Clinical and School Identification and Intervention for Youth with ASD: Culturally and Linguistically Responsive Interdisciplinary Considerations

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Abstract Despite dramatic demographic changes over the past five decades specifically, culturally and lingustically diverse (CLD) children are more likely to receive delayed diagnosis and misidentification of ASD as well as experience significant barriers to obtaining ASD services in general. Delays in ASD identification or intervention provision can negatively impact future outcomes and may indicate that professionals are missing important cultural or linguistic considerations when providing services to CLD children and families. Strong interdisciplinary care practices can improve the outcomes of CLD children and their families with ASD. This chapter presents the challenges and successes to the facilitation of interdisciplinary care among CLD children. As services for ASD most often occur in clinical and school-based settings, the chapter will focus on both settings. Recommendations for culturally and linguistically responsive interdisciplinary care for children with ASD are provided.

Racial/ethnic diversity in the United States (U.S.) has changed rapidly, particularly in the past five decades. In 1965, the non-Hispanic White population was 84% of the U.S. population (Pew Research Center, 2015). By 2015, this percentage fell to 62% (Pew Research Center, 2015) and by mid-century, the non-Hispanic White population is expected to be less than 50% of the U.S. population (U.S. Census Bureau, 2017). Alternatively, the size of non-White populations across the U.S. has been increasing nationwide, with some states experiencing more growth than others. For example, California, Hawaii, New Mexico, and Texas identify themselves as states where the non-Hispanic White population is considered the minority population.

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Alternatively, the states of Maine, Vermont, New Hampshire, West Virginia, New Hampshire each have less than 10% of the population that identifies as non-White, the lowest percentages in the U.S. (Maciag, 2015). Children under the age of 18 in the U.S. are more likely to identify as non-White than the adult population and projections indicate that the child population is expected to be increasingly racially diverse in future decades. In 2018, 50% of U.S. children were non-Hispanic White, 25% were Hispanic, 14% were Black, 5% were Asian, and 5% were "all other races" (Federal Interagency Forum on Child and Family Statistics, 2019).

The U.S. has long been a country of linguistic diversity although compiling records pertaining to languages spoken did not begin until the 1980 U.S. Census. Since this date, the American Community Survey of the U.S. Census has gathered this data every decade (e.g., 1980, 1990, 2000, 2010). The findings of the 2010 report detailed a dramatic decrease over time of English-only households in the United States (89.1% of the population in 1980–79.7% in 2010). Persons age 5 and older that speak a language other than English rose from 11 to 20.3% during that same time period. Over two-thirds of the people that report speaking another language identify as Spanish speakers (Rambaut & Massey, 2013). Children are more likely to live in a linguistically diverse household than adults, and 22% of children in the U.S. (ages 5–17) report speaking Spanish in the home. Furthermore, there are almost 500 languages spoken in the U.S. (U.S. Census Bureau, 2010). Similar to racial/ethnic diversity, states within the U.S. vary extensively pertaining to the language use of their population. For example, California reported 43.3% of their population speaks a language other than English. Alternatively, West Virginia, Mississippi, Kentucky, Montana, North Dakota, and Alabama, identified between 2 and 5% of their population as those that speak another language besides English (Rambaut & Massey, 2013).

Notably, the authors would like to acknowledge that there are many terms utilized in this chapter pertaining to race/ethnicity, culture and language. Often, we use the terms utilized in the cited literature. When possible, we attempt to use strengths-based and culturally responsive terms. For example, we prefer the term "bilingual" or "multilingual" children when possible as these terms speak to the additive benefit of being bilingual and more accurately describe the child than other common terms (such as English language learner). The authors would also like to state that this chapter will focus on race/ethnicity and language diversity; however, we acknowledge that there are many other culturally diverse populations that are not represented in this chapter. More research is needed in all areas of diversity within the field of ASD, and we encourage all future research to consider its potential impact on diverse contexts and populations.

The following chapter will describe considerations when providing interdisciplinary school and clinical services to children from culturally and linguistically diverse (CLD) families including diagnostic assessments and intervention services. The recommendations provided within may assist with reducing ASD service disparities in both clinical and school settings and ultimately improve the outcomes of children with ASD from CLD populations.

Disparities in ASD Identification and Service Utilization

ASD Identification and Diagnosis

It is imperative that children with ASD receive an early diagnosis so that they can receive early intervention services and potentially improve later outcomes (Bryson, Rogers, & Fombonne, 2003; Rogers & Vismara, 2008; Stahmer & Mandell, 2007). Often, parents of children with ASD identify first concerns in their children when they are around 12–24 months (Guinchat et al., 2012; Herlihy, Knoch, Vibert, & Fein, 2015; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011). However, on average, children with ASD tend to receive an ASD diagnosis at age 4 (Baio et al., 2018).

