


# The Impact of Culture on Autism Diagnosis and Treatment: Considerations for Counselors and Other Professionals

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## Abstract

This article explores the impact of culture on families' perceptions of autism diagnosis and treatment. Competencies for counselors and other professionals that address the needs of children with autism and their families are presented. Therapeutic interventions, applications of technology, and strategies for responsive family-centered care and advocacy are highlighted.

## Keywords

autism, culture, diagnosis, technology, treatment

Autism is a complex neurological disorder that impedes or prevents effective verbal communication, effective social interaction, and appropriate behavior (American Psychiatric Association [APA], 2000). Autism is a spectrum of disorders that contains five diagnostic labels: Asperger's Syndrome, Rett's Disorder or Rett's Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Delay—Not Otherwise Specified, and Autistic Disorder or Classic Autism. Paul Eugen Bleuler, a Swiss psychiatrist, first used the term autism to describe the self-absorbed nature of adults with schizophrenia (Autism Epicenter, 2008-2011). More than 30 years passed before the work of two other researchers expanded the definition of autism. Leo Kanner used the term early infantile autism (in 1943) to describe children who displayed self-absorbed characteristics (The Alan Mason Chesney Medical Archives, 2009). In 1944, Hans Asperger noted the exceptional abilities of children he observed with autism (Long, 2007; The Alan Mason Chesney Medical Archives, 2009). It was once thought that individuals with Autism Spectrum Disorders (ASD) were consumed by their interests and preferred to operate in their own world. This is a misnomer; in recent years, it has been discovered that the autistic brain is less able to track relationships between self and others, and it struggles to process information about itself. So rather than being self-dominant, the person with ASD has difficulty engaging in social interaction because of the difficulty understanding and recognizing his or her thoughts and feelings as well as those of others (Lombardo et al., 2009).

According to the Center for Disease Control and Prevention (CDC, 2010), the number of children diagnosed with ASD is 1 in 110. This may be attributable to criteria broadly specified in the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, text revision (DSM-IV-TR; APA, 2000), increased awareness because of information dissemination through the

World Wide Web, and more or better reporting. The cause of ASD is still a mystery; researchers continue to explore biomedical, environmental, and genetic factors that may be responsible for this neurological disorder (Ratajczak, 2011).

## The Intersection of Culture and Autism

The decisions families make about autism diagnosis and treatment are directly influenced by the family's cultural background. Culture can be defined as "the values, beliefs, language, rituals, traditions, and other behaviors that are passed from one generation to another within any social group . . ." (Helms & Cook, 1999). This broad concept takes into account individual perspectives of culture, and the manner in which societal practices are sanctioned (Helms & Cook, 1999). It is culture that shapes individual and familial beliefs about disability in general, and autism in particular (Griffen, Peters, & Smith, 2007).

This article explores the impact of culture on families' perceptions of autism diagnosis and treatment for their children. The ways counselors and other professionals can effectively negotiate cultural milieus with children with autism, their

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families, and their communities are also examined. Cultural groups, with a focus toward racial and ethnic groups, are identified using broad descriptions. At present, these general descriptors appear to be the prevailing trend in the sparse autism and culture literature (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Mandell & Novak, 2005). Counselors and other professionals are reminded to treat reasonable generalizations about the groups discussed as “probabilities not certainties” as they consider various cultural characteristics (McAuliff & Associates, 2008, p. 25).

### **Cultural Perspectives on the Etiology of ASD**

The origin of autism is unknown; however, many diverse cultural groups have their own wisdom about the causes of the disorder. Though the why and how of autism are unknown, there are some certainties. Among these, autism is referred to as a spectrum of disorders that affects more males than females (Fombonne, 2005; Morrier, Hess, & Heflin, 2008). The defining characteristic of autism is impairment in social and communicative development; this factor makes ASD different from other neurodevelopmental conditions like mental retardation, learning disabilities, and language disorders (Bregman, 2005; Durand, 2005). The diagnosis of ASD is on the rise (CDC, 2010; Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Fountain, King, & Bearman, 2009). Autism is a life-long disorder that may have comorbid conditions like attention deficit disorder (ADD)/attention deficit/hyperactivity disorder (ADHD), anxiety disorder, stereotypical and self-stimulatory behaviors, insomnia, intellectual disabilities, obsessive compulsive disorder, seizure disorder/epilepsy, Tourette syndrome, Tic disorders, gastrointestinal problems, and other conditions (Bregman, 2005; Simonoff et al., 2008). Another certainty, there is no cure at this time.

Herbert and Koulouglioti (2010) reviewed the literature concerning parental beliefs about the etiology of autism. The authors discovered parents believe genetics, environmental factors, and events related to childbirth are contributing factors. Many anecdotal reports from parents supported the hypothesis that vaccinations were responsible for the development of autism in their children. Genetics, birth trauma, illnesses, heredity, perinatal damage, environment, or some combination of these is thought to cause the disorder (Gourdine, Baffour, & Teasley, 2011; Hughes, 2008). Many families believe that genetic factors are a significant cause of ASD in their children (Mercer, Creighton, Holden, & Lewis, 2006; Selkirk, Veach, Lian, Schimmenti, & LeRoy, 2009). Much more research is needed on diverse cultural groups and their genetic and biological makeup relative to a diagnosis of ASD; moreover, only a handful of studies have been conducted with non-Caucasians (Cuccaro et al., 2007; Dyches et al., 2004). When it comes to cultural perspectives on the etiology of autism, Pitten (2008) suggested Anglo Americans generally accept the concept of physicality and some believe that immunizations or other physical elements cause the disorder. African Americans generally believe that nontraditional issues like diet,

food processing, and contamination cause autism. Asian Americans tend to hold the perspective that autism and other disabilities are a punishment for violating a religious, ethical, or cultural code or disharmony between yin and yang forces (Danesco, 1997; Dyches et al., 2004). Some Latino mothers have a more favorable view of autism, believing it is a blessing or gift from God that will provide the mothers with the opportunity to become more useful and sacrifice a part of their life to serve another (Dyches et al., 2004; Wilder, Dyches, Obiakor, & Algozzine, 2004). Beliefs about the cause of autism or other developmental delays from a specific cultural perspective should be cautiously interpreted, because these beliefs vary among members within any given social group (Skinner, Correa, Skinner, & Bailey, 2001).

### ***Etiological Controversy and Autism***

The development of autism as a diagnosis has not been without great social and cultural debate. Mothers and childhood vaccines are two topics that have been researched as plausible causes for the disorder. A long-held belief about the cause of autism initially came from Kanner's term, “refrigerator mother,” and was later popularized by Dr. Bruno Bettelheim. Bettelheim's research blamed mothers for their children's difficulty speaking, atypical behavior, and rigid rituals. The “refrigerator mother” withheld affection and was emotionally frigid; her cold and detached behavior and inability to nurture her child were thought to cause autism (Autism Epicenter, 2008-2011). As time passed, Dr. Bettelheim's theory was refuted, because it relied too much on the belief that the parents of children with autism had perverse personality characteristics that had not been systematically observed (Schreibman, 2005).

The neurotoxin thimerosal (ethylmercury) has been examined as another cause of autism (CDC, 2010). In 1997, the passage of the Food and Drug Administration (FDA) Amendment Act of 1997 required the analysis of all food and drugs containing mercury compounds (Offit, 2007). The findings raised concern about the high levels of mercury children received from vaccines and as a result, the CDC and the American Academy of Pediatrics requested the removal of thimerosal from vaccines as a precautionary measure in 1999 (Offit, 2007). Though the controversy continues, empirical scientific studies have failed to provide credible evidence linking thimerosal and autism (CDC, 2010; Offit, 2007; Parker, Schwartz, Todd, & Pickering, 2004).

