

# Advocating for Early Intervention: Our Passion, Our Future

Thursday, March 28, 2024





## What is Early Intervention?

The Early Intervention Program for Infants and Toddlers with Disabilities, Part C of the Individuals with Disabilities Education Act (IDEA), entitles infants and toddlers with disabilities and their families to Early Intervention services that:

- **Enhance the development** of infants and toddlers who have or are at risk for developmental delays or disabilities
- **Build the capacity of families** to meet individual needs of their children
- **Minimize the need for special education** and related services when eligible infants and toddlers reach school age



# Speakers

**Leanne Barrett**, Senior Policy Analyst, Rhode Island Kids Count

**Sadia Batool**, Early Childhood Family Lead for Early Childhood Comprehensive Systems, Pennsylvania Office of Child Development and Early Learning

**Zareen Kamal**, Policy Specialist, Illinois Policy, Start Early

**Libbie Sonnier**, Executive Director, Louisiana Policy Institute for Children

## Moderator

**Karen Berman**, Senior Director, Illinois Policy, Start Early

# RI KIDS COUNT

Rhode Island KIDS COUNT is a **statewide children's policy organization** that provides information on child well-being, stimulates dialogue on children's issues, and promotes equity and accountability.

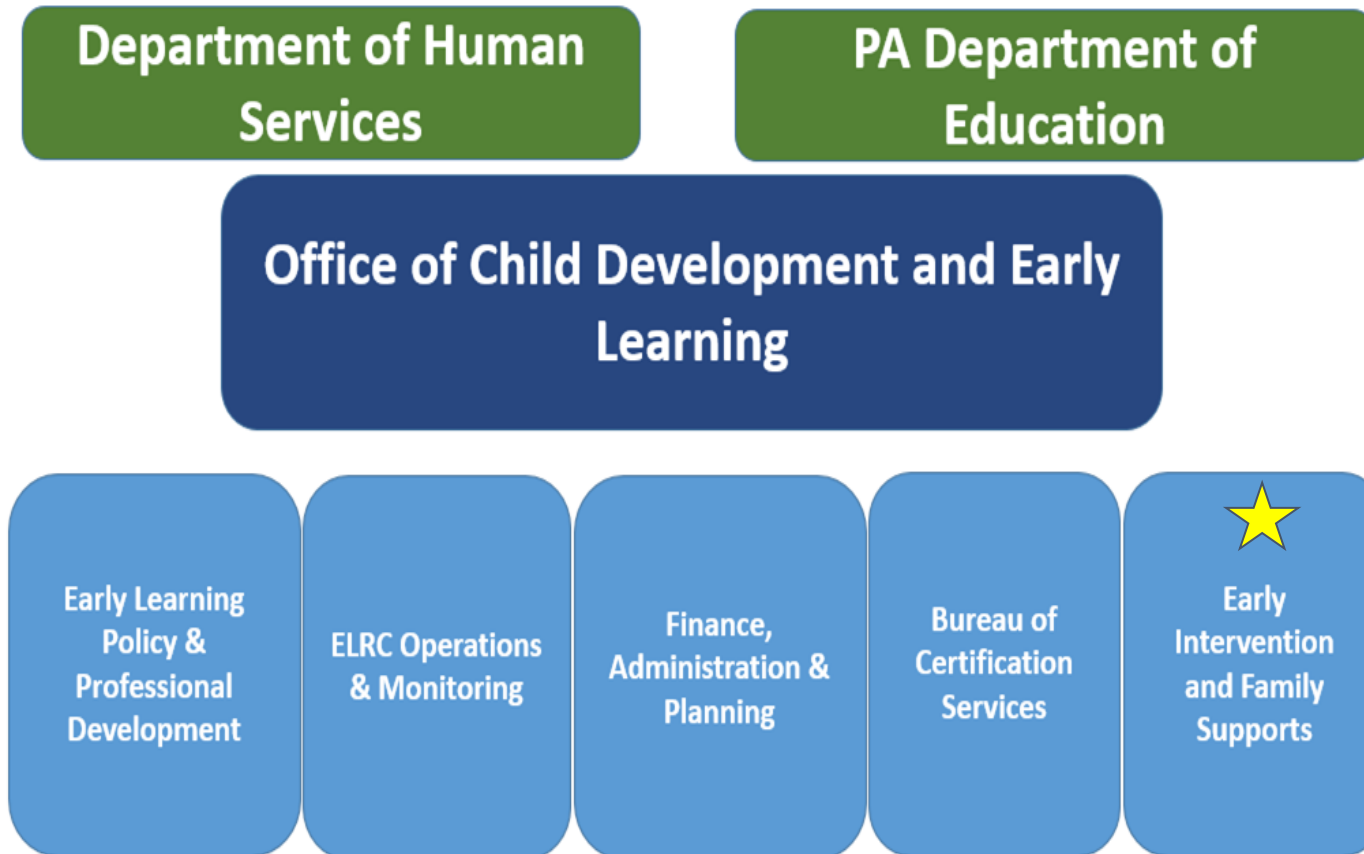
Rhode Island KIDS COUNT coordinates the **Right from the Start Campaign, a legislative and budget campaign led by eight organizations** to advance policies that help ensure ALL Rhode Island babies and young children, regardless of zip code, race, ethnicity, or family income, get off to the right start.



**Right** from the  
**Start**



## Pennsylvania Office of Child Development and Early Learning



# OCDEL Partnerships

The  
Pennsylvania Key  
(PA Key)

Early   
Intervention  
Technical  
Assistance (EITA)

Professional  
Development  
Organizations  
(PDO)

19 Early  
Learning  
Resource  
Centers (ELRC)



For nearly 40 years, Start Early has brought expertise in program delivery, research and evaluation, professional development, and policy and advocacy, in partnership with communities and other experts, to drive systemic change so that millions more children, families, and educators can thrive.

- **The Illinois Policy Team (IPT)** plays a leading role in the development of Illinois' early childhood system and for decades has engaged in policy advocacy on behalf of children with special needs.
- As a federal Head Start grantee, Start Early convenes our delegate agencies in the **Early/Head Start Network** to continually improve our practice to provide early learning services to young children and their families in Chicago.
- **Start Early Consulting** supports our partners to ensure that prenatal to five systems are high-quality and integrated, are resourced to be sustainable, and are designed to serve children and families from historically marginalized communities.





# The Louisiana Policy Institute for Children

- ❑ **Mission:** Advancing policies to ensure that Louisiana's young children are ready for success in school and in life.
  - ❑ **Vision:** We envision a Louisiana in which all young children, birth through age four, are safe, healthy, and reach their full potential.
  - ❑ **Our Work:** The Policy Institute seeks to be a source of nonpartisan, independent information on issues concerning children ages birth through four in Louisiana.
-

As you're listening, please use the chat:

What resonates with you and the struggles/solutions you are advocating for in your state?

Any other reflections or clarifying questions for the presenters



# Our Struggles

## Rhode Island: EI Financial and Staffing Crises

- Early Intervention enrollment more than doubled between 2001 and 2019. State has usually been in top 5 nationally for participation rates. Financed through Medicaid and Commercial Insurance billing, payment rates set in 2002 had been cut in 2009 and frozen (in 2022 rates were lower than in 2002).
- Early Intervention wages were not competitive, and staff turnover rates averaged 33% per year with many agencies needing to replace 50% to 60% of staff per year.
- In November 2021, a statewide waiting list was established that grew to 1,000 within one year. Typical enrollment in EI is 2,300 children.
- Even after a 45% rate increase won through legislation that passed in 2022 and \$11 million in ARPA funds over two years, staffing challenges and waiting lists continue (900 waiting in July 2023, 600 waiting in February 2004).
- Similar financing and staffing problems in Preschool Special Education System statewide with parent driven lawsuit in Providence for systemic failures.



**Right** from the  
**Start**





## Early Childhood IDEA Programs in Rhode Island: Challenges Families Face



### MANY RHODE ISLAND FAMILIES:

- **Don't know how to access Early Intervention or Preschool Special Education** and often do not receive reliable information or support from people in the community— including health care providers, child care providers, and school districts.
- **Don't know that they can call** an Early Intervention provider or their school district directly to **request a screening or evaluation whenever they have concerns** about their child's development.
- **Have scheduling challenges and struggle to access** services because they are working long hours and have very limited paid time off.
- **Don't see people from their own culture/race** or meet people who **speak their home language** providing Early Intervention or preschool special education services.
- **Have great difficulty finding and paying for quality child care** for children with special needs.