The age of diagnosis tends to increase when children are from racially/ethnically diverse backgrounds, living in rural areas, foreign-born, or lower SES (Daniels & Mandell, 2014; Fountain, King, & Bearman, 2011; Kogan et al., 2009; Mandell, Novak, & Zubritsky, 2005; Sansosti, Lavik, & Sansosti, 2012; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). In fact, two recent studies reported that White children are approximately 30 and 50% more likely to have an ASD diagnosis at age 8 years than African American or Hispanic children, respectively (Baio, 2014); and Latino children are less likely to have a school identification of ASD or a comprehensive evaluation by age 3 than their White and African American peers (Baio et al., 2018). Finally, parents from non-English primary language households with children with ASD tend to describe their child's ASD symptoms as more severe than parents from homes where English is the primary language (Lin & Stella, 2015; Reyes et al., 2018). These results may indicate that parents of children from culturally diverse backgrounds are less likely to seek diagnostic services if their children display mild symptoms of ASD.

Researchers have also identified several cultural factors that may influence parent first concerns pertaining to ASD symptomatology. For example, in studies of parents of children with ASD, American and Japanese parents reported that they were first concerned about delayed speech (De Giacomo & Fombonne, 1998; Ohta et al., 1987), whereas urban Indian parents reported that they were primarily concerned about their child's impaired social functioning (Daley, 2004). In addition, cultural variations in communication exist. Zhang, Oetzel, Gao, Wilcox, and Takai (2007) conducted research to investigate nonverbal communication methods and their different cultural meanings in China. The researchers found that pointing with the index finger and eye contact with adults are considered inappropriate behaviors within the Chinese culture (Zhang et al., 2007). These behaviors are commonly assessed within ASD assessments to confirm the presence of ASD. Furthermore, Norbury and Sparks (2013) provided a review of potential cultural differences within ASD assessment including pretend play, public displays of emotion, and the extent to which children (especially boys) play with toy dolls. The researchers found cultural differences to the extent that adults engage in pretend play with children and adult discusson of emotional states (Norbury & Sparks, 2013). Furthermore, Pachter and Dworkin (1997) found that Puerto Rican mothers anticipated certain social milestones, such as recognizing the mother and smiling at others, later in age than Caucasian mothers indicating that there are cultural differences in developmental milestone expectations. These differences in cultural values and expectations likely have an impact on family access to clinical early intervention and school-based services, ASD identification, and professional interpretation of ASD assessment data.

Access to Clinical and School Services

As soon as children receive an ASD diagnosis, families are encouraged to seek intervention services. It is often recommended that children diagnosed with ASD receive at least 25 h per week of academic and intervention services (National Research Council, NRC, 2001; Odom, Boyd, & Hall, 2010a, Odom, Collet-Klingenberg, Rogers, & Hatton et al., 2010b). However, it is well documented that children with ASD do not receive the recommended amount of services that they need (Magaña, Lopez, Aguinaga, & Morton, 2013; Siller, Reyes, Hotez, Hutman, & Sigman, 2014; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Moreover, families of children with ASD often report having more difficulties accessing clinical services than families with children with other developmental disabilities (Chiri & Warfield, 2012; Montes, Halterman, & Magyar, 2009; Vohra, Madhavan, Sambamoorthi, & Peter, 2014).

Disparities in accessing clinical intervention services have also been reported in ASD. For instance, families from minority backgrounds, with low parental education, and living in rural areas tend to receive fewer intervention services than their peers (Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016; Magaña et al., 2013; Murphy & Ruble, 2012; Thomas et al., 2007). For example, Latino children from families with low SES tend to receive fewer clinical intervention services than their White and more affluent counterparts (Liptak et al., 2008). Overall, access to intervention services for children with ASD has been reported to be particularly limited for racial and ethnic minorities and those with low parental education.

Although the reasons for these disparities are likely to be complex, barriers to accessing an ASD diagnosis and intervention services in families from diverse backgrounds have been identified, including psychosocial, economic, political, and healthcare factors (Iland, Weiner, & Murawski, 2012). Specifically, regarding ASD diagnosis, Latino families have reported several barriers to obtaining clinical diagnostic assessments for ASD, including having limited knowledge about ASD, understanding of the medical system, and knowing where to go for help (Zuckerman et al., 2017). With respect to clinical services, Latino parents have also reported barriers, such as increased community stigma, limited care services due to poverty, limited English proficiency, and an inability to take advantage of services (Zuckerman et al., 2014).

Despite the aforementioned challenges with disparities in accessing ASD services among CLD populations, school settings may be one potential institution that can reduce these disparities (Harris et al., 2019). A large percentage of children (38%)

with ASD are identified through educational evaluations and do not receive a clinical diagnosis of ASD (Pettygrove et al., 2013). For CLD children, schools may be the only place where ASD services are accessible to families. In school settings, evaluations and services are federally mandated (when eligible) and are provided at no cost. Thus, for CLD children, schools may potentially contribute to earlier identification and accessible service allocation. However, despite an increase in access to ASD assessment and intervention within school settings over time, some researchers have found that disparities in ASD school identification persist (Pettygrove et al., 2013).

Assessment of ASD in Clinical Settings

Since no biological markers exist for diagnosing ASD, the diagnosis is made based on caregiver information and behavioral observations (Centers for Disease Control and Prevention, 2020). Clinicians use ASD-specific screeners and diagnostic tools to identify social impairments by comparing an individual's social behavior to operational definitions of "normative" social behavior. However, because culture defines what is typical and atypical, there is cross-cultural variation in normative social behavior (i.e., what is considered typical in one culture may be atypical in another culture). The operational definitions of normative social behavior that are included in ASD-specific screeners and diagnostic tools are often based on the majority culture of the U.S. and fail to account for the variability in social norms across cultures, resulting in measures that may lack sensitivity to cross-cultural variation in social behavior.

First, given the central role that culture plays in the establishment of normative social behaviors, we must carefully consider if and when variation in social behaviors is truly deviant and warrants a diagnosis of a disorder (Norbury & Sparks, 2013). For example, abnormalities in social communication, including eye contact, are a core feature of ASD, with the absence of (or poor) eye contact suggestive of ASD. However, cross-cultural differences in the use of eye contact in social interactions are well documented (Fugita, Wexley, & Hillery, 1974; Uono & Hietanen, 2015), and may significantly impact an individual's performance on ASD-specific measures. In fact, a recent study found that Black and Hispanic children were more likely to have atypical (i.e., higher) scores on the Unusual Eye Contact item on the ADOS-2 than White children, which may lead to inaccurate estimations of social impairments among Black and Hispanic children (Harrison, Long, Tommet, & Jones, 2017). Without careful assessment practices, the use of culturally loaded measures may place culturally and linguistically diverse (CLD) children at-risk for being over- or under-identified with ASD.

Moreover, another factor to disparities in ASD identification is the assessment practices and interpretation utilized by professionals conducting ASD evaluations. All ASD evaluation tools are culturally loaded, which impacts the performance and applicability of children from diverse cultural groups (Harris, Barton, & Albert, 2014). Cultural variations in behavior may contribute to inappropriate assessment practices and data interpretation. For example, Zhang et al. (2007) found that eye contact with adults and pointing with the index finger are considered inappropriate behaviors within the Chinese culture (Zhang et al., 2007). These behaviors are commonly assessed within ASD evaluation and are directly assessed on the Autism Diagnostic Observation Schedule (ADOS) as the absence of these behaviors may indicate the presence of ASD. Norbury and Sparks (2013) conducted a review of potential cultural differences within ASD assessment. The authors found that pretend play, public displays of emotion, and the extent to which children (especially boys) play with toy dolls varies based on cultural factors. These differences may impact the interpretation of ASD assessments and potentially contribute to misidentification or delayed identification (Norbury and Sparks, 2013).

Also, while some of the ASD-specific screening and diagnostic tools that were developed in Western, English-speaking countries have undergone cultural adaptations for use across cultural groups, such adaptations have mainly involved surface-level adaptations, such as translation to facilitate use in non-English-speaking populations (Al-Maskari, Melville, & Willis, 2018). It is important to note that measures that have been translated but not normed or standardized with a given population may not be valid for the population as the translation does not ensure that the English and non-English versions of the measures are functionally equivalent (Soto et al., 2015). For example, although most of the activities in the Autism Diagnostic Observation Schedule, Second Edition 2 (ADOS-2), a commonly used ASD diagnostic tool that has been translated into several languages, was found to be culturally appropriate for a sample of Afrikaans-speaking individuals residing in the Western Cape of Africa, some elements of the ADOS-2 were unfamiliar to this population, and would benefit from adaptation to make the elements culturally appropriate (Smith, Malcom-Smith, & de Vries, 2017). These findings highlight the need to examine the validity and cultural appropriateness of measures that have only undergone surface-level adaptations (e.g., translation) and lack diverse norms for use in CLD populations.

Finally, the administration, scoring, and interpretation of commonly utilized and researched ASD diagnostic tools (i.e., ADOS-2 and the Autism Diagnostic Interview [ADI-R]) require substantial training. In addition to concerns related to the cultural appropriateness and validity of ASD-specific screeners and diagnostic tools for use in CLD populations, the assessment of ASD in CLD populations is also negatively impacted by a shortage of professionals who have sufficient training to conduct ASD assessments (Marrus et al., 2014). Moreover, the number of professionals who have training and experience in conducting ASD assessments with CLD populations is even smaller. Thus, although several tools are available for the screening and diagnosis of ASD, several factors can hinder the accurate and timely diagnosis of ASD among CLD populations.

ASD Assessment in School Settings

Children may qualify for special education services under the Autism[1] eligibility category per the Individuals with Disabilities Education Act (IDEA) within the educational setting. Receiving a medical diagnosis of ASD does not guarantee a child will receive an education identification of Autism as the child must demonstrate an educational impact of the disability to qualify for school-based services (IDEA law, Section 300.8 (c)). There are several challenges associated with the educational identification of Autism. First, while school personnel likely have access to ASD-specific screeners, access to psychometrically stronger diagnostic tools (e.g., ADOS and ADI-R) may not be readily available or feasible for school personnel as these measures are costly and time-intensive. Second, schools may lack or have few qualified professionals who are trained to conduct ASD assessments, particularly among culturally and linguistically diverse populations (Harris et al., 2019). That is, school districts may lack the resources needed to provide school personnel with the comprehensive training necessary to reliably administer ASD assessments (Campbell, Ruble, & Hammond, 2014). Third, there is no clearly defined process that exists for the educational identification of Autism. As such, it is the responsibility of individual school districts and state boards to establish procedures and processes for the educational identification of Autism that align with federal law and state guidelines for students with disabilities.

Using IDEA special education eligibility data, Sullivan (2013) found the prevalence rate for educational identification of Autism in school settings to be 1 in 228. While this prevalence rate is lower than the CDC's ADDM prevalence rate, clinical diagnosis and educational identification of ASD are two different processes and cannot be equated. However, this rate is problematic as it is much lower than the general prevalence rate, varies extensively by state (see Barton et al., 2016), and consists of significant disparities among CLD populations. For example, Hispanic and American Indian/Alaskan Native students were less likely to be identified with ASD compared to White students while Asian/Pacific Islander students were more likely to be identified with ASD than their White counterparts (Sullivan, 2013). In summary, White and Asian children are more likely to receive an educational identification of ASD than other racial groups, mirroring disparities in the clinical diagnosis of ASD.

Culturally and linguistically responsive identification and evaluation of students with ASD is a critical first step for professionals in providing effective school-based services (Harris et al., 2019). Evaluations in the school context can be completed as early as age 3, when children are first eligible to receive school-based services under IDEA Part C (Dilly & Hall, 2019). Professional organizations (i.e., the American Psychological Association [APA]) have not specifically outlined recommendations for ASD assessment of CLD children; however, they do provide some guidance. Both the American Psychological Association (2014) and National Association of School Psychologists (2010) recommend that psychologists utilize evidence-based

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[1] For the purpose of increased clarity, the term "Autism" will be used to describe an educational identification and "ASD" will be used to describe a medical/clinical diagnosis.

assessment practices. Specific to ASD, evidence-based assessment practices should include the use of reliable and valid measures in a comprehensive, multisource developmental assessment (Campbell, Ruble, & Hammond, 2014; Huerta & Lord, 2012; Wilkinson, 2014).

Limited research has been conducted regarding school-based ASD assessment practices, particularly with CLD populations. A recent mixed-methods study investigated the self-reported experiences of school psychologists when conducting ASD evaluations with CLD students (Harris et al., 2019). There were many perceived barriers that school psychologists endorsed regarding implementing culturally and linguistically responsive ASD assessment. One of the most striking results was the limited endorsement of engaging families in the ASD assessment process. Because of this potential low level of involvement, it is also possible that families lack sufficient knowledge pertaining to school systems to best advocate for their children's needs. Regarding ASD methods specifically, the use of observations was minimally endorsed by school psychologists. The utilization of native language and English within an ASD assessment was also minimally endorsed. In addition, few respondents endorsed utilizing interdisciplinary practices when engaging in ASD evaluation among CLD children. Multiple school psychologists also stated that they have limited or poor assessment tools for CLD populations and that they are not confident regarding interpreting data from children that are CLD. School psychologists also commonly reported that language barriers were a challenge when conducting ASD evaluations (Harris et al., 2019). This study highlights that school psychologists face multiple barriers when conducting ASD assessment with CLD families, and these barriers may indeed contribute to access to timely and accurate identification of ASD.

Although there are challenges associated with conducting ASD assessments in schools (e.g., fewer qualified school personnel to conduct ASD assessments), schools play a critical role in identifying children with ASD, particularly those who may have been "missed" by the healthcare system (Pettygrove et al., 2013). Moreover, there are several benefits of conducting ASD assessments in schools. First, schools provide greater and more equitable access to services for CLD students and their families than specialty clinical settings (Broder-Fingert, Shui, Pulcini, Kurowski, & Perrin, 2013). Second, unlike clinical settings, there are no waitlists for ASD assessments in schools as IDEA mandates that school-aged assessments are conducted within 60 days of signed parent consent to evaluate. Third, school personnel have the ability to conduct more naturalistic observations of students, especially peer-to-peer interactions. Fourth, IDEA mandates the use of interpretation services when necessary; therefore, linguistically diverse students and families may have easier access to a linguistically appropriate assessment in school settings than clinical settings.

When conducting evaluations for the educational identification of Autism, utilizing a multidisciplinary approach is not only best practice, but also required by IDEA. Each of the team members, who may include school psychologists, teachers, English language acquisition support staff, and speech therapists (among many others), provide unique perspectives and guidance to the evaluation process and eligibility determination. Teams are also required to include parents, as engaging families in this process is critical. Families may have diverse experiences and understanding of disabilities such as ASD or have varied cultural values and beliefs pertaining to behavior and communication. As such, the collaboration between multidisciplinary team members is critical during the evaluation process, as it allows team members to compare and share assessment findings (Kroncke, Willard, & Huckabee, 2016).

ASD Assessment in Clinical/Community Settings

Due to a shortage of adequately trained professionals, families often wait months to receive a comprehensive diagnostic assessment in clinical and community settings (Bisgaier, Levinson, Cutts, & Rhodes, 2011). Moreover, diagnostic assessments conducted in clinical settings often are time-consuming, and require multiple visits to complete (Kalb et al., 2012). Given the challenges associated with receiving timely diagnostic assessments in clinical settings, efforts have been made to develop accurate and efficient strategies for the screening and assessment (please refer to chapters 'Screening and Surveillance' and 'Interdisciplinary Evaluation of Autism Spectrum Disorder' for more information about screening and interdisciplinary evaluation) of ASD in clinical settings.

Training established for community providers in the screening and evaluation of ASD has demonstrated effectiveness in increasing access to diagnostic assessments in community settings. For example, ECHO (Extension for Community Health Outcomes) Autism STAT is a hybrid model for training primary care providers (PCP), who work in underserved areas in the screening and diagnosis of children at-risk for ASD using the STAT assessment (Stone et al., 2004). ECHO Autism STAT combines ECHO Autism (Mazurek, Brown, Curran, & Sohl, 2017), a videoconference-based collaboration that connects PCPs to an interdisciplinary team of autism experts (see chapter 'ECHO Autism' for additional information on ECHO Autism), and the Screening Tool for Autism in Toddlers and Young Children (STAT; Stone et al., 2004), an autism diagnostic training for pediatric medical providers. The implementation of ECHO Autism STAT was shown to increase PCP's administration of autism screeners and their self-efficacy in autism screening and identification, autism referral and resources, assessment and treatment of psychiatric comorbidities, and additional aspects of care for autism (Mazurek, Curran, Burnette, & Sohl, 2019).

Partnering with community agencies has also been proven effective in promoting local, timely access to comprehensive ASD evaluations. One such program, the Autism Diagnosis Education Project (ADEP; OCALI, n.d.), facilitates unique partnerships between community-based primary care practices and professionals providing early intervention and early childhood services in Ohio to conduct local comprehensive multidisciplinary ASD evaluations. Through ADEP, children suspected of having ASD receive a psychoeducational evaluation from a local early intervention team. Then, children receive a medical evaluation from a community medical provider, who either diagnoses or rules out ASD. That is, instead of experiencing long wait times and driving long distances for a comprehensive diagnostic evaluation, families of children suspected of having ASD are able to receive more timely diagnostic services through local community providers. The implementation of ADEP has resulted in the reduction in the average age of ASD diagnosis of children in Ohio from 62 months to 30 months for the evaluation of 1,078 children between 2013 and 2018.

Another evidence-based strategy for increasing access to diagnostic assessments in clinical settings, particularly among minority and low-income populations, involves the use of patient navigators. Patient navigation, which has a strong evidence-base in adult oncology, involves providing individualized assistance to patients, caregivers, and families to help overcome healthcare system barriers and facilitate timely access to quality care (Freeman & Rodriguez, 2011). Recent studies have found that the use of patient navigators is a feasible and effective practice to address barriers that impede timely ASD diagnosis among low-income families. For example, Feinberg et al. (2016) found that children who received patient navigation were significantly more likely to complete an ASD diagnostic evaluation than children who received routine clinic care. Additionally, children who received patient navigation underwent diagnostic evaluations earlier than those who received routine clinic care. The Screening and Linkage Services for Autism (SaLSA) is another promising practice that aims to improve access to autism screening follow-up, diagnostic evaluation, and early intervention services for ASD among predominantly Spanish-speaking, low-income families through autism patient navigators (Project SaLSA, HRSA Grant R40MC27702, 2014).

Community providers may find resources to gain competency in conducting ASD assessments in CLD populations through professional organizations. For example, the American Psychological Association (APA) and the American Education Research Association provide ethical requirements for the assessments of individuals from diverse populations. Additionally, the CDC's "Learn the Signs. Act Early" campaign has resources and materials for community providers, educators, and families. Additionally, the Ohio Center for Autism and Low Incidence (OCALI), which is primarily funded by the Ohio Department of Education, has online and in-person training that are designed to assist school evaluation teams and other school personnel with identifying and serving students with ASD.

