

Barriers to Evaluation for Early Intervention Services: Parent and Early Intervention Employee Perspectives

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ABSTRACT

OBJECTIVE: To explore barriers to early intervention (EI) evaluation among referred infants and toddlers.

METHODS: We conducted semistructured interviews with parents of children referred for EI services and with EI staff. We purposively sampled families according to whether they received an EI evaluation. Families were recruited from a randomized controlled trial testing implementation of developmental screening. Parents filled out demographic surveys. Interviews were recorded, transcribed, and coded. We identified themes within and across respondent groups using modified grounded theory.

RESULTS: We reached thematic saturation after interviewing 22 parents whose child was evaluated by EI, 22 not evaluated, and 14 EI employees. Mean child age at first referral was 16.7 months, and 80% were referred as the result of language concerns. We identified 5 primary themes: (1) Parents reported communication problems with their pediatrician, including misinterpreting reassurance and not understanding the referral

process; (2) Many parents saw themselves as experts on their child's development and felt they should decide whether their child pursues EI services; (3) Some families preferred to wait for the developmental concern to resolve or work with their child on their own prior to seeking EI services; (4) For ambivalent parents, practical obstacles especially limited completion of evaluation, but highly motivated parents overcame obstacles; and (5) EI employees perceived that families avoid evaluation because they mistake EI for child protective services.

CONCLUSIONS: Communication between pediatricians and families that addresses practical logistics, families' perceptions of their child's development and EI, and motivation to address developmental concerns may improve the completion of EI referrals.

KEYWORDS: developmental delay; early childhood development; early intervention

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WHAT'S NEW

Parents and early intervention employees described barriers to early intervention evaluation. Communication problems included not addressing referral logistics, parents' perception of their child's development, and motivation to address the concern. Addressing these areas may improve referral success.

INTRODUCTION

THROUGH GUIDELINES AND policy statements, the American Academy of Pediatrics (AAP) has advocated for improved detection of infants and toddlers with developmental delay.^{1,2} However, detection does not guarantee intervention. Programs like early intervention (EI), as authorized by Part C of the Individuals with Disabilities Education Act (IDEA),³ can improve developmental outcomes, reduce secondary behavioral complications, and help families feel more confident about caring for their child,^{4–8} but up to 90% of eligible children do not receive services.⁹

Part C EI services are community-based and government-funded. Thus, when a pediatrician refers a child to EI, the process requires linking the medical home to a community-based resource. The AAP advocates for coordination between the medical home and community-based services like EI,^{10,11} but this remains a significant challenge for pediatricians.¹² The EI referral process can fail at many different stages. We know little about why the EI referral process is unsuccessful and even less about modifiable risk factors that lead to failed referrals. We designed this study to better understand, from the perspective of families and EI employees, why children referred to EI often are not evaluated.

METHODS

STUDY DESIGN

We conducted qualitative, semistructured interviews with parents of children who were referred to EI and evaluated parents of children who were referred to EI but not evaluated and EI employees to compare and contrast their experiences with the EI referral process. Qualitative

research methods were well-suited for this study because little is known about the topic and we wanted to explore participants' experiences in depth.¹³ We purposively sampled families whose children were referred to EI by their pediatrician on the basis of whether their child was evaluated by EI. The parent(s) of each child was interviewed. In addition, we interviewed local EI intake staff and service coordinators to gain a third perspective on the referral process. We received approval from the Institutional Review Boards at the University of Pennsylvania and the Children's Hospital of Philadelphia. All participants provided informed consent.