### ***Cultural Groups and a Diagnosis of ASD***

Regardless of the cause of autism, early intervention with evidence-based treatments is the most effective way to help individuals with autism learn skills that will increase the quality of their lives (Durand, 2005; Scott & Baldwin, 2005). In order to receive early intervention, an accurate diagnosis is essential for all cultural groups; the signs of a developmental delay must be recognized and investigated. Minority parents may view problems with or delays in language and social skills

as a temporary phenomenon which will be outgrown (Danesco, 1997). They may see delays in language/communication and social skills as a normal process their child encounters as he or she moves through developmental stages. As a result, they may not identify important but subtle cues for ASD (lack of pointing, lack of imitation, lack of eye contact, and a lack of socially appropriate behavior); instead, they may associate ASD with repetitive language, ritualistic behavior, and gross delays in motor skill development. The literature highlights age-related differences in the diagnosis of ASD across cultural groups. Researchers mention that White Americans are diagnosed earlier than ethnic minorities—usually 1.5 years before African Americans and other groups (Gibson, 2007; Mandell & Novak, 2005; Morrier et al., 2008; Tek & Landa, 2012). Beger, Bouk, Boussaid, Terwogt, and Koot (2009) found that ethnic minorities were underrepresented in a sample of 712 children referred to autism institutions, and pediatricians judged clinical vignettes of European children as autistic more often than clinical vignettes of non-European children. Mandell, Ittenbach, Levy, and Pinto-Martin (2007) noted several disparities in the diagnosis of African American children prior to their getting a diagnosis of autism. The authors examined information from 406 Medicaid-eligible children. African American children were 2.6 times less likely (than White American children) to receive a diagnosis of autism on their first specialty visit. It was more common for African American children to be diagnosed with ADHD. It was also more common for African American children to receive an adjustment disorder (5.1 times more often than their White American counterparts), and they were 2.4 times more likely (than their White American peers) to receive a diagnosis of conduct disorder.

Mandell et al. (2009) found significant racial and ethnic disparities in the recognition of ASD among various cultural groups. The authors speculate that perceptions and the presence of an intellectual disability may affect whether or not a physician conducts further analysis to confirm a diagnosis of ASD. By examining the records of 2,586 eight-year-olds, it was determined (through logistic regression with random effects for site) that 58% of the children had a diagnosis of ASD. The data were adjusted for gender, IQ, birth weight, and maternal education, and results indicated that children who were African American, Hispanic, Asian, and of other ethnicities were less likely than Anglo-American children to have a documented diagnosis of ASD.

According to the Autism Society of America (n.d.), the lifetime cost of caring for a child with autism is 3.5 million to 5 million dollars. A families' socioeconomic status (SES) can make a tremendous difference in the intervention planning, education, technology utilization, and support services provided to a child with autism. SES also affects access to regular health care and directly impacts whether or not a child gets specialized training and support. According to Weinick and Krauss (2000)

... studies have shown that Black and Hispanic children are more likely to lack a usual source of care and less likely to have an office-based source of care than White Children ... Black

and Hispanic children are more likely to be uninsured ... (p. 1771)

Without a regular source of care, observations of a child's developmental milestones may be incomplete and inconsistent. Inadequate record keeping and inconsistent observations by different providers may delay a diagnosis and prevent early detection of ASD. SES does not determine whether or not a child has autism, but it may play a role in determining whether or not a physician screens for ASD (Gibson, 2007). A surveillance-based study by Durkin et al. (2010) was conducted to determine whether or not the prevalence of ASD in children in a cross section of the United States was positively associated with SES. An analysis of a sample of 3,680 ASD cases stratified by ethnicity/race, gender, and data source indicated that the prevalence of ASD increased with SES. Significant increases were noted in both children with and those without a preexisting diagnosis of ASD. The authors suggest further study due to the possibility of ascertainment bias and a disparity in access to services.

### *Cultural Perspectives of ASD Treatment*

Culture plays a role in the diagnosis of autism, and it plays a role in a families' acceptance of a child with autism and their acceptance of a treatment modality. In terms of child rearing, Trembath, Balandin, and Rossi (2005) indicate that minority families tend to teach their children to work interdependently within groups, cooperate, and comply when needed. Majority families tend to teach their children to be self-directed learners who are independently oriented and socially interactive (Sue & Sue, 2008; Trembath, Balandin, & Rossi, 2005). These values are often reflected in the avenues for help the families pursue and in the values they teach their children.

