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Telehealth Family Navigation for Early Autism Services Access: The Autism ALERT Project

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Presenter Information

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Telehealth Family Navigation for Early Autism Services Access: The Autism ALERT Project

Background: Delays in access to educational services for autism are common and more likely among children from families of color and/or with low income. In-person family navigation accelerates autism diagnosis; however, the effectiveness of telehealth autism diagnostic navigation is unknown.

Objectives: To test preliminary feasibility and efficacy of a telehealth autism navigation program.

Method: This was a site-randomized pilot trial of autism family navigation for Oregon children in 2021-2022. The intervention used layperson family resource specialists based at Oregon's Help Me Grow program as navigators for families of children with autism symptoms. Pediatric clinics with >30% Medicaid, located in 5 Oregon counties, were invited to enroll children in the study. 7 clinics (49 primary care providers [PCPs]) participated; 4 were randomized to the family navigation intervention and 3 to usual care. PCPs in both arms received training on autism screening and referral to medical/educational services. PCPs then referred any child age 1-55 months with a positive screen and/or provider autism concern to the study. For children in intervention arm clinics, the navigator called parents, providing information about autism and the autism diagnostic process, assistance with paperwork, social support, and appointment reminders. Control arm clinics/children received no calls. Study enrollment continued until 50 children (30 intervention, 20 control) enrolled. Child Early Intervention/Early Childhood Special Education (EI/ECSE) data were collected from Oregon's state database 6 months after enrollment. Primary study outcomes compared intervention and control arms on: % of children receiving EI/ECSE referrals within 6 months, % receiving an evaluation in EI/ECSE within 6 months, time from enrollment to EI/ECSE evaluation, and % of evaluated children receiving an autism educational label within 6 months.

Results: All clinics enrolled children; children were 40.8% (n=20) white, 26.5% (n=13) Latino, and 32.7% (n=9) multiracial and/or other race/ethnicity. 16% were female (n=8); median age was 2. Intervention families received a median of 12 navigator telehealth contacts. Overall, 70% (n=21) of intervention arm and 42% (n =8) of control arm families were successfully referred to EI/ECSE (p = 0.05). Of those referred, 86% (n=18) of intervention arm and 100% (n=8) of control arm children were evaluated in EI/ECSE (n.s.). Median time to EI/ECSE evaluation was 103 days in the intervention and 162 days in the control arm (p = 0.68; Figure 1). Overall, 40% of intervention arm (n = 12) and 21% (n = 4) of control arm children had an autism placement, with a trend toward autism as the primary placement type in the intervention arm (p = 0.12).

Conclusion: Telehealth family navigation shows promise for improving access to autism services in EI/ECSE, especially for securing an early EI/ECSE evaluation, and increasing autism educational labels. A full-scale trial can investigate more distal outcomes including receipt of medical diagnosis and therapeutic services use.

Figure 1: Kaplan-Meier survival curve comparing time from Autism Alert study consent to evaluation in Early Intervention/Early Childhood Special Education between intervention and control arm families; 183 days = end of 6-month follow-up period