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A mixed-methods process evaluation of Family Navigation implementation for autism spectrum disorder

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Patient Navigation (PN) is an evidence-based approach to improving access to health services by eliminating barriers to care. PN is designed as a means to reduce time to diagnosis by shortening the interval between a positive screen (e.g., a mammogram for breast cancer) and definitive diagnosis. Family Navigation (FN) is a version of PN that involves a focus on the family unit as opposed to an individual patient. FN is a particularly promising intervention for improving access to care for children with autism spectrum disorder (ASD) who experience significant challenges in obtaining diagnoses and accessing both ASD and non-ASD health services. Despite growing interest, there is little data about the implementation of FN for families of children with ASD. Our study looked at this across three US states. By asking nine experts in FN for ASD to rate each step in the FN implementation process we found five implementation steps where problems were likely to occur: 1) setting up community-based services; 2) initial family meeting; 3) navigator training; 4) fidelity monitoring of navigators (i.e., making sure FN navigators were implementing FN as they should be); and 5) attending testing appointments. Reasons for this included: families not being receptive; issues regarding scheduling; and insufficient training time for nevigators. The process identified as the highest-priority issue was "setting up community-based services". Problems in "attending testing appointment" was rated as the most severe potential problem. The results of our study are important as they can guide those working to implement FN for children with ASD.