Traditional cultural perspectives affect treatment recommendations for ASD. African Americans may seek recommendations from family, friends, or their church members before they seek professional assistance, while White Americans may employ traditional treatments and professional services (Sue & Sue, 2008). Asian Americans generally tend to be hesitant to get professional help; they are more likely to "go it alone," and seek help when they are unable to manage (Dyches et al., 2004; Sue & Sue, 2008). Latino Americans may seek nontraditional treatments, such as the use of folk healers (Sue & Sue, 2008). Mandell and Novak (2005) state that families who believe autism can be cured tend to follow treatment mandates designed to cure, while families who do not believe this are less likely to challenge the course of the disorder.

Religion across cultural groups can help families emotionally and socially, and it plays a large role in parents' coping ability; however, this will vary depending on individual families (Dyches et al., 2004; Skinner et al., 2001). Ultra Orthodox Jewish families may turn to the medical community and counsel from their Rabbi (Pitten, 2008). Pitten (2008) and Shaked and Bilu (2006) indicate that if treatment modalities are in conflict, the Rabbi's counsel is followed. Jegatheesan,

Miller, and Fowler (2010) conducted ethnographic field work with multilingual immigrant South Asian Muslim families of children who have autism. The parents were raising their children in keeping with their religious beliefs (Islamic doctrine), and they planned to incorporate them into ordinary social, religious, and linguistic activities in their home and community. The parents were striving for a normal existence for their children; they felt that the knowledge and opinions of the autism experts they consulted undermined their children; the parents strongly contested the expert's advice.

Parents across cultural groups seek the best quality of life for their child with ASD, and many go to great lengths to locate and implement a variety of interventions. The problem is there are so many possibilities—some of which are efficacious with strong research support, others are promising, and others lack support completely. Scott and Baldwin (2005) present a partial list of therapies that offer benefits or are purported as beneficial; the list contains more than 50 different therapies arranged in alphabetical order. Parents face a daunting task as they research and select interventions. Many are expensive and time intensive, and proper implementation requires training, careful record keeping, evaluation, and research. Simpson (2005) lists basic questions parents should ask as they select a program or treatment for individuals with ASD: (a) What are the anticipated outcomes and their established efficacy; do the outcomes match the needs of the student? (b) What risks are associated with the intervention? (c) How was the intervention or method evaluated? After a careful review of 33 of the most common interventions and treatments for children with ASD, the interventions were graded by Simpson and his team as scientifically based, promising, practices with limited support, and those that were not recommended. The interventions were placed in the categories listed above based on six factors: reported effects of the intervention, qualifications of those implementing the program, administration of the intervention (how, when, and where), risks, costs, and evaluation methods. Four interventions were rated as scientifically based practices (i.e., those having convincing and significant empirical efficacy and support): Applied Behavior Analysis (ABA), Discrete Trial Teaching, Pivotal Response Training, and Learning Experiences: An Alternative Program for Preschoolers and Parents. Eleven interventions were rated as promising practices (those that had efficacy and utility) to include Picture Exchange Communication, Incidental Teaching, Structured Teaching, Augmentative and Alternative Communication, Assistive Technology, Joint Action Routines, Cognitive Behavior Modification, Cognitive Learning Strategies, Social Stories, Social Decision-Making Strategies, and Sensory Integration. Limited support (those interventions that lacked convincing evidence but had undecided, possible, or potential efficacy) was found for 17 interventions, and two (Holding Therapy and Facilitated Communication) were not recommended because they lacked efficacy and could prove harmful. In an earlier study, Odom et al. (2003) reviewed literature from 1990 to 2002 and found 37 studies that met their inclusion criteria. The studies were evaluated and classified into one of three groups: well-

established evidence (adult-directed teaching and differential reinforcement—fundamental elements of Discrete Trial Training), emerging and effective practices (peer-mediated interventions, self-monitoring, involvement of family members, and visual supports), and probably efficacious (positive behavior support, videotaped model, and the use of children's preferences). Parents who have this type of information are in a better position to select interventions that may be helpful for their children.

### *Technologies for Individuals Diagnosed With ASD*

Families across cultural groups are selecting interventions and using technology tools to educate and entertain their children with ASD; technology can be used to help children with autism communicate, observe appropriate behavior, and learn social interaction skills. Some applications of technology gaining momentum include augmentative and alternative communication devices (AACs), video modeling (VM), and virtual reality.

