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Race, Culture, and Autism Spectrum Disorder: Understanding the Role of Diversity in Successful Educational Interventions

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The reported prevalence of autism spectrum disorder (ASD) has increased dramatically since the 1980s. In response, researchers, educators, and policy makers have sought to develop effective technologies for assessment and intervention. A focus on evidenced-based practices is logical, given significant deficits in language, social interaction, cognition, and adaptive behavior that comprise these conditions. Although critical, a technology of best practices is insufficient without understanding the important role that diversity plays in helping persons with ASD, particularly those with the most severe impairments, to lead fulfilling lives. The aim of the current article is threefold. First, we explore the concept of diversity with particular attention to neurodiversity among persons with ASD. We describe how cultural and linguistic diversity influence identification of students with ASD in special education, with data to suggest that racially diverse students are underrepresented in the autism category. We then examine the educational process with particular focus on the impact of parent and family culture on perception of disability, the influence of diverse family systems on interventions, and the successful interventions for diverse contexts. We conclude with recommendations for culturally competent practice and research.

DESCRIPTORS: autism spectrum disorder, diversity, disproportionate representation, administrative preference

Autism spectrum disorder (ASD) is believed to affect children equally, regardless of culture, community, language, and socioeconomic status (Fombonne, 2007). However, as the proportion of culturally and linguistically diverse (CLD) families rises (U.S. Census Bureau, 2007), educators must be prepared to work with children of backgrounds that differ substantially from their own. Further-

more, practitioners, researchers, and policy makers must understand factors that contribute to the disproportionate representation of students from diverse backgrounds in special education. Although existing research examines these issues, the literature predominantly deals with high-incidence disabilities (e.g., learning disability, emotional or behavioral disorders; Artiles, 2003; Artiles & Bal, 2008; Artiles, Rueda, Salazar, & Higuera, 2005; Donovan & Cross, 2002; Harry & Klingner, 2006).

The purpose of this article was to provide direction for a field that has only recently begun to explore the significance of diversity in ASD (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Rogers-Adkinson, Ochoa, & Delgado, 2003; Welterlin & LaRue, 2007). Although much attention has been given to multicultural perspectives in special education (Donovan & Cross, 2002), there is a paucity of research on the impact of cultural and linguistic diversity on students with ASD and their families. We rely on the literature specific to ASD as well as the larger research base dealing with diversity issues in special education (a) to offer guidance for the field regarding practice issues and (b) to stimulate further discussion and scientific examination of diversity issues in ASD. Specifically, we explore the recent movement to recognize individuals with ASD as neurologically diverse rather than disabled. In addition, we explore how race or ethnicity influences special education eligibility under the autism category. We further examine cultural differences in perception of disability, the variable nature of family systems, and the development of interventions for diverse learners with ASD. We conclude with recommendations for culturally competent research and practice.

Neurodiversity in ASD

The cliché that “no two people are alike” certainly holds true when applied to individuals on the autism spectrum. In the earliest accounts, Kanner (1943) and Asperger

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(1991/1944) noted both similarities and dramatic differences among children with these conditions. For example, some children with ASD are highly verbal and conversationally engaging whereas others do not speak. The heterogeneity of characteristics in ASD may help to explain why these conditions are often not recognized until two or more years after the initial signs appear (Filipek et al., 2000; Perry, 2004). In recent decades, the term ASD has evolved to encompass these differences and to acknowledge the individuality of persons with ASD.

ASD is characterized as a clinical condition with deficits in social interaction and language and repetitive or stereotyped behaviors (American Psychological Association, 2000). That is to say, persons with ASD have been primarily defined in the negative in terms of both their deficits and the resulting of impacts on educational, social, and adaptive functioning. The deficit-based understanding has spawned much “cause and cure” research aimed at identifying the etiology of the disorders for developing treatments and, ultimately, for preventing the occurrence of ASD (Dawson, 2008). The “cause and cure” approach has been questioned, however, as it neglects the important role of educational and behavioral supports in empowering individuals with ASD to lead fulfilling lives (Carr, 2007).

Recently the term *neurodiversity* has evolved to counter the conception of persons with ASD as intrinsically flawed (Fenton & Krahn, 2007). Neurodiversity is an increasingly significant component of diversity as more individuals on the spectrum classify themselves as neurodiverse as opposed to disabled (Bumiller, 2008). The movement for neuroequality questions the clinical approach to defining ASD as a pathology and challenges social institutions that rank persons with ASD according to a hierarchy defined by so-called *neurotypical persons*. Rather, the spectrum of behaviors that define ASD is viewed as part of the normal continuum of human functioning. From this point of view, individuals with ASD are not flawed but simply different. Neurodiversity advocates stress that understanding the strengths and preferences of persons with ASD helps them to navigate the world. The autobiographical accounts of successful adults with high-functioning autism such as Temple Grandin (1996) and Steven Shore (2003) illustrate how qualities that were perceived to be deficits can actually be strengths.

As we acknowledge the significance of neurodiversity among persons with ASD, we must also recognize that many individuals are in need of substantial educational and behavioral supports. Providing evidence-based, intensive interventions, particularly with young children, is not tantamount to coercion or suppressing of individual personalities (cf. Baker, 2006). For instance, Temple Grandin’s (1996) account of her early life with autism highlights the importance of structured teaching and repetitive therapy to promote social interaction and speech. Indeed, such intensive interventions are often necessary for children with ASD to achieve their true potentials.

