

Why can't they walk with us on this journey?: Family perspectives on accessing early intervention services

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ISEI Conference
September 2025



Project Background

- Model demonstration project in the US focused on improving early identification, uptake of EI
- Working with 3 community-level teams
- Family voice centered through interviews, participation on community teams

Centering Family Voice: Interviews

- $N = 24$ virtual interviews (~1 hr in length)
- Families shared their experiences seeking services for young children (prior to age 3)
- Categories that emerged:
 - Facilitators and Barriers:
 - Medical Community
 - Local EI Program
 - Public Awareness
 - Family Recommendations



Barriers

- Families' concerns dismissed – “wait and see” message from medical providers, family, and friends
- Families referred straight to therapists
- Families unaware they self-refer, confused about how to find EI, who was contacting, how they could benefit
- Conflicting messages, delays re: ASD-related diagnoses
- Family capacity when handling multiple medical appointments
- Limited Spanish-speaking EI staff

Facilitators

- Quick referrals to EI from their medical providers.
- Positive referral, evaluation, service-planning experiences, great connections to EI staff
- Some families know about the EI program from past experience, family, or friends
- Some families know about developmental milestones from experience with older children
- Some independent therapists connected families with the EI program



Participant Suggestions for Improvements

- Share information about EI and referral via social media, at community gatherings
- Share information on developmental milestones in pediatricians' offices (posters with QR codes)
- Provide EI info in packs that go home from neonatal intensive care unit
- Share info with pediatricians about how to talk with families who bring concerns
- Provide families with talking points for bringing concerns to pediatrician

Insights from Family Workgroup

- Parents who feel supported are more likely to take up/continue services for their child, however, on the whole:
 - Services feel impersonal
 - Lack of support/acknowledgement of lifestyles/routines
 - Constant focus on child deficits without acknowledging family efforts to support child progress
 - Parents are starved for connection and a place to feel understood and adequate

Family Workgroup Recommendations

- For service providers, take time to talk about what is going well for the child, give encouragement to the parent
- For decision-making groups, provide options for family-only working sessions or ad-hoc gatherings
- Find ways to make materials aimed at helping families adjust to their new path widely available (virtual and hard copy resources)
- Find ways to support families to tell their story

Thank you!

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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.

