

2021 Gatlinburg Conference Poster Submission

Title: Caregivers' Perspectives on Family Involvement during the Autism Evaluation Process

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Introduction: Autism spectrum disorder (ASD) is a neurodevelopmental disorder that persists throughout the lifespan and is typically marked by challenges in social communication and interaction (Baio, 2014). Diagnosis of ASD during early childhood is optimal, as early intervention leads to improved outcomes later in life (Fountain, King & Bearman, 2011). Yet, notable disparities exist in age of diagnosis, with children of minority ethnic and racial groups being diagnosed later in childhood compared to White children (Mandell, Listerud, Levy & Pinto-Martin, 2002; Travers & Krezmien, 2018). Previous research has noted that social support post-diagnosis, such as family involvement, can be instrumental in sharing caregiver responsibility and improving outcomes for children with ASD (Ekas, Lickenbrock & Whitman, 2010). However, available research has not yet explored family involvement *during* the autism evaluation process, nor accounted for cross-cultural differences in family roles and involvement. Understanding the role of family involvement *during* the autism evaluation process may provide insight into factors that contribute to better caregivers' ability to navigate the autism evaluation process and overall outcomes for children with ASD. As such, the current qualitative study sought to explore culturally-diverse caregivers' descriptions of how family involvement affected their experiences of the autism evaluation process.

Method: Culturally-diverse caregivers (N=32) of children who screened positively for ASD in primary care were recruited (Broder-Fingert et al., 2018). Of these, 26 completed the ASD evaluation process and did not receive an ASD diagnosis and 6 did not complete the ASD evaluation process. To ensure breadth within the sample, purposive sampling was used to recruit families based on race/ethnicity, child's gender and age, and absence or presence of developmental concerns raised by parents prior to screening. Participants completed in-depth qualitative interviews assessing their identification of initial developmental concerns, experiences with developmental screening and assessment, familial and social support, decision-making processes, and perceived contributors to navigating and connecting with services. Data were transcribed verbatim, cleaned, systematically coded, and analyzed using applied thematic analysis (Guest, Macqueen & Namey, 2012). All data were stratified by partner status (i.e., Partnered: married/engaged, or living with a partner vs. Without Partners: single, separated/divorced or widowed) to examine differences in support and family involvement across varying family types.

Results: Caregivers described family involvement throughout the autism evaluation process. Descriptions of family involvement were primarily related to caregivers' 1) decision-making processes, 2) navigation of logistical challenges, and 3) emotional needs. Differences in family involvement based on partner status only emerged in the context of decision-making processes. When describing decision-making processes, most caregivers reported involving family members in initial identification of developmental concerns and when deciding whether to confer with medical providers. Caregivers without partners described involving their parents or other family members when conferring about developmental concerns. Conversely, caregivers with partners described involving their partners first and then extended family members when making decisions related to the autism evaluation process. Yet, when conflicts arose, many caregivers reported making final decisions independently, regardless of partner status. With regard to navigating logistical challenges (i.e., scheduling and attending appointments), family involvement was helpful for providing child-care and transportation assistance related to the autism evaluation process and services. Lastly, there was variability in how family involvement satisfied caregivers' emotional needs. While some caregivers reported relying on family members for emotional support, others reported family involvement as a contributor to emotional distress.

Discussion: Overall, caregivers reported nuanced benefits of family involvement. Findings from this project specifically highlight how family involvement and family structures contribute to caregivers' functioning during the autism evaluation process. Harnessing *supportive* family involvement may be especially important to improving caregivers' emotional and logical management and decision-making processes during the autism evaluation process and consequently child outcomes.

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