



*Trends and Opportunities from
EI SNAPSHOT: Lessons learned from
families, providers, and EI systems*

PRESENTERS: DIANE BEHL AND SARA MENLOVE DOUTRÉ

CONTRIBUTING RESEARCH STAFF: KARL R. WHITE (PI),
JULIANA PLUCINIK, AND HEATHER MARIGER



Today's objectives

Provide an overview of the EI SNAPSHOT study

Share findings from the Family Survey

Highlight trends

Discuss opportunities to address the needs of families



Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities, and Trends (EI SNAPSHOT)

Funded by the Maternal and Child Health Bureau & Oberkotter Foundation

One year study

Broad Scope

- Family Perceptions
- EI Provider & Audiologist Perceptions
- EHDI and Part C Infrastructure
- Deaf Education Personnel Preparation Programs
- Family-to-Family Organizations, Part C Websites



EI SNAPSHOT Family Survey

Method:

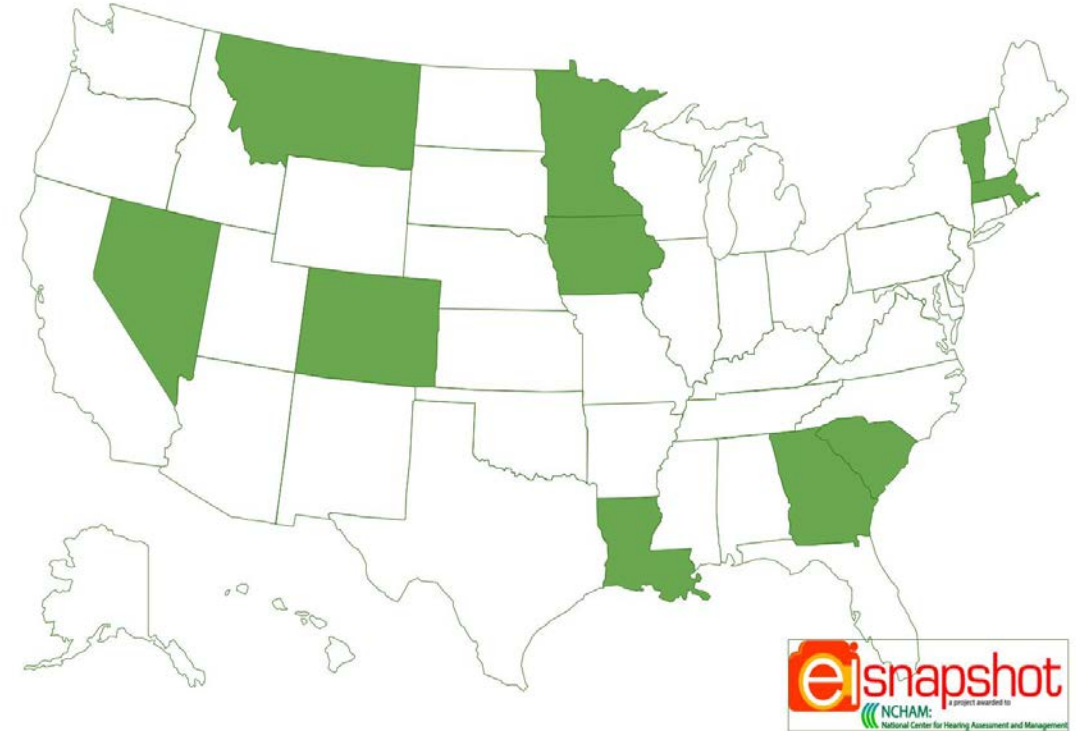
- Families Identified by EHDI/Part C
- 10 diverse states, 318 respondents (10%)
- Paper and online options

Child Characteristics:

- Children ages 2-6 years
- Range of HL from unilateral to bilateral profound loss;
- Primarily speech/language delays
&/or other diverse developmental delays/disabilities

Family Characteristics:

- 10% high school or less, 63% some college/bachelors, 27% masters or doctorate
- 48% with public insurance, 70% private (not exclusive)
- 9% Latino ethnicity; 83% Caucasian, 12% African American, 11% other race



snapshot family survey on early intervention services

Please help us learn about your family's experience with early Intervention (EI) services—those therapies and supports received for children who are between birth and 3 years of age. Though your child may be much older, we want to get your input about these early years.

- A parent or primary caregiver who knows about the services you received should complete this survey.
- Your responses will give states a better idea about how to improve programs, so they can better serve children and families.
- Please provide honest feedback. The survey does not collect sensitive information, and no identifiable information about your family or child will be shared.
- This survey takes about 15 minutes to complete. Simply mail the survey back in the enclosed envelope, or complete the survey online by going to eisnapshot.org.



about your child

1 When was your child born?
Month Year

2 When was your child first diagnosed as D/HH?
Month Year

3 What is their current, unaided degree of hearing loss? *(check all that apply)*

	None	Mild	Moderate	Moderate/Severe	Severe	Profound
Right ear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Left ear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4 Does your child currently have any of the following? *(check all that apply)*

	None	Mild	Moderate	Severe
Speech/language development delay	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motor delays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social/emotional delays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autism diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive delays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vision problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other <i>(please specify)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

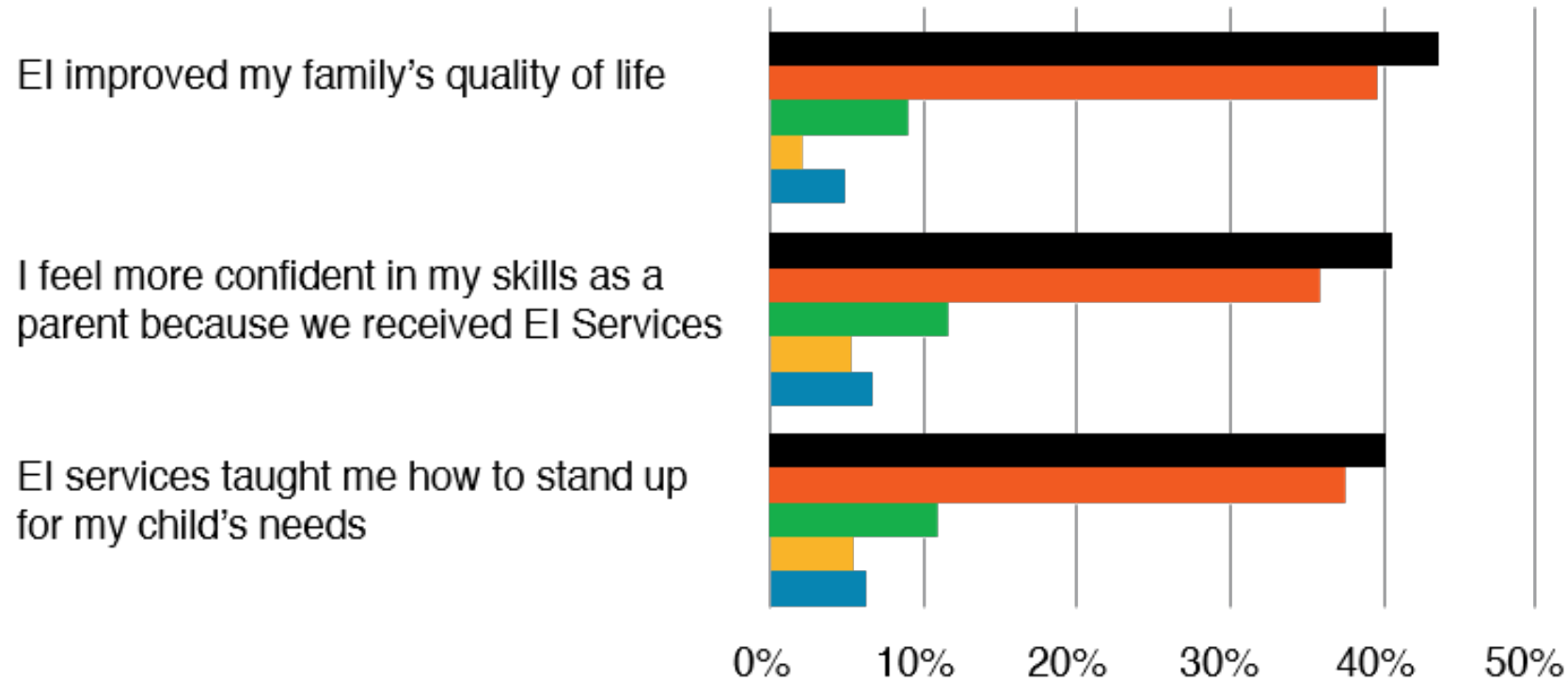


Age of Diagnosis in Relation to Age Beginning of EI

Percent that Began Early Intervention

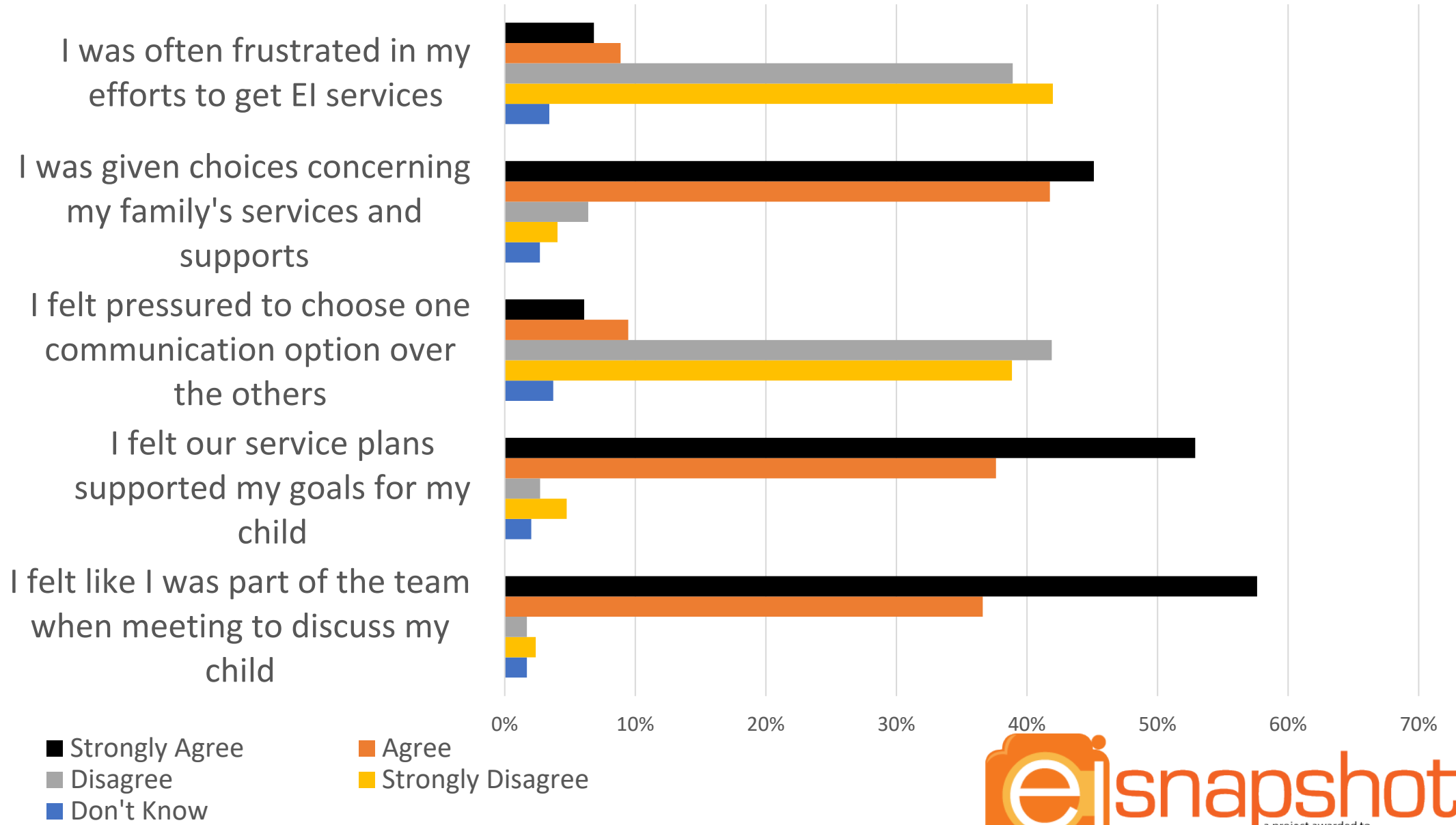
Age at Diagnosis	By 6 months	Between 6 and 12 months	Between 13 and 24 months	Between 25 and 36 months
0-3 months (n=192)	72%	18%	8%	2%
4-6 months (n=21)	57%	33%	10%	0%
7-12 months (n=9)	22%	67%	11%	0%
13-24 months (n=24)	21%	25%	37%	17%

Family Report of EI Impact on their Family



■ Strongly Agree ■ Agree ■ Disagree ■ Strongly Disagree ■ Don't Know

EI Service Experiences



Family Report of Child's Primary Communication Modality

Communication Modality	Percentage of Families
Listening and Spoken Language only	49%
Sign Language only	3%
Mostly Listening and Spoken Language (supplemented by sign language, cued speech, or other)	17%
Mostly Sign Language (supplemented by listening and spoken language, cued speech, or other)	3%
Mostly Cued Speech (supplemented by listening and spoken language, or other)	12%
Equal Parts Sign Language and Listening and Spoken Language (including total communication)	14%
Other	1%

Family Report on Quality of Information Provided About Communication Choices Upon Diagnosis

Communication Modality	Excellent	Good	Fair	Poor
Listening and Spoken Language	46%	30%	10%	14%
Sign Language	38%	29%	17%	17%
Total Communication	36%	28%	15%	21%
Cued Speech	22%	21%	25%	32%

Poll Question: Which do you think is the most difficult for families to access?

- a. Opportunities to interact with adults who are deaf or hard of hearing
- b. Meeting with other families with children who are deaf or hard of hearing
- c. Genetic counseling
- d. Sign language instruction
- e. Assistive hearing devices (hearing aids, cochlear implants, etc.)
- f. Family Training
- g. Auditory/verbal or listening and spoken language therapy

Family Report of Services Needed and Problems Accessing Services

Service	We needed this and received it with no problems	We needed this but had problems getting it
Opportunities to interact with adults who are deaf or hard of hearing	22%	23%
Meeting with other families with children who are deaf or hard of hearing	34%	25%
Genetic counseling	35%	15%
Sign language instruction	34%	15%
Speech/language therapy	71%	15%
Assistive hearing devices (hearing aids, cochlear implants, etc.)	75%	11%
Family Training	40%	11%
Auditory/verbal or listening and spoken language therapy	55%	14%

Poll question: How would you rate the degree of financial burden most families face due to hearing related needs?

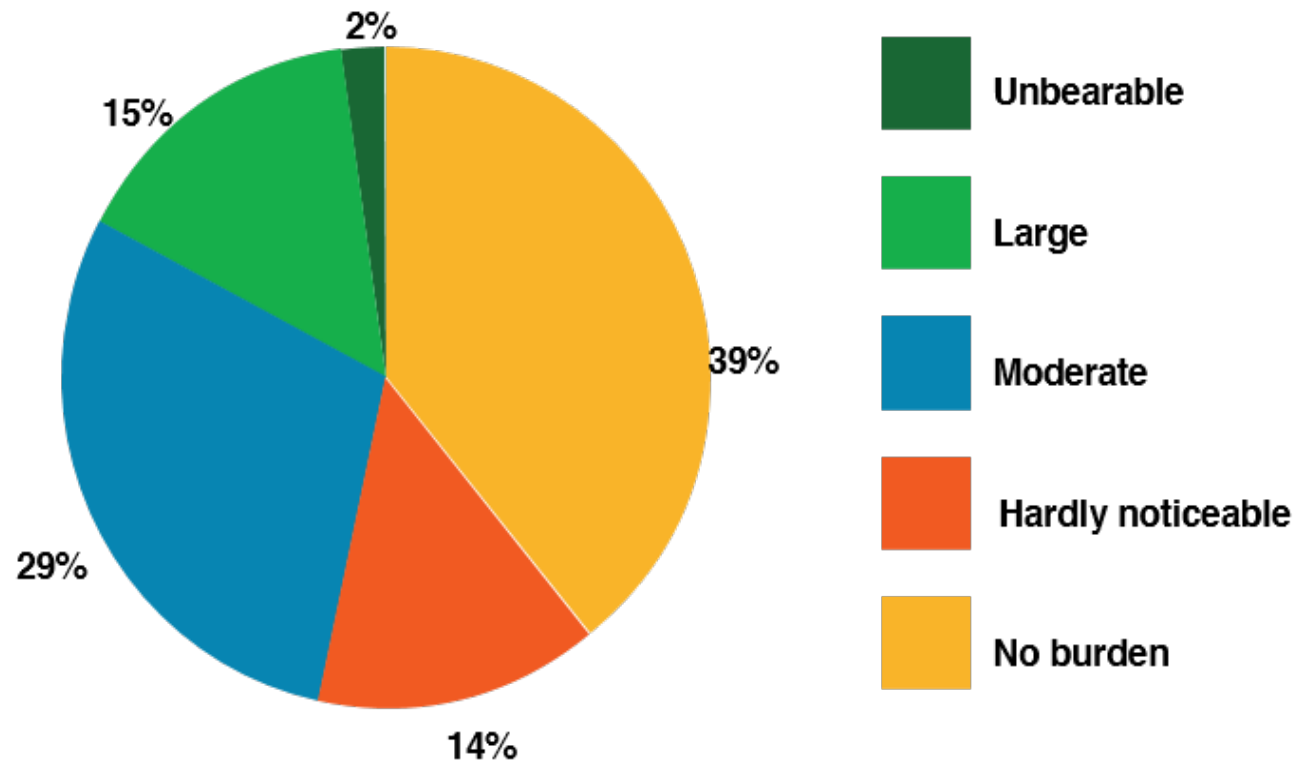
Large

Moderate

Hardly noticeable

Family Report of Perceived Financial Burdens Associated with Hearing Related Needs

Chart 7. Family Report of Perceived Financial Burdens Associated with Hearing Related Needs



“Our insurance does not cover hearing devices and the copayment for his audiologist is pretty high. I’m glad we could afford it, but at the time we struggled to pay it.”

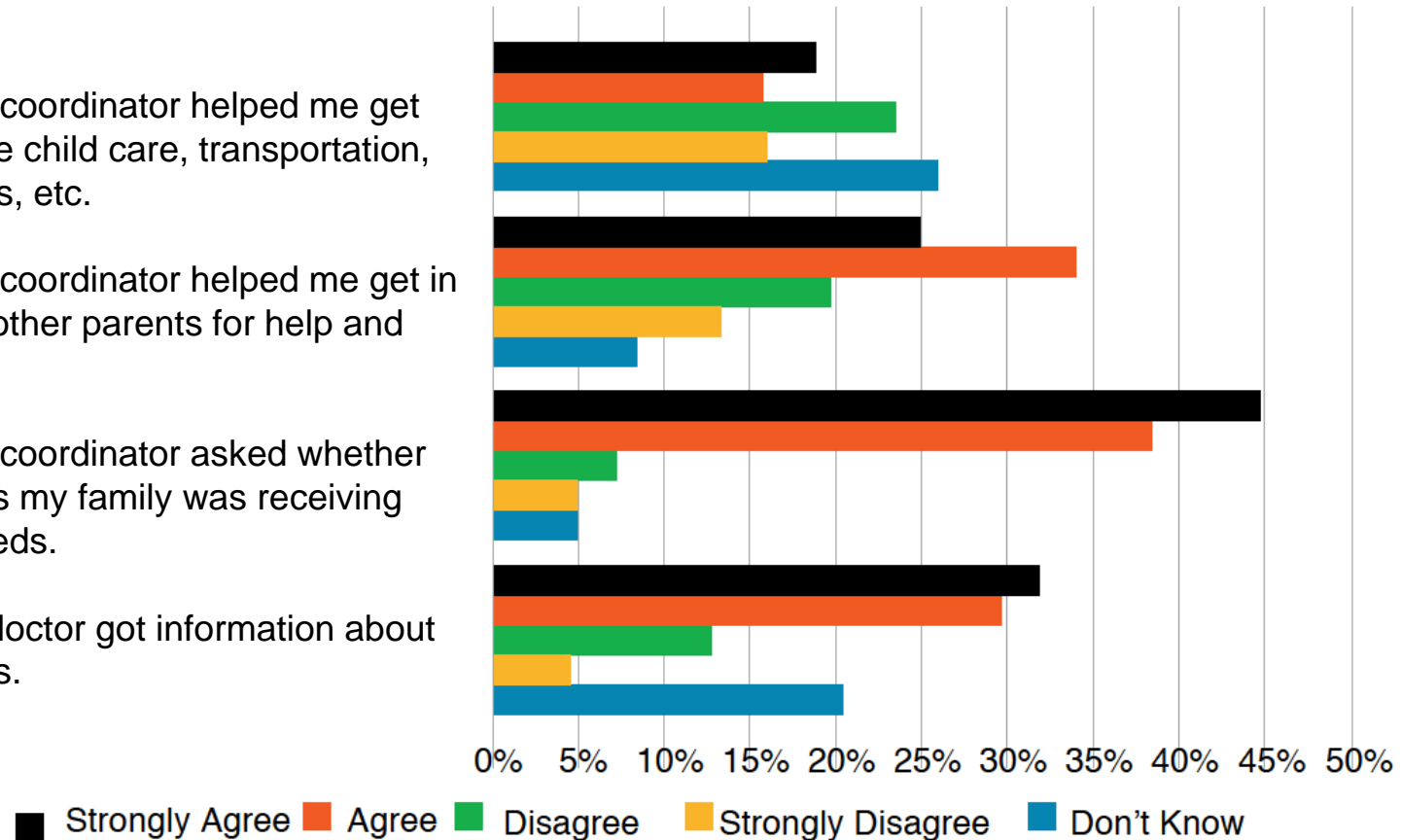
Family Report of Service Coordination Help in Accessing Services

My service coordinator helped me get services like child care, transportation, food stamps, etc.

My service coordinator helped me get in touch with other parents for help and support.

My service coordinator asked whether the services my family was receiving met our needs.

My child's doctor got information about our services.



Poll question: How would you rate the quality of information provided to families about family-to-family organizations (PTI's, F2FHIC's, H&V's) in your state?

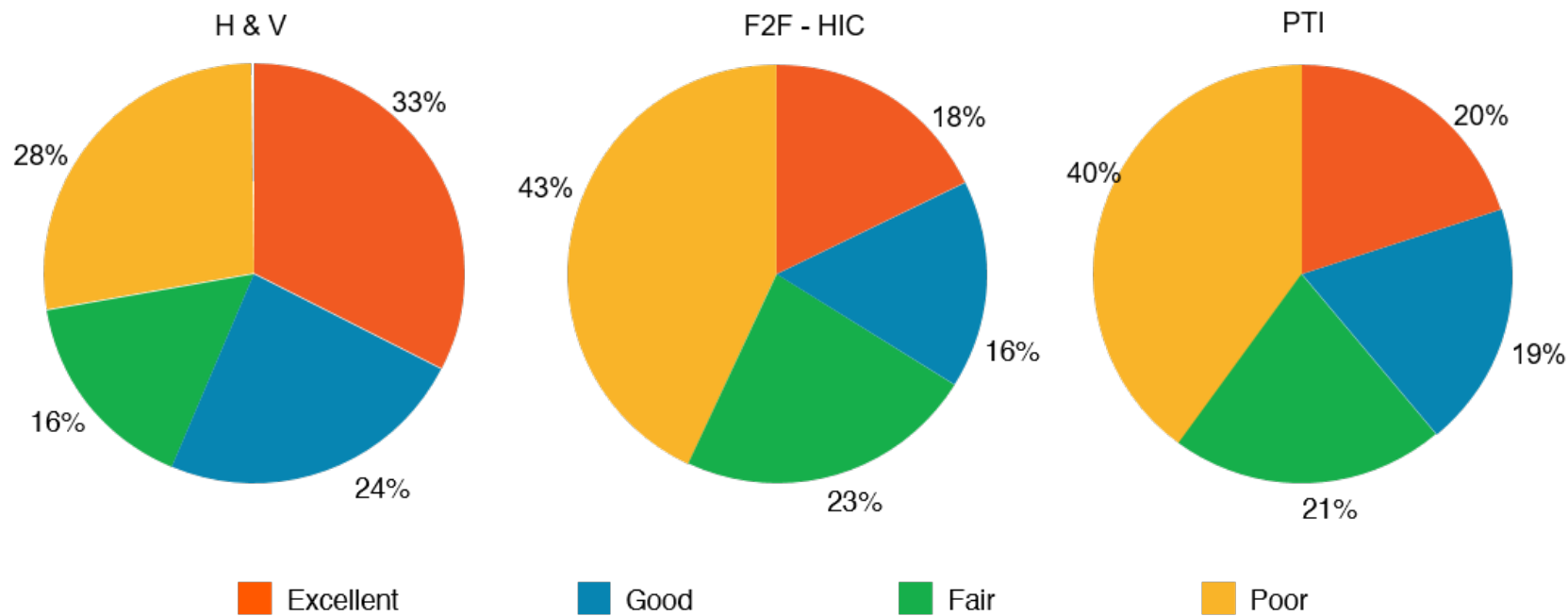
Excellent

Good

Fair

Poor

Family Report on the Quality of Information Received about Family Organizations



Note: H&V - Hands & Voices; F2F-HIC - Family-to-Family Health Information Center; PTI - Parent Training Information Center;

Open-ended Family Comments

Advice:

1. Don't wait (for services, hearing aids, being involved)
2. Ask for what you need
3. Use all resources (e.g. Other parents & services)
4. Advocate

Barriers:

1. Insurance troubles (don't cover services, high deductibles, trouble accessing)
2. Travel to Appointments (distance)
3. Struggling with cost
4. Unaware of Services
5. Wish I had known... (e.g. I should learn ASL now, get second opinions, services in general)

"(This therapy) was never offered, I wish that I would have educated myself more. I was just going off what I was told through the program he was in."

"I had very difficult time trying to get speech pathologist to come to my house, once my child's cochlear implant was placed. Months went by and I needed to do a lot of work on my own. El had trouble with the process. His situation changed so I needed a specialist, had to enroll in other programs."

(It was) A lot all at once. Confusing/overwhelming. Then and now still feel my child isn't getting everything he needs to improve in every area, like pulling teeth. Great all the way up until he reached school age and it's like he lost everything because of technicalities or state guidelines.



Trends and Opportunities

Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities, and Trends

- **Trends:** Consistent themes identified across methodologies and stakeholders.
- **Opportunities:** Potential ways that EHDI, Part C, family organizations, and other stakeholders can work together to improve the EI system.



Trends and Opportunities

Trends:

- Families report that it's easy to get into EI and that EI improved their child's life (90%+).
- EI Providers are positive about their jobs and serving children.

Opportunity:

- Increase the number of children who receive EI by 6 months (71%).



Trends and Opportunities

Trends:

- Almost one third of families reported arranging for supplemental private EI services.
- Almost two thirds of audiologists received requests from parents seeking supplemental EI services.
- Very few personnel preparation programs for teachers of the deaf provide coursework or practical experience focused on EI or early childhood education.

Opportunity :

- Increase the number of providers who are prepared to work with children who are DHH in EI.



Trends and Opportunities

Trends:



- Roughly 40% of families reported that their medical home did not receive information about their EI services.
- About ¼ of service coordinators reported that coordination with the medical home providers and family support organizations “needs more work.”
- Only 32% of audiologists reported receiving copies of their clients IFSP’s; only 13% reported that they participated in an IFSP meeting.

Opportunity:

Provide better training to Part C service coordinators and audiologists on medical homes and how to effectively coordinate among service providers.



Trends and Opportunities

Trends:

- About two-thirds of families reported little to no information provided about federally funded general disability focused family-to-family support organizations, and 44% received little to no information about DHH-specific groups like Hands & Voices.
- A third to half of EI providers reported inadequate knowledge of family-to-family support organizations.
- Family-to-family organizations (PTIs and F2FHICs) do not know about EHDI and the resources available through EHDI (<10%).
- Fewer than half of Part C websites – an initial source of information for families – have information about family-to-family support organizations.

Opportunity:

- Create new partnerships between EHDI and family-to-family support organizations.



Trends and Opportunities

Trends:

- The majority of families reported little or no opportunities to meet with other parents of children who are DHH.
- 25% of parents reported that they wanted to interact with deaf adults and other families of children who are DHH but had problems getting that service.

Opportunity:

- Create more opportunities for parents to interact with other parents of children who are DHH and adults who are DHH.



Trends and Opportunities

Trends:

- Almost half of families reported that their child's hearing-related needs posed a moderate to unbearable financial burden.
- About two thirds of families reported that their service coordinator had not helped them get non-therapeutic services such as child care or food stamps.
- 18% of EI providers reported that they never helped families get services like child care, transportation, respite care, or food stamps. Only 22% of EI providers reported they always helped families connect to these community services.

Opportunity:

- Ensure that service coordination addresses all of the needs of the family and provides community resources and connections to available support.



Trends and Opportunities

Trends:

- Good working relationships and formal referral processes to support families exist in most states between EHDI and Part C EI.
- Federal and state laws can be barriers to sharing data to improve referral processes.
- A few states are able to share child-specific data across agencies but most are not.

Opportunity:

- Determine and create ways to share the most important data on kids and services between EHDI and Part C.

H **e** **a** **l** **t**
I **n** **s** **u** **r** **a** **n** **c** **e**
P **o** **r** **t** **a** **b** **i** **l** **i** **t** **y**
A **c** **c** **o** **u** **n** **t** **a** **b** **i** **l** **i** **t** **y**
A **c** **t**



 **e** **s** **n** **a** **p** **s** **h** **o** **t**
 **NCHAM:** a project awarded to
National Center for Hearing Assessment and Management

Trends and Opportunities

Trends:

- Part C early intervention and EHDI programs are in the same state agency or department in only 43% of states.
- Referral systems vary across states. In some states EHDI programs refer children directly to Part C and in others audiologists are responsible for making referrals.
- Eligibility criteria vary across states and across programs within states.

Opportunity:

- Explore the affect of differences in state administration and adopt practices that show the best outcomes for children.



Study Limitations & Next Steps

Family survey return rate relatively low (10%)

Greater SES, cultural diversity needed

Difficult to determine services provided via Part C and broader EI

Plan to “drill down” to learn more

Analyze very rich information from open-ended comments

Want to learn more about EI SNAPSHOT?



A digital copy of our final report along with supporting documents and protocols is available online:

<http://www.infanthearing.org/ei-snapshot/>

A hard copy of the report will be mailed to EHDI, Part C, and Family organizations soon.



EI Snapshot Final Report

These results of these analyses can be found in the [final report \[PDF\]](#)

Appendices

In addition to the [final report \[PDF\]](#), this project generated the development of a wide range of support documents and presentations. These materials are available below, listed by their categorization in the final report.

- [Appendix A: Categorizations of Family Survey Open Ended Questions \[PDF\]](#)
- [Appendix B: Categorization of EI Provider Survey Open-Ended Questions \[PDF\]](#)
- [Appendix C: Categorization of Audiologist Survey Open-ended Questions \[PDF\]](#)
- [Appendix D: Categorizations of Graduate Student Survey Responses to Open Ended Questions \[PDF\]](#)

Bibliography

- [EI SNAPSHOT Bibliography \[PDF\]](#)

EI SNAPSHOT Tools and Presentations

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In the spirit of collaboration, NCHAM invites others using these tools or those conducting similar research to contact [Karl White](#).

Family Perceptions, Needs, and Choices

- [EI SNAPSHOT Parent Survey – English \[PDF\]](#)
- [EI SNAPSHOT Parent Survey – Spanish \[PDF\]](#)
- [2017 EHDI Presentation - EI Snapshot: Family Perceptions on Early Intervention for Children Who Are DHH \[PDF\]](#)

EI Service Provider and Audiology Perceptions

Preview from: <http://www.infanthearing.org/ei-snapshot/>



Thank you!

Please contact us for further information.

Diane Behl: diane.behl@usu.edu

Sara Doutre: saradoutre@gmail.com

Karl White: karl.white@usu.edu

<http://www.infanthearing.org/ei-snapshot/>

