US Department of Education Records	ASD, Developmental delay	-	-	AIAN, Asian/PI, Black, Hispanic/Latino, White

^a Metropolitan Atlanta Developmental Disabilities Surveillance Program. ^bAlabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, Wisconsin, West Virginia. ^c Hammill Institute on Disabilities.

Table 1 (cont.)

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Explaining Low Rates of Autism Among Hispanic Schoolchildren in Texas	Palmer, R., Walker, T., Mandell, D., Bayles, B., & Miller, C.	2010	American Journal of Public Health	ASD prevalence in 1184 school districts ^a	2004-2005	K-12 grade	Texas	Texas Education Agency	ASD, learning disability, intellectual disability	-	location & median household income	Hispanic, White
Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study	Durkin, M., Maenner, M., Meaney, F., Levy, S., DiGuseppi, C., Nicholas, J., Kirby, R., Pinto-Martin, J., & Schieve, L.	2010	PLoS ^b One	3680 children	2002-2004	8 yrs	12 National Sites ^c	ADDM	ASD, intellectual disability	All	tertiles based on poverty level, parental education & median household income	White, Black Hispanic, Asian, other
Age of Diagnosis for Autism: Individual and Community Factors Across 10 Birth Cohorts	Fountain, C., King, M., & Bearman, P.	2011	Journal of Epidemiol-ogical Communi-ty Health	17,185 children	1992-2001	2-8 yrs	California	Birth & administrative records, DDS ^d , census data	ASD	Medi-Cal Private Insurance	maternal race, sex, poverty status, maternal birthplace, maximum years of parental education, zip code	Black, Hispanic, White, other
The Association of Autism Diagnosis with Socioeconomic Status	Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M.	2011	Autism	586 children	2000 & 2002	8 yrs	New Jersey	Census data, ADDM data	ASD	-	Median income	White, Black, Hispanic, Asian, Other

^aApproximately 3,487,500 total students with approximately 14,055 children with ASD Because actual sample size was not provided, we relied on the mean autism rate and the number of students enrolled in Texas school districts at the time of study. ^bPublic Library of Science. ^cAlabama, Arkansas, Arizona, Colorado, Georgia, Maryland, Missouri, North Carolina, New Jersey, Pennsylvania, South Carolina, & Wisconsin. ^d Department of Developmental Services (California).

Table 1 (cont.)

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Sociodemographic Risk Factors Associated With Autism Spectrum Disorders and Intellectual Disability	Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbons, P., Nangle, B., Randall, H., & McMahon, W.	2011	Autism Res ^a	26,108 children	1994-2002	8 yrs	Utah	Multiple source surveillance system using retrospective records of birth & tax information.	ASD, ID	-	mother's ethnicity, parental age/education, adjusted gross income, federal taxes paid, tax exemptions	White, Black, Hispanic
Socioeconomic Status and the Increased Prevalence of Autism in California	King, M., & Bearman, P	2011	American Sociological Review	18,731 children	1992-2006	6-14 yrs	California	Birth & diagnostic records for all children born in California 1992 - 2000.	ASD	All	location, education, insurance	-
Racial Disparity in Administrative Autism Identification Across the United States During 2000 and 2007	Travers, J., Krezmien, M., Mulcahy, C., & Tincani, M.	2012	Journal of Special Education ^b	2000: 84,082; in 2007: 265,725 children	2000 & 2007	K-12 grade	National	IDEA ^c data accountability center, NCES ^d	ASD	-	-	White, Black, Hispanic
Autism Spectrum Disorders and Race, Ethnicity, and Nativity: A Population-Based study	Becerra, T., von Ehrenstein, O., Heck, J., Olsen, J., Arah O., Jeste, S., Rodriguez, M., & Ritz, B.	2014	Pediatrics	1,626,354 children	1998-2009	3-5 yrs	Los Angeles County	DDS records	ASD	Medi-Cal Private Insurance Other	-	White, Black, Hispanic, Asian/PI

^aAutism Research. ^bHammill Institute on Disabilities. ^cIndividuals with Disabilities Education Act, from the U.S. Department of Education. ^d

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Table 1 (cont.)

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Sociodemographic Barriers to Early Detection of Autism: Screening and Evaluation Using the M-CHAT, M-CHAT-R, and Follow-Up	Khowaja, M., Hazzard, A., & Robins, D.	2014	Journal of Autism & Developmental Disorders	11,845 children	-	1-3 yrs	National	Modified checklist for Autism in toddlers at pediatric visits.	Autism	-	maternal education & race	White; Black; Asian; White-Hispanic; Black-Hispanic; Asian-Hispanic; other-Hispanic; multi-racial/other
Age at Autism Spectrum Disorder (ASD) Diagnosis by Race, Ethnicity, and Primary Household Language Among Children with Special Health Care Needs, United States, 2009–2010	Jo, H., Schieve, L., Rice, C., Yeargin-Allsopp, M., Tian, L., Blumberg, S., Kogan, M., & Boyle, C.	2015	Maternal & Child Health Journal	2,729 children	2009-2010	3-17 yrs	National	National survey of children with special health care needs	ASD	None, public, private	Highest education of guardian, household income relative to the federal poverty level, type of health insurance	White, Black Hispanic, (English) Hispanic (other language)
Sociodemographic Disparities in Intervention Service Utilization in Families of Children with Autism Spectrum Disorder	Nguyen, C., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K.	2016	J Autism Dev Disord	696 families	-	2-5 yrs	California	Surveys, CHARGE data	ASD	Medi-Cal private insurance	Maternal socio-demographic information ^a	White, Hispanic, Asian, Black, mixed/other

^a Age at delivery, birthplace, education level, race/ethnicity, primary language spoken at home, marital status, homeowner status, insurance at time of delivery.

Table 1 (cont.)

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Autism Spectrum Disorder Among Children (2002-2010): Socioeconomic, Racial, and Ethnic Disparities	Durkin, M., Maenner, M., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee, L., Schieve, L., Van Naarden Braun, K., Wingate, M., & Yeargin-Allsopp, M.	2017	American Journal of Public Health	1,308,641 children	2002-2010	8 yrs	National	Population based surveillance, census, survey data.	ASD, intellectual disability	-	Census data & educational attainment	Black, White, Hispanic
Autism Spectrum Disorder Reporting in Lower Socioeconomic Neighborhoods	Dickerson, A., Rahbar, M., Pearson, D., Kirby, R., Bakian, A., Bilder, D., Harrington, R., Pettygrove, S., Zahorodny, W., Moyé, L., Durkin, M., & Wingate, M.	2017	Autism	2489 Census Tracts ^a	2000-2008	8 yrs	National	ADDM network surveillance data & US census data	ASD	private/public	mother's education, median household income, college education, percent below poverty line	White, Black, Hispanic, other
Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families	Zuckerman, K., Lindly, O., Reyes, N., Chavez, A., Macias, K., Smith, K., & Reynolds, A.	2017	Pediatrics	352 children	2014-2015	2-10 yrs	Los Angeles, Denver, Portland	Current & former members of the Autism Speaks Autism Treatment Network	ASD	Public, private	education, employment, insurance	Latino English proficient, Latino limited English proficient, non-Latino White

^aA census tract has 1,200-8,000 people, so this sample includes at least 2,986,800 individuals.

Table 1 (cont.)

Source	Authors	Year	Journal	Sample Size	Years Studied	Age/ Grade	Location	Method of Gathering Data	Diagnoses	Insurance	Determination of SES	Race
Racial Disparities in Autism Identification in the United States During 2014	Travers, J., & Krezmien, M.	2018	SagePub	510,099 children	2014	K-12 grade	National ^a	IDEA Data center, NCES	ASD	-	-	White, Hispanic, Black, Asian, Native Hawaiian/ PI, AIAN, mixed race
Exploratory Spatial Analysis of Autism Rates in New York School Districts: Role of Sociodemographic and Language Differences	McGrath, K., Bonuck, K., & Mann, M.	2020	Journal of Neurodevelopmental Disorders	895 School Districts ^b	2016-2017	3-21 yrs	New York	New York Department of Education	ASD	Private/ Public	Economic disadvantage	Hispanic, Black, AIAN, Asian, White
The Social Patterning of Autism Diagnoses Reversed in California Between 1992 and 2018	Winter, A., Fountain, C., Cheslack-Postava, K., & Bearman, P.	2020	Proceedings of the National Academy of Sciences of the United States of America	13,272, 573 children	1992-2018	3-6 yrs	California	DDS, birth records	ASD	Medi-Cal & private	Medi-Cal status, maternal education level	White, Latino, Black, Asian

^a Excludes Wyoming due to lack of data. ^b 2,629,970 students total, 37,435 with ASD, per the New York State Education Department (2017).

Table 2

Age of Diagnosis/Age at First Use of Services by Race

Source	Race								Primary Language			
	White	Black	Hispanic/ Latino	Asian	AIAN ^a	Hawaiian/ PI	Mixed Race	Not specified	English	Other		
Mandell, D., Novak, M., & Zubritsky, C. (2005)	[Comparable age of diagnosis across all ethnicities]								-	-	-	-
Wiggins, L., Baio, J., & Rice, C. (2006)	1st evaluation: 48 months 1st diagnosis: 62 months	1st evaluation: 50 months 1st diagnosis: 60 months	Other: 1st evaluation: 45 months 1st diagnosis: 63 months				-	1st evaluation: 38 months 1st diagnosis: 51 months.	-	-		
Mandell, D., Ittenbach, R., Levy, S., & Pinto-Martin, J. (2006)	Age at first visit: 6.3 years	Age at first visit: 7.1 years	Other: Age at first visit: 6.8 years				-	-	-	-		
Becerra, T., von Ehrenstein, O., Heck, J., Olsen, J., Arah O., Jeste, S., Rodriguez, M., & Ritz, B. (2014)	US-born diagnosis: 3.2 years Foreign born diagnosis: 3.6 years	U.S. born diagnosis: 3.6 years Foreign-born diagnosis: 3.4 years	U.S. and foreign born diagnosis: 3.6 years		-	U.S. and foreign born diagnosis: 3.6 years	-	-	-			
Fountain, C., King, M., & Bearman, P. (2011)	Diagnosed earlier.	Diagnosed later.	Effect diminishes in later cohorts.			-	Diagnosed later. Effect diminishes in later cohorts.	-	-			
Nguyen, C., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K. (2016)	1st classroom service: 2.57 years	1st classroom service: 2.04 years	1st classroom service: 2.52 years	1st classroom service: 2.68 years	Other: 1st classroom service: 2.35 years			-	1st classroom service: 2.32 years	1st classroom service: 2.55 years		

^a American Indian/Alaskan Native (AIAN).

Table 2 (cont.)

Age of Diagnosis/Services by Race

Source	Race							Primary Language		
	White	Black	Hispanic/ Latino	Asian	AIAN	Hawaiian/ PI	Mixed Race	Not specified	English	Other
Jo, H., Schieve, L., Rice, C., Yeargin-Allsopp, M., Tian, L., Blumberg, S., Kogan, M., & Boyle, C.	50.8% of mild/moderate ASD diagnosed late. 49.9% of ASD/no ID diagnosed late. 16.4% of severe ASD diagnosed late. 34% of children with ASD/ID diagnosed late	33.5% of mild/moderate ASD diagnosed late. 33.3% of ASD/no ID diagnosed late. 37.8% of severe ASD diagnosed late. 39% of children with ASD/ID diagnosed late	See language	-	-	-	-	-	Hispanic: 43.5% of mild/moderate ASD diagnosed late. 40.9% of ASD/no ID diagnosed late. 30.8% of severe ASD diagnosed late. 44.1% of children with ASD/ID diagnosed late.	Hispanic: 18% of mild/moderate ASD diagnosed late. 26.6% of ASD/no ID diagnosed late 12% of severe ASD diagnosed late. 13.4% of children with ASD/ID diagnosed late.

Table 3

Prevalence Rates by Race

Source	Race							Primary Language	
	White	Black	Hispanic/Latino	Asian	AIAN	Hawaiian/PI	Mixed Race	English	Other
Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G. (2008)	Prevalence = 0.051	Prevalence = 0.046	Prevalence = 0.026	-	-	-	-	-	-
Palmer, R., Walker, T., Mandell, D., Bayles, B., & Miller, C. (2010)	10% in white children is correlated with a 9% increase in Autistic Disorder diagnoses	-	10% increase in Hispanic children is correlated with an 11% decrease in Autistic Disorder diagnoses	-	-	-	-	-	-
Durkin, M., Maenner, M., Meaney, F., Levy, S., DiGuiseppi, C., Nicholas, J., Kirby, R., Pinto-Martin, J., & Schieve, L. (2010)	Prevalence = 0.0069	Prevalence = 0.0057	Prevalence = 0.0051	Prevalence = 0.0076	-	-	-	-	-
Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2011)	Used as standard for comparison (PR ^b = 1)	PR = 0.9	PR = 0.9	PR = 1.2	-	-	-	-	-
Travers, J., Krezmien, M., Mulcahy, C., & Tincani, M. (2012) ^c	Reference group	Number of states under-identifying Black students increased from 8 to 32 between 2000 and 2007	Number of states under-identifying Hispanic students increased from 8 to 27 between 2000 and 2007.	-	-	-	-	-	-
Morrier, M., & Hess, K (2010). ^d	Underrepresented: 4% of states; overrepresented: 20% of states	Underrepresented: 8.16% of states; overrepresented: 6.12% of states	Underrepresented: 85.42% of states; overrepresented: 0% of states	Underrepresented: 15.56% of states; overrepresented: 5.56% of states	Underrepresented: 37.21% of states; overrepresented: 2.33% of states	-	-	-	-

