Christina Cheung, Jacqueline Jones PhD, Kristina Hightshoe MSPH, Jeanette Cordova, Yurico Gutiérrez DrPH MPH, Jodi K. Dooling-Litfin PhD, Margaret M. Tomcho MD MPH, Silvia Gutiérrez-Raghunath, Cordelia Robinson Rosenberg PhD, Steven A, Rosenberg PhD, Carolyn DiGuiseppi MD MPH PhD

Parent and Provider Perspectives on Family Navigation for Early Identification of Children With Autism Spectrum Disorder

Abstract

Early identification can improve developmental outcomes among children with autism spectrum disorder (ASD), but underdiagnosis and undertreatment are common among low-income families and children of racial/ethnic minorities. The Screening and Linkage to Services for Autism (SaLSA) trial (ClinicalTrials.gov Identifier: NCT02374541) demonstrated that autism family navigation (AFN) improved the likelihood that young children at risk for ASD completed a diagnostic evaluation. We recruited parent participants, healthcare and EI providers and staff, and project staff from the SaLSA trial to participate in semi-structured telephone interviews on acceptability and feasibility of AFN services for families seen in urban safety-net clinical settings. Secondary qualitative content analysis was performed. A community focus group was conducted for data source triangulation to improve validity. Results demonstrated four main themes: (1) "It's all in a name: the risk of engagement"; (2) "Community partnerships require authentic trust"; (3) "System interactions and interrelationships"; and (4) "What is an AFN: family navigation or clinical role?" This study adds perspectives of interested parties of AFN within an urban underserved population. Recommendations for navigation program content and delivery based on these findings can inform future modifications to AFN programs in the context of the communities they serve.