The Influence of Demographic Factors on the Identification of Autism Spectrum Disorder: A Review and Call for Research

Kerri P. Nowell[1] · Christie M. Brewton[1] · Elizabeth Allain[1] · Sarah S. Mire[1]

Abstract Autism spectrum disorder (ASD) diagnoses are made based on a pattern of behavioral symptoms, yet a growing body of research indicates that when, and indeed whether, an individual receives a diagnosis of ASD is influenced by myriad demographic factors including race, ethnicity, socioeconomic status (SES), and parental education level. The current manuscript provides a focused review of a subset of existing literature chosen to demonstrate how demographic factors may be related to the identification of individuals with ASD within the United States. Several possible explanations for existing disparities are discussed, along with clinical implications for professionals working with children from diverse backgrounds who are suspected of having ASD. Additional research in this area is needed to facilitate development of effective means to eliminate the diagnostic disparities.

Receiving an accurate autism spectrum disorder (ASD) diagnosis at a younger age is associated with more positive functional outcomes in later life (Harris and Handleman 2000; Turner et al. 2006), presumably as a result of the relationship between ASD diagnosis and receipt of targeted treatments. Early intervention is a key prognostic indicator of more positive outcomes in youth with ASD (Corsello 2005; Itzchak and Zachor 2011; Woods and Wetherby 2003). Although various early intervention programs currently exist and comparative efficacy research is mixed, reported positive outcomes include gains in cognitive functioning (Landa and Kalb 2012; Sallows and Graupner 2005), communication (Landa and Kalb 2012; Woods and Wetherby 2003), adaptive behavior (Eikeseth et al. 2012; Reichow 2012), and fewer social problems and problem behaviors (Eikeseth et al. 2007). Considering the documented benefits of early and accurate identification of ASD, understanding the factors influencing identification processes in medical and school settings is critical. In particular, demographic factors such as race, ethnicity, and socioeconomic factors (i.e., family income, parent education) appear to play an important moderating role in the accuracy and timeliness of clinician and/or educational classification.

A growing body of research indicates timely and accurate identification of ASD in individuals residing in the United States is influenced not only by manifestation of patterns of social communication and restricted, repetitive interests/behaviors (American Psychiatric Association APA 2013) but also by demographic factors (Dyches et al. 2004; Mandell et al. 2002; Ravindran and Myers 2012; Thomas et al. 2012). Thought to be the result of a complex interaction between genetics and environmental factors, the etiology of ASD remains unknown and no single biological marker exists. Consequently, diagnosis is based on observed behavioral characteristics and parent report and, as with any behaviorally defined disorder, the point at which normal variation becomes deviant and how such deviation is interpreted is strongly influenced by cultural context (Norbury and Sparks 2013), including demographic factors such as race/ethnicity, family income, and parental education level (Dyches et al. 2004; Mandell et al. 2002; Mazurek et al. 2014; Ravindran and Myers 2012; Thomas et al. 2012).

Within the United States, an individual may receive a clinical diagnosis of ASD in a medical setting and/or an

✉ Kerri P. Nowell
knowell@uh.edu

[1] Department of Psychological, Health, and Learning Sciences, University of Houston, Farish Hall 491, Houston, TX 77204, USA

educational classification of Autism (AU) in a public school setting. Identification criteria—and therefore the processes that result in identification—vary across the two settings. Specifically, in a medical or clinical (i.e., non-school) setting, the Diagnostic and Statistical Manual—Fifth Edition (DSM-5; American Psychiatric Association APA 2013) is used as a guide for diagnosis. Under the DSM-5 criteria, ASD is defined as a neurodevelopmental disorder characterized by varying degrees of impairments in two domains: (1) social communication and social interaction deficits, and (2) restricted and repetitive interests/behaviors (American Psychiatric Association APA 2013). The precursor to the DSM-5, the Diagnostic and Statistical Manual—Fourth Edition, Treatment Revision (DSM-IV-TR; American Psychiatric Association 2004), differed in that there were three domains: (1) qualitative impairment in social interaction, (2) qualitative impairment in communication, and (3) restricted and repetitive interests/behaviors (American Psychiatric Association 2004). Although the DSM-5 is the most current version of the diagnostic manual, much of the available research discussed in this review was completed prior to the release or application of the DSM-5; thus, was based on the DSM-IV-TR (American Psychiatric Association 2004) manual or earlier versions.

In a school setting, however, students are given "educational classifications" rather than "clinical diagnoses", and the criteria for a student to qualify for the educational classification of AU in a school setting is outlined in the Individuals with Disabilities in Education Act (IDEIA 2004). Qualifying for AU under IDEIA criteria (i.e., for educational classification) does not require a DSM-5 diagnosis, but there must be a documented disability resulting in educational need (i.e., symptoms must adversely affect some aspect of educational performance) (IDEIA 2004). It is important to emphasize that receiving a DSM-5 diagnosis of an ASD in a medical or clinical setting does not necessarily result in a special education classification of AU because of the requirement that there is evidence of both a disability condition and educational need for an individual to receive special education services. Similarly, it is possible for a child to be eligible for special education under the category of AU and not have a clinical diagnosis (i.e., from the DSM-5). The difference in DSM-5 diagnosis and IDEIA 2004 classification necessitates different identification processes across settings, including types of professionals involved, data collection tools used, and resulting recommendations for treatment/intervention. These differences have implications for who is identified as having ASD and when an individual is identified.

The Role of Race and Ethnicity

Studies investigating the role of race and ethnicity in ASD diagnostic rates have yielded equivocal results, which often vary in terms of survey techniques, measurement approaches, and operational definitions, and are complicated by other factors often correlated with race and ethnicity (e.g., socioeconomic status [SES], acculturation) (Hill et al. 2014). Overall, however, epidemiological research has found no differences by race or ethnicity in the incidence or clinical presentation of ASD (Chaidez et al. 2012; Dyches et al. 2004; Fombonne 2007; Valicenti-McDermott et al. 2012). Thus, one would expect that representation of children from various racial and ethnic backgrounds diagnosed with ASD would be aligned with their proportional representation in the general population. Contrary to epidemiological research, discrepancies are evident in the rate of identification of ASD (i.e., disproportional representation) across race/ethnicity and socioeconomic status (SES) in the extant literature (e.g., Becerra et al. 2014; Durkin et al. 2010; Mandell et al. 2009; Sullivan 2013).

Proportional Representation

Clinical/Community/Medical Settings Disproportional representation of non-white individuals with ASD diagnoses occurs in both clinic and community mental health settings (Becerra et al. 2014; Begeer et al. 2009; Centers for Disease Control and Prevention 2014; Liptak et al. 2008; Mandell et al. 2009; Rosenberg et al. 2009). A significant difference in prevalence of ASD diagnoses exists for all ethnic groups when compared to children from Caucasian backgrounds within CDC samples (Centers for Disease Control and Prevention 2014; Mandell et al. 2009). Specific findings regarding disproportionality across racial and ethnic groups are somewhat inconsistent, however. For example, using a nationally representative sample of youth (sampled with the National Survey of Children's Health [NSCH]), differences of ASD prevalence across demographic subgroups were assessed, and results revealed significantly lower prevalence of ASD diagnoses in families identifying as Latino (26/10,000) compared to non-Latinos (51/10,000); however, no differences in rates of ASD diagnoses were found between families identifying as Black (46/10,000) or White (51/10,000) (Liptak et al. 2008). The most recent ADDM study, which used a standardized algorithm to make ASD determinations of children living in 11 communities in the United States, found that non-Hispanic White children were ~30 % more likely to be identified than Black children, and White children were ~50 % more likely identified than Hispanic children in a population of children with ASD aged 8 years (Centers for Disease Control and Prevention 2014). Becerra et al. (2014) concluded that children of foreign-born immigrant mothers were at higher risk of "developing or being diagnosed with [Autistic Disorder], specifically with [Intellectual Disability] and impaired expressive language", though they acknowledged that such results could be related to disparate access

to diagnostic and treatment services, including appropriate instruments for measuring cognitive and language ability.

School Settings As previously described, AU is a special education category under which students with symptoms consistent with ASD can receive special education supports and services, and a medical diagnosis of ASD does not necessarily result in eligibility under AU and vice versa. However, the majority of services received by school aged children with ASD are provided via school settings and there has been a recommendation that all children with a medical diagnosis of ASD should also be eligible under the special education category of AU (National Research Council 2001). Using special education data from the U.S. Department of Education (USDOE) from 2007–2008 academic year, Morrier and Hess (2010) found significant underrepresentation of all ethnicities (i.e., American Indian/Native Alaskan, Asian/Pacific Islander, Black/African American, Hispanic/Latino, and Caucasian) in 80 % of states under the AU eligibility category when compared to the CDC-based prevalence of ASD suggesting that, in contrast to the recommendation made by the NRC (2001), these findings indicate that not all children with ASD are provided supports and services under the AU category. Moreover, existing research strongly indicates that disproportional representation exists across races/ethnicities for children who are provided special education services under the AU category (Dyches et al. 2004; Morrier and Hess 2010; Morrier et al. 2008; Travers et al. 2013) in that children who are identified as belonging to traditionally underrepresented racial and ethnic groups are even less likely to be identified under the AU eligibility category than children identified as Caucasian.

Using a combination of 2008 I.E. state-based child-count data and 2008 census estimates of school-aged children across states, Sullivan (2013) found that not only were states serving fewer students under the AU category than would be indicated by CDC prevalence rates but also that considerable differences existed in AU identification across racial groups nationally, and based on absolute numbers of students with an AU diagnosis. For example, this study revealed that White students were significantly more likely to be classified with AU than Black, Hispanic, or American Indian/Alaskan Native students, with Hispanic students being almost 40 % less likely to be identified with AU compared to White students. However, Asian/Pacific Islander students were significantly more likely than White students to be identified with AU (Sullivan 2013).

In one study that investigated the percentage (based on estimated resident population) of students with autism aged 6–21 years served under IDEIA, children identified as African-American or Asian/Pacific Islander were classified under the AU category at a rate two times above that of children who identified as American Indian, Native Alaskan, or Hispanic (Dyches et al. 2004). However, an analysis of data reported in the 28th IDEIA Report to Congress for students classified

under AU and enrolled in special education for the 2006–2007 school year revealed that, while students identifying as Asian/Pacific Islander were proportionally represented, African American, American Indian/Alaskan Native, and Hispanic students were underrepresented (Tincani et al. 2009). An investigation of proportional representation in the state of Georgia also found that youth from ethnically diverse backgrounds were underrepresented under the AU eligibility category while youth identified as Caucasian were overrepresented relative to their numbers in the overall population (Morrier et al. 2008). Other research has specifically found significant underrepresentation of Hispanic youth under the AU category, with indications that such an underrepresentation occurs in approximately 95 % of states (Morrier et al. 2008).

Taken together, these studies suggest that identification of youth with ASD under the AU eligibility category from all race/ethnic groups is inconsistent with epidemiological data (Morrier and Hess 2010) and that potential bias in the identification process may contribute to these differences (Sullivan 2013). The general underrepresentation of children from all racial/ethnic backgrounds under the AU category in special education may result from the requirement of establishing evidence of educational need as one component of special education eligibility determination. However, of particular importance, research indicates that there are significant differences in proportional representation under AU eligibility between race/ethnic groups.

Race-Related Disparity in Timeliness of ASD Diagnosis

In addition to disparities in proportional representation across race/ethnic groups, there is evidence that when children from traditionally underserved populations do receive an ASD diagnosis, it is significantly delayed compared to children identified as Caucasian and from higher SES brackets, with respect to time spent in treatment prior to diagnosis and age (Mandell et al. 2002). Mandell and colleagues (2002) examined the amount of time a sample of 405 Medicaid-eligible children was exposed to mental health treatment before an ASD diagnosis was received. These authors found that African-American children required significantly more time in mental health treatment (i.e., more visits) before they received an ASD diagnosis compared to White or Hispanic children (Mandell et al. 2002). Differences in age of diagnosis according to race were also found. Specifically, the data indicated that, on average, Medicaid-eligible African-American children and Hispanic children did not receive their first ASD diagnoses until age 7.9 and 8.8 years, respectively, compared to an average age of 6.3 years for the Caucasian sample. The same investigators found that 50 % of the Medicaid-eligible Caucasian children had received an ASD diagnosis by age 5 compared to only 27 % of Medicaid-eligible African-American children.

Some inconsistencies, mostly related to methodological differences across studies, have been revealed in the research literature examining the relationship of race/ethnicity and age of first ASD diagnosis. For example, in contrast to the findings described above, in a non-Medicaid sample, Mandell, Novak, and Zubritsky (2005) found no relationship between ethnicity and age of diagnosis. Importantly, one of the primary distinctions between the two samples was method of recruitment; the Medicaid sample was one of convenience whereas the non-Medicaid sample consisted of those parents who were willing to complete a survey either online or by mail.

Discrepancies in age of diagnosis may be less evident when ASD symptoms are more consistent with prototypical ASDs. In a hospital clinic sample of 399 children, Valincenti-McDermott and colleagues (2012) found that Hispanic American and African-American children were significantly more likely to be diagnosed with ASD after their fourth birthday than were Caucasian children. The difference remained significant after accounting for maternal education, second language, maternal country of origin, insurance status, and family history of ASD (Valicenti-McDermott et al. 2012). The age-at-diagnosis discrepancy was not evident in those cases where children had experienced language regression, exhibited unusual mannerisms, or had a family history of ASD (Valicenti-McDermott et al. 2012), suggesting that children with more obvious symptom profiles were more likely to be referred for an evaluation at an earlier age, regardless of race or ethnicity. Notably, there is minimal research investigating age of first identification under the AU category in public schools, and to the authors' knowledge, there are no published studies investigating the timing of such identification, rendering this an important area for future research.

The Role of Socioeconomic Status

Race and ethnicity appear to be significantly related to the timeliness and accuracy of ASD diagnosis; however, research findings are inconsistent in some respects. Consequently, additional demographic factors have been identified as potential moderators for the relationship between receipt of a diagnosis of ASD and race/ethnicity. SES is posited as one such potential moderator. Depending on methodology, level of parental education may be subsumed under SES or may be investigated as a separate variable. Generally, individuals from higher SES brackets are more likely to receive an ASD diagnosis or be enrolled in public school under the AU category, while belonging to a lower SES bracket may result in delayed receipt of an ASD diagnosis or services under the AU category (Boswell et al. 2014; Liptak et al. 2008; Palmer et al. 2005; Thomas et al. 2012).

Proportional Representation

Clinical/Community/Medical Settings An analysis of ADDM network and National Survey of Children's Health (NSCH) data found a positive relationship between SES and rate of ASD diagnosis (Durkin et al. 2010; Liptak et al. 2008). In fact, when adjusted for income, some research suggests that there is no difference in rate of ASD diagnosis across race/ethnicity (Thomas et al. 2012). Similarly, Maenner, Arneso, and Durkin (2009) found a positive association between SES and the prevalence of ASD among 8-year-old children in Wisconsin. Using paternal educational attainment and income to define SES, autism prevalence increased from 2.6 cases per 1000 in the lowest SES quintile to 6.8 cases per 1000 in the highest SES quintile. Compared to the lowest SES, the prevalence ratios for each quintile, from second lowest to highest, were 1.7, 1.9, 2.3, and 2.6. These results indicate that the economic makeup of a community may influence the prevalence rates of ASD in children. Moreover, a study by King and Bearman (2011) found that children receiving Medicaid in California residing in the wealthier neighborhoods of the state were, on average, approximately 250 % more likely than children receiving aid who lived in more disadvantaged neighborhoods to be diagnosed with autism. The authors suggested that neighborhood resources are significantly correlated with autism prevalence rates, and are particularly relevant for children born to parents with fewer economic resources.

School Settings There is limited research investigating SES factors and rates of eligibility under the category of AU in school settings. Of the existing research, SES (i.e., parent income or educational level) has not been investigated per se. Instead, research in this area has investigated the relationship between variables such as resources available to a school district (i.e., district revenue and budgets), mean county incomes, and percentages of Title 1 eligible students with rates of AU eligibility. While rates of AU eligibility do appear to be increasing over time (Maenner et al. 2009), the use of AU as a special education category does not appear to be uniformly applied across school districts (Maenner et al. 2009; Palmer et al. 2005) and is potentially linked to district resources with higher enrollment of students under the AU category in school districts with more resources (Boswell et al. 2014; Palmer et al. 2005).

In an investigation of changes of AU identification over time in one state, Palmer and colleagues (2005) found that rates of identification significantly differed depending on district resources (i.e., district revenue) and that the proportion of economically disadvantaged students was inversely related to rates of identification. Importantly, while rates of identification significantly increased over time for some school districts, those districts identified as having lower resources and

a higher proportion of economically disadvantaged students showed minimal increases in rates of identification (Palmer et al. 2005). In a more recent study investigating rates of AU enrollment in Maryland, Boswell and colleagues (2014) found that in districts with higher median county incomes and lower proportions of Title 1 students, there were higher proportions of students enrolled under the AU category. Interestingly, while both studies found that the proportion of Title 1 students was inversely related to the proportion of students identified under AU, Palmer and colleagues (2005) found that there was no relationship to community economic status.

Causal factors for the findings described above are likely complex; however, several possible hypotheses have been suggested. It is plausible that families of children eligible under the AU category relocate to districts with more resources, and presumably better services, to support their child. Also, given that AU eligibility is not uniformly applied across districts, district policy and staff training likely plays a role in the disparity. Finally, while public school services are available to all students, regardless of SES, it is possible that families with fewer resources exhibit different help seeking behaviors. For example, they may interpret their child's behavior differently, they may be less willing to seek special educations services, or they may lack the resources to advocate for their child and obtain appropriate evaluation and services from the school.

SES-Related Disparity in Timeliness of ASD Diagnosis

The age at which an individual receives an ASD diagnosis may also be delayed in individuals from lower SES brackets. Durkin and colleagues (2010) found the lowest rate of parent-reported ASD occurred in children younger than 6 years of age who were described as "poor", despite the fact that the overall rate of ASD diagnoses in families defined as "poor" was not significantly different from that of other SES brackets. It is plausible that the delay in identification results from a lack of access to services; however, this finding was consistent across both clinic and school settings, suggesting that access to services (i.e., theoretically all children have access to school services) is not the primary factor mediating the relationship between SES and age of ASD diagnosis (Durkin et al. 2010). Maternal education also appears to operate as an influential factor in the timeliness of ASD diagnoses, and a positive relationship has been found between maternal education level and receipt of an ASD diagnosis (Kogan et al. 2009; Mandell et al. 2009). Furthermore, maternal education level may also operate as a moderating variable in the relationship between cognitive impairment and diagnosis of ASD and, "maternal education may be a proxy for greater knowledge of developmental milestones or ability to advocate" (Mandell et al. 2009).

In sum, SES and parent education level, specifically maternal education level, appear to moderate the relationship between race, ethnicity, and timeliness of ASD diagnosis (Durkin et al. 2010; Liptak et al. 2008; Mandell et al. 2009; Thomas, et al. 2012), suggesting that parental knowledge of developmental differences together with financial resources may result in the most timely receipt of ASD diagnosis. Also, as with race and ethnicity, SES and parental education impact whether a child will receive an ASD diagnosis across both clinical and school settings.

Potential Contributing Factors to Disparity

Clearly, though ASD is a behavioral diagnosis (i.e., presence of atypical behaviors, absence of typical developmental behaviors), factors other than behavioral symptoms influence the timeliness of an ASD diagnosis. Many studies indicate that discrepancies in ASD diagnoses exist across varying demographic groups (Becerra et al. 2014) and that ASD may be underdiagnosed in traditionally underserved populations (Durkin et al. 2010; Dyches et al. 2004; Liptak et al. 2008; Mandell et al. 2002, 2009; Sullivan 2013; Thomas et al. 2012). Furthermore, research indicates that when children from underserved populations do receive an ASD diagnosis, it is significantly delayed when compared to the cultural majority (i.e., Caucasian children, higher SES [i.e., family income] and parents with higher education levels) (Thomas et al. 2012; Mandell et al. 2009). Myriad explanations have been posited for such discrepancies, but the most commonly proposed explanatory hypotheses include a lack of access to high quality medical care, cultural differences (i.e., language differences, cultural norm differences), providers who delay referrals, and diagnostic biases on the part of clinicians (Begeer et al. 2009; Chaidez et al. 2012; Cooper-Patrick et al. 1999; Kalkbrenner et al. 2011; Liptak et al. 2008; Sullivan 2013; Thomas et al. 2012). Also, given the somewhat inconsistent research and, in particular, emerging research suggesting that maternal nativity may be related to ASD diagnosis, differences in proportional representation may provide etiological clues (Becerra et al. 2014).

Barriers to Care

Access to health care providers appropriately trained in the screening and diagnosis of ASD can be influenced by multiple variables, including race/ethnicity, family income, geographic location, and parental education level. Families from underserved groups may disproportionally face barriers such as limited access to medical professionals, financial concerns, transportation issues, time constraints, and a cultural mismatch with the available providers. The American Academic of Pediatrics (AAP) has established a set of developmental and

autism-specific screenings. Developmental screenings are recommended at 9, 18, and 30 months, while autism screenings are recommended at 18 and 24 months using standardized tools. However, these guidelines are not universally adhered to by all pediatricians (Daniels and Mandell 2014) and lack of training and time allocated with individual families may disproportionally affect families from traditionally underserved populations (Thomas et al. 2012). Moreover, such guidelines alone are insufficient for accurate early identification; many providers may not be aware of developmental differences unless the parents/caregivers alert the provider to their concerns (Daniels and Mandell 2014) and, in the case where a family's dominant language is not English, communication barriers may interfere even when a parent does detect a developmental difference in their child.

Cultural Differences in Perception of Developmental Differences

In addition to a family's home language, it is also important to consider how cultural differences in the perception of developmental differences may impact both parent report and clinician diagnostic practices. By definition, symptoms of ASD exist on a continuum of severity, and caregivers may overlook ASD symptoms or delay seeking professional assistance because of perception and/or parenting styles (Chaidez et al. 2012; Tincani et al. 2009). Also, developmental progression of skills such as language may be perceived by providers to be the result of second language acquisition (Wilder et al. 2004).

Expectations of children's behavior differ across cultures and, in general, forms of developmental disabilities may not be recognized as disorders by some parents and, consequently, they simply may not seek help (Chaidez et al. 2012; Liptak et al. 2008; Tincani et al. 2009). For example, families who identify as Latino may wait longer or may only seek evaluation if symptoms are severe (Liptak et al. 2008). The type of first concerns may vary among families from different cultural contexts and may be a function of those developmental skills valued by that particular society. For example, parents from the United States with children diagnosed with ASD may be more likely to recognize problems related to their child's lack of expressive language development as initial indicators of developmental deviance (Coonrod and Stone 2005), whereas parents from India may be more likely to first notice social interaction deficits (Daley 2004).

Diagnostic Biases

Differences in the rates of ASD diagnoses in children from underserved populations are also potentially the result of test bias, as well as diagnostic biases on the part of clinicians (Begeer et al. 2009; Burgess et al. 2007). Possibly health care professionals are not attending to or recognizing the signs of ASD in underserved populations. More specifically, despite the increased dissemination of information identifying the signs of ASD, health care providers may have preconceived notions of what ASD "should" look like. In fact, there are suggestions that spontaneous clinical judgments on the part of pediatricians may be biased toward underdiagnoses of children from families that are, or have been, underrepresented in the general population (Begeer et al. 2009). Furthermore, for those children in families who speak a language other than English, health care providers may attribute language delays to second language issues and fail to thoroughly investigate the presence of other early signs of ASD (Begeer et al. 2009).

Racial discrepancies in ASD diagnostic rates can also occur when clinicians have various expectations about the probability of ASD occurring in Caucasian and non-Caucasian children (Balsa and McGuire 2001). For example, some researchers have suggested that clinicians may be more likely to diagnose ASD in Caucasian children but intellectual disability (ID) in non-White children (Mandell et al. 2009). In a related study, researchers administered a survey to 185 medical and mental health care providers (e.g., speech pathologists, psychologists, and psychiatrists) (Cuccaro et al. 1996). Each individual was given two vignettes, one describing a child with ASD symptoms and the other describing a child with attention deficit hyperactivity disorder (ADHD) symptoms. Each scenario had the following variations: Caucasian or Black child, low or high SES. The researchers found that providers were more likely to consider ASD in the high SES scenarios, while SES did not appear to be a consideration for providers reading the ADHD scenarios.

With regard to formal, traditional testing, children from underserved demographic groups, particularly those from non-English-speaking families, may perform poorly on standardized measures of cognitive functioning, which may be attributable in part to cultural test bias. As a result, some children from non-English-speaking families may be misdiagnosed with intellectual disability (ID) while the possibility that they have an ASD is not investigated (Chaidez et al. 2012). Relatedly, it has been suggested that parental concerns may be discounted by providers more frequently in traditionally underrepresented groups (Mandell et al. 2002). Given research showing that parents of African-American children rated their medical visits as significantly less participatory than parents of Caucasian children (e.g., Cooper-Patrick et al. 1999), and the possibility that providers may act more dismissively toward dismissing non-white parents' concerns, this possibility warrants further investigation.

Clinical Implications and Recommendations

There is increasing understanding of ASD among the general public and targeted campaigns designed to decrease age of

first ASD diagnosis have been developed. For example, in 2004, the Centers for Disease Control introduced its "Learn the Signs. Act Early" campaign which targeted education of parents on developmental milestones and causes for concern (Peacock and Lin 2012). For professionals, practice parameters for the screening and evaluation of ASD (e.g., National Research Council 2001; Volkmar et al. 2014) have been offered. In addition, there is emerging evidence that, on average, age of first ASD diagnosis is decreasing (Mazurek et al. 2014). However, given the extant research, it is clear that more work is necessary to ensure that all children with ASD, regardless of sociodemographic factors, are identified quickly and provided with evidence-based interventions beginning at a young age. Broadly speaking, efforts should be made not only to ensure that school-based, mental health, and medical providers are systematically screening for the presence of ASD but also to ensure that efforts are made to educate families and facilitate their ability to access appropriate services.

Addressing Barriers to Care

As described previously, multiple barriers to care (i.e., limited access to appropriately trained providers, financial concerns, transportation issues, time constraints, and a cultural mismatch between families and providers) may exist for families from diverse cultural backgrounds. The recent requirement of covering applied behavior analysis services for Medicaid-eligible children with ASD may represent a move toward increased access to medical professionals for families from lower SES backgrounds. However, there is an evident need for systematic screening using objective measures. Public school systems are in a prime position to address barriers related to access to providers, finances, and transportation. With the charge to identify children with disabilities between the ages of 3 and 21 years (IDEIA 2004), and with many districts providing pre-school programming, public schools could play an important role in screening for ASD. Models for improving identification of ASD within public schools have been presented (e.g., Noland and Gabriels 2004), but much work remains in this area.

Beyond public school systems, the provision of passes for public transportation, providing teleconsultation with primary care physicians or other direct service providers in remote locations, and encouraging employers to excuse absences related to mental health and medical visits may facilitate families' access to care. Providers and major clinics should also consider providing weekend and evening hours to match working parents' schedules. Focusing recruitment efforts such that persons of diverse backgrounds are encouraged to study/train in the area of ASD is vital for the field. For established practitioners, there does appear to be an increasing emphasis in recognizing the importance of considering diversity in clinical practice. For example, Texas State Board of Examiners of

Psychology now requires licensees to obtain three hours of continuing education credit in multicultural practice. However, the current research suggests that specific training in the influence of multicultural factors (i.e., demographic factors) on the identification of ASD in particular appears warranted for any mental health and medical professional involved in the screening and identification of developmental disabilities.

Addressing Differences in Cross-Cultural Perceptions of Developmental Concerns

At the family level, parental education appears to play a key role in timeliness of ASD diagnosis and investigators recommend increased public health efforts to raise awareness, especially among Hispanic-American families, about the indicators of developmental delay and ASD (Chaidez et al. 2012). Autism Speaks has recently recognized the need to target families from underserved groups and released their Maybe Campaign, a campaign targeted at reducing the disparities in age of diagnosis across race and ethnic groups (http://www.autismspeaks.org/site-wide/maybe-campaign).

Addressing Diagnostic Biases

Evidence suggests that providers' diagnostic bias may be reduced via the use of standardized and structured instruments (Begeer et al. 2009). Examples of such measures includes the Modified Checklist for Autism in Toddlers (M-CHAT-R; Robins et al. 1999), the Autism Diagnostic Observation Schedule (ADOS-2; Lord, et al. 2012), and the Autism Diagnostic Interview-Revised (ADI; Rutter et al. 2003). In addition, providing specific training in attribution biases, a focus on the cognitive strategy of individuation (i.e., versus categorization), and increasing the awareness of the existence and implications of under-identification and misidentification of children from underserved populations have the potential to address potential diagnostic biases (Burgess et al. 2007). For example, in a study of Dutch pediatricians, when providers were explicitly told to rate the likelihood of an ASD using standardized instruments (i.e., to not rely solely on spontaneous judgments), the rate of ASD diagnosis increased to proportional levels for children from underrepresented families (Begeer et al. 2009).

Thus, clinicians may need more training in (1) more accurate identification of ASD symptomatology, (2) investigating parent concerns more seriously, (3) cultural competence (i.e., differences in what may be identified as concerns by parents of diverse backgrounds), and (4) differential diagnoses (i.e., overlap of symptoms from other developmental disorders [i.e., delayed speech]; overlap of comorbid concerns such as overactivity, obsessive behaviors). Other methods of

addressing potential biases include enhancing interprofessional collaboration between professionals in settings where children with ASD are seen (i.e., medical, educational/school, clinical/mental health), seeking out the expertise of various professionals within multi-disciplinary teams, and requiring multiple sources of information for screening and diagnosis (i.e., parent and teacher reports, standardized rating scales, behavioral observations, developmental checklists). Use of a Family Centered Care model and including families as members of multi-disciplinary teams may also ensure that cultural factors are being considered during the screening and evaluation process (Dyches et al 2004; Montes and Halterman 2011). Models and recommendations to ensure that clinicians are cognizant of unconscious bias and systematically consider multi-cultural factors have been proposed, but additional research into the effectiveness of such approaches is warranted before widespread adoption (Burgess et al. 2007; El-Ghoroury and Krackow 2012).

Call for Research

In addition to the aforementioned recommendations for improving clinical care for children with ASD, several areas of research must also be extended in order to better serve underrepresented groups some of which are highlighted below. ASD is one of the most prevalent and increasingly diagnosed disorders among children of all racial/ethnic and socioeconomic backgrounds. However, there is limited research investigating multicultural factors and ASD (Mandell, et al. 2009; Palmer et al. 2010), and limited research investigating why disproportionate differences in ASD diagnosis exist across various racial/ethnic groups and SES levels (Thomas et al. 2012).

Of particular importance, there should be an increased focus on ASD diagnoses in families identifying as Hispanic. The Hispanic population has more than doubled since 1990, from 22 to 52 million in 2011, and it is expected to grow to over 100 million in 2040 (U.S. Census Bureau 2012). Determining whether the difference in diagnostic rates between families identifying as Hispanic compared to those identifying as non-Hispanic White children is due to physiological and/or environmental reasons (i.e., are there unknown protective factors in Hispanic background) or if diagnostic differences are due to other factors (i.e., timely diagnosis, access to health care) is important for all children suspected of ASD. Also, research has indicated while developmental ASD screenings by primary providers is low across all ethnicities, Spanish-language screenings are particularly low. This may be due to limited screening measures in Spanish, higher cost of Spanish screening measures, and lack of provider knowledge regarding bilingualism and language development (Zuckerman et al. 2013). Furthermore, one research study found that Hispanic children were identified later if their mother was born outside the United States, but more research should be done to examine this variable further (Fountain, King, and Bearman 2011).

Given that much of the existing large-scale ASD studies include families who reside within higher SES and Caucasian backgrounds, more research is needed that includes families from lower SES and minority backgrounds (e.g., Durkin et al. 2010). Additional research using comparative studies across demographic factors may also help to elucidate the factors related to timeliness and accuracy of diagnoses (Chaidez et al. 2012) as well as help us to develop better diagnostic algorithms. Finally, research investigating the validity of proposed models designed to address clinician bias and to ensure that multicultural factors—including the demographic factors discussed in this review—are systematically considered during screening and subsequent evaluation is warranted.

References

American Psychiatric Association. (2004). Diagnostic and statistical manual of mental disorders. (Revised 4th ed.). Washington, DC: Author

American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Balsa, A. I., & McGuire, T. G. (2001). Statistical discrimination in health care. *Journal of Health Economics, 20*(6), 881–907.

Becerra, T. A., Ehrenstein, O. S. von, Heck, J. E., Olsen, J., Arah, O. A., Jeste, S. S., … Ritz, B. (2014). Autism spectrum disorders and race, ethnicity, and nativity: a population-based study. Pediatrics, peds.2013–3928. http://doi.org/10.1542/peds.2013-3928.

Begeer, S., Bouk, S. E., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. *Journal of Autism and Developmental Disorders, 39*, 142–148. doi:10.1007/s10803-008-0611-.

Boswell, K., Zablotsky, B., & Smith, C. (2014). Predictors of autism enrollment in public school systems. *Exceptional Children, 81*(1), 96–106. doi:10.1177/0014402914532230.

Burgess, D., van Ryn, M., Dovidio, J., & Saha, S. (2007). Reducing racial bias among health care providers: lessons from social-cognitive psychology. *Journal of General Internal Medicine, 22*, 882–887. doi:10.1007/s11606-007-0160-1.

Census Bureau, U. S. (2012). *The 2012 Statistical abstract of the United States*. Washington: U.S. G.P.O.

Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network (ADDMN), 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report (MMWR), Surveillance Summaries, 63*(SS02), 1–21.

Chaidez, V., Hansen, R. L., & Hertz-Picciotto, I. (2012). Autism spectrum disorders in Hispanics and non-Hispanics. *Autism, 16*(4), 381–397. doi:10.1177/1362361311434787.

Coonrod, E. E., & Stone, W. L. (2005). Screening for autism in young children. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders, vol. 2: assessment, interventions, and policy (3rd ed.)* (pp. 707–729). Hoboken, NJ, US: John Wiley & Sons Inc.

Cooper-Patrick, L., Gallo, J. J., Powe, N. R., Steinwachs, D. S., Eaton, W. W., & Ford, D. E. (1999). Mental health service utilization by African Americans and Whites: the Baltimore Epidemiologic Catchment Area Follow-Up. *Medical Care, 37*, 1034–1045. doi:10.1097/00005650-199910000-00007.

Corsello, C. M. (2005). Early intervention in autism. *Infants & Young Children, 18*, 74–85. doi:10.1097/00001163-200504000-00002.

Cuccaro, M. L., Wright, H. H., & Rownd, C. V. (1996). Brief report: professional perceptions of children with developmental difficulties: the influence of race and socioeconomic status. *Journal of Autism & Developmental Disorders, 26*, 461–469. doi:10.1007/BF02172830.

Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social Science & Medicine, 58*, 1323–1335. doi:10.1016/S0277-9536(03)00330-7.

Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: a critical review. *Autism, 18*, 583–597. doi:10.1177/1362361313480277.

Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., et al. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a U.S. cross-sectional study. *PLoS ONE, 5*(7), e11551. doi:10.1371/journal.pone.0011551.

Dyches, 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. doi:10.1023/B:JADD.0000022611.80478.73.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: a comparison controlled study. *Behavior Modification, 31*(3), 264–278. doi:10.1177/0145445506291396.

Eikeseth, S., Klintwall, L., Jahr, E., & Karlsson, P. (2012). Outcome for children with autism receiving early and intensive behavioral intervention in mainstream preschool and kindergarten settings. *Research in Autism Spectrum Disorders, 6*, 829–835. doi:10.1016/j.rasd.2011.09.002.

El-Ghoroury, N. H., & Krackow, E. (2012). Enhancing the identification of autism spectrum disorders via a model of culturally sensitive childhood assessment. *Professional Psychology: Research and Practice, 43*(3), 249–255. doi:10.1037/a0027354.

Fombonne, E. (2007). Epidemiological surveys of prevalence of developmental disorders. In F. Volkmar (Ed.), *Autism and pervasive developmental disorders* (Secondth ed., pp. 33–68). Cambridge : Cambridge University Press.

Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: a four- to six-year follow-up. *Journal of Autism and Developmental Disorders, 30*(2), 137–142. doi:10.1023/A:1005459606120.

Hill, A. P., Zuckerman, K. E., & Fombonne, E. (2014). Epidemiology of autism spectrum disorders. In F. R. Volkmar, S. J. Rogers, R. Paul, & K. A. Pelphrey (Eds.), *Handbook of autism and pervasive developmental disorders* (4th ed., pp. 57–96). Hoboken, NJ: Wiley.

Individuals with Disabilities Education Improvement Act (IDEIA), 20 U.S.C. § 1400 (2004).

Itzchak, E. B., & Zachor, D. A. (2011). Who benefits from early intervention in autism spectrum disorders? *Research in Autism Spectrum Disorders, 5*(1), 345–350. doi:10.1016/j.rasd.2010.04.018.

Kalkbrenner, A. E., Daniels, J. L., Emch, M., Morrissey, J., Poole, C., & Chen, J.-C. (2011). Geographic access to health services and diagnosis with an autism spectrum disorder. *Annals of Epidemiology, 21*(4), 304–310. doi:10.1016/j.annepidem.2010.11.010.

King, M. D., & Bearman, P. S. (2011). Socioeconomic status and the increased prevalence of autism in California. *American Sociological Review, 76*, 320–346. doi:10.1177/0003122411399389.

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics, 124*(5), 1395–1403. doi:10.1542/peds.2009-1522.

Landa, R. J., & Kalb, L. G. (2012). Long-term outcomes of toddlers with autism spectrum disorders exposed to short-term intervention. *Pediatrics, 130*(Suppl 2), S186–S190.

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. doi:10.1097/DBP.0b013e318165c7a0.

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule: ADOS-2*. Torrance: Western Psychological Services

Maenner, M. J., Arneson, C. L., & Durkin, M. S. (2009). Socioeconomic disparity in the prevalence of autism spectrum disorder in Wisconsin. *Wisconsin Medical Journal, 108*, 37–39.

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(12), 1447–1453. doi:10.1097/00004583-200212000-00016.

Mandell, D. S., Novak, N. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480–1486. doi:10.1542/peds.2005-0185.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, 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), 493–8.

Mazurek, M. O., Handen, B. L., Wodka, E. L., Nowinski, L., Butter, E., & Engelhardt, C. R. (2014). Age at first autism spectrum disorder diagnosis: the role of birth cohort, demographic factors, and clinical features. *Journal of Developmental & Behavioral Pediatrics, 35*(9), 561–569. doi:10.1542/peds.2013-3928.

Montes, G., & Halterman, J. S. (2011). White-black disparities in family-centered care among children with autism in the United States: evidence from the NS-CSHCN 2005–2006. *Academic Pediatrics, 11*(4), 297–304. doi:10.1016/j.acap.2011.02.002.

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. doi:10.1177/0022466910372137.

Morrier, M. J., Hess, K. L., & Heflin, L. (2008). Ethnic disproportionality in students with autism spectrum disorders. *Multicultural Education, 16*(1), 31–38.

National Research Council. (2001). Educating children with autism. Committee on Educational Interventions for Children with Autism. In C. Lord & P. J. McGee (Eds.), *Division of behavioral and social sciences and education*. Washington, DC: National Academy Press.

Noland, R., & Gabriels, R. (2004). Screening and identifying children with autism spectrum disorders in the public school system: the development of a model process. *Journal of Autism & Developmental Disorders, 34*(3), 265–277.

Norbury, C. F., & Sparks, A. (2013). Difference or disorder? Cultural issues in understanding neurodevelopmental disorders. *Developmental Psychology, 49*(1), 45–58. doi:10.1037/a0027446.

Palmer, R. F., Blanchard, S., Jean, C. R., & Mandell, D. S. (2005). School district resources and identification of children with autistic disorder. *American Journal of Public Health, 95*(1), 125–30.

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), 270–2.

Peacock, G., & Lin, S. C. (2012). Enhancing early identification and coordination of intervention services for young children with autism spectrum disorders: report from the Act Early Regional Summit Project. *Disability and Health Journal, 5*(1), 55–59. doi:10.1016/j.dhjo.2011.10.001.

Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: a review and focus on autism. *Journal of Child and Family Studies, 21*(2), 311–319. doi:10.1007/s10826-011-9477-9.

Reichow, B. (2012). Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(4), 512–520. doi:10.1007/s10803-011-1218-9.

Robins, D. L., Fein, D., & Barton, M. L. (2009). The Modified Checklist for Autism in Toddlers (M-CHAT) self-published. *Storrs, CT*

Rosenberg, R. E., Daniels, A. M., Law, J. K., Law, P. A., & Kaufmann, W. E. (2009). Trends in autism spectrum disorder diagnoses: 1994–2007. *Journal of Autism and Developmental Disorders, 39*(8), 1099–1111. doi:10.1007/s10803-009-0723-6.

Rutter, M., Le Couteur, A., & Lord, C. (2003). Autism diagnostic interview-revised. Los Angeles, CA: Western Psychological Services.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: four-year outcome and predictors. *American Journal on Mental Retardation, 110*(6), 417–438.

Sullivan, A. L. (2013). School-based autism identification: prevalence, racial disparities, and systemic correlates. *School Psychology Review, 42*(3), 298–316.

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2012). The association of autism diagnosis with socioeconomic status. *Autism, 16*(2), 201–213. doi:10.1177/1362361311413397.

Tincani, M., Travers, J., & Boutot, A. (2009). Race, culture, and autism spectrum disorder: understanding the role of diversity in successful educational interventions. *Research & Practice for Persons with Severe Disabilities, 34*(3/4), 81–90.

Travers, J. C., Tincani, M., & Krezmien, M. P. (2013). A multiyear national profile of racial disparity in autism identification. *The Journal of Special Education, 47*(1), 41–49. doi:10.1177/0022466911416247.

Turner, L. M., Stone, W. L., Pozdol, S. L., & Coonrod, E. E. (2006). Follow-up of children with autism spectrum disorders from age 2 to age 9. *Autism, 10*(3), 243–265. doi:10.1177/1362361306063296.

Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012). Age at diagnosis of autism spectrum disorders. *The Journal of Pediatrics, 161*(3), 554–556. doi:10.1016/j.jpeds.2012.05.012.

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., State, M., & American Academy of Child and Adolescent Psychiatry (AACAP) Committee on Quality Issues (CQI). (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*(2), 237–257. doi:10.1016/j.jaac.2013.10.013.

Wilder, L. K., Dyches, T. T., Obiakor, F. E., & Algozzine, B. (2004). Multicultural perspectives on teaching students with autism. *Focus on Autism and Other Developmental Disabilities, 19*, 105–113.

Woods, J. J., & Wetherby, A. M. (2003). Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language, Speech, and Hearing Services in Schools, 34*(3), 180–193. doi:10.1044/0161-1461(2003/015).

Zuckerman, K. E., Mattox, K., Donelan, K., Batbayar, O., Baghaee, A., & Bethell, C. (2013). Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics, 132*, 445–453.