In addition to finding resources through professional organizations and community agencies, community providers are also encouraged to collaborate with other clinical providers when conducting ASD evaluations in CLD populations. Given the complexities and variability in symptoms of ASD, collaboration with other clinical providers is beneficial as it allows clinicians to gather information to make differential and/or comorbid diagnoses. Community providers may decide to collaborate with a number of providers from various disciplines, including speech and language pathologists, developmental pediatricians, audiologists, occupational therapists, and geneticists. For example, collaborating with a speech and language pathologist or can be used to determine if a child's communication deficits are due to ASD, a language disorder, or being a bilingual learner; the latter is important for children with limited English language exposure.

Questions to Consider When Conducting ASD Diagnostic Assessments with Diverse Populations

The following questions are presented to aid professionals in utilizing culturally and linguistically sensitive ASD assessment practices.

1. Are the social-communicative impairments the result of typical variations of cultural norms? That is, are the social-communicative impairments observed due to differences in cultural expectations and/or values?
2. Are language impairments accounting for observed social-communicative impairments?
3. Is the assessment culturally and linguistically responsive?
    a. Do the caregivers and children understand the concepts and questions that are being asked?
    b. Are cultural and/or linguistic factors impacting the child's performance and/or the validity of information gathered during the assessment?
4. Have personal biases that may influence the assessment process been identified and addressed?
5. Are evidence-based assessment practices being employed?
6. Is data being collected from multiple sources including standardized and qualitative information?
7. Are multiple professionals involved in a collaborative assessment process?
8. When interpreting the assessment data, are considerations pertaining to culture and language discussed as potential influences?

ASD Intervention: Considerations for Culturally and Linguistically Diverse Children and Families

Substantial research has identified the benefit of early intervention on future outcomes for children with ASD (e.g., Fernell, Eriksson, & Gillberg, 2013; Kuppens & Onghena, 2012; Magiati, Tay, & Howlin, 2014). Although there are numerous evidence-based interventions for ASD, the selection of such will be warranted by symptom severity and family needs. Across all interventions, evidence supports combining parent-mediated interventions with professional-implemented interventions to maximize outcomes (Landa, 2018). Typically, evidence-based intervention falls into two categories: Naturalistic Developmental Behavioral Interventions (e.g., Schreibman et al., 2015) and those that are more commonly referred to as Applied Behavior Analysis (ABA; see chapter 'Coordinating ABA Services') utilizing a foundation of discrete trial training formats. However, limited research has been conducted pertaining to CLD children and ASD intervention. Furthermore, researchers acknowledge the limited inclusion of CLD children in ASD research which greatly impacts knowledge pertaining to evidence-based practices (see Wong et al., 2015). Furthermore, behavioral interventions for children with ASD that are effective for one population, may not be effective for other populations (Buzhardt et al., 2015). Thus, the influence of cultural factors on the utility, implementation, and design of these interventions is generally unknown. More research on evidence-based interventions for CLD children with ASD is critical.

There are numerous challenges reported pertaining to providing optimal ASD intervention to CLD children and families. One of the challenges pertaining to current ASD intervention practice is the reliance on translating materials into another language. While this practice has good intentions, translation alone does not improve cultural factors that may not be considered. For example, Buzhardt et al. (2015) found that translating an evidence-based intervention into Spanish may not improve "cultural congruence" for Latinos. Instead, interventions need to be analyzed for potential alignment with cultural values, expectations, and perceptions (DuBay et al., 2018). Historically, families from CLD families have reported higher levels of discontent with early intervention services. This may be due to this aforementioned cultural incongruence as well as other factors such as language barriers that may impact the ability to create strong relationships with professionals (Iland et al, 2012).

Given that ASD is a complex disorder, in recent years, a wide range of professionals often work with this population and collaboration among interventionists is critical to effectively serve families (American Academy of Pediatrics, 2014; Strunk, Leisen, and Schubert, 2017; World Health Organization, 2010). In fact, children with ASD are often served by psychologists, social workers, speech and language pathologists, occupational therapists, physical therapists, teachers, nurses, dietitians, psychiatrists, and developmental pediatricians (Myers & Johnson, 2007). Thus, working in collaboration is described as a best practice model and one that can increase culturally and linguistically responsive services (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005).

An example of that approach is the Treatment and Education of Autistic and Related Communication Handicapped CHildren (TEACCH), which was one of the first programs that included an interdisciplinary approach, including clinical services, family involvement, and counseling. TEACCH shows some promising results in being effective as an interdisciplinary intervention, although early intensive behavioral intervention shows the strongest evidence-base for children with ASD (Virués-Ortega, Arnold-Saritepe, Hird, & Phillios, 2017). Although this research is in its infancy (Carbone, Behl, Azor, & Murphy 2010; Soares, Baum, & Frick, 2015), it is likely that using an interdisciplinary approach will improve treatment planning and service coordination when providing services to children with ASD from traditionally underserved groups.