AACs support the development of language in children and adults with ASD who have limited verbal skills, echolalia (repetitive responses), or are nonverbal. According to Millar, Light, and Schlosser (2006), AAC use increased speech production in individuals with developmental disabilities and autism who had inadequate speech to meet their communication needs. In instances where expressive language is weak or absent, augmentative and alternative communication devices can be used to help a person with ASD make demands from his environment and communicate his or her wants and needs by selecting symbols, pictures, letters, words, signs, and expressions which can be stored and retrieved through electronic messages or voice output (Glennen & DeCoste, 1997). Augmentative and alternative communication tools can be simple, non-electric books or boards or more complex high-tech devices that use eye gaze, head or mouth pointers to assist users who have physical limitations.

VM is a technology-based strategy supported by a body of evidence (National Autism Center, 2009), which visually supports a learner with ASD by allowing him or her to observe visual sequences, procedures, and social interactions and learn appropriate forms of behavior and procedures. It has been used to teach individuals with autism a variety of social, procedural, and functional skills by presenting acceptable behaviors, attitudes, and actions of respected role models. VM has been used successfully to improve social interaction, joint attention, imaginative and pretend play, emotional perception, spontaneous requesting, and perspective taking (D'Ateno, Mangiapanello & Taylor, 2003; MacDonald, Clark, Garrigan, & Vangala, 2005; Nikopoulos & Keenan, 2007; Owen-DeSchryver, Carr, Cale, & Blakeley-Smith, 2008).

Virtual environments are appealing for users with ASD because they have detailed graphic presentations, offer control over real-world scenarios, and capture detailed performance data (Parsons, Rizzo, Rogers, & York, 2009). A virtual environment presents a realistic setting and training scenario that

lacks danger, harm, and the long-lasting consequences of inappropriate behaviors or actions.

AAC, video modeling, and virtual environments may be cost-prohibitive technology applications for some families, but stimulating visual aids for autistic individuals can be created using manipulatives and web-based resources. Counselors and other professionals working with families should be sensitive to the families' needs and ideologies particularly when using symbols, colors, signs, and verbiage in AAC devices, virtual scenarios, or video, since meanings vary across cultural groups. According to Trembath et al. (2005), cultural and linguistic background impacts the use of AAC devices. Symbols, colors, and verbiage that are fine in one culture can be offensive and rude in another culture. Video modeling and virtual environments should be created with family input to ensure congruence with family values and ideologies.

### *Implications for Counselors and Other Professionals*

The needs and issues of families and their cultural background impact their ideas about the etiology of ASD, diagnosis, treatment planning, and the use of technology. Family counselors and other professionals must employ approaches that creatively meet the needs of the diverse families they serve (Sue & Sue, 2008). This involves a more active and direct role in joining with families. In essence, family counseling with children with ASD and their families can extend beyond the traditional office setting. It is important for counselors and other professionals to use multicultural counseling and advocacy competencies to support families living with ASD. The 3-fold multicultural competencies include personal awareness, cultural knowledge, and appropriate skills (Sue & Sue, 2008), and will be addressed in turn, followed by the advocacy competencies.

### *Multicultural Counseling Competencies*

**Personal Awareness.** Before counselors or other professionals can work effectively with children with autism and their families, they must take the time and effort to examine their thoughts, feelings, and actions—both positive and negative—about autism. If, for example, family counselors find themselves taking on the paternalistic perspectives of sympathy or pity associated with persons with disabilities, they can challenge themselves to determine the validity of their emotions (Griffen et al., 2007). Professionals must ask themselves if they are in any way an obstacle that helps to create a barrier for the child with ASD or his or her family. If the answer is affirmative, personal assumptions should be explored. Beyond that, consultation with colleagues versed in therapy with families with disabilities, professional development opportunities, multimedia presentations, and other resources can illuminate counselor perspectives. In order to be effective, professionals must understand autism from the perspective of the family. There can be guilt, shame, fear, and a host of emotional issues that must be addressed before a family can process and accept a diagnosis of ASD. The diagnosis brings with it a complicated

set of issues which may involve finances, general health care, spousal tension, parental stress, respite care, and intervention planning. In order to effectively help families find the best path of support and care, family counselors must understand the interrelationships among these issues and help families find appropriate resources.