## Family Engagement -Needs identified

- Invisibility of Family Leadership opportunities
- Barriers to access e.g. transportation, language, technology
- Lack of family-friendly leadership opportunities
- Lack of standardized supports for families
- Lack of dedicated staff for family engagement

## PENNSYLVANIA EARLY CHILDHOOD COMPREHENSIVE SYSTEMS HEALTH INTEGRATION PRENATAL TO THREE PROGRAM



OCTOBER 2022

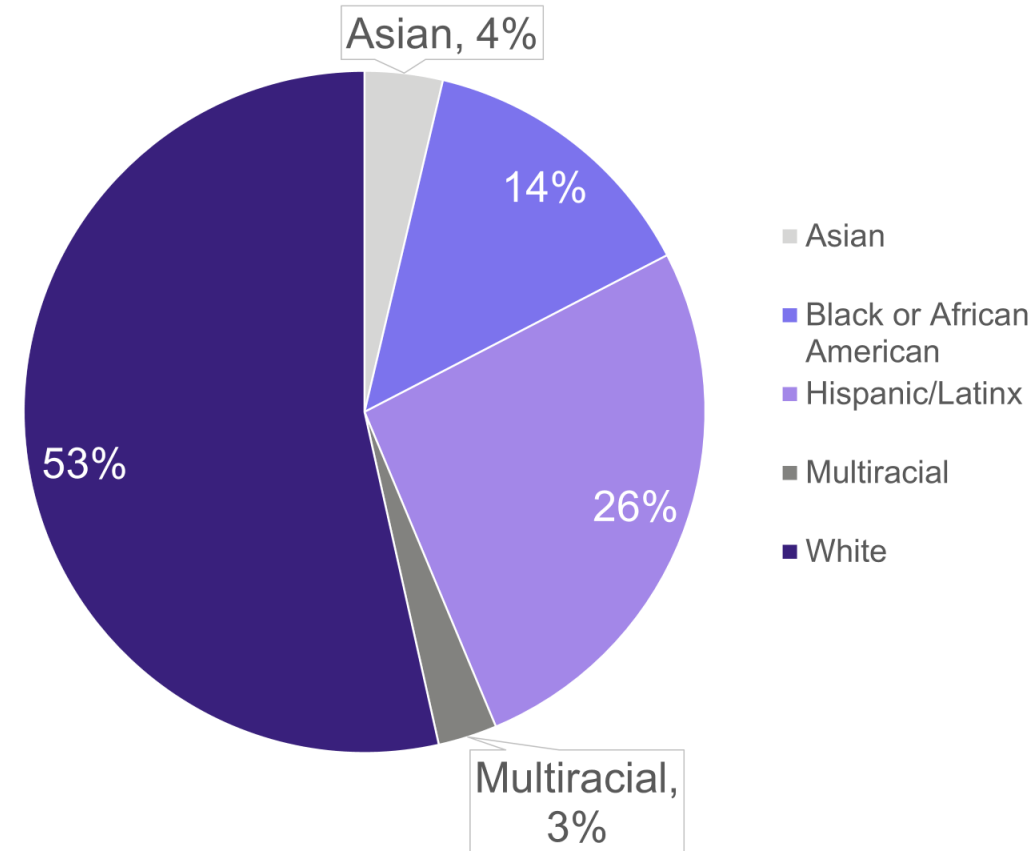
### System Asset and Gap Analysis

CHRISTINA HARRIS, M.S.  
SADIA BATOOL, MBBS  
BENJAMIN COHEN, PH.D.



## IL Early Intervention System: A Snapshot

- 25 statewide regional points of entry through which families can access the program.
- 26,700 children served in January 2024.
- Nearly half of families served are Medicaid benefit recipients.
- Provide 16 different services, including speech, physical, occupational, developmental, and other therapies and service coordination.
- 43% of children who participated in Early Intervention are functioning within age expectations by 3 years old.
- Of those who exit functioning below age expected levels, 75% of children substantially increased their rate of growth by 3 years old.



