

Executive Summary: Challenges and Opportunities for Early Intervention Systems

Lessons Learned from a State Advocacy
Landscape Analysis

MAY 2026

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Executive Summary

Early 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.

Suggested Citation: Fisher, K., Reidt-Parker, J., Barreca, J., & Berman, K. (2026). Challenges and Opportunities for Early Intervention Systems: Lessons Learned from a State Advocacy Landscape Analysis. Chicago, IL: Start Early.