**Cultural Knowledge.** Teasing out the complexities of culture for individuals and families provides more information that can assist counselors and other professionals as they join with families. The RESPECTFUL model of counseling is a framework that helps counselors explore markers of cultural identity that are salient for their clients (Lewis, Lewis, Daniels, & D'Andrea, 2003). Though not an exhaustive list, the use of this model invites counselors and others to consider the following 10 cultural points (pp. 9–17): R—religious/spiritual identity; to include the manner in which individuals identify with formal and informal transcendental forces; E—economic class background; to note the impact of class on one's cultural perspective; S—sexual identity; acknowledges gender identity and roles, as well as one's sexual orientation; P—level of psychological maturity; includes differences in psychological development; E—ethnic/racial identity; involves an exploration of intragroup and intergroup variations; C—chronological/developmental challenges; considers generational diversity from birth through old age; T—various forms of trauma and other threats to one's sense of well-being; considers the impact of various forms of stress upon one's psyche; F—family background and history; the personal sense of one's family constellation; U—unique physical characteristics; understanding how societal images can marginalize those who are physically different from idealized norms; and L—location of residence and language differences; how one is situated in terms of geographical locale and linguistic variations.

The authors emphasize the fact that cultural identity is not one-dimensional. Counselors and other professionals must be willing to investigate how several cultural identities interact and influence clients. Lewis, Lewis, Daniels, and D'Andrea (2003) also encourage counselors to employ this model as a personal awareness tool. Ethnic and racial identity of clients may lead clinicians to form negative or inappropriate assumptions about families who have a child with ASD. In a case study by Gourdine, Baffour, and Teasley (2011), an African American couple with a child with autism received insensitive remarks from both the psychologist evaluating their child and the clinician testing their child. The psychologist was stunned to learn that the mother was a professional clinician; it had been assumed that both parents were uneducated. The parents were told not to be hopeful about their son's future.

A cultural group's history can be filled with trauma—unfair treatment, devaluation, experimentation for medical purposes, discrimination, political and economic disenfranchisement, and other negative factors that can make it difficult for members of the cultural group to fully trust mainstream health care and service providers. These are the sociocultural and political realities of many diverse families that family counselors cannot afford to ignore (Sue & Sue, 2008). Family counselors working

with parents who experience these types of environmental stressors may need to be especially mindful of the way they shape the initial therapeutic alliance. A discussion of expectations on the part of the counselor and family members can set the stage for an attentive and transparent relationship. Language can also interact with other identities to create a problem for the family with an autistic child. If there is no word to describe or explain autism in the culture of the family, the family is at a disadvantage; it may be very difficult for the parents to understand, manage, and seek interventions that will help the child. Tincani, Travers, and Boutot (2010) indicate that more research is needed on culture, language, and the development of educational programs for students with ASD; “. . . There is limited research on the impact of cultural and linguistic diversity on the development of effective educational programs for students with ASD . . . ” (p. 86). It behooves family counselors, then, to become as familiar as possible with the culturally infused verbal and nonverbal communication styles of the families they work with. They can then effectively assist family members struggling with ASD to develop strategies for improving positive communication amongst themselves.

**Appropriate Skills.** Families with autism have many needs which may mean counselors and other professionals have to be flexible in the application of theories and skills. Sue and Sue (2008) highlight the applicability of the communication and structural approaches to family therapy to the worldview of many diverse families. They state that these approaches tend to focus on the significance of the collective unit, are specific, focus on a generational and historical view of family structure, reframe communication and family patterns, and view the counselor as the expert. However, theoretical issues can result from the manner in which “. . . goals and strategies are translated into concepts of “the family” or what constitutes the “healthy” family (Sue & Sue, 2008, p. 190).

