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DIVISION OF EARLY CHILDHOOD

Early Intervention Cost Modeling & Payment Reform: Focus Group Findings

March 2024

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Provider Focus Group Findings

November-December 2023

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Provider focus groups engaged 310 participants across 9 sessions.

Focus groups were attended by a range of provider types:

- Independent providers
- Agency employees
- CFC staff
- Contractors
- Former EI providers
- Advocates

Group	Attendees
Southern IL Service Coordinators and Providers	28
Providers serving low incidence populations (Mainly Developmental Therapists)	45
Speech, Occupational, and Physical Therapists	84
Service Coordinators	45
Translators, Interpreters, and Bilingual providers	19
Open: Any provider or advocate	50
Providers who have left the field	13
Open: Any provider or advocate	18
CFC Managers	8

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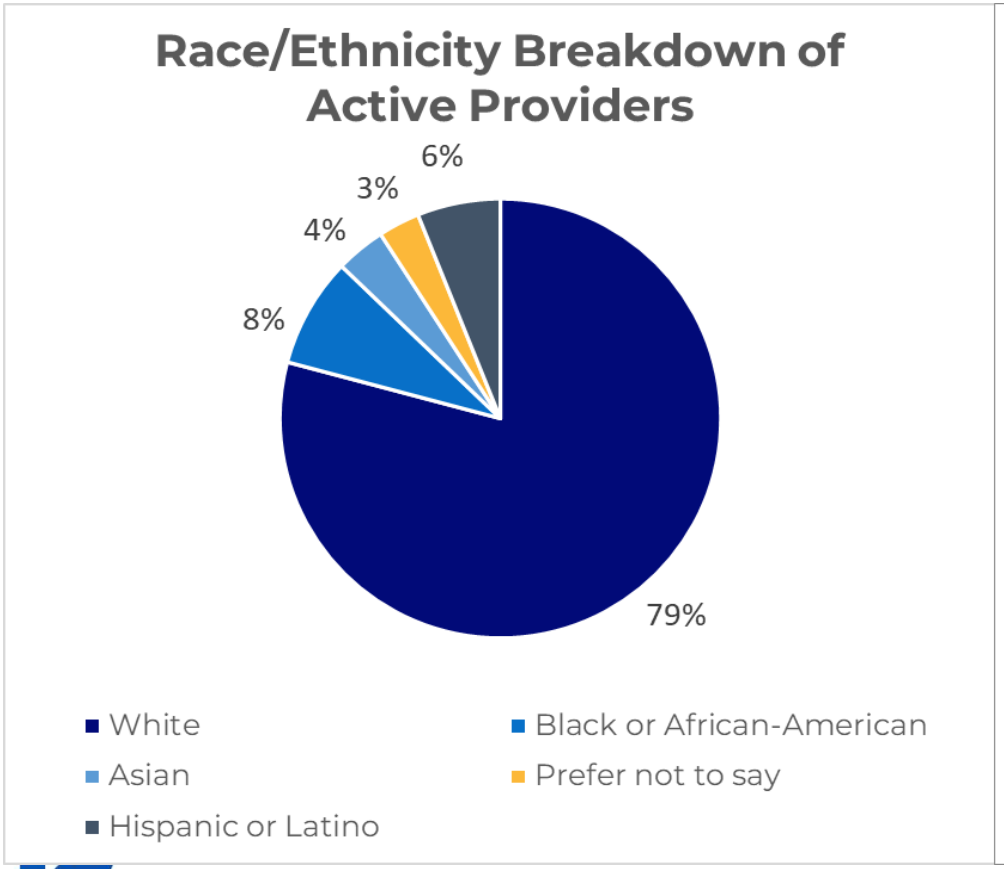
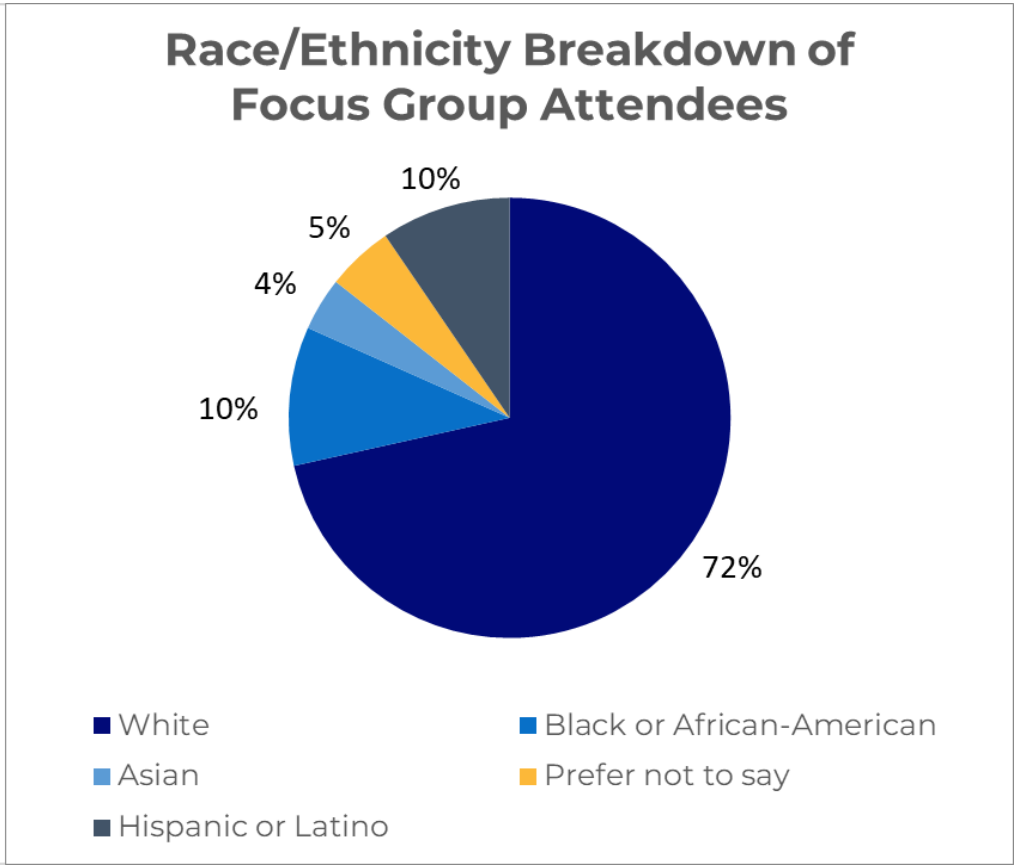
Participants were representative of the current race and ethnicity makeup of the EI provider workforce.





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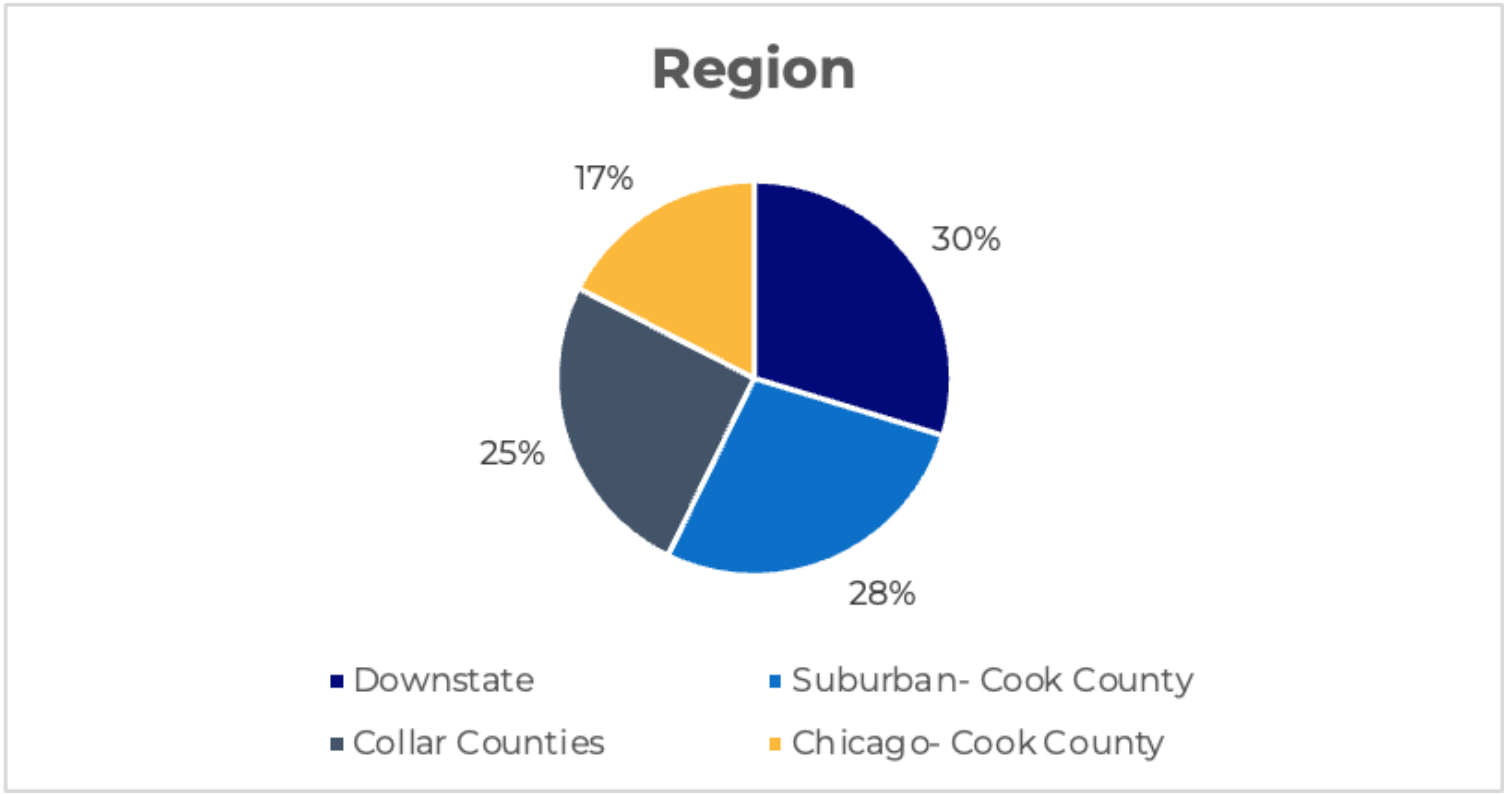
There was approximately equal participation from all four state regions, with every CFC represented.



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EI providers expressed dissatisfaction with low compensation and hidden costs.

- 90% of providers believe that current reimbursement rates are too low.
  - Similar roles in different settings pay higher rates, as does private insurance
- Hidden costs are a prominent concern, specifically travel time, lack of pay for cancellations, and lack of benefits.
- Many EI professionals noted their passion for this work and the flexibility in their schedules as their favorite things about EI.

What we heard:

"If you're a small mom and pop like you and me, people think we can keep the business running but I don't know how much you really can... 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

“Even if we were to get paid fairly, I don’t think it matters... if you don’t get that check on a consistent, confirmed basis... I literally put mortgage bills on a credit card and have to pay 20% in interest because I did not get my expected check.”

-Occupational Therapist, CFC 15

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The burden of administrative tasks weighs heavily on current providers.

- In focus groups, independent providers reported spending significant amounts of time on authorizations and billing:
  - Billing insurance
  - Contacting CBO to understand denials
  - Dealing with inadequate technology
- Providers often receive delayed payments or are not compensated at all.
- Certification is a major barrier and challenge to retention and recruitment.
- Administrative tasks were the 5th most common barrier cited in the 2023 Provider Workforce Survey.

What we heard:

"I love what I do. I'm really good at what I do, but sometimes it takes a toll... I spend maybe 2 hours every week just with CBO, 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

Interpreters, translators and bilingual providers are taking on unpaid work to support non-English speaking families.

- Interpreters and translators are experiencing significant frustration with the EI system, and often feel disrespected and undervalued in comparison with providers.
  - Interpreters expressed challenges with authorizations, specifically noting that they often do not receive authorizations at the same time as providers, causing challenges with compensation.
- Interpreters often become a point of contact for families, spending significant time communicating via text or phone with families, which they cannot bill for.
- Their work is reliant on the provider, so if the provider is delayed or cancels, they do not get compensated.
- Many expressed challenges with the CBO and noted frequent denials.
- Bilingual providers and SCs felt they should be compensated at higher rates due to additional workload.

CFC offices are dealing with difficulty recruiting and retaining Service Coordinators (SCs), increasing the burden across all employees.

- CFC managers noted high turnover for SCs, citing pay-related issues, lengthy hiring processes, and the inability to compete with other organizations offering higher salaries.
  - Starting salaries for SCs were between $33,000 to $42,000 per year.
  - CFC managers believe they would have to offer at least $50,000 to be competitive.
- The shortages place increased pressure on existing staff to meet intake deadlines
  - CFC managers are taking cases and increasing their own caseloads to try to reduce the burden on SCs and reduce turnover.
  - When SCs take vacations, there is no one to cover, which places increased burden on other staff or results in delays.
- Most, but not all, CFCs offer health insurance. Some struggle with high premiums.
  - Benefits and flexible hours are the “selling points” of the job (health insurance, retirement, PTO).

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Service coordinator shortages are negatively affecting both the provider and family experience.

- All service coordinators (SCs) agreed that their existing compensation is too low.
  - The average response for a fair wage was $30/hr
  - Not all SCs receive benefits
- Many are experiencing burnout and do not envision this role as a long-term career
  - They often are unable to take PTO due to lack of coverage
- Unmanageable SC caseloads also affect direct service providers.

What we heard:

“Service coordinators are salaried, but I live at home with my parents and would never be able to move out on my salary. It's not a forever career job.”

– Service Coordinator, CFC 7

"There are times that we provide services that we will never get paid for. Sometimes it's an accident and either an authorization wasn't entered correctly... I don't think it should be the responsibility of the service coordinator alone. I think that's a lot of pressure to be responsible for everybody's pay, essentially. You know, I just don't think it's appropriate to put that on someone who has a giant caseload.”

- Occupational Therapist, Northern Illinois

Current grant structure doesn't provide CFCs with adequate compensation for additional staff and admin costs.

- CFC managers reported that grant amounts do not cover all the staff that is needed to support a CFC, including:
  - Managers
  - Assistant managers
  - Lead coordinators
  - Support staff
- This was the top desired change to CFC funding.

What we heard:

"We're funded so many dollars per service coordinator, which is based on our total active case rate, but there's nothing in there that really identifies [that] every CFC has to have a manager. You have to have one, but there is no separate funding for their salaries. We have to have secretaries. We have to have administrators. Yet there's no separate funding for that. So all of those salaries come out of the service coordinator dollars."

- CFC Manager, Southern IL

Former EI professionals cited various reasons for leaving the field beyond the challenge of low compensation.

- Participants cited inconsistent pay as one of the recurring challenges in EI work, stemming from challenges with maintaining desired caseloads as well as high cancellation rates.
  - Covid exacerbated uncertainties in pay
- Lack of benefits was a barrier to returning to the field,
- Many providers cited expiring credentials as the reason they stopped providing EI services.
  - Process to renew was complicated and unclear
  - Did not receive information or notices that their credentials were expiring
- Some expressed that EI requirements and paperwork became increasingly burdensome over the years.

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Family Focus Group Findings

January-February 2024

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Family focus groups engaged 107 participants across 5 sessions.

- Afton partnered with the following groups to host sessions:
  - Raising Illinois
  - Birth to Five Illinois
  - COFI
- 8 participants emailed their responses to focus group questions or participated in a 1:1 phone interview.

Who attended?

- Approximately 68% of families were currently receiving services, 22% were on a waitlist or experiencing delays, and 9% had recently exited the system.
- 17% of families lived in rural ZIP codes.
- Slightly over 8% of participants participated in a Spanish language session or breakout group.

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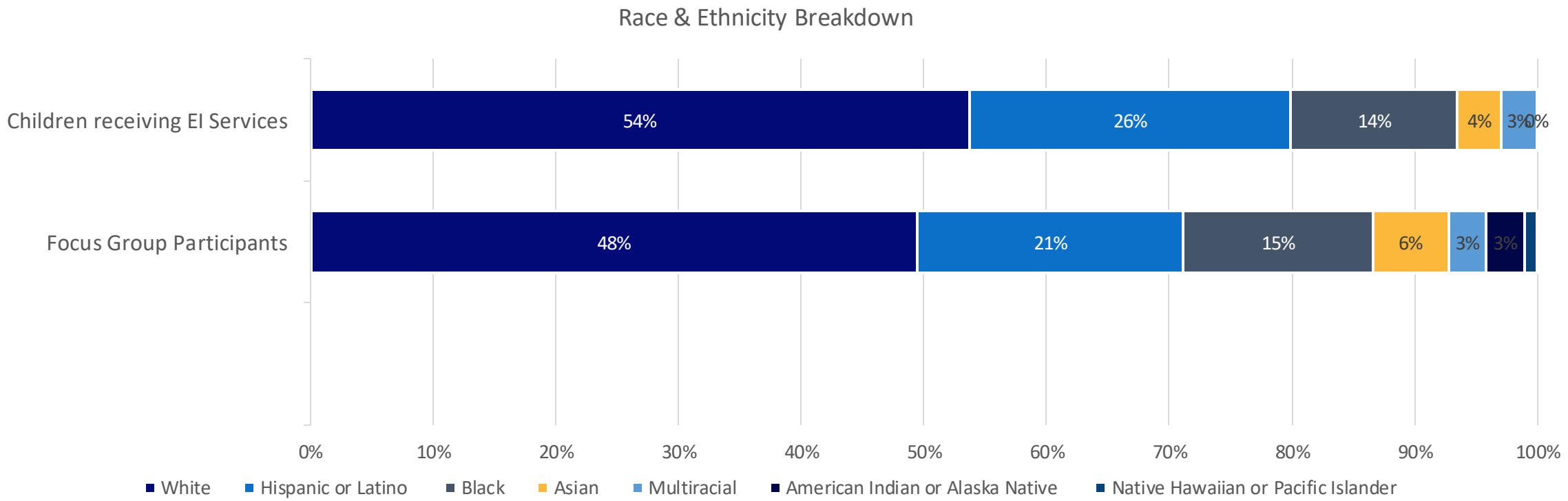
Participants were generally racially and ethnically representative of families in the EI system.



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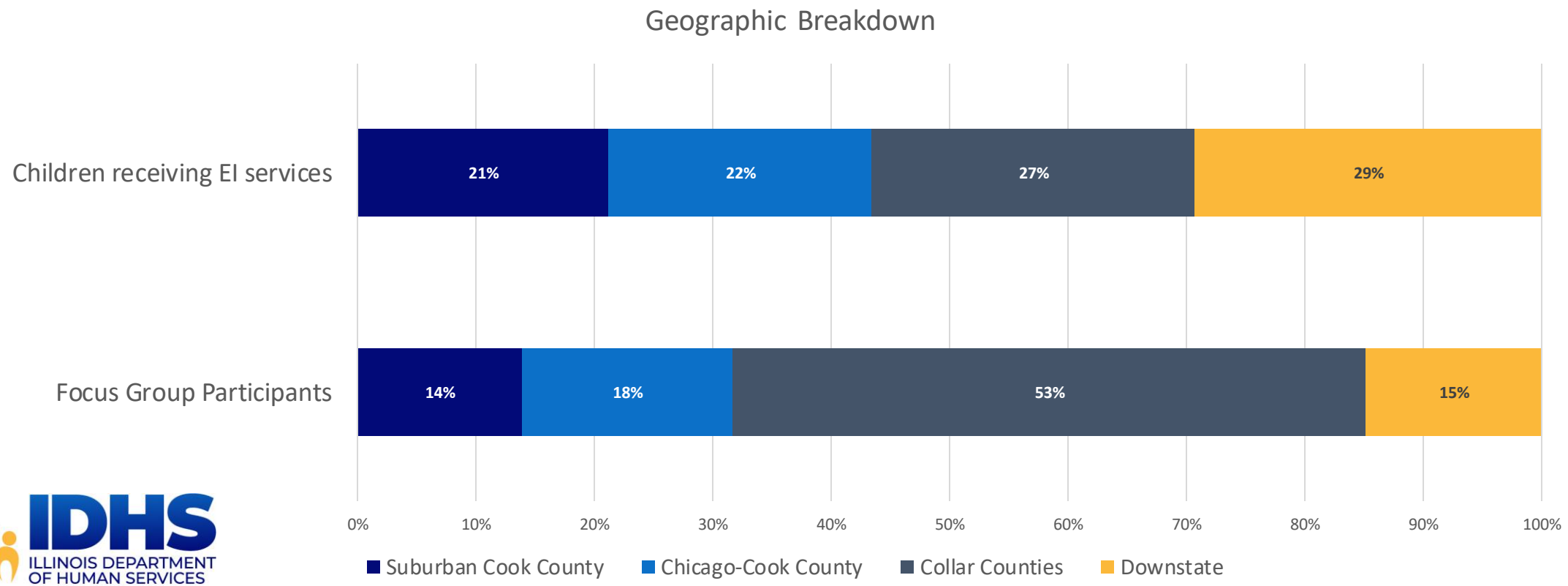
Collar county families were over-represented, while downstate and suburban Cook County families were under-represented.



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Many families lack awareness of Early Intervention, and those who have experience with the system have an advantage.

- Families who had a parent or relative who was involved with EI, social work, or the education system were more familiar with EI.
  - This familiarity meant that they were more likely to push for services for their child.
  - Lack of awareness of EI contributed to longer wait times and service delays.
- Most parents are hearing about EI through their pediatricians, while others heard from friends or family, or their child care provider.
- Many participants felt that there was unmet need for services in their communities due to factors such as lack of awareness or interest.

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What we heard:

"I'm just lucky enough that in my last position I worked alongside EI. If this would have happened to me with my first daughter, I wouldn't have known any better. I would have accepted everything. And I would have trusted them. And I'm thankful that that wasn't the case this time because my daughter would be really, really delayed right now."

— EI Parent, O'Fallen, IL

"It wasn't until I made several calls and left a message to the manager that I finally heard back. That was my first encounter. You just have to be pushy, I guess..."

— EI Parent, Gurnee, IL

Parents and caregivers are frustrated with service delays and long wait times.

- Lack of communication from service coordinators, particularly during wait times, contributed to a negative experience for families dealing with delays.
- Many parents expressed that they had to spend considerable amounts of time to reach coordinators and find therapists.
  - Multiple participants described finding services and being in EI as a full-time job.
- Difficulties in finding available therapists were particularly notable for children and families in rural areas.
- Speech therapy was the service that was noted most frequently for delays.

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What we heard:

"Being a full time, stay at home parent helps because navigating EI services was my full-time job. My child had very mild needs compared to others, and I spent a lot of time asking questions... 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

From a waitlist family: "Because of where we live, EI is the only option, we'd have to drive an hour and a half away to get any private services. Those are the only options. We are eagerly awaiting preschool so he can get services."

- EI Parent, Stephenson County, IL

Families are generally happy with the quality of services and providers.

- Most parents described EI as having a positive impact on their child's development.
  - Parents benefited from seeing their child's growth, receiving guidance, and learning how to better support their child.
- Parents valued the convenience and accessibility of receiving services in their homes and child care programs.
- Participants expressed that their providers were knowledgeable and provided parents with guidance and information.
- Negative experiences were usually attributed to inconsistency in services, lack of professionalism, and unclear or limited communication.
  - These parents emphasized the need for more supervision and noted that some providers seemed inexperienced.

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What we heard:

"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

"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

"We have an OT right now who's very young and inexperienced (she'll tell you that herself). Her schooling was during COVID and she didn't get a lot of hands on [experience]." - EI Parent, O'Fallen, IL

Parents and caregivers prefer in person services and do not feel that LVV meets their needs.

- Many families had experienced LVV services, often because this was their only option.
- Parents and caregivers noted that due to the children's young ages it was difficult to keep them engaged through Zoom.
  - This was particularly a challenge for parents who were caring for multiple young children.
- Some families cancelled services or sought private treatments instead of doing LVV.
- Although most parents preferred in-person services, there were some who liked having a virtual option.

What we heard:

"I was so desperate for an in-person provider as opposed to a LVV that I was willing to commute anywhere for an in-person visit. I didn't care where I had to take my daughter, as long as she got an in-person therapist... I did not have a good experience through Zoom. The personal connection is what I love the most."

– EI Parent

"I really appreciate having the meetings virtually, it's just easier scheduling-wise. Having 5-6 people in person in my home would be a little less comfortable for me."

– EI Parent, Chicago, IL

Relationships with service coordinators (SCs) greatly impact families' EI experience.

- Relationships with SCs were varied.
- Those who had good relationships with SCs mentioned that they were quick to respond to emails and communications and were helpful and timely in finding providers.
- Many participants expressed challenges with their SCs, including difficulty in reaching their coordinator and delayed responses.
    - Parents mentioned that it was clear when their SC had too many cases because it impacted communication.
    - High turnover increased inconsistency in communication for families.
    - Many families noted that they had to follow-up repeatedly with their SCs to ensure progress or find their own therapists.

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What we heard:

"My service coordinator was a nice person, but it was obvious at times that her caseload was too heavy. She was getting our kids mixed up with other kids and there were meetings that should have been scheduled that were missed altogether… If somebody can make those loads a bit lighter just so communication flows better and more easily, that will improve the relationship."

– EI Parent, Peoria, IL

"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 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

Families valued shared experiences and backgrounds with their service providers.

- Many parents commented that having providers who were also moms, especially if they had children in Early Intervention, allowed for deeper connection and support.
- Parents who received services in other languages felt that home-language therapy was important for their child's development.
    - Limited availability of diverse providers is a noted challenge, and many multi-lingual families were not able to receive services in their preferred language.

What we heard:

"No, the people that work in the CFC do not look like me or most of the people in the community. We're mostly Black and Latino/Hispanic and most people at the CFC are white or may identify as white. I think it impacts the experience, because it makes people feel some kind of way. And even most of the service providers are white, not Black... I think it helps, even, if they are culturally competent. I think my service coordinator would identify as white, but she had recently been through the process so I think that's where a lot of empathy came from..."

- EI Grandparent, Chicago suburbs

"We had a physical therapist, but she moved to another state so we no longer have her, but she was Colombian. And I did notice that she clicked more with my son and achieved more, because she was speaking in his language... I feel like it made him much more cooperative with therapy."

– EI Parent, Chicago, IL