Strength-based assessment (SBA; Cosden, Koegel, Koegel, Greenwell, & Klein, 2006) is an alternative to the deficit-based understanding of ASD that complements the neurodiversity perspective. SBA seeks to highlight positive qualities of individuals with ASD and incorporate those qualities into potential support strategies. To illustrate, a traditional assessment of a young child with autism might include negative statements about his lack of speech, problem behavior, and desire to be alone. Alternatively, SBA describes the child’s positive qualities, such as his preferred items (e.g., balloons, raisins), emerging communication abilities (e.g., uses gestures and single words), and other skills (e.g., able to follow a schedule). The latter approach provides a positive outlook for parents and affords the educational team valuable insights on intervention strategies. Similar, it is logical to consider the strengths of the family system and how these can support educational strategies. For example, siblings can play a crucial role in implementing behavioral and social skills interventions (Dodd, Hupp, Jewell, & Krohn, 2008), and grandparents can provide valuable practical and emotional support for families (Trute, 2003).

Underrepresentation of Students With ASD in Special Education

Disproportionate representation describes the over- or underidentification of students from a particular racial or ethnic group within a category of special education (Artiles & Bal, 2008). Culturally diverse students have historically been overrepresented in high-incidence disability categories of special education (Dunn, 1968; Kauffman, Hallahan, & Ford, 1998; Oswald & Coutinho, 2001; Trent & Artiles, 1995), and recent examinations of African American, Hispanic, and American Indian/Alaskan Native students indicate that disproportionate representation continues (Donovan & Cross, 2002; Oswald & Coutinho, 2001). For example, African American and American Indian/Alaskan Native students have recently been overrepresented in the categories of emotional disturbance (ED) and intellectual disability (ID; Oswald & Coutinho, 2001). Regions in the United States with larger Hispanic populations have tended to have disproportionately higher percentages of Hispanic students in the ED and ID disability categories as well (Artiles et al., 2005; Donovan & Cross, 2002; Oswald & Coutinho, 2001). Speculative causes for overrepresentation of students from diverse backgrounds align with social injustices such as institutional racism and poverty (Artiles, 2003). In contrast, the disproportionate representation of students with low-incidence disabilities, including ASD, has received less attention.

Although early theorists believed that ASD occurred more frequently in White upper middle class families (cf. Bettelheim, 1967), current epidemiological evidence indicates that the prevalence of ASD is the same regardless of race, ethnicity, or country of origin (Fombonne, 2007).

Despite the apparent uniformity of ASD across groups, there are emerging data to suggest that ASD is under-identified in racially and ethnically diverse children. Mandell, Listerud, Levy, and Pinto-Martin (2002) examined a group of 406 children with the autism diagnosis receiving Medicaid services in Philadelphia, finding that African American children received their diagnosis, on average, a year and a half later than White children. They noted that African American children required three times the number of visits over a period three times as long as White children before being diagnosed. Similarly, Mandell et al. (2009) analyzed a sample of 2,568 8-year-old children identified through the U.S. Center for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) network, finding that children who were African American, Hispanic, or of other race or ethnicity were less likely to have been documented as having an ASD than were White children.

One implication of delayed diagnosis and under-identification is that children will not be provided with appropriate special education services in a timely manner. The National Research Council, charged with examining the extent of disproportionate representation of minority students in special education, included an analysis of students eligible for special education services in the autism category (Donovan & Cross, 2002). Using the 1998 data from the Office of Special Education Programs and the Office of Civil Rights to calculate odds ratios (ORs) representing the likelihood of eligibility for special education relative to White students, they found that Asian/Pacific Islander and African American students were overrepresented in autism (OR = 1.17 and 1.21, respectively), whereas Hispanic and American Indian/Alaskan Native students were underrepresented (OR = 0.67 and 0.58, respectively). These data partially corroborate the findings of Mandell et al. (2002, 2009) in that Hispanic and American Indian/Alaskan Native students were less likely to be identified with autism, although the findings of Mandell et al. indicated an underidentification of ASD in African American children as well, which counters the findings of Donovan and Cross (2002).

The reported prevalence of ASD has risen substantially in the last decade. Therefore, to explore the issue of disproportionate representation of students with ASD

using more recent figures, we examined 2006–2007 data on the number of students classified as having autism and other disabilities in the 50 U.S. states and Washington DC by race or ethnicity as reported in the 28th Individuals with Disabilities Education Improvement Act (IDEA) Report to Congress in relation to the National Center for Education Statistics enrollment figures for all students by race or ethnicity. Oswald and Coutinho's (2001) formula was used to calculate OR for placement of minority students in special education across disability categories (see Figure 1). The IDEA data covered students ages 6–21 years, whereas the National Center for Education Statistics data covered students in grades K–12; therefore, similar to Dyches et al. (2004), an adjustment was made to the number of students with autism and other disabilities in each ethnic group to account for differences in age ranges between data sets. Thus, the number of minority students from the IDEA Report was multiplied by 13/16 (.8125); the proportion of minority students within each category was then divided by the proportion of White students in the same category to determine OR.

Table 1 shows OR for students by race or ethnicity and disability category. Consistent with previous findings (Donovan & Cross, 2002; Oswald & Coutinho, 2001), African American, American Indian/Alaskan Native, and Hispanic students were overrepresented in the high-incidence MR and LD categories, whereas Asian/Pacific Islander students were underrepresented in these categories. Similarly, African American and American Indian/Alaskan students were overrepresented in ED, whereas Asian/Pacific Islander and Hispanic students were underrepresented in ED.