One tool to help professionals understand family beliefs about autism, treatment, and family expectations is a rubric developed by Levy et al. (as cited in Mandell & Novak, 2005). Questions such as these address the diversity that is a part of each family:

- What did you call your child’s problem before it was diagnosed?
- What do you think caused it?
- Why do you think it started when it did?
- What do you think autism does? How does it work?
- How severe is it? Will it have a short or long course?
- What are the chief problems your child’s autism has caused?
- What do you fear most about it?
- What kind of treatment do you think your child should receive? What do you expect from this treatment? (p. 113)

Concomitantly, the questions raised may also bring up adverse feelings of individual and parental self-worth, which can impact familial interactions (Harris, Durodoye, & Ceballos,

2010). Family counselors can assist parents to work through these feelings toward a reconstructed relationship that increases more positive interfamilial relationships. Moreover, family counselors can help siblings and other family members acknowledge the perspectives of the child with ASD and help these members become more understanding of the behavioral, communication, and social skill impairments displayed. Assisting families to focus on their individual and collective strengths is yet another way that family counselors can help families balance their views.

### **Advocacy Competencies**

Society’s beliefs about autism are shaped by culture, which, in turn, reflect society’s institutional values (Griffen et al., 2007). These values, however, tend to be weighted toward those without disabilities. Given this situation, the question for family counselors and other professionals becomes how can we become advocates for family members as they negotiate societal systems and environments? According to Lee (2007), “Advocacy refers to the process or act of arguing or pleading for a cause or proposal, either of one’s own or on behalf of someone else” (p. xvi). Lewis, Arnold, House, and Toporek (2002) offer advocacy competencies that can be useful to counselors and other professionals working through issues of autism with clients and their families. Within the domains of client/student, school/community, and the public arena, counselors can assess whether they need to serve on behalf of their clients through advocacy or work with their clients more directly. Counselors can also decide on the cost and benefits of working on a micro level or a macro level for any of the domains.

**Client/Student.** Client/Student Advocacy involves access to essential resources (Lewis, Arnold, House, & Toporek, 2002). In order to aid families with children diagnosed with ASD, family counselors must be aware of available resources at the local, state, national, and international level. For example, families who are interested in ABA Programs should be directed to recognized clinics and approved university training programs which are supervised by board certified Behavior Analysts. Knowledge of other efficacious treatment options and those that are promising should be made available to families along with complete information on the benefits, costs, and needs. In addition, other resources are needed for parenting support, educational options, general information on disabilities and available services, transition programming, and sibling support. Shared knowledge of locally available resources for the above are excellent support for families negotiating the myriad of issues involved in ASD.

**School/Community.** Counselors and other professionals can be advocates for families by encouraging them to find out about their rights and responsibilities regarding the educational direction for their child. Parents and children may need assistance in deciphering the meanings and implications of laws, terms, and

documents they will encounter as they traverse the educational system. For example, the Individuals with Disabilities Act (IDEA, 2004) requires schools to adhere to an Individualized Education Program (IEP) for each child with a documented disability. The IEP addresses the child's educational needs by defining measurable goals and objectives that are observed and reported during the course of the school year for children receiving special education services (Moore-Abdool, 2010; Wilczynski, Menousek, Hunter, & Mudgal, 2007). Family counselors can assist families of children with autism by facilitating family interactions with school personnel and supplying helpful resources to both the family and the school.

**Public Arena.** Counselors and other professionals can encourage individuals without autism to become more sensitive and more aware of issues surrounding families dealing with autism. Personal contacts with leaders in the business community can be used as a resource to promote an awareness of ASD, and business owners can be encouraged to include individuals with autism in their business establishments. Too often, children with ASD are not given the chance to work in the community, learn job skills, and become productive members of their communities. Here, more acceptance, understanding, and knowledge would go far toward helping individuals with ASD become important and valued members of their communities.

## Conclusion

There are many unknowns that continue to surround ASD. Societal advances are such that more answers are available to families caring for children with autism regarding diagnosis, treatment, and outcomes. Successful work with children with autism and their families means that family counselors and other professionals can be invaluable resources for families struggling with ASD. Counselors must acknowledge the ways in which culture can impact perspectives about ASD. In addition to this view toward diversity, successful counselors and other professionals working with families who have a child diagnosed with ASD will be those that recognize and preserve the families' dignity, advocate for client services and resources, practice active listening skills, make appropriate accommodations, set reasonable and progressive goals, value and recognize the wisdom of the family, avoid harmful labels, disseminate resources, and demonstrate a positive attitude (Kluth, 2003). This requires individual flexibility and practical therapeutic adjustments that provide support and assistance to families as they make decisions for the future well-being of their child with ASD.

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