**Symposium Title:**  Toward Equity in Identification and Service Delivery for Latino Families and Children with ASD

**Chair:** Jan Blacher

**Overview:** “The worst form of inequality is to try to make unequal things equal.” Surely Aristotle was not referring to screening, diagnosis, and intervention for autism spectrum disorder (ASD). Yet for the last decade and a half, we as a field have realized inequities in services for underrepresented families who had children with ASD. Merely translating an instrument or delivering an “intervention as usual” may not smooth the uneven playing field. This symposium delves into this issue by considering ethnicity in a more nuanced manner, or by developing or delivering interventions for ASD to Latino families with more cultural sensitivity. The first presentation sets the stage for those that follow by presenting screening clinic results that provide insights into some of the inequities in ASD diagnosis and allocation of services in California. The second presentation focuses on an educational program for Spanish-speaking parents of children with ASD, *Parents Taking Action (PTA)*, in California. This program is delivered via promotoras de salud (community health workers) who are bilingual Latina mothers of children with ASD. The third presentation also describes implementation of the *PTA* program, but in Bogota, Colombia, and with a methodological twist – comparing delivery by student therapists and mothers of children with ASD. Finally, the fourth presentation focuses on the transition to adulthood, and the speaker will present results of a pilot study documenting the cultural adaptation of the *Transitions Together* program. We aim for audience discussion and consideration of the progress made toward meeting intervention needs of Latino families who have children and adolescent youth with ASD.

1University of California, Riverside

---

**Paper 1 of 4**

**Paper Title:** Anglo-Latino Differences in Autism Screening: Service Inequity or a Diagnostic Conundrum?

**Authors:** Jan Blacher, Yasamine Bolourian, Katherine Stavropoulos

**Introduction:** Although there are few systematic differences in the prevalence of ASD among ethnically diverse children (CDC, 2009), Latino children are less likely than their Anglo peers to be diagnosed with ASD (Zuckerman et al., 2015). One reason may be that fewer concerns are reported by Latino parents (Blacher et al., 2014), suggesting differences in perception of symptoms between cultures. Furthermore, once ASD is identified, Latino families may experience more limited access to services (Magaña et al., 2013).

Research questions: (1) Do earlier findings of ethnic differences in parent concerns hold up with a larger sample (Blacher et al., 2014)? (2) Within Latino families, do primary language and maternal education affect parental ratings of child symptoms? (3) Do ethnic differences relate to services received?

**Methods:** Participants were 218 parents (Anglo = 85; Latino = 133) and their children referred for autism screening at a university clinic in a large county where Latino families constitute 48.4% of the region (U.S. Census Bureau, 2016). Mothers completed an intake form to determine: parent’s current concerns (22 checklist items, 0 = not a concern and 1 = yes, a concern), parental education, and primary language (Spanish versus English). Autism classification and symptomology were determined by the Autism Diagnostic Observation Schedule (Lord et al., 2012) and the Social Responsiveness Scale (Constantino & Gruber, 2005). Child problem and social behaviors were assessed with the parent-completed Child Behavior Checklist (Achenbach & Rescorla, 2001) and the Social Skills Improvement System (Gresham & Elliott, 2008).

**Results:** (1) There was a significant main effect of ethnicity on current concerns, $F(1, 193) = 14.52, p < .001$; Anglo mothers reported more concerns. Additionally, there was a significant main effect of age, $F(1, 193) = 5.48, p = .02$; mothers of children older than 6 years reported significantly more current concerns than mothers of younger children. There were no significant ethnic differences on ADOS classification or SRS symptoms. (2) Spanish-speaking Latino mothers reported significantly more symptoms than English speaking Latino mothers on the SRS, $t(48) = 2.08, p = .04$. Also, Latina mothers with less education reported more symptoms on the SSIS, $t(58) = 2.38, p = .02$, and the CBCL, $t(74) = 2.21, p = .03$, than more educated Latina mothers.
(3) A 2 x 2 ANOVA found Anglo-Latina differences on total services received by ADOS classification. A significant interaction effect, $F(1, 188) = 8.82, p < .01$, indicated that Anglo children with ASD received more services than Latino children with ASD.

Discussion: There are three take-away findings: (1) Despite no child ethnic differences on the ADOS, Anglo mothers reported more concerns. (2) The differences between reports of Spanish vs. English speaking Latino mothers should be explored further, given that mothers who are less acculturated are nonetheless tuned in to the challenges of their children and can report concerns. (3) Latina mothers who received a confirmatory diagnosis of ASD for their child were at risk of being left behind when it comes to the number of services received (Harstad et al., 2013).