Strikingly, African American, American Indian/Alaskan Native, and Hispanic students were substantially underrepresented in the autism category (OR = 0.70, 0.49, and 0.47, respectively), whereas Asian/Pacific Islander students were represented more proportionately (OR = 0.94). Mandell et al. (2009), who calculated ORs for the presence of documented autism in 8-year-old minority children through the CDC's ADDM network, also found underidentification of autism in African American children (OR = 0.79) and Hispanic children (OR = 0.76; they did not calculate separate ORs for American Indian/Alaskan Native or Asian/Pacific Islander children). Although Mandell et al. used a different procedure to determine

$$\text{Odds Ratio} = \frac{\begin{array}{l} \# \text{ of students of X ethnicity with autism or other disability} \times (.8125) / \\ \# \text{ of students of X ethnicity in entire student population} \end{array}}{\begin{array}{l} \# \text{ of White students with autism or other disability} \times (.8125) / \\ \# \text{ of White students in entire student population} \end{array}}$$

Note: .8125 was used to adjust the IDEA data set for comparable analysis with NCES enrollment data.

Figure 1. Formula for calculating odds ratio of minority to White students in autism and other disability categories.

Table 1
OR for Disability According to Ethnicity from the 2006 to 2007 IDEA and the National Center
for Education Statistics Enrollment Figures

Ethnicity	Disability category								
	Autism	Mental Retardation	Specific Learning Disabilities	Emotional Disturbance	Multiple Disabilities	Hearing Impairments	Orthopedic Impairments	Speech or Language Impairments	Other Health Impairments
African American	0.70	2.17	1.24	1.66	1.12	0.98	0.82	0.82	0.82
American Indian/ Alaskan Native	0.49	1.12	1.35	1.19	1.02	1.06	0.75	1.24	0.79
Asian/ Pacific Islander	0.94	0.51	0.37	0.23	0.53	1.09	0.71	0.60	0.26
Hispanic	0.47	0.78	1.07	0.53	0.59	1.14	0.96	0.77	0.39

Note. OR = odds ratio; IDEA = Individuals with Disabilities Education Improvement Act.

OR and did not focus on educational classification of autism (i.e., administrative preference); specifically, the similarity in findings highlights the possibility of a relationship between delayed identification of ASD and delayed provision of special education services among minority populations.

Aggregated data in the current analysis do not permit evaluation of variables that mediate underrepresentation of diverse students in the autism category of special education. Moreover, the data should be interpreted with caution because they represent a comparison of two different data sets, one representing an age grouping of students with disabilities from 6 to 21 years old and the other representing a grouping of all students by grades K-12 (see also Donovan & Cross, 2002, p. 39). None the less, several potential factors bear consideration in the apparent underrepresentation of African American, American Indian/Alaskan Native, and Hispanic students in the autism category.

Although autism can be reliably diagnosed in children 2 years of age or younger (Filipek et al., 2000), African Americans have decreased access to quality health care, and their children experience larger intervals between pediatric appointments (Flores, Bauchner, Feinstein, & Nguyen, 1999; Mandell & Novak, 2005). Thus, effective screening for ASD and referral to local agencies are less probable. Even when they do have access to health care services, it may take longer before they receive an appropriate diagnosis (Mandell et al., 2002). Impoverished African Americans parents often send their children to dilapidated schools with less experienced teachers and are less involved in neighborhood school activities (Evans, 2004), including those that might facilitate parents' awareness of ASD. It is possible that these factors act as barriers to an autism eligibility determination. American Indians may also have limited access to adequate health care (Utley & Obiakor, 2001), contributing to delayed identification among the American Indian/Alaskan Native stu-

dent population. Geographical location, unique and distinct tribal beliefs about disability, poverty, and the historical impact of large-scale economic and political oppression may also influence delayed identification. The mental health and health care literature has frequently reported racial and ethnic disparities in access to and provision of mental and other health care by Hispanic individuals (Gudino, Lau, Yeh, McCabe, & Hough, 2009; Kataoka, Stein, Nadeem, & Wong, 2007; Padilla, Radey, Hummer, & Kim, 2006). Factors associated with these disparities include poverty, lowered levels of education, lowered levels of employment (Padilla et al., 2006), fear of deportation by undocumented immigrants (Bowden, Rhodes, Wilkin, & Jolly, 2006), and migratory patterns (Smith & Weinman, 1995). These may, in turn, preclude timely evaluations for autism and related developmental disorders and subsequent referral for services in this population.

Importantly, the factors responsible for underrepresentation of diverse students with ASD in special education are speculative. More research is needed to explore variables that mediate both identification and timely provision of services across diverse groups, particularly given contradictory findings (cf. Donovan & Cross, 2002). Still, as the signs of ASD are often present in young children before entering the educational system, parents play a crucial role in the timely identification of ASD. Moreover, the substantial literature on parent involvement in the intervention process, described next, highlights the critical role of diverse families in shaping successful interventions. As we will see, significant gaps in our understanding of diversity are apparent as we navigate the literature on parent and family involvement.

Parent and Family Involvement and Diversity

IDEA 2004 and its previous versions stipulate that parents have a primary role in shaping educational programs for students with disabilities. Parent participation has been

identified as necessary for successful inclusion of students with severe disabilities (Hunt & Goetz, 1997), and parent implementation of behavioral interventions is a critical variable that mediates positive outcomes (Dunlap, Newton, Fox, Benito, & Vaughn, 2001). The importance of parent involvement is apparent from myriad books and instructional materials that target parents and from well-publicized accounts of parents' experiences as advocates for their children with ASD (e.g., Maurice, 1993). Collectively, "families are the most committed, enduring, and knowledgeable source of personal support available for their children" (Dunlap et al., 2001, p. 215). Yet the literature reveals key differences in CLD parents' perception of ASD, the composition of their family systems, and the nature of successful educational and behavioral interventions for these children.

