

Psychopathology, Families, and Culture: Autism

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KEYWORDS

- Autism spectrum disorders • Culture • Families
- Developmental disabilities

BACKGROUND AND OVERVIEW

Autism spectrum disorders (ASDs) are now considered to be the most common of the developmental disorders. However, the effect of cultural influences on the diagnosis and treatment of ASDs has received limited attention. The lengthy diagnostic processes, complicated treatment planning, and associated medical symptoms pose challenges to clinicians in considering the cultural influences on the disorder. Furthermore, cultural factors affecting diagnostic processes, adaptation of the family to having a child with autism, and treatment differences may have received less attention because neurodevelopmental changes seem to be much more significant in contributing to the abnormal social interaction, behaviors, and communication problems. Although symptoms of biologic disorders may be similar across cultures, symptom description, interpretation, and acceptance can vary tremendously. Despite the limited research data available at present, evidence suggests that culture does play a role.

This article reviews the available literature on cultural differences in diagnosis, acceptance, and treatment of ASD. It is important to focus on both macrolevel cultural factors—factors at the dominant culture level that affect the people in that society and microlevel factors—factors at the family level that affect response to diagnosis or treatment choice. Both can play a role in the course and outcome of an individual with ASD. Macrolevel factors, such as the availability of services, societal acceptance of the disorder, and existence of national- and/or state-funded treatment options,

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significantly affect the quality of diagnostic and intervention services provided, which directly influences the outcome for an individual with autism. In addition, cultural factors at the microlevel within families, such as individual response and acceptance of the diagnosis, vary considerably and can affect outcome. Although parenting behavior and parenting style are clearly not related to the development of ASD, parental perspectives of ASD and parental responses to receiving a diagnosis influence educational and treatment choices. As outlined later, research into macrolevel cultural factors and family-specific factors indicate that both the factors significantly affect the understanding of ASD, the diagnosis and treatment of the disorder, and the course of the disability.

PREVALENCE OF ASD ACROSS CULTURES

Median prevalence rates of ASD across international surveys are estimated to be 13 per 10,000 for autistic disorder, 21 per 10,000 for pervasive developmental disorders not otherwise specified, and 2.6 per 10,000 for Asperger disorder.¹ These estimates range from 91 per 10,000 in the United States² to 22 per 10,000 in the United Kingdom,³ 7.2 per 10,000 in Denmark,⁴ and 13.2 per 10,000 in Iceland.⁵ In a review of epidemiologic studies of ASD, Fombonne¹ found that the prevalence rates were related to sample size and reported a large sample variability both within and between countries because of different methodologies. The diagnostic process and the ability to accurately diagnose ASD within the spectrum also vary within and across countries. Obtaining accurate prevalence estimates in some countries may be hampered by increased childhood mortality, poverty, and health issues. Furthermore, some cultures may not recognize ASD as a disorder or may group individuals with ASD under another diagnostic category. Inconsistent medical record keeping in some countries makes estimating ASD prevalence impossible. In addition, cultural beliefs and practices can affect identification and integration of individuals with ASD into a society. As a result, some individuals with ASD may be missed in epidemiologic studies, with true estimates significantly affected.⁶ Fombonne¹ concluded that the unique design features of epidemiologic studies account for the between-study variability, suggesting that the true prevalence rates are likely to be comparable across countries.

Kogan and colleagues⁷ found differential prevalence rates as a function of racial or ethnic background in the United States. Through a nationwide phone survey, they found that the odds of having an ASD were 57% lower for non-Hispanic African American children than for non-Hispanic White children. The odds of having an ASD diagnosis was 42% lower for non-Hispanic multiracial and non-Hispanic other single race (not African American or White) children when compared with non-Hispanic White children.⁷ The investigators attribute the difference in rates to parental reporting of current diagnosis and suggest that the differential age of diagnosis and availability of services for ethnic/racial minorities and low socioeconomic status may account for the observed disparity. Similar findings were noted by the Autism and Developmental Disabilities Monitoring Network; the investigators concluded that ascertainment issues, environmental risk factors, and genetic susceptibility may influence the observed racial/ethnic differences.² However, a study of birth cohorts in California over a 7-year period failed to find any differences in prevalence rates between racial and ethnic groups.⁸ The conflicting findings indicate that further exploration of effects resulting from differential access to treatment and diagnostic services is warranted.

Kanner⁹ noted that some parents of children with autism had substantial educational backgrounds and were employed as physicians, lawyers, and professors.

Subsequent reports^{10,11} indicated elevated rates of ASD in families of higher socioeconomic status. However, the reports are likely a result of bias, because individuals of high socioeconomic status have greater access to service or time to participate in research.¹² More recent reports failed to find an association between socioeconomic status and ASD.⁸

Long-term cohort studies, such as the Taiwan Birth Cohort Study,^{13,14} are currently underway in Hong Kong and Taiwan to study ASD in native populations. A review of cases of children diagnosed with autism in different areas of Taiwan found that children living in urban areas were more likely to undergo a shorter diagnostic process and receive the autism diagnosis at a younger age compared with suburban and rural peers.¹⁵ Much of the disparity occurred from a lack of specialty and coordinated services in the suburban and rural areas because most of the specialty providers were concentrated in urban regions in the Northern areas of Taiwan, with no significant differences in socioeconomic status.

CULTURAL PERSPECTIVES ON ASD SYMPTOMS, DIAGNOSIS, AND CHARACTERIZATION

The birth of a child is universally accepted as a life-changing event. Most adults anticipate the birth of their child with a combination of joy and trepidation. Inevitably, expectations of the child's appearance, temperament, and developmental path arise based on wishes and past experiences. When a child is noted to have delays in speech development, abnormal repetitive behaviors, and problems with reciprocal social interaction, a decision to seek evaluation may be prompted. Because diagnostic instruments and standards may be different in different cultures, there may be significant differences in time from detection to diagnosis.

One of the core problems of ASD is in reciprocal social interaction. As a result, differences in cultural beliefs about appropriate social behavior can affect the accurate diagnosis of ASD. For instance, in Asian culture, direct eye contact with authorities is considered to be a sign of disrespect.^{16,17} However, reduced eye contact is considered to be a part of the impaired nonverbal behavior criteria for diagnosis of ASD. By extension, children raised in Asian culture may avoid eye contact not because of ASD but because of the social norms of their culture.

In a review of the Indian literature on ASD, Daley¹⁸ considered that the greater emphasis on conformity to social norms and the value placed on social relatedness in Indians could result in Indian parents recognizing social symptoms earlier and seeking treatment. However, despite social difficulties being observed by Indian parents earlier, the median age range of recognition is 25.7 months versus the 14.9 to 19.1 months in the West. In many cases, the parents delayed seeking helps as long as 2 years and 8 months after initial symptom presentation, because of the cultural beliefs of the parents and family. Examples of misinterpretation of symptoms leading to delayed diagnosis include the following cases¹⁸:

1. A parent with a 3-year-old girl who did not relate socially with peers her age considered her a mature child because she responded well to adults.
2. A mother was not alarmed that her son was still not speaking at age 4 years because Indian boys talk later.
3. A child who keeps quiet and to oneself was perceived as a good child because he or she is trouble free.

Macrolevel cultural factors that can contribute to delayed diagnosis also include requirements of the society for continuing medical education and recertification. The lack of requirements for recertification and requirements to keep up-to-date on

new medical information may contribute to delayed diagnosis.¹⁹ The older and well-respected Indian doctors were speculated to have possibly had an outdated view of autism, resulting in the late or misdiagnosed cases in the review.¹⁸

CULTURAL INFLUENCES IN DIAGNOSIS AND ASSESSMENT OF ASD

The gold standard assessment tools for diagnosing ASD are the Autism Diagnostic Observation Schedule (ADOS)²⁰ and Autism Diagnostic Interview.²¹ These instruments have drastically improved the standardization of assessment and characterization of ASD; however, they were not designed to consider cultural variables or influences. Although the behavior-based ADOS has been translated into 12 languages, the effect of potential cultural confounds on the validity and reliability of the instrument has not been thoroughly assessed.

There is limited research examining the diagnosis and characterization of ASD in non-Western countries. This may be, in part, because in many cultures there is not a single word or label for ASD. For example, in Native Hawaiian and Native American languages, ASD is defined by longer descriptions of behaviors than by a single term.²² In addition, some Asian languages do not have a word for ASD,²³ whereas others use a term that does not accurately reflect what is known about the disorder at present.

A recent report describing referral patterns in a sample of 50 consecutive clinic cases of ASD in a hospital in Saudi Arabia found that the presenting complaint for most of the cases was communication problems and that girls were diagnosed at a later age than boys, although in the similar 3:1 ratio as previously reported.²⁴ The investigators suggest that the delay in diagnosis in girls may result from societal expectations that boys be more outgoing, therefore, those girls with social deficits may be considered simply shy or lacking opportunities to interact.