References/Citations:

- United States Census Bureau, *Quick Facts, California*. doi: https://www.census.gov/quickfacts/CA

1University of California, Riverside

Paper 2 of 4

Paper Title: Parents Taking Action California: Addressing Disparities in Services and Improving Outcomes for Latino Children with ASD

Authors: Kristina Lopez1, Sandy Magaña2, Wendy Machalicek3, & Miguel Morales4

Introduction: Research indicates racial and ethnic disparities among children with autism spectrum disorder (ASD) in services and treatment access, which can affect outcomes for children and their families. The California Department of Developmental Services (DDS) purchasing data shows Latinos, the largest racial/ethnic group of RC consumers have the lowest amount of authorized services and expenditures than all other major ethnic/racial groups served by the RCs (State of California Department of Developmental Services, 2016). Relevant to these data but independent from DDS, we conducted a randomized controlled trial of a culturally informed parent psychoeducation program, Parents Taking Action (PTA) in California to determine its utility in reducing documented disparities there. PTA addresses disparities for Latino children with ASD and their families and is delivered by promotoras de salud (community health workers) who are bilingual Latina mothers of children with ASD. PTA informs parents about ASD, service navigation, and how to implement evidenced-based (EB) strategies.

Methods: Participants included 26 Latino mother-child dyads. Children were diagnosed with or at risk for ASD. Following a baseline assessment, dyads were randomly assigned to a treatment now (n=12) or treatment later (n=14) group. Those in treatment now (mothers mean age 40.6, SD=5.1; children mean age 5.1, SD=1.9) immediately received the 14 sessions of PTA and two follow-up assessments (after completing the program and 4 months following). The treatment later group (mothers mean age 37.4, SD=6.1; children mean age 5.4, SD=2.1) was offered PTA after 4 and 8 month assessments. Child measures
included the Childhood Autism Rating Scale, Social and Communication Questionnaire (SCQ), and service use questions. Parent measures included the Family Outcome Survey (FOS) and parent’s efficacy with using EB strategies. The data included in this study are from the baseline and time 2 assessments. A repeated measures analysis of variance (ANOVA) was conducted to assess whether the change from baseline to time 2 was significant between the treatment and control groups for each child and parent outcome.

**Results:** For child outcomes, the repeated measures ANOVA revealed significant decreases in SCQ scores $F(1, 25) = 15.0, p < .01$ and an increase in the number of child services received $F(1, 25) = 10.8, p < .01$ for the treatment now group (vs treatment later). Findings for the parent outcomes indicate greater knowledge of rights $F(1, 25) = 13.0, p < .01$; greater access to the community $F(1, 25) = 13.1, p < .01$; increased total FOS score $F(1, 25) = 20.3, p < .001$; and enhanced efficacy in use of EB strategies $F(1, 25) = 4.6, p < .05$ among the treatment now group compared to treatment later.

**Discussion:** The findings indicate that PTA can help to increase empowerment and efficacy in using evidence based strategies among Latina mothers of children with ASD; and can enhance child social communication and the number of treatment services Latino children receive. Thus, PTA could be a useful program to address disparities identified by the California DDS system.

**References/Citations:**

---

**Paper Title:** Parents Taking Action in Colombia

**Authors:** Sandy Magaña¹, Marie Tejero Hughes⁴, Kristen Salkas², & Marisol Moreno³

**Introduction:** ASD affects approximately 1% of the world’s population and many children with ASD around the globe, including in Latin America are not receiving the supports needed due to services being limited or not available. In collaboration with a team from the Universidad Nacional de Colombia in Bogota, Colombia, we adapted and pilot-tested a parent educational intervention, Parents Taking Action for parents in. The intervention uses community health workers or promotoras, which is a mode of intervention used widely across global settings and is a cost-effective way to deliver education about health conditions and disabilities. In this study we compared two groups: families who received the intervention delivered by parents of children with ASD (parent promotoras), and families who received the intervention delivered by therapists in training (student promotoras). Our research questions are 1) did parents improve on parent outcomes between pre- and post-test in the overall sample? and 2) were there differences in parent improvement between those who had parent promotoras and those who had student promotoras?

**Methods:** Parents of children with ASD were recruited through an inclusive public school in Bogota, and 26 were enrolled in the study and randomized to the two groups. Parent outcome measures included the Family Outcome Scale (FOS), the Center for Epidemiological Studies Depression Scale (CES-D) and a scale developed by the authors to measure use of evidence-based strategies. Paired sample t-tests were used to analyze pre and post-test changes in each group. Statistical significance at the .10 level was used due to the small sample size.

**Results:** Twenty parents completed the study indicating a 77% retention rate. Overall sample results show that parents improved on the FOS subscales, understanding child’s strengths and needs, $t(20) = -2.7, p = .015$; and helping their child develop
and learn, $t(20)=-2.0, p=.065$; the overall FOS, $t(20)=-2.0, p=.068$; and their use of evidence-based strategies, $t(20)=-4.9, p=.000$. They also reported fewer depressive symptoms $t(20)=2.6, p=.018$. We found that outcomes differed by group, parents who had student promotoras reported fewer depressive symptoms at post-test, $t(10)=2.9, p=.017$; and improved on helping their child develop and learn, $t(10)=-2.4, p=.038$; and having support systems, $t(10)=-2.5, p=.033$. Parents who had parent promotoras improved on understanding their child’s strength and needs, $t(10)=-2.3, p=.050$. Both groups improved in the use of evidence-based strategies, however, the student promotoras group showed a stronger pre-post-test result (parent promotoras, $t(10)=-2.0, p=.074$; student promotoras, $t(10)=-7.7, p=.000$).

Discussion: Our findings suggest that using promotoras to deliver parent education shows promise with improving parent outcomes for parents of children with ASD in Latin America. Furthermore, both parent and student promotoras lead to positive changes in parent outcomes. However, there were more positive outcome results for student promotoras. Because students can often participate as part of an internship for their professional training, these findings demonstrate a promising parent education intervention that can be cost-effective.

1University of Texas at Austin
2University of Illinois at Chicago
3Universidad National de Colombia, B

Paper 4 of 4

Paper Title: Cultural Adaptation and Implementation of a Transition Program for Latino Families of Youth with ASD

Authors: Jocelyn L. Kuhn¹, Sandra B. Vanegas², Rod Salgado³, Stephanie K. Borjas⁴, Sandy Magaña², Leann Smith Dawalt⁴

Introduction: During the transition to adulthood, effective and culturally relevant supports are critical for families of youth with autism spectrum disorders (ASD). There is a dearth of documented program development and research on supports for Spanish-speaking Latino families during this life stage. The present project aimed to address this gap by implementing a systematic process of cultural adaptation of an evidence-based transition program for Latino youth with ASD and their families.

Methods: Building on the success of the Transitioning Together program (DaWalt, Greenberg, & Mailick, in press), the current project engaged in the cultural adaptation process and pilot implementation of a Spanish-language adaptation, Juntos en la Transición (JET). The cultural adaptation process was based on the Ecological Validity Framework (EVF) to address seven dimensions important for culturally-informed interventions (Bernal, Bonilla, & Bellido, 1995). The JET program adaptation process included the following steps to inform the seven EVF category areas: building a partnership with a local Latino parent support group, identifying a need for and interest in the program, reviewing literature on transition and Latino families, collecting local stakeholder feedback on an initial curriculum, continually updating the curriculum, and implementing the adapted program. The resulting JET program included initial joining sessions with families to obtain background information, identify youth and family goals, and foster rapport between families and the JET facilitators. The JET model also included four group sessions that consisted of simultaneous teen groups and parent psychoeducational groups on topics: Autism in Adulthood, Adult Independence and Community Involvement, Guardianship and Legal Issues, Transition/College/Employment Planning, Risks to Health and Well-being, and Intimate Relationships and Sexuality. A pilot program evaluation was conducted of the JET model with five Latino families of Mexican and Colombian backgrounds. All families had youth between 12 and 15 years of age who had an ASD diagnosis or educational classification of ASD. Satisfaction surveys were collected after each group session and exit interviews were conducted to assess social validity and acceptability.

Results: Satisfaction survey ratings found that all families reported being satisfied or very satisfied with the content of the program and all reported that the information provided was easily understood in their primary language of Spanish. At post-intervention exit interviews, parents reported that the program met an unmet need for linguistically relevant and accessible information about transition and their youth with ASD that was not easily accessed through other means (e.g., school,
community). Parents also reported that participation in the JET program empowered them to pursue services and supports for their youth with ASD and that they felt more informed about issues associated with transition (e.g., guardianship, identification card). Overall, families reported that the JET program was informative in addressing issues of transition for youth with ASD.

**Discussion:** The current work suggests that a careful process of cultural adaptation which includes consideration of the EVF framework and stakeholder input may be one way to address the significant disparities in access among culturally and linguistically diverse youth with ASD and their families.

**References:**

1 Harvard Medical School
2 University of Texas at Austin
3 University of Oregon
4 University of Wisconsin-Madison