

Arda Hotz MD,¹ Elizabeth Ward PhD,¹ Rosa Seijo MD,² Hannah Brooks MS,³ Nicole Brown MD MPH MHS¹

¹Department of Pediatrics, Albert Einstein College of Medicine and the Children's Hospital at Montefiore, Bronx, NY, United States.

²Children's Evaluation and Rehabilitation Center, Rose F. Kennedy Center, Albert Einstein College of Medicine, Bronx, NY, United States

³Albert Einstein College of Medicine, Bronx, NY, United States

BACKGROUND

Despite the shared goals of Early Intervention (EI) and the patient centered medical home, communication between EI service providers, primary care providers (PCPs), and caregivers remains suboptimal.

Little is known about perceived barriers and facilitators of communication and collaboration between EI service providers, PCPs, and parents of children who have been referred to, or receive, EI services.

OBJECTIVES

To characterize EI service provider, parent, and pediatric provider perspectives and experiences with communication and collaboration.

DESIGN/METHODS

- Qualitative study using in-depth semi-structured 1:1 interviews. Interviews were ongoing until the point of thematic saturation.

- All interviews were digitally recorded and professionally transcribed.

- A five person multidisciplinary team utilized the constant comparison method to iteratively code transcripts and identify key themes.

- Dedoose software was used to facilitate qualitative data organization and retrieval

RESULTS

Participants (N=24):

- 7 caregivers of children** evaluated by New York City's EI program (5 receiving or received services, 1 awaiting initiation of services, and 1 found not to be eligible for services)
- 5 pediatricians** (2 academic, 2 community, 1 developmental-behavioral)
- 12 EI service providers**

KEY THEMES AND ILLUSTRATIVE QUOTES

Barriers to Effective Communication & Collaboration

- A lack of a system to facilitate timely bidirectional communication and sharing of child progress.
"Sometimes it feels like we're separate from the therapies and we don't necessarily know the exact diagnosis. And it's hard to measure progress when you don't know exactly what's going on."
- General Pediatrician (Community Clinic)
- A lack of education and understanding by PCPs, EI providers, and caregivers regarding both their own and others' roles in the EI process.
"I find it sometimes challenging for the parents to understand that I want to stay involved in the process and that it's part of what we're going to talk about at the follow ups, and that sometimes they just think of it as a separate entity and don't even bring up that they're getting early intervention services."
- General Pediatrician (Academic Teaching site)
- Delays in paperwork
- Time limitations
- Cultural, language, and socioeconomic barriers
"I told them I would like the doctor to know about it too. So we had to sign a paper that yes, the doctor can get that information too. Because I don't want to be holding it all by myself when I don't understand what he's talking about."
- Grandmother of a 2 year old with global developmental delay
"When I tell him I am coming over to do an evaluation, he is saying, 'What? For what? I can just send this to you from the doctor.' Like, 'No, I have to come over there and get the evaluation done.' He is so confused."
- EI Service Coordinator

Facilitators of Effective Communication & Collaboration

- Continuity with a single EI provider and agency improves timely delivery of services and information sharing.
- Advocacy by any party improves both the referral and the EI service delivery processes.
"As a Service Coordinator, I am like a thread between the doctor, the parent, and the city. So, I go around, I have to connect the parent to the evaluation agency, and then the services."
- EI Service Coordinator
"We're asking the parents to sort of be the leaders in this process and often it's a lot to navigate on their own... So I think if we knew what the evaluations said we could translate some of that for the parents and then just being able to sort of explain the reason for the therapy and why it's so important."
- General Pediatrician (Community Clinic)
- Medically complex children tend to have teams with more successful communication and collaboration, as all parties prioritize these patients.
- A team-based approach to care improves collaboration.

CONCLUSIONS AND RECOMMENDATIONS

Standardize ways to communicate, and enable routine communication between all stakeholders to optimize delivery of care and care coordination.

- Consider allocating more space for PCPs to communicate their concerns on the EI referral form. Package referral form with child physical and medical release forms.
- Individual Family Service Plans (IFSP) should be succinct and easily accessible to PCPs and caregivers.
- Use of technologies such as an online referral system, an electronic portal system, and/or a mobile phone application may help facilitate routine communication.
- Formalizing a system to help "close the loop" would be facilitated by having easily available clear contact information for all parties.

Educate caregivers, EI service providers, and PCPs about the EI process and their respective roles in the process to achieve better communication and collaboration across stakeholders.

- Parent handout in multiple languages about EI referral and evaluation processes
- Peer advocates may help caregivers navigate the system
- Webinars and other learning material for PCPs about:
 - The EI process in general
 - The role of the PCP
 - Which children are automatically eligible
 - The appeal process
 - Appropriate surveillance of a child who is delayed but has not qualified for EI services.
- Educational resources for pediatric staff (ie receptionists who field calls and complete paperwork for PCPs)

IMPLICATIONS

Caregivers, PCPs, and EI service providers identified barriers and facilitators of effective communication and collaboration. Our findings may inform future interventions aimed at optimizing care coordination, caregiver support, and communication.

ACKNOWLEDGEMENTS

- This research was supported by an AAP Resident CATCH grant.
- Thank you to the NYC Department of Health and Mental Hygiene/New York State Early Intervention Program who served as an advisor to this project.