Symposium Title: Challenges and Perspectives of Immigrant Families of Children with Developmental Disabilities

Chair: Yue Xu

Overview: Immigration has become a topic central in political and public debate in the US. The number of immigrants accounts for 13.6% of the US population (US Census, 2017). And it is predicated that immigrants and their descendants will account for 88% of U.S. population growth through 2065 (PEW Research Center, 2019). However, there is a huge gap in research on immigrant families of children with developmental disabilities (DD). While there is a large body of work that has examined experiences and challenges faced by families of children with DD, much of the research has focused on individuals with DD and families from primarily White, middle-class, English-speaking households. The lack of literature on the fast-growing immigrant population is alarming as more and more immigrant families encounter the personal, cultural and systemical challenges raising children with DD.

The ecological framework has been applied in this symposium. The four papers address different levels of experiences of immigrant families of children with DD. The first presentation focuses on stress and coping among Asian immigrant families raising children with DD in the micro level. The second presentation explores the similarities and differences in how US-born and non-US-born parents experience the autism spectrum disorder (ASD) screening and assessment process. The third paper examined factors related to the age of diagnosis of children with ASD from immigrant and non-immigrant backgrounds. These two papers on diagnosis and screening highlight the meso level experiences of immigrant families of children with ASD. Finally, the fourth paper touches on issues in-between the meso and macrolevel systems by thoroughly synthesizing existing evidence on barriers and access to services among immigrant families of children with DD. Collectively, these presentations underscore the challenges faced by immigrant families of children with DD and advocate for policies and practices that better support these families.

Paper 1 of 4

Paper Title: Stress and Coping of East Asian American Parents of Children with Developmental Disabilities: A Scoping Review

Authors: Irang Kim, Yao Wang, Sarah Dababnah

Introduction: Corresponding to the fast growth of the U.S. Asian population, the number of Asian American (AA) children with developmental disabilities (DD) is increasing (Rice et al., 2010). Yet, the academic literature on the experiences of AA families is limited. Research generally finds parents of children with DDs reported higher levels of parenting stress compared to parents of typically developing children (Gupta, 2007). In light of the limited research on AA parents raising children with disabilities, we reviewed the extant literature related to this population. Given the diversity of cultures within the AA communities, we focused on East AA, who share similar cultures. We posed the following research questions: 1) How were East AA populations represented in studies? 2) what the risk and protective factors did the articles identify for coping with parenting stress?

Methods: A reference librarian searched four databases (PsycINFO, Academic Search Complete, ERIC, and Scopus) from inception to October 2018. The keywords include (autism OR Asperger’s OR pervasive developmental disorder) AND (Asian American OR Chinese American OR Korean American). In total, we retrieved 100 references from all databases after removing duplicates. We screened the titles and abstracts of all the articles we retrieved. We included both studies focusing on East AA parents of individuals with DDs in the U.S., and studies in which East AA parents are part of sample to compare between East AA

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and other race/ethnicity groups. We excluded studies conducted more than twenty years ago. The number of final analytic papers is eleven.

**Results:** Most studies (n=7) used qualitative methods and were conducted in California. Eight studies targeted immigrants who mostly lived U.S. more than 10 years. The parents were raising children of various ages, ranging from 2 to 22 years old including autism, intellectual disabilities, communication disorder, and Down syndrome. Disability-related shame, understanding of the nature of child’s DD, language barriers, and Asian American ethnicity are identified as risk factors to cope with stress. Family and community support, parents’ perceptions of a better U.S. educational system, social services, positive attitudes, spiritual support, and using passive appraisal are identified as protective factors to cope with stress.

**Discussions:** Overall, studies on East Asian American families of children with DDs used limited research methods, samples characteristics, sample sizes, which indicate the samples do not represent the East Asian populations in the U.S. Identified risk factors indicate that shamefulness is the dominant emotional reaction toward their child with DDs, but parents who lived more than 10 years in the U.S and were highly educated did not feel shameful toward their child diagnosis. Language barriers impeded the utilization and navigation of U.S. health care system among AA parents of children with DDs. For families of specific AA ethnic group, we found that most Korean samples reported they received a lot of community supports from local Korean churches while how Chinese American parents are involved in community services is unknown. The review suggests that there is a need for a comprehensive nationwide data collection on East Asian American families that includes various sample characteristics to generalize findings to this population.

**References/Citations:**


**Title:** Parents’ Decision Making After A Positive Autism Spectrum Disorder Screen: Perspectives From US-Born and Non-US-Born Parents

**Authors:** Deniz Kizildag¹, Jenna Eilenberg, MA, MPH³, Anjali Oberoi, BA⁴, Kristin A. Long, PhD³

**Introduction:** A growing body of research has shown the positive effects of early diagnosis and intervention in improving the quality of life of individuals with autism spectrum disorder (ASD) (Elder et.al., 2017). In line with this research, the American Academy of Pediatrics recommends universal autism screening at the 18 and 24-month well-child visit (Gura et. al., 2011). However, in 2016, the US Preventive Services Task Force (USPSTF) published a report determining that there was insufficient evidence to support universal screening for ASD in primary care. The report cited a lack of sociodemographic diversity in ASD research as one of the reasons for its conclusion (Siu et. al., 2016). Perceptions of developmental delays vary by culture (Bernier et. al., 2010), but little is known about how cultural perceptions influence parents’ decision-making processes after a positive ASD screen. The current study explores similarities and differences in how US-born and non-US-born parents experience the ASD screening and assessment process, specifically how language and culture affect a family’s interaction with medical professionals and interpretation of medical advice.

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Method: Parents whose child received a false-positive ASD screen from Boston, Philadelphia, and New Haven were recruited through an ongoing trial aiming to reduce disparities in ASD diagnosis. Parents completed semi-structured, in-person interviews, conducted in Spanish or English according to parents’ preference. Families were asked questions about their experiences with (1) autism screening, (2) pediatrician recommendations, (3) the developmental assessment process in which they made several visits to a clinic for further evaluation. A coding structure was developed based on recurring themes and was updated through an iterative process. For this analysis, parents were stratified into two groups - parents born outside the US and parents born in the US - in order to examine cultural differences that influence families’ experiences with communicating with medical professionals and navigating through the evaluation process.

Results: Twenty-seven racially and ethnically diverse families participated (56% US-born, 44% non-US-born). All parents reported that they decided to follow their pediatrician’s recommendations after a positive ASD screen; however, their reasoning for following recommendations differed according to US nativity. US-born parents reported deciding to follow the recommendations primarily because of the benefits to their child’s development. Non-US-born parents expressed deciding to follow the recommendations primarily because the referrals made by the pediatrician, family navigator, and Early Intervention specialists gave direction to them when they were overwhelmed and confused about navigating the developmental evaluation process. Non-US born parents also discussed differences in the way child development is viewed and monitored within their culture, and parents who were immigrants from countries where ASD wasn’t a well-known diagnosis expressed confusion about what autism meant and how it was different from having developmental delays. Non-US born parents also expressed that having medical providers who understood their culture increased their trust in the provider and their likelihood to follow through on recommendations.

Discussion: Overall, all parents mentioned following recommendations to the best of their ability and expressed appreciation for the services. Whereas US-born mothers followed pediatrician recommendations after a positive ASD screen primarily because they believed the services would improve their child’s development, non-US-born mothers followed the recommendations because it gave them concrete steps to follow in an otherwise confusing process. The experiences of non-US-born parents in this study also highlight the importance of culture- and patient-specific communication and understanding of different views of child development in different cultural contexts. These data address the concerns of the US Preventive Services Task Force report about the lack of diversity in ASD research by contributing the perspectives of racially and ethnically diverse parents who have received a false positive ASD screen. Findings indicate that universal ASD screening is beneficial for families from diverse backgrounds because it triggers a series of concrete steps that lead to helpful services, regardless of whether or not the child receives an ASD-specific diagnosis.

References/Citations:

**Paper Title:** Examining Factors Related to the Age of Diagnosis of Children with ASD from Immigrant and Non-Immigrant Backgrounds

**Authors:** Sandra B. Vanegas

**Introduction:** Significant disparities continue to persist among racial/ethnically diverse children with ASD despite increased efforts to improve awareness and outreach (Magaña et al., 2013). However, within racial/ethnically diverse communities, immigrant families may face additional challenges in accessing health care and related services (Becerra et al., 2014; Lin, Yu, & Harwood, 2012). This may be due to a number of issues, such as awareness of health care policies, language, and financial resources (Fellin et al., 2013; Welterlin & LaRue, 2007). These factors can pose significant barriers to children with ASD in receiving timely services and supports for improved long-term outcomes. To improve our understanding of the unique challenges faced by immigrant families of children with ASD, it is important to consider the underlying factors that may affect the age of diagnosis.

**Methods:** Medical records were reviewed for all children who had received an ASD diagnosis at a developmental disabilities clinic located in a large, metropolitan city in the Midwest, United States. Records were reviewed for all children who had received a clinical evaluation between 2004 and 2014. Data was obtained from the intake documentation, diagnostic reports and records (education, healthcare) that were requested at the time of the clinical evaluation. Maternal immigration status and years in the U.S. was extracted from the clinical reports. The final sample included 219 children, with 110 children with ASD with U.S.-born mothers and 109 children with ASD with non-U.S.-born mothers.

**Results:** Univariate analysis of variance was conducted to identify significant factors on the age of diagnosis of children with ASD. Maternal immigrant status, primary home language, child language status, and insurance status were entered into the model as between-subjects factors. Maternal education level was entered as a covariate in the model. Significant two-way interactions were found: Maternal Immigrant Status X Primary Home Language, \( F(1, 202) = 4.41, p = .037, \eta^2_p = 0.02 \). Maternal Immigrant Status X Child Language Status, \( F(1, 202) = 3.76, p = .025, \eta^2_p = 0.04 \). Among children with ASD with mothers born in the U.S., the age of diagnosis was later for children who resided in homes with a non-English language as a primary language (\( M = 5.38, SE = 1.59 \)) when compared to children with ASD who resided in homes with English as a primary home language (\( M = 4.07, SE = 0.47 \)). Additionally, minimally verbal children with ASD with U.S.-born mothers were diagnosed earlier (\( M = 4.41, SE = 0.84 \)) than monolingual children with ASD (\( M = 5.16, SE = 0.26 \)). This was in contrast to children with ASD with non U.S.-born mothers where age of diagnosis was later for minimally verbal children (\( M = 5.38, SE = 0.81 \)) than bilingual children (\( M = 4.24, SE = 0.68 \)). Additional analyses will disentangle the role of language factors in the early diagnosis of children with ASD.

**Discussion:** This study set out to examine factors that were related to the age of diagnosis among children with ASD who had visited a developmental disabilities clinic in a large, metropolitan city. By examining medical records, we could more closely examine the specific child and family characteristics from populations that are typically under-represented in research studies. The results of this study showed that home language, child language status may play a differential role in the age of diagnosis among children with U.S.-born and non U.S.-born mothers. These findings can inform general policies and practices in clinical settings to facilitate the diagnostic services that are provided to culturally diverse communities.

**References/Citations:**

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**Paper 4 of 4**

**Paper Title:** A Scoping Review on Barriers and Access to Services Among Immigrant Families of Children with Intellectual and Developmental Disabilities (IDD)

**Authors:** Weiwen Zeng6, Yue Xu1, Yao Wang2, Sandy Magaña6

**Introduction:** In the past two decades, the number of international migrants has grown drastically (United Nations, 2017). With the rise of immigration, it is critical to examine the experiences of immigrant families of children with IDD. Literature has shown that immigrant families of children with IDD are underserved in current healthcare system (Lin, Yu, & Harwood, 2012). Barriers to diagnosis and treatment services often lead to negative outcomes for both children with IDD and their family caregivers (Sritharan & Koola, 2019). Culturally relevant evidence-based interventions to address immigrant families’ needs are emerging (Lopez, Magaña, Morales, & Iland, 2019). However, there is a lack of systematic synthesis of existing literature on the barriers and access to services. A close examination of barriers faced by immigrant families can help inform intervention design and clinical practices with this population. Therefore, this study sought to systematically review existing research evidence from peer reviewed journals published between 2000 and 2019 and unpublished doctoral dissertations, on barriers and access to services among immigrant families of children with IDD in North America.

**Methods:** We conducted a systematic search in ten electronic databases and assessed the reference lists of relevant studies and reviews to identify eligible articles. Three reviewers independently screened studies, extracted data, and synthesized relevant findings. For qualitative studies, we used thematic analysis strategy to identify themes that were relevant to barriers and access to services. For quantitative studies, we sought to identify significant socioeconomic and cultural factors that predicted these barriers.

**Results:** Our search yielded 665 studies with 25 meeting the inclusion criteria. Eighteen qualitative and seven quantitative studies were included for the final synthesis. A total of 1300 immigrant parents of children with IDD were included in these studies (425 residing in Canada, 875 in the US). Only one intervention study addressing barriers faced by immigrant families was found. Thematic analysis results based on qualitative studies suggest that language barriers, misinformation on IDD, the lack of information on how to access services, inadequate provision and coverage of health insurance, and the lack of care coordination in the service system are the most salient barriers, as perceived by immigrant parents/primary caregivers of children with IDD. Quantitative synthesis results suggest that barriers were associated with immigrant status, parents’ nativity, English language proficiency, child age, and availability and affordability of services.

**Discussion:** To our knowledge, this scoping review is the first to systematically examine existing evidence on barriers and access to services among immigrant families of children with IDD. More culturally relevant intervention research is needed to address barriers faced by this population. Findings from this study also illustrate the importance of providing culturally competent and

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accessible services to immigrant families in the US and Canada, given the rapid growth of immigrant population, and an increasingly hostile political atmosphere towards this marginalized group.

References/Citations: