

Factors Associated With Early Intervention Referral and Evaluation: A Mixed Methods Analysis

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ABSTRACT

OBJECTIVE: To identify parent, child, community, and health care provider characteristics associated with early intervention (EI) referral and multidisciplinary evaluation (MDE) by EI.

METHODS: We conducted a mixed methods secondary analysis of data from a randomized controlled trial of a developmental screening program in 4 urban primary care practices. Children <30 months of age not currently enrolled in EI and their parents were included. Using logistic regression, we tested whether parent, child, community, and health care provider characteristics were associated with EI referral and MDE completion. We also conducted qualitative interviews with 9 pediatricians. Interviews were recorded, transcribed, and coded. We identified themes using modified grounded theory.

RESULTS: Of 2083 participating children, 434 (21%) were identified with a developmental concern. A total of 253 children (58%) with a developmental concern were referred to EI. A total of 129 children (30%) received an MDE. Failure in 2 or more domains on developmental assessments was associated with EI referral (adjusted odds ratio [AOR] 3.15, 95% confidence in-

terval [CI] 1.89–5.24) and completed MDE (AOR 2.16, 95% CI 1.19–3.93). Faxed referral to EI, as opposed to just giving families a phone number to call was associated with MDE completion (AOR 2.94, 95% CI 1.48–5.84). Pediatricians reported that office processes, family preference, and whether they thought parents understood the developmental screening tool influenced the EI referral process.

CONCLUSIONS: In an urban setting, one third of children with a developmental concern were not referred to EI, and two thirds of children with a developmental concern were not evaluated by EI. Our results suggest that practice-based strategies that more closely connect the medical home with EI such as electronic transmission of referrals (eg, faxing referrals) may improve completion rates of EI evaluation.

KEYWORDS: care coordination; developmental delay; early childhood development; early intervention

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WHAT'S NEW

Despite guidelines and policy statements, many children identified with developmental concerns in the medical home are not linked to early intervention (EI). Strategies that more closely connect the medical home to EI (eg, faxing referral forms) may improve referral success.

EARLY INTERVENTION (EI) improves outcomes for children with developmental delays and their families^{1–3} but as many as 90% of potentially eligible children do not receive services.⁴ Part C of the Individuals with Disabilities Education Act (IDEA) provides financial assistance to states to implement EI programs for infants and toddlers with developmental delay,⁵ and the American Academy of Pediatrics (AAP) prioritizes linking the med-

ical home to these services.^{6–8} However, the path from a pediatrician's office to EI involves multiple steps, each presenting potential obstacles to service receipt. Many children identified with a developmental concern in the medical home are not referred to EI.⁹ Surveys and retrospective studies suggest that pediatric providers consider factors such as the presence of a medical diagnosis, type and number of concerning developmental domains, child gender, and age when making a referral to EI.^{10–13} Pediatricians may also choose not to refer to EI because they lack familiarity with local resources or to avoid causing parental anxiety.¹⁴ These studies are limited in that they provide limited insight into actual clinician behavior.

Even when referred to EI, many families do not complete the referral.^{9,15,16} Studies using parent report or EI administrative data suggest that minority race, young

maternal age, low income, low education level, not speaking English, and poverty negatively predict receipt of EI services.^{17–19} Among EI service recipients, families from minority backgrounds, with low income, and with low educational achievement were more likely to report difficulty learning about and initiating services.²⁰ Similarly, residing in a low-income neighborhood has been associated with a delay in EI service receipt.²¹ It is worth noting that studies using only EI administrative data may underestimate disparities in EI service receipt because these sources omit children who were referred to EI but never made contact with the agency.

Previous studies suggest that many children identified with a developmental concern are not linked to EI services,^{9,15} but these studies have provided limited insight into why linkages do not occur. Using referral information from the pediatricians' offices, administrative data from EI regarding whether referrals were completed and data on parent reported psychosocial risk factors we sought to identify parent, child, community, and health care provider factors associated with EI referral and completed EI multidisciplinary evaluation (MDE). We also conducted interviews with pediatricians to better understand provider factors that influence the EI referral process because qualitative methods are particularly well suited to explore why events occur^{22,23} and can complement quantitative methods when used together.²⁴ Our goal was to help inform practice-level quality improvement efforts aimed at linking the medical home to community resources like EI as well as state-level efforts to comply with IDEA requirements regarding identification of children with developmental delay and service delivery. Given the long-term benefits of EI,^{1–3} this information may also be relevant to public and private payers as they increasingly take on responsibility for the care of individuals throughout their life course and are thus incentivized to improve long-term health trajectories.²⁵

METHODS

STUDY DESIGN AND DATA SOURCE

Data came from a secondary data analysis and qualitative interviews. We conducted a secondary analysis of data from the Translating Evidence Based Developmental Screening (TEDS) study,¹⁵ a US Centers for Disease Control and Prevention–funded randomized controlled trial that tested the effectiveness of developmental screening protocols compliant with the 2006 AAP developmental surveillance and screening guidelines.⁶ These data were supplemented with a survey of parent-reported measures of psychosocial risks²⁶ that provided information on parent, child, and community factors. To contextualize our findings and gain deeper insight into provider factors that influence the EI referral process than was available in these data sets, we also conducted in-depth interviews with pediatricians who participated in the TEDS study.

The TEDS study consisted of 3 arms: 1) developmental screening using validated tools at the 9-, 18-, and 30-month well visits with the assistance of dedicated office staff who

conducted the screening, 2) developmental screening at the 9-, 18-, and 30-month visits without additional staff support, and 3) usual care. Clinicians and the dedicated office staff were trained in the use of the validated screening tools. Data were collected between December 2008 and June 2010. The TEDS study was conducted within the Children's Hospital of Philadelphia Pediatric Research Consortium, a 2-state hospital-owned primary care network including >200,000 children. Participants came from 4 urban teaching practices; <35% were privately insured.

STUDY POPULATION

Our study population consisted of parent–child dyads who enrolled in the TEDS study, completed surveys, and were identified with a developmental concern. Children born prematurely (<36 weeks' gestation), >30 months of age, with congenital anomalies or genetic disorders, in or out of home foster care, or enrolled in EI services were excluded from the TEDS study and thus were not included in this analysis.

DEPENDENT VARIABLES

The dependent variables in this study were child referral to EI (aim 1) and child receipt of MDE by the EI agency if they were referred (aim 2). EI referral was confirmed by review of the electronic medical record (EMR). Children who had a health appraisal and prescription to EI or written documentation in their medical chart were considered referred to EI. MDE was confirmed through EI administrative records. This information was available through an agreement between EI and participating practices.

INDEPENDENT VARIABLES

Our conceptual framework was informed by previous studies that explored EI referral and service receipt^{10–14,17,18,20} and the clinical experience of the study team. We hypothesized that parent, child, and health care provider characteristics would be associated with EI referral and evaluation, and we chose from available variables according to this framework. Additionally, given previous work that links residing in low-income neighborhoods to a delay in EI service receipt,²¹ we also included parent reported community characteristics.

Parent characteristics included race (African American, other), age (<30 years, ≥30 years), income (<\$20,000, ≥\$20,000), single or dual parent household, and parental education (high school diploma or less, some college or more). We also included an assessment of caregiver depression using an adaptation of the Patient Health Questionnaire-2 (PHQ-2).²⁷ The PHQ-2 was administered as 2 yes-or-no questions. We considered a positive response to either or both as signaling depression symptoms.

Child characteristics included gender, age, presence of special health care needs, and number of concerning developmental domains. Age when the developmental concern was first identified was included in models for EI referral,

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