**2025 Gatlinburg Conference Poster Submission**

**Title:** Characterizing Family Quality of Life, Parenting Stress and the Relationship Between These Factors in Families Raising Infants with Early Social Communication Delays

**Authors:** Daltrey Schmidt1 B.S., Lourdes Marizcal Gonzalez1 B.S., Deepinder Nagra1 M.P.H., Sarah Dufek1 Ph.D., Meagan R. Talbott Ph.D1

**Introduction:** Families raising children on the autism spectrum experience higher levels of stress compared to families caring for other groups of children, both those who are neurotypical and those with other developmental or intellectual diagnoses (Sanders and Morgan 1997; Bonis 2016). Prior studies of families raising autistic children found that parenting stress can negatively impact satisfaction with family quality of life (Hsiao et al. 2017). However, quality of life amongst families navigating the period between first developmental concerns and formal diagnosis has not been investigated. The present study aims to characterize family quality of life in this heterogenous group. Research Questions: (1) What are the characteristics of family quality of life amongst families of infants with social communication delays in the first year of life? and (2) What is the relationship between family quality of life and parenting stress?

**Methods:** Participants included 43 families enrolled in an ongoing longitudinal study of infants with early social communication delays. Infants 6-12 months were recruited nationwide. Eligibility criteria includes: 1) Scores within "Concern" range on the Communication and Symbolic Behavior Scales Developmental Profile (Wetherby and Prizant, 2002); 2) no significant motor, sensory, or developmental delays. 3) sufficient English-language skills to consent and complete surveys and sessions. Some parents expressed explicit concerns about their child’s development and others did not. Online questionnaires completed at intake include: 1) The Beach Center Family Quality of Life Scale (FQoL, 2006), measuring satisfaction in four domains on a 5 point Likert scale from 1 (very dissatisfied) to 5 (very satisfied); 2) Parenting Stress Index-4 Short Form (PSI-4 SF, 1995), rating agreement with statements about parenting stress in three domains on a 5 point Likert scale from 1 (strongly disagree) to 5 (strongly agree). Descriptive analyses were completed in R (Version 2024.04.2+764).

**Results:** Caregivers in our sample were majority white (60%, n=26) identified as female (77%, n=33), and were of high socioeconomic status; 77% (n=33) of participants possessed at minimum a bachelor’s degree and 50% (n=22) reported income of $100,000 or more. At intake infants were 9.5 months and caregivers were 35 years old. Average overall family quality of life was 4.13 (SD = 0.65), closely corresponding to Likert rating of 4 or “satisfactory”. One way ANOVA showed significant effect of domain category on average score (F=9.78, p<0.001) and subsequent pairwise T tests with Bonferroni correction demonstrated that Emotional Wellbeing domain scores (M=3.63, SD=0.95) were significantly lower than Family Interaction (p=0.003), Parenting (p=0.012), and Physical/Material Wellbeing (p<0.001). The highest rated domain was Physical/Material Wellbeing (M=4.51, SD = 0.63). Approximately 60.5% of caregivers (n=26) rated their overall quality of life as “satisfactory” or “very satisfactory”. 18.6% (n=8) of caregivers scored at or above the 84th percentile on the PSI-4 SF and were classified as the “High Stress” group. The remaining participants who scored below the 84th percentile were categorized as “Low Stress” (81.4%, n=35). FQoL scores for “High Stress” were lower than “Low Stress” (mhigh stress = 3.64, mlow stress = 4.24). However, these mean differences were not statistically significant (t = 2.10; p = 0.06). Across all families, FQoL raw scores were significantly negatively correlated with PSI-4 SF total raw scores (*rₛ* = -0.60, p <.001).

**Discussion:** Overall, it is reassuring that most caregivers in this study reported they are satisfied with their quality of life. Only a sub-set of caregivers reported clinically significant levels of stress. However, many of these families are at the beginning of the “diagnostic odyssey” (Lappé et al., 2018) and will go on to experience more stressors as their child’s developmental differences become more pronounced and demands of caregiving increase. However, the significant negative correlation we observed between parenting stress and family quality of life suggests that supporting caregivers’ emotional wellbeing has the potential to improve families’ quality of life during this pre-diagnostic period. An important limitation of this study is the homogenous, high socioeconomic status of the caregivers. Future research should evaluate the influence of race, class, education level, language, and culture on both parenting stress and family quality of life in order to develop supports to help families of all backgrounds thrive.

**References:**

1. Bonis S. (2016). Stress and Parents of Children with Autism: A Review of Literature. *Issues in mental health nursing*, *37*(3), 153–163. <https://doi.org/10.3109/01612840.2015.1116030>
2. Hsiao, Y. J., Higgins, K., Pierce, T., Whitby, P. J. S., & Tandy, R. D. (2017). Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Research in developmental disabilities*, *70*, 152–162. <https://doi.org/10.1016/j.ridd.2017.08.013>
3. Jones, S., Bremer, E., & Lloyd, M. (2017). Autism spectrum disorder: family quality of life while waiting for intervention services. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation*, *26*(2), 331–342. <https://doi.org/10.1007/s11136-016-1382-7>
4. Lappé, M., Lau, L., Dudovitz, R. N., Nelson, B. B., Karp, E. A., & Kuo, A. A. (2018). The Diagnostic Odyssey of Autism Spectrum Disorder. *Pediatrics*, *141*(Suppl 4), S272–S279. https://doi.org/10.1542/peds.2016-4
5. Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down Syndrome: Implications for intervention. *Child & Family Behavior Therapy, 19*(4), 15–32. [https://doi.org/10.1300/J019v19n04\_02](https://psycnet.apa.org/doi/10.1300/J019v19n04_02)
6. Wetherby, A. M., & Prizant, B. M. (2002). *Communication and Symbolic Behavior Scales: Developmental Profile,* (1st normed ed.). Paul H Brookes Publishing Co.

1Department of Psychiatry and Behavioral Sciences, MIND Institute, University of California Davis