Challenges and Opportunities for Early Intervention Systems:

Lessons Learned from a State Advocacy Landscape Analysis

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Together for Young Children with Disabilities

Acknowledgments

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State	Name	Organization
California	Mike Odeh	Children Now
Georgia	Callan Wells	Georgia Early Education Alliance for Ready Students
	Caitlyn Sanders	Georgia Early Education Alliance for Ready Students
Illinois	Allison Liddle	Illinois Interagency Council on Early Intervention (chair), EI provider
	Brittni Monreal	Illinois Interagency Council on Early Intervention – (Parent Rep), IL Families for EI (Co-founder), EI Clearinghouse (Parent Leader)
	Darcy Armbruster	EI Grassroots Alliance
	Sarah Ziemba	EI Grassroots Alliance
Indiana	Rita Davis	My Noble Life
	Molly Cleek	My Noble Life
Kentucky	Brianna Hairston	Kentucky Speech-Language-Hearing Association
	Leigh Anne Roden	Kentucky Early Intervention Providers Association
	Caitlin Conley	Kentucky Early Intervention Providers Association
Maryland	Melissa Rock	Maryland Family Network
Michigan	Alan Oman	Early Childhood Investment Corporation
	Mina Hong	Early Childhood Investment Corporation
New Jersey	Kasey Dudley	SPAN Parent Advocacy Network, New Jersey
	Winifred Smith-Jenkins	Advocates for Children of New Jersey
New York	Brigit Hurley	The Children's Agenda
	Lisa Hiley	Nazareth University/Project RISE
North Carolina	Erica Palmer Smith	NC Child
	Theresa Roedersheimer	NC Early Childhood Foundation
Ohio	Troy Hunter	Elevate DD, Ohio
	Brittany Boulton	Groundwork OH
	Caitlin Feldman	Groundwork OH
Oregon	Matt Serres	Oregon Council on Developmental Disabilities
	Hannah Baker	Oregon Council on Developmental Disabilities
Pennsylvania	Maggie Livelsberger	PA Partnerships for Children
	Kari King	PA Partnerships for Children
	Jennifer DeBell	PennAEYC
	Kris Bowman	The Amoore Group
Rhode Island	Leanne Barrett	RI Kids Count (formerly)
Texas	Alec Mendoza	Texans Care for Children

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Executive Summary

Eary intervention (EI) provides essential services to infants and toddlers with or at risk of developmental delays or disabilities. Despite its strong evidence base, families face significant and growing barriers to accessing timely and consistent services. Meanwhile, the EI advocacy landscape remains underdeveloped. More dedicated, experienced advocates and stronger coordination are needed to drive sustained system change.

This is a pivotal moment for the EI system. We have seen rapid shifts in both state and federal landscapes. At the same time, longstanding challenges facing EI have not diminished. Given this confluence of factors, now is a critical time to take stock of where state EI systems stand, and what shifts in policy and advocacy can strengthen these systems over the next three to five years.

This landscape analysis synthesizes federal and state policy, research, and qualitative interviews with early childhood advocates, providers, and family leaders from 17 states. The purpose of this work is to provide an understanding of the shared systemic barriers and gaps in EI systems across states, effective policy levers, and advocacy strategies that can inform further recommendations to advance access to EI for infants and toddlers with or at risk for developmental delays or disabilities and their families. In this report, we elevate critical issues within the EI landscape, highlight effective policy levers and advocacy strategies that states are using to improve EI, and discuss the importance of increasing advocacy capacity at the state and federal levels. This information is offered in support of federal, state, and local systems leaders and advocates who are working to drive improvements within the EI system.

Problems and Issues Identified

Our analysis identified six systemic challenges within state EI programs. While not an exhaustive list, these are some of the most pressing, current issues:

1. **Workforce shortages** caused by a confluence of factors and particularly impact speech-language pathologists, occupational therapists, and physical therapists.
2. **Inadequate funding and rates** due to disinvestment and low reimbursement and salary rates.
3. **Waiting lists, service delays, and inconsistent access**, especially for babies under 1 year old, that can significantly impact children's developmental trajectory.
4. **Barriers to effective family and parent advocacy**, including communication barriers, lack of resources, and language and cultural differences.

5. **Challenges to system reform and governance**, specifically: (1) limited awareness, capacity, and prioritization for EI within systems and (2) a lack of full integration of EI into states' child-serving systems.
6. **Data and research gaps** related to fragmented and siloed data systems.

Policy Levers to Improve Early Intervention

While the challenges facing EI systems are complex and multifaceted, we identified a core set of policy levers available to strengthen EI access, funding, workforce challenges, and lack of advocacy capacity and focus within the broader early childhood system that can address the challenges discussed above. Each of the levers detailed below address structural barriers within the Part C system, with a special focus on strengthening capacity in the workforce and advocacy spaces. Five consistent strategies were identified across the 17 focus states:

1. **Cost modeling and provider rate reform** to set rates aligned with the true cost of EI service delivery.
2. **Medicaid optimization and billing reform** to maximize federal funding and reduce administrative burden on providers.
3. **Eligibility expansion** to align policy with developmental science and ensure earlier identification.
4. **Service delivery improvements**, including evidence-based parent coaching models and expanded telehealth options.
5. **Cross-system collaboration** to coordinate referrals, data systems, child find campaigns, and family support.

Advocacy Strategies to Improve EI Systems

Effective advocacy requires a combination of clear strategy, dedicated resources, strong relationships, and a supportive environment. This landscape analysis identified seven key strategies advocates in our sample states leveraged to improve their state EI systems. The full report also provides a state-level example for each.

1. **Coalition building and cross-sector partnerships** to share knowledge, strategies, and capacity with other advocates, policymakers, providers, and families across programs and disciplines.
2. **Authentic & effective provider and family advocacy** to increase effectiveness and capacity.
3. **Administrative advocacy**, where advocates collaborate directly with government administrators and providers to develop EI policy.
4. **Legislative education and relationship building** to help legislators understand how policy decisions impact young children and connect those impacts with real stories.

5. **Strategic communications**, sharing timely messages to drive policy decisions.
6. **Individual family advocacy – rights & due process** – can be supported by providing parents with training opportunities to increase knowledge, leadership skills, and confidence as advocates.
7. **Data- and research-driven advocacy**, leveraging legislatively mandated studies and annual data reports to identify EI service gaps and other challenges.

Employing any of these strategies requires significant advocacy capacity, which the field is currently lacking. However, advocates and states are leveraging a variety of strategies to enhance their capacity. Our analysis identified two primary needs that they are focused on addressing: (1) building a deeper "bench" of advocate knowledge of EI state policy and (2) ensuring authentic family and provider voice. Start Early is supports leaders to build advocacy capacity through its Together for Young Children with Disabilities campaign, the Early Childhood Disability State Advocate Collective, and Start Early Consulting.

Taken together, this landscape analysis points to an urgent but achievable path forward: with coordinated action, adequate investment, and authentic engagement of those most impacted, states can create stronger, more accessible EI systems—ensuring that young children with developmental needs receive timely, high-quality services during the years when they matter most.

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I. Introduction

Early Intervention (EI), authorized under Part C of the Individuals with Disabilities Education Act (IDEA), provides critical services to infants and toddlers with or at risk for developmental delays or disabilities and their families during a period of rapid brain development. Decades of research demonstrate EI's positive impact on child development, family wellbeing, and long-term public cost savings. Despite its strong evidence base and legal entitlement, families across the United States face significant and growing barriers to accessing timely and consistent EI services.

As these challenges intensify, the advocacy landscape surrounding EI remains notably underdeveloped. In most states, there are too few advocates dedicated to EI, and even fewer with the deep policy expertise required to influence effective system change. Existing advocates operate in relative isolation, inconsistently incorporated into broader early childhood coalitions, and lacking the shared infrastructure that supports coordinated action in other areas of the early childhood system. As a result, wins in this area, when they happen, tend to be disconnected and limited.

States and communities find themselves at a pivotal moment for EI services. In recent years, we have seen rapid shifts in both state and federal landscapes. At the same time, longstanding challenges facing EI have not diminished. Workforce shortages, rising service demands, fiscal constraints, and persistent barriers to referral and access continue to strain state and local programs. Given this confluence of factors, now is a critical time to take stock of where state EI systems stand, and what shifts in policy and advocacy can strengthen these systems over the next three to five years.

Purpose

The purpose of this landscape analysis is to provide an understanding of the shared systemic barriers and gaps in EI systems across states, effective policy levers, and advocacy strategies that can inform further recommendations to advance access to EI for infants and toddlers with or at risk for developmental delays or disabilities and their families. This report provides information for federal, state, and local systems leaders and advocates who are working within the EI system and the early childhood landscape more broadly.

This landscape analysis is part of a national campaign called Together for Young Children with Disabilities, which aims to strengthen state and federal advocacy for young children with disabilities and their families. Through this effort, Start Early convenes a national coalition of advocates and organizations committed to advancing inclusion and support for young children with disabilities, provides consultation to state and local leaders, and creates and shares tools and resources with the field.

Report Methodology and Structure

This landscape analysis synthesizes federal and state policy, research and qualitative interviews with early childhood advocates, providers, and family leaders from 17 states (Alaska, California, Georgia, Illinois, Indiana, Kentucky, Maine, Maryland, Michigan, New Jersey, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, and Texas). These states were selected to represent multiple regions of the country as well as varying policy environments.

This report describes key policy trends, systemic gaps, and opportunities to strengthen EI access and delivery in state systems. Examples from states are derived from a combination of interviews and a review of publicly available information, such as reports and policy agendas from advocacy organizations and state reporting to the US Education Department. Descriptions of the policy levers and advocacy at the state level that can be employed to improve the experiences for children with disabilities and their families, as well as recommendations for improving the advocacy landscape, are provided as well.

Throughout this report, we will refer to Part C when discussing the federal requirements and EI when discussing the program that is implemented by the states.

II. Problems & Issues Identified

This section investigates six systemic challenges within state EI programs. The challenges described are not an exhaustive list, but instead highlight and explain some of the most pressing issues currently shared by the focus states. With EI already underserved in the broader advocacy ecosystem, they must compete alongside many other early childhood issues for the limited advocacy capacity of families, providers, and advocates.

1. Workforce Shortages

Speech-language pathologists (SLPs), occupational therapists (OTs), and physical therapists (PTs) are a significant part of the EI workforce, yet state EI programs consistently report significant shortages across these three groups. A recent national report indicates 93% of states are experiencing a shortage of SLPs, 91% report shortages of PTs, and 84% report a shortage of OTs.[1] Advocates and policy reports identify stagnant and inadequate reimbursement rates, lack of professional development and mentoring opportunities, provider burnout, and excessive administrative requirements as key factors contributing to the ongoing workforce crisis. Without an adequate number of EI providers, waiting lists and service delays for families will continue to grow. For example, one advocate in Illinois shared: "The EI system is struggling to recruit and retain practitioners who are often severely under-compensated for their field, with current rates at approximately half of what would be required to cover the full cost of delivering EI services."

2. Inadequate Funding and Rates

EI systems are financed differently in each state through a variety of funding sources including federal IDEA Part C funds, state and local allocations, Medicaid and private insurance, family fees, and in some cases private funding streams. Chronic disinvestment and low reimbursement rates or salaries for providers have led to workforce shortages and delayed EI services. It is crucial to educate the public, most importantly parents and legislators, on EI's purpose and role in supporting timely and consistent services for infants and toddlers with disabilities and delays and their families.

[1] IDEA Infant and Toddler Coordinators Association, *"2024 Tipping Points Survey: System Challenges and Opportunities," January* 2025

3. Waiting Lists, Service Delays, and Inconsistent Access

Families frequently encounter delays in accessing EI services due to a myriad of interconnected factors including inadequate funding, poor compensation rates, and resulting workforce shortages. Even short delays of a few weeks can significantly impact the developmental trajectory of a young child. Interviews with state early childhood advocates highlight these persistent challenges and further reveal additional concerns regarding the availability of services and eligibility criteria.

To initiate EI services, children and families must be identified, referred, complete the intake process, undergo an evaluation or assessment, and be determined eligible before an Individualized Family Service Plan (IFSP) can be developed and services can begin. Barriers at each stage of this process can significantly delay timely access to EI enrollment and service provision. One primary challenge for addressing service delays and inconsistent access is a strained and depleting workforce. Research shows families experience differences in access to EI services across racial groups and geographical regions, including urban and rural areas. Additionally, states vary in how consistently they refer families with complex needs, such as those who experience homelessness, child welfare involvement, and those with complex medical conditions.

Barriers to Connect Babies Under 1 Year Old to Services: A review of national data shows that while approximately 4% of young children, from birth through their third birthday, receive EI services, just over 1% of children under the age of 1 receive EI services. This is critical because a delay in services for children who qualify can have lasting effects on their developmental trajectory. Many children ages birth to three who are eligible for EI do not receive services. According to the Prenatal to Three Policy Impact Center, "approximately 6.9% to 7% of children under age 3 in the U.S. receive EI services over a 12-month period. However, this percentage varies widely by state, ranging from as low as 2% to over 20%. At any single point in time, roughly 3.2% to 3.7% of children are enrolled in these services." Several factors contribute to the failure to connect infants to EI services, including differences in state eligibility criteria. Many babies under 1 year will not meet a state's developmental delay criterion. Limited understanding of how certain medical diagnoses automatically qualify a child for EI services and the general barriers to access that affect many families further compound these challenges for families of infants.

My son was My son was a 26 weeker…. A pound and a half. And I was still a self-referral to early intervention. How does that happen? – EI Parent

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4. Family and Parent Advocacy

Parents often face overwhelming stress and difficulty understanding the complex rights of Part C and state EI service systems. Communication breakdowns with providers, rigid eligibility, lack of resources, and cultural differences can all hinder effective advocacy and service access. Family leaders must balance work, daily caregiving and other responsibilities which can make attending meetings or engaging in training difficult. Professionals using jargon or failing to explain referrals can also discourage engagement. Families may face language barriers or cultural differences particularly if EI services are not culturally responsive. These obstacles can reduce parental confidence and engagement, limiting their effectiveness in securing necessary services, according to research on parental involvement.[2]

Parent voice ensures we are solving the right problems – the ones families experience every day, not just the problems that are visible to systems leaders – Michigan Advocate

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[2] Gonzalez C, Morawska A, Haslam DM. Enhancing Initial Parental Engagement in Interventions for Parents of Young Children: A Systematic Review of Experimental Studies. Clin Child Fam Psychol Rev. 2018 Sep;21(3):415-432. doi: 10.1007/s10567-018-0259-4. PMID: 29611061.

5. Systems Reform and Governance

This research identified two major challenges to systems reform and governance that prevent EI from effectively meeting the needs of children and their families. First, there is limited awareness, capacity, and prioritization for Early Intervention within systems. There is a need to increase awareness about EI, requiring intentional and consistent outreach to multiple partners in the early childhood system – health practitioners, social workers, home visitors, child care providers, etc. The systems needs to be set-up to ensure that those who interact most frequently with young children and their families understand the eligibility criteria and are equipped to support families with referrals.

Second, many states have not fully integrated EI into its child-serving systems. The children who benefit from EI are often also engaged with other programs and systems designed to serve young children and their families. Too often, families experience service gaps or disruptions due to poor communication, with information lost between educational, health, and social services. Lack of shared information systems often results in the undue burden of parents holding all the information and working as the sole messengers between health providers, educators, and social workers. These challenges are exacerbated by the need to integrate different, and sometimes opposing, models of care into a single, cohesive plan for the child and family. In addition, a lack of cross-sector collaboration that integrates EI means missed opportunities to quickly and effectively identify, refer, and deliver services to children and families who need them.

6. Data and Research

EI data systems are fragmented and siloed within disparate systems (health, education, social services), making it difficult to form a holistic picture of a child's needs. Limited funding and trained staff restrict the capacity to implement sophisticated data-driven approaches at the state level. All these challenges lend themselves to missed opportunities to use data for identifying areas for improvement. States with longitudinal data systems could benefit from ensuring that EI data systems are integrated and not separated from the educational and health data points used to track child and program outcomes.

Table 1 on the next page shows the shared systems challenges identified as current priorities by the advocates interviewed in the focus states as well as those highlighted as current priority areas of focus in state level reports and policy agendas. The number of challenges identified for each state generally correlates with the advocacy capacity of that state. Items not checked do not necessarily indicate areas where there are no current challenges for the state but, rather, an area where there isn't currently capacity for targeted advocacy efforts.

TABLE 1: SYSTEM CHALLENGES CURRENTLY PRIORITIZED BY STATE ADVOCATES

State	Workforce Shortages	Inadequate Funding & Rates	Waiting Lists, Service Delays & Inconsistent Access	Family & Parent Advocacy	System Reform & Governance	Data & Research
Alaska		✓	✓		✓	✓
California			✓	✓		
Georgia	✓	✓	✓		✓	
Illinois	✓	✓	✓	✓	✓	✓
Indiana	✓	✓		✓		✓
Kentucky	✓	✓			✓	✓
Maine	✓	✓			✓	✓
Maryland	✓	✓	✓			
Michigan	✓	✓	✓		✓	
New Jersey	✓	✓	✓	✓		
New York	✓	✓	✓	✓	✓	✓
North Carolina	✓		✓	✓		
Ohio	✓	✓	✓	✓		
Oregon		✓		✓	✓	✓
Pennsylvania	✓	✓	✓	✓	✓	✓
Rhode Island	✓	✓		✓		✓
Texas	✓	✓	✓	✓		✓

III. Policy Levers to Improve Early Intervention

While the challenges facing EI systems are complex and multifaceted, we identified a core set of policy levers available to strengthen EI access, funding, workforce challenges, and lack of advocacy capacity and focus within the broader early childhood system that can address the challenges discussed above. Each of the levers detailed below address structural barriers within the Part C system, with a special focus on strengthening capacity in the workforce and advocacy spaces. Five consistent strategies were identified across the 17 focus states:

1. **Cost modeling and provider rate reform** to set rates aligned with the true cost of EI service delivery.
2. **Medicaid optimization and billing reform** to maximize federal funding and reduce administrative burden on providers.
3. **Eligibility expansion** to align policy with developmental science and ensure earlier identification.
4. **Service delivery improvements**, including evidence-based parent coaching models and expanded telehealth options.
5. **Cross-system collaboration** to coordinate referrals, data systems, child find campaigns, and family support.

1. Cost Modeling and Provider Rate Reform

Cost modeling studies are tools that analyze the true cost of delivering Early Intervention services by examining provider compensation, time use, overhead expenses, and other factors to establish evidence-based rate recommendations. These studies can lead to data-informed policy decisions aimed at increasing reimbursement rates in meaningful and productive ways. Provider reimbursement rate increases involve raising the rates that EI service providers receive for delivering services to infants, toddlers, and their families. The goal is to increase reimbursement rates so that they are closer to actual market rates that providers could receive in private practice and to cover the full cost and time required to provide services.

Strengths & Advantages:

- **Evidence-based advocacy:** Cost modeling provides objective, data-driven evidence of the true cost of EI services and the need for rate increases, making it harder for policymakers to dismiss.
- **Addresses workforce crisis and reduces waitlists:** Delays and inconsistencies of EI service delivery are often driven by provider shortages, and these shortages are often driven by the lack of financial feasibility for providers to stay in EI rather than working in the private market. Rate increases can make it possible for these providers to stay in public service. This can improve the provision of timely services and cuts waitlists for EI services children are legally entitled to. One advocate reflected: “A core issue in this problem is providers not having gotten raises and providers being expected to do so much unpaid work that it is no longer financially feasible for them to stay in Early Intervention. There must be changes…or we're going to keep losing the providers we so desperately need.”
- **Comprehensive approach to EI service provision:** A cost study provides thorough accounting of work that is not direct service and that often goes unpaid as “non-billable,” such as preparing to provide services effectively, traveling, and documenting appointments and progress. Rate increases that take this “non-billable” time into consideration will be more likely to retain EI providers.

Challenges & Barriers:

- **Significant financial investment required with competing budget priorities:** The level of rate increase recommended by the cost studies is often steep, particularly in the states that are furthest behind in provider compensation, which can produce sticker shock among the policymakers who make budget decisions. Advocates are also challenged to explain why EI rate increases are important as compared to other early care and education

efforts in an environment of budget scarcity. Advocates must be wary of where budget cuts may be made, even within the EI budget, to pay for rate increases.

- **Unintended policy responses:** Cost studies may result in policymakers focusing on other policy responses like reducing identified cost drivers or shifting costs to families through co-pays rather than increasing provider rates as advocates intend.
- **Time-intensive process:** A truly comprehensive and accurate cost study with provider and community engagement will likely take one to two years at minimum, so any positive impacts on provider shortages, service delays, and waitlists will not manifest for multiple years.
- **Provider fear of retaliation:** Providers may be hesitant to advocate openly for rate increases due to concerns about damaging relationships with state lead agencies and regional EI intermediates, who are their funders and have a power differential over them.
- **Securing state agency and/or legislative partnership and funding:** Comprehensive cost studies require significant financial resources that individual advocacy organizations cannot fund, necessitating partnership with the state lead agency and/or the support of the legislature to commission and resource the study. This can be difficult to navigate if the state agency knows it will reveal funding gaps they cannot address or feel unprepared to request.

2. Medicaid Optimization and Billing Reform

Medicaid optimization and billing reform involves maximizing federal Medicaid reimbursement for EI services and strengthening the systems and infrastructure needed to bill Medicaid and private insurance effectively. Many states leave federal funds “on the table” and fail to maximize Medicaid and private insurance reimbursements that could help cover EI funding gaps or expand services to more potentially eligible infants and toddlers. Strategies could include developing centralized billing systems, partnering across state agencies to maximize use of federal funding, increasing the number of EI services that can be billed to Medicaid, and improving billing capacity to lessen administrative burden for providers.

Strengths & Advantages:

- **Maximizes federal funding:** Maximizing federal funding to support EI, rather than relying largely on state general revenue funds or the limited federal IDEA Part C grant, reduces state budget pressure.

- **Infrastructure investment:** Developing centralized billing systems and strengthening billing capacity creates long-term system improvements that benefit multiple programs even beyond EI.
- **Promotes cross-agency collaboration:** Collaboration not only maximizes federal revenue but also improves coordination and service delivery more broadly.

Challenges & Barriers:

- **Complex billing requirements:** Billing Medicaid may require providers to engage in more difficult Medicaid billing processes, denials, administrative burdens, etc., making participation in EI as a service provider more unsustainable.
- **Administrative infrastructure gaps:** Many states, counties/regions, and providers lack the centralized billing systems and administrative capacity needed to implement effective billing of Medicaid/track reimbursements.
- **Inadequate Medicaid rates:** Even when Medicaid billing is optimized, Medicaid reimbursement rates for EI services may be inadequate and not reflect the true cost of service delivery.
- **County/regional-level variation:** In county-administered systems, billing practices and capacity may vary significantly across counties, creating inconsistencies in Medicaid utilization and exacerbating access issues for geographic and cultural communities.
- **Supplantation:** There is a risk that policymakers could optimize Medicaid to shift costs for EI and not implement EI rate increases with state revenue.
- **Start-up costs:** Developing centralized billing systems and strengthening Medicaid infrastructure requires upfront investment before revenue gains are realized.

3. Eligibility Expansion

Eligibility expansion in EI refers to the process by which states broaden their criteria to allow more infants and toddlers (birth to age 3) with developmental delays, disabilities, or risk factors to access federal IDEA Part C services. This shift often involves lowering the percentage of delay required to qualify, adding new qualifying diagnoses (such as social-emotional or medical conditions), or including risk factors like child abuse, neglect, or very low birthweight. States can also extend the age of eligibility to 4 years old, allowing for a longer period of service and delaying the transition to a school-based service plan.

Strengths & Advantages:

- **Evidence based:** This aligns with developmental science by targeting the critical birth-to-three window, when brain plasticity is highest and EI can prevent or reduce long-term developmental delays.
- **Yields future savings:** Early detection and treatment of developmental delays lessen the need for services in K-12 settings, thus reducing the cost for that system.
- **Family support:** This provides support and education to families who otherwise might need greater intervention later in the child's life.
- **Early detection:** Risk factor eligibility criteria can improve access for children who would benefit developmentally from services but might otherwise not receive them.

Challenges & Barriers:

- **High initial cost:** Expanded eligibility requires a willingness of legislatures to explore ways to increase revenue for the program.
- **Disruption to the system:** Because of the revenue challenges and the already strained workforce capacity, there is a sequencing dilemma of what should come first: determining the eligibility expansion parameters or addressing workforce/funding issues.
- **Overloading the system:** If sequencing isn't well determined, then financial, staffing, and operational constraints of expanded eligibility can lead to higher caseloads for providers, potentially resulting in fewer or less thorough sessions for each child, as well as longer wait times for evaluation, defeating the original purpose of expansion.

4. Service Delivery Model Improvements

In 1997, the requirement that EI services for infants and toddlers with disabilities are provided in natural environments to the maximum extent appropriate was strengthened. As a result, states have worked to design EI service delivery systems to be provided in natural environments – the home and the community – through family-centered, transdisciplinary approaches, often incorporating coaching to build caregiver capacity in natural environments such as the home and child care settings. Despite many improvements over the decades, challenges still exist to effectively and sustainably deliver all services in natural environments, building lessons learned over the years. Key improvements still needed focus on providing professional development to develop and increase coaching skills, reflective supervision to process the high emotional demands of the work, improving access through telehealth, and strengthening service coordination to improve child outcomes and family engagement.

Strengths & Advantages:

- **Family centered:** This approach ensures family centered care and reduces the logistical barriers of schedules and transportation.
- **Developmentally appropriate:** Children learn skills in the actual context where they are used (e.g., practicing eating in the kitchen), making it easier to apply those skills daily. Services build upon daily routines (meals, bath time) rather than clinical settings, thus fostering caregiver confidence and competence.
- **Telehealth/Live Video Visits:** When appropriate, services can be provided via telehealth. This approach can be an effective modality for EI, particularly given the coaching models implemented by states. Families may benefit from a hybrid model within person services one week and telehealth the other. This approach can be particularly beneficial for rural families by increasing access to specialists without the burden of significant travel for both the family and the specialist. This approach can also be beneficial for medically fragile children, reducing risks of exposure to illnesses.

Challenges & Barriers:

- **Provider supports needs:** Providers need guidance and support to ensure effective delivery of services in community settings, with creative methods for navigating busy homes and child care settings without the specialized equipment supports of a clinic. Ongoing professional development can help providers learn to shift from direct therapy methods with the child to parental coaching, as well as navigating how to deliver services in community settings such as a library or child care classroom. The telehealth service option requires more study to understand who is receiving in person services and who is receiving

telehealth, ensuring families have a choice in their service delivery. Additionally, providers need sufficient training and support for all service modalities.

- **State administrator and legislative resistance:** Without using telehealth, home or community-based delivery models that are evidence-based and yield the best results for infants and young children also often require significant travel for specialists to children's homes. This may result in lower numbers of sessions providers can deliver, which some state administrators and legislators may interpret as a negative trend. Additional education and data collection is needed to support state leaders in understanding the relationship between travel time, quality, and sessions delivered.

5. Cross System Collaboration

There are opportunities to increase cross-sector collaboration that incorporates EI into other early childhood and family support systems at multiple levels. At the family experience level, shared frameworks for service delivery, agreement on shared data elements and centralized data systems to track referrals and screenings, and aligned service plans can alleviate challenges.

System collaboration is critical for successful Child Find and outreach campaigns. Successful initiatives are consistent, localized, and use multi-channel communication strategies to identify and connect with families. All child and family service agencies throughout state government should be engaged in the promotion. Key elements also include community-based partnerships, multilingual materials, and targeted engagement for underserved populations, such as in rural areas. Outreach campaigns should be designed for multiple audiences including parents, health care providers, social workers, and child care providers. Professional development for the sectors that serve young children and their families on what EI is and how it is implemented in the state is also an essential part of a strong outreach and identification approach.

Strengths & Advantages:

- **Increased efficiency:** Effective partnerships, including shared data and joint case planning, reduce service silos, speed up referrals, and address complex needs. State agencies can develop clear referral protocols and expedited access agreements to reduce the burden on families seeking services.
- **Improved identification of service gaps:** States can use data to understand the status of EI services in communities, using the information to address gaps and identify strengths that can be scaled for greater impact.

- **Family centered:** Implementing shared decision-making meetings and data-sharing protocols ensures consistent, family centered care. Additionally, having multi-disciplinary representation at meetings can reduce the number of meetings family leaders have to attend as well as the number of visitors that are coming to their homes.

Challenges & Barriers:

- **Organizational differences:** Different sectors (health, education, social services) often have conflicting priorities, languages, and professional ideologies, leading to competition over resources rather than collaboration.
- **Workforce disruptions:** High staff turnover leaves families with inconsistent support, while the training available to EI providers is often insufficient to address the complex, multidisciplinary nature of early childhood needs.
- **Differing interpretations of data usage:** Disagreements about how to share data, where the data should be housed and managed, as well as interpretations of the Health Insurance Portability and Accountability Act (HIPPA) requirements can hinder the ability to coordinate care effectively.

IV. Advocacy Strategies to Improve EI Systems

Effective advocacy requires a combination of clear strategy, dedicated resources, strong relationships, and a supportive environment. When the enabling conditions are strong for a specific policy lever, savvy advocates take advantage and act upon that goodwill. This landscape analysis identified seven key strategies advocates in our sample of 17 states leveraged to improve their state early intervention systems. For each strategy, a case example of where and how it was used by advocates is highlighted.

1. Coalition Building and Cross-Sector Partnerships

Advocates need coalitions and cross-sector partnerships to share knowledge, strategies, and capacity with other advocates, policymakers, providers, and families. In these coalitions, different disciplines of service providers join forces with a specific EI advocacy lens. To increase their reach and capacity, traditional early childhood advocates need to engage with all the different sectors that impact the lives of children with disabilities – the convenors and connectors – to tell the story collectively.

Strategy in Action: Maryland

The strategies employed by Maryland Family Network include joining all the possible coalitions and groups looking at the issue, including the Maryland Behavioral Health Coalition, Poverty Free MD; Time to Care Coalition; Maryland Tax Credits for Families Coalition; and Blueprint Coalition. These coalitions range from a focus on infant early childhood mental health, to low-income rights advocacy, tax policy, and early care and education.

2. Authentic & Effective Provider and Family Advocacy

Advocates know that policymakers listen more to families and providers than to advocates alone, so strategically engaging, educating, and empowering these stakeholders to advocate for EI can be a powerful way to increase capacity. Advocates can engage families and providers in different ways to weigh in on and support specific policy levers (e.g., service-specific policy levers can benefit from families and providers sharing their stories).

When considering working with families, advocates benefit from building personal connections to those who have experienced the system and services first-hand. Personal experience with family members or loved ones who have participated in EI is an important tool in strengthening legislative advocacy, as it helps lawmakers make personal connections and better understand the real-world impact of their decisions. Most states have citizen legislatures – the delegates are teachers, farmers, lawyers, and retirees. They have real life experiences that often include having a family member, friend, or neighbor with a disability. That can create a strong connection with the parents who are advocating for improvements to the EI system.

Strategy in Action: Texas

In 2023, Texans Care for Children supported providers and parents in building relationships with legislators by hosting Zoom calls. Providers and parents were able to tell their stories and provide a personal connection for a legislator who advocated for an increase in state funding for EI. The education and relationship building was successful particularly with the chair of the committee responsible for health and human services, who became a strong advocate for increased investments in the EI system, known as Early Childhood Intervention in Texas. The Legislature included a $57 million increase in the initial draft of the state budget and then added an extra $6 million on top of that through a budget amendment in April. This resulted in an increase of $63 million in state revenue.

"We want them to tell their story. We aren't really wanting to dictate some of these things... this is their experience. This is their story that they're wanting to share." - Texas Advocate

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3. Administrative Advocacy

Meaningful change can be achieved when advocates collaborate directly with key partners and the government administrators responsible for developing EI policy. Although providers play a key role in delivering EI services, they are often siloed within their own professions or separated by geography. Building trust across providers and administrators requires intentional engagement, such as informal dialog, formal advisory group participation, or combining storytelling with relevant data.

Strategy in Action: Kentucky

EI providers in Kentucky came together across disciplines to form a coalition the Kentucky Early Intervention Providers Association (KEIPA) - prioritizing relationship-building with state administrators prior to making requests to the legislature. The coalition developed a three-year advocacy and policy agenda and, when ready to advocate, started improving their relationships with state agency leadership. The coalition organized meetings with state agency leadership, allowing EI providers to share their experiences related to workforce retention, administrative challenges, and reimbursement needs. By investing time in trust and collaboration, the providers established allies to support their request for improving the payment structure and processes. Members of the coalition were included in decision-making discussions on rate restructuring with state administrators. Support from one key state administrator ultimately led to a 15% rate increase through a budget increase.

4. Legislative Education and Relationship Building

Legislative education related to IDEA Part C and the state EI system provides clear, non-partisan information on how policy decisions impact young children with disabilities and families. Although data on wait lists, provider rates, and return on investment are crucial aspects of understanding the EI system, family testimony remains a key component of legislative advocacy. The family voice provides a powerful, personal connection between the purpose of the law and the real-world impact of EI on children, families, and communities.

Blending legislative education with intentional relationship building between legislators, families, providers, and advocates helps policymakers to better support effective EI policies. Together these strategies can increase understanding of the lived experiences of families, foster collaborative partnerships, and ultimately contribute to policies that improve the EI systems for young children with disabilities and their families.

Strategy in Action: Pennsylvania

In June 2022, a cohesive policy action agenda with actionable recommendations to strengthen PA's EI system, was spearheaded by the Pennsylvania Association for the Education of Young Children and Partnership for Pennsylvania's Children using a structured process to review state and national EI resources, analyze state EI data, and facilitate small group discussions with key partners, including local and state leaders, health care providers, early care and education advocates, EI providers, and family leaders. The findings were synthesized, validated through participant review and finalized into a report and disseminated to key partners, legislators and state administrators.

5. Strategic Communication

Advocates connect with essential partners, including families, EI providers, and other early childhood advocates to coordinate and deliver unified messaging and coordinated requests to local and state leaders in support of EI policy priorities. Utilizing intentional strategies to share messages which are consistent, clear and timely is key to influencing policy decisions and advancing system change. To that same end, media advocacy supports the EI system by increasing public awareness through strategic use of news, social media, and storytelling. Media advocacy emphasizes the importance of EI services for young children and families by building public support and increasing visibility of systemic issues. Advocates capitalize on ways to raise public awareness of the existing challenges within the EI system by sharing data, explaining barriers, and highlighting stories of providers, families, and legislative champions.

Strategy in Action: New York

The Children's Agenda, a statewide advocacy organization based in Rochester, NY, and LIFTOFF WNY, an early childhood funders group focused on the western part of the state, participated in a local NPR program to discuss issues, engage listeners, and garner support from community members. This event was in support of a report released by the Children's Agenda, "Reimagine the Future: The Need to Reform Early Intervention in New York State."

6. Individual Family Advocacy - Rights & Due Process

Families use a variety of advocacy approaches to support their own children and address broader structural issues within EI. Interviews and desk research surfaced several factors that strengthen families' ability to advocate for their own child and for broader systemic policy change. Understanding parental rights and the EI system significantly strengthens advocacy efforts, while limited knowledge often creates barriers. Intentional efforts from providers and advocates can create meaningful opportunities for families to connect with peers to facilitate connections.[3] Informal and formal advocacy opportunities allow parents to develop leadership skills and act as peer navigators, drawing on their own lived experiences to guide, educate, and empower other families as they navigate the EI system.

To ensure families fully understand their rights and participate effectively, IDEA Part C establishes procedural safeguards that protect infants and toddlers with disabilities and their families. These safeguards establish requirements for confidentiality, consent, and timely resolution of complaints under IDEA Part C Section 1439. Despite these protections, many families struggle to access and comprehend the information provided. A recent national review of procedural safeguard notices found that only half included all required components, were written at a reading level above high school, lacked plain language, and were not always available in languages other than English.[4] To address these barriers, researchers recommend the U.S. Department of Education creates a plain-language template for states to adapt, develops a shared repository for translations, and produces captioned videos in multiple languages to support families with low literacy.

Strategy in Action: New Jersey

The SPAN Parent Advocacy Network provides family rights trainings for families of children with disabilities in every county in the state, disseminate guides and provide technical assistance for families and youth to advocate for themselves with the state administration responsible for implementation of EI. In addition, SPAN provides an intensive training program designed to educate volunteers to help parents with disabilities and special health needs to understand their rights and responsibilities under federal and state laws, the SPAN Resource Parent Program. This training is provided both online and in person.

[3] Terol, A. K., Fulton, K., Hardy, A., & Burke, M. (2025). Exploring advocacy among caregivers of children receiving Early Intervention services. *Journal of Early Intervention*, *47*(4), 418-437.

[4] Cycyk, L. M., Griffin, M., Gillis, M., Batz, R., Underwood Carrasco, V. I., Wease, S., Lim, S., Jade, N., & Zuckerman, K. E. (2025). Part C Early Intervention Procedural Safeguard Notices: Are They Supporting Parents to Understand Their Rights? *Topics in Early Childhood Special Education*, *44*(4), 330-341.

7. Data- and Research-Driven Advocacy

Studies, commissions, and reports that are legislatively mandated can spark EI reforms, but advocates need support to push agencies on implementation and accountability. Advocates can also use the 618 data reports submitted annually to the federal government, state-level performance plans, and family surveys to identify EI service gap.

Strategy in Action: Maine

A legislative study on EI revealed significant challenges in the system, noting that while 69% of evaluated children were eligible, only 34% of total referrals resulted in enrollment. The findings from the study highlighted a need for improved communication, better tracking of referrals to prevent service gaps, and adequate, consistent funding for high-performing services, as discussed in this blog from the Maine Children's Alliance. An advisory committee was charged with making recommendations that informed part of the study. The recommendations focused on:

- Improving communication between referral sources and providers to support enrollment, as well as initiating follow-up calls to ensure children are not lost in the referral process
- Improving systems for more efficient billing documentation and claiming processes that meet Medicaid requirements
- Expanding eligibility, including allowing children to remain in EI until the school year after their third birthday, rather than immediately switching to Part B (preschool) and encouraging practitioners to use the Informed Clinical Opinion for eligibility, particularly for infants.

Summary of Advocacy Strategies & Tactics

The table below summarizes examples of each of the strategies discussed above and lists the states where these strategies are primarily being deployed.

TABLE 2: ADVOCACY STRATEGIES EMPLOYED BY STATE ADVOCATES

Strategy	Examples	States
Coalition Building and Cross Sector Partnerships	Coordinating with advocacy organizations that retain lobbyists to promote EI-related policy change. Organizing a Leadership council of advocates representing the various sectors that impact lives of children with disabilities and their families	Indiana, Kentucky, Maryland, New York, Oregon, Texas
Provider and Family Advocacy	Collecting parent stories through video to share with legislators and policymakers. Supporting parents on calls/visits with legislators to share their experiences and providing testimony for specific legislation.	Kentucky, New Jersey, New York, Ohio, Texas,
Administrative Advocacy	Providing support as an extra pair of hands for research on what other states have done, or conducting surveys with providers and parents Building trusting relationships for stronger communication and feedback loops regarding the implementation in practice of the polices developed by legislative and administrative actions	Kentucky, Pennsylvania, Texas
Legislative Education and Relationship Building	Organizing Capital Days for providers and parents with legislative visits, committee hearings, etc. Inviting legislators to visit EI provider sites	Illinois, Indiana, Kentucky, New Jersey, Rhode Island, Maine, Texas

TABLE 2 (CONTINUED): ADVOCACY STRATEGIES EMPLOYED BY STATE ADVOCATES

Strategy	Examples	States
Strategic Communication	Advocacy newsletters Relationships with journalists and news outlets to provide stories and build public awareness	New Jersey, New York, Ohio
Individual Family Advocacy – Rights and Due Process	Helping family leaders understand their rights to ensure families are active partners in the decision-making process regarding service plans, evaluations, and service delivery. Supporting family leaders during due process and dispute resolution activities	Illinois, New Jersey
Data and Research Driven Advocacy	Using 618 report data to advocate for expanding eligibility Cost studies to demonstrate gaps in payment policies and operating costs	Alaska, Georgia, Illinois, Kentucky, New York, Ohio, Pennsylvania, Maine, Michigan

V. Increasing Advocacy Capacity

Employing any of the strategies discussed above requires significant advocacy capacity to inform, guide, and sustain policymaker action. Successful advocacy considers what strategy is best suited to advance a particular policy goal or system improvement from concept to implementation. Advocates employ a wide variety of strategies at the same time, whether coalition building, developing relationships with state administrators, inviting legislators to visit programs and meet with parents, or supporting legislation that improves how families and providers interact with the EI system.

However, the field is struggling from a lack of overall advocacy capacity for EI systems improvements. To address this challenge, advocates are nimbly employing several strategies to enhance their limited capacity. At the same time, there are strategies available to state governments to offer legislative support to further improve capacity to drive and sustain more substantive improvements to the EI system and, ultimately, better outcomes for children and families. Over the course of the analysis of documents and interviews with advocates, two primary needs for bolstering and sustaining advocacy for EI were consistently demonstrated.

Building a Deeper "Bench" of Advocate Knowledge of EI State Policy

The EI advocacy landscape reveals a significant capacity gap, with advocates' knowledge of EI ranging from highly focused expertise to just baseline awareness of how the system works. In many states we've talked to, EI is just one of many issues on a single early childhood advocate's plate, leaving limited bandwidth to engage in sustained or strategic policy work – and dedicated funding would allow them to focus on EI more intentionally. In states just getting started or considering EI advocacy, there's huge potential to spark ideas and build momentum just through building knowledge of key EI issues and potential policy levers to address them – even modest investments in this area could be an easy win. In contrast, states further along in their EI advocacy need more intensive support to strategize and push meaningful policy improvements. Early childhood advocacy organizations would benefit from staff with deep content knowledge in EI and how that system interacts with the other early childhood systems such as home visiting, child care, child welfare, as well as the systems that families interact with such as health care, housing, nutrition services, etc.

You're not going to win these things if you just have one advocacy org that's running around trying to do all of this. - New York Advocate

Ensuring Authentic Family and Provider Voice

Centering advocacy efforts around family leaders and providers ensures that the people most frequently interacting with the EI system have influence on the changes and improvements needed. It is their experiences and wisdom that should shape the policies and solutions for structural changes. Effective strategies for engaging families and providers include establishing parent advisory boards, holding town halls, and providing leadership training. Policy and advocacy approaches are strengthened when families with EI experience and EI providers can co-create advocacy goals, with advocacy organizations serving more as backbone and support. This requires time and financial resources as well as tools and strategies (like surveys and coordinated agendas) to move beyond one-off stories and ensure broad family/provider consensus. Structures and funding need to be in place for parental involvement in advocacy efforts to be sustainable. Family leadership development and parental compensation can strengthen the family members' advocacy skills while paying for their lived experience and time outside of child caring. In addition, programs where experienced parent advocates mentor new parents in the role can support sustainability.

When you're doing early childhood, if you don't have a dedicated group of folks or like families and providers, then it's hard because you're trying to carry so many needs for the system out of your organization. - North Carolina Advocate

VI. Conclusion

Across states, EI systems are confronting a constellation of persistent and interconnected challenges—workforce shortages, inadequate funding, inconsistent access, limited awareness, and fragmented cross-sector coordination. These systemic barriers not only delay services for infants and toddlers but also strain families and undermine the effectiveness of providers who are committed to delivering high-quality support. At the same time, states are experimenting with promising policy levers and advocacy strategies—from cost modeling and Medicaid optimization to eligibility expansion, telehealth innovations, and deeper collaboration across agencies and sectors that impact the lives of children with disabilities and their families.

The experiences shared by advocates, families, and providers make clear that meaningful EI reform requires both structural change and sustained advocacy capacity. Policymakers, state agencies, and advocacy organizations must work together to invest in the workforce, modernize funding structures, expand access, and strengthen family-centered support systems. Equally important is building stronger advocacy capacity in states across the country: sharing strategies and tools across states; building a deeper, more diverse bench of advocates; and ensuring that family and provider voices guide decision-making at every level.

Taken together, this landscape analysis points to an urgent but achievable path forward: with coordinated action, adequate investment, and authentic engagement of those most impacted, states can create stronger, more accessible EI systems—ensuring that young children with developmental needs receive timely, high-quality services during the years when they matter most

Join Us

Advocacy for young children with disabilities is stronger when we do it together. Sign up at this link to receive Together for Young Children with Disabilities campaign updates, resources, and invitations to future webinars and convenings. Advocates, families, and providers are also invited to join the recently formed Early Childhood Disability State Advocate Collective.

Appendix A: Spotlight on State Advocacy Efforts

The advocates interviewed for this report are consistently striving to strengthen the systems designed to serve young children with disabilities and their families. Below are some examples of their efforts as well as reports from state administrators.

Provider Reimbursement & Workforce Shortages

- Kentucky Coalition Secures Pay Increase for Early Intervention Providers: This May 2025 article from *The ASHA Leader* details a significant advocacy victory for speech-language pathologists (SLPs) and audiologists involved in Kentucky's early intervention program, First Steps. The core of the "win" involves a substantial increase in reimbursement rates and a restructuring of how providers are compensated. This report can serve as a roadmap for SLPs in other states facing similar reimbursement challenges. It highlights that professional associations, when combined with parent advocacy, can successfully influence state policy to secure the future of early intervention services.
- Modeling the Cost of Early Intervention in Illinois: Analysis and Recommendations: This November 2024 report is a comprehensive study commissioned by the Illinois Department of Human Services (IDHS) to evaluate the financial health of the state's Early Intervention (EI) system. The report highlights a critical funding gap and provides a roadmap for restructuring provider compensation to address severe practitioner shortages. The cost model serves as a flexible tool for policymakers to prioritize investments that will stabilize the workforce and ensure children receive critical support during their most formative years.
- Re-Building the Early Intervention Workforce: This report, published by The Children's Agenda in January 2024, highlights the growing crisis in New York State's Early Intervention (EI) system. The system is designed to provide life-changing services to infants and toddlers with developmental delays, but it is currently hampered by a severe shortage of qualified professionals.
- Pennsylvania Early Intervention Rate Study: This report, conducted by Public Consulting Group (PCG) for the Pennsylvania Department of Human Services (OCDEL) in March 2025, presents a comprehensive analysis of the Infant Toddler Early Intervention (EI) system's rates. The primary goal of the study was to determine the true cost of providing services to ensure the system is compliant with federal requirements (IDEA Part C), supports staff retention, and remains competitive in the labor market.

Funding & Budget Advocacy

- FY26 EI Appropriation Budget Fact Sheet (v2.0) from Raising Illinois, a coalition focused on prenatal-to-age-three advocacy, serves as a call to action for the Illinois General Assembly to address a growing crisis in the state's Early Intervention system.
- Investing in the Professionals who Support Young Children with Disabilities, from Georgia Early Education Alliance for Ready Students (GEEARS) is a policy advocacy one-pager focused on the need for increased funding for specific staff within Babies Can't Wait (BCW), Georgia's early intervention program for children ages 0–3 with developmental delays.

Access & Eligibility

- Closed Loop Referrals and Warm Handoffs: A brief published by Children Now in March 2025, focuses on improving how children and youth in the Medi-Cal system are connected to essential health and social services. The document highlights a critical gap: many children are screened for developmental, mental health, or social needs, but they often fail to receive the follow-up care they are entitled to because of "broken" referral systems.
- Extend Pre-K Eligibility to Children with Disabilities: This May 2026 testimony to a legislative committee from Texans Care for Children advocates for a policy change to make children with disabilities automatically eligible for public pre-K in Texas. Currently, these children are often excluded unless they meet other specific criteria (such as low income or foster care status). The testimony urges the Texas Legislature to pass this proposal in 2027 to provide automatic pre-K eligibility for children with disabilities.
- Recommendations to Expand Eligibility and Funding for the Alaska Infant Learning Program (ILP) is a comprehensive policy analysis developed by the ILP's Interagency Coordinating Council Finance Subcommittee. It examines Alaska's current Part C eligibility criteria and compares Alaska's enrollment rates to national averages and peer states. The report makes detailed recommendations for expanding eligibility, optimizing Medicaid billing, and improvement funding sustainability.

General Resources

- The webpage for Thriving PA, a non-partisan, statewide advocacy campaign focused on a broad array of early learning and health issues, serves as both a resource for parents to understand their rights and access free services, and an advocacy hub to improve the Early Intervention system in Pennsylvania.

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