



Barriers and Facilitators of Early Identification of Delays and Disabilities: Family, Child Care, Medical, and Community Perspectives

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Background

- Identifying infants and toddlers with disabilities and developmental delays as soon as possible and screening, referring, evaluating, and enrolling them into early intervention services is essential to their optimal developmental, academic, and life outcomes (Hebbeler & Spiker, 2016; Institute of Medicine & National Research Council, 2000).
- Part C early intervention (EI) programs struggle to identify and enroll infants and toddlers with delays and disabilities as early as possible (McCoy et al., 2017).
- The proportion of children in Part C is low compared with the proportion of school-age children served by Part B (Rosenberg et al., 2008).
- Primary referral sources, such as medical professionals and early care and education (ECE) professionals, are critical partners in ensuring children and families are identified and referred to EI.
- State and local EI programs and their partners need more information about the perspectives of families, medical professionals, and ECE professionals to understand barriers and facilitators to EI and referral to effectively plan for child find system improvements.

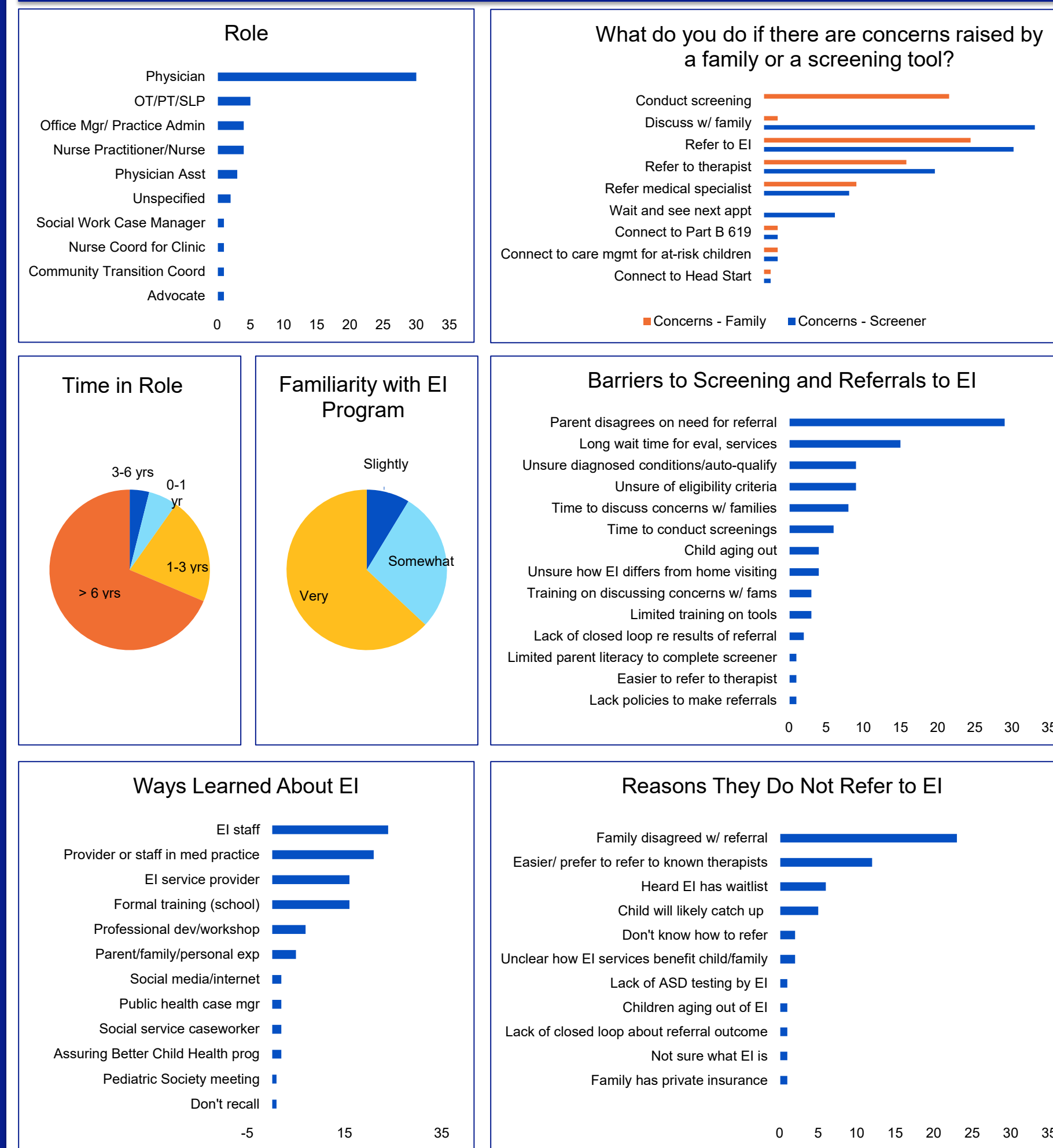
Context for the study

- Data were collected within a community-engaged/informed model demonstration project operating in three county-level communities in one southeastern state. The project aims to discover family and community perspectives on the child find process to inform improved access to and uptake of EI services for families.
- In each community, local EI agency staff, ECE program-serving agencies, families, social services staff, health department staff, and other child find-relevant key partners form a community leadership team (CLT).
- CLTs meet monthly and use data to identify, explore, and understand challenges to local child find processes and practices.
- CLTs select, adapt, and implement evidence-based practices to improve access and uptake of EI services.
- A state leadership team addresses state- or system-level barriers and opportunities based on CLT-identified needs.
- EI program data indicate physicians are the source of the greatest number of referrals to the EI program in the state and in each county, which is consistent with nationwide trends (Government Accountability Office, 2023).
- EI program data show a limited number of referrals from ECE programs in each community.

Methods

- Local Child Find Self-Assessment (L-CFSA)
 - Local adaptation of a state-level tool designed to document how Part C programs are meeting child find regulations and how cross-sector agencies and organizations are implementing best practices for strong and effective child find systems.
 - Completed by the CLT in each community to map its child find efforts across agencies, including efforts that had been in place that had been paused or discontinued.
 - Addresses efforts undertaken by the EI program as well as key partner agencies to promote awareness of the EI program and timely and appropriate referrals.
- Family Interviews
 - 60-minute interviews conducted via Zoom or phone with families in the three communities who had concerns about their children when they were under age 3. Interviews focused on their experiences seeking services for them.
 - 24 interviews completed.
- Early Care and Education (ECE) Survey
 - Online survey of ECE teachers and program administrators, including family child care home providers, working with children under age 3 in the three communities. Survey focused on their screening and referral practices and their communication with families about concerns.
 - Completed by 50 respondents.
- Medical Professionals Survey
 - Online survey of medical professionals working with children under age 3 statewide. Survey focused on screening, developmental monitoring, and referral practices.
 - Completed by 54 respondents.

Medical Professionals Survey Results



Family Interview Results Summary

Medical Community

- Pediatricians and other health care providers not referring families to their local EI programs
- Taking a “wait and see approach,” dismissing parent concerns voiced in office visits, and ignoring parent concerns recorded in developmental screenings
- Referring families straight to therapists
- Recommending referral but not explaining benefits of program
- Not sharing EI program/referral info with expectant parents as genetic conditions diagnosed in utero
- Out-of-county neonatal intensive care units (NICUs) not collaborating/ coordinating with local EI programs in new parents’ home counties

Autism Spectrum Disorder (ASD)-Specific Issues:

- Belief that only developmental pediatrician can make ASD diagnosis
- Long wait time for developmental pediatrician appointment
- View that ASD diagnosis as impossible or irrelevant with children under age 2

Local Program

- Name of local program may be confusing to families
- Lack of bilingual staff limits connections with non-English-speaking families
- Lack of clarity for families around who is contacting them (and why), especially for families participating in multiple programs or initiatives

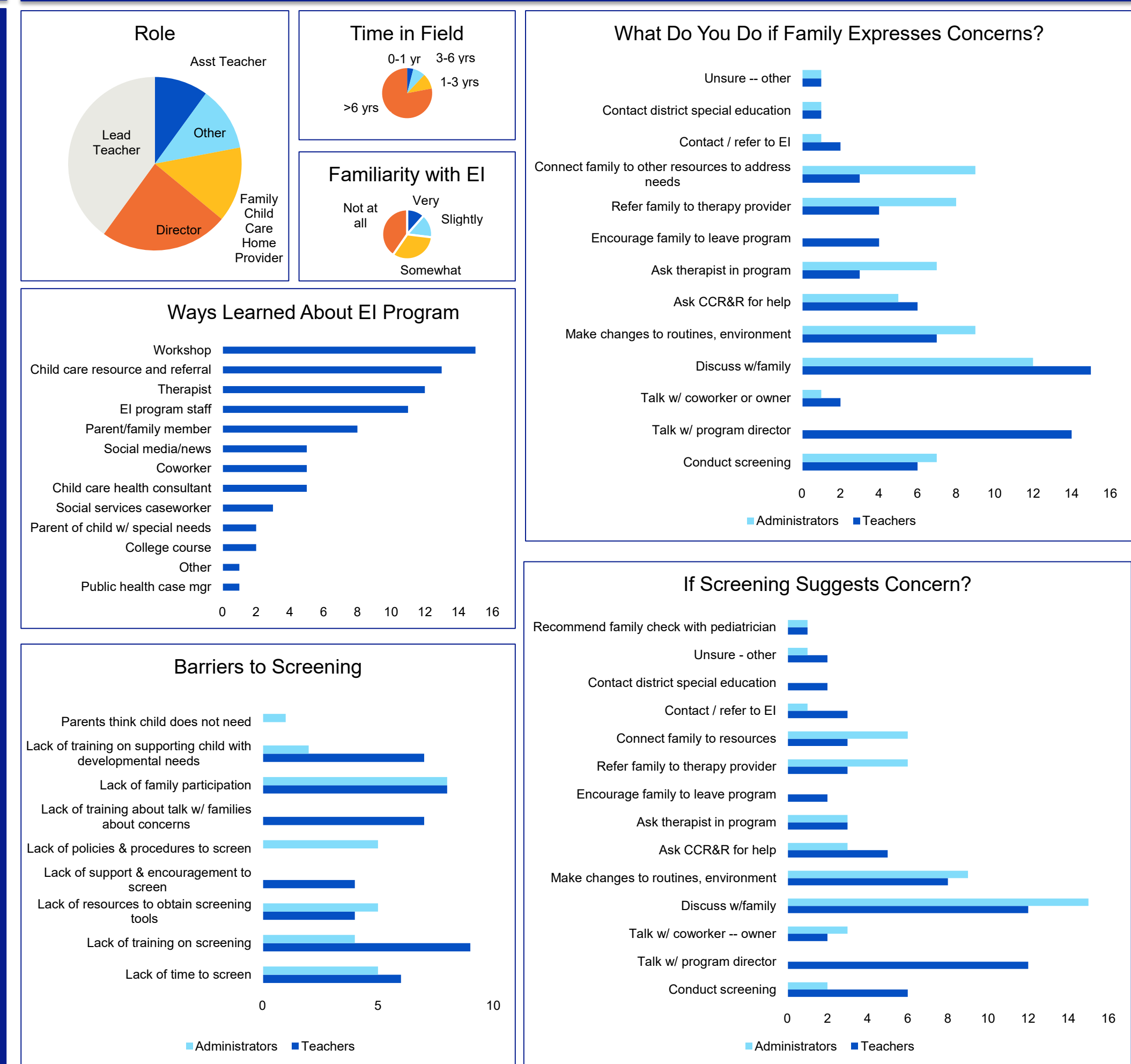
Public Awareness

- Families do not know how/where to find the local EI program
- Families are unaware that they can self-refer
- Families are unaware of benefit/value of EI and are getting “wait and see” messages from friends/family
- Families may have limited capacity to participate or consider EI services when juggling complex medical appointments

Early Care and Education (ECE)

- ECE may be missing concerns regarding children’s development
- ECE programs are referring families straight to therapy

ECE Survey Results



Local Child Find Self Assessment Results Synthesis

Barriers

- Many outreach activities undertaken by EI programs and partner agencies, including public health and child care resource and referral (CCR&R), were paused or discontinued during the COVID-19 pandemic and have not resumed.
- Turnover among physicians during and after the pandemic and the ongoing child care workforce crisis seem to be impacting the lack of awareness of the EI program, eligibility criteria, and/or referral process.
- Many families, particularly military families, do not see the same primary care provider (e.g., pediatrician, family practitioner, nurse practitioner) for each well child visit, which may contribute to the “wait and see” approach to families’ concerns about and delays in EI referrals.

Facilitators

- CCR&R, public health, Early Head Start/Head Start, family organizations, and other agencies, including those that are members of local interagency coordinating councils, are critical partners for local EI programs in outreach to their respective constituencies to raise awareness about the EI programs and provide training and support for developmental monitoring, screening, and referral.
- Organizations that connect families of children who have received EI with families going through the referral and evaluation process help families understand the benefits of EI from a family’s perspective and can answer questions about the process.

Implications for Early Care and Education

- With their close, trusting relationships with infants and toddlers and their families, teachers, directors, and family child care home providers can support families in documenting their children’s development and any concerns, understanding how EI could benefit their children and families, and understanding that they can self-refer to EI.
 - This may be particularly important if a family has concerns and the doctor is acting as a gatekeeper.
- CCR&R agencies and similar organizations can provide training and resources to ECE programs, including access to and training on screening tools, tips for talking with families about developmental concerns, information about the EI referral process and services, and resources for supporting children with developmental needs.
 - These trainings and resources can help build providers’ awareness, skills, and confidence in identifying possible delays, talking with families about concerns, making appropriate referrals, and working with children with developmental delays and disabilities.

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