

Modeling the Cost of Early Intervention in Illinois: Analysis and Recommendations

January 2025

Executive Summary



DIVISION OF
EARLY CHILDHOOD



A word from IDHS Secretary Dulce M. Quintero: The Illinois Department of Human Services (IDHS) Division of Early Childhood commissioned this cost model study to better understand the decline of Early Intervention (EI) providers in Illinois and to quantify what it will take to expand the supply of providers. This model has given us a stronger sense of direction, and we acknowledge there is always more work to do. IDHS, in collaboration with the new Illinois Department of Early Childhood, is moving into a new development and design phase to find an equitable approach to improving the accessibility and timeliness of EI services. We share this cost model in the spirit of transparent, honest dialogue with families, providers, advocates, and others in the field, acknowledging the work that remains.

Click the links to read the full [letter from the secretary](#) and full [report](#).

Early Intervention (EI) services play a crucial role in supporting young children in Illinois by serving infants and toddlers from birth to 36 months experiencing or at risk of developmental delays or disabilities and their families. EI is a federal entitlement program covering 16 core services including speech, physical, occupational, developmental, and other therapies, plus service coordination. The goals of EI services are to enhance child development, build family capacity, and minimize future need for special education services. Studies have shown that EI services can change a child's developmental trajectory, leading to better outcomes in various domains, and can reduce the need for future special education services.¹

Illinois has made strides in its EI system, including a 10% rate increase to all EI service providers in State Fiscal Year (SFY) 2024, and is often recognized as a leader in the field.² However, in recent years, Illinois, like many other states, has struggled to meet the needs of all families and children in EI or those who could qualify for and benefit from the service. Since SFY 2018, EI caseloads in Illinois have risen 5.6%, while the workforce has shrunk by 6.6%. During the same time, service delays have almost doubled, with 8.8% of children and families experiencing service delays as of May 2024. Intake delays, defined as cases where the child has not received an evaluation and service plan within 45 days, have increased from roughly 0% to 7.6%.

1. "The Importance of Early Intervention for Infants and Toddlers with Disabilities and their Families." The National Early Childhood Technical Assistance, July, 2011. <https://ectacenter.org/~pdfs/pubs/importanceofearlyintervention.pdf>.

2. "2022 Prenatal-to-3 State Policy Roadmap." Prenatal-to-3 Policy Impact Center, n.d. <https://pn3policy.org/pn-3-state-policy-roadmap-2022/us/early-intervention/>.

Recognizing the urgency of improving the family experience and reducing delays, the Illinois Department of Human Services (IDHS) commissioned Afton Partners (Afton) to develop a cost model to understand the cost of the EI system and propose recommendations for payment reform to improve the family experience. The cost model is a flexible tool that can be used to estimate the cost to provide services in different scenarios. While a cost model can inform policy decisions by estimating the cost of those decisions, it cannot provide a holistic picture of what families want, the costs, benefits, and tradeoffs of a decision, or the judgement and insight of policymakers. A cost model is not a budget or funding allocation.

The purpose of this report is to describe the cost model as well as the revenue levers that can help to progress toward the modeled cost of services. These revenue levers can include the various sources of funding available to most states for Early Intervention: federal IDEA Part C, Medicaid, State General Revenue, county tax levies, state special education funds, private insurance, and private co-pay.

This work started as Illinois Governor JB Pritzker announced the intent to create a new Department of Early Childhood to create a simpler, better, fairer early childhood system for parents and families. The work was completed as PA 103-0594, the enacting legislation for the Illinois Department of Early Childhood (IDEC), was being passed by the Illinois General Assembly. As such, this report focuses on the current Early Intervention program and does not discuss future connection to other early childhood state programs and systems or the new capacity to reimagine early childhood in Illinois.

This work to support the EI system contributes to Governor JB Pritzker's Smart Start Illinois initiative, which makes a commitment to reach young children and vulnerable families with early support. The Illinois Department of Human Services can use this report and cost model, alongside other research into other states' best practices, to continue implementation of Smart Start Early Intervention in Illinois.



"I love all of our providers... My husband and I call them the Dream Team. We feel very blessed.... **It feels as though they are genuinely invested in our family** and my daughter and I'm so grateful."
- EI Parent, Normal, IL

Over the past year, Afton has conducted research, focus groups, and surveys to better understand the system challenges. This process has included over 1,300 engagements with EI practitioners and families. Findings from practitioners and families include:

- 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 modeled cost of delivering EI services. The lack of competitive wages, among other challenges, serve as a barrier for providers to work in EI.
- Direct service providers rely on fee-for-service billing that does not fully cover the overhead costs of delivering services, outside of the time spent directly providing therapy. On average, 36% of providers' time is billable, meaning that they spend nearly two hours preparing for, traveling to, and documenting appointments for each hour spent with the child. Additionally, approximately 20% of appointments are cancelled and not rescheduled. Current rates do not fully cover the costs associated with this non-billable time.
- Caseloads for Service Coordinators are too high, with an average caseload of 65 compared to Illinois' recommended caseload of 45, which makes it difficult for families to access services and hinders the timeliness³ and accuracy of payment authorizations. Given the significant responsibilities, Service Coordinator salaries are insufficient to attract and retain staff.⁴
- Infants and toddlers outside of Cook and the Collar counties, and Black infants and toddlers, face disparities in access to services, both in receipt of services and in service delays.
- Families report frustration with service delays, long waitlists, and difficulty communicating with their Service Coordinators. However, those that are receiving services are generally very satisfied with the quality of their providers and the services their child has received.