## The Workforce Crisis and Systems Challenges

- EI provider shortage
- Families experiencing barriers at every step of the process
  - Rising waitlists
  - Unmet EI timelines
  - Barriers to access
- Service delays have **more than doubled in the past two years**
  - FY22 avg 4.6%
  - FY23 avg 8.3%
  - FY24 YTD avg 9.4%

**Toddlers with developmental delays are missing out on help they need. It can hurt them long term**



Alexander, 3, who is being treated for developmental delays, plays with his dinosaurs in the living room of his West Chicago, Ill., home, Tuesday, Aug. 8, 2023. Alexander qualified for five Early Intervention therapies in summer 2021, physical, occupational, developmental, behavioral and speech when he was about a year old. But the family waited more than a year to get any of these services in-person. (AP Photo/Charles Rex Arbogast)

▶ Videos 1

📷 Photos 18



BY CLAIRE SAVAGE

Updated 11:11 PM CDT, October 7, 2023

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Our Solutions

## Rhode Island: Advocacy Strategies

- Data from a 2018 Early Intervention staff survey and stories from Early Intervention family surveys showed staffing problems have been brewing for years.
- Key Advocacy Partners: Parents Leading for Educational Equity - grassroots parent organizing, RI Parent Information Network - Parent Training and Information Center. RI Chapter of the American Academy of Pediatrics - influential advocacy.
- [Powerful Advocacy Video](#) featuring RI family and Early Intervention therapist.
- Continued media attention to waiting list.

### **Infants, toddlers face long wait for crucial Early Intervention services in R.I.**

“The child gets on the waitlist and by the time you’re able to get them, they’re within a year of aging out,” a provider told the Globe. “And we know how critical it is to get to them in those early years.”



**Right** from the  
**Start**



## Rhode Island: Priority Solutions

- Governor has recommended a 15% rate increase in his FY25 budget and talked about Early Intervention in his State of the State speech.
- Legislation has been introduced asking for a **25% Medicaid rate increase in FY25, an annual Cost of Living Adjustment (COLA), + free child care for staff who work in Early Intervention** (expansion of Child Care for Child Care Educators).
- Legislation has been introduced asking the General Assembly to establish and fund a statewide **Early Childhood IDEA Task Force** to review and develop a financing and staffing plan to ensure all children from birth up to kindergarten entry that need IDEA services are screened, evaluated, and enrolled promptly and receive the IDEA services they are entitled to and that meet the needs of families.



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**Start**



## The Pennsylvania Family Engagement Birth through College, Career, Community Ready Framework

A tool to guide the implementation of effective practices, use of shared language, and a family engagement continuum for families across their child's educational lifespan.



## Pennsylvania's Family Engagement Birth through College, Career, Community Ready Framework: A Companion Guide for Families



