Family Perspectives on Seeking Early Intervention Services for Infants and Toddlers

Margaret Gillis, PhD
SRI International



Society for Research in Child Development Biennial Meeting

Minneapolis, MN

May 2, 2025

Background

- Identifying infants and toddlers with developmental delays and disabilities and getting them into early intervention (EI) services is essential to their optimal developmental, academic, and life outcomes (Hebbeler & Spiker, 2016; Institute of Medicine & National Research Council, 2000).

- However, families experience barriers to accessing EI services (Jimenez et al., 2012; Little et al., 2015) and EI programs struggle to identify and enroll children as early as possible (McCoy et al., 2017).

- Primary health care providers are the most common referral source, followed by families (GAO, 2023). Other referral sources include child care programs, social services, and NICUs/hospitals.

Child Find ACCESS

Child Find

- Required by Part C of the Individuals with Disabilities Education Act
- Process for identification, screening, referral, evaluation, and tracking of children who are potentially eligible for EI
- Involves coordination with programs and people who work with infants and toddlers and their families (e.g., physicians, child care programs, social services)



Context: Child Find ACCESS Model Demonstration Project

- Funded by the Office of Special Education Programs, U.S. Department of Education
- October 2021 - September 2025 (Dissemination Oct. 2025 - Sept. 2026)
- Phased implementation in 3 county-level sites in North Carolina
- Goals focus on improving child find to:
  - Increase appropriate referrals to EI
  - Increase coordination of screening, tracking, and referrals
  - Promote access to and uptake of EI services by families who are missed by current efforts

Family Interviews

- 25 interviews with families with children currently under age 8 who had concerns about their child when they were under age 3
- 60-minute interviews conducted via Zoom or phone
- Interviews focused on families' experiences seeking services for their child
- Member checking: sent summary of "big ideas" from the interview to the participant for corrections
- Analysis: constant comparative method to evaluate themes

Child Find ACCESS

Results



Barriers to EI Access Related to Pediatricians and Other Medical Professionals

- Pediatricians not referring families to EI
- Lack of information-sharing about benefits of EI
  - When recommending referral
  - When genetic conditions are diagnosed in utero
- Lack of coordination between EI programs and NICUs, especially when NICU is out of the catchment area for the family's local EI program
- Autism-specific barriers
  - Belief that only developmental pediatricians can make diagnosis
  - Long wait times for appointments with dev. peds.
  - Beliefs regarding age of diagnosis



Child Find ACCESS

Other Barriers to EI Access



- Families unaware…
  - EI is available and don't know how or where to find their local program
  - They can self-refer
  - Of the benefit or value of EI for very young children
- Lack of bilingual staff in EI programs limits connections with non-English-speaking families
- Families may have limited capacity to participate or consider EI services when juggling complex medical appointments

Child Find ACCESS

Facilitators to EI Access

- Some pediatricians quick to refer when parents express concern and explain why they recommend the EI program if parents seem hesitant
- Some families are persistent in finding a pediatrician who will take their concerns seriously
- Some families learn about the EI program from extended family or friends who explain the benefits they experienced



Implications



- EI provides supports for the whole family - not just the child
  - Outreach needed to ensure referral sources are aware of the existence and benefits of EI
- Needs for support navigating concerns and EI process
  - Potential of ECE to provide support

Thank you!

margaret.gillis@sri.com

The contents of this presentation were developed under a grant from the U.S. Department of Education, #H326M210002. The contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer: Yolanda Lusane.

Child Find ACCESS

IDEAs that Work
Office of Special Education Programs

SRI