"The truth is that my coordinator is very good, very, very attentive, **but I think that they do have too many cases...** I had told her that I was also searching [for a provider] and she told me the truth is that it's not your job, but if you find someone, tell me because I really can't cope."

– EI Parent, Chicago, IL



3. "Special Education - EI Child & Family Connections (25-444-84-2880-01)." Illinois Department of Human Services, April 26, 2024. <https://www.dhs.state.il.us/page.aspx?item=160835>

4. "Illinois Early Intervention Provider Handbook." Illinois Department of Human Services, July 2022.

<https://providerconnections.org/wp-content/uploads/2022/05/Final-DRAFT-Provider-Handbook-R07-2022.pdf>

After listening to practitioners and families, and using data from practitioners to construct the cost model, the following recommendations were developed to address the major concerns raised:

1

To improve recruitment and retention, ultimately increasing families' access to services, rates for direct services and Child and Family Connections (CFC) Office grants should make progress towards aligning to the modeled cost of service delivery. The state should consider available

revenue levers to make progress toward this goal, and should develop a multi-year implementation plan and strategy to bring rates and grants more in line with modeled cost.

a. Direct service payment rates need to be increased to move compensation closer to the labor market and rates need to cover the modeled cost and time required to provide services. Depending on the providers' discipline, the modeled cost of service delivery translates into a rate of between \$127 and \$199 for an hour of direct services, compared to current rates of \$65 to \$101 per hour of direct services. Overall, direct service rates need to increase by an average of 95% over current rates to fully cover providers' costs and time. Statewide, this level of rate increase is estimated to cost approximately \$150 million annually. The rates reflected in the cost model would bring Illinois' rates in line with EI rates in other states with a similar cost of living.

b. CFC grants should be modified to make progress towards reflecting the modeled costs of providing timely services, including adequate staffing, and set minimum Service Coordinator salaries that are competitive for roles with similar credentials. These changes would require the average grant size for a CFC to increase from approximately \$2.3 million to approximately \$3 million per year. The statewide cost of this increase is estimated at approximately \$18.4 million annually, in addition to the \$150 million for rate increase noted above.

c. In service of the above recommendation, the State should partner across agencies to **maximize federal revenues and Medicaid reimbursements** for Early Intervention, now and as EI transitions to IDEC. This should include peer state analysis, evaluation of capacity throughout the field to complete billing, and development of a plan to strengthen that capacity. This work should be done in partnership with other state agencies and alongside efforts to strengthen Medicaid billing practices in other services.

"I lost more than 50% of [my providers]. **They just left EI because they're getting better wages and salaries in other areas**, whether it's a nursing office, hospital clinics, when there's a school system, everywhere else... [providers] are getting better wages."

- EI agency owner, Chicago area



2

To support equitable access to EI services, the state should consider layering additional financial incentives to promote service delivery in underserved areas and to expand the multilingual provider workforce.

Service delays are disproportionately concentrated in rural areas with few providers; enhanced payment rates can encourage providers to travel longer distances to reach families in these areas. Additionally, because families typically prefer services provided in their home language, multilingual providers should be incentivized to offer these services through higher rates and/or recruitment bonuses or stipends. Payment changes should be coupled with training and support, such as reflective supervision,⁵ to support providers in meeting families where they are. This approach should be developed and implemented in alignment with the forthcoming transition to IDEC, which is centering families with special needs and the providers that serve them.

3

IDHS-Division of Early Childhood (DEC) should pilot other structural changes that need further exploration to improve the attractiveness of the EI field, including Grow Your Own programs⁶ to provide a pathway for

community members to join the EI field, alternative employment structures to support new providers through salaried roles, mentorship and coaching opportunities that allow for experienced EI providers to use their expertise to support other providers, benefits pools that allow EI providers to access health and retirement benefits, and improvements to billing to make the process easier for providers, including through technological innovations. This should be done in partnership with and through the IDEC Transition Advisory Committee Workgroups on Funding Design, Data, Insights, and Analysis, Workforce, and Intermediary Alignment.



As Illinois transitions toward the new IDEC, there will be numerous opportunities to work across systems to improve services for children with developmental delays and their families. This includes opportunities to better coordinate across EI and Early Childhood Special Education, which serves children three and older. The two systems not only serve many of the same families, but also share many professionals who work in both systems during their careers. To more fully understand equity in timely access to EI services and to identify how to rectify inequities through investments, policy changes, and other levers, the State should analyze service data across Early Intervention for infants and toddlers and Early Childhood Special Education for preschoolers and early elementary school students.

To make the changes necessary to meet the needs of all children and families, the State will need to make a significant investment in the EI workforce, addressing both immediate needs and planning for long-term changes that support high-quality, accessible services for Illinois' families.

5. Reflective Supervision is regular collaborative meetings between a professional that provides services to families and young children (clinical, intervention, early educator, etc.) and a trained Reflective Supervision provider. They meet to reflect and build skills, using the provider's thoughts, feelings, and values and how they apply within the context of providing services. (Kansas Association for Infant and Early Childhood Mental Health).

6. Grow Your Own is an umbrella term that describes the many and dynamic, community-driven, equity-centered, holistic approaches designed to help communities support, strengthen, and sustain a well-qualified, experienced, and diverse ECE workforce by nurturing the talents that exist within it and removing barriers to entering and staying in the field. (National Early Care and Education Workforce Center).