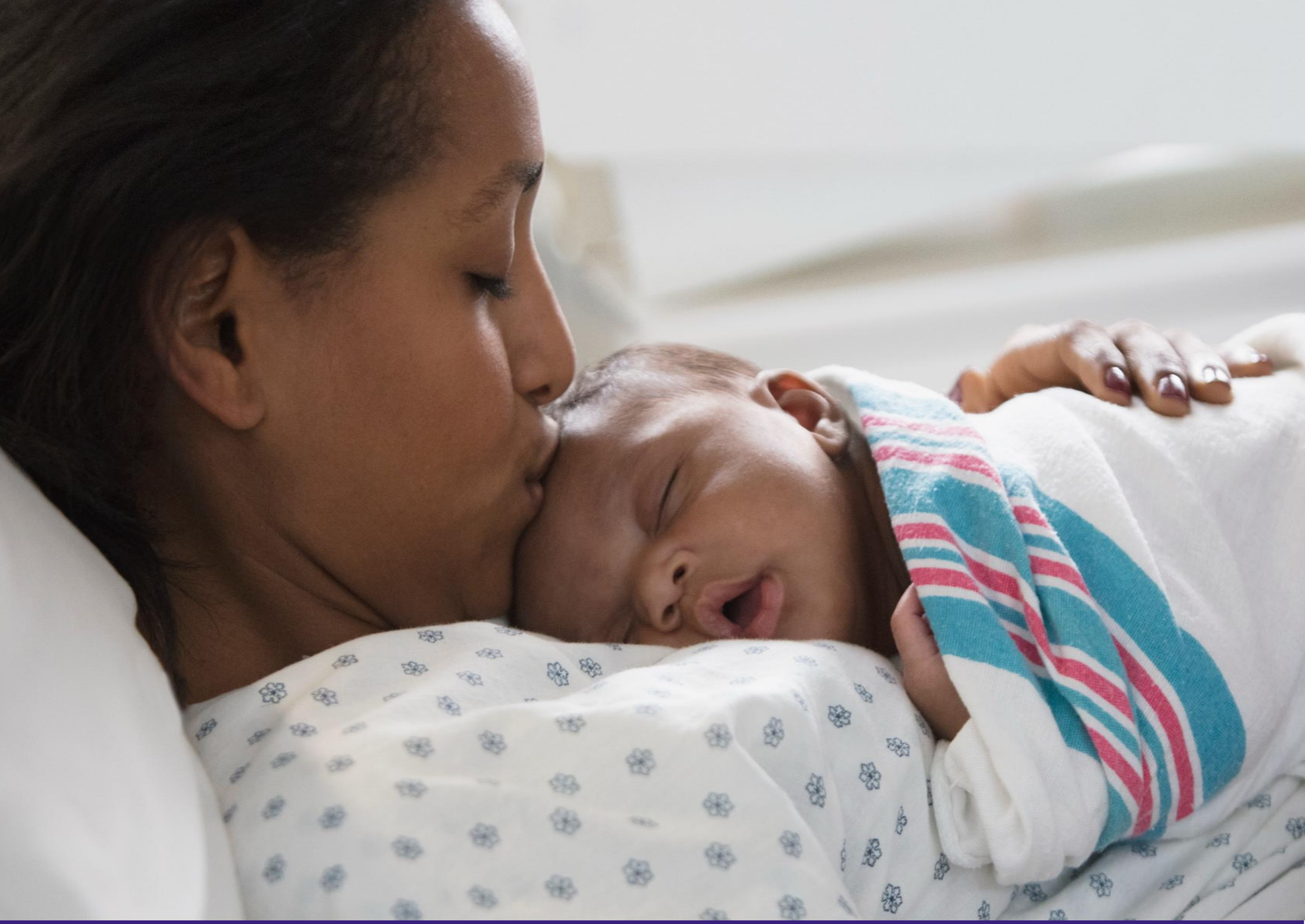

Bridging the Gap: Improving Early Intervention Access for NICU Families

Findings and recommendations from Project INITIATE to improve timely access to Early Intervention (EI) services for infants discharged from Neonatal Intensive Care Units (NICUs).

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Champions for Early Learning

Table of Contents

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I. Introduction and Background

Illinois' Early Intervention (EI) program ensures that infants and toddlers with 1) developmental delays or disabilities, 2) diagnosed medical conditions with a substantial likelihood of delay, or 3) other factors that put them at risk of substantial delay have the best chance for healthy development through family-centered therapeutic, developmental, and social-emotional services.

The Early Intervention Program for Infants and Toddlers with Disabilities was established as Part C of the Individuals with Disabilities Education Act (IDEA) in 1986 in recognition of "an urgent and substantial need" to:

- enhance the development of infants and toddlers with disabilities;
- reduce educational costs by minimizing the need for special education through early intervention; and
- enhance the capacity of families to meet their child's needs.[1]

IDEA Part C is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities and their families. Currently, all states and territories participate in Part C, and approximately 4% of infants and toddlers receive services each year.[2] To participate in the program, states must ensure that it will be available to every eligible child and its family; eligibility is not contingent on income. Decades of research have shown clear benefits of EI for infants and toddlers with developmental delays or disabilities and their families.[3]

Illinois' Early Intervention Program

In Illinois, nearly 44,000 families were served by EI in FY2024, and about half of families served are Medicaid recipients.[4] EI provides 16 different services, including speech, physical, occupational, developmental, and other therapies and service coordination to eligible families from all income levels and in every county across Illinois. These critical services have shown to improve developmental outcomes for young children, with 40% of children who participated functioning within age expectations by 3 years old, and 73% of those who exit functioning below age expected levels having substantially increased their rate of growth by 3 years old.[5]

The Illinois Department of Human Services-Division for Early Childhood (IDHS-DEC) serves as the lead agency and has designated the Bureau of Early Intervention to oversee the EI program and partners, complete requisite reporting, comply with regulations for federal funding, manage statewide data collection, and share data. In July 2026, administration of the EI program will transition to the new Illinois Department of Early Childhood. The Illinois Interagency Council on EI (IICEI) advises and assists the Bureau in the performance of its responsibilities and support to EI agencies.

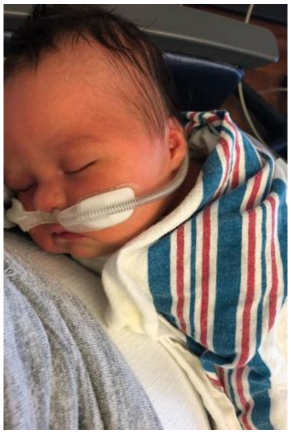
Families access EI through 25 regional intake entities called Child and Family Connections (CFCs) located throughout the state. The CFCs include Service Coordinators, Program Managers, Local Interagency Council (LIC) Coordinators, Parent Liaisons, and Social-Emotional Consultants. They support the family in navigating the EI Program, provide developmental pediatric consultation services, and help with transition to local school districts at age three. Service coordinators partner with the family through each stage of the Individualized Family Service Plan (IFSP) process, generate authorizations to the EI providers who will be providing services to the family, and support families as they exit or transition from EI.[6]

EI services are delivered by trained professionals who provide services based on the IFSP (the legal document outlining the recommended supports and services). These service providers include developmental therapists, speech-language pathologists and audiologists, occupational therapy practitioners, physical therapists, psychologists; social workers, nurses, registered dietitians, family therapists, vision specialists, orientation and mobility specialists, pediatricians and other physicians. In Illinois, providers are fee-for-service contractors, not state-employed staff. They may work independently or as part of a small or large provider agency and be part-time or full-time providers in the system.[7]

EI Eligibility, Timelines, and Families' Rights

There are three ways that a child can be eligible for EI:

1. An infant or toddler with a **developmental delay** in one or more of the following domains: cognitive, physical including vision and hearing, communication, social or emotional, and adaptive. States have the discretion to determine the level of delay that makes a child eligible, and **Illinois defines it as 30% or greater.**
2. An infant or toddler with a **diagnosed medical condition** with a high probability of resulting in developmental delay. The state provides a list of EI-eligible conditions that make a child automatically eligible for services, and if a child has a condition that is not listed but is likely to lead to a 30% or greater developmental delay, EI approval is still possible through the recommendation of a physician.