Perception of Disability

There is evidence to suggest that parents' culture plays a prominent role in interpreting the nature of their child's disability. For instance, Bishop, Richler, Cain, and Lord (2007) found that African American mothers reported lower levels of perceived negative impact of having a child with ASD than did Caucasian mothers. A possible implication of this finding is that some African American parents view their children's impairments differently on the basis of their cultural beliefs. Similar, Rogers-Adkinson et al. (2003) propose that parents from Puerto Rican, Mexican, and Columbian cultures with strong religious and spiritual beliefs are more accepting of their children's limitations. They suggest that educators may misinterpret parents as resisting their child's educational progress, when in fact they are questioning the very nature of the student's disability. Indeed, non-Western cultures tend to have varying definitions of conditions such as ASD that do not conform to the strict clinical definitions adhered to within the dominant cultures of U.S. and European countries (Welterlin & LaRue, 2007). Labels such as autism and intellectual or severe disability may not exist in the parent's native culture. In immigrant cultures where education is highly valued and seen as the primary means for economic advancement, a disability may be misinterpreted as a lack of cooperation rather than a genuine impairment of the child (Huer, Saenz, & Doan, 2001). Consequently, parents may be less likely to seek services, provide input during the educational process, and assist in the implementation of interventions. Indeed, these factors may also contribute to delayed identification of ASD and timely provision of services previously discussed (see also Mandell & Novak, 2005).

Unfortunately, educators may be inclined to dismiss differing views toward disability as evidence that families are "in denial" about their child's condition (Rogers-Adkinson et al., 2003) or are simply unwilling to participate in their child's education. For educators, a more fruitful approach would be to involve the family fully in the special education process with thoughtful considera-

tion of culturally defined preferences and strengths. Full consideration of diverse family systems may in fact be central to developing successful interventions.

Family Systems

In addition to differences in perception, parents may have varying approaches to child rearing on the basis of their cultural backgrounds. Zhang (2005) found differences in how Asian, African American, and immigrant parents encouraged self-determination (as defined by Western cultures) in comparison with nonimmigrant parents from Anglo cultures. For instance, children from Caucasian and nonimmigrant families were reported to participate more in household chores and interacting with salespeople in their daily lives, indicating less emphasis on the importance of self-determination within some culturally diverse families. Interestingly, parents of children with disabilities were less likely to involve their children in choice making than parents of children without disabilities, irrespective of culture.

In a qualitative study of 20 culturally diverse family members of children with ASD and developmental disabilities who displayed chronic challenging behavior, Fox, Vaughn, Wyatt, and Dunlap (2002) found that problem behaviors had a pervasive impact on families' functioning. They noted difficulties in parents' coming to terms with their child's disability and coping with the constant demands of challenging behavior on family relationships, physical circumstances, social networks, and daily activities. Dyches et al. (2004) highlighted the varying ways in which culture influences families' appraisal of disability and response to the stress of raising a child with ASD. The support of extended family systems and caring professionals appears to be crucial for diverse families to negotiate the demands of supporting a child on the autism spectrum (Dyches et al.; Fox et al., 2002).

Importantly, families' culture shapes their beliefs with regard to what constitutes best outcomes of intervention. Goals such as increased independence and enhanced self-determination reflect Western beliefs about autonomy and freedom as optimal states of being (Welterlin & LaRue, 2007). Educators may take for granted that parents place value on an outcome such as the child's inclusion in general education, when it is in fact a relatively low-ranking goal in comparison with, for example, academic achievement (Huer et al., 2001).

The unique nature of family systems coupled with varying economic, social, and cultural influences makes it difficult to draw general conclusions about how best to support diverse families of children with ASD. Given the neurodiverse nature of individuals on the spectrum and the myriad cultural and linguistic contexts from which they emerge, educators must caution against making generalizations about students on the basis of preconceptions. This is especially so considering the dearth of research on the role of mediating variables, including those related to the family, on intervention outcomes for

children with ASD (National Research Council, 2001; Wolery & Garfinkle, 2002). Although traditional didactic models of parent training have yielded fruitful outcomes on specific target responses (Matson, Mahan, & LoVullo, 2009), less is known about how parents' cultural and linguistic background affect these outcomes. Next, we explore the influences of language and culture on the development of specific interventions for diverse learners with ASD with recommendations for educators.

Interventions for Diverse Learners and Families

Many evidence-based practices have evolved to teach children with ASD new skills. Interventions to address communication are quite prevalent (Simpson et al., 2005), as this is a core deficit of the disorder (American Psychiatric Association, 2000). Augmentative and alternative communication (AAC) systems help individuals who cannot talk to communicate functionally through sign language, pictures, and voice output devices (Mirenda, 2003). Although English is the language of instruction most frequently employed by educators, children of immigrant families may speak a second language at home or live with family members who lack English language proficiency. Thus, a key problem for educators is how to incorporate students' native languages into their AAC systems to promote proficiency in home, school, and community environments.

To date, there has been little research examining the effects of AAC systems with second language learners. Despite strong evidence to support the efficacy of AAC systems in promoting functional communication and collateral behaviors, such as speech (Mirenda, 2003; Sulzer-Azaroff, Hoffman, Horton, Bondy, & Frost, 2009), there is little literature to guide professionals responsible for selecting or adapting these systems for students who communicate in more than one language or who communicate with those who lack English proficiency. For instance, one study indicates that nonnative English speakers have more difficulty than native English speakers understanding synthesized English speech transmitted from a voice-output device (Alamsaputra, Kohnert, Munson, & Reichle, 2006). In practice, if a family member lacks sufficient second language proficiency to understand a child's initiations with a voice-output device, the educational team could consider another system (e.g., picture based) or adapt the system to meet the language needs of the family (e.g., simplify or teach vocabulary). This is one of many potential ways in which the family's cultural and linguistic context influences intervention, yet empirical evidence to support best practice in these situations is lacking.

The unique attributes of persons with ASD, their dynamic family systems, and their unique cultural and linguistic contexts underscores the importance of parent and family involvement in the development of interventions. Family-centered positive behavior support (PBS) is an exemplar of an approach that is sensitive to these vari-

ables (Dunlap et al., 2001; Lucyshyn, Albin, & Nixon, 1997; Vaughn, White, Johnston, & Dunlap, 2005; Vaughn, Wilson, & Dunlap, 2002). Contextual fit is the tailoring of interventions to match the individual, the implementers, and the setting (Albin, Luchyshyn, Horner, & Flannery, 1996) and is central to family-centered PBS. Characteristics of family-centered PBS include consideration of (a) how problem behavior impacts the focus person's and family's quality of life, (b) the capacity of family members to support interventions, and (c) the impact of the intervention on natural routines and situations.

Vaughn et al. (2002) demonstrated the effects of family-centered PBS with Tolu, a boy with ASD and severe intellectual disabilities whose parents emigrated from Nigeria to the United States. Tolu displayed chronic challenging behavior that substantially impacted the family's daily routines. The authors worked with Tolu's mother to identify a daily routine in which challenging behavior was particularly a barrier to the family's quality of life—eating a meal in a fast-food restaurant. Next, they conducted a functional assessment to identify aspects of the routine that provoked Tolu's challenging behavior and then collaborated with his mother to develop reinforcement-based interventions that she could implement to reduce his problem behavior and to increase his task engagement. The intervention increased Tolu's prosocial behavior and positive adult interactions in the restaurant, illustrating how active family involvement in behavioral intervention enhances successful outcomes for diverse families.

Recommendations for Practice

There is limited research on the impact of cultural and linguistic diversity on the development of effective educational programs for students with ASD. We make the following recommendations for culturally competent practice on the basis of our emerging knowledge of critical issues affecting children and families.

1. Conduct SBA. Intervention should proceed from an SBA (Cosden et al., 2006) of the child and the family. SBA should include affirmative statements of the child's preferences and skills and critical features of the family system—for example, assistance from grandparents (Trute, 2003)—that support interventions. SBA can detail the child's preferences, emerging communication and other skills, and specific ways that extended family members can support interventions.
2. Consider parents' perception of disability. CLD parents may interpret their child's disability from a non-Western perspective (Bishop et al., 2007; Huer et al., 2001; Rogers-Adkinson et al., 2003; Welterlin & LaRue, 2007). Moreover, some parents may identify with a neurodiverse perspective, viewing their child's ASD as a different state of being rather than a problem in need of repair. Parents may be more

accepting of their child's disability than professionals or may otherwise view the child's impairment differently on the basis of their unique cultural background. Further, educators may take for granted that parents have awareness of Western clinical and educational disability categories. Therefore, it is critical to evaluate parents' perceptions and awareness of their child's ASD. Professionals can

- assess parents' knowledge and awareness of the clinical features of ASD as a disability category with open-ended questions (e.g., "What were your experiences with autism in your home country?" "How does autism affect your son/daughter?"),
 - provide an overview of the educational characteristics of students with ASD, highlighting the relationship of these characteristics to educational goals,
 - evaluate parents' short- and long-term goals for intervention to understand what outcomes are valued by the family and the culture.
3. Consider ASD in the context of the family system. The impact of a severe disability on the family system is pervasive (Fox et al., 2002). Understanding how the child's ASD interacts with the family's routines, resources, and values helps to guide intervention (Vaughn et al., 2002, 2005). To gain this understanding, professionals should
- ask questions to evaluate parents' views of their child's disability and how it (ASD) impacts family functioning (e.g., "What routines does the family do on a daily basis?" "How, if at all, does your child's ASD affect your daily routines?"),
 - evaluate the family's resources and stressors as they affect their ability to support intervention; for example, one parent's long work hours might preclude direct involvement in interventions whereas another parent functions as the primary caretaker and thus can implement intervention,
 - maintain reasonable expectations for the family's capacity to support interventions.
4. Fully involve the family in the intervention process. The family's active involvement is necessary for interventions to have a good contextual fit (Albin et al., 1996). Consequently, the team must recognize that parents possess differing capacities to support intervention and their input should not be devalued because they are unable or unwilling to implement procedures in the home and community (Vaughn et al., 2005). Full involvement means
- conducting person-centered planning to identify intervention goals of critical importance to the student and stakeholders,

- seeking the family's input on the identification target behaviors that are important to the family's daily routines,
- developing interventions that family members can implement in the home and community with technical assistance from professionals,
- helping the family to create data-based systems for ongoing progress monitoring.

Implications for Research

The proportion of CLD families in the United States is increasing. Approximately one in three persons in the United States now represent a minority group, with Hispanics comprising the largest and fastest growing segment (U.S. Census Bureau, 2007). Our discussion reveals a need for future studies to explore the efficacy of strength-based approaches, the influence of cultural and linguistic diversity on identification of ASD and placement in special education, the inclusion and access to effective interventions among diverse students, and the interventions that work in the context of diverse family systems.

Strength-Based Approaches

SBA focuses on positive characteristics of individuals with ASD to develop effective interventions (Cosden et al., 2006). SBA and strength-based approaches seem particularly well suited to diverse populations as they capitalize on individuals' and family's inherent strengths regardless of racial, ethnic, or socioeconomic background. Preliminary research has explored the utility of SBA and strength-based interventions for individuals with high functioning autism, demonstrating promising results (Winter-Messiers et al., 2007); however, more studies are needed to develop specific strategies and techniques, particularly with individuals who have more severe levels of impairment.

