



Equity in Early Intervention (EI): An Innovative Approach

The Arc of Illinois 73rd Annual Convention
"Reimagining Expectations"

Alison Liddle and Zareen Kamal

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How are you feeling right now?

1



2



3



4



5



6





Alison Liddle
PT, MPP, PCS



Zareen Kamal
Policy Specialist, Start Early



Who we are

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.

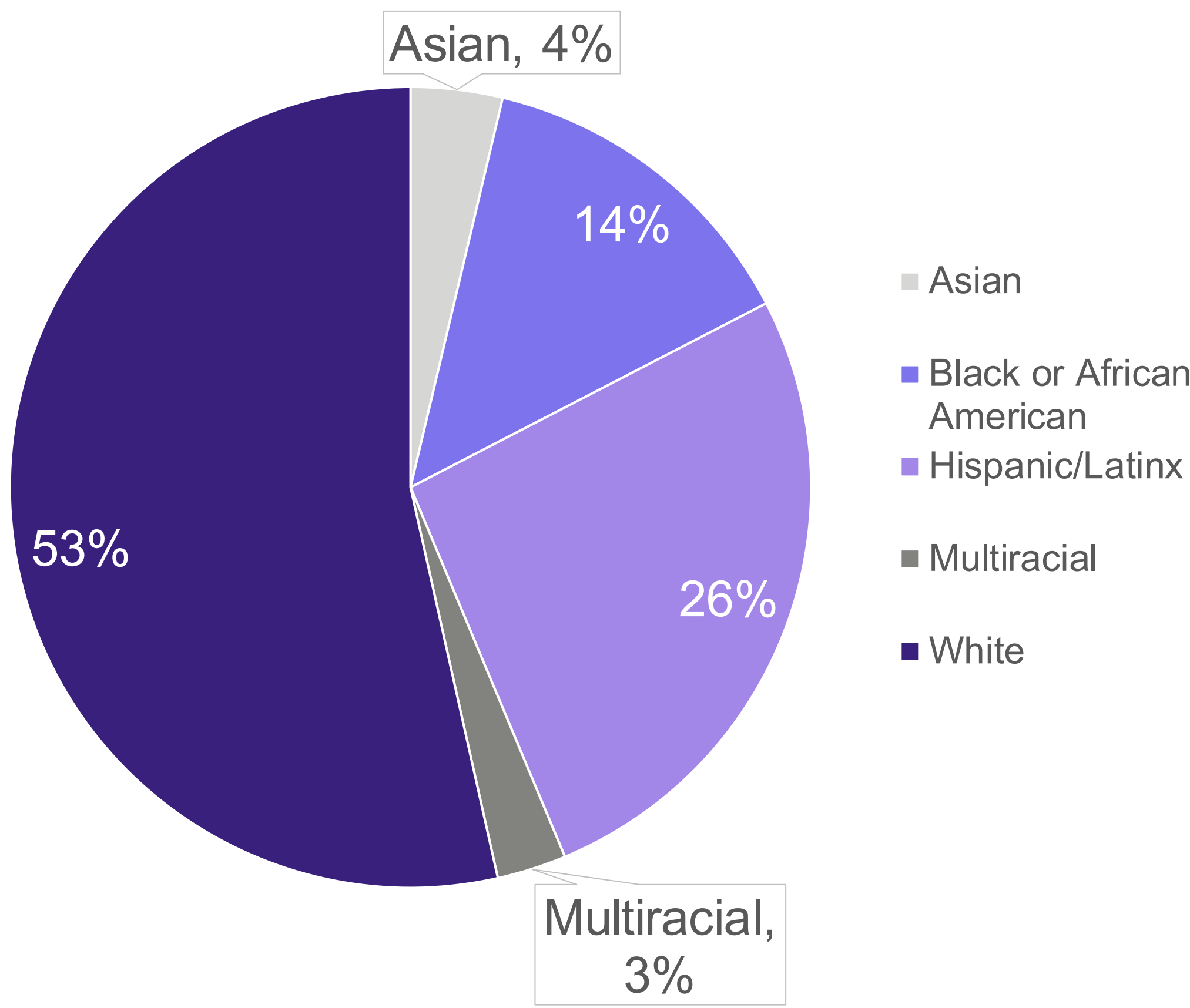
What is Early Intervention?