3. States may choose to serve children **at risk of substantial developmental delay or disability** in their eligibility definition. In Illinois, the following make a child automatically eligible for EI services:
    a. Child is the subject of abuse or neglect;
    b. Parent has been diagnosed with a mental illness that results in significant impairment in functioning; or
    c. Three or more risk factors defined by IDHS (e.g., substance abuse by caregiver, parent under 15 years).[8]

Anyone can make a referral to EI including early childhood providers, pediatricians, and parents. In Illinois, referrals can be accepted by CFCs via phone, in writing, or in person, and any of these methods starts the 45-day timeline the CFC must meet to complete intake, evaluate the child, and develop an IFSP. The parent/legal guardian determines how to proceed and there are set timelines in state and federal law that states must follow:

- Families must receive a call back from their CFC **two business days** after a referral is made.
- The intake/evaluation, eligibility determination, and creation of the IFSP must occur within **45 calendar days of referral**.
- Services must be initiated within **30 calendar days** of parent/guardian consent to the IFSP.[9]
- The IFSP must be reviewed every six months and updated annually, and transition to special education must occur by the child's third birthday.

EI is a legal entitlement for families and they have protections under the law if their rights are not being met. This includes submitting a written complaint to the lead agency (must be done within one year of the violation), requesting mediation, and requesting a due process hearing (must be done within three months of the violation).[10]

Barriers in EI Access for Babies Under One and Legislative Efforts

Despite a robust process for identifying and enrolling eligible children and families into the system, EI services remain significantly underutilized both in Illinois and nationwide. Fewer than 4% of infants and toddlers receive EI services, while research suggests that 13%-20% of children from birth to age three may have developmental delays or disabilities that would make them eligible.[11] In Illinois, state data estimates that **the number of children eligible for EI services is more than double the number currently being served**. Disproportionate barriers in access also persist. Black newborns are five times less likely than White newborns to receive EI services, and Medicaid eligible children and families often face delays in connecting to services after discharge from the NICU.[12] Geographic challenges further compound these barriers to access.

Underutilization is especially stark among infants under one year of age, with just over 1% receiving services both nationally and in Illinois.[13] Given the difficulty in detecting a 30% developmental delay at such an early age, most infants served in this age group qualify based on medical diagnoses with a high likelihood of delay—such as Down syndrome, cerebral palsy, or Rett syndrome.

While advancements in neonatal care have greatly improved survival rates for infants with chronic medical conditions, the incidence of neurodevelopmental impairments remains high, especially among those discharged from NICUs or CICUs. Standard care for these infants often includes a combination of physical, occupational, and feeding therapies during their hospital stay. As discharge approaches, referrals to EI are commonly made. However, systemic barriers often hinder timely access to services, particularly for families from historically underserved communities, limiting opportunities for continued support and early intervention. Research from other states shows that when families receive help navigating the transition through an advocate or navigator, their connection to EI is significantly improved. In fact, the most successful transitions often begin in the hospital before discharge, underscoring the importance of proactive engagement and coordination.[14]

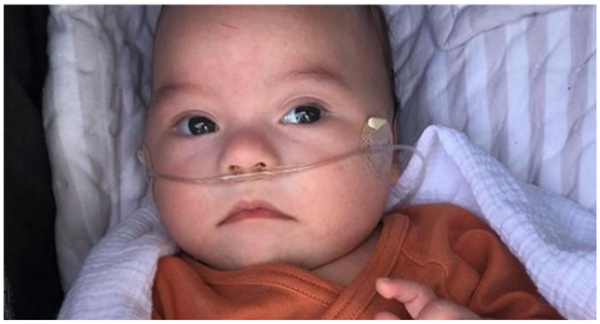
In an effort to address barriers in access to EI services for infants under one year old, the Illinois Legislative Black Caucus introduced the Early Education Act in 2021 (*325 ILCS 21*). The legislation seeks to better serve children and families who have historically faced barriers to accessing needed services. One key recommendation calls for IDHS to establish public-private partnerships with hospital NICUs to pilot demonstration projects aimed at improving coordination and ensuring timely EI referrals. The General Assembly recommended that implementation begin by January 1, 2022 (*P.A. 101-654, effective March 8, 2021*).[15]

Although the Department has not yet acted on this directive, a collaborative research effort—Project INITIATE—has emerged to explore solutions. Led by neonatologists and researchers at Ann & Robert H. Lurie Children's Hospital, Prentice Women’s Hospital, The University of Chicago, and The University of Illinois at Chicago, in partnership with community-based therapists, the project examined barriers and facilitators to EI access for infants who are automatically-eligible due to medical conditions.

II. Project INITIATE Study Findings and Policy Implications

Project INITIATE, supported by the Illinois Council on Developmental Disabilities (ICDD) and Patrick M. Magoon Foundation, was designed to pilot a direct NICU-to-Home service delivery model that connects auto-eligible infants with physical therapy (PT) services before or immediately following discharge, maximizing the opportunity to initiate services during the critical window of development. The study evaluated both developmental and neuromotor outcomes in infants who received early PT care while simultaneously evaluating the timing of EI service initiation.

All participants had Medicaid as their primary insurance and were automatically eligible for EI due to qualifying medical diagnoses, which included prematurity, orthopedic conditions, neurological impairments, and genetic disorders. In total, 63 infants and their families participated in the pilot: 49 in the intervention group and 14 in the control group. Two families in the intervention group withdrew, and one infant tragically passed away during the study.



Infants were recruited from four Level III and Level IV NICUs and CICUs in Chicago. The study excluded infants not in parental custody and those whose parents were non-English speaking. Participation concluded when infants reached 3-4 months corrected age. Infants were assigned to one of two groups based on their home address:

- *Intervention Group*: Infants residing within Chicago city limits received home-based physical therapy through the INITIATE program beginning within two weeks of NICU discharge.
- *Comparison Group*: Infants living outside of Chicago city limits received standard care, which consisted of a referral to EI at hospital discharge, but no direct home-based PT through INITIATE.

Study Aims and Key Findings

Aim 1: Feasibility of Early Home-Based Physical Therapy After NICU/CICU Discharge

- **Goal:** Assess whether early initiation of home PT is feasible for Medicaid-insured infants.

- **Finding:** 78% of infants in the intervention group received at least one PT session.
    - Median time to first visit: 12.5 days post-discharge.
    - Therapy was feasible even for infants from neighborhoods with very low Childhood Opportunity Index (COI) scores (91% of intervention group).

Aim 2: Motor Outcomes

- **Goal:** Compare early motor outcomes (using the Test of Infant Motor Performance, or TIMP) between infants who received early therapy and those who did not.
- **Finding:** Overall TIMP score changes were not statistically different between groups. However, infants who received 8–10 sessions had significantly higher TIMP scores than those with fewer sessions.

Aim 3: Timeliness of EI Access

- **Goal:** Track whether infants received EI evaluations and services by 3–5 months.
- **Finding:** Despite all 63 infants being referred to EI at discharge, only **33% (21 of 63) received an EI evaluation by their 3-5 month follow-up visit** and only **13% (8 of 63) were receiving any EI services**. Two infants with auto-eligible diagnoses were incorrectly deemed ineligible.

Policy Implications for Improving Timely Connection to EI

Project INITIATE identified significant challenges and barriers to timely connection to EI, which is so important within the critical window of development. All participants received an EI referral by the study team at the time of hospital discharge. By the 3- to 5-month follow-up visit, 63% of consented families reported contact with EI. Among those, 33% had an EI evaluation, and **only 13% had begun receiving at least one EI service.** None of the families reported having received all of the services on their plan, and **67% (42 families) were still waiting for an evaluation.** Though all children had auto-qualifying diagnoses, two families were incorrectly informed they did not qualify for services after their initial evaluation. The full study findings were published in the Journal of Clinical Medicine in December 2024.[16]

These findings and procedural insights underscore systemic barriers to EI access, including misinterpretation of auto-eligibility criteria, long delays even when referrals are made immediately, understanding the auto-eligibility criteria, and the complexities in access when administering EI services. Program administrators and healthcare providers must work together to bridge the gap to ensure access to crucial developmental resources for all children. A policy advisory body was formed in June 2023 to translate the research study findings into cross-systems policy recommendations to improve timely connections to EI for infants exiting the NICU.

Developing the Recommendations

The policy recommendations were developed collaboratively with over forty stakeholders. In its role as convener, Start Early formed a policy advisory committee with broad public and private representation from state agencies, legislators, philanthropy, the EI system, the healthcare system, families, and advocates. The full committee met three times between June and October 2023 and reconvened for a final time in March 2025. Throughout the process, feedback was collected via surveys and three 90-minute focus groups to better understand the barriers and facilitators to access. A working group was also convened to develop and vet the recommendations.