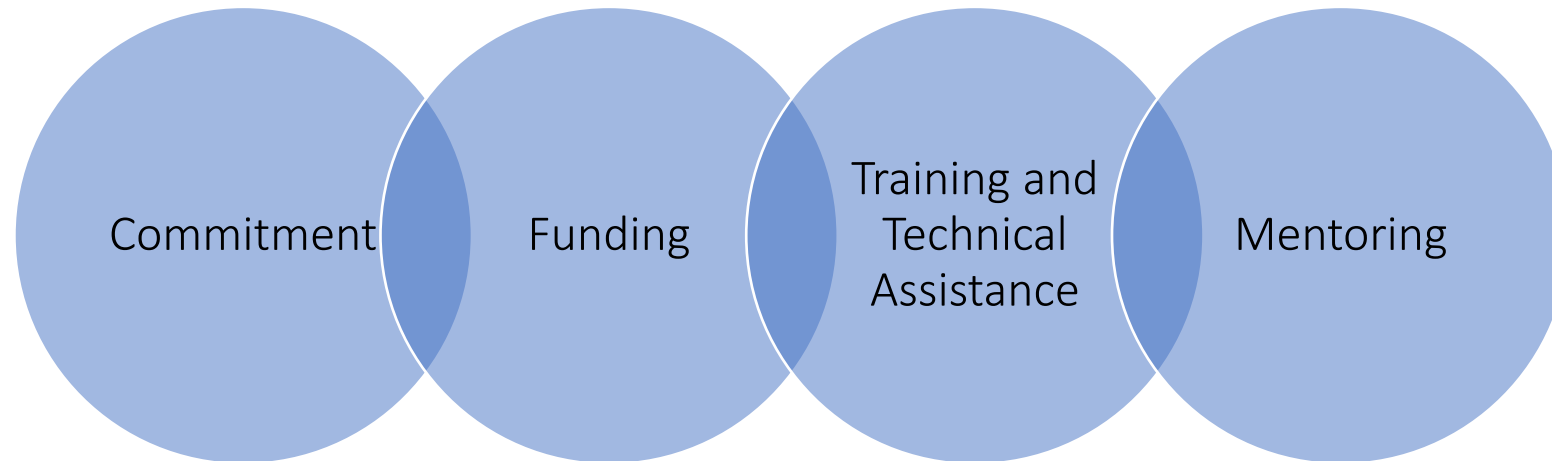
# Family Engagement Definition

Effective family engagement is *intentional, meaningful and impactful*.

Learning Communities value and support families in their role as a child's first teacher, and *leverage the expertise, knowledge and leadership of families and community partners* to shape the educational environment at the program, classroom, school, state and national level.

These partnerships are *strengths based, culturally responsive and rely on two-way communications*. They focus on the *shared goal* of positive learning and developmental outcomes for children.

# Supports for Family Engagement



# Organization Readiness and Leadership Buy-In



**FREE leadership development training for families of children receiving Early Intervention Infant/Toddler or Preschool services.**



**Competence and Confidence:  
Partners in Policymaking  
EARLY INTERVENTION (C2P2 EI)**

C2P2EI training has been the most impactful experience I have had since becoming a parent. It has completely transformed my mindset, **shifting me from feeling like a powerless victim to becoming an agent of change**. This training equips me with the necessary tools to empower and advocate for my children.

Through this training, I have acquired valuable advocacy and leadership skills, enabling me to speak up for other families and assist policymakers in introducing groundbreaking bills that can revolutionize the lives of Pennsylvania families with special needs.

*C2P2EI Graduate W.S*



# Parents as Partners in Professional Development (P3D)



## Parents as Partners in Professional Development (P3D)

P3D brings together families of children receiving Early Intervention or Family Support Services. Family members share their experiences to improve training and resources.

Why should I join P3D?

P3D members can participate in family engagement, leadership development, informational sessions, and networking events!

Members can also contribute to professional development and pre-service learning!



And P3D is an opportunity to share your EI family story at the SICC meeting or other events!

Families are reimbursed for their expenses and provided an honorarium, per guidelines!

Join P3D and receive information about the SICC Meet and Greet and other family engagement opportunities too!

To join P3D, use this link or QR code  
[P3D Sign-up Form](#)  
For more information, please contact  
Mary Mikus at [mmikus@pattankop.net](mailto:mmikus@pattankop.net)



## The Three P's of Compensating Family Leaders

### POLICY

- Internal reimbursement policy document
- Honorariums, reimbursements for child care and travel expenses