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 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

IL Early Intervention System: A Snapshot

- 25 statewide regional points of entry through which families can access the program.
- 26,940 children served in February 2023, a 5.6% increase from FY22 average.
- 46.7% of families served were 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.



Source: PN3 Legislative Hearing, IDHS, March 2023



The Unmet Needs in EI for Children Under One

- In Illinois and nationally, infants under one year of age represent the smallest percentage of children in Early Intervention (EI).
- Medicaid eligible children and families are more likely to experience delays in connection to EI services when they leave NICUs.
- Late or limited access to EI is more common in children of Black and Latina mothers and infants with public insurance or residing in areas with >10% poverty rates.
- Black newborns are 5 times less likely receive EI services than white children.
- Other underserved children include children experiencing **homelessness**, newborns with **prenatal substance exposure**, and children involved in the **child welfare system**.

Early Intervention Eligibility

Children from birth to age 3 *and* a qualifying disability

1. experiencing a **delay** in one or more of the following areas: cognitive, physical, social-emotional, communication, or adaptive; or
2. experiencing a **medically diagnosed** physical or mental condition that typically results in developmental delay like Down Syndrome, Cerebral Palsy or Rett syndrome; or
3. **at risk** of substantial developmental delay because of *multiple* factors like homelessness, teen parent, and substance abuse.

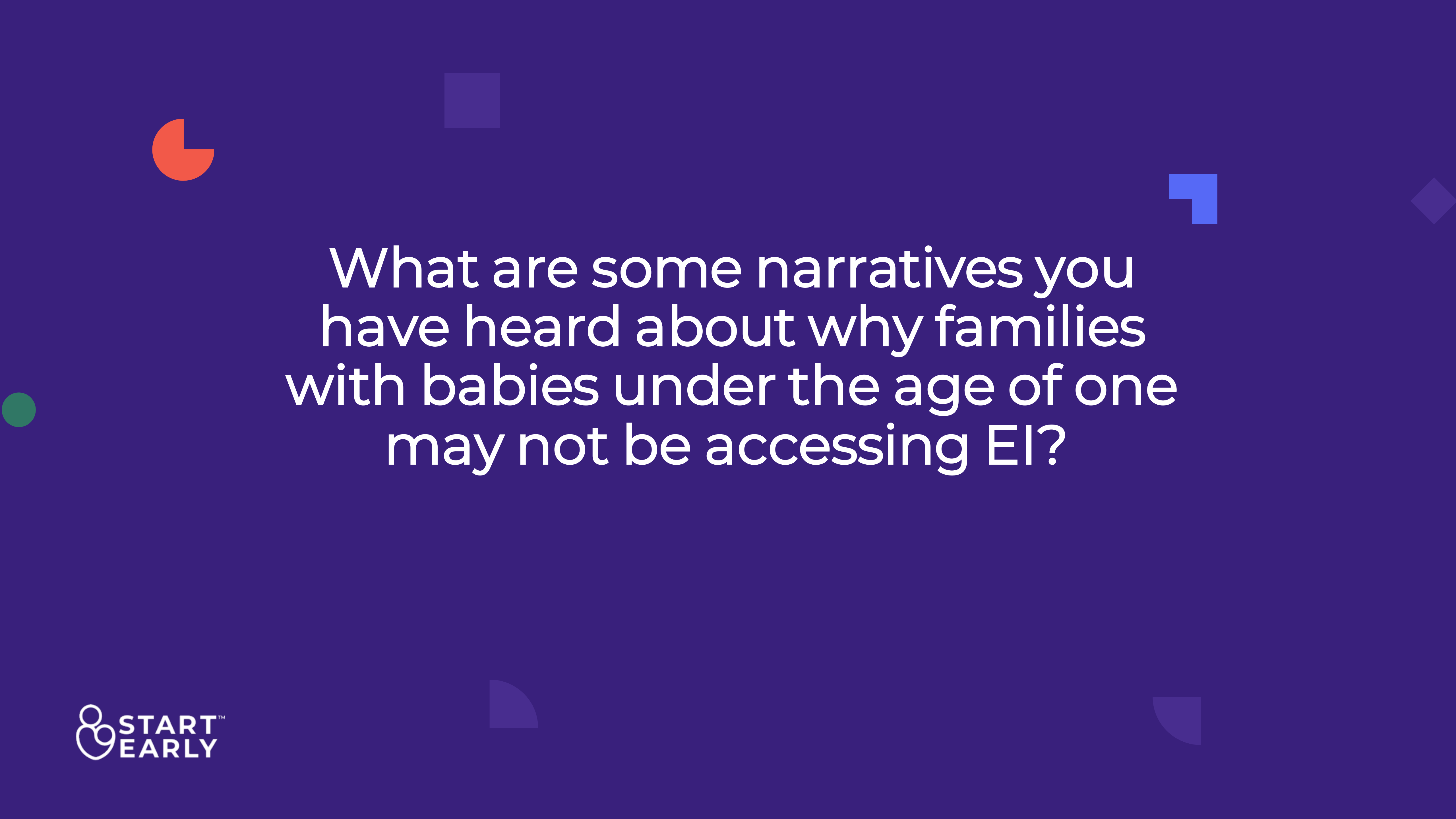
Why aren't we moving the needle on children under one?

Barriers exist within **both** the health and EI systems

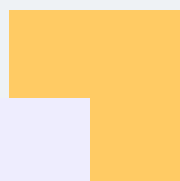
- Misunderstanding and misuse of the eligibility criteria
- The system has not caught up to the science
- Workforce challenges
- Siloed and fragmented systems
- Lack of family engagement and awareness

The Early Education Act (325 ILCS 21)

Establish demonstration projects with at least two hospital neonatal intensive care departments to promote better coordination and timely connections to EI services.



What are some narratives you
have heard about why families
with babies under the age of one
may not be accessing EI?



INITIATE Participant, Crystal



Adraniece Johnson, El Parent



Raising
Illinois

“

The only explanation that was given as to why we would wait so long and why we still had to wait for a therapist is because there was no therapist available in our area to come in-home.

”

- Adraniece Johnson, EI Parent

Project INITIATE

Pilot a NICU-to-home service delivery model (Project INITIATE) in order to provide prompt and equitable therapy service that improves infant and family outcomes.

- Feasibility of a NICU-to-home service delivery model for infants at high risk for neuromotor complications.
- The secondary objective will be to compare motor outcomes at 3-4 months corrected age in Project INITIATE participants and those who received standard discharge services and to compare parental quality-of-life outcomes at discharge and at 3-4 months corrected age.



PROJECT INITIATE

Ann & Robert H. Lurie
Children's Hospital of Chicago



Patrick M. Magoon
Institute for Healthy Communities



Illinois Council on
Developmental
Disabilities

Needs

01

Need #1:
Implementation of prompt
and equitable access to
early therapy services upon
discharge from NICU

02

Need #2:
Improve coordination and
streamline access to early
therapy services

03

Need #3:
Inform policy
recommendations for
system improvements

Project INITIATE Aims

1

Test the feasibility of a NICU-to-home service delivery model for infants at high-risk for neuromotor complications.

2

Compare motor outcomes at 3 months corrected age in Project INITIATE participants and those who received standard discharge services.

3

Compare parental quality-of-life outcomes at discharge and at 3 months corrected age between Project INITIATE participants and those who received standard discharge services.

Initial Outcomes

AIM 1 - Feasibility of NICU to Home

Percentage of eligible patients who agree to participate

- 25/26 families agreed to participate
- 22/25 families received ongoing in home therapy services
- 16 have reached 3 months corrected age and 13/16 have had a clinic visit.

Time from discharge/referral to EI Enrollment

- Of the 13 who attended a 3-month clinic visit:
 - 2 received EI services
 - 4 had evaluation/scheduled for an evaluation
 - 1 of the 4 evaluated told they were not eligible for services

Timeline of initiation of services by Project INITIATE team

- Average time from discharge to initiation of services by Project INITIATE team was 11 days.

Number of completed home visits

- 124 home visits to enrolled participants
- 117 phone calls



AIM 3 - Parental Quality of life

Top Questions endorsed by the highest number of caregivers as "often" or "Almost Always"

32% I worry about my child's future

21% I feel tired when I wake up in the morning

18% I do not have enough energy for social activities

18% Lack of communication between family members

Disparities by Insurance Type

There is a marked disparity in access to outpatient pediatric physical therapy services based on type of insurance

- Minimal options for early therapy services outside of the EI system for children with Medicaid
- 11/158 private clinics in Illinois providing outpatient pediatric physical therapy that accept Medicaid
- Legislative and policy discussions are needed to ensure equitable access to therapy services

How to Move the Needle, Together

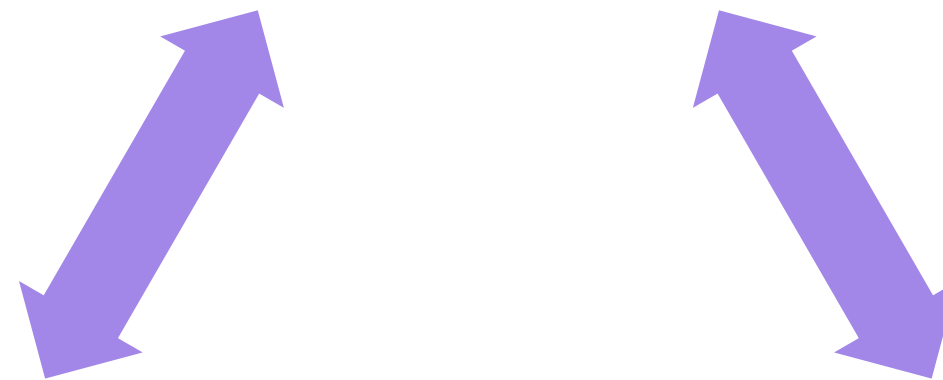
- Awareness & investment are key – *tools and resources are not enough.*
- Improve ways to connect the families
- Workforce training
- Improve ways to translate research on early detection and diagnosis
- Address the salaries, caseloads and supports provided to our EI workforce, including service coordinators and mental health consultants.
- Continue to identify and serve children in EI and address racial and income disparities in access.
- Recommendations for improvement and implementation of NICU-to-home across the state of Illinois.



Next Steps: Translate Research into System Change

Development of advisory body for
immediate research translation

Policy/Advocacy
(Start Early)



Community
Providers



NICU Team

Implementation of early detection Initiatives

Direct referral and personal introduction between
the NICU team and community-based provider

Family Quotes

"We appreciated the regular check-ins by the home therapist to make sure that she is developing appropriately ."

– Dominique, Isis Mom

"It helped me know what to do with my baby so she could develop and learn, and now she is doing great – she has definitely progressed."

– Shuanice

"It helped my whole family."

– Toya

"I am worried, because the INITIATE program will be ending shortly. We have not yet had any contact with Early Intervention. Despite a referral being sent from the hospital to Early Intervention at NICU discharge, it has been over 4 months and we have not received a call back."

– Study participant

Thank You!

Illinois Council on Developmental Disabilities

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Patrick M. Magoon Institute for Healthy Communities

All the participating families

Study Team Members

- Lurie Children's Hospital / Prentice Women's Hospital
 - Raye-Ann deRegnier, MD, Denise Barns, APN, Lynn Boswell, PT, MS, Dawn Drumm, PT, DHSc
- University of Illinois at Chicago Hospital
 - Shannon Murphy, MD, Mrinal Bageshwari, Vanessa Barbosa, OT, Rena Linderer, DO, Phornphat Rasamimari, MD, Sarah Davey, MS, LPC, CRC, De-Ann Pillers, MD, Helene Gussin PhD, CRA, Susana Shretha, MPH, MBBS
- University of Chicago Comer Children's Hospital
 - Bree Andrews, MD, Pat Bryne-Bowens, PT
- In-Home Physical Therapist
 - Alison Liddle PT, MPP, PCs, Jessica Trenkle, PT, DPT, PCS



Alison Liddle aliddle@mstreetpeds.com

Zareen Kamal zkamal@startearly.org

f /startearlyorg

t @startearlyorg

in /startearlyorg

o /startearlyorg