^a Used average prevalence, found prevalence increased as SES increased for all races. ^bPR = Prevalence ratio. ^cOnly 35 states had enough information to complete analysis of black children and only 26 states had enough information to complete analysis of Hispanic children. ^dIncludes DC but not Vermont.

Table 3 (cont.)

Prevalence Rates by Race

Source	Race							Primary Language	
	White	Black	Hispanic/Latino	Asian	AIAN	Hawaiian/PI	Mixed Race	English	Other
Travers, J., & Krezmien, M.	46 states identified < than California (1.6%)	All states identified < 1.6%. Significant under-identification: 37 states	All states identified < 1.6%. Significant under-identification: 42 states	All states identified < 1.6%	Significant under-identification in 21 states	40 states identified <1.6%. Significant under-identification in 14 states.	Under-identified in 13 states	-	-
Dickerson, A., Rahbar, M., Pearson, D., Kirby, R., Bakian, A., Bilder, D., Harrington, R., Pettygrove, S., Zahorodny, W., Moyé, L., Durkin, M., & Wingate, M. ^d	PR = 1.09	PR = 0.94	[Other: PR = 0.86]		-	-	-
McGrath, K., Bonuck, K., & Mann, M.	Districts with highest ASD rates: 5-6% fewer White students	Districts with highest ASD rates: 2-4% more Black students	Districts with highest ASD rates: 2-3% more Hispanic students	Districts with highest ASD rates: <1% more Asian students	Districts with highest ASD rates: <1% fewer American Indian students	-	Districts with highest ASD rates: <1% more multiracial students	English Language Learner status was not a statistically significant predictor of ASD prevalence	
Winter, A., Fountain, C., Cheslack-Postava, K., & Bearman, P. ^e	Prevalence increased from 1992 to 2018	Prevalence increased from 1992 to 2018 with rates being notably higher in non-MediCal populations by 2018. Remained similar to White.	Prevalence increased from 1992 to 2018. Remained similar to White.	Prevalence increased from 1992 to 2018, with rates being notably higher in MediCal populations by 2018. Slightly lower than White populations.	-	-	-	-	-

^d Used White children with only school records as prevalence ratio of 1. ^eValues are approximated based on graphs, which provide information on 1998-2018.

Table 3 (cont.)

Prevalence Rates by Race

Source	Race							Primary Language	
	White	Black	Hispanic/Latino	Asian	AIAN	Hawaiian/ PI	Mixed Race	English	Other
Jo, H., Schieve, L., Rice, C., Yeargin-Allsopp, M., Tian, L., Blumberg, S., Kogan, M., & Boyle, C.	Mild/Moderate PR = .0139 severe PR = 0.0024	Mild/Moderate PR = .0084; Severe PR = 0.0025	See Language	-	-	-	-	Hispanic: Mild/ Moderate PR = 0.0127 Severe PR = 0.0010	Hispanic: Mild/ Moderate PR = 0.0030 Severe = 0.0011

Table 4

Odds Ratios (OR) and Risk Ratios by Race

Source	Race								
	White	Black	Hispanic/ Latino	Asian	AIAN	Hawaiian/PI	Mixed Race	Not specified	
Becerra, T., von Ehrenstein, O., Heck, J., Olsen, J., Arah O., Jeste, S., Rodriguez, M., & Ritz, B. ^a	U.S. born used as standard for comparison (risk ratio = 1) Foreign born = 1.04	U.S. born risk ratio = 1.14 Foreign born risk ratio = 1.76	U.S. born risk ratio = 1.13 Foreign born risk ratio = 1.06	U.S. born risk ratio = 1.04 Foreign born risk ratio = 1.02	-	-	-	-	
Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbons, P., Nangle, B., Randall, H., & McMahon, W.	Odds of ASD only child: 5.19. No association between race/ethnicity & ASD/ID group	Other: Used as standard for comparison (OR = 1). No association between race/ethnicity and ASD/ID group						-	-
Bhasin, T., & Schendel, D. ^b	Used as standard for comparison (OR = 1)	ASD Only: OR = 1.5; ASD and MR: OR = 3.6	-	-	-	-	-	-	
Mandel, D., Wiggins, L., Carpenter, L., Daniels, J., DiGuseppi, C., Durkin, M., Giarelli, E., Morrier, M., Nicholas, J., Pinto-Martin, J., Shattuck, P., Thomas, K., Yeargin-Allsopp, M., & Kirby, R.	Used as standard for comparison (OR = 1)	IQ < 70 OR = 0.67 IQ ≥ 70 OR = 0.68	IQ < 70 OR = 0.53 IQ ≥ 70 OR = 0.88	IQ < 70 OR = 0.38 IQ ≥ 70 OR = 1.22	[Other: IQ < 70 OR = 0.52; IQ ≥ 70 OR = 0.65]			-	

^a Risk ratio is adjusted for maternal age, type of birth, parity, infant gender, year of birth, gestational age, trimester start of prenatal care, pregnancy complications, maternal education, and regional center. ^b Odds ratios are adjusted for all other demographic variables (sex, age, mother's age/education, median family income level, as well as birth factors).

Table 5

Utilization of Services by Race (Odds Ratios)

Source	Race							Primary Language		
	White	Black	Hispanic/ Latino	Asian	AIAN	Hawaiian /PI	Mixed Race	Not specified	English	Other
Thomas, K., Ellis, A., McLaurin, C., Daniels, J., & Morrissey, J.	Used as standard for comparison (OR = 1)	Case manager OR = 0.48; Psychologist OR = 0.27; Developmental pediatrician OR = 0.28; Sensory Integration OR = 0.25		-	-	-	-	Case manager OR = 0.48; Psychologist OR = 0.27; Developmental pediatrician OR = 0.28; Sensory Integration OR = 0.25	-	-
Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G.	Used as standard for comparison (OR = 1)	Problem getting care from specialist OR = 0.34; Not getting acute care in timely fashion OR = 5.95 Not visiting personal doctor for preventative care OR = 1.03	Problem getting care from specialist OR = 3.84; Not getting acute care in timely fashion OR = 18.60; Not visiting personal doctor for preventative care OR = 5.25	-	-	-	-	-	-	-
Nguyen, C., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K.	[Maternal race/ethnicity was not associated with hours of service]	-	Marginally more likely to receive >25 hours of services per week	Marginally more likely to receive <15 hours of service per week

Table 5 (cont.)

Utilization of Services by Race (Odds Ratios)

Source	Race								Primary Language	
	White	Black	Hispanic/ Latino	Asian	AIAN	Hawaiian/ PI	Mixed Race	Not specified	English	Other
Zuckerman, K., Lindly, O., Reyes, N., Chavez, A., Macias, K., Smith, K., & Reynolds, A.	Used as standard for comparison (OR = 1)	-	See language	-	-	-	-	-	Hispanic English proficient: < 1 hr of weekly therapy OR = 1.61 Behavioral therapy OR = 0.87 Prescriptions = 1.15 Unmet therapy needs OR = 1.55	Hispanic limited english proficient: < 1 hr of weekly therapy: OR = 4.51 Behavioral therapy: OR = 0.63 Prescriptions: 0.87 Unmet therapy needs: OR = 2.12

Table 6
Misdiagnoses by Race

Source	Race						
	White	Black	Hispanic/ Latino	Asian	AIAN	Mixed Race	Not specified
Mandell, D., Ittenbach, R., Levy, S., & Pinto-Martin, J.	60.2% diagnosed with Autism on first visit. Used as standard for comparison (OR = 1)	34.7% diagnosed with autism on first visit. Odds of receiving a diagnosis other than autism = 2.6 Odds of adjustment disorder diagnosis: 5.1 Odds of conduct disorder diagnosis = 2.4	50% diagnosed with Autism at first visit. Odds of receiving a diagnosis other than autism = 1.4. Odds of adjustment disorder diagnosis = 4.1 Odds of conduct disorder diagnosis = 0.9	Other:		-	-
Khowaja, M., Hazzard, A., & Robins, D. ^a	Used as standard for comparison (OR = 1)	Odds of screening positive for ASD = 1.84 Follow-up outcomes were only affected by race in the lowest education group with minorities less likely to screen positive a second time. Less likely to complete follow-up visits than white families.			-	Odds of screening positive for ASD = 1.84 Follow-up outcomes were only affected by race in the lowest education group with minorities less likely to screen positive a second time. Less likely to complete follow-up visits than white families.	

^a Considered Black, Hispanic/Latino, Asian, Mixed Race, and Not Specified minority populations together, so results were found to be the same.

