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# ***El Snapshot: Family Perceptions on Early Intervention for Children Who Are DHH***

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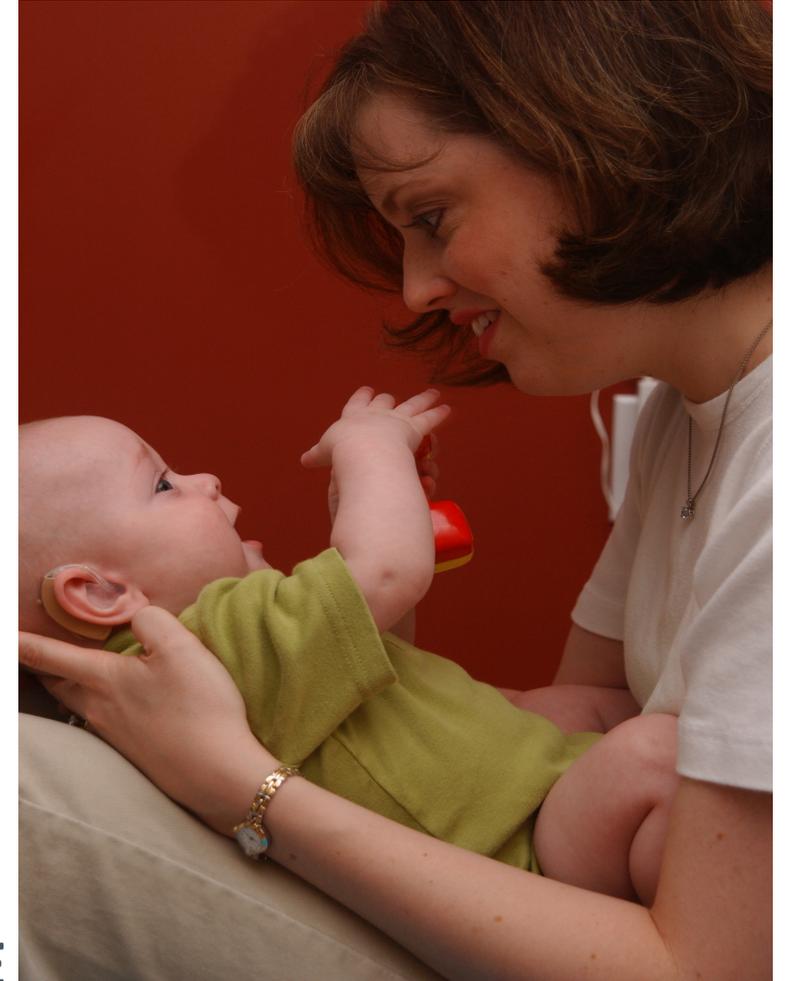
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# Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities, and Trends (EI SNAPSHOT)

- › Funded by the Maternal and Child Health Bureau & Oberkotter Foundation
- › One year study
- › Family perceptions
- › EI Provider & Audiologist Perceptions
- › EHDI and Part C Infrastructure
- › Deaf Ed. Personnel Prep. Programs
- › Family access to Public Info.

