Modeling the Cost of Early Intervention in Illinois: Community Engagement Process Overview

January 2025

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.

Beginning in August 2023, the Illinois Department of Human Services (IDHS) partnered with Afton Partners to develop a cost model to understand the cost of the Early Intervention (EI) system and propose recommendations for payment reform to improve the family experience. Over the course of a year, Afton conducted a variety of community engagements to ensure that both the cost model and payment reform recommendations were rooted in the lived experiences of the practitioners and families who interact with the system. This resulted in over 1,300 engagements across multiple focus groups, a cost survey, a time use study, and continued engagement with the Illinois Interagency Council's EI Workforce Workgroup. This brief summarizes the key findings from this process, which informed Afton's analysis and recommendations for payment in the EI system.

Community Engagement Overview:

Focus Groups	Cost & Payment Reform Survey	Time Use Study
• Practitioner focus groups were held in November and December 2023, engaging **310 EI practitioners.** • Family focus groups were held in January and February 2024, engaging **107 EI parents and caregivers.**	• **707 EI practitioners** responded to the EI Cost Survey in February and March, providing input on payment reform priorities and sharing their cost data if applicable.	• **237 EI providers** participated in the Time Use Study in February and March to share their daily time use and provide data on billable time. • Providers also had the opportunity to attend a reflection session for continuing education credit.

Ongoing Input from the IICEI Workforce Workgroup

IICEI Workforce Workgroup

This group was convened to advise the Bureau of Early Intervention on workforce recruitment and retention strategies, including support and collaboration in developing payment reform recommendations. The Workforce Workgroup included various direct service providers, CFC staff, interpreters, advocates, and EI parents. The role of the group included providing input and feedback and surfacing potential unintended consequences for the cost model and payment reform options. The Workgroup specifically discussed cost and payment issues at four meetings between November and May. The meetings covered a variety of topics, including coming to a shared understanding of system challenges and discussing potential payment reform solutions. Their input and feedback were critical in developing payment reform recommendations.

EI Focus Groups

Between November 2023 and February 2024, Afton Partners conducted 13 focus groups to engage Early Intervention practitioners and families.

EI practitioner focus groups were conducted to gain a better understanding of how practitioners were experiencing payment structures and practices in the field. Over 300 practitioners, including direct service providers, CFC Managers and staff, interpreters and translators, and former EI professionals, participated. Practitioner focus groups were racially and geographically representative of the field.

Practitioner Focus Group Key Findings:

- EI providers expressed dissatisfaction with low compensation and overhead costs, including significant administrative burden.
  - Compensation in EI is far lower than in comparable roles.
  - Lack of benefits, uncompensated travel, and cancellations impact pay.
  - Providers experience high administrative burden, specifically from billing and authorizations.

"I seem to average 9 to 12 billable hours of time while putting in about 35 to 40 total hours of EI work per week, this was enlightening and terrifying at the same time since **my income is less than half of what my Physical Therapy colleagues in other settings make**."
- Physical Therapist, Kendall County, IL

"**There are times that we provide services that we will never get paid for.** Sometimes it's an accident and an authorization wasn't entered correctly... I don't think it should be the responsibility of the Service Coordinator alone... I just don't think it's appropriate to put that on someone who has a giant caseload."
- Occupational Therapist, Northern Illinois

- CFC offices had difficulty recruiting and retaining Service Coordinators, increasing the burden across all employees.
  - Service Coordinators were experiencing burnout from low pay and high caseloads.
  - CFC Managers felt that funding CFC offices based on service coordination fails to account for other costs, noting that additional personnel are needed for a successful program.

- Interpreters, translators, and bilingual providers were growing increasingly frustrated with the EI payment system and often took on significant amounts of unpaid work to support non-English speaking families.
- Former EI professionals cited various reasons for leaving the field beyond the known challenge of low compensation, including inconsistent pay and difficulty renewing credentials.

"I love what I do. I'm really good at what I do, but **sometimes it takes a toll...** I spend maybe two hours every week just with the Central Billing Office, trying to figure out what I'm getting paid for and what was denied... And that is money that has been lost."
-Interpreter, CFC 4 & 5

Afton also conducted family focus groups to reach parents and caregivers who currently or recently experienced the EI system. These focus groups sought to understand families' perspectives and experiences with the EI system, including access and quality of services. Over 100 parents and caregivers across the state participated in these sessions.

Family Focus Group Key Findings:

- Many families lacked awareness of Early Intervention services, and those who had experience with the system were at an advantage.
- Parents and caregivers were frustrated with service delays and long wait times.

"If you don't get on this early, you could have a 1.5-year-old and maybe not be seen until your kid turns two. And then you have very little time left to utilize these services, so it's very hard and disheartening... **Within our county [people] are having challenges getting the therapy that they need through EI because of the wait list** and ultimately, they are then going to private centers or providers."
- EI Parent, Frankfort, IL

"Being a full time, stay at home parent helps because **navigating EI services was my full-time job**... They hand you these packets and it's not easy reading. I can't imagine how you'd navigate if English isn't your first language, or you don't have a higher education level."
– EI Parent, Frankfort, IL

- Most parents and caregivers preferred in-person services and did not feel that Live Video Visits (LVV) met their needs.
- Relationships with Service Coordinators greatly impacted families' experience.
- Families valued shared experiences and backgrounds with their service providers.

- Families were generally happy with the quality of services they were receiving and had good relationships with their providers.
  - Those who had negative experiences cited lack of experience and professionalism as major challenges.

"My team is amazing. All three are moms, which I think helps... Since they come to our home, they are able to interact with my daughter and me and answer all my questions. I cannot think of anything needing improvement - **they are knowledgeable, communicative, and amazing.**"
- EI Parent, Skokie, IL

EI Cost and Payment Reform Survey

In February 2024, Afton conducted an Early Intervention Cost and Payment Reform Survey for EI practitioners. The survey was intended to gather information on costs that EI providers incur to provide services and to gather further practitioner input on priorities for payment reforms. More than 700 providers responded to the survey, and cost information from over 220 providers was used as a primary source of data for the EI Cost Model.

Cost & Payment Reform Survey Key Findings:

- There were minimal cost differences across provider disciplines and regions.
- When asked about potential payment reform options, EI providers rated the following as their top three preferred solutions:
  - Raise rates for direct services.
  - Implement an annual cost of living increase for EI rates and CFC funding.
  - Pay practitioners for canceled or missed appointments.
- CFC staff rated the following as their top three preferred payment reform solutions:
  - Reduce caseloads for Service Coordinators.
  - Implement annual cost of living increase for EI rates and CFC funding.
  - Pay higher rates to practitioners serving areas with shortages of EI practitioners.

Agencies:

- On average, agencies employed 1.7 full-time equivalent (FTE) administrative staff, including directors/assistant directors (0.7 FTE), administrative assistants (0.4 FTE) and billing specialists (0.6 FTE). The average agency employed 8.2 FTE direct service providers. There was substantial variation in size and staffing patterns across the 18 agencies who responded to the survey, ranging in size from 1.25 total staff to 33 total staff.

Non-Personnel Expenses (Top 3)	Median Annual Cost (Independent Contractors)	Median Annual Cost (Agencies)
Transportation	$5,000	$8,480
Facilities/Office Space	$3,000	$7,670
Technology and Software	$2,408	$7,250

EI Time Use Study

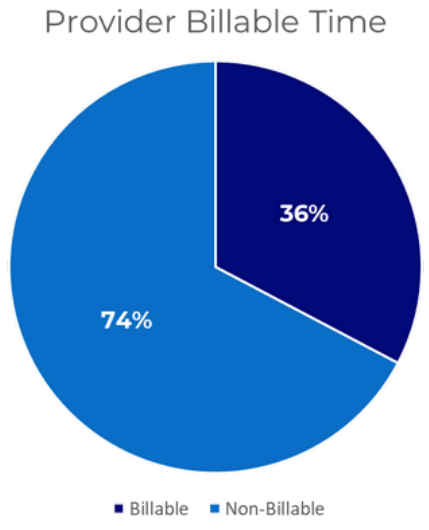
Between February and March 2024, Afton conducted a time use study with EI direct service providers to better understand the time spent on providing services, including billable and non-billable work. Over 200 EI providers tracked their time spent on EI-related activities for ten working days in 15-minute increments, yielding detailed data on the time required to provide EI services.

Time Use Study Key Findings:

- On average, approximately 36% of EI providers' time was billable, meaning time spent working directly with a child or in IFSP development.

Non-Billable Tasks:

- Travel
- Documentation and reporting
- Communicating with families
- Preparation and planning
- General administrative tasks
- Billing
- Time spent on cancelled appointments



Billable Tasks:

- Providing services to children/families
- Conducting evaluation appointments
- Participating in IFSP meetings

- Time spent on travel was about the same for all regions of the state, although caseloads were lower in rural regions.
- The average cancellation/missed appointment rate across the state was 21%.
- There was no significant difference in percentage of billable time between different provider disciplines.
- Interpreters and translators had a higher average percentage of billable time at 47%.
- Self-employed providers had a slightly lower percentage of billable time at 34%, compared to agency providers at 39%.
- Onsite and virtual service providers had a slightly higher proportion of billable time in comparison to offsite service providers, but count sizes were low.

Afton Partners and the Illinois Department of Human Services extend their gratitude to the many families and practitioners who gave their time to participate in this research. The information and data from these engagements played a key role in informing the development of the cost model and payment reform recommendations.