Table 7

Impact of Parental Education on Access to ASD related care

Source	Education Categories Detailed	Method of Determining Education	Education Categories		
			Low	Middle	High
Thomas, K., Ellis, A., McLaurin, C., Daniels, J., & Morrissey, J. (2007)	Low- Less than high school Middle- High school degree High- College degree & above	Parental Education	Lower levels of care compared to those with more than high school education.		Parents with a college/graduate degree had 2-4 times the odds of using services ^a
Mandell, D., Wiggins, L., Carpenter, L., Daniels, J., DiGuseppi, C., Durkin, M., Giarelli, E., Morrier, M., Nicholas, J., Pinto-Martin, J., Shattuck, P., Thomas, K., Yeargin-Allsopp, M., & Kirby, R. (2009)	Low- Less than high school graduate, Middle- High school graduate or equivalent, High- Some college	Maternal Education	Reference (OR = 1.0)	Odds of ASD diagnosis: 1.31	Odds of ASD diagnosis: 1.44
Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G. (2008)	Low- Less than high school, Middle- High school graduate, High- More than high school	Parental Education	2% of the children with ASD surveyed	23% of the children with ASD surveyed	72% of the children with ASD surveyed ^b
Durkin, M., Maenner, M., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee, L., Schieve, L., Van Naarden Braun, K., Wingate, M., & Yeargin-Allsopp, M. (2017)	Educational attainment tertiles based on Census and American Community Survey data	Adults aged ≥25 with at least a bachelor’s degree ^c	Reference (PR = 1.0)	PR of health & school ascertainment = 1.23 PR of health only = 1.20 PR of school only = 1.45	PR of health & school ascertainment = 1.43 PR of health only = 1.60 PR of school only = 1.28
Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbons, P., Nangle, B., Randall, H., & McMahon, W. (2011)	Low- less than 12 years, Middle- 12 to 13 years, High- more than 13 years	Maternal Education	ASD only OR = 1.03 ASD/ID OR = 2.01	Reference (OR = 1.0)	ASD only OR = 1.5 ASD/ID OR = 2.13
Nguyen, C., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K. (2016)	Low- High school or less, Middle- Some college/vocational, High- Bachelor degree	Maternal Education	PR ^d of 15-24 hrs = 0.75 PR of < 15 hrs = 0.88 prevalence for < 15 hrs	PR ^d of 15-24 hrs = 0.94 PR of < 15 hrs = 1.12 prevalence for < 15 hrs	Reference (PR = 1.0)

^aNeurologist, PECS system, hippotherapy or therapeutic horseback riding. ^bThis was 65% in mothers of children without ASD. ^cPercentage per census tract. ^dClassroom based services.

Table 7 (cont.)

Impact of Parental Education on Access to ASD-related care

Source	Education Categories Detailed	Method of Determining Education	Education Categories		
			Low	Middle	High
Dickerson, A., Rahbar, M., Pearson, D., Kirby, R., Bakian, A., Bilder, D., Harrington, R., Pettygrove, S., Zahorodny, W., Moyé, L., Durkin, M., & Wingate, M. (2017)	Low/Middle- not college educated, High- college educated	Maternal Education	Standard for comparison (OR & PR = 1)		0.9 times the odds of beings diagnosed in healthcare only and 1.12 the odds in both healthcare and schools. 1.07 PR of college educated
Winter, A., Fountain, C., Cheslack-Postava, K., & Bearman, P. (2020) ^a	Low- less than high school, Middle- high school graduation, High- college degree or higher ^a	Maternal Education	1992- 0.002 prevalence, 2016- 0.011 prevalence	1992- 0.0035 prevalence, 2016- 0.012 prevalence	1992- 0.006 prevalence, 2016- 0.008 prevalence
Bhasin, T., & Schendel, D. (2007)	Low- < 12 years, Middle- 12 years, 13–15 years, High- 16 years, >16 years	Maternal Education	0.7 times the odds of autism/no MR, No ascertainment location difference	Standard for comparison (OR = 1)	2.4 times the odds of autism/no MR, No ascertainment location difference
King, M., & Bearman, P. (2011) ^c	Low- 25th percentile for college graduates, Middle- between 25th and 75th percentile of college graduates, High- 75th percentile of college graduates	Percentage of adults aged 25 or older with a bachelor’s degree or higher per census tract	1992- 0.002 chance of ASD diagnosis, 2000- 0.004 chance of ASD diagnosis	—	1992- 0.0025 chance of ASD diagnosis, 2000- 0.0035 chance of ASD diagnosis
Khowaja, M., Hazzard, A., & Robins, D. (2014) ^d	Low- high school or less, Middle- some college, High- bachelor’s degree or graduate degree	Maternal Education	0.469 ppv	0.543 ppv	Bachelor’s degree- 0.538 ppv, Graduate degree- 0.705 ppv

^aThis source gave data from 1992 to 2016. Only the results for 1992 and 2016 were given to account for trends and better comparison among sources. ^b“Some college” category was eliminated for simplicity in comparison. The results were similar to the “high school” category. ^cThis source gave data from 1992 to 2000. Only the results for 1992 and 2000 were given to account for trends and better comparison among sources. ^dPPV is calculated as the proportion of children who screened positive and also received an ASD diagnosis (i.e., true positives) to all cases who screened positive on the M-CHAT(-R) regardless of diagnosis.

Table 8

The Impact of Insurance on Access to ASD-related Care

Source	Private	Public	No insurance	Insurance Comparison
Mandell, D., Ittenbach, R., Levy, S., & Pinto-Martin, J. (2006)	—	3.4 times more likely for children with autism to receive a diagnosis other than ASD if Medicaid eligible for more than 1 year.	—	Medicaid eligible for greater than 1 year vs less than 1 year
Thomas, K., Ellis, A., McLaurin, C., Daniels, J., & Morrissey, J. (2007)	—	Children covered by public insurance had 2 to 11 times the odds of using medically necessary and therapeutic services than those covered by private insurance.	4.94 times the odds of using a case manager than those with insurance.	Private insurance only, Medicaid but no private insurance, Medicaid and private insurance, Public insurance (other than Medicaid) only, No major treatment approach
Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G. (2008)	Standard for comparison (OR = 1)	0.66 times the odds to have had problems with preventive care, 0.78 times less likely to not receive prescription medications	—	Any insurance, Uninsured, Non-Medicaid insurance, Medicaid/SCHIP
Nguyen, C., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K. (2016)	Standard for comparison	37 % more likely to receive <15 (vs. ≥25) hours of service	—	Public insurance, Private insurance
Winter, A., Fountain, C., Cheslack-Postava, K., & Bearman, P. (2020) ^a	1992- 0.004 prevalence, 2016- 0.01 prevalence	1992- 0.002 prevalence, 2016- 0.012 prevalence	—	No Medi-Cal, Medi-Cal delivery
King, M., & Bearman, P. (2011) ^b	Standard for comparison (OR = 1)	1992- 0.90 times the odds of ASD diagnosis, 2000- 0.97 times the odds	—	Medi-Cal, Other
Jo, H., Schieve, L., Rice, C., Yeargin-Allsopp, M., Tian, L., Blumberg, S., Kogan, M., & Boyle, C. (2015)	Child's health insurance was not statistically significant in timing of diagnosis.			Private/both/other, Public, Uninsured

^aThis source gave data from 1992 to 2016. Only the results for 1992 and 2016 were given to account for trends and better comparison among

sources. ^bThis source gave data from 1992 to 2000. Only the results for 1992 and 2000 were given to account for trends and better comparison among sources.

Table 9

Impact of Relation to Poverty Level on Access to ASD-related care

Source	Below Poverty Line	At or Near Poverty Line	Above Poverty Line	Poverty Categories	Percent Below Poverty Line
Mandell, D., Novak, M., & Zubritsky, C. (2005)	Received diagnosis 0.2 years later	Received diagnosis 0.9 years later	Standard for comparison	Below poverty level, From poverty level to 100% above, Greater than 100% above	-
Durkin, M., Maenner, M., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee, L., Schieve, L., Van Naarden Braun, K., Wingate, M., & Yeargin-Allsopp, M. (2017)	-	-	-	Percent in poverty area (at least 20% of people have income under poverty level), Non-poverty area	31.6% health and school ascertainment, 23.1% health only and 39.9% school only
Fountain, C., King, M., & Bearman, P. (2020)	-	-	-	Percent of households below poverty line	No statistically significant correlation.
Dickerson, A., Rahbar, M., Pearson, D., Kirby, R., Bakian, A., Bilder, D., Harrington, R., Pettygrove, S., Zahorodny, W., Moyé, L., Durkin, M., & Wingate, M. (2017)	-	-	-	Percent below poverty line	In areas below the poverty line there was 0.79 times ASD prevalence. There was 0.95 times the odds of diagnosis in school and 1.39 times the odds from healthcare
Jo, H., Schieve, L., Rice, C., Yeargin-Allsopp, M., Tian, L., Blumberg, S., Kogan, M., & Boyle, C. (2015)	-	-	-	Less than or equal to 200% of federal poverty level, greater than 200% of federal poverty level	Children living in households with incomes <200% of the federal poverty level were 1.44 times more likely to have a later ASD diagnosis
Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbons, P., Nangle, B., Randall, H., & McMahon, W. (2011)	-	-	-	Less than or equal to 200% poverty line vs. greater than 200% above	200% under poverty line was 0.88 times less likely to have ASD than general population, 1.13 times as likely to have ID compared to general population and 0.73 times as likely to have ASD compared to ID
Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G. (2008)	3.26 times the odds of having a problem getting care from a specialist, 9.10 times the odds of the child not having a personal doctor or nurse	2.54 times the odds of having a problem getting care from a specialist, 2.10 times the odds of the child not having a personal doctor or nurse	Standard for comparison (OR = 1)	Poor (less than 100% poverty level), near-poor (100% of poverty level to below 200% poverty level), and not poor (at or above 200% poverty level)	-

Table 10

Impact of Income on ASD-related care

Source	Income Categories	Low	Middle	High
Thomas, K., Ellis, A., McLaurin, C., Daniels, J., & Morrissey, J. (2007)	Low- income below \$50,000, High-income at or above \$50,000	Reference 1.0	–	Odds of visiting developmental pediatrician: 3.53 Odds of speech therapy: 2.49 Risk of autism: 1.11 Risk of ID: 0.81 Risk of learning disability: 0.95
Palmer, R., Walker, T., Mandell, D., Bayles, B., & Miller, C. (2010)	Middle- County median household income (\$36,911), High- \$10,000 above county median household income	–	Standard for comparison (OR = 1)	
Durkin, M., Maenner, M., Meaney, F., Levy, S., DiGuseppi, C., Nicholas, J., Kirby, R., Pinto-Martin, J., & Schieve, L. (2010)	Low, Middle, High median household incomes (no income values given)	Prevalence: 0.005	Prevalence: 0.0065	Prevalence: 0.008
Pinborough-Zimmerman, J., Bilder, D., Bakian, A., Satterfield, R., Carbons, P., Nangle, B., Randall, H., & McMahon, W. (2011)	Low (<\$26,500.02), Middle (\$26,500.02–\$32,203.47), High (>\$33,203.47),	Odds of ASD: 1.28 Odds of ID: 1.34 Odds of ASD/ID: 1.55	Standard for comparison (OR = 1)	Odds of ASD: 1.51 Odds of ID: 1.1 Odds of ASD/ID: 1.08
Dickerson, A., Rahbar, M., Pearson, D., Kirby, R., Bakian, A., Bilder, D., Harrington, R., Pettygrove, S., Zahorodny, W., Moyé, L., Durkin, M., & Wingate, M. (2017)	Low/Middle- Median income in the 0 to 75th percentile, High- Median income within the highest 25th percentile ^a	Standard for comparison (OR = 1)		PR of ASD: 1.39 School ascertainment OR: 0.90 Healthcare ascertainment OR: 0.69 School & healthcare ascertainment OR: 1.36
Bhasin, T., & Schendel, D. (2007)	Low- \$32,011 and below, Middle- \$32,012-\$44, 913, High- \$44,914-\$150,001,	Odds of ASD: 0.5. Odds of school & non-school ascertainment: 0.4. Odds of school ascertainment: 0.4. Odds of non-school ascertainment: 1.1	Standard for comparison (OR = 1)	Odds of ASD: 1.6. Odds of school & non-school ascertainment: 2.0. Odds of school ascertainment ^b : 1.2. Odds of non-school ascertainment: 2.9. Odds of school ascertainment only:
Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2011) ^c	Reference- Less than or equal to \$30,000 (OR = 1) Low- \$30,001–60,000, Middle-\$60,001–90,000, High- more than \$90,000	OR = 1.2	OR = 1.7	OR = 2.2
McGrath, K., Bonuck, K., & Mann, M. (2020) ^d	School districts with most economically disadvantaged students had the highest proportion of ASD cases.	–	–	School districts with lower amounts of economically disadvantaged students had lower amounts of ASD cases.

^aBased on US Census data. ^bThis value became 2.1 when adjusting for no MR. ^cThe lowest income group was chosen as the reference and not shown in the table. ^dThis study did not specifically quantify what it meant to be economically disadvantaged and did not give statistical evidence for these results.