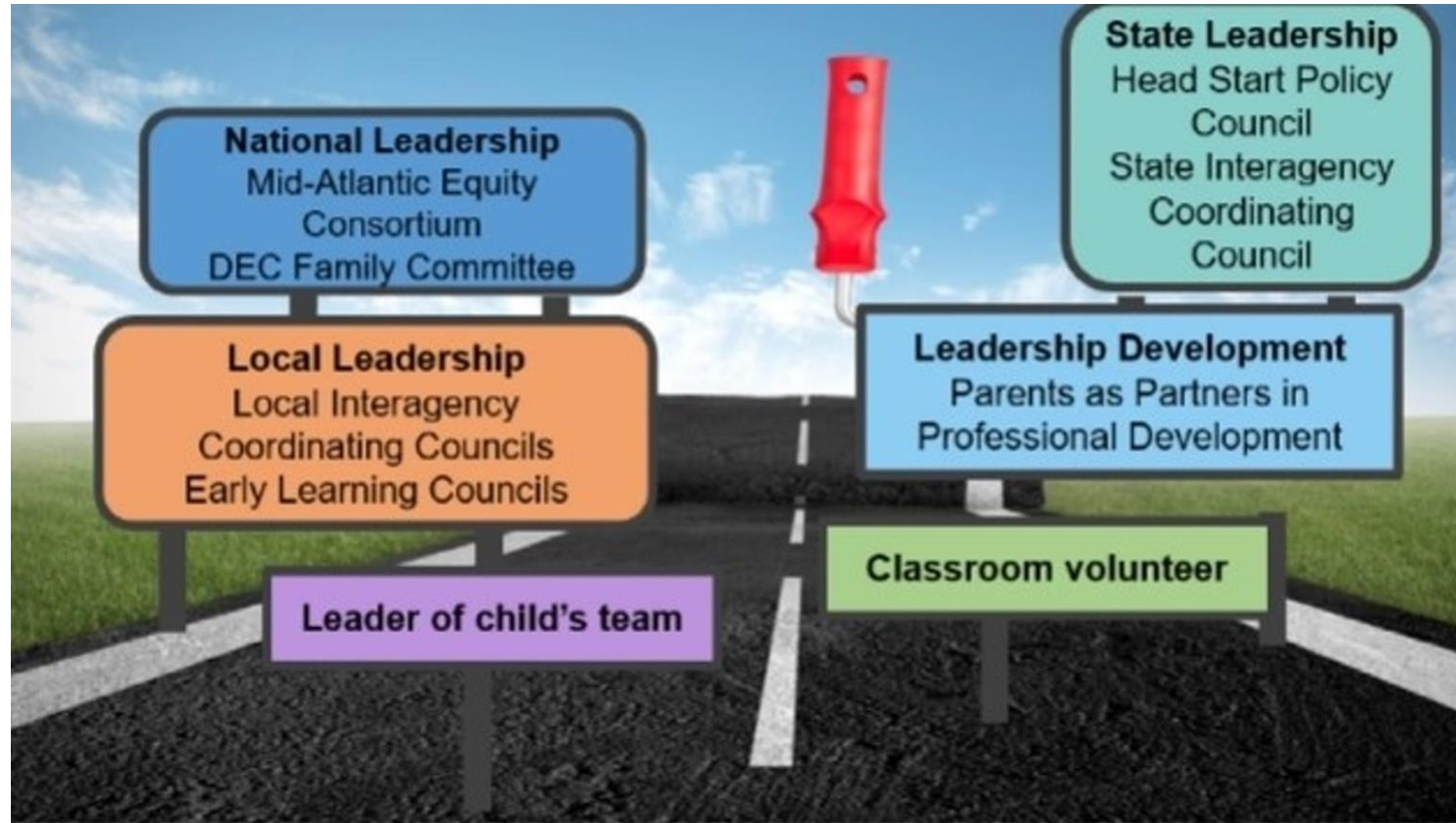
### PROCEDURES

- Dedicated fiscal staff
- Dedicated family engagement consultants
- Family-friendly reimbursement form

### PRACTICES

- Lodging and flight reservations made in advance by fiscal staff
- Onsite and individualized support provided for reimbursement related queries
- Timely processing of reimbursements

# Family Leadership Pathways



# How We Did It: Collective Advocacy & Partnering with the Field

- Authentic provider engagement and grassroots advocacy
  - Provider-led petition, meetings, surveys, and fact sheets
- Family engagement and voice
  - Disseminated family-friendly flyers on rights and advocacy
  - Co-hosted two bilingual sessions on families' rights and advocacy
  - Launched *Babies Can't Wait!* virtual postcard campaign
    - 100+ postcards collected and delivered to legislators
- Partnership with champion legislators
  - Pushed for supplemental funding for EI for FY23 (Lame Duck – January)
    - 900+ emails to legislative offices sent
  - Prenatal-to-3 legislative hearings in support of Smart Start



## ...The Struggle Continues!

# Advocate Request v. Governor's FY25 Budget Proposal

### Early Intervention (EI):

**Goal: \$40 million increase**

**Proposed: \$6 million increase for the Early Intervention program (3.8% over FY 2024)**

- FY25 request: \$40 million (25.7%) increase over FY24
- With additional funds, we'd like to see:
  - Increased compensation for providers and service coordinators (10% increase = \$20M)
  - Funds to accommodate the state's growing caseload



## Where We Are Now

- Change.org [petition](#)
- [Letters to legislators](#)
- [Early Childhood Advocacy Day](#)
- Opportunities for family engagement:
  - *Babies Can't Wait!* [postcard campaign](#)
  - [Resources](#) for families waiting for EI



**TAKE ACTION FOR IL FAMILIES TODAY!**  
Because this is my family's Early Intervention story:

My son started therapy at age 2. He had delays in language development. He is now in second grade and is so close to reaching all his IEP goals, and won't need services. He is my future scientist.