PATIENT POPULATION

Parents were recruited from the CDC funded Translating Evidence-Based Developmental Screening (TEDS) Study.¹⁴ The TEDS study was a randomized controlled trial that tested the effectiveness of developmental screening protocols compliant with the 2006 AAP developmental surveillance and screening policy statement.¹ The study consisted of 3 arms: developmental screening using validated tools at the 9-, 18-, and the 30-month well visits with the assistance of staff for the screening and EI referral process; developmental screening at the 9-, 18-, and the 30-month visits without additional staff support; and usual care consisting of routine developmental surveillance at all well visits. The TEDS study assessed the feasibility of adoption of the AAP guidelines, the effectiveness of protocols consistent with the AAP guidelines, and the adoption and acceptance of the guidelines by urban pediatric practices. Children previously diagnosed with developmental delay, prematurity, and major congenital anomalies/genetic disorders were excluded from the TEDS study. Data collection for the TEDS study was completed in October 2010.

Of 2092 total participants who were largely low-income and African American, 332 children were referred to EI by their pediatrician. Pediatricians either provided parents a phone number and asked them to call EI or directly faxed the referral to EI. Only 170 of the 332 were evaluated by the local EI provider. The group that was not evaluated included parents who did not make contact with EI and parents who made contact but were not subsequently evaluated. The TEDS study took place within The Children's Hospital of Philadelphia Pediatric Research Consortium, a 2-state, hospital-owned, primary care network that includes >235,000 children. Participants came from 4 urban teaching practices, where both attending physicians and residents care for children and <35% of patients have private insurance.

We obtained a list of contact information for parents of the 332 children referred to EI from the TEDS study. Parents were divided into 2 groups (evaluated and not evaluated) and stratified by primary care site. Then, within each site and in order of the list, eligible subjects were invited to participate. The number of parents we could not reach were similar for both groups (83 in the group not evaluated vs 78 in the group that was) as were the number who refused to participate (21 in the group not evaluated compared with 22 in the group that was). However, twice the number of

parents of children who were not evaluated did not show up for the interview (n = 32) compared to parents of children who were evaluated (n = 15). Parents were asked to confirm that they were the child's primary caregiver during recruitment. Recruitment stopped once thematic saturation was achieved, when interviews stopped generating new themes. A list of EI employees, grouped by their role as service coordinators or intake staff and by the region of Philadelphia they covered, was provided to the research team. All referred employees were interviewed.

DATA COLLECTION

We used a detailed review of the literature and consultation with pediatricians, developmental pediatricians, developmental psychologists, EI employees, and experts in qualitative research to develop our interview guide. We prompted participants to share their experience with the EI referral process. (Sample question 1: Based on our records from the TEDS study, it seems your doctor voiced a concern about [insert child's name]'s learning or development. I'd like you to think about when she/he expressed these concerns to you. Tell me about it. Sample Question 2: What was it like to get in touch with early intervention?) One of three research assistants conducted all interviews between June and September 2011. Research assistants were trained by a medical anthropologist (F.B.) and conducted pilot interviews before they interviewed participants as part of their training. Most parent interviews lasted between 30 and 60 minutes and were conducted in person in an office setting or by phone. Employee interviews lasted between 15 and 50 minutes and took place at the EI agency. Members of the study team met at least weekly to ensure data quality and modify the interview guide to explore emerging themes more deeply. Parents completed a brief demographic survey. Interviews were recorded and transcribed verbatim. We used NVIVO 9 software (QSR International, Melbourne, Australia) to assist with data management.

DATA ANALYSIS

We analyzed the data by using modified grounded theory.¹⁵ Four members of the research team coded the first 5 transcripts to develop an initial coding scheme. Consistent with grounded theory, codes were allowed to emerge from the data rather than imposed by the research staff. Two trained research assistants then coded each transcript independently and each coded transcript was reviewed by the primary author (M.J.). We used the constant comparative method,¹⁶ in which newly collected data were compared with codes that emerged from previously collected data.

The research team met regularly and, through an iterative process, developed and revised the coding tree. Disagreements among team members were resolved by consensus. The research team attended to repetitions and patterns among codes to identify themes. Themes were compared within and across the group of parents whose children were referred to EI but not evaluated, the group that completed the evaluation, and EI employees. Themes are presented in no particular order. We present representative quotes for each theme.

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