# EI SNAPSHOT Parent Survey

## Method:

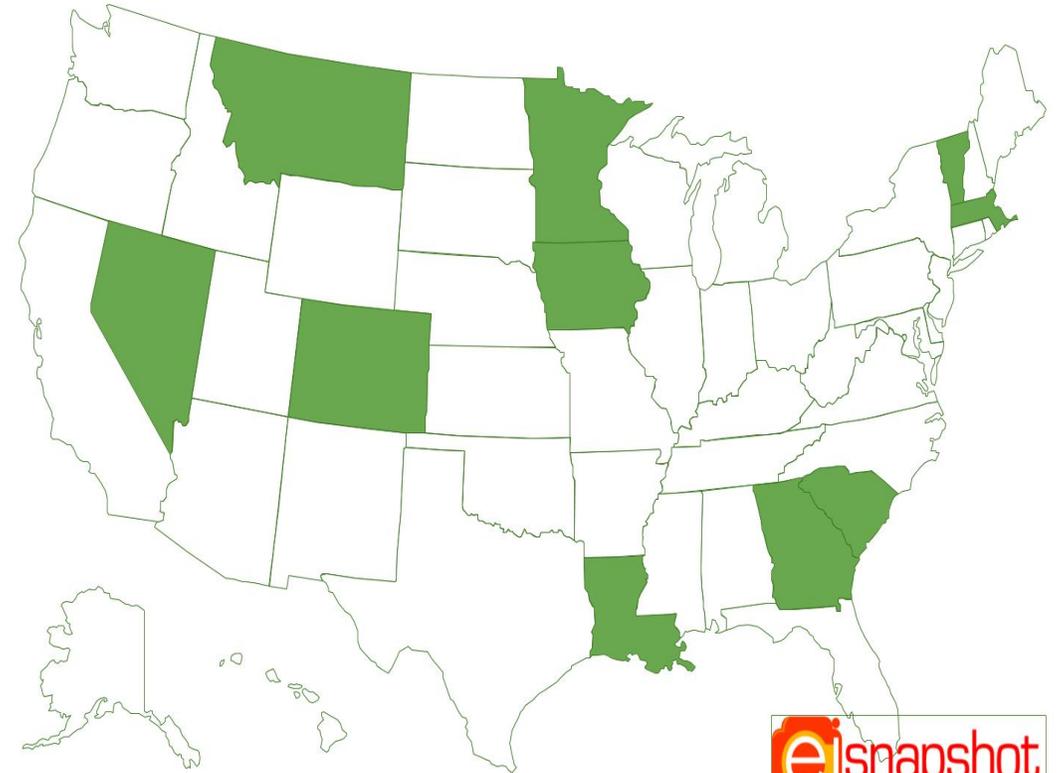
- Families Identified by EHDI/Part C
- 10 diverse states, 318 respondents (10%)
- Paper and online options

## 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 doctorat
- 48% with public insurance, 70% private (not exclusive)
- 9% Latino ethnicity; 83% Caucasian, 12% African American, 11% other race



# eisnapshot 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](http://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"/>					
Left ear	<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"/>

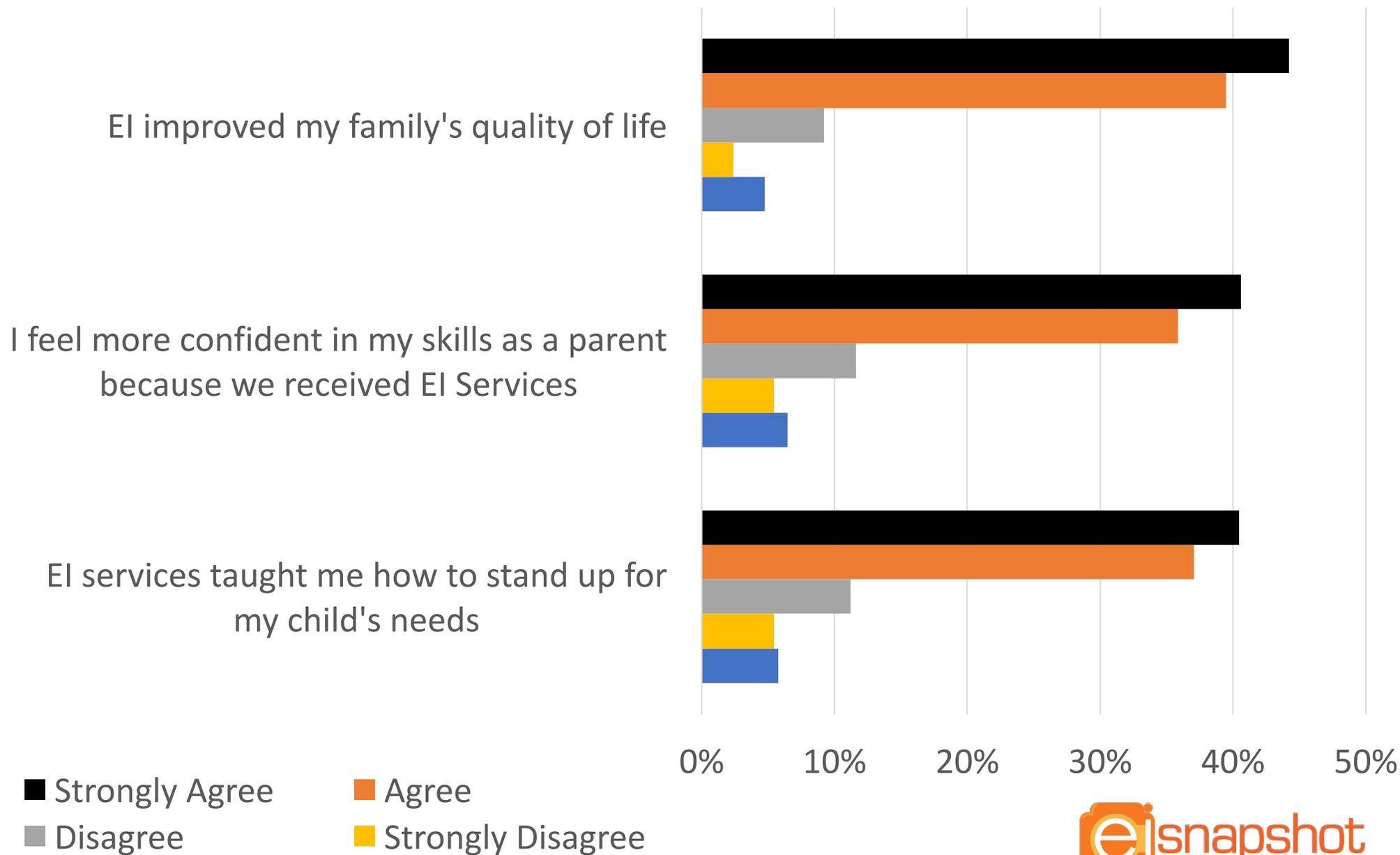
# How many families were connected by 6 months?

Of the 216 diagnosed by age 3 months:

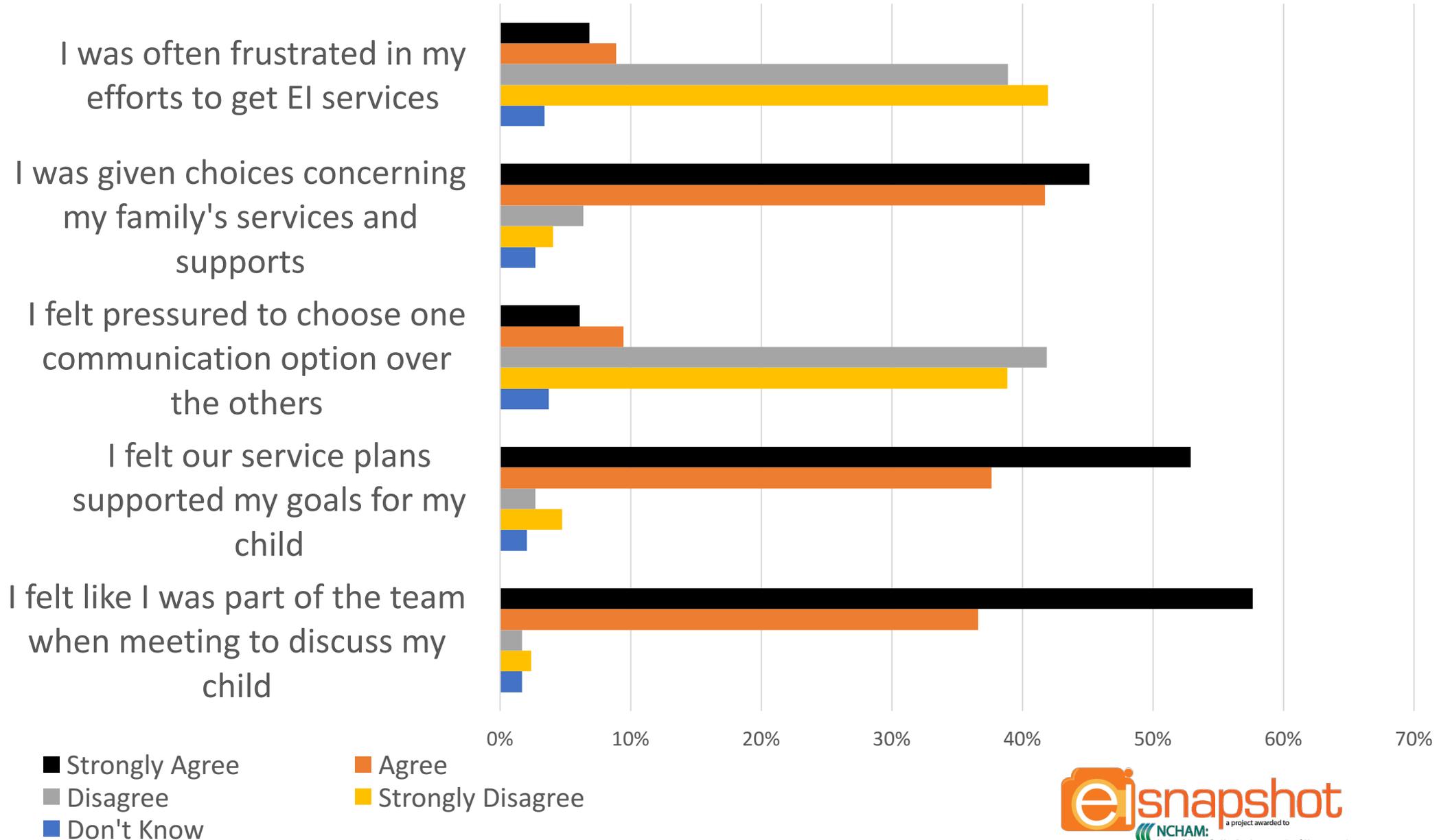
- 71% received EI between 0-5 months
- 18% received EI by 6-12 months
- 11% received EI after 13 months of age



# EI Impact on Family



# EI Service Experiences



## Family open-ended comments

- › *(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.*
- › *Early intervention was the best thing that could have happened for our son. He would never be where he is now without them. They gave us hope and pushed through goals that we wanted our son to accomplish! Things that we never thought he could do...they got him to do them!*

# Services Needed and Problems Accessing

	We needed this and received it with no problems	We needed this but had problems getting it
Genetic counseling	35%	15%
Sign language instruction	33%	15%
Speech/language therapy	71%	15%
Assistive hearing devices (hearing aids, cochlear implants, etc.)	74%	11%
Family training	40%	11%
Auditory/verbal or listening and spoken language therapy	54%	14%
Opportunities to interact with adults who are deaf or hard of hearing	21%	23%
Meeting with other families with children who are D/HH	33%	26%

## FAMILY OPEN-ENDED

### 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

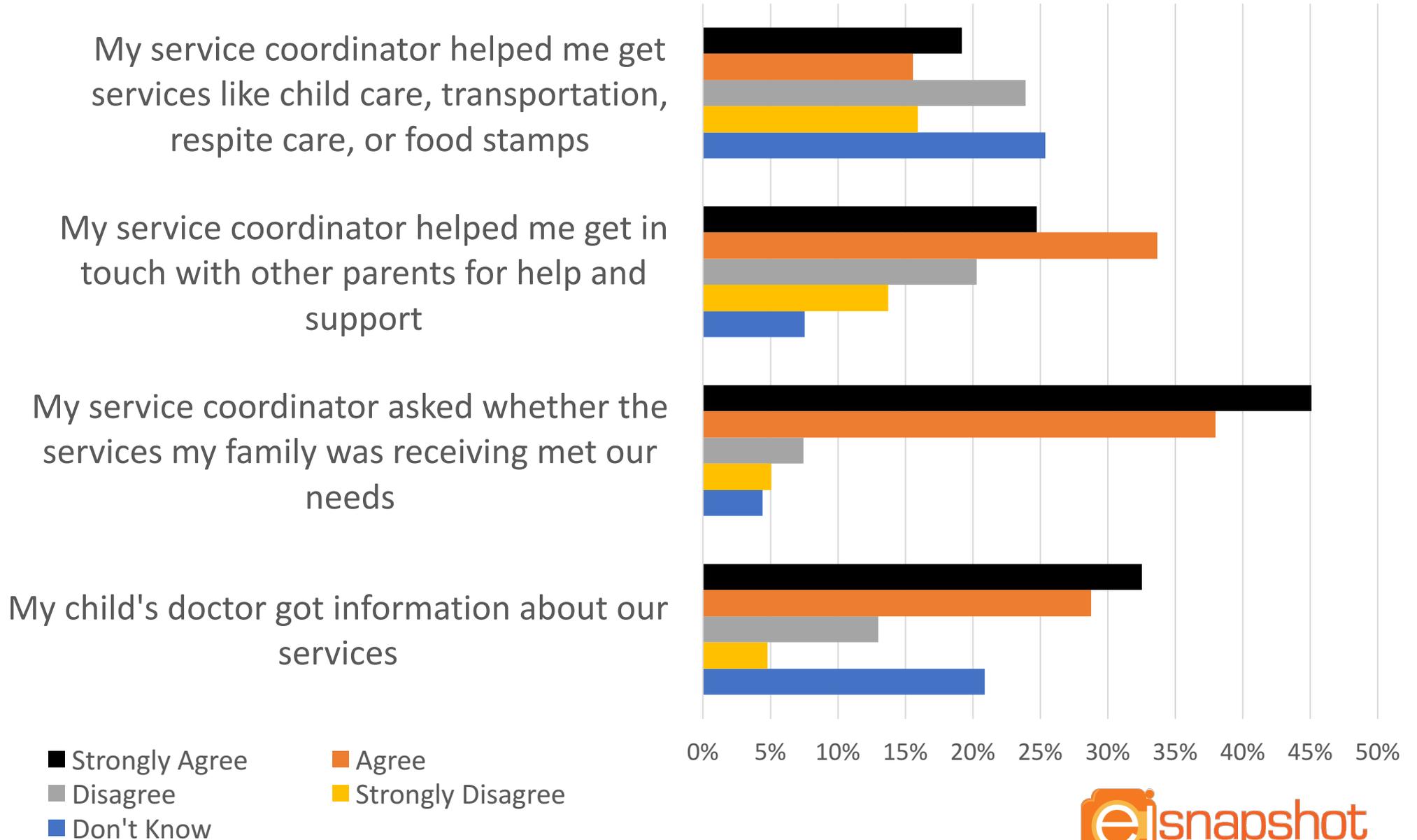
#### Barriers:

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."*

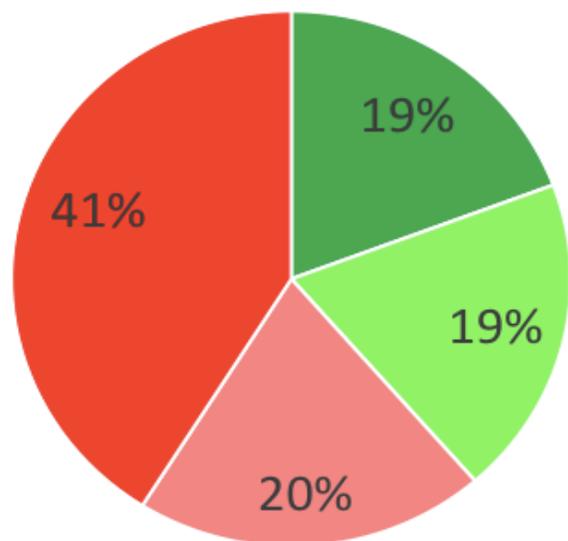
*"I had very difficult time trying to get speech pathologist to come to my house, once my child's cochlear implant was placed. Months went by and I needed to do a lot of work on my own. EI had trouble with the process. His situation changed so I needed a specialist, had to enroll in other programs."*

# EI Service Coordination Experiences

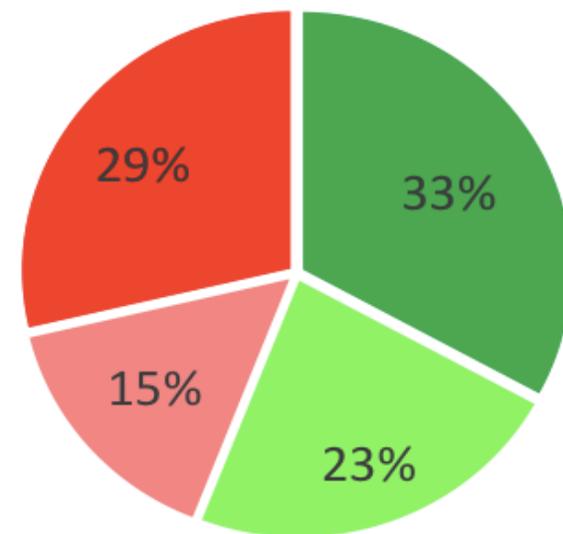


# Rate the quality of information provided to you about:

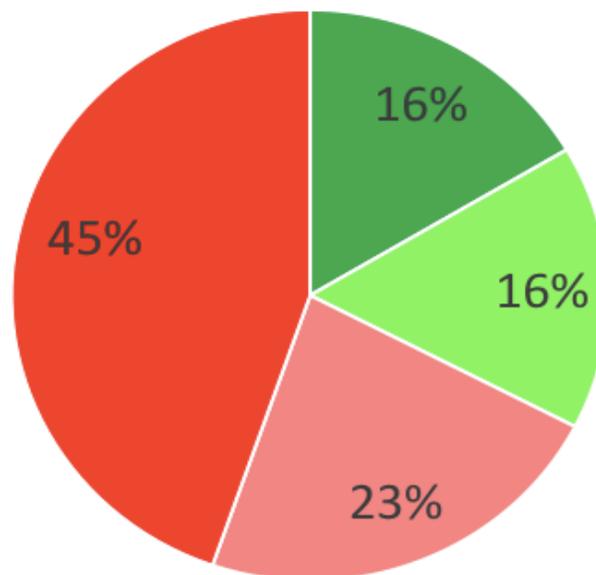
PTI



Hands & Voices

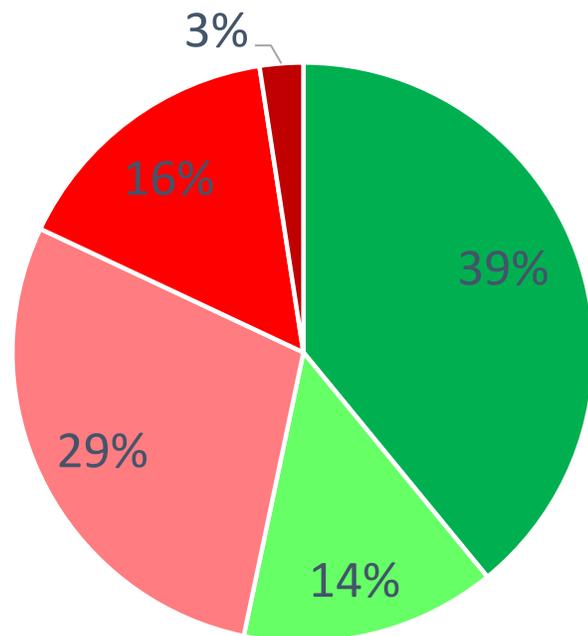


F2F HIC



■ Excellent ■ Good ■ Fair ■ Poor

# Extent to which hearing related needs (including therapies) are a Financial Burden:



- No burden
- Hardly noticeable
- Moderate
- Large
- Unbearable

*“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.”*

# Conclusions: Primary Challenges



- Understanding role of Service Coordinator to receive comprehensive, coordinated services
- Family support: Getting connected with:
  - Family support organizations
  - Connecting with other families of children who are DHH
  - Connecting with DHH adult role models/mentors
- Financial burdens

# Potential Impacts from the state systems level

- › Part C Service coordination models vary
- › Part C and EHDI often in different departments
- › State data bases don't contain needed info & difficult to share
- › State level Family Organizations on limited budgets
- › DHH Adult Role Models, Guide By Your Side programs too limited



# Study Limitations & Next Steps

Return rate (10%) relatively low

Having family email addresses may work better

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

Questions?  
Comments?

Thank you!

Please stay for Provider Survey Report