In many parts of India, there are few professionals experienced in ASD and religious healers are often first consulted to help children with ASD. When medical provision is sought, medication or vitamin prescriptions are often the first method of intervention rather than referral for behavioral interventions that have been shown to be effective, although this pattern is changing.²⁵ In the United States, parents and professionals are more likely to detect general developmental delays or regression in language skills.²⁶ Language delays are not considered to be a core feature of ASD by some Indian parents and professionals because of the belief that boys acquire speech later than girls.²⁷ Daley²⁷ hypothesizes that these differences in what behaviors are first observed and considered as core to ASD are due to increased importance of social conformity in Indian culture when compared with the dominant US culture, which is more focused on language development.

There is limited research on ASD in Africa; however, a recent study examined health care workers' knowledge of ASD in Nigeria and highlighted gaps in understanding social impairments and repetitive and restricted interests. Further, more than half of the 134 interviewed health care professionals held the belief that facilities providing services and laws covering children with ASD were lacking.²⁸ Grinker²⁵ reported that Africans are less likely to use psychiatric treatment and more likely to pursue traditional healers because of cultural beliefs embedded in historical experiences. It was also reported that a common belief held by Europeans who colonized Africa was that Africans were assumed to be too primitive to suffer from mental illnesses because of their lack of exposure to stresses associated with life in industrialized societies. As a result, when Africans did show signs of mental illness, they were incarcerated rather than treated at hospitals.²⁵

In the United States, research examining the effects of race and ethnicity on diagnosis indicates that the age at which children are diagnosed with ASD varies as a function of ethnic background. A study of Medicaid-eligible children with ASD in Philadelphia County found that on average, White children receive a diagnosis about 1.5 years earlier than African American children and 2.5 years earlier than Latino children.²⁹ Further, African American children spend more time in treatment before receiving the diagnosis of ASD. In a follow-up study, Mandell and colleagues³⁰ found that the African American children ultimately diagnosed with ASD were nearly 3 times more likely than White children to first receive another diagnosis, such as conduct or adjustment disorder. The investigators concluded that African American parents might be more likely to emphasize on disruptive behavior during the assessment rather than social oddities in their children. Other possible explanations are that general prejudices held by the clinician, specific stereotypes about health-related behaviors, and statistical discrimination in which the clinician has different expectations on the probability of ASD occurring in children of different ethnicities result in the observed differences in diagnostic outcomes.³¹

CULTURAL INFLUENCES IN PARENTAL ADJUSTMENT TO AN ASD DIAGNOSIS

One of the most difficult tasks that a parent faces is the response to the diagnosis of ASD. The most important adjustment for a parent raising a child with ASD is to successfully modify the original expectations of raising a typically developing child and to accept the child and the child's unique developmental trajectory and behavioral differences. Therein lie the unique challenges for the parent of the child with autism. For the family caring for a child with autism, the hardship is tangible and creates more substantive changes to the family system because of the permanence of the condition. Cultural factors affect the family's ability to accept the child and provide the resources necessary to promote the child's adaptation and development.

After the diagnosis of autism, many parents experience shock, trauma, and grieving for the loss of the normally developing child that they had planned for. Feelings such as denial about the diagnosis, anger about the unfairness of having to raise a child with developmental delays, and fear for the future of the child are all common reactions to the diagnosis. In some cases, the imperfect child, who is perceived as a reflection of the parent's own competence, may represent a narcissistic injury. The stark contrast between the imagined parenting experience and the reality of caring for a child with autism and intellectual disability may lead to intense disappointment and self-blame. Unlike other illnesses or events that may be time limited, having a child with autism creates a lifetime of multidimensional issues and demands for the family. Families may develop a new sense of self-organization as they are coping but may still feel marked by a distinct sense of tragedy.³²

Variations in coping styles of parents have tremendous effect on their ability to accept and care for their child with ASD. When compared with White parents, Asian parents use reframing techniques³³ and redirect their energy toward positive actions such as the main coping strategies.³⁴ A recent study of Southeast Asian parents revealed 9 distinct set of coping style patterns when dealing with a child with autism, including denial or passive coping, empowerment, redirecting energy, shifting of focus, rearranging life and relationships, changed expectations, social withdrawal, spiritual coping, and acceptance.³⁵ Traditionally, Southeast Asian families lived in clans and depended on each other for all the family's needs. In addition, the researchers found that parents relied heavily on their extended family, when available, and that mothers resented the lack of adequate support from spouses and had an

overall frustration about their weakness in English-speaking skills, which they thought impeded their abilities to maximize help for their children.³⁵ As a result, consideration of the immigrating families' experience in being physically detached from most of their extended family members is essential.

