

Title: Interventions for Infants and Toddlers at Risk for Developing ASD: A Systematic Review

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Introduction: Early life experiences can have a substantive impact on later development. The purpose of early intervention (EI) is to alter the trajectory of atypical development and promote optimal outcomes for families and children with and at risk for disabilities, such as autism spectrum disorder (ASD). Evidence-based EI programs for young children diagnosed with ASD have demonstrated both short- and long-term benefits, including decreased ASD symptom severity, increased IQ, language, social, and adaptive skills, and normalization of activity in related areas of the brain, though it is unclear if these results can be generalized to infants and toddlers at-risk for developing ASD. Although the Center for Disease Control (CDC) and American Academy of Pediatrics (AAP) recognize 2 years as the age for reliable ASD diagnosis and recommend screening all infants beginning at 9 months, the average age of diagnosis is between 4 and 8 years. Prior to diagnosis many children are recognized as being “at-risk.” IDEA Part C defines “at-risk” as a child under the age of 3 who, without intervention is at risk of experiencing substantial developmental delay. This risk may be biological or environmental. While specific eligibility requirements for a child at-risk varies by state, prior to diagnosis children with early symptoms of ASD may be classified as at-risk if they do not concurrently demonstrate clear and substantive delays in multiple developmental domains. Despite recognition of the importance of EI for at-risk infants and toddlers, only five states and two territories provide EI services for at-risk children. Thus, at-risk infants and toddlers are often excluded from federal, state, and insurance sponsored EI programs. The following systematic review summarizes the literature on the outcomes of EI for infants and toddlers at risk for ASD and provides recommendations for future research and best practices.

Method: Using the PRISMA guidelines, a comprehensive search of relevant databases and bibliographies of key articles was conducted. The database search included ERIC, PsycINFO, PsychARTICLES, and PubMed with search terms such as ‘autism,’ ‘autis,’ ‘ASD,’ ‘AS,’ ‘risk,’ and ‘intervention,’ for the period July 2008 to July 2018. Qualitative, single-subject, and experimental studies with direct implications for intervention and identification of at-risk infants and toddlers were included in this analysis. Studies requiring participants to have an established ASD diagnosis were excluded. Studies utilizing drug interventions to treat pre-existing, co-occurring conditions associated with increased ASD risk (e.g., infantile spasms) were also excluded. Study characteristics, methods, and outcomes were organized and reported in tabular form. Studies were also appraised for methodological quality (Jinks, Cotton, & Rylance, 2010) and level of evidence (OCEBM Levels of Evidence Working Group, 2011).

Result: A total of 431 articles were retrieved. Abstracts and titles were reviewed. A total of 80 full-text articles were considered for this review; 19 were included for analysis. Of the articles included in this analysis, 15 were quantitative intervention studies, three qualitative or mixed methods, and one retrospective cost-effectiveness analysis. Participant ages ranged from 0-46 months with three studies focusing on adult-aged caregivers and providers. Most studies (n=13) reported the results of brief (M=15 sessions), low dose (M=1 session per week), caregiver mediated interventions. Sample sizes were relatively small, ranging from three to 87 participants (M=36). The mode of delivery for these interventions varied from a direct service model to group and parent-mediated intervention models. The average quality score was 6 of a possible 8, with a range of 4-8. Five of the 19 studies met a relatively high level of evidence (Level 1-2), 13 studies met a moderate to somewhat low level of evidence (Levels 3-4), and one demonstrated a low level of evidence (Level 5).

Discussion: Infants and toddlers identified as at-risk for developing ASD represent a unique population presenting challenges for both clinicians and researchers. In line with current research regarding evidence-based EI practices for young children diagnosed with ASD, the interventions analyzed in this paper generally fell within a behavioral or developmental theoretical framework. Commonalities between interventions with positive results included specifically targeting core ASD deficits such as social interactions and communication. Although most studies reported favorable outcomes for parent responsiveness, acceptability, and specific prodromal or symptomatic behaviors, overall symptom severity and developmental improvements were not uniform among participants or across studies. Small sample sizes and lack of statistical power to analyze the indirect effects of the

intervention may also account for some of the mixed results. Based on the results of the current analysis, it appears that higher intensity programs incorporating direct therapist, parent, and child interactions had more positive outcomes. This suggests the need for higher intensity interventions focusing on both parent and child skill building. Qualitative studies highlighted the need for a parental “warm-up” period to enhance intervention acceptance. Additional research is also needed to better understand the interplay between child characteristics, treatment outcomes, and dosage. In a societal-level analysis of two evidence-based EI programs, even the most intensive services (20 hours a week for two years) demonstrated significant cost-benefits. Yet it remains unclear how such interventions can be disseminated or funded within a community setting. Due to the lack of funding for EI for at-risk infants and toddlers, future research needs to focus on identifying current community interventions and services utilized by this population. The results of this review also highlight the lack of reliable instruments and professional hesitation to diagnose ASD in infants and toddlers resulting in a lack of access to more intensive EI services. Ongoing research on early biomarkers for the identification of ASD is likely to significantly improve future diagnostic methods and, in turn, access to EI services.

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