

Symposium Title: Parenting Interventions for Diverse and Low-resourced Families and Communities

Chair: Weiwen Zeng¹

Discussant: Sarah Dababnah²

Overview: Parents are central to supporting children with autism spectrum disorders (ASD) in accessing diagnostic and early intervention services. Researchers increasingly use parents as a medium in interventions. Studies found that parenting interventions are associated with positive child and family outcomes such as reduced challenging behaviors, increased parent-child interaction and reduced maternal depression (McConachie & Diggle, 2007; Kasari et al., 2015). However, racially/culturally diverse children with ASD and their families, who often live in low-resourced rural areas, are extremely underrepresented in intervention research (West et al., 2016).

Our symposium highlights the most up-to-date research on the development and evaluation of the feasibility, acceptability, efficacy, and effectiveness of three different interventions that aimed to improve the quality of life of many diverse and low-resourced families of children with ASD. These interventions use innovative and accessible methods to target a wide range of disparities faced by families including challenges brought by the COVID-19 pandemic. The first presentation pilot tests telehealth as a means to connect underserved families of young children on the waitlist for an ASD diagnosis, and assesses how coaching for parents was associated with positive changes in the child's flexible and inflexible behaviors. The second presentation evaluates the development and pilot implementation of a culturally informed, parent-mediated intervention (ASPEN) for families of children with ASD living in low-resourced communities. The third presentation examines maintenance of intervention effects over time in a culturally tailored parent psychoeducation program (PTA) for Latinx parents of children with ASD, using a two-site randomized waitlist-control trial research design. These presentations represent different stages in intervention research, and altogether, they also show the future of intervention development for racially/culturally diverse and low-resourced families and communities.

References/Citations:

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Paper 1 of 3

Paper Title: Coaching via Telehealth: Caregiver-Mediated Intervention for Young Children on the Waitlist for an Autism Diagnosis

Authors: Megan Kunze³, Wendy Machalick³, Qi Wei³, and Stephanie St. Joseph³

Introduction: The average age for an autism spectrum disorder (ASD) diagnosis in the U.S. is 4-years-old, which is devastatingly late as caregivers often report initial concerns in their child's development around 12-months-old and reliable autism diagnosis can be made by 18-months (Pierce et al., 2019). For children from under-resourced families in rural communities, the age of diagnosis is even later, around 5-years-old (Martinez et al., 2018). Early diagnosis of ASD provides toddlers access to medically necessary interventions beyond federally funded early intervention during a vital window of developmental opportunity (Pierce et al., 2019). Late diagnosis often leads to under-served families despite economic status or geographic location.

Methods: Six mother-child dyads whose child (a) was between 18 and 36-months-old, (b) demonstrated difficult levels of inflexible behaviors (i.e., higher-order restrictive and repetitive behaviors and interests; HO-RRBIs), and (c) was on an ASD diagnostic waitlist were recruited from pediatrician offices and service districts throughout the Pacific Northwest and Texas. All families were considered under-served, under-resourced, or living in rural locations representing diverse communities. Using a concurrent multiple baseline design across participants, caregivers were paired with an early interventionist via telehealth, where they were coached to decrease HO-RRBIs and increase flexible child behaviors during play sessions. Five evidence-based, applied behavior analytic strategies were used: modeling, prompting, time delay, differential reinforcement of appropriate behaviors, and response interruption and redirection.

Results: A visual analysis of the data combined with Tau-U revealed a strong basic effect between the intervention package and parent strategy use as well as child flexible and inflexible behavior with the minimal exception. Standardized mean difference was beyond zero for all participants. All mothers rated their participation in the study as favorable. Results of distal and non-experimental outcomes (i.e., stress, quality of life, and self-efficacy) are discussed based on individual family experiences (e.g., impact of COVID-19, family diversity, and equity). Implications for science and practice in early intervention for families whose children are at-risk for ASD are discussed.

Discussion: This study contributes explicitly to the influence applied behavior analytic technologies have on flexibility for toddler-aged children. Parents in this study used modeling most frequently and showed high levels of behavior change. While few studies have targeted HO-RRBIs for toddler-aged children, research points to the frequency and intensity of inflexible behaviors as a contributory factor to high-stress levels in families (Harrop, McBee, & Boyd, 2016). Coaching parents to change their child's inflexibility resulted in more positive interactions and decreased parent stress and increased both quality of life and a parent's self-efficacy. However, participants who identified as members of diverse communities (e.g., Latinx and indigenous to North America) reported mixed results when reporting experiences with COVID-19, family stress, and overall quality of life. Early intervention agencies should consider the impact of RRBIs on the child and family and include effective strategies, as demonstrated in this study during intervention with their toddler-aged child at risk for ASD. Future research on ABA technologies for toddler-aged children around RRBIs and cultural adaptations is necessary to bolster early intervention effectiveness for all young children.

References/Citations:

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Paper 2 of 3

Paper Title: Development and Pilot Implementation of the ASD Screening and Parent ENGagement (ASPEN) Intervention Program in Low-Resource Communities

Authors: Sandra B. Vanegas⁴, Sandy Magaña¹, Mariana Davila⁴, Christopher Le⁴, Stephany Soto-Samudio⁴, & Angelica Hernandez⁴

Introduction: Children with ASD from racial/ethnic minority backgrounds and low-resource communities face many barriers in early identification of ASD and access to evidence-based, culturally informed interventions (Magaña et al., 2013). Parent-mediated intervention programs can address these disparities as they have been shown to improve children’s communication and social development, daily living skills, and even have positive effects on parent outcomes (e.g., competence, stress; Oono et al., 2013). However, many parent-mediated intervention programs have not focused on the unique needs of culturally diverse children and families in low-resource communities. The objective of this research was to develop and pilot a culturally informed parent-mediated intervention program for families in low-resource communities.

Methods: A review of existing parent-mediated intervention programs was conducted to identify critical components of evidence-based practices. The initial version of the ASPEN Intervention Program was reviewed and piloted with two families from racial/ethnic minority backgrounds. After this initial implementation, the revised ASPEN Intervention Program was then piloted with an additional 12 families. Families were primarily Spanish-speaking and had children between 18 months and 6 years of age who were either at risk for ASD or had an ASD diagnosis. The ASPEN intervention program includes 12 sessions and was delivered across two formats by a student clinician and a peer leader: Group delivered sessions or Individually delivered sessions. Child and parent outcome data were collected using the Mullen Scales of Early Learning, Vineland Adaptive Behavior Scales, Family Outcome Scale, Parenting Stress Index-Short Form, and parent-report on use of intervention strategies. Additional feasibility, fidelity, and acceptability data were collected to assess the implementation of the ASPEN Intervention Program.

Results: Overall, 5 families participated in the group-delivered ASPEN intervention sessions and 7 families have completed or are completing individual sessions. At baseline, children across both groups were on average 4.01 years of age, all had an ASD diagnosis, 67% were male ($n = 8$), 92% were Latino, 92% were born in the United States, and 58% used verbal language to communicate. The majority of caregivers were born outside of the United States (83%), had a high school or lower education (83%), and had an annual household income lower than \$35,000 (80%). Families participating in the group delivered sessions completed on average 8.2 sessions (out of 12) and 100% of sessions received high ratings of usefulness (Very useful, extremely useful). Currently, preliminary data from families participating in individual sessions show that 96% of sessions were reported as very useful or extremely useful. Additional data will be reported on child and parent outcomes to examine change between baseline and post-intervention assessments.

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Discussion: This presentation describes the development and pilot implementation of a culturally informed, parent-mediated intervention designed specifically for families of young children in low-resource households. The preliminary data suggests that the ASPEN Intervention Program holds promise for providing support to typically underserved families. Recommendations and lessons learned will be highlighted to inform program development for culturally and linguistically diverse families in low-resource communities.

References/Citations:

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Paper 3 of 3

Paper Title: Reducing Disparities for Latinx Families of Children with ASD: Evidence from A Two-site RCT Study at Four-Months Post Intervention

Authors: Weiwen Zeng¹, Sandy Magaña¹, and Kristina Lopez⁵

Introduction: Latinx children with ASD and their families are less likely to receive required diagnostic and specialty services (Broder-Fingert et al., 2013; Smith et al., 2020). Parents Taking Action (PTA) is a culturally tailored parent psychoeducation intervention program that was developed to address disparities in services faced by Latinx families of children with ASD (Magaña et al., 2020). Promotoras (peer mentors who are also mothers of children with ASD) delivered the 14-sessions educational program through face-to-face home visits after receiving training on the content and intervention protocol. A randomized waitlist-control trial was conducted across two sites (Illinois and California) in which parent-reported assessments were conducted at baseline, four-months, and eight-months post baseline. The purpose of this study is to examine the maintenance of intervention effects from baseline to eight-months post baseline.

Methods: The participants were 93 (intervention=41, control=52) Latina mothers of children with ASD aged 8 years or younger, who completed all three assessments. Mothers who were assigned to intervention groups received the intervention right after the baseline assessment, while control group mothers remained in the waitlist condition until all three assessments were completed. Parent and child outcomes examined include family empowerment (Family Outcome Scale; FOS), mother's confidence in using evidence-based (EB) strategies, and frequency of using EB strategies; the child's challenging behaviors, social communication impairments (Social Communication Questionnaires; SCQ), and the number of services received. We assess maintenance of intervention effects by conducting repeated measures analysis of covariance (ANCOVA) models for all parent and child outcomes. Maternal education was controlled for since it was the only significant between-group demographic variable. We also analyze differences in intervention effects by site by running OLS regression models.

Results: Compared to control mothers, intervention mothers achieved 4.4 points higher in confidence ($F_{[1, 90]}=8.61, p<.001$), and 3.8 points higher in frequency ($F_{[1, 90]}=3.83, p=.02$) of using EB strategies scales across timepoints. Children whose mothers were in the intervention groups on average received 1.4 additional services ($F_{[1, 90]}=3.16, p=.04$) across timepoints. Overall, there were no significant treatment differences in family empowerment, the child's challenging behaviors, or SCQ scores. When analyzed by

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site, however, we found significant treatment differences in FOS' *assessing community resources* subscale ($F_{[1, 23]}=7.33, p=.002$) and in child's SCQ scores ($F_{[1, 23]}= 9.08, p<.001$) in California sample, but not in the Illinois sample.

Discussion: Intervention mothers at both sites had greater confidence in, as well as increased frequency of using EB strategies eight-months post baseline compared to the control. Additionally, our findings indicated greater receipt of services by children of mothers in the intervention groups compared to those in controls four-months post intervention. Together, these findings suggest that the content, structure, and delivery mode of PTA allow for intervention effects to maintain well beyond the timeframe of the intervention program. Treatment differences by site seem to indicate that although PTA addresses a number of service barriers by enhancing Latina mothers' knowledge about the service systems, state policies retain the power to block access to services which may have contributed to our findings related to site differences. Therefore, the intervention may show more robust improvements for families depending on state policies and availability of services.

References/Citations:

- Broder-Fingert, S., Shui, A., Pulcini, C. D., Kurowski, D., & Perrin, J. M. (2013). Racial and ethnic differences in subspecialty service use by children with autism. *Pediatrics, 132*(1), 94-100.
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