Stigma exists about mental illness in Chinese culture, and many families feel ashamed about having a child with a disability, thinking that mental illness is the punishment for a parent's behavior, particularly, the mother's behavior.³⁶ In addition, societal pressures for conformity in Chinese culture allow little room for the acceptance of individual differences, such as a child's disabilities. In China, 43 caregivers of children with ASD were interviewed about the experiences of raising a child with ASD.³⁷ Despite societal disapproval of ASD, parents reported wanting only what was best for their children. Most of the families in the study devoted considerable financial resources and time to their child. All the interviewed caregivers conveyed fear that their child's disability would result in discrimination and that the family would be judged in accordance with the traditional Chinese belief that a child's behavior and success directly reflects on the parents. Caregivers also reported concerns that their children would not receive proper care and services, citing that the stigma can discourage families from seeking out an evaluation and reporting a diagnosis to the school.

The reported reluctance to seek services or treatment for a disability because of the stigma is found in other cultures. South Asian families reported a reluctance to refer their child for services because of the stigma associated with the diagnosis and highlighted fears of a possible negative effect on arranged marriages, particularly for girls.³⁸

CULTURAL INFLUENCES ON ASD TREATMENT

In addition to diagnostic differences in ASD, usage rates of special education and treatment services differ as a function of race and ethnic background. Dyches and colleagues,³⁹ in a review of the US Department of Education's 2001 Individuals with Disabilities Education Act report, found that students identified as African American or Asian or Pacific Islander received educational services under the category of ASD at twice the rate of American Indian/Alaskan or Hispanic students. The investigators concluded that the reluctance of families within some cultures to use the ASD label could account for the discrepant usage rates.

Disparities in access to and use of services of racial and ethnic minorities have been noted in children both with and without ASD.^{40,41} Decreased access to treatment for Latino, African American, and socioeconomically deprived children with ASD have been noted.⁴² Racial and ethnic minority families are also less likely to use the services of professionals such as case managers, psychologists, and developmental pediatricians.⁴³ It has been proposed that the disparity may be explained by the poor outreach and cultural competency of providers,⁴⁴ general mistrust of the system as a function of institutionalized discrimination,⁴⁵ and greater reliance on extended family members and friends than professionals.⁴⁶

Perceptions of treatments are influenced by cultural values. In mental health, the choice of treatment is based on the family's belief about the cause of the diagnosis, but understanding of the cause varies across cultures. African American, Asian American, and Latino families may be less likely to view a child's symptoms as related to a health condition and therefore be less likely to seek out traditional medical treatments. Instead, these families may explore alternative therapies such as diet changes and supplemental vitamins.^{47,48} For example, one study found that Latino children

diagnosed with ASD were 6 times more likely to be treated using nontraditional strategies than children of other ethnicities.⁴⁹

A 2006 study examining mothers' experiences of raising a child with ASD in an ultra-orthodox Jewish community in Israel suggested that in this culture, ASD is believed to be associated with mystical forces.⁵⁰ Facilitated communication, repeatedly found by controlled studies to be an ineffective intervention,⁵¹ involves the use of an adult's support to a child's hand while a child types on a keyboard to communicate. This technique continues to be used in the ultraorthodox Jewish community in Israel because it is considered as a way for children with autism to "impart hidden knowledge from heaven."^{50(p20)}