Policy Advisory Committee and Focus Group Findings

Focus groups were held with a range of stakeholders—including representatives from six CFCs, EI caregivers, medical providers, EI providers, and agency partners—to identify barriers and potential solutions for improving access to EI upon NICU discharge.

The following challenges emerged:

- **Structural and Capacity Challenges at CFC:** CFCs face significant infrastructure and staffing limitations, including outdated technology, high caseloads, and frequent staff turnover. These factors contribute to inefficiencies in tracking and managing referrals.
- **Breakdowns in Communication:** There is a lack of bi-directional communication and no consistent process for follow-up between CFCs and pediatricians. Staff turnover across both CFCs and hospital systems exacerbates these issues, making it difficult to obtain complete and accurate referral information.
- **Limited Family Awareness:** Families often lack information about available services and supports they can request, such as vision assessments or evaluations by developmental pediatricians.

- **Challenges with Timely Follow-Up:** Families report deep frustration with the lack of timely follow-up from EI, citing repeated unanswered calls and emails over months. Conversely, CFCs describe making multiple outreach attempts, but note that if families do not respond within the first week, they must move on given the influx of new incoming referrals. As a result, many families are unintentionally lost to follow-up. Additionally, calls often come from agency main lines labeled with the fiscal agent's name, which can be confusing for families. Communication challenges are further compounded by disconnected phone numbers and housing instability.
- **Post-Discharge System Navigation Challenges:** EI does not currently accept referrals prior to NICU discharge due to the often uncertain timelines for medically complex infants. As a result, families are expected to initiate contact with their local CFC after discharge—while simultaneously managing complex medical needs, navigating insurance and equipment logistics, and scheduling multiple follow-up appointments. The responsibility of navigating the EI system without adequate support places a significant burden on families during a particularly vulnerable time.

> *"The system is so fragmented. We need better communication and coordination between hospitals and EI providers to ensure that these infants don't fall through the cracks."*
> *–EI service provider*

Facilitators to EI access that emerged from focus groups include:

- **Centralized Referral Review at CFCs:** A designated point person at one CFC reviews all referrals for infants under one year of age to assess for automatic eligibility. This added layer helps inform service coordinators and streamlines the intake process.
- **Specialized Training for Service Coordinators:** Preparing service coordinators to tailor their intake approaches for infants with medical complexities, trauma histories, or other high-needs situations improves engagement and ensures the intake process is responsive and appropriate.
- **Proactive Connections Calls Prior to Discharge:** In Project INITIATE, hospital staff scheduled a virtual orientation meeting between families and EI prior to discharge. These "warm hand-offs" helped establish early rapport, clarify expectations, and contributed to more timely initiation of services after discharge.
- **Collaborative Discharge Planning:** Close coordination between NICU teams and community-based providers in Project INITIATE ensured timely referrals and smoother transitions from hospital to home-based care. This collaboration was critical in ensuring that families received timely referrals and support as they transitioned to EI services.

Key Insights and System-Level Considerations

Persistent system-level gaps are contributing to infants and families falling through the cracks. Both the research study and policy advisory work surfaced recurring themes that may help explain why more infants under one are not being served:

- **Limited awareness of automatic eligibility criteria.** Many families, and even professionals, lack a clear understanding of EI's automatic eligibility criteria. In the study, two families were deemed ineligible after evaluation despite meeting automatic eligibility requirements due to a qualifying medical condition. In policy advisory focus groups, one parent reported being evaluated for eligibility despite their child's low birth weight (an automatic qualifier), and another shared that they were never informed about EI while in the hospital, despite having auto-eligible triplets. These stories point to a broader need for consistent training and clear guidance on automatic eligibility, especially for medically complex infants, and for awareness on the preventive nature of EI for children not yet showing delays. Clearer understanding would help reduce variability in referrals and ensure eligible infants are not overlooked.[17]
- **Fragmented and siloed systems.** The lack of integration between the hospital and EI systems contributes to missed connections. Strengthening coordination between these systems—especially given the critical role medical providers play in referring families[18]—would help ensure more timely and effective engagement with EI services.[19]
- **Barriers by socioeconomic status and insurance type.** Families living in lower-opportunity areas face disproportionate barriers to care, including transportation, housing instability, and inconsistent access to phones or internet. In addition, insurance status shapes access: families with Medicaid encounter longer wait times and fewer outpatient therapy options due to a shortage of providers who accept public insurance. In contrast, families with private insurance often have broader networks to turn to, making EI the only realistic option for those on Medicaid.
- **Workforce shortages and capacity constraints.** A strained EI workforce is contributing to service delays that directly impact families.[20] High caseloads and staffing shortages make it difficult for service coordinators to follow up promptly, and medical providers have expressed concern about setting realistic expectations with families around when services will begin. Addressing recruitment and retention across the EI workforce is critical to improving both access and quality of care.

