

Cultural and Linguistic Diversity in Autism: Opening the Door
By Jessica Kinard
4/12/2022

“Yo siempre pensaba, tú entre más conozcas el problema, más puedes ayudar...”
“I always thought, the more you know about the problem, the more you can help...”
-Mother of a child with autism
(Kinard, 2015)

This quote comes from a Hispanic parent of a child with autism, reflecting the belief that knowledge is power, especially when it comes to helping your little one with autism blossom and learn to socialize and communicate. Unfortunately, knowledge is often behind a door—and for culturally and linguistically diverse families, one of the biggest doors to accessing that knowledge is language (Singh & Bunyak, 2018).

Imagine that you are a parent and that you are concerned about your toddler’s development. Your child is not talking, does not look up when you call his name, and turns his back to avoid you when you try to play with him. What do you do? One of your first actions might be to look for information—searching about child development online, talking with family and friends, and asking your child’s pediatrician for their opinion. When you search online, though, you find very little information online in your language. When you speak with family and friends, they encourage you to “wait and see” how your child progresses on his own. The pediatrician does not speak your language, either, so you need to speak with them through an interpreter. When the pediatrician tells you not to worry, that it is normal for a bilingually exposed child to speak late, you realize your concerns are getting lost in translation. You also start to wonder if exposing your child to two languages has confused him and if you are somehow at fault for the language delay. You decide to follow the advice you are receiving to “wait and see.”

Although this is a hypothetical example, and certainly not the story for all families, experiences such as this one are well documented in the literature, with language barriers (between practitioners and families, as well as adults’ perceptions of the child’s communication skills) creating obstacles at each step toward an autism diagnosis (Singh & Bunyak, 2018; St Amant et al., 2018). These obstacles are reflected in current prevalence data. Overall, autism prevalence is similar across racial and ethnic groups, but the diagnosis rate in Hispanic versus non-Hispanic children is significantly lower across many regions in the United States (Maenner et al., 2021). Once an autism diagnosis is obtained, language continues to create barriers as families seek out early intervention services, but are unable to find providers who speak or even encourage the use of the family’s language, or interventions that have been developed with the family’s culture and language in mind (DuBay et al., 2018; Kinard, 2015; Yu, 2016). Imagine, again, that you finally get your child into therapy, despite all the language barriers, but now your child is being taught to speak another language.

If knowledge is power and language is the door, then we, as healthcare professionals, need to unlock the door. Feel empowered that you can make a difference for families, even if you do not speak the same language. Here are examples of “keys” you can use to start opening the door—to help families learn more about autism—so that they can, in turn, use that knowledge to help their little one grow.

- **Make connections with community leaders:** Reach out to leaders in the Hispanic community and exchange ideas about how to best help Spanish-speaking families in the context of your practice. Think about how this partnership with the community could

benefit families, whether that is through informal meetings where you and the community leader get to know one another, or through more formal partnerships, where members of the community provide direct assistance. For example, here at UNC Chapel Hill, two resources include (1) the Carolina Latinx Center (<https://clc.unc.edu/>), which provides opportunities for those with an interest in Hispanic/Latinx issues to connect with one another and share ideas; and (2) the NC TraCS Multilingual Research Advancement for Health (MURAL) program (<https://tracs.unc.edu/index.php/services/inclusive-science-program/mural>), which provides resources for researchers and community health partners. Other examples of potential community partners include the Autism Society of North Carolina, healthcare practices serving Spanish-speaking populations, local religious organizations, or other local community groups, such as El Centro Hispano.

- **Recruit Hispanic and Spanish-speaking team members:** To make a direct connection with families, it would be invaluable to have team member(s) who identify with the family's cultural background and fluently speak their language. In addition to professional team members, consider recruiting students who could assist while pursuing their degrees in a related field. For example, students could potentially be supported by the UNC Chapel Hill Work-Study program and/or could benefit from clinical or research hours that would support them in their degree requirements. The relationships that you establish with leaders in the Hispanic community could also help generate ideas for recruiting Spanish-speaking team members.
- **Allocate resources for written translations:** Translation (translation of written material) is critical for reducing language barriers. It would be ideal if written translations were completed by native Spanish-speakers (i.e., grew up in a Spanish-speaking family and received academic instruction in Spanish). Even better would be if two native Spanish-speakers could work on the translation together, to double-check for dialectal differences and oddities in how sections are phrased. Finally, once you have a translation you feel comfortable with, it is recommended that you show the translation to Spanish-speaking families to get their feedback. Issues to consider are: (1) Does the translation match the original English meaning?; (2) Does the content match the cultural experiences of the families (i.e., is this an activity or concept that the family would be familiar with, or does it need to be explained in a different way?); and (3) Is the information presented in multiple formats that families from a variety of backgrounds and resources could easily access (i.e., online vs. hard copy; pictures vs. text; etc.) (DuBay & Watson, 2019; DuBay et al., 2021). Again, connections you create with the Hispanic community could provide another pair of eyes to look over your translations.
- **Allocate resources for interpreting:** Interpretating (translation of spoken word) is another critical component of reducing language barriers. The best interpreter is a medically certified interpreter with experience in your field. Avoid using family members as interpreters. Also remember that, even if a family can participate in casual conversations in English, this does not necessarily mean that they feel comfortable having in depth conversations about their child's healthcare in English, so check with families about their preferences. When working with an interpreter, it is helpful to speak with the interpreter beforehand about what will be discussed during the sessions, so they can adequately prepare. Consider creating a "glossary of terms" that are frequently used during your sessions, so the interpreter can have these on hand. Offer a pad of paper, so that the interpreter can take notes. Other important topics to check about with the interpreter include: how comfortable they are conveying emotional information, such as an autism diagnosis; if they prefer to use simultaneous interpretation (speaking at the same time as you) or sequential interpretation (speaking after you); and how much you should say before allowing the interpreter time to speak. During the session, speak directly to the family, rather than orienting yourself toward the interpreter. After the

session, remember to debrief with the interpreter about what went well and what could be improved for the next time. More information about working with interpreters can be found at: https://www.asha.org/practice-portal/professional-issues/collaborating-with-interpreters/#collapse_1

- **Become familiar with bilingual development and collaborate with experts in bilingualism:** When working with children who are exposed to two or more languages, information about bilingual language development will help parse apart “language differences” from “language disorders.” Collaborating with experts in bilingualism, such as bilingual speech-language pathologists, will help this process of determining difference from disorder. An important piece of information to share with families is that being exposed to two languages does not “confuse” children or cause them to have language disorders. Families should feel empowered to speak their family’s language with their child, so that they are surrounding their child with rich language models. In the case of autism, remember that social communication skills can be practiced in any language (Yu, 2013, 2016). See these resources for more information about typical bilingual language development: “Learning Two Languages” from the American Speech-Language-Hearing Association (<https://www.asha.org/public/speech/development/learning-two-languages/>) and “Bilingualism in the Early Years: What the Science Says” by Drs. Byers-Heinlein and Lew-Williams (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6168212/>)
- **Promote the idea of acting early:** Rather than relying on a “wait and see” approach, encourage families to monitor their child’s development and reach out when they have concerns. The Centers for Disease Control and Prevention (CDC) has developed a “milestones tracker” app that is available in Spanish. With this app, families can learn about what skills their child is expected to do at certain ages, along with video examples: <https://www.cdc.gov/ncbddd/spanish/actearly/spanish-milestones-app.html>
- **Use family-centered practice:** As with all families, a “golden rule” will be to implement principles of family-centered practice into your work with families. Consider going through these three stages of family-centered practice: (1) the “respect” stage, where you listen to the family’s concerns, identify what types of supports or resources the family would like to have, and learn about the family’s daily life; (2) the “reciprocity” stage, where you empower the family to make well-informed decisions about their child’s care, including preferences related to the parents’ and child’s language; and (3) the “responsiveness” stage, where you follow-through with the plan that you developed with the family and follow-up on the family’s continued needs (Barrera & Corso, 2002; Dunst et al., 1988; Trivette et al., 2010). By going through these stages, you can discover which “doors” are still in the families’ way and brainstorm how best to help families access the information they need.

References

- Barrera, I., & Corso, R. M. (2002). Cultural competency as skilled dialogue. *Topics in Early Childhood Special Education, 22*(2), 103-113.
- DuBay, M., & Watson, L. R. (2019). Translation and cultural adaptation of parent-report developmental assessments: Improving rigor in methodology. *Research in Autism Spectrum Disorders, 62*, 55-65.
- DuBay, M., Watson, L. R., Baranek, G. T., Lee, H., Rojevic, C., Brinson, W., Smith, D., & Sideris, J. (2021). Rigorous Translation and Cultural Adaptation of an Autism Screening Tool: First Years Inventory

- as a Case Study. *Journal of Autism and Developmental Disorders*.
<https://doi.org/10.1007/s10803-020-04837-1>
- DuBay, M., Watson, L. R., & Zhang, W. (2018). In search of culturally appropriate autism interventions: Perspectives of Latino caregivers. *Journal of Autism and Developmental Disorders*, 48(5), 1623-1639.
- Dunst, C. J., Trivette, C. M., Davis, M., & Cornwell, J. (1988). Enabling and Empowering Families of Children With Health Impairments. *Children's Health Care*, 17(2), 71-81.
https://doi.org/10.1207/s15326888chc1702_2
- Kinard, J. L. (2015). *Start that coexistence: Three studies of parent responsiveness to children with or at-risk for autism spectrum disorder (Doctoral dissertation)*. ProQuest LLC.
- Maenner, M. J., Shaw, K. A., Bakian, A. V., & al., e. (2021). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *Morbidity and Mortality Weekly Report (MMWR)*, 70(11), 1-16.
- Singh, J. S., & Bunyak, G. (2018). Autism Disparities: A Systematic Review and Meta-Ethnography of Qualitative Research. *Qual Health Res*, 1049732318808245.
<https://doi.org/10.1177/1049732318808245>
- St Amant, H. G., Schragger, S. M., Pena-Ricardo, C., Williams, M. E., & Vanderbilt, D. L. (2018). Language Barriers Impact Access to Services for Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 48(2), 333-340. <https://doi.org/10.1007/s10803-017-3330-y>
- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influences of Family-Systems Intervention Practices on Parent-Child Interactions and Child Development. *Topics in Early Childhood Special Education*, 30(1), 3-19. <https://doi.org/10.1177/0271121410364250>
- Yu, B. (2013). Issues in bilingualism and heritage language maintenance: perspectives of minority-language mothers of children with autism spectrum disorders. *American journal of speech-language pathology*, 22(1), 10-24. [https://doi.org/10.1044/1058-0360\(2012/10-0078\)](https://doi.org/10.1044/1058-0360(2012/10-0078))
- Yu, B. (2016). Bilingualism as Conceptualized and Bilingualism as Lived: A Critical Examination of the Monolingual Socialization of a Child with Autism in a Bilingual Family [journal article]. *Journal of Autism and Developmental Disorders*, 46(2), 424-435. <https://doi.org/10.1007/s10803-015-2625-0>