Despite limited research on this topic, a recent review of 18 studies investigated the effects of utilizing the heritage language (i.e., native language) in ASD intervention. The majority of the studies found demonstrated small effects for utilizing the heritage language in ASD intervention. The authors also found problematic research designs in many studies; thus, the implications of these studies should be interpreted with caution. However, these findings indicate that utilizing the heritage language of the child can demonstrate favorable outcomes and should be considered during intervention design (Lim et al., 2019).

While there are benefits to obtaining ASD intervention in clinical and home settings, ASD intervention within the school setting offers the family the ability to receive services with reduced barriers (e.g., transportation, cost). Intervention for ASD in a school setting may look different from clinical settings for a variety of reasons as school professionals tailor special education intervention to goals in the Individualized Education Plan. There are many advantages to providing school-based interventions to children with ASD as the child is in a natural environment, with peers, and intervention can occur within multiple school settings and in real time during structured (such as the classroom setting) and unstructured settings (such as recess or lunch).

Strengthening Partnerships with Culturally and Linguistically Diverse Families

Evidence-based practices for ASD often require heavy family involvement and resources to implement them consistently. Although evidence-based practices (EBPs) have been shown to be promising in addressing and alleviating some ASD symptoms and related difficulties, some families with a child with ASD might struggle to include these interventions in their daily lives (Hume, Bellini, & Pratt, 2005; Wainer, Hepburn, & Griffith, 2017; Williams & Wishart, 2003). Specifically, it is well documented that families of children with ASD often experience increased levels of stress; navigating and accessing services might also be a source of stress for them (Sanders & Morgan, 1997). For some families, they may have to modify their work schedules or stop working altogether because several evidenced-based interventions require family involvement (Karst & Van Hecke, 2012). For other families, they may feel that they have minimal involvement in the planning or implementation of these interventions (Kohler, 1999; Wainer et al., 2017). Also, after receiving an ASD diagnosis, families may face other challenges, including their own mental and physical health issues, marital problems, parent-child relationships, sibling relationships, family resources, parent copying styles, parental self-efficacy, and social support (Karst & Van Hecke, 2012). Families from CLD backgrounds may experience similar difficulties when caring for a child with ASD (Kheir et al., 2012; Moh & Magiati, 2012; Pakenham et al., 2005; Sivberg, 2002; Wang, Michaels, & Day, 2011).

Families may also face an increased number of barriers that may widen disparities in accessing ASD services (Zuckerman et al., 2018). Thus, several factors might need to be considered when working with diverse or traditionally underserved families. For example, when delivering evidence-based interventions to families from different linguistic and ethnic background it may be important to include bilingual and bicultural staff to communicate effectively with families (Barnett, Gonzalez, Miranda, Chavira, & Lau, 2018), or at least provide adequate interpreter services.

Also, it may be useful to understand the family's beliefs and views about their child as well as family values (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Reyes et al., 2018; Zuckerman, Lindly, Sinche, & Nicolaidis, 2015). Families may also benefit from information on how to navigate their health care system, early intervention, and school services (Moody et al., 2019). To increase family satisfaction, it may also be beneficial to include and involve families in the treatment planning (Wainer et al., 2017) and to include culturally informed interventions (Lopez, Magaña, Morales, & Iland, 2019). Moreover, families may find it helpful to participate in interventions designed to address their own difficulties when raising a child with ASD (Mirza, Krischer, Stolley, Magaña, & Martin, 2018). Finally, with families from rural areas, it might be valuable to include telehealth services to provide services that they otherwise would not have access to (Hepburn, Blakeley-Smith, Wolff, & Reaven, 2016; Ingersoll, & Berger, 2015; Lindgren et al., 2016; Vismara, McCormick, Young, Nadhan, & Monlux, 2013; Wacker et al., 2013).

In both the clinical and school settings, family support resources will be accessible to all families. In the school setting specifically, schools will have resources such as family liaisons and parent organizations, however, the focus on supporting CLD families will vary by school and district. School districts are legally mandated to provide a family advocacy office where families can receive educational advocacy support. If a child has an educational identification of Autism, the family can also access state legal advocacy resources through federally mandated offices. Although these resources exist, research surrounding the effectiveness of these resources with CLD families is not currently available.

In the clinical/community setting, families have additional opportunities for resources by accessing parent training programs. Parent training programs are effective for families of children with ASD to reduce caregiver mental health concerns, improve family knowledge of ASD, and increase caregiver self-advocacy (Matson, Mahan & Matson, 2009; McConachie & Diggle, 2007; Matson et al., 2009). For example, Magaña et al. (2017) found that Spanish-speaking Latinx mothers of children with ASD that participated in a parent training program reported improvements in understanding of ASD, awareness of their child's strengths and needs, knowledge of their child's rights, support systems, access within the community, and efficacy of evidence-based strategy implementation. In addition, children with ASD had reduced impaired language between pre- and post-test (Magaña, Lopez, & Machalicek, 2017).

