**Symposium Title:** Moving Beyond Ethnic Disparities in ASD: Transforming Cultural Strengths into Tangible Tools

**Chair:** Shana R. Cohen¹

**Discussant:** Sandy Magaña²

**Overview:** Low-income, Latino families, have lower rates of ASD diagnosis, special education use and participation in treatment in comparison to White families (Bilaver, et. al., 2016; Magaña, et. al., 2016). Studies have shown that the provision of ASD diagnostic protocols and treatment may be dependent upon race and ethnicity. For example, race-based discrepancies in state spending of ASD services persist across California. In 2014-2015, the California Department of Developmental Services spent a total of $9,571 per Latino child, as compared to $11,480 per White child (Leigh, et. al., 2016). Numerous studies have acknowledged that systemic barriers exist for culturally diverse families accessing diagnostic and treatment services. Few studies have identified culturally responsive modifications of evidence-based ASD treatments for immigrant families (Harris, et. al., 2014; Lau, 2006). The following four studies utilized strength-based approaches to better understand how to transform interventions to be more meaningful for immigrant children and families. The first paper utilizes a case study methodology to describe the process of obtaining an ASD diagnosis for four Mexican immigrant families. The second paper follows Latino parents after having received an ASD screening to examine the quality and quantity of child-centered services, and how parents accessed those services. The third paper examined immigrant mothers’ and children’s daily activities, and how those activities were integrated into ASD interventions. Findings will support focused modifications of ASD interventions. The fourth paper examined how parent promotoras were utilized to support parent participants engaging in a randomized control study of a newly developed parent advocacy program. Collectively, these four studies capitalize on the strengths and resources of immigrant families to support the development of culturally informed interventions.

**Paper 1 of 4**

**Paper Title:** Understanding the ASD Referral Process of First-Generation Immigrant Mothers Who Rear Children with ASD

**Authors:** Jessica Miguel¹, Jessica Trejos Canela¹, Shana R. Cohen¹

**Introduction:** Securing and providing access to an autism diagnosis is a difficult task for both parents (Suma et al, 2016) and practitioners (Zuckerman et al, 2013). However, Latino and immigrant communities often experience increased barriers to diagnosis (Gonzalez et al., 2015; Hibel & Jasper, 2012; Liptak et al., 2008). Research indicates that Latino and Black children have a higher incidence of difficulties acquiring access to specialists and obtaining care within a reasonable time frame, as well as a higher mean age of diagnosis for ASD (Liptak et al., 2008; Wise et al, 2010). Additionally, research conducted on migrant communities’ points to a lower incidence of services for immigrant children in school systems and an increased risk for diagnosis of a learning disability as they go up in grade level (Hibel & Jasper, 2012). American health and education professionals cite impediments in diagnosing ASD among migrant communities such as lack of specialists in the community, and clinicians’ lack of cultural and linguistic competence (Gonzalez et al., 2014; Jegatheesan, Fowler, & Miller, 2010). The purpose of this study was to provide an in-depth understanding of four first-generation immigrant mothers referral experiences in obtaining an ASD diagnosis for their child.

**Methods:** The present sample was drawn from a larger study of 38 Mexican-heritage mothers in border communities in Southern California. Four mothers were selected as representative of the larger group. Participants were selected by three key characteristics; child’s age of diagnosis, number of referrals prior to diagnosis, and number of notable referral circumstances. The three markers were identified by isolating the trajectory to ASD diagnosis of each of the 38 participants. Then, each trajectory was coded for each of the three characteristics. Notable referral circumstances included any experiences that may have impacted the referral and diagnosis process (i.e. child receiving a diagnosis in Mexico; child receiving two separate diagnoses). The four participants selected have a mean age of 42 (SD = 2.16), immigrated to the United States between the ages of 16 and 38 years old, and have at least one child diagnosed with ASD. For a full examination of each mother’s key characteristics, please refer to Figure 1.

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In order to effectively detail the referral process, this study employs a case study approach to develop each family’s referral story based on the three key characteristics. Utilizing a critical sociocultural approach (Holloway et al., 2018) and grounded theory (Miles et al., 2014) interview transcripts were read, analyzed, and summarized, identifying key details of the referral process. Each family’s referral story was read and edited by all research members.

**Results:** Mothers’ referral stories had very different pathways to ASD diagnosis. The first mother, Elena³, felt that she had received the appropriate services and interventions for her child, as she stated how much her child flourished after receiving a diagnosis and appropriate treatment. She explained that her pediatrician had listened to her initial concerns about her child’s development. The second mother, Emilia, describes the diagnostic pathway for her first son, out of three, all diagnosed with autism. She described the difficulty in coming to terms with the diagnosis. Emilia also described how she obtained ASD services in Mexico and her beliefs about advocating for her children without U.S. citizenship. The third mother, Marcela, had two children with ASD and described her experience living in a border town close to Mexico. While her initial access to diagnosis and intervention was timely, she described how her child’s current services had been removed and she was seeing signs of regression in her child due to this halt in services. The fourth mother, Graciela, described her emotional difficulty in accepting the diagnosis, the difficult transitions that occurred due to breaks in services and the re-evaluations required in order to restore services.

**Discussion:** This qualitative examination of the referral experiences for Mexican-heritage mothers provides a narrative to much of the data that exists on diagnostic disparities in ASD (Liptak et al., 2008; Zuckerman et al, 2013). Emphasizing the sociopolitical and day to day realities of these four families can help practitioners in creating culturally relevant and accessible diagnostic pathways. Specific recommendations will be provided to support clinicians and practitioners in the development of culturally appropriate diagnostic protocols.

**References/Citations:**


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³ All participants’ names are pseudonyms to protect privacy.
Figure 1 Key Characteristics of Study Participants
Paper 2 of 4

Paper Title: From Screening to Services: A Follow-Up of Latino Parents with Children At-Risk of ASD

Authors: Ann Marie Martin4, Yasmine Bolourian4, Jan Blacher4

Introduction: Early identification for children with autism spectrum disorder (ASD) has been widely encouraged for its potential to improve developmental and behavioral outcomes (Withrow, 2008). The effectiveness of early screening and diagnosis hinges on the successive receipt of interventions and service supports. Yet, many parents of children with ASD, particularly those from minority backgrounds, experience a disconnect in the pipeline from screening to services. For Latino families, barriers contributing to service inequities include English proficiency, cultural discrimination, and limited knowledge about the child’s disability (Angell & Solomon, 2017; Magaña et. al, 2013; Ravindran & Myers, 2012). However, the various pathways from screening to services from the first-hand accounts of Latino parents with at-risk children are poorly understood. Thus, the purpose of this study was to follow up with Latino parents after an ASD screening to explore the quality and quantity of child-centered services, as well as the possible mechanisms involved in accessing services.

Methods: Participants were 15 Latina mothers of children (M age=7.3, SD=3.7) who were screened for ASD at a university research center in an ethnically diverse and underserved region of Inland Southern California; this follow up took place on average 7.9 months later. At the time of screening, children were assessed for ASD using gold standard assessments (e.g., Autism Diagnostic Observation Schedule; Lord et al., 2012). Vineland Adaptive Behavior Scales (Sparrow et al., 2016) was used to assess daily living skills. Cognitive functioning was assessed using age-appropriate instruments (e.g., Weschler Abbreviated Scale of Intelligence; Weschler, 2011). Parents of children who screened positive for ASD received an educational consultation, as well as recommendations for appropriate services.

Telephone follow-up interviews consisting of open- and closed-ended questions, were administered in English (n=10) or Spanish (n=5). Responses were recorded using verbatim note-taking. Parents were asked about community- and school-based services acquired since screening, language preference for services, and whether recommended services were accessible.

Data on the number and types of services before and after screenings were compared. Qualitative data will be analyzed using thematic analyses. Interviews are ongoing; we expect to have completed a total of 30 interviews.

Results: School-based services: 46.7% of children had an Individualized Education Plan (IEP) prior to screening. Of children who did not have an IEP prior to screening, 40% were still unable to acquire an IEP or receive school-based services. Service Access: 40% of children secured additional services following screening. Of children who did not receive services prior to screening, 66% were still unable to access services following screening. Preferred Language for Services: 13.3% of families expressed wanting services to be in Spanish, and 20% of families felt that language was a barrier towards accessing services. Specific Service Referrals: 26.7% of families followed through and secured the recommended service, 33.3% did not follow through, and 40% attempted to follow through, but were ultimately unsuccessful.

Discussion: Forthcoming qualitative analyses are expected to reveal additional service barriers, utility of screening assessments, and parent suggestions for improved systems of care. Emphasizing a focus on culturally relevant practices, key recommendations based on these findings will be provided. This continued engagement in parent education and outreach is necessary to ensure that minority families will be better equipped to understand their children’s needs and advocate for services down the road.

References/Citations:

- Angell, A. M., & Solomon, O. (2017). ‘If I was a different ethnicity, would she treat me the same?’: Latino parents’ experiences obtaining autism services. Disability & Society, 32(8), 1142-1164. doi: 10.1080/09687599.2017.1339589

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Paper Title: Examining the Daily Routines and Activities of Immigrant Families and Their Children with ASD

Authors: Shana R. Cohen¹, Jessica Miguel¹

Introduction: Research suggests that autism interventions are most effective when they are integrated into the daily routines and activities of the family (Bernheimer & Weisner, 2007; Kashinath, Woods, & Goldstein, 2006). Few studies have examined the daily routines of Mexican immigrant mothers and their children with ASD. Utilizing a strength-based perspective within an ecocultural framework, this study examined immigrant mothers’ and children’s daily activities, mothers’ assessment of those activities, and how those activities were integrated into ASD interventions. Findings will be used to adapt standardized interventions to be more meaningful and efficacious for immigrant families.

Methods: Participants included (N = 38; M age = 36.09; SD = 6.13) first generation, immigrant mothers living in border communities around San Diego rearing young children with ASD (M age = 6.1; SD = 2.37). The majority of the sample, 61.2%, reported an annual income under $35,000, and 72% of mothers had less than an associate degree. Mothers completed daily, repeated online surveys (5 times per day over 5 days) asking them to describe their activity at the moment, whether the activity was a part of the child’s intervention, and how parents valued that particular activity (e.g., 1 = not important; 5 = very important; 1 = not enjoyable; 5 = very enjoyable). Paired sample t-test were used to compare the frequency of each activity considered to be an intervention or non-intervention activity.

Results: Of the total documented observations (N = 721), mothers’ most prevalent activities included: Self-Care (e.g., showering; 22%), General Caregiving (e.g., cooking dinner; 19%), and House Chores (e.g., laundry; 13%). Children’s most common individual daily activities included Academics (28%), Self Care (27%), and Playing with Others (13%). The most frequent joint activities between mother and child included General Caregiving (21%), Playing with Others (16%), and Using Electronics (14%). Mothers reported being less likely to consider their own (t = -4.05, p < .05, Cohen’s d = 0.61), their child’s (t = 3.41, p < .01, Cohen’s d = .50), or joint (t = -3.50, p < .05, Cohen’s d = 0.91) Self Care activities as part of an ASD intervention. Mothers were less likely to consider House Chores as part of an ASD intervention (t = -3.71, p < .001, Cohen’s d = 0.78). Mothers were more likely to consider Playing with Others and Academics as part of their child’s intervention (Mother: t = 2.41, p < .05, Cohen’s d = 0.38; Mother: t = 2.41, p < .05, Cohen’s d = 0.48; Joint: t = 2.02, p < .05, Cohen’s d = 0.31). Mothers were less likely to consider Traveling or Border Crossing as part of their child’s intervention (Mother: t = -2.54, p < .01, Cohen’s d = 0.52; Joint: t = -3.17, p < .01, Cohen’s d = 0.71).

Mothers’ perceived value of the activity was measured along four domains: Importance, Interest, Enjoyment, and Difficulty. Engaging in Self Care activities was associated with lower ratings on importance (r = -0.38, p < 0.05), interest (r = -.42, p < 0.05), and enjoyment (r = -0.50, p < 0.05). General Caregiving was associated with positive ratings on importance (r = .42, p<0.05). House Chores was associated with positive ratings on enjoyment (r = .39, p < 0.05). Working out of the House was associated with positive ratings on interest (r = .72, p = 0.05).

To examine how mothers integrated ASD intervention activities into daily routines, we compared the proportion of time each activity was identified as part of the child’s intervention to the total number of times the mother reported engaging in each activity. Of the 721 total observations, mothers identified 26% of their daily activities (N = 187.5 observations) as part of the
child’s ASD intervention program. Intervention activities were commonly integrated into Academics, Playing With Others, and General Caregiving.

**Discussion:** Self Care and General Caregiving activities were considered the most frequent activities for mothers. Findings partially align with previous cross-sectional studies showing that immigrant mothers engage in more child-centered (e.g., playing with the child) and household activities (e.g., cooking) (Holloway, et. al., 2014). In this study mothers reported more frequent household activities. Children were engaging in activities in which interventions could easily be integrated. Yet, immigrant families and their children with ASD are spending less than one third of their daily activities participating in ASD interventions. Mothers and children are jointly spending time in General Caregiving, Playing with Others, and Using Electronics. Practitioners should focus on integrating evidence-based interventions into these daily routine activities where they are already together.

**References/Citations:**

  https://doi.org/10.1097/01.IYC.0000277751.62819.9b


**Paper Title:** Parents Taking Action: Influence of Community Health Worker Engagement with Latina Mothers of Children with Autism Spectrum Disorder

**Authors:** Kristina Lopez⁵, Sandy Magaña², Mariana García⁶, & Jessica M. Marroquin⁵

**Introduction:** Persistent disparities in age of diagnosis and treatment access exist for Latinx children with autism spectrum disorder (ASD). In order to reduce disparities among Latinx children with ASD, culturally informed interventions are recommended (Lopez, 2014). Parents Taking Action (PTA; Magaña, Machilicek, Lopez, & Iland, 2018) is a culturally tailored psychoeducation program designed to address disparities for Latinx children with ASD and their families. A 14-week intervention curriculum was developed in collaboration with community-based partners. An important aspect of addressing the cultural needs of participants was to have the intervention delivered by promotoras de salud, or community health care workers who were also parents of children with ASD. Subsequently, parent promotoras can provide peer-mentorship from both a cultural and disability standpoint. For the present study, we were interested in exploring how promotoras influenced the participants in the study.

**Methods:** We conducted a randomized control trial of PTA in which 110 Latinx mothers were randomly assigned to a treatment now or treatment later group. Methods and findings from the larger study were reported elsewhere (Magaña et al., 2018). For the purposes of the present study, those in treatment now (mothers mean age 37.9, SD=5.3; children mean age 5.5, SD=1.8) were asked to participate in focus groups after completing the follow-up assessments. Focus groups were conducted to collect qualitative data about the experience’s mothers had throughout their participation in PTA and areas for development. Five focus groups were conducted with 20 mothers in Spanish, the preferred language of participants. The majority of mothers were immigrants to the US. Focus groups were recorded, transcribed, translated to English, and analyzed using directed content analysis.

**Results:** Themes emerged regarding the role of the promotoras throughout the intervention program. Participants shared that promotoras provided a source of social support. Social support was defined as “someone to share with... like a friend... similar to a therapist and counselor”. Another theme endorsed by participants was that the promotoras were empathic. Participants

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stressed they felt the empathy because “promotoras had personal experience like theirs... had already gone through what we were going through... just understood”. A third theme was the value of continuity of the relationship with promotoras. Mothers were able to develop a strong rapport with their promotora over the time of the intervention.

Discussion: The results of this study indicate that Latinx mothers of children with ASD may benefit and desire peer to peer support programs, delivered in a culturally informed manner. Having peers as interventionists may be especially salient for immigrant mothers of children with ASD who often feel isolated linguistically, culturally and because of their child’s disability. Implications for research and practice will be discussed.

References/Citations: