Symposium Title: Family Stress & Well-Being: Caring for Individuals with ASD Across the Lifespan

Chairs: Lauren Baczewski\(^1\) and Kyle Sterrett\(^1\)

Discussant: Amanda Gulsrud Ph.D.\(^1\)

Overview: Caregivers are the primary providers of social and financial support in the lives of individuals with ASD and given that many individuals with ASD remain living in the home after high school (Anderson et al., 2014), caregiver’s roles are often long term and ongoing. Regardless of overall level of functioning, adaptive social skills are a prominent impairment in individuals with ASD across the life course which results in the need for continued support from caregivers over this period (Anderson, Oti, Lord, & Welch, 2009). As a result of this consistent need for support, stress is elevated among caregivers of an individual with ASD in comparison to those caring for a child with other developmental diagnoses or no diagnosis (Quintero & McIntyre, 2010). Therefore, it is imperative that we better understand nuanced factors related to self-rated caregiver stress and well-being across the life course. To address this gap in knowledge, this symposium includes presentations that examine well-being and stress among caregivers of individuals with autism at different points in the life course. The first presentation examines child behavioral factors that contribute to parenting stress among caregivers of infants and toddlers at high risk for ASD during the first two years of life. The second presentation models associations between child behavioral problems, family-level resources, parenting self efficacy, and parenting stress among Medicaid-eligible families of children with ASD. Finally, the third presentation investigates the relationship between cognitive and adaptive skills and caregiver well-being among adults with ASD. Collectively, these presentations highlight the importance of greater understanding of specific behaviors and characteristics associated with increased stress and lower well-being among caregivers of those with ASD. This will inform our understanding of what interventions and supports may be most meaningful to families as their child with ASD grows and develops.

Paper 1 of 3

Paper Title: Characterization of Challenging Behaviors and their Association with Parenting Stress in Infants-Toddlers at Risk for ASD

Authors: Kyle Sterrett\(^2\), Lauren Baczewski\(^3\), Amanda Dimachkie\(^3\), Amanda Gulsrud\(^1\), & Connie Kasari\(^1\)

Introduction: Parents of children with ASD have been consistently found to have higher levels of parenting stress than parents of TD children and children with other developmental disabilities (Quintero & McIntyre, 2010). Reports of children’s challenging behaviors supersedes autism severity and children’s adaptive skills when predicting levels of parenting stress (McStay et al., 2014), while findings have been mixed regarding the contribution of children’s age (Schieve et al., 2011; Tehee et al., 2009). Given that parenting stress may interfere with children’s response to early intervention (Osborne et al., 2008) and overall family well-being and functioning (Hayes & Watson, 2013), it is necessary to better understand the nuanced contributors to caregiver stress in parents of infants at risk for ASD.

Methods: The sample for this cross-sectional analysis included 80 infants with ASD (M Age= 17.66 months, 54% non-white, 80% Male) who met for mild to moderate concern on the ADOS Toddler Module (Luyster et al., 2009). Children’s social and emotional problems were measured using the Infant-Toddler Social Emotional Assessment (ITSEA; Carter, Briggs-Gowan, Jones & Little, 2003) and parent’s level of stress and burden around childcare issues was measured using the Parent Daily Hassles Scale (Crnic & Greenburg, 1990). Lastly, children’s developmental quotient was calculated using the Mullen Scales of Early Learning. First, descriptive information on each subscale was calculated separately across 12-17 month and 18-24 month olds to provide a nuanced characterization of socio-emotional problems. Multiple linear regression was then used to predict parent’s frequency

\(^1\) University of California, Los Angeles
and intensity of caregiving burden and stress from ITSEA domain scores (externalizing and dysregulation domains) controlling for developmental level.

**Results:** The most frequently reported socio-emotional problems in the 12-17 month old children included attentional issues, compliance, sleep, separation distress and impulsivity. For the 18-24 month old children the most common problems included attentional issues, compliance, separation distress and inhibition. In the older children both the frequency and intensity of caregiver burden was predicted by dysregulation (t(31) = 2.98, b = .01, p = .005) and t(31) = 2.05, b = .005, p = .05 respectively) but not externalizing scores (p > .05). In the younger children both the overall regression models and all individual parameters were non-significant (p > .05) indicating little of the variance in caregiver burden is explained by the ITSEA scores in the younger children.

**Discussion:** Findings of this study elucidate the evolution of parent-reported challenging behaviors during the second year of life of infants at risk for ASD. These challenging behaviors, specifically dysregulation (around sleeping and eating behaviors, negative emotionality, and sensory sensitivities) were found to be the sole predictor of the frequency and intensity of parenting stress among parents of infants between 18 and 24 months. These findings were not replicated in parents of infants between 12 and 18 months, lending credence to findings that child age plays a role with respect to how parents report their caregiver burden and stress (Tehee et al., 2009). Given that many of the infants in this sample were identified early in life as high risk for ASD, these results suggest that early intervention providers should take into account child behavior problems that are most relevant and challenging in the view of the parents. Early interventions that specifically target daily living skills and provide parents with strategies to cope with these behaviors may be especially appropriate.

**References/Citations:**

**Authors:** Kevin Stephenson\(^2\), Rachel Fenning\(^3,4\), Eric Macklin\(^5\), Frances Lu\(^5\), Megan Norris\(^2\), Robin Steinberg-Epstein\(^4\), Eric Butter\(^2\)

**Introduction:** Emotional and behavioral problems (EBP) are common in children with autism spectrum disorder (ASD). There is ample research to show that EBP, particularly externalizing behaviors, are associated with increased parenting stress and related negative family experiences. Studies have shown that parental self-efficacy (PSE) is an important variable in terms of parental stress and has been hypothesized as a potential mediator between EBP and parental stress. A limitation of extant research on families of children with ASD is the infrequent focus on underserved populations. This is needed, especially given evidence of associations between family resources, parenting self-efficacy, and parenting stress in impoverished families without ASD. To address this gap in the literature, we modeled associations between child EBP, family-level resources, parenting self-efficacy, and parenting stress in Medicaid-eligible families of children with ASD who were characterized by significant comorbid developmental and behavioral needs. We hypothesized that 1) PSE would mediate the relationship between EBP and parenting stress, 2) the mediation effect would be greater for externalizing (EBP-E) versus internalizing (EBP-I) behavior problems, and 3) the amount of family resources would moderate the degree of mediation such that lower family resources would be associated with a stronger relationship between lower PSE and increased parenting stress.

**Methods:** Participants included (106) families of children with ASD between the ages of 3 and 13 who were recruited as part of a larger study on improving dental care. Families exhibited racial (32% Non-Caucasian) and ethnic (39% Hispanic) diversity, and all were underserved as defined by Medicaid-eligibility. Children completed the Autism Diagnostic Observation Schedule–2nd Edition (ADOS-2) and Stanford-Binet–5th Edition, abbreviated battery (ABIQ). Parents completed questionnaire ratings of PSE, Family Resources, Parenting Stress, and Child EBP. We used path analysis to test the hypothesized moderated mediation model.

**Results:** Initial model fit was poor, but became excellent after adding an additional mediation effect of family resources between EBP-E and PSE based on modification indices (mediating 24% of the relationship). All associations between variables were in the hypothesized direction. As hypothesized, PSE mediated the relationship between EBP-E (but not EBP-I) symptoms and parental stress. Level of family resources moderated the mediation effect (index of moderated mediation = -.05) such that lower levels of family resources were associated with a larger mediation effect. Results were unchanged after controlling for autism symptom severity and intellectual ability. An exploratory multi-group model based on ethnicity indicated no differences in the relationship between the study variables among the two groups (Hispanic vs. Non-Hispanic). A model with alternative directionality was also tested, but did not fit as well as the final model.

**Discussion:** Our data provide evidence that behavioral problems are associated with increased parental stress through a mechanism of decreased parental self-efficacy, particularly when resources are limited. Behavioral problems were also associated with increased family resource strain, which was in turn linked to decreased parental self-efficacy. Although data are cross-sectional and require replication and extension through longitudinal study, findings reveal family-level resources and parenting self-efficacy to be critical mechanisms underlying the association between child challenging behaviors and parenting stress in underserved families of children with ASD. In addition to developing interventions to enhance parenting self-efficacy, directly targeting parents’ generalized sense of controllability may be especially important in the context of limited family resources and heightened child developmental and behavioral comorbidities.

**References/Citations:**

\(^2\) Nationwide Children’s Hospital  
\(^3\) California State University, Fullerton  
\(^4\) University of California, Irvine  
\(^5\) Massachusetts General Hospital


Paper 3 of 3

Paper Title: Relations between Caregiver Well-Being and IQ-Adaptive Behavior Discrepancies in Adulthood

Authors: James B. McCauley1, Rebecca Elias1, Catherine Lord1

Introduction: We need to better understand caregiver well-being as individuals with autism spectrum disorder (ASD) reach adulthood, given that most remain in the family home after high school exit (Anderson et al., 2014). Parent well-being has previously been associated with maladaptive behavior problems in individuals with ASD (Lounds et al., 2007), but little is known about the how cognitive and adaptive skills relate to parent well-being across a wide range of ability levels. Previous studies have found the discrepancy between IQ and adaptive behavior to be informative to psychiatric co-morbidities in adults with ASD (Kraper et al., 2017), and we hypothesized this discrepancy may also inform our understanding of parent well-being.

Methods: The current study analyzes the data from 106 participants with ASD who were seen in adulthood for diagnostic and cognitive assessments (Mage = 26.05). The participant pool is drawn from a longitudinal study of ASD comprised of children clinically-referred prior to age 3. Children and parents were seen frequently in early childhood through adulthood for diagnostic follow-up. In addition to diagnostic and cognitive testing, primary caregivers completed questionnaires pertaining to their individual functioning and the functioning of their child. For the purposes of this study, parent well-being and child adaptive skills are examined in future detail. Specifically, self-reported well-being on the Psychological Well-being Scale (PWB; Ryff, 1989) and on their child’s adaptive behavior on the Vineland (VABS-II Sparrow et al., 1994), were assessed at regular intervals starting in adolescence. To calculate the discrepancy between IQ and adaptive behavior, the z transformed verbal IQ was subtracted from the z transformed Adaptive Behavior Composite from the VABS-II, with higher, positive scores reflecting higher adaptive behavior relative to IQ, and lower, negative scores reflecting lower adaptive behavior relative to IQ.

Results: A multiple regression was used to predict caregiver well-being in adulthood from the interaction between IQ and the discrepancy between adaptive behavior and IQ while controlling for caregiver education and living situation of the adult. There was a significant interaction between the VABS-IQ discrepancy score and adult IQ, indicating that for individuals with an IQ 70 and above, there was a non-significant positive relation (β = 0.52; p = 0.19), but for adults with an IQ under 70, there was a significant negative relation between the VABS-IQ discrepancy and caregiver well-being (β = -0.77; p = 0.02). This relation indicated that higher levels of adaptive behavior relative to IQ were associated with lower levels of caregiver well-being (See Figure 1). These relations remained significant when accounting for IQ, and when we recalculated IQ-adaptive behavior scores to reflect only daily living skills.

Discussion: The current study aimed to investigate the adaptive skills of adults relative to their IQ as a mechanism for understanding caregiver well-being. We found interesting divergent patterns between individuals with and without comorbid intellectual disabilities. For caregivers of individuals with IQs under 70, having an adult with more adaptive skills relative to IQ may be related to less overall well-being. However, for caregivers of individuals with IQs above 70, caregiver well-being was...
associated with greater adaptive skills relative to IQ. The differential abilities of adults with ASD should be taken into account when discussing caregiver well-being.

References/Citations: