

FAMILY MATTERS: CULTURAL CONSIDERATIONS FOR FAMILIES WITH AUTISM

By: Cultural and Linguistic Diversity (CLD) Committee Members

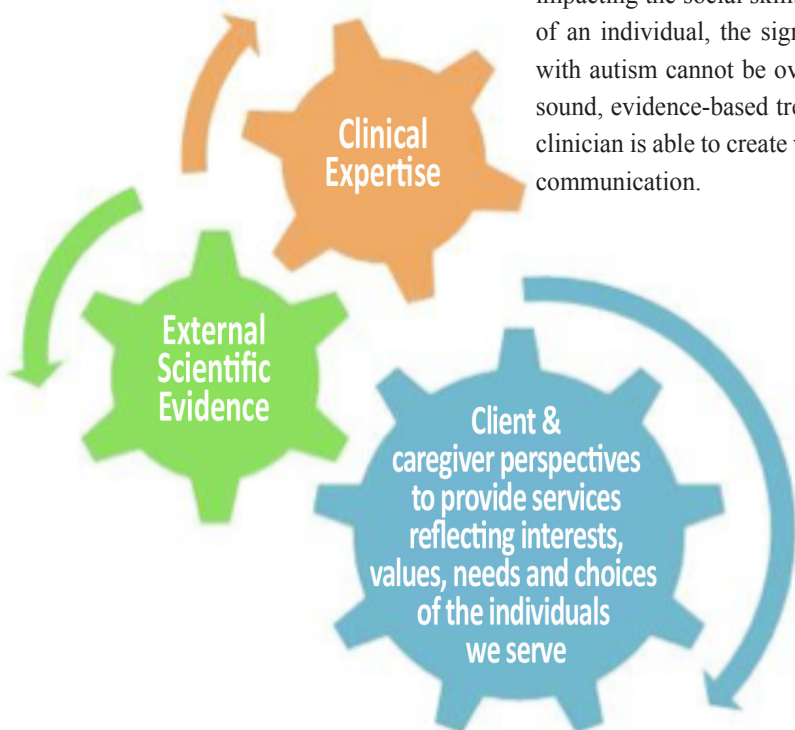
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The CLD Corner was created in an effort to provide information and respond to questions on cultural and linguistic diversity. Questions are answered by members of the TSHA Cultural and Linguistic Diversity (CLD) Committee. Members for the 2014-2015 year include **Lisa Carver, MA, CCC-SLP (co-chair); Ivan Mejia, MA, CCC-SLP (co-chair); Raul Prezas, PhD, CCC-SLP; Christina Wiggins, MS, CCC-SLP; Brittney Goodman, MS, CCC-SLP; Sarah Panjwani, MS, CCC-SLP; Mary Bauman, MS, CCC-SLP; Phuong Lien Palafox, MS, CCC-SLP; Marisol Contreras, BS; and Alisa Baron, MA, CCC-SLP.** Submit your questions to ivanmejia@bilingualspeech.org and look for responses from the CLD Committee on TSHA’s website and in the Communicologist.

As speech-language pathologists (SLPs), audiologists, and communication sciences professionals, we receive training in assessment, diagnosis, and therapeutic interventions. When serving those with autism, SLPs and audiologists play an important role when working on receptive/expressive language, social communication, and executive functioning skills. Emphasis and consideration is given to our clinical skills; however, the client’s primary support system (i.e., family/caregivers) is an essential part of the team during the assessment and intervention processes. The family is the primary implementer of the strategies communication professionals suggest to help a client diagnosed with pragmatic language disorders and autism spectrum disorders. When we think about the general description of autism as a developmental disability impacting the social skills (e.g., social reciprocity, joint attention, self-regulation) and language of an individual, the significance of those who support and care for our clients and students with autism cannot be overstated. By practicing cultural competence paired with scientifically sound, evidence-based treatment methods and considering the family’s unique perspective, the clinician is able to create well-designed treatment plans to best help the client achieve successful communication.