Treatment goals are also influenced by cultural perspectives. For example, a high value is placed on individualism in Anglo-American culture, whereas some other cultures have a more collectivist orientation, prioritizing the group over the individual. As a result, some families may focus on treatment of behaviors that facilitate family and community activities rather than individual competence and autonomy. This approach could clash with behavioral treatments often aimed at fostering independence and self-help skills.⁶ Differences in child-rearing practices and cultural values between and among racial and ethnic groups have implications that providers must consider when designing and implementing a treatment plan. For example, child-rearing practices of Mexican American mothers tend to focus more on teaching politeness and obeying authority figures, whereas Anglo-American mothers more often value self-directed learning and independent thinking.⁵² Cultural differences have also been noted with regard to families' treatment decisions when dealing with a child with autism. Complementary and alternative medicine (CAM) use and Asian cultures are frequently associated with each other in the literature; however, recent research indicates that CAM use depends on the type of CAM.⁵³ In a cross-sectional survey of children's CAM use in Hong Kong, Wong⁵³ found that Western families used biologic therapies such as dietary management, whereas the 3 most common CAM types used by families in Hong Kong were acupuncture, sensory integration, and Chinese medicine. In addition, 76.9% of the families held expectations that it would augment the conventional treatments. The use of CAM in Hong Kong (40.8%) was less than that in Canada (52%) or the United States (74%). The father's job and the mother's religion were the 2 factors that were most significantly related to CAM use.⁵³ A study in Hong Kong reviewed the application of the Treatment and Education of Autistic and related Communication-handicapped CHildren (TEACCH) program in Chinese preschool children with autism. When compared with the control group, which received the typical in-school services through Individualized Education Plan and private therapy, the children in the TEACCH program showed significantly more improvement in perception and fine motor and gross motor tasks at 6 months and had gradual and significant improvement in all developmental domains at 12 months.⁵⁴

Many ASD interventions include goals focusing on recognition and expression of emotion. However, some cultures value private over public displays of emotion and discourage outward emotional displays.⁵⁵ A treatment attempting to elicit outward emotional expression may contradict the values of these cultures. In addition, in many ASD interventions parents are encouraged to be an active member of the treatment team and implement interventions at home and in other settings for their child. However, expectations about the role of parent, teacher, and provider vary across cultures. In some cultures, parents do not expect to have a role and may expect therapists and educators to be the primary providers. These differences in focus can affect treatment goals in a service plan. To effectively collaborate with families in developing treatment goals and plans, cultural influences must be considered.

DEVELOPMENTAL CONSIDERATIONS

For a family with a child with ASD, early childhood is characterized by the family's recognition of the child's impaired social interaction, speech delay, and unusual behaviors. After diagnosis, there is a gradual appreciation and acceptance of an atypical developmental trajectory. Often, stress on the parents is increased by the extended family members' responses to the diagnosis, which although well-meaning, may include suggestions for intervention that may be unrealistic or impractical. Many parents stop working to coordinate their children's treatment and are thus faced with increasing financial burden.⁵⁶ Furthermore, parents may experience stress related to their children's inappropriate and disruptive social behaviors. The stereotyped, unpredictable, and repetitive behaviors of autistic children limit the family's opportunities for social activities and disrupt the family's daily routine, thereby compounding stress.

Typical problems that parents confront during this period include the child's irregular sleep patterns, hyperactive or disruptive behavior, lack of communication skills, restricted eating habits, and inability to achieve independent elimination habits. Concerns about keeping the child safe and an inability to obtain appropriate daycare or respite further increase stress. Unpredictable, disruptive, and unusual behaviors frequently lead parents to avoid public situations because they fear others' responses; however, this can lead to feelings of isolation and frustration. Normally developing siblings may resent missing activities because they are not tolerated by the child with autism. Parents may have to divide time so that one parent may accompany the sibling to a cherished activity.

Significant tasks for the family during this stage involve accepting the diagnosis, obtaining community services, and integrating complex treatment interventions. Clinicians must consider the macrolevel and microlevel cultural influences on the acceptance of the diagnosis and consideration of treatment options. The behaviors that are considered to be significant and first noted by parents may vary as a function of cultural background. For example, White families may be keenly aware of language delays and are concerned with communication problems, whereas families from other cultures with a focus on social conformity, such as Indian culture, may focus more on the socially disrupted behaviors. In some cultures, the stigma that is attached to having a child with a disability can affect the family's experience of receiving a diagnosis and so clinicians must rely on culturally specific coping strategies to make the diagnostic process successful. For example, many Asian families rely on reframing and directing their energy toward positive actions such as coping techniques. Clinicians could build on this approach by exploring options for positive outlets to direct family actions, such as directing energy toward treatment or participating in research to enhance understanding about the disorder. Ultimately, in the early phase after the diagnostic evaluation, clinicians can help the families by providing education about the disorder, discussing the variations in the developmental trajectory for children with ASD, and, most importantly, providing information about local resources for family support, educational programs, speech therapy, behavioral interventions, and physicians who are comfortable with working with children who have ASD.