One specific example of an evidence-based parent training program is the Parents Taking Action (PTA) program by Magaña et al. (2017). This parent training program was created for Spanish-speaking families to address disparities for Latinx children with ASD. The researchers utilized the ecological validity model to adapt and develop their materials in the PTA program (Bernal, Bonilla & Bellido, 1995). In this model, there are eight cultural domains that are considered when creating interventions, not only for interventions for ASD. These include language, persons, metaphors, content, concepts, goals, methods, and context. This model can be of assistance when professionals would like to evaluate, modify, or align existing evidence-based interventions within culturally or linguistically diverse populations. Magaña et al.

(2017) found various positive effects of the PTA program not only within the families, but also the ASD symptoms of the children.

Magaña et al. (2017) found that the use of promotoras was essential to the change reported by Spanish-speaking parents enrolled in the parent training program. Promotoras, also known as promotores de salud, is the Spanish term for "community health worker." Promotoras are typically employed in clinical settings such as hospitals and agencies, and are sometimes referred to as family navigators. The focus of the promotoras is to work within a Spanish-speaking community as a lay health worker, disseminating resources to families. This resource can be provided at a low cost and, by definition, will provide culturally and linguistically responsive support (Rotheram-Borus, Swendeman, & Chorpita, 2012).

Questions to Consider When Conducting ASD Intervention with CLD Populations

The following questions are presented to aid professionals in utilizing culturally and linguistically responsive ASD intervention practices.

(1) Serve as an advocate. Does the family have knowledge of ASD, ASD service providers, and agencies/institutions for ASD services? Are there parent training programs? Promotoras? If not, can you utilize telehealth services to access these resources?
(2) What does the family desire for their child's current interventions and future outcomes?
(3) What are language considerations of the family? Is an interpreter or translator required? Are materials needed in the native language?
(4) In what ways are school and clinical intervention service providers collaborating? What are the barriers to effective collaboration? How can this collaboration be improved?

Interpretation and Translation Services

Interpretation and translation services are required in both medical and school settings, although to varying degrees. Interpretation refers to oral communication, and translation refers to written communication. While there are multiple laws that ensure proper interpretation and translation services in the medical setting, few laws pertaining to these services exist in the school setting. If a family requires interpretation or translation services under IDEA services (also known as special education services) in the school setting, these services are provided by the school district. However, schools generally use their discretion regarding the use of interpretation/translation services at other times outside of IDEA services (e.g., parent–teacher conferences, parent association meetings). In the medical setting, interpretation requires more specific coursework and certification; interpretation in the school setting requires the certification of the school district, and district practices vary extensively.

Professionals will likely utilize interpreters for family interviews and multidisciplinary meetings. It is recommended that professionals hold a pre-meeting with the interpreter to plan for the session and discuss technical words that may be challenging to interpret. In addition, discussions around the manner of interpretation are important. For example, some interpreters use simultaneous interpretation while other models will require the speaker to pause and allow for time for interpretation. Professionals should note that the direct interpretation of standardized assessments into other languages voids standardization and is not recommended by professional associations (American Educational Research Association, 2014).

Discussion

Disparities in ASD services by CLD children and families exist, and ultimately contribute to poorer outcomes. Interdisciplinary collaboration can increase cultural and linguistic responsiveness of ASD services. When practitioners are trying to rule out the difference from disability, it is important that substantial data is collected in a culturally and linguistically responsive manner, multiple perspectives are considered and various professionals and family members are involved.

Currently, evidence-based ASD identification practices exist, although have not been comprehensively researched within culturally and linguistically diverse populations. Thus, professionals have the responsibility of considering the impact of culture and language throughout their evaluation and to interpret their data with caution due to potential biases. Partnering with families in the assessment process cannot be understated, as cultural and linguistic factors must be considered throughout the evaluation. Professionals must also consider when it is appropriate to report standardized scores and how the lack of standardized measures for CLD children and families may influence assessment data. Assessment data should be compiled comprehensively with a team, and with the intention of supporting family, child and school intervention goals.

While there is more emerging research pertaining to ASD intervention practices within CLD families, there continues to be a disproportionate amount of ASD research on non-White children and families. This limits the ability of professionals to identify evidence-based practices with the families and children they serve, likely impacting appropriate service allocation. Some promising practices exist, such as the use of promotoras and parent training programs, although this research is emerging and includes small segments of CLD families. Ultimately, professionals have limited research regarding potential cultural or linguistic influences on the performance of all interventions deemed evidence-based for treating ASD.

As disparities occur in both school and clinical settings among CLD children, the collaboration between settings can potentially improve disparities and the outcomes of children with ASD. Future research should focus on innovative ways to collaborate between settings to aid in timelier ASD identification and service allocation. Furthermore, training programs and professional development that is designed to be collaborative and completed in multidisciplinary teams can also be beneficial. Ultimately, it is critical that all professionals serve first and foremost as advocates so that all children can access appropriate and individually tailored services. Both clinical and school settings serve important roles in this process, and should be viewed as complementary.

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