Bilingualism and Autism

There are a variety of studies that have been conducted to examine bilingualism and biculturalism in the home with children with autism (e.g., Hably & Fombonne, 2012; Kay-Raining Bird, Lamond, & Holden, 2012; Ohashi et al., 2012). The outdated practice of recommending that families with children with autism ignore their home language and focus instead on speaking English (regardless of the family’s proficiency in English) interferes with the support system of the client with a long-term disability but is also contraindicated due to what we know about how the bilingually exposed individual develops language. Some well-intentioned professionals still recommend this approach because they try to ensure that the child will be exposed to simple language to help with language learning, especially in the



academic setting. However, as culturally competent professionals representing the client with the communication disorder, the SLP or audiologist may have to act as an advocate and educate professionals about current research and what is known about the theories of language development and bilingualism. The interdependence hypothesis (Cummins, 1979) explains that when the first language is underdeveloped, the ability to acquire a second language is limited. Therefore, when families are advised to only speak English when the child has not yet acquired the home language, this can be very detrimental to the child's language development overall.

Kay-Raining Bird et al. (2012) conducted a survey of parents with children with autism from culturally and linguistically diverse backgrounds on several different topics. One of the variables they asked was about the recommendations professionals gave to bilingual families. A large portion of parents (43 percent) received advice from a professional (pediatrician, psychologist, teacher, social worker, SLP) to only speak to their child in one language while only 16 percent of the professionals recommended the continued use of both languages. Furthermore, it is important to note that 50 percent of the world's population is bilingual and knowing at least two languages is mandatory, not optional, in many societies (de Houwer, 1999). The most current thinking suggests that children with autism should learn the home language as well as English so they can communicate and participate in all aspects of their home and school environments (Kay-Raining Bird et al., 2012).

Other studies also have compared children from CLD backgrounds who were continually exposed to two languages and CLD children whose families focused on only the mainstream language (e.g., Hably & Fombonne, 2012; Ohashi et al., 2012). Findings have indicated that children with autism who are exposed to two languages are not at a disadvantage because of their exposure to more than one language and do not experience additional delays in language development (Hably & Fombonne, 2012; Ohashi et al., 2012). Furthermore, Seung, Siddiqi, and Elder (2006) showed that providing services in the home language first, to create a foundation, is best and ultimately results in more positive treatment outcomes for the individual. A gradual transition to English intervention is recommended once the home language is firmly established.

Language, Culture, and the Home Environment

Language development is directly related to the language input a child receives. An understanding of the organization of daily life is acquired through the language communicated by the people the child knows best. As Kremer-Sadlik (2005) explained, "A child is not only socialized to use language but is also socialized through language," and a child learns how to communicate, understand emotions, and think critically through a situation by being in the context of the family environment. Therefore, it is critical for children to understand the language of the home in order to be fully immersed in the family culture so they can learn all aspects of language. If a child cannot understand the home language, he or she may feel isolated and he or

she may experience more communication breakdowns. In a study by Kremer-Sadlik (2005), some families shared that they stopped using the home language with their child with autism but continued to speak the home language with everyone else in the home. When these families were observed during mealtimes, conversations were often held in the home language; the children with autism did not participate in family conversations, and parents did not directly speak to the child with autism frequently. Parents who continued to use their native language with their child with autism were observed to be more effective and engaging with their children (Wharton et al., 2000). When the home language is continued, parents can become teachers in the home and explicitly explain certain social interactions, expectations, and motivations as well as create social stories or scripts for a variety of situations their child may encounter on a regular basis (Attwood, 1998). Baron-Cohen and Staunton (1994) showed that parents' language is especially influential as children with autism seem to benefit more from parent input than peer input. Parents, consequently, play a vital role in the language input and practice of language whether the child with autism participates in the interactions or just listens to the conversations that occur daily within the family unit.

Family Perspectives

In this article, we wanted to provide insight into the lives of our families. From diagnosis to therapy to future considerations, we need to take the time to fully realize the scope of our professional efforts. As a result, we may come to realize the impact we can make in helping to meet the needs of this special population. Below are two perspectives from families that discuss their challenges, struggles, and achievements from their personal experiences with autism.

Spanish-speaking family: Maria is the mother of Ivan, a kindergarten with autism (Prezas, Personal communication with family in Spanish, 2014).

When was your child referred for an evaluation?

My son Ivan was three years old at the time. He was our only child. In the back of my mind, I knew something was different about him. Ivan didn't act like the other children his age in our family. Initially, my husband was convinced nothing was wrong and did not support my decision to have him evaluated. I was alone with my child (whom I love dearly) on the day of the evaluation and during subsequent meetings with school personnel. Initially, I was concerned because Ivan wasn't talking. Other children his age were speaking in sentences while he didn't talk at all. I never imagined he would be diagnosed as having autism (a word that I knew little about at the time).

What was your experience with the assessment process?

Ivan was to have an evaluation with the early childhood team in our local school district. Although I had been informed that there would be different professionals attending the evaluation, I guess I was not fully prepared for what I encountered that day. There really

is no better way to say it other than I felt as though my son and I were under a microscope. Looking back, I realize that the team was just doing its job. They were very polite and professional. However, it was an odd situation because there was only one person on the team who spoke Spanish. She was very nice and helpful; however, I remember feeling very overwhelmed hearing questions in English and having them interpreted in Spanish. I was very nervous as a result and remember feeling very defensive at first. The assessment team asked me questions, very personal questions. And I didn't feel as connected to the professionals who spoke English because I didn't understand what they were saying. As each question was asked, I started to feel as though I had to protect my son, as if I had to stand up for him and his skills/abilities. First, I can't speak the language of the majority of the team members. Second, I have to rely on one person to tell me what everyone else is saying. I remember thinking, "How do these people really feel about me and my son?" I caught myself (a couple of times) slightly exaggerating his abilities, something I'm not proud to say. My initial fear at the start of the assessment turned to anger (at the questions) and then sorrow. For example, one examiner asked me if I had tried having Ivan drink with a regular cup (I still had been feeding him with a bottle because, to be honest, it was much easier to do so with his mobility issues and behaviors). I immediately became embarrassed. I explained to the team that I had tried it before, and in my explanation, I just broke down and started crying. The staff was very nice, and they consoled me. I was given some time, and then I informed them I was ready to continue.

After that moment, something interesting happened. As they continued asking me questions, I started to realize that I was answering "yes" to a lot of them. Some behaviors included spinning in circles, avoidance of certain textures, flicking the light switch on and off, and avoidance of eye contact. I was surprised at how their questions seemed to match what my child was going through. After that moment, I became more and more interested in the questions I was being asked.

How did you feel when you first heard the word "autism"?

I had heard of autism from a friend. However, we don't have internet, and I really didn't know much about it—and, frankly, I was afraid to ask. Everything I had heard was in a negative light, and as a result, the word just sounded horrible [to me]. The first time I heard the word in relation to my son was the day of the evaluation. After they asked their questions and worked with Ivan, the evaluation team sat with me and went over their thoughts. When they gave me the news about my child, I immediately broke down again and started crying. Part of me knew what they were going to say, and the other part of me wasn't ready for the news. I think deep in the back of my mind I always had a suspicion that something wasn't right. I love my son dearly and wanted the best for him. At the same time, I don't think I was ready for that word [at the time].

How have things changed with your family after the evaluation and since your child has received therapy?

When we left the evaluation, I remember sitting in my car and just crying. I was trying to figure out how I was going to tell my husband, who is very "machismo" and traditional. We named our son after him, and I knew the news would break his heart. However, with time and lots of discussions, I am thankful to have his support. As for my extended family, I was initially reluctant to share the information with them. However, they were surprisingly very supportive. We don't talk about it much, but I can tell they are happy we are receiving help.

