**Title**: What drives caregiver pursual of an ASD diagnosis in a multi-stage screening study?

**Authors**: Lara Cunningham1, Sarah Heath1, Caitlin Boyd1, R. Christopher Sheldrick2, Abbey Eisenhower1, and Alice Carter1

**Introduction**: Improving Autism Spectrum Disorder (ASD) identification requires not only accurate screening but also effective systems to ensure that children with elevated ASD likelihood are properly identified (Sheldrick et al., 2019).Identifying the factors that motivate caregivers to pursue intervention services after a referral is essential in ensuring that children who may benefit from these services receive the necessary support. Previous studies have found that caregiver and provider concerns, and positive screening scores are important predictors of caregiver help-seeking behaviors (Godoy et al., 2014; Sheldrick et al., 2019). This study aims to differentiate child ASD specific behaviors from general social-emotional behavior (SEB) problems in their predictive likelihood of caregiver help-seeking in ASD diagnostic services.

**Method**: Participants (N=1,095) were part of a larger multi-stage screening study (Eisenhower et al., 2021) focused on the identification of autistic children in the Part C Early Intervention (EI) system. Eligible children were between 14 and 36 months of age, had received EI services for ≥8 weeks, and did not already have an ASD diagnosis. For Stage 1, caregivers completed the 42-item Brief Infant-Toddler Social and Emotional Assessment (BITSEA), a nationally standardized screener for 12- to 36-month-olds, reflecting on child behaviors over the previous month from 0 (Not Ture/Rarely) to 2 (Very True/Often) (Briggs-Gowan & Carter, 2006). Internalizing, externalizing, dysregulation, and ASD problem and ASD competence subscales were used for measuring different facets of child SEB. Based on positive screening scores and provider and/or caregiver concerns from Stage 1, caregivers were encouraged to pursue further assessment in Stage 2. Help-seeking behavior was defined by those who continued to Stage 2, as opposed to those who were referred but did not move on.

**Results**: A logistic regression was conducted with help-seeking behavior as the dependent variable and BITSEA autism and non-autism subscale scores, caregiver-reported worry, and child age and sex as predictors. The overall model was statistically significant (𝜒²(8, N = 1,095) = 80.49, p < .001); statistically significant predictors included caregiver-reported worry, child age, BITSEA dysregulation, ASD problems, and ASD competence subscales. Higher ASD problem scores and older child age were associated with a higher probability of caregiver help-seeking. Higher ASD competence and dysregulation scores were associated with a lower probability of caregiver help seeking. Bivariate associations between dysregulation scores and help-seeking behavior had a positive non-significant association indicating a suppression effect when ASD scores were added to the model. Caregivers who reported being 'Worried to Very Worried' about their child were 9.74% more likely to seek help, compared to those reporting 'Little to No Worry.'

**Discussion:** Results indicate that the presence of ASD problem and competence behaviors, non-ASD dysregulated behaviors, caregiver worry, and child age are stronger predictors of caregiver help-seeking than child non-ASD internalizing and non-ASD externalizing behaviors. The suppression effect on dysregulated behaviors from ASD subscales may reflect that when dysregulation symptoms are low (e.g. problems with eating, sleeping, and/or crying) it is easier for caregivers to be concerned about observed autism characteristics in their children. Findings highlight circumstances in which caregivers are more likely to seek help in diagnosing their child with autism. This is important in understanding ways to increase participation in screening for and identifying ASD in young children.

**References:**

Briggs-Gowan, M., & Carter, A. S. (2006). *Brief infant toddler social emotional assessment (BITSEA)* (pp. 17–19). Pearson.

Eisenhower, A., Martinez Pedraza, F., Sheldrick, R. C., Frenette, E., Hoch, N., Brunt, S., & Carter, A. S. (2021). Multi-stage screening in early intervention: A critical strategy for improving ASD identification and addressing disparities. *Journal of Autism and Developmental Disorders, 51*(3), 868-883. <https://doi.org/10.1007/s10803-020-04429-z>

Godoy, L., Carter, A. S., Silver, R. B., Dickstein, S., & Seifer, R. (2014). Mental health screening and consultation in primary care: The role of child age and parental concerns [corrected]. *Journal of Developmental & Behavioral Pediatrics, 35*(5), 334–343. <https://doi.org/10.1097/DBP.0000000000000060>

Sheldrick, R. C., Frenette, E., Vera, J. D., et al. (2019). What drives detection and diagnosis of autism spectrum disorder? Looking under the hood of a multi-stage screening process in early intervention. *Journal of Autism and Developmental Disorders, 49*(6), 2304–2319. <https://doi.org/10.1007/s10803-019-03913-5>

 University of Massachusetts, Boston

2 University of Massachusetts, Chan Medical School