



Racial Disparities in Autism Diagnosis, Assessment, and Intervention among Minoritized Youth: Sociocultural Issues, Factors, and Context

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Abstract

Purpose of Review Despite the increasing prevalence of autism spectrum disorder (ASD) among youth, disparities exist when it comes to access to diagnostic assessment and intervention of ASD in clinical and school settings. A review of the literature on sociocultural issues that contribute to these disparities would allow psychiatrists, clinicians, and researchers to better understand these challenges and aid in the development of culturally responsive approaches to support racially, ethnically, and linguistically diverse families of youth with ASD.

Recent Findings Disparities in ASD services are primarily due to system-level factors, including access to information or healthcare, stigma, and discrimination. Similarly, interactional factors, such as language/communication barriers, a lack of trust in professionals, and limited training in cultural responsiveness, can hinder support for diverse families of youth with ASD.

Summary This review focuses on several areas: (1) structural inequities that contribute to disparities in ASD services, (2) sociocultural issues in assessment and diagnosis, (3) sociocultural issues in interventions and service use, and (4) neurodiversity. This review underscores the importance of including diverse samples in ASD research to improve understanding of the strengths, challenges, perspectives, and preferences of underrepresented and underserved families of youth with ASD. These efforts can lead to culturally responsive service delivery.

Keywords Autism · Youth · Culture · Disparity · Neurodiversity · Diagnosis · Intervention

Introduction

Autism spectrum disorder (ASD) is often characterized as a life-long neurodevelopmental disorder characterized by social interaction and communication difficulties, as well as repetitive, restricted patterns of behavior, interests, and activities [1], with onset occurring before the first 3 years of life. Research has found individuals with ASD demonstrate variations in their intelligence and memory, with strengths in visual pattern processing [2–4]. According to the Centers for Disease Control and Prevention, autism occurs in all racial,

ethnic, and socioeconomic groups [5]. Although ASD is prevalent with strong biological and genetic underpinnings, the reporting of symptoms and willingness to seek support is influenced by sociocultural factors [6]. Culture is defined as a set of behavioral norms, meanings, and values or reference points utilized by members of a particular society to construct their view of the world [7]. Sociocultural considerations include variables related to parental education, socioeconomic status, and economic resources which have been found to affect individuals' adaptive behavior and be used as means to navigate their environment [8]. Sociocultural considerations are especially important for the implementation of ASD services since these issues influence how parents/caregivers, school-based mental health service providers, and medical professionals interpret children's social behaviors and development, thereby affecting the diagnosis, perceived need, and the effectiveness of treatment.

Previous research has indicated disparities in educational and clinical diagnoses of ASD, with Hispanic children being less likely to be identified with ASD and

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Asian-American children being more likely to be identified with ASD in addition to negative outcomes resulting from these disparities [9]. The most recent overall prevalence of 1 in 44 provided by the Centers for Disease Control and Prevention indicated that the gap in diagnostic prevalence between White and minority children is closing [5]. Data from 2018 indicate that ASD prevalence per 1000 children aged 8 years was similar among Hispanic (2.25%), Black (2.23%), Asian American/Pacific Islander (2.22%) White children (2.1%), although American Indian/Alaska native was among the highest (2.9%) [5]. Recent studies found that racial and ethnic disparities in clinical diagnosis of ASD have changed from 2017 to 2021, where rates among minority youth aged 8 showed increased prevalence: Asian American/Pacific Islander (4.47%), Black (4.01%), Hispanic (4.24%), compared to White (3.89%) [10]. Among youth ages 3–11, another study reported somewhat higher prevalence rates among Black (3.02%) than White children (2.40%), but the reverse was found for the ages 12–17 group where White (3.0%) had a higher prevalence than Black children (2.60%) [11]. These findings indicate that among minority youth, earlier identification of ASD, more effective outreach, and more widespread screening have led to improved access to mental healthcare prior to adolescence. Compared with White children, Black youth were more likely to be diagnosed with attention-deficit hyperactivity disorder or an adjustment disorder prior to being diagnosed with ASD, which may explain why those children receive ASD services later than other children [12•].

Despite the increasing prevalence of ASD across racial, ethnic, and linguistic minority youth, disparities persist when it comes to access to diagnostic and intervention services in clinical and school settings [5, 9, 13]. The causes of healthcare disparities among racial, ethnic, and linguistic minority groups in the USA are multifaceted, stemming from a complex interplay of factors. Health disparities have been defined as inequitable differences in services received by the two groups that are due to system-level factors, including access to information or healthcare, stigma, and discrimination (e.g., bias and stereotyping) along with interactional factors, such as communication barriers, a lack of trust in professionals, and a lack of cultural responsiveness in assessment [14]. Race, culture, socioeconomic status, and neighborhood play a significant role in ASD diagnosis [15]. This review addresses the sociocultural issues that contribute to these disparities when it comes to the diagnosis and treatment of ASD among racial, ethnic, and linguistic minority youth. Sociocultural considerations in ASD research are needed to address these disparities properly by developing and implementing culturally responsive interventions and preventative strategies.

System-Level Factors Contributing to Disparities

Barriers posed by structural inequities include a lack of diversity among professionals to provide multilingual or culturally responsive services, a disproportionate concentration of ASD service providers in rural or underserved communities, and insurance reimbursement, all of which contribute to disparities in ASD clinical service use [16]. Although school systems provide more accessible ASD services under the Individuals with Disabilities Education Act of 2004, school-based mental health service providers also struggle with diversification to meet the needs of diverse children in those settings [17]. Demographics from a national survey indicate significant underrepresentation of racially, ethnically, and linguistically diverse school psychologists in the workforce: 86% are White, 8% are Hispanic/Latinx, and 4% are Black/African American, which differs sharply from the student population [18, 19]. Additionally, only 8% of school-based mental health service providers reported providing services in languages other than English in the USA. Lacking recruitment and retention of racially, ethnically, and linguistically diverse providers coupled with limited training in culturally responsive services pose significant barriers to children and families who are underserved and in need of ASD support, such as first-generation or immigrant families in the USA who may have limited knowledge of navigating the USA healthcare and educational systems and public resources [20, 21]. Moreover, some of these families may fear negative encounters with the legal system or deportation [22].

Socioeconomic inequality reduces the likelihood that children with ASD in underserved communities will be diagnosed in a timely manner (or at all) and contributes to disparities in ASD services in the USA, where healthcare is not universally available [23•]. Several studies found that parental education level and higher socioeconomic status (SES) are associated with the age of diagnosis, suggesting that more highly educated parents may have access to information about ASD symptoms and development and express concerns to a healthcare provider earlier than parents with a lower level of education [24, 25]. Moreover, SES and parent education level, specifically maternal education level, appear to moderate the relationship between race, ethnicity, and timeliness of ASD diagnosis [25], suggesting that parental advocacy and knowledge of developmental differences along with financial resources among high-SES minority (e.g., Black) households may result in the more timely receipt of an ASD diagnosis.

More recent studies did not find an association between SES and age at diagnosis, where Black children, for

example, are less likely to be diagnosed with ASD, even after controlling for variables such as SES and IQ [26, 27]. Findings from cross-cultural research indicate initial concerns related to ASD are culturally specific, where parental recognition and knowledge of ASD symptoms influence engagement and use of resources within the community [28, 29]. Even when controlling for symptom severity, for example, Black parents of children with ASD reported fewer ASD concerns, including those related to repetitive behavior and restrictive interests compared to White parents [30]. Reasons for reporting fewer ASD concerns by Black parents of children with ASD may include having less knowledge of the condition or having different thresholds for perceiving ASD concerns. Some Black parents of children with ASD have expressed not receiving access to information about ASD compared to White parents [31]. In addition, Hispanic/Latinx and Black families might wait longer to seek evaluation unless symptoms (e.g., repetitive behaviors or restricted interests) are severe and interfere with daily living [31]. The type of initial concerns may vary among families from different sociocultural backgrounds and may be a function of developmental skills as valued by that particular culture. These findings also have implications when it comes to the diagnostic assessment of developmental disabilities, as differences in knowledge or manifestation of ASD symptoms and adaptive functioning could contribute to disparities by affecting the validity of screening and diagnostic tools or by creating discrepancies between clinician and caregiver perceptions [31].

Racial, ethnic, and linguistic minority youth with ASD experience delays in diagnosis and obstacles to service access, as well as high percentages of comorbid intellectual disability [32]. For example, the proportion of Black children with ASD and comorbid intellectual disability is nearly double that of White children (49.8% vs 29.7%, respectively) [5]. The reasons for this difference are not entirely clear, although research has suggested that contributing factors, such as poverty and preterm birth, may explain a higher prevalence of intellectual disability among Black children with ASD [5]. They also experience greater delays between families' initial concerns to time of diagnosis, suggesting that parents/caregivers may face challenges in communicating their concerns to providers, navigating systems, or gaining access to service providers and specialists [32, 33]. Language barriers are common among linguistic minority families, while others experience negative interactions with healthcare providers who demonstrated limited awareness and understanding of parents' or caregivers' cultural views [34]. Parents/caregivers are likely to wait longer to convey their concerns to a provider, which could be due in part to cultural stigma, distrust of providers and systems of care, and discouragement from their family or community [35•].

Improvements to healthcare and education systems, including the development of ASD guidelines and the training of professionals to implement these guidelines, are crucial to screening and diagnosing ASD earlier in children.

Sociocultural Issues in Diagnosis of ASD

Cultural Expectations and Expressions of Behavior

Cultural expectations of socially appropriate behavior and communication in children can vary widely and are often dependent on parents/caregivers, schools, and the community where they are raised. The point at which any given behavior becomes a problem or a cause for concern is partly influenced by these cultural expectations [36]. Autistic symptoms, therefore, are more appropriately understood in relationship to their sociocultural context. Since the causes of ASD are not well known, and to date, there is no definitive medical or genetic test to determine whether an individual has ASD, cultural beliefs can shape how people think about the etiology of ASD. Previous research has revealed that specific manifestations vary according to age and gender within a population [37, 38]. For example, the age of diagnosis, on average, is later in girls than in boys, and girls exhibit fewer restrictive and repetitive behaviors than boys [39]. Clinicians may find that girls may not meet the functional impairment criteria for a clinical diagnosis, despite higher-level autistic expression, and that the diagnosis may be needed at a later developmental stage compared to males [37]. Some researchers also suggest that these differences may be based on gender bias, where social difficulties among girls may be perceived by clinicians as “being shy,” and therefore may be underidentified at an earlier age than boys [40].

Racial, ethnic, and linguistic minority children are often underrepresented in autism research, as the majority of participants in these studies are from White and high-SES communities [41]. As a result, knowledge of how autistic behaviors are expressed, the screening and diagnostic tools, and the interventions developed to support children with ASD are likely to be culturally and contextually biased [42]. Cultural expectations regarding the socially appropriate behavior and communication of children in racially, ethnically, and linguistically diverse families can vary widely. For example, in Western cultures, avoiding eye contact is a common ASD symptom in nonverbal communication. However, in Asian and Hispanic/Latinx cultures, making direct eye contact with adults is often considered disrespectful in children [43, 44]. Thus, the nonverbal communication difficulties characteristic of ASD may be considered the norm in other sociocultural contexts. The types of play exhibited by young children can also be misconstrued as symptoms of ASD. For

example, in one study, Korean-American children spent a greater proportion of time in parallel play than in social and pretend play compared with White children [43]. Clinicians therefore need to demonstrate an understanding of their own cultural identities, beliefs, and practices as well as those of the child and family. Such information and knowledge are important in reducing clinician bias and promoting cultural humility when assessing ASD in minority children [45].

Language and Social Communication

Language differences between parents/caregivers and clinicians or healthcare providers are often barriers for families to access ASD services in both clinical and school settings [46]. Families may encounter challenges in communicating concerns to healthcare providers [47]. Moreover, language differences between the child and the clinician can make it difficult to screen and/or diagnose when it comes to social and verbal communication skills. In one survey study, primary care physicians reported more challenges assessing ASD in Hispanic children whose primary language is Spanish, and approximately one-fourth of the respondents provided ASD screening in Spanish [32]. With few research studies examining multilingual children with ASD, clinicians and researchers often struggle to develop practical recommendations for children raised in multilingual environments [47]. Consequently, families often may not know where to seek information about ASD, particularly if they encounter language barriers with mental health service providers [46].

Parents/caregivers may also be concerned about potential delays in language development especially when children are exposed to multiple languages at home. Due to systems prioritizing English as the standard in USA schools and society, the language development of multilingual learners is often viewed differently compared to that of monolingual learners, yet nascent research often compares learning or language outcomes between these two language groups [48]. Nevertheless, findings from systematic literature reviews suggest that bilingualism is not considered a risk factor for ASD and that any delays in either language may be considered typical language development for multilingual learners [48, 49]. Specifically, findings have not supported assertions that multiple languages interfere with the language learning of children with speech or language impairments or that learning a home language impairs or significantly delays the learning of a second language [50].

Differential diagnosis of ASD can also be difficult in children who are deaf or hard of hearing (DHH) given the heterogeneity of ASD and the sensory challenges on social development, communication, and behavior [51•]. The estimated prevalence of ASD in DHH populations is 9% [52]. Children who are DHH often use facial expressions to communicate

meaning and emotionality. Clinicians assessing deaf children for ASD may likely encounter difficulties due to the children's lack of exposure to early language experiences and the potential risk of misinterpreting gestures, hand movements, or signs as repetitive or restrictive behaviors [53]. Limited screening and diagnostic tools have been validated for use with children who are DHH; however, the Autism Diagnostic Interview-Revised (ADI-R), one of the “gold-standard” instruments for assessing ASD, was recently adapted and validated for deaf children. Further research on the feasibility and validity of the tool may be warranted across countries and with children of diverse cultural backgrounds [54].

Assessment Tools

Since ASD symptoms are likely to present themselves differently across diverse cultural groups, screening tools should be refined for children that address language, behavioral, and developmental issues. Recent studies have examined cross-cultural variability and measurement invariance in widely used ASD assessments. For example, the ADI-R, which has been translated into over 20 languages, has demonstrated lower sensitivity and specificity in the communication domain when used with Spanish-speaking populations [55]. The Autism Diagnostic Observation Schedule (ADOS), 2nd edition, another “gold-standard” measure, has also been widely translated and includes items that examine social behaviors with cross-cultural variability, including eye contact and facial expressions [56]. However, emerging research has examined the effects of potential sociocultural confounds on the validity and reliability of ADOS-2 [57, 58]. One research study found that race, gender, and ethnicity may have a small impact on ADOS scores, where Black children were more likely to have atypical ratings on items assessing levels of unusual eye contact, stereotyped word use, and immediate echolalia, while Hispanic children were also more likely to have more atypical ratings on the item assessing unusual eye contact [57]. However, a more recent study did not find systematic measurement bias across race or gender with the ADOS-2 [56, 58]. Future investigations would benefit from examining sociocultural variables (e.g., SES, acculturation, and language) that correlate with the expression and interpretation of a child's behaviors.

Other screening instruments, such as the Modified Autism Checklist for Toddlers (MCHAT), have been found to have false positives in low socioeconomic and ethnically diverse settings within the United States [59]. However, the use of the structured follow-up interview has been shown to improve validity among these groups [60]. For ASD checklists, such as the Childhood Autism Rating Scale (CARS), one study found that the CARS lacked cross-cultural validity, with items related to social communication

and interaction displaying the lowest levels of cross-country non-invariance compared to items about stereotyped behaviors/sensory sensitivity [61]. Overall, findings across various cross-cultural studies suggest that some of the most common ASD screening measures lack sufficient psychometric analyses to assess ASD among racial, ethnic, and linguistic minority populations. Without adequate psychometric data supporting the use of these tools for specific racial, ethnic, and linguistic minority groups, clinicians should rely on supplemental qualitative data from developmental histories, comprehensive interviews with professionals and family members, and home and school behavior observations, which may yield more useful information when sociocultural or language factors are likely to influence the interpretation of ASD behaviors [62].

An increasing number of studies have developed and examined cultural adaptations of various ASD screening instruments in attempts to address cross-cultural validity and other psychometric issues [63, 64]. Nevertheless, future research should continue to consider underlying sociocultural factors to guide their efforts in developing not only culturally responsive assessments, but also improving clinicians' awareness and understanding of these factors when working with diverse children and families [65]. Confounders such as these can contribute to delays in diagnosis with a resultant discrepancy in services for minority youth with ASD [44]. Clinicians should be aware of the inherent biases that stem from assessments conceptualized from a Eurocentric perspective [66]. The American Psychological Association's (APA) multicultural guidelines and the International Test Commission guidelines seek to eliminate practices, which may ultimately contribute to adverse outcomes for racial, ethnic, and linguistic minority youth [45, 67].

Workforce training and ongoing education are therefore necessary when providing a culturally responsive assessment for ASD. This may include reviewing the standardization sample of current ASD assessment screening tools and being mindful that many of these tools have not been validated for use with different cultural groups and therefore should be used with caution. When it comes to gathering information from caregivers, youth, or families about ASD behaviors, clinicians must demonstrate cultural humility and understanding that family concerns about the child may differ from the concerns expressed by a clinician, depending on their respective cultural backgrounds and expectations. Cultural humility is a life-long process that involves self-examination of implicit biases, power, privilege, and positionality while also demonstrating genuine regard for other cultures and their intersectionality [68]. Online modules for cultural humility training for clinicians and healthcare professionals are available [69]. Moreover, using a semi-structured interview to assess sociocultural variables, such as the APA's Cultural Formulation Interview, can be useful

for collecting data on sociocultural and contextual factors to inform clinical assessment practice [70]. These approaches can foster a greater understanding of the family's worldview and their familiarity with ASD, which can also aid in intervention planning.

Sociocultural Issues in ASD Intervention and Service Use

Autism experts recommend that children with ASD receive early intervention services, characterized by at least 20 h per week of behavioral intervention, during the preschool years [71]. However, racial, ethnic, and linguistic minority children with ASD are less likely than White children with ASD to access publicly funded community-based services and are less likely to follow through with the entire service [33, 72]. Parents/caregivers experience various challenges and barriers related to intervention use that may be due to pragmatic reasons. For instance, low-income families reported more challenges in consistently attending intervention sessions when they may have complex work schedules or if their priorities are securing basic needs, such as housing or food [35]. Distances from large cities reduced both access to and quality of services often leaving families struggling to find adequate support such as daycare, transportation, and moral or social support.

School-Based Interventions

Approximately 40% of children with ASD who qualify for special education services under the IDEA spend 80% or more of their time in general education classrooms [73]. IDEA stipulates that educators are to use practices that are empirically supported to the extent that such practices are practical [17]. Furthermore, the Every Student Succeeds Act (ESSA) requires educators to use evidence-based practices when instructing students in school settings [74]. School-based interventions for students with ASD often focus on (1) explicit instruction of academic skills or school readiness, (2) positive behavioral supports, (3) forms and functions in communication, (4) social engagement and social skills, and (5) peer-mediated interventions [75]. However, these interventions are often selected based on the availability of school resources, are not often consistently implemented or with fidelity, and are not culturally responsive, which may limit the effectiveness and sustainability of these supports for racial, ethnic, and linguistic minority youth [76]. Many interventions were designed to be delivered through individual therapy (e.g., applied behavioral analysis), rather than through the group instruction that is more traditionally used in schools [77]. Moreover, considering that sociocultural

factors are likely to contribute to intervention acceptability and effectiveness, limited research exists on culturally adapting interventions for diverse children with ASD [78].

Digital technologies have become more widespread and can aid in supporting children with ASD. Technology-aided instruction and interventions such as speech-generating devices, computer-assisted instruction, video-based instruction, virtual reality, and robot-mediated interventions are often used to promote social-communication skills among individuals with ASD [79]. However, since some technologies may be newer (e.g., virtual reality and robots), they can also be costly and therefore not feasible to purchase or implement in under-resourced schools. These interventions may also require additional empirical support to examine the effectiveness on children across different ages and cultures [80]. However, one study noted that smartphone-based technologies and personal computers were rated favorably by expert reviewers for overall feasibility, cultural appropriateness, and affordability for use in ASD interventions [81]. On the other hand, in low-income communities and countries, computer- or tablet-based communication tools may not be as feasible due to limited access to electricity and potential unfamiliarity with the technology that may likely hinder child progress.

Although ASD interventions may be more accessible in school settings than in clinical settings, parents and educators often report a lack of resources and trained professionals in ASD [82]. One study noted that parents of children with ASD reported being dissatisfied with the special education and related services their children received [82]. Integrated behavioral and mental health may allow a greater level of support for families by cultivating partnerships between local schools, medical centers, universities, and agencies that specialize in ASD. School-wide practices, such as Positive Behavioral Interventions and Supports, emphasize school-wide screening, functional behavioral assessment, and evidence-based interventions [83]. These system-level practices take a broader approach than the individualized approaches used for students with ASD and therefore may be easier to integrate into existing professional development activities [82].

Home and Parent-Mediated Interventions

Families of children receiving ASD interventions at home or in a clinical setting most often receive individualized support while parents/caregivers were present [34]. Some researchers indicated that racial, ethnic, and linguistic minority parents/caregivers value open communication with clinicians, including frequent communication and parental support [84]. Findings from a survey study with Hispanic/Latinx caregivers indicate that they perceive verbal or visual

prompting strategies, reward systems and consequences, and modeling as effective strategies to use for their children with ASD [84]. In particular, parents/caregivers noted video modeling as potentially beneficial and feasible to use at home. They also indicated discrete-trial training as a strategy frequently used by clinicians but were not as widely used in home settings [34] due to being a time-intensive approach. Discrete trial training is an applied behavioral analytic method in which skill learning is simplified into small units of instruction (usually 5–20 s) whereby trainers teach new forms of behavior (e.g., speech sounds or motor skills) and new discriminations (e.g., responding accurately to specific requests) on a one-to-one basis [84].

Parent-mediated interventions can be a useful alternative to clinician-directed interventions as they may be more cost-effective to implement behavioral strategies [85]. These support systems allow parents to develop knowledge and skills on how to deliver interventions in their home and/or community through a structured parent training program. Parent-mediated interventions are shown to be sustainable and economically feasible on small scales and effective in decreasing ASD symptoms in children in low-income communities [86]. Typically, families in rural and geographically remote areas have access to fewer medical doctors, specialists, and psychologists than those in urban and suburban areas, so providing this method of intervention can reach a larger and more diverse clientele through community centers or other accessible public venues for families [87].

Few studies have explicitly reported the use of cultural adaptation practices in interventions with diverse individuals with ASD. Considering cultural variability in social norms, language, and behavior, intervention research needs to include diverse samples while considering sociocultural factors that may influence intervention acceptability and child outcomes. Limited research has examined cultural adaptations of social skill intervention research among individuals with ASD, particularly in the USA [88]. When adapting interventions, the most common considerations include modifications in either the program content or the delivery of the intervention. Some examples of adaptations to program content include surface structure adaptations, which incorporate processes that match people or language (e.g., translation of content) to observable racial or ethnic characteristics of the population [88, 89]. On the other hand, deep structure adaptations are more abstract and involve content strategies that match the cultural practices, dynamics, values, and belief systems within a group (e.g., consideration of family dynamics) [89]. Since deep structure adaptations incorporate cultural, social, historical, environmental, or psychological aspects that influence the target minority group's behavior, they are time-consuming to adapt, yet more likely to improve the effectiveness of interventions.

Findings from a meta-analysis suggest that cultural adaptations of interventions significantly improved ethnic and racial minority clients' behavioral and psychological functioning compared to nonadapted versions ($d = 0.32$) [90]. Several studies have adapted and evaluated the effectiveness of parent-mediated interventions for children with ASD, more notably in low-income communities with several sites outside of the USA [91]. Results indicated improvement in parental/caregiver knowledge and skill development when implementing effective behavioral supports with their child [92]. For example, parents/caregivers in rural Bangladesh indicated that the parental training and guidance received from a culturally adapted ASD intervention were better addressed during individual sessions than group sessions. They also believed that the interactions with parents of other children with ASD during the group sessions were beneficial and informative and served as both moral and social support systems [86].

Additional research should focus on how to continue to collaborate and support parents to deliver ASD interventions to improve intervention acceptability and accessibility. The process of creating culturally appropriate materials requires considerable time and resources, as well as collaboration with stakeholders in the community [91]. Future research in this area should focus on developing systematic procedures for culturally adapting ASD intervention materials that are easily transferable to school-based settings. Considering the intersectionality and intragroup differences that may occur among diverse children with ASD, adaptations and modifications to existing interventions are complex yet needed to accommodate the unique cultural and linguistic needs of diverse children. Additional research should explore methods in which community stakeholders and individuals with ASD can be a part of the development and adaptation of interventions to reduce stigma and maximize effectiveness.

Considering Neurodiversity

Neurodevelopmental disorders, particularly ASD, heavily rely on criteria based on deviations in behavior when determining diagnosis and treatment [93]. Stemming from a medical model in psychiatry, this classification system tends to omit behavioral strengths, the social context for these behaviors, and society's role in defining appropriate behaviors [94]. In recent years, advocates and scholars have increasingly called to replace the conventional medical model and proposed that autism should be viewed through the lens of neurodiversity, where autism is seen as one form of natural human variation and should be considered a separate minority culture as opposed to a deficit or disorder [95]. They emphasize children's subjective well-being and adaptive behavior rather than what is perceived as typical

functioning and oppose interventions that aim to eliminate harmless behaviors, such as avoiding eye contact or repetitive body movements, which may serve as their method of self-regulation or coping [96•]. However, some scholars believe that awareness of neurodiversity and celebrating autism as a positive identity may indicate a convergence of sociocultural and medical model perspectives [97].

Differences in cultural beliefs about autism also influence the language used to describe the condition. Researchers have commonly used terms such as “dysfunction” or “impairments” to describe atypical behaviors or cognition related to ASD, which may contribute to negative self-perceptions and stigma [97]. Professionals have often recommended using person-first language (“child with autism”), although many individuals on the autism spectrum when asked about this phrase, did not prefer or endorse it and preferred identity-first language (“autistic child”) [98]. Additionally, researchers suggested avoiding phrases such as “special interests” and “special needs” and instead using alternative phrases such as “focused interests” and specific descriptions of the child's needs [98]. Medical or deficit language such as “at risk for autism” may be replaced with “increased likelihood of autism.” However, many of these findings are based on English-speaking participants where a disproportionate amount of whom are White. Although the use of these terms or phrases may be a political choice, positively reframing autism can aid children on the autism spectrum to cope and improve their quality of life [97].

Conclusions

Sociocultural factors should be strongly considered in the diagnosis, assessment, and intervention of ASD among children. Structural inequities contribute to delays in accessing ASD services, stemming from racial bias and discrimination experienced by families, a lack of diversity among clinicians or other mental health service providers (impacting clinician-client/family relationships), and a lack of resources in communities or school settings. Despite gradual improvement in screening and detecting ASD among youth, clinicians should continue to demonstrate self-awareness and cultural humility at both the individual and system levels to address structural inequities and to advocate for youth with ASD and their families.

This review also underscores the importance of culturally responsive assessment and interventions that may require adaptation to address the unique needs of racial, ethnic, and linguistic minority youth with ASD. Further areas of research should continue to focus on developing psychometrically valid ASD assessment tools for diverse groups, in addition to constructing semi-structured interviews that directly address sociocultural factors and contexts.

Additional research should continue to include the perspectives of underrepresented youth with ASD to mitigate stigma, improve service delivery, and reframe the condition by potentially shifting the focus somewhat from deficits to overall well-being, such as how avoiding eye contact and repetitive movements may be self-regulatory behaviors and how restrictive interests can build success in their education and areas of strengths. Research should also continue with developing a systematic approach to adapting evidence-based interventions to incorporate the linguistic and cultural backgrounds of caregivers and families of youth with ASD. These efforts, along with continuous professional development on these issues, will aid in improving clinicians' knowledge, skills, and cultural humility, as well as mitigating structural inequities that contribute to disparities in ASD services.

Declarations

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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