> *"Who you know, and whether you know how powerful EI is, was really important."*
> *—EI caregiver and Project INITIATE Participant*

III. Policy Advisory Committee Recommendations

The Project INITIATE study and policy advisory committee findings highlight an urgent need to address the issue of under-serving infants under one year old in EI—a gap initially raised by the Illinois Legislative Black Caucus in 2021. Delays in connecting babies to EI result in missed opportunities for critical, evidence-based supports during a period of rapid brain development when intervention can have the greatest lifelong impact.

A key recommendation to address this issue is to co-locate EI service coordination directly in NICUs to ensure smoother, earlier connections for all eligible infants.[21] This would enable families to be introduced to EI, and for IFSPs to be developed before hospital discharge.

> *"We were fortunate to have a pediatrician who understood the importance of Early Intervention and pushed for services. Without her, I don't think we would have received the help we needed in time."*
> *—EI caregiver*

Recommended Model: Co-Located EI Service Coordination in NICUs

This approach includes three core components:

1. **Dedicated EI service coordinators in NICUs.** EI service coordinators would be physically present in NICUs to build relationships, participate in medical rounds, and lead the intake-to-IFSP process for auto-eligible infants. IFSP outcomes should be developed in collaboration with NICU therapy teams already working with the family.
2. **Structured Hospital-EI Collaboration.** Hospital staff (e.g., social workers) and EI service coordinators would coordinate closely to facilitate warm hand-offs, share information, and support families during transition. This would help ensure continuity of care and clear expectations post-discharge.
3. **Coordination with Local CFCs.** Prior to discharge, NICU-based coordinators would begin working with families' local CFC offices to identify service providers and ensure a timely start to EI services after discharge.

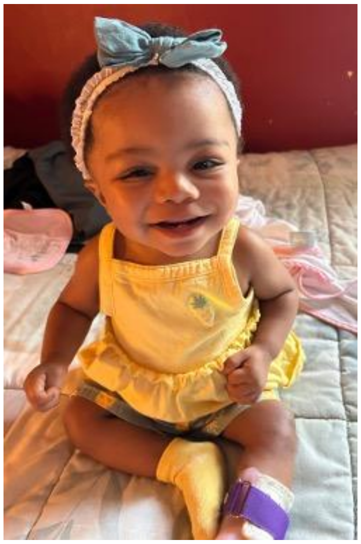
Pilot Implementation Key Considerations:

- Phased rollout with select CFCs and hospitals to test and refine the model

- Targeted training for EI service coordinators on working with medically complex infants, cultural competency, trauma-informed care, effective communication, and navigating systemic barriers in underserved communities.
- Pilot evaluation and data collection to track impact, outcomes, and identify improvement areas.
- Ongoing cross-system policy advisory group with representation from public agencies, healthcare providers, families, advocates, legislators, researchers, EI professionals, and philanthropy to guide pilot implementation and sustainability.

By aligning NICU discharge planning with EI engagement, families would receive timely support, clearer information, and better continuity of services. This model offers a pathway toward reducing barriers, improving follow-through, and ensuring more infants receive the care they need during the most critical period of development.

Recent Legislative Win



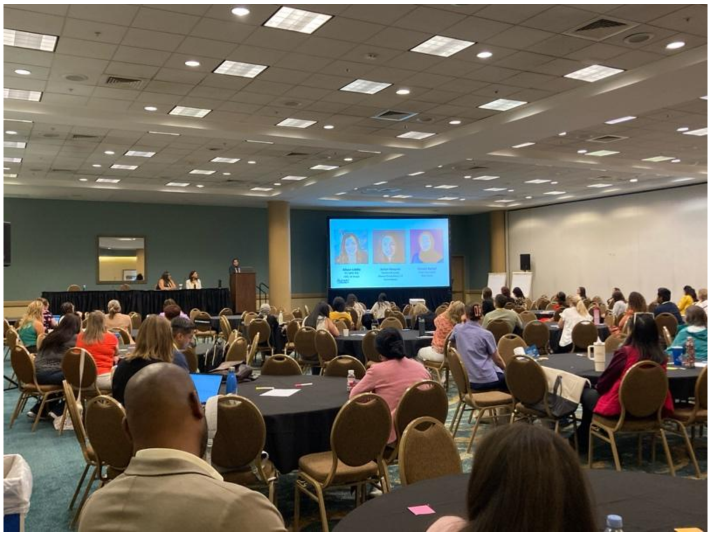
As we continue advocating for co-located service coordination to ease transitions into Early Intervention (EI) for infants discharged from the NICU, Illinois took a meaningful step forward this fiscal year—reflecting both growing awareness and a sense of urgency around this issue. The General Assembly passed HB 3327, sponsored by Representative Janet Yang Rohr and Senator Ram Villivalam, which requires hospital staff to provide families with information about EI and submit a written referral for children who are automatically eligible for services. The legislation was signed by Gov. Pritzker and will take effect in January 2026. We hope the state will build on this momentum by advancing the policy recommendations outlined above that will ensure increased access to Early Intervention for Illinois' youngest and most vulnerable children.

> *"It should be a default, like how you can't leave the NICU before you place your kid in the car seat, for example, just so that parents who are taking their kids from the NICU have the information."*
> ***—EI caregiver and Project INITIATE participant***

IV. National Engagement

Start Early and Project INITIATE members have engaged a national audience about this work through conference presentations, individual meetings with other state advocates and researchers (Colorado, California, Ohio, and Maryland), and media coverage.

Key Conference Presentations:



- 2023 Division for Early Childhood (DEC) Conference – Advancing Equity in Early Intervention
- 2023 Arc of Illinois – Equity and Access in Early Intervention
- 2023 Zero to Three Conference – Equity and Access in Early Intervention
- 2023 National Association of Councils on Developmental Disabilities – Advocacy in Action for Young Children
- 2024 Zero to Three Conference – Advancing Equity in Early Intervention: Parent, Provider, and Policy Perspectives
- 2024 Early Intervention Provider Training - Advances in Early Detection: A discussion on Implementation for Illinois Early Intervention Providers and Service Coordinators.

Related Media Coverage:

- Why aren't we serving enough infants in early intervention? (New America, July 2024).
- Parents of premature babies struggle to get help their children are entitled to (The Hechinger Report and Chalkbeat, January 2025).
- Bill notifying families of NICU baby early intervention services arrives on Pritzker's desk (WAND News, July 2025).
- Mother shares struggles getting help for her children through early intervention (CBS Chicago, July 2025).
- Premature babies must be connected to live-changing therapies under new Illinois law (The 19th, August 2025).

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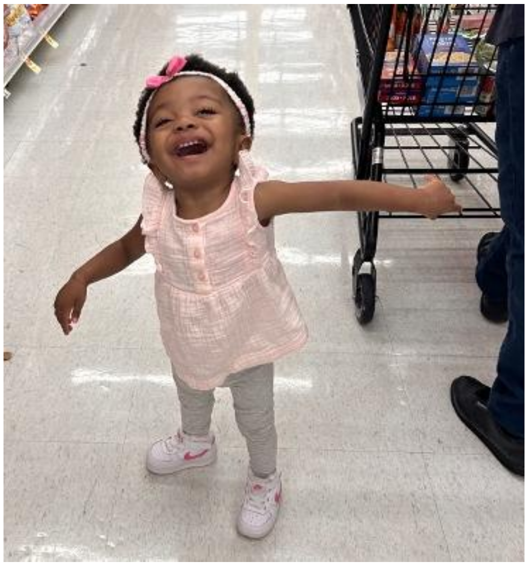

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