From,  
Liam



# Systems Changes to Address Equity Challenges

1. EI cost modeling
2. Cross-state research
3. Demonstration projects for modified service delivery



Thank you!



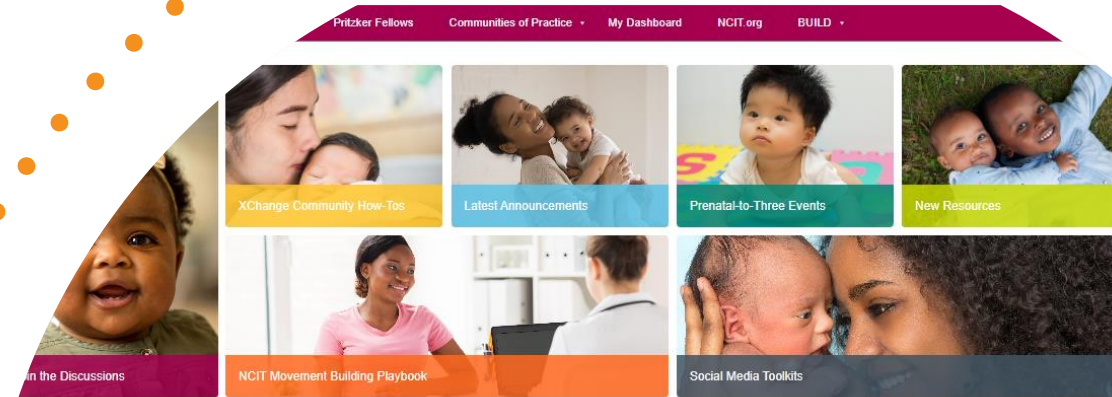
# Join the PN-3 XChange today!

☐ Go to:

<https://www.pn3xchange.org/user/createuser>

☐ Features:

- ✓ Ask questions and join discussions with peers and experts
- ✓ Find timely resources and events
- ✓ Share resources with the network
- ✓ Learn from what others are doing
- ✓ Use the PN-3 Help Desk to get expert help
- ✓ Over 2,700 members from all 50 states
- ✓ And more!



## Welcome to the Prenatal-to-Three XChange Community!

The Prenatal-to-Three XChange was created to provide a dedicated Online Community for prenatal-to-three leaders, advocates, coalitions, consultants, partners, practitioners, providers, and parents... anyone who is a champion for infants and toddlers. Our mission is to build a stronger and more effective prenatal-to-three network through the sharing of knowledge and insights to improve the lives of infants and toddlers and their families.

The XChange community not only provides access to timely and targeted resources, members of the XChange can ask questions of experts and peers, engage in discussions, share insights, and post materials they have found most helpful in their work. Additionally, there are regular announcements of events of interest to the community, job announcements and alerts about new research, legislation, and publications.



Community, like communities everywhere, is made up of various neighborhoods. Activities are going on across the XChange but the heart of the community is in the Leaders & Champions neighborhood, where everyone comes together to engage and share.

As we work together to advance better policies, systems, and supports for our youngest children, the XChange can support your work by providing the expertise of leaders and champions dedicated to prenatal-to-three.

## Need help with a PN-3 challenge?

[Submit your request](#)

## or call the PN-3 Help line

**833-275-6248**

## My Groups

[Charlemos- Let's Chat!](#)

[Carols playground 2](#)

[Child Care](#)

[Coaching/TA System Leaders](#)

[Communicators](#)

[Community Learning Table](#)

[A sharing space for PCI Community Systems grantees](#)

[Community Partners](#)

[Community Planning](#)

[Coordinators](#)

[Counties for Kids](#)

[XChange Support](#)

[XChange Guidelines](#)