Therapy has been a blessing! We have an in-home trainer who is bilingual and who has helped me with my son's behaviors. My child's speech teacher at school is wonderful! She also is bilingual and has provided us with so many resources. I have learned so much from this experience. The best part is that I have seen Ivan improve and grow. I am happy to report that we finally got him drinking with a regular cup!

Is there anything else you want to say to professionals out there who are working with families?

I think the one thing I would say is that there really never is a right moment for parents to hear that their child has a disorder. If we appear defensive or angry, we are not trying to be rude or disrespectful. We are just hurting for our children. We are scared and worried. Parents need time. Second, I would tell assessment teams that multiple questions can be very overwhelming, especially when you are hearing questions in a language you do not understand. Anything you can do to make families feel comfortable is appreciated. I would also tell the same professionals to keep doing what you do! I am forever grateful for the evaluation team and how they took care of us. Looking back, they did everything they could to console me and help me through this journey. They were positive, friendly, and kind. Words cannot express how thankful I am for their kindness.

Laotian family: Laty is the mother to Ethan, a third-grader with autism (Palafox, Personal communication with family, 2014).

How does your culture play a role in the diagnosis of your child?

I feel that in the Asian culture, at times, autism is not a part of our vocabulary. Since I was raised here, I understood it. It was different for my parents and in-laws when Ethan was first diagnosed. For me, it was a relief. I had an answer, and I could move forward. When we told our families, they said, "What are you talking about? Are you sure?" They second-guessed the diagnosis and stated that he was just "acting like a boy." It was frustrating; however, over time, it got better. We explained in our native language what autism is, the impact it has, and the improvements Ethan will make. Eventually, they began to see the change, and they supported all of our endeavors.

Are there considerations to his current services and your culture?

Right now, I am happy with his services. Once my extended family understood autism, we have all been working toward strategies to help Ethan. For example, my mother-in-law tries her best to

continually communicate and engage with Ethan. She is not comfortable using English, so she speaks to him in Laotian. She says it's important to teach him his native language, and I agree. My father-in-law will take Ethan on trips to community locations, like the gas station, to work on his communication. They also ask us about Ethan's therapies, and it's great! I consider myself lucky.

What are your future thoughts?

I want him to be a functional member of society. In our culture, when parents get older, we typically live with our adult children. My husband and I do not want to be a burden for Ethan and his younger brother Matthew. If Ethan cannot be independent, it's our job to take care of him. But I have a strong feeling Ethan will be able to give and contribute to society and be on his own. He's on a really good path. And he'll have Matthew. After all, that's what family is about.

We want to sincerely thank our families for their contributions. By sharing their stories, we are able to dynamically learn from one another. We are grateful for their willingness to give insight into their thoughts, feelings, and small and big life moments.

Summary

Whether we consider ourselves specialists in the area of autism or not, we all can learn from available research, culturally-competent practices, and the families that we serve. Best practices inform us that we need to encourage speakers of other languages to foster their native language(s) at home. Professionals also are

encouraged to develop a rapport and strong working relationships with families. Building trust and engendering a positive environment is a major take-home message from our family perspectives. Moreover, we must be mindful that challenges also may exist within families in regards to understanding and acceptance of a child with a disability. We must always consider the background of others and remain culturally competent so that we can be strong advocates and better serve our diverse families and clients.

In conclusion, we are left with the thoughts from an SLP in the field who offers additional insight regarding our role as professionals:

"In the beginning of my career, I solidly understood what it took to conduct an assessment and then provide clinical recommendations for my clients with autism. Then, somewhere along the way, I realized that I was not just providing speech-language therapy in my client's native language. Essentially, I was working with entire families who must balance the cultural components of everyday living. I spoke with a single, working mother living in a multi-generational home. She worked all day. Then she would spend her evenings making visuals for her son in English and Spanish. When he went to bed, she would take the time to convince her father, the child's caretaker, to implement effective strategies for her son while she was working. As an SLP, I need to understand these family matters. Without understanding the core of my families' priorities and lives, therapeutic recommendations would not be as impactful."
(P. Palafox, 2014) ★

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