Influence of CLD on Eligibility for Special Education

As we have seen, racial and ethnic diversity influences eligibility of children for special education. Preliminary evidence (Mandell et al., 2002, 2009), in tandem with our analysis, indicates that certain groups of minority children—those of African American, Hispanic, and American Indian/Alaskan Native lineage in particular—are less likely to be identified with and ASD or are less likely to be eligible for special education under the autism category. This finding is troubling as it suggests that substantial numbers of minority children are being denied appropriate (and often intensive) services that could remediate the deficits of ASD. Additional studies are needed (a) to verify the over- or underrepresentation of minority students in the autism category of IDEA, (b) to assess factors that contribute to disproportionate eligibility of minority students, and (c) to develop strategies for ensuring equitable eligibility practices. For example, given the

overrepresentation of African American students in the ID category of special education and the high prevalence of intellectual disabilities among persons with ASD, diagnostic substitution could contribute to misplacement of African American students with ASD in the ID category, which would indicate flaws in the eligibility process. If so, future studies could focus on refining special education assessment and referral procedures to facilitate valid assessments and appropriate placement.

Specific attention should focus on the process of non-discriminatory assessment to identify students with ASD. For instance, the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2002) is one of the most commonly used tools to diagnose students with ASD. Although research has explored the reliability and validity of the ADOS as applied across culturally and geographically diverse populations (e.g., Overton, Fielding, & de Alba, 2008; Papanikolaou et al., 2009), there is little guidance on how administration and interpretation of the ADOS, in addition to other common diagnostic tools, differs for children on the basis of CLD factors. Moreover, there is little guidance on how diagnosticians who are working with CLD families approach the task of diagnosis differently to ensure accurate and timely identification. These are particularly salient issues given the apparent delay in diagnosis among African American children with ASD and the underrepresentation of African American, American Indian/Alaskan Native, and Hispanic students with in the autism category.

Influence of CLD on Inclusion and Access to Effective Education

Artiles, Trent, and Palmer (2004) suggest that culturally diverse students are more likely to be placed in restrictive settings because of bias, discrimination, and systematic deficiencies in public education. In 2004, approximately 42% of all students served under the autism category of IDEA were educated outside regular education environments for at least 60% of their school day (U.S. Department of Education, 2008); thus, it seems likely that diverse students with ASD are particularly prone to exclusionary placements. Experts have called for more expansive national demographic data sets of special education populations, specifically data on ethnicity according to educational placement (Artiles, 2003; Donovan & Cross, 2002). Unfortunately, these data remain elusive. This omission prohibits state and local education agencies as well as researchers from understanding how racial or ethnic diversity relates to educational eligibility, thereby preventing the exploration of potential solutions and large-scale policy changes. We echo the calls by Artiles (2003) and Donovan and Cross (2002) and request a federal data set that includes educational placement according to ethnicity for each disability category, including ASD, to support the examination of potentially unjust educational practices beyond eligibility in special education.

Access to effective interventions is a related and pressing issue. IDEA 2004 and its previous versions call for a Free Appropriate Public Education for all students, including those with severe disabilities. Students with ASD often require intensive and costly interventions to achieve optimal therapeutic progress. Applied behavior analysis is a common intervention accessed by parents and families. Preliminary evidence indicates that socio-economic status and geographical region influence access to applied behavior analysis and other interventions (Baker, 2006), yet there are limited data on how families' cultural and ethnic diversity interacts with service delivery systems to mediate access. Given evidence to suggest that CLD children with ASD are diagnosed later than White children and that certain groups of minority children are less likely to be identified with ASD, research examining disparities in access to appropriate and effective interventions for ASD is also needed.

Family-Focused Interventions for Diverse Learners

Finally, our discussion highlights the varying ways in which families' culture influences interventions for children with ASD. Unfortunately, few studies have systematically examined how families' culture and ethnicity mediates successful outcomes or the effects of interventions that are responsive to diverse family systems. Family-centered PBS is one promising approach that has been validated within diverse settings (Dunlap et al., 2001; Lucyshyn et al., 1997; Vaughn et al., 2002, 2005), yet there is a need to expand beyond strategies for learners with severe challenging behavior to interventions that primarily focus on building communicative, social, and adaptive skills.

Conclusions

We have explored diversity issues as they relate to neurodiversity, identification of ASD, and support of CLD children and families. In examining the limited literature, it is clear that significantly more work is needed to ensure that students have access to high-quality services that yield positive outcomes and increased quality of life. We hope that our article will encourage further exploration of these critical issues and that the Office of Special Education Programs (2009) in the U.S. Department of Education will recognize the importance of providing current (and retrospective) data sets that will allow researchers to examine the extent of educational disparities, especially those that may indicate disproportionate, restrictive educational placement for minority students with ASD. Importantly, these data should not be limited to students with ASD or severe disabilities but should be provided for all disability categories under IDEA. Lastly, we encourage teacher educators and practitioners to actively explore and confront sensitive issues related to diversity. With in-depth, productive dialogue, ongoing reflection of personal beliefs about one's own culture, and continual learning about the culture of their students, practitioners can have

a more immediate positive impact on students with ASD and their families.

References

- Alamsaputra, D., Kohnert, K., Munson, B., & Reichle, J. (2006). Synthesized speech intelligibility among native speakers and non-native speakers of English. *Augmentative and Alternative Communication*, 22, 258–268.
- Albin, R. W., Luchyshyn, J. M., Horner, R. H., & Flannery, K. B. (1996). Contextual fit for behavioral support plans: A model for “goodness of fit.” In L. Koegel, R. Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community*. Baltimore: Paul H. Brookes.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders—Text revision* (4th ed.). Washington, DC: Author.
- Artiles, A. J. (2003). Special education’s changing identity: Paradoxes and dilemmas in views of culture and space. *Harvard Educational Review*, 73, 164–202.
- Artiles, A. J., & Bal, A. (2008). The next generation of disproportionality research: Toward a comparative model in the study of equity in ability differences. *Journal of Special Education*, 42, 4–14.
- Artiles, A. J., Rueda, R., Salazar, J. J., & Higareda, I. (2005). Within-group diversity in minority disproportionate representation: English language learners in urban school districts. *Exceptional Children*, 71, 283–300.
- Artiles, A. J., Trent, S. C., & Palmer, J. (2004). Culturally diverse students in special education: Legacies and prospects. In J. A. Banks & C. M. Banks (Eds.), *Handbook of research on multicultural education* (2nd ed., pp. 716–735). San Francisco: Jossey-Bass.
- Asperger, H. (1944). Die “autistischen Psychopathen” im Kindesalter. *Archiv für Psychiatrie und Nervenkrankheiten*, 117, 76–136. [Translated by U. Frith in U. Frith (Ed.) (1991). *Autism and Asperger syndrome* (pp. 36–92). Cambridge: Cambridge University Press].
- Baker, D. L. (2006). Neurodiversity, neurological disability and the public sector: Notes on the autism spectrum. *Disability & Society*, 21, 15–29.
- Bettelheim, B. (1967). *The empty fortress*. New York: Free Press.
- Bishop, S., Richler, J., Cain, A., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation*, 112, 450–461.
- Bowden, W., Rhodes, S., Wilkin, A., & Jolly, C. (2006). Socio-cultural determinants of HIV/AIDS risk and service use among immigrant Latinos in North Carolina. *Hispanic Journal of Behavioral Sciences*, 28, 546–562.
- Bumiller, K. (2008). Quirky citizens: Autism, gender, and re-imagining disability. *Signs*, 33, 967–991.
- Carr, E. (2007). The expanding vision of positive behavior support: Research perspectives on happiness, helpfulness, hopefulness. *Journal of Positive Behavior Interventions*, 9, 3–14.
- Cosden, M., Koegel, L., Koegel, R., Greenwell, A., & Klein, E. (2006). Strength-based assessment for children with autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, 31, 134–143.
- Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*, 20, 775–803.
- Dodd, S., Hupp, S., Jewell, J., & Krohn, E. (2008). Using parents and siblings during a social story intervention for two children diagnosed with PDD-NOS. *Journal of Developmental and Physical Disabilities*, 20, 217–229.
- Donovan, S., & Cross, C. (Eds.) (2002). *Minority students in special and gifted education*. Washington, DC: National Academy Press.
- Dunlap, G., Newton, J., Fox, L., Benito, N., & Vaughn, B. (2001). Family involvement in functional assessment and positive behavior support. *Focus on Autism and Other Developmental Disabilities*, 16, 215–221.
- Dunn, L. M. (1968). Special education for the mildly retarded: Is much of it justifiable? *Exceptional Children*, 35, 5–22.
- Dyches, T., Wilder, L., Sudweeks, R., Obiakor, F., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34, 211–222.
- Evans, G. W. (2004). The environment of childhood poverty. *American Psychologist*, 59, 77–92.
- Fenton, A., & Krahn, T. (2007). Autism, neurodiversity and equality beyond the “normal.” *Journal of Ethics in Mental Health*, 2, 1–6.
- Filipek, P. A., Accardo, P. J., Ashwal, S., Baranek, G. T., Cook, E. H., Dawson, G., et al. (2000). Practice parameter: Screening and diagnosis of autism. Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55, 468–479.
- Flores, G., Bauchner, H., Feinstein, A. R., & Nguyen, U. S. (1999). The impact of ethnicity, family income, and parental education on children’s health and use of health services. *American Journal of Public Health*, 89, 1066–1071.
- Fombonne, E. (2007). Epidemiological surveys of prevalence developmental disorders. In F. Volkmar (Ed.), *Autism and pervasive developmental disorders* (2nd ed., pp. 33–68). New York: Cambridge.
- Fox, L., Vaughn, B., Wyatt, M., & Dunlap, G. (2002). “We can’t expect other people to understand”: Family perspectives on problem behavior. *Exceptional Children*, 68, 437–450.
- Grandin, T. (1996). *Thinking in pictures: And other reports from my life with autism*. New York: Vintage.
- Gudino, O., Lau, A., Yeh, M., McCabe, K., & Hough, R. (2009). Understanding racial/ethnic disparities in youth mental health services: Do disparities vary by problem type? *Journal of Emotional and Behavioral Disorders*, 17, 3–16.
- Harry, B., & Klinger, J. (2006). *Why are so many minority students in special education?* New York: Teachers College Press.
- Huer, M., Saenz, T., & Doan, J. (2001). Understanding the Vietnamese American community: Implications for training educational personnel providing services to children with disabilities. *Communication Disorders Quarterly*, 23, 27–39.
- Hunt, P., & Goetz, L. (1997). Research on inclusive educational programs, practices, and outcomes for students with severe disabilities. *Journal of Special Education*, 31, 3–35.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kataoka, S., Stein, B., Nadeem, E., & Wong, M. (2007). Who gets care? Mental health service use following a school-based suicide prevention program. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46, 1341–1348.
- Kauffman, J. M., Hallahan, D. P., & Ford, D. Y. (1998). Introduction to the special section. *Journal of Special Education*, 32, 3.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2002). *Autism Diagnostic Observation Schedule*. Los Angeles: Western Psychological Services.
- Lucyshyn, J., Albin, R., & Nixon, C. (1997). Embedding comprehensive behavioral support in family ecology: An experimental, single case analysis. *Journal of Consulting and Clinical Psychology*, 65, 241–251.
- Mandell, D., & Novak, M. (2005). The role of culture in families’ treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11, 110–115.
- Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1447–1453.

- Mandell, D. S., Wiggins, L. D., Yeargin-Allsopp, M., Carpenter, L. A., Daniels, J., Thomas, K. C., et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*, 493–498.
- Matson, J., Mahan, S., & LoVullo, S. (2009). Parent training: A review of methods for children with developmental disabilities. *Research in Developmental Disabilities, 30*, 961–968.
- Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. New York: Ballentine.
- Mirenda, P. (2003). Toward functional augmentative and alternative communication for students with autism: Manual signs, graphic symbols, and voice output communication aids. *Language, Speech, and Hearing Services in Schools, 34*, 202–215.
- National Research Council. (2001). *Educating children with autism*. Washington, DC: National Academy Press.
- Office of Special Education Programs. (2009). *Students ages 6 through 21 served under IDEA: Part B. By disability category, educational environment and state: Fall 2007*. Retrieved July 12, 2009, from www.ideadata.org.
- Oswald, D. P., & Coutinho, M. J. (2001). Trends in disproportionate representation: Implications for multicultural education. In C. A. Utley & F. E. Obiakor (Eds.), *Special education, multicultural education and school reform: Components of quality education for learners with mild disabilities* (pp. 53–73). Springfield, IL: Charles C. Thomas.
- Overton, T., Fielding, C., & de Alba, R. (2008). Brief report: Exploratory analysis of the ADOS revised algorithm: Specificity and predictive value with Hispanic children referred for autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 1166–1169.
- Padilla, Y., Radey, M., Hummer, R., & Kim, E. (2006). The living conditions of U.S. born children of Mexican immigrants in unmarried families. *Hispanic Journal of Behavioral Sciences, 28*, 331–349.
- Papanikolaou, K., Paliokosta, E., Houliaras, G., Vgenopoulou, S., Giouroukou, E., Pehlivanidis, A., et al. (2009). Using the Autism Diagnostic Interview-Revised and the Autism Diagnostic Observation Schedule-Generic for the diagnosis of autism spectrum disorders in a Greek sample with a wide range of intellectual abilities. *Journal of Autism and Developmental Disorders, 39*, 414–420.
- Perry, R. (2004). Early diagnosis of Asperger's disorder: Lessons from a large clinical practice. *Journal of the American Academy of Child and Adolescent Psychiatry, 43*, 1445–1448.
- Rogers-Adkinson, D., Ochoa, T., & Delgado, B. (2003). Developing cross-cultural competence: Serving families of children with significant developmental needs. *Focus on Autism and Other Developmental Disabilities, 18*, 4–8.
- Shore, S. (2003). *Beyond the wall: Personal experiences with autism and Asperger Syndrome* (2nd ed.). Shawnee Mission, KS: Autism Asperger Publishing Company.
- Simpson, R., de Boer-Ott, S., Griswold, D., Myles, B., Byrd, S., Ganz, J., et al. (2005). *Autism spectrum disorders: Interventions and treatments for children and youth*. Thousand Oaks, CA: Corwin Press.
- Smith, P., & Weinman, M. (1995). Cultural implications for public health policy for pregnant Hispanic adolescents. *Health Values: The Journal of Health Behavior, Education & Promotion, 19*, 3–9.
- Sulzer-Azaroff, B., Hoffman, A., Horton, C., Bondy, A., & Frost, L. (2009). The Picture Exchange Communication System (PECS): What do the data say? *Focus on Autism and Other Developmental Disabilities, 24*, 89–103.
- Trent, S. C., & Artiles, A. J. (1995). Serving culturally diverse students with emotional or behavioral disorders: Broadening current perspectives. In J. M. Kauffman, J. W. Lloyd, D. P. Hallahan, & T. A. Astuto (Eds.), *Issues in educational placement: Students with emotional and behavioral disorders* (pp. 215–245). Hillsdale, NJ: Erlbaum.
- Trute, B. (2003). Grandparents of children with developmental disabilities: Intergenerational support and family well-being. *Families in Society, 84*, 119–126.
- U.S. Census Bureau. (2007, May 17). *Minority population tops 100 million*. U.S. Census Bureau News. Washington, DC: U.S. Department of Commerce.
- U.S. Department of Education. (2008). *28th Report to congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Author.
- Utley, C. A., & Obiakor, F. E. (2001). Multicultural education and special education: Infusion for better schooling. In C. A. Utley & F. E. Obiakor (Eds.), *Special education, multicultural education and school reform: Components of quality education for learners with mild disabilities* (pp. 53–73). Springfield, IL: Charles C. Thomas.
- Vaughn, B., White, R., Johnston, S., & Dunlap, G. (2005). Positive behavior support as a family-centered endeavor. *Journal of Positive Behavior Interventions, 7*, 55–58.
- Vaughn, B., Wilson, D., & Dunlap, G. (2002). Family-centered intervention to resolve problem behaviors in a fast-food restaurant. *Journal of Positive Behavior Interventions, 4*, 38–45.
- Welterlin, A., & LaRue, R. (2007). Serving the needs of immigrant families of children with autism. *Disability & Society, 22*, 747–760.
- Winter-Messiers, M. A., Herr, C. M., Wood, C. E., Brooks, A. P., Gates, M. A., Houston, T. L., et al. (2007). How far can Brian ride the Daylight 4449 Express? A strength-based model of Asperger syndrome based on special interest areas. *Focus on Autism and Other Developmental Disabilities, 22*, 67–79.
- Wolery, M., & Garfinkle, A. (2002). Measures in intervention research with young children who have autism. *Journal of Autism and Developmental Disorders, 32*, 463–478.
- Zhang, D. (2005). Parent practices in facilitating self-determination skills: The influences of culture, socioeconomic status, and children's special education status. *Research and Practice for Persons with Severe Disabilities, 30*, 154–162.

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