Symposium Title: Diverse Parent Perspectives on the Diagnosis and Treatment of Children with ASD

Chair: Sandra B. Vanegas

Discussant: Katherine Zuckerman

Overview: Autism Spectrum Disorders (ASD) is a neurodevelopmental disorder characterized by difficulties in social communication and the presence of restricted interests and repetitive behaviors (APA, 2013). The prevalence of ASD is currently reported to be 1 in 68 children (CDC, 2016); however, ASD identification rates differ widely within the United States. While there is a large body of work that has examined the diagnostic process and treatment options for individuals with ASD, much of the research has focused on individuals with ASD and families from primarily White, English-speaking households in urban communities. Throughout the United States, numerous disparities in access to diagnosis and treatment have been identified across diverse cultural, linguistic, and geographical communities. These disparities result in poorer outcomes for individuals with ASD and their families. To better understand how to ameliorate these disparities, it is important to examine perspectives from parents of children with ASD across cultures, languages, and geography. The three presentations included in this symposium explore diverse parent perspectives on the diagnosis and treatment of their children with ASD. The first presentation addresses how cultural beliefs factor into the decision to disclose or not disclose an ASD diagnosis. The second presentation focuses on Latino families of children with ASD navigating two cultures and two languages. Finally, the third presentation examines the needs, barriers, and experiences of parents of children and youth with ASD living in rural communities. Together these presentations highlight parent perspectives from historically underserved and underrepresented communities to stimulate research, practice, and policy change to improve outcomes for individuals with ASD and their families.

Paper 1 of 3

Paper Title: The Influence of Culture on The Decision-Making Process of Disclosing a Child’s Autism Diagnosis to Family and Friends: A Qualitative Study of Parents’ Experiences

Authors: Andrea Chu, Monica Gordillo, Kristin Long

Introduction: For many families, a child’s autism diagnosis necessitates a cycle of adaptation and associated changes in their routines and social relationships (Lutz, Patterson, & Klein, 2012; Blanche, Diaz, Barretto, & Cermak, 2015). Communication with healthcare providers and members of a family unit about the diagnosis can impact families’ experiences with autism. Parents may find themselves seeking social support, counseling, and additional information about the diagnosis. They may also assume the role of advocate for their child (Lutz et al., 2012; Osborne & Reed, 2008). While research has primarily focused on parent-provider communication at the time of diagnosis (Osborne & Reed, 2008; Nissenbaum, Tollefson, & Reese, 2002), there is limited research on parents’ decision-making process of disclosing an autism diagnosis to family and community members. Particularly among ethnic minority families, it is important to understand how cultural beliefs about autism and developmental milestones shape disclosure of a diagnosis and resulting relationships within and outside the family, as this may have profound effects on perceived social support and pursuit of services. The purpose of this study was to understand how ethnic minority parents decide whether to share their child’s autism diagnosis and the resulting impact of disclosure on social relationships.

Methods: Semi-structured qualitative interviews, approximately 1.5 to 2 hours in length, were conducted with a culturally diverse sample of mothers of children with autism spectrum disorder (n=20) in the greater Boston area. Four mothers were
White, 8 were Hispanic, 2 were Black/African American, and 6 were “other” (from Algeria, Morocco, Jamaica, India, Vietnam, and the Philippines). The age of children with autism ranged from 4 to 13 years of age, with an average age of 7 years. Data collection continued until thematic saturation was reached. Interviews were recorded and transcribed, and approximately 50% of all transcripts were double coded. Interviews were analyzed via content and thematic analysis.

**Results:** Mothers primarily disclosed an autism diagnosis to immediate family members (e.g. the child’s grandparents) to seek informational and emotional support. Mothers asked family members if there were other cases of autism in the family (informational support) and hoped that sharing the diagnosis would garner more understanding for the child and mom herself (emotional support). However, mothers’ disclosure of the diagnosis was often met with denial by family members who believed the child would “grow out of the autism,” or who associated autism with severe impairment and perceived it as a mental health disorder. This was particularly salient among mothers who identified as ethnic minorities. Consequently, ethnic minority mothers would assume the role of educator, having to explain what autism is, the spectrum of the disorder, and the severity exhibited by their child’s behavior. Mothers attributed family members’ denial of the autism diagnosis to interrelated factors associated with cultural values and beliefs about child development in their country of origin, including lack of awareness about autism and pronounced stigma surrounding autism and mental health conditions.

In contrast to their tendency to disclose autism to immediate family members, mothers tended not to share the diagnosis with extended family out of fear that their child would be treated differently, which resulted in strained family relationships. Mothers also reported feeling more comfortable talking about the diagnosis with other parents of children with autism to learn about available services.

**Discussion:** This study indicates that a primary concern for mothers in disclosing their child’s diagnosis to family members is fear of negative perceptions and evaluations related to their child’s behavior. Additionally, while parent-provider communication about autism is important, it is also imperative to understand how cultural beliefs influence parents’ decision-making about whether to share their child’s diagnosis or not. Examining the cultural nuances at play may help adapt interventions and existing social services to promote communication within the family and reduce parents’ experiences of isolation and low social support.

