Title: Leveraging Pediatric Primary Care Systems to Address Disparities in Autism Diagnosis and Engagement in Services: Implementation of a Family Navigation Intervention

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Introduction: Although evidence that interventions for very young children can impact the core deficits of ASD continues to grow, systems changes supporting screening, evaluation, and timely access to services have not kept pace with advances in diagnosis and treatment. Feasible, systemic interventions with broad scale-up potential are necessary. Leveraging pediatric primary care systems creates opportunity to decrease racial and ethnic disparities in identifying children with autism and providing them timely, quality services by expanding reach and supporting maintenance of effective interventions. Patient Navigation is a primary care-based care management approach that focuses on overcoming logistical hurdles to care during a defined episode. The objective of this study was to use the RE-AIM framework to evaluate Family Navigation’s (FN) external validity and potential for broad scale-up

Methods: We developed FN, a version of Patient Navigation designed for low-income, urban families of children with suspected ASD. Pilot data provided evidence of FN’s efficacy to reduce time to ASD diagnosis. We are now conducting a multi-site randomized comparative effectiveness trial (n=250) of our systemic, lay-delivered FN protocol, which begins at a child’s 18 or 24-month health supervision visit. The trial takes place in three urban, integrated pediatric care networks. The basic structure of both arms is a collaborative care system. The conventional care management arm (CCM) is consistent with the type of care provided within a traditional - but high quality – medical home. The FN arm provides more intensive, individually tailored, care coordination and theory-based family support. The navigators are bicultural, bilingual, and trained in motivational interviewing and collaborative decision making. Children are followed by their navigator for 100 days after diagnosis, and for 12 months by our study team. We report findings related to intervention reach and implementation.

Results: Regarding intervention reach, we conducted telephone confirmatory screening in the family’s primary language using the M-CHAT-R/F with 448 of 496 eligible children 18-27 months who had a positive primary-care administered M-CHAT. Autism risk was not confirmed in 22%; 16% declined participation; 56% were enrolled. Enrolled children were 22 months (mean), 31% were Hispanic, 55% Black, and 82% low-income. Regarding intervention implementation, mean time to confirmatory screening was 5 days; mean time to diagnostic resolution 109 days; 69% of children have completed diagnostic assessment, of whom 59% received an autism diagnosis. Among families randomized to receive FN, 80% completed the 3 core in-person visits (pre diagnostic assessment; post diagnostic resolution; wrap-up/termination of navigation); only 2% did not engage with the navigator. Follow-up rates over 12 months were 85%.

Discussion: Findings regarding intervention reach and implementation support the generalizability of FN. The study successfully enrolled children representative of those receiving primary care services at participating sites. Key elements of the FN protocol were successfully implemented, improved efficiency of primary care screening, and provided clinically relevant information. Further analyses will provide real world primary care practices with a replicable model of care and determine FN’s role in increasing access to and engagement in timely diagnostic and early intervention services for a vulnerable population of urban families.