Middle childhood may become challenging as parents search for appropriate educational settings for their children. Options vary by depending to a large degree on the intellectual level of the child. Children with ASD who have moderate intellectual disability may be able to participate in special education public school settings with ASD educational programs. Often families who are not able to afford a private program relocate to obtain services from a public school district that has appropriate programs for children with ASD. If the child has a significant intellectual disability and is not toilet

trained, the search for appropriate school settings is much more difficult. Few private schools for children with ASD accept children who are not toilet trained because of the significant staff time required to provide individualized intensive interventions. Often parents have to develop a unique program for their child based on a combination of public and private resources encompassing behavioral interventions, such as applied behavioral analysis (ABA) or Floor Time therapy, speech and occupational therapy, and social skills training. The stress of implementing intensive ABA programs has been noted to contribute to maternal stress and depression.⁵⁷ The focus of the programs, in addition to traditional education, may be on the development of adaptive behaviors in the areas of self-care, domestic chores, and social behaviors. Clinicians must consider the cultural influences on treatment goal choice and treatment choice in general during this time. Although White families tend to emphasize independence and language development, which are the traditional goals for behavior-based interventions, these treatment goals may not be appropriate for children across all cultures. Clinicians must explore treatment goals with the family to ensure that the goals synthesize with the culturally relevant goals of the family. Further, during middle childhood, intense sadness can often arise in situations in which parents are confronted by the contrast between their child's developmental delays and those of a typically developing child. Clinicians can aid parents by predicting that these feelings of grief will occur and are common among parents raising a child with autism. Given the important role of extended family members in many cultures, such as Asian and Latino families, helping parents to find activities that they can share with their child allows them to be among other parents and family members and can be invaluable.

Adolescence and young adulthood are marked by transitions that are influenced by a family's cultural background. For example, some cultures value interconnected family networks closely, whereas others value independence. The treatment goals of this developmental period could vary as widely as skills for independence to foundational social skills to increase family interaction. Clinicians must be sensitive to the family culture to ensure that these treatment goals mesh with the cultural expectations.

CONSIDERATIONS FOR PRACTICE

Clinicians must be aware that the diagnostic process, developmental progression, and treatment selection in autism are influenced by culture at the macro- and micro-levels. Diagnosticians and treatment providers must have the basic knowledge about how family members of differing cultures may perceive autism and must be aware that differing levels of cultural identity and personal experience can affect a family member's adherence to or acceptance of those cultural norms. Clinicians must also have the skills to consider and incorporate these family and cultural norms into the diagnostic and treatment processes for individuals with autism.

It is essential for clinicians to consider the stigma that is associated with autism in many cultures and how it influences both their work with families with autism and the family's perception of the child with autism. To consider stigma at the societal and cultural levels, clinicians must be aware of their own cultural biases on how autism is characterized and treated.

Clinicians must be aware of the cultural influences on a family's perception of what autism is and what the diagnostic process means. Families in many cultures underuse mental health services for the evaluation and treatment of autism. By conducting the diagnostic evaluation and communicating about the process in a manner that is consistent with the cultural perceptions of autism, it may be possible to keep families engaged and potentially improve outcomes.

Clinicians must consider that the goals of treatment may vary as a function of culture and modify those treatment goals accordingly. CAM usage also varies by cultural groups, and given the widespread use of treatments that have not been empirically evaluated, clinicians must provide a framework for families to evaluate the applicability and utility of these treatments for their children.

SUMMARY

Regardless of the developmental stage or progression, a clinician's understanding of the parents' experience of their child's diagnosis and the cultural influences on the family's perception of diagnosis and treatment is paramount to providing services that are beneficial to the family.

There is limited research on the cultural influences in the diagnosis, treatment, and course of ASD, and much work is needed in this area. Existing studies examining prevalence rates suggest differential diagnostic rates as a result of differential usage rates of treatment services, age differences in diagnosis, and ethnic or racial group membership algorithms; however, environmental exposure or genetic factors cannot be ruled out. An important next step in ASD research is identifying the true prevalence rates and exploring each of these potential factors. Research needs to be conducted to identify and eliminate the barriers to service use for both diagnosis and treatment to increase usage rates and decrease the age of diagnosis for minority children. Other important steps for future research include validity testing of the existing gold standard diagnostic instruments in other languages and cultures and the examination of the efficacy of existing interventions (eg, ABA-based therapies) in differing cultures. ASDs are the most prevalent developmental disorders and affect families from all ethnic and racial backgrounds. Identifying the cultural factors at the macro- and microlevel that influence early detection, the diagnostic process, and treatment is the important next step to advance the understanding of ASD in a way that is helpful and influential for people of all backgrounds.

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