**References/Citations:**

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**Paper Title:** Borderlands of Culture and Disability: The Experiences of Bilingual, Bicultural Latino Parents of Children with Autism Spectrum Disorder in Los Angeles County

**Authors:** Amber M. Angell⁵, Lucía I. Floríndez⁶, Daniella C. Floríndez⁶

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Introduction: Latino children in the U.S. experience persistent barriers in access to ASD diagnosis and services (Magaña et al., 2013; Zuckerman et al., 2017). There is a growing body of research attempting to understand and address these disparities. However, there is a dearth of research using longitudinal, in-depth qualitative methods to investigate the complex role of culture in how, when, and what Latino families come to know about ASD. Further, few ASD studies investigate differences among groups of Latinos with varying degrees of acculturation, e.g. parents who are recent immigrants to the U.S. versus those who occupy a “borderland” (Anzaldúa, 2012) of biculturalism. Therefore, the purpose of this study was to understand the experiences of bilingual, bicultural Latino families in Los Angeles County related to obtaining an ASD diagnosis and services for their children.

Methods: This 12 month ethnographic study with 12 bilingual Latino families of children with ASD and was carried out in two phases. Phase 1: Two audio-recorded narrative interviews were conducted with 12 families (19 parents, 1 grandmother) about their experiences obtaining a diagnosis and services for their children. After Phase 1, 6 families were recruited using heterogeneity sampling to continue to the next phase. Phase 2: Narrative interviews and participant observation were conducted with 6 families (11 parents, 7 children with ASD) in home, clinic, school, and community contexts. Children’s health and educational records provided data triangulation. The total data corpus consists of almost 80 hours of audio- and video-recorded data (40 interviews, 10 observations, 60 fieldnotes) and 333 records. The first author used NVivo 10 software to code all references to Latino culture or related concepts, using a narrative approach of keeping stories intact. The three authors then independently coded the subcorpus for this analysis (56 single spaced pages of transcripts), using a narrative and discourse analytic approach (Angell & Solomon, 2014), and discussed and resolved any differences.

Results: The parents’ narratives about coming to understand ASD, obtaining a diagnosis for their child, and managing their child’s services, revealed their place at the intersection of three socioculturally-influenced views of ASD: 1) An embedded Latino cultural view of disability, represented by extended family projecting feelings of stigma, pity, or blame for the child’s developmental and behavioral challenges; 2) a biomedical view of ASD, represented by professionals’ emphasis on ameliorating the child’s impairments; and 3) an “acceptance” view of ASD, propagated in social media and parent support groups that emphasized accommodating the child’s differences. The parents’ conflicted feelings about the opinions of their extended family members led to reduced contact with them, which the parents described as a significant loss. At the same time, the parents also viewed their culture as positively contributing to their determination and persistence to support their child. These competing interests exemplify the difficulty of constantly having to navigate “borderlands.”

Discussion: To reduce disparities in ASD diagnosis and services, a more nuanced understanding of different groups of Latinos with different degrees of acculturation is needed. These findings provide insight into how bicultural, bilingual Latino families’ place within a cultural “borderland” influenced their understanding of ASD, and how this shifted over time. These findings have implications for education and support of bilingual, bicultural Latino parents of children with ASD.

References/Citations:

Paper Title: Barriers and Needs of Parents Caring for Children with ASD in Rural Areas

Authors: Yue Xu⁵, Sandra B. Vanegas¹, Sandy Magaña¹, & Tamar Heller⁵

Introduction: Research on Autism Spectrum Disorders (ASD) has found significant disparities in access to services and outcomes in rural communities. Rates of diagnosis are lower among rural areas when compared to urban areas (Dickerson et al., 2017), and when children from rural areas are diagnosed, they are typically diagnosed much later than children from urban areas (Mandell, Novak, & Zubritsky, 2005; Kalkbrenner et al., 2011; Rhoades, Scarpa, & Salley, 2007). Little is known about the experiences of parents of children with ASD in rural communities. With more information about the barriers and needs of parents in rural areas, we can identify and address the specific needs of children with ASD and their families within rural communities. The objective of the current study is to identify the unmet needs and barriers parents of children and youth with ASD face in rural communities.

Methods: Parents of children and youth with ASD under 22 years of age within rural counties in eastern Illinois were recruited to participate. Rural counties were defined by the Office of Rural Health Policy (2016). Parents were recruited through schools, community agencies, and service providers. Two experienced investigators led the focus group discussions and followed a specific order of topics and prompts. The focus groups were semi-structured to provide parents with an opportunity to share openly and took place in a local community agency. The focus group focused on the following topics: Sources of information, Barriers to accessing services, Transition/future planning, and Impact of ASD on families. The focus group included a total of 8 participants and lasted approximately 150 minutes. It was audio-recorded and transcribed to identify common themes.

Results: The focus group participants were seven mothers and one father of children/youth with ASD ranging from seven to eighteen years of age. The following themes were commonly expressed by parents under the topics identified above. 1) Source of information: Other parents of children with ASD and online social media parent groups were the main sources of information. 2) Barriers to accessing services: Long distance travel for needed services and a lack of trained educational and healthcare professionals were the most common barriers. 3) Transition/future planning: Parents expressed lack of timely information about transition and legal support for future planning. 4) Impact of ASD on families: Parents reported social isolation, lack of attention devoted to typically developing siblings, and positive influences on parenting practices. Families also reported the resilience of parents and siblings as underlying the impact of caring for a child with ASD in rural communities. Specific subthemes and recommendations to address barriers and unmet needs will be discussed.

Discussion: Little is known about the experiences of parents of children with ASD in rural areas. As many disparities regarding access to and receipt of services have been identified for children with ASD and their families in these areas, it is critical to identify ways to adequately address these disparities. In identifying the critical needs and barriers parents experience in rural areas of the United States, greater efforts can be made to alleviate these disparities.

References/Citations: