



The use of El SNAPSHOT for state EHDI – El systems building: Applications from the Field

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Today's objectives

✓ Learn key findings from the EI SNAPSHOT study

✓ Identify tools to guide systems building

✓ Examples from state EHDI programs





Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities, and Trends (El SNAPSHOT) 2016-2017 Funding from Maternal and Child Health Bureau & Oberkotter Foundation

Methodologies:

- Family Perceptions Survey (n=321)
- El Provider & Audiologist Perceptions Surveys (n=424/327)
- EHDI and Part C Infrastructure Interviews (33 states)
- Family-to-Family Organizations, Part C Websites Review, Interviews (n=79) Deaf Education Personnel Preparation Programs Review, Interviews (n=72)



Explored these important questions:

- ✓ How are families connecting with EI?
- ✓ What services are families receiving & are they meeting their needs?
- ✓ What about connections to other families, deaf mentors?
- ✓ What are characteristics, challenges of El providers & audiologists?
- ✓ How do families access information web-based, family organizations?
- ✓ What are state policies that support or hinder access to EL & coordination?



"Take-home messages" from the study



Trends: Consistent themes across methodologies & stakeholders.



Opportunities: Working together to improve the El system.



Need for specialized services







- Apx 1/3 of families arranged for supplemental EI services
- Apx 2/3 of audiologists get parent requests for supplemental El services
- Apx. ½ of El providers rate their training in DHH as inadequate/very inad.
- Few teachers of the deaf personnel prep programs provide coursework or practical experience focused on EI/early childhood education

Opportunities:



- Support expansion of Deaf Education to comprehensively cover El
- Increase T/TA among El staff, audiologists, EHDI
- Increase access to information about supplemental El services via partners

Need for improved coordination with audiologists, medical homes



- Apx 40% of families reported their medical home did not receive information about their El services
- Apx 43% of SC's said coordination with the medical home providers and family support organizations "needs more work"
- Only 32% of audiologists received any copies of IFSP's; 13% participated in an IFSP meeting



Opportunities:

 Improve training of SC's & audiologists re: coordination, teaming



Improve family-to-family support connections





Trends:

- Apx. 66% families reported little/no information re: general disability family-to-family support organizations;
- 44% received little to no information about DHH-specific groups like Hands & Voices.
- 1/3-1/2 EI providers reported inadequate knowledge of family-to-family support organizations.
- < 10% of Family-to-family organizations (PTIs and F2FHICs) know about EHDI resources.</p>
- Fewer than ½ of Part C websites contain information about family-to-family support organizations

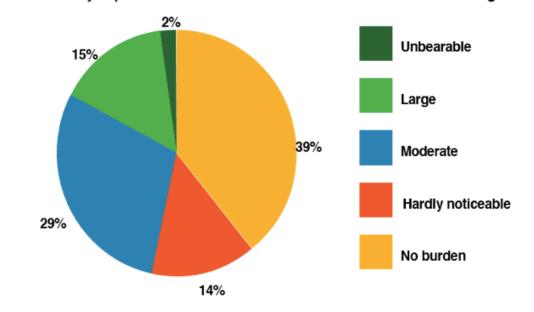


Opportunities:

- Improve access to information on Part C, EHDI websites
- Create more opportunities for parents to interact 1:1 with one another & adults who are DHH.
- Increase info available on Part C, EHDI websites
- Foster coordination among family org's
- Share tools such as "Just in Time" NCHAM resource



Help with financial supports needed





Trends:

- Apx. 1/2 of families reported hearing-related needs posed a moderate unbearable financial burden.
- Apx 2/3 reported their SC had not helped them get services such as child care or food stamps.
- 22% of EI providers reported they always helped families get services like child care, transportation, respite care, or food stamps; 18% of EI providers reported that they never helped with this.



Opportunities:

Ensure SC addresses <u>all</u> needs of the family, especially those needing economic support Partner with family-to-family org's, EHDI to help families access financial supports Educate state legislators on needs of families, e.g., hearing aid coverage mandates

Interagency communication needs

Trends:

- Formal referral processes between EHDI & Part C EI in place
- Almost all EHDI boards include Part C representation
- 43% of states have Part C & EHDI are in the same state agency/department
- Referral systems vary from centralized to local level
- Eligibility criteria for Part C, Schools for Deaf vary across states
 - Few states are able to share child-specific data across agencies

Opportunities:

- Review/revise data sharing policies online data systems
- Create online data systems between EHDI, Part C
- Explore HIPAA security solutions





Ideas for Applying our "Lessons Learned"

- ➤ Share extant El SNAPSHOT data with interagency teams do results generalize to your state?
- ➤ Collect your own state-specific data use or adopt surveys
- Adapt methods, age range; consider phone calls, online option; interviews/focus groups with under-represented populations
- ➤ Hire parents of DHH children to collect data
- ➤ Online surveys work well with El Providers & audiologists to ID T/TA needs
- ➤ Use our "scenario" interview protocol to explore T/TA needs for family-to-family organizations
- ➤ Use our EHDI, Part C website review protocols to assess if info is available for families



Want to use El SNAPSHOT in your state?

http://www.eisnapshot.org/

http://www.infanthearing.org/eisnapshot/

Component

Resources

States

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EHDI Components EI SNAPSHOT: Early

- Newborn Hearing Screening
- Early Childhood Hearing Screening
- Diagnostic Audiology
- Early Intervention
- Family Support and Partnership
- Medical Home
- Data Management
- Financing & Reimbursements

EI SNAPSHOT: Early Intervention for Children who are Deaf or Hard of Hearing: Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities, and Trends

What is EI SNAPSHOT?

From November 2015 through May 2017, NCHAM



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]

EI SNAPSHOT Family Survey

LINDA HAZARD, ED.D

PROGRAM DIRECTOR

Vermont Early Hearing Detection and Intervention Program (VTEHDI)



Vermont

Vermont participated in the nationwide El SNAPSHOT Survey Project

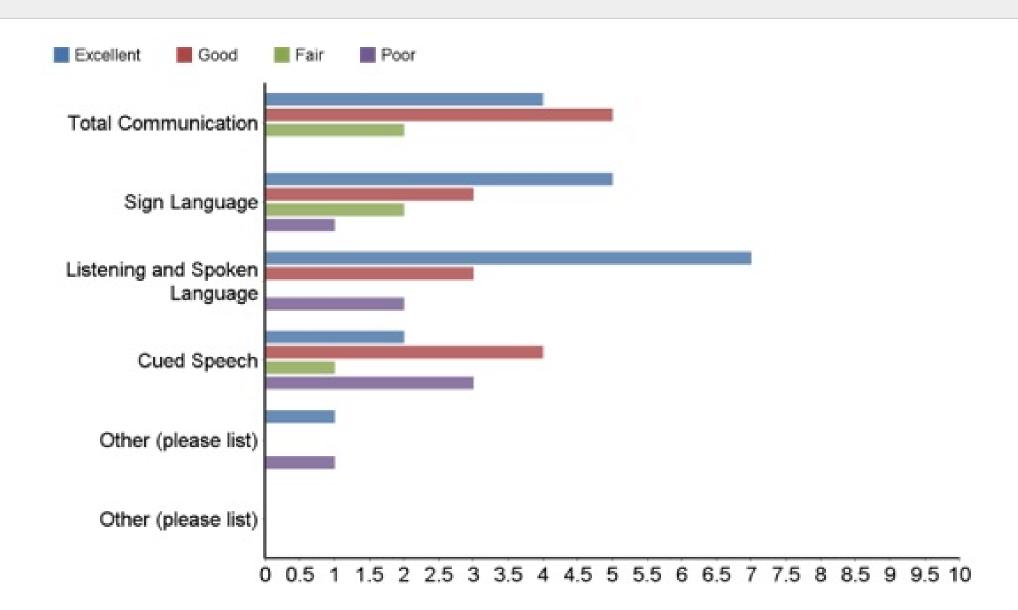
60 surveys sent -20% of families responded

The survey was sent to families of babies born in years 2010 through 2015.

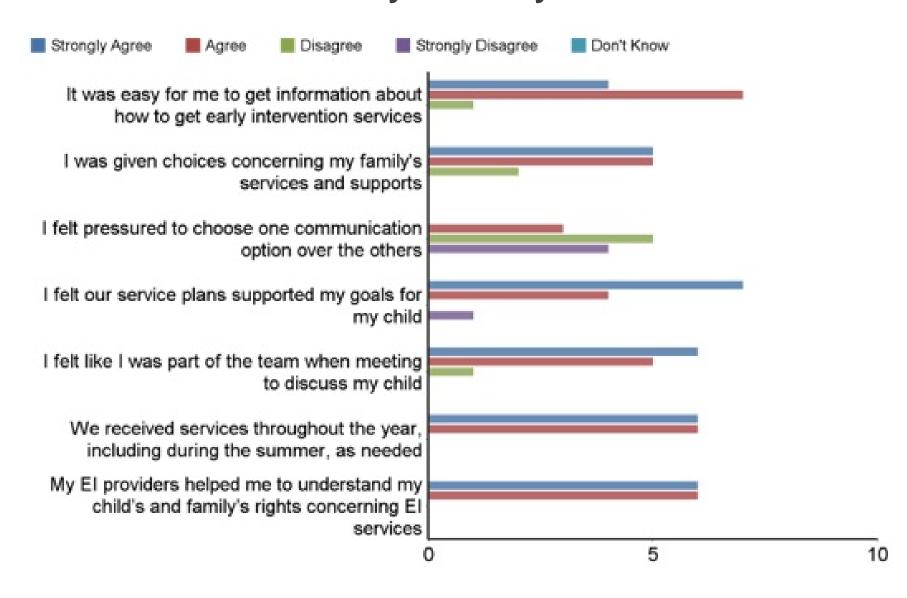
Vermont Center for Deaf and Hard of Hearing closed during this time frame and early intervention services were transitioned to a new service provider.



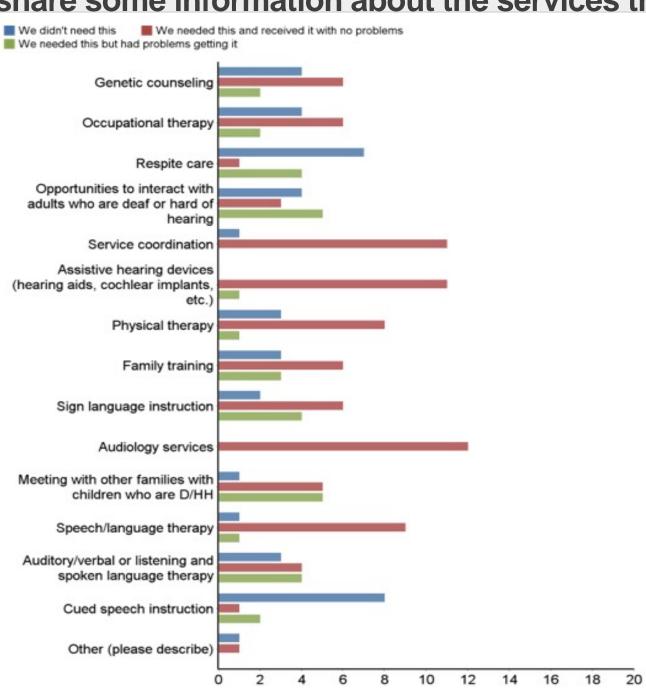
Rate the information you received about each communication choice when your child was first diagnosed:



Early Intervention Services How much do you agree with the following statements about Early Intervention services your family received?



Please share some information about the services that you received



Northern New England Collaborative: Maine, New Hampshire and Vermont

- •Oberkotter Funding: identify gaps in services in the 3 states.
- •EI SNAPSHOT Survey used as a template
- •Questions were modified to meet the needs of the three states with permission from NCHAM.
- •Families surveyed with children currently in early intervention birth to 2 years 11 months
- Vermont's new provider of Early Intervention in place during the survey period.



Q8. Rate the information you received from an	Early Interventi	on representative	e. (n=40)		
	Excellent (through information was provided)	Good (I mainly understood the information provided or had some questions)	Fair (little information was provided)	Poor (information was not provided)	I don't remember
My child's hearing loss	50%	35%			5%
How hearing loss affects language development	50%	43%	5%	3%	0%
Early brain development	33%	35%	23%	8%	3%
Early ways to communicate with my child	43%	45%	8%	3%	3%
American Sign Language	45%	38%	8%	8%	3%
Bilingual Bimodal	20%	20%	18%	18%	25%
Cued Speech	30%	35%	13%	13%	10%
Total Communication	36%	37%	18%	8%	0%
Listening and Spoken Language	48%	33%	8%	8%	5%
Hearing Assistive Devices like hearing aids and					
cochlear implants	43%	33%	18%	0%	8%

Q9. Please respond regarding the presentation of the information you receiveed in the previous question (n=40)					
	Strongly Agree	Agree	Disagree	Strongly Disagree	I don't remember
The information was complete and presented in an					
unbiased manner	60%	35%	5%	0%	0%
The presenter told me about their own education,					
experience and area of specialty	53%	30%	8%	0%	10%
The presenter was equally knowledgeable about all					
communication options	43%	40%	13%	0%	5%
I felt pressured to choose one communication					
option over the others	0%	3%	38%	55%	5%
I felt pressured to choose one early intervention					
provider over others	5%	8%	30%	53%	5%
The presenter offered me the opportunity to talk					
directly with other parents regarding their					
communication choices in a timely manner	30%	28%	15%	8%	20%
The presenter offered me the opportunity to talk					
directly with providers that specialized in					
communication options I wanted to explore further					
in a timely manner	25%	48%	10%	5%	13%

Q8. Rate the information you received from an Early Intervention representative.					
	Excellent	Good (I mainly		Poor	
	(through	understood the	Fair (little	(information	
	information	information	information	was not	
	was	provided or	was provided)	provided)	I don't remember
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Total Communication	36%	38%	18%	8%	0%
Listening and Spoken Language	48%	33%	8%	8%	7%
Hearing Assistive Devices like hearing aids and					
cochlear implants	43%	33%	18%	0%	8%
Additional Comments (optional)					

Q9. Please respond regarding the presentation of the information you receieved in the previous question

Q3. Flease respond regarding the presentation of the information you receieved in the previous question					
	Strongly Agree	Agree	Disagree	Strongly Disagree	I don't remember
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unbiased manner	60%	35%	5%	0%	0%
The presenter told me about their own education,					
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communication options I wanted to explore					
further in a timely manner	25%	48%	10%	5%	13%

Conclusions:

El SNAPSHOT survey drives quality improvement initiatives.

NNE: Families want more opportunities to meet with other families and for family engagement activities.

NNE: More information on brain development in the area of language.

Vermont survey results showed significant improvement with current Early Intervention provider.



Minnesota's Collaborative Plan

"The Collaborative Plan is a network of agencies and organizations who work together to create positive, systematic changes in order to achieve better education and career outcomes for students who are deaf, deafblind, and hard of hearing."



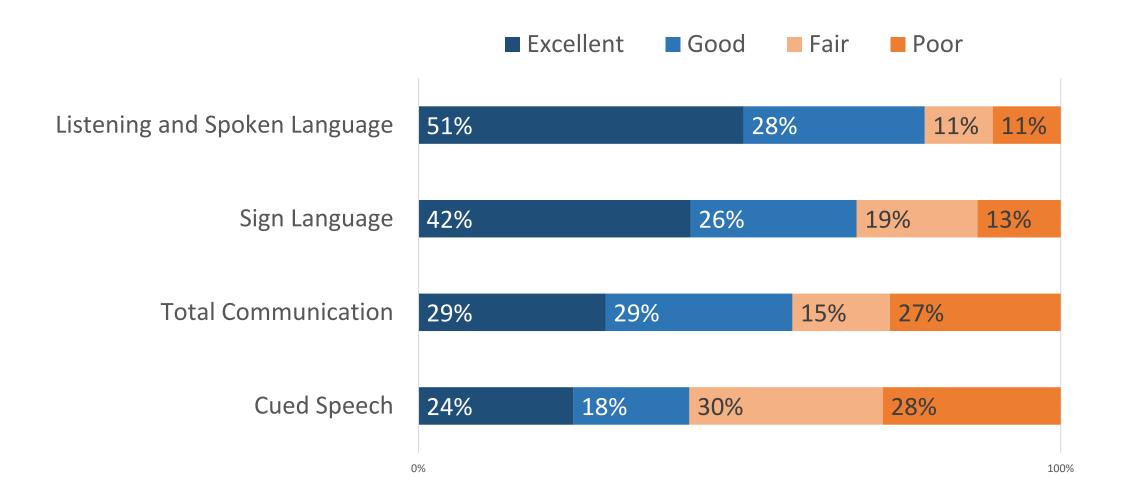
Minnesota Collaborative Plan Priorities

Collaborative used a systems **self-assessment** tool to ensure progress on the **JCIH 2013 recommendations** and identify priorities

- Ensure families have access to accurate, balanced, and comprehensive resources and information
- Identify the percent of families who receive timely access to service providers
 with specialized knowledge and skills for working with children who are d/hh



Rate the information you received about each communication choice when your child was first diagnosed:



Concerning information provided to you about family supports, how would you rate the quality of the following:

AG Bell Minnesota Family Voices

American Society for Deaf Children Minnesota EHDI program

Associations of the Deaf Opportunities to interact with adults who are

d/HH

D/HH Mentor Role Model Program
Opportunities to meet parents of children who

are D/HH

Hands & Voices Pacer Center

Deaf and Hard of Hearing Services (DHS)





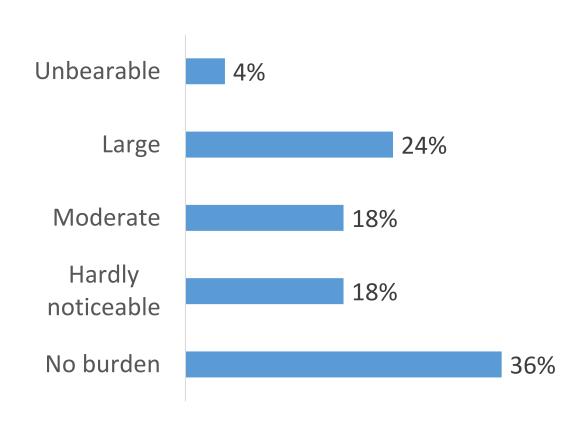
What You Need To Know

Resources for families

800-728-5420 www.health.state.mn.us/cyshn

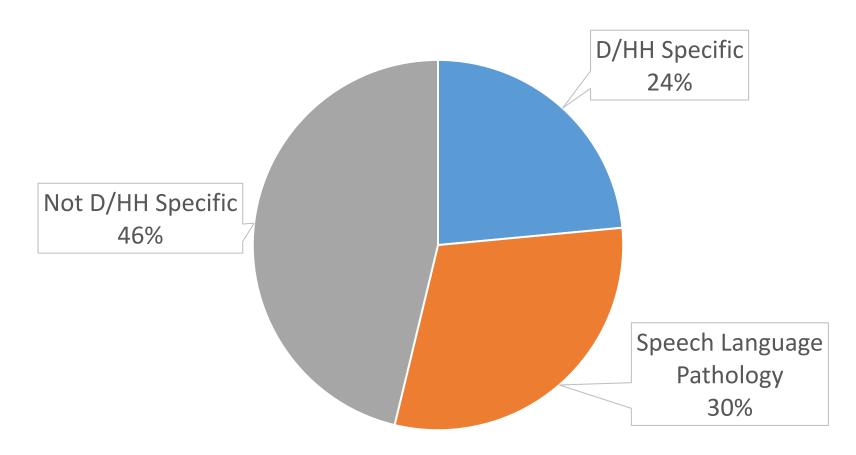


Was spending out of pocket money [on services and hearing technology] for you a financial burden?

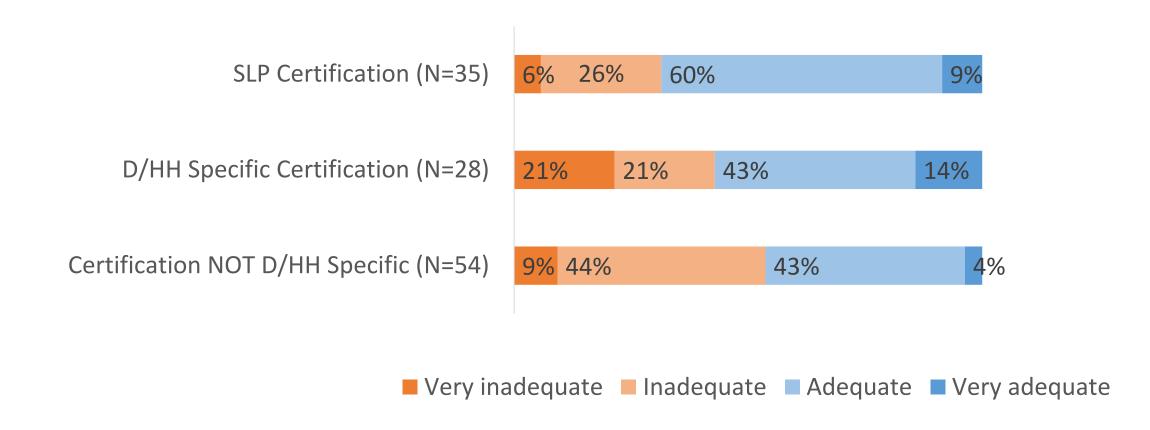


"We were lucky to receive his first hearing aid from the Lion's organization, which is why I chose 'No Burden.' Otherwise, the hearing aid was not covered at all by insurance and would have been. I think this is the biggest barrier."

In what area was your degree? What certifications do you hold that pertain to serving children who are D/HH?

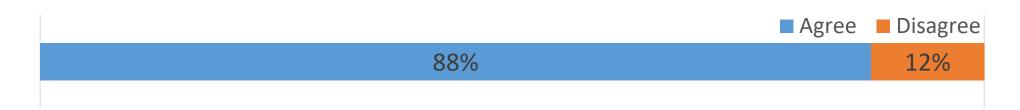


How adequate was your educational program in preparing you to provide early intervention services to families of children who are D/HH?



Service coordination works well for most, but not all families.

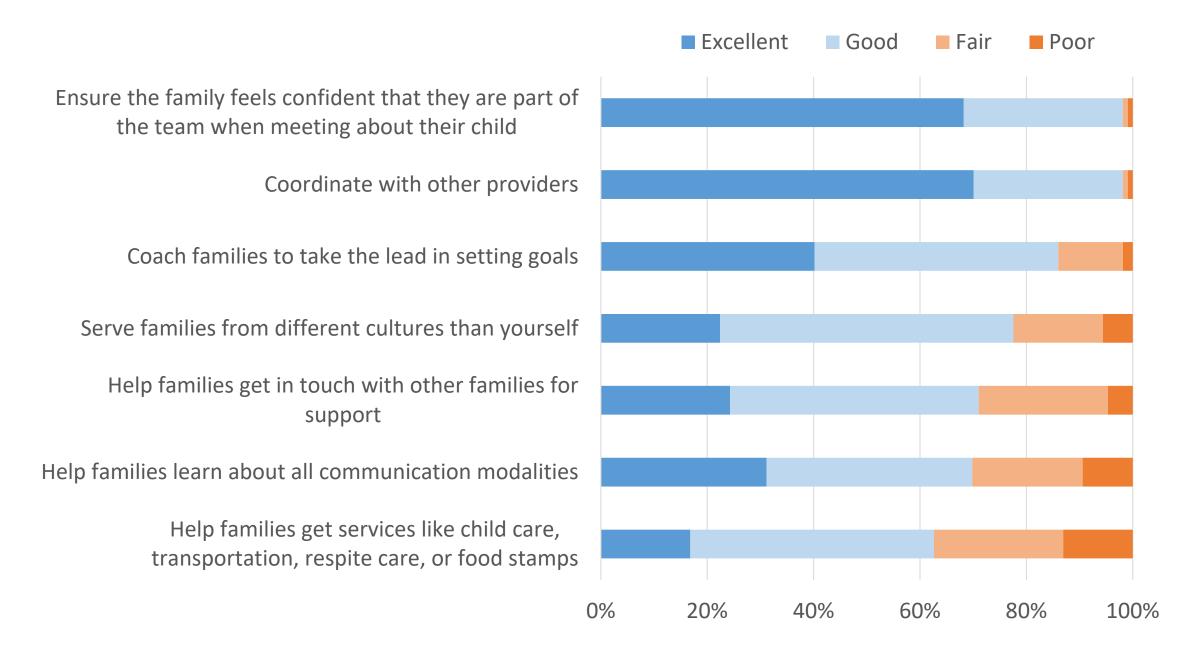
My child's providers coordinated well with one another



"[...]Through our audiologist, MN Hands and Voices, and our school district and the SPED [special education] coop they work with have been second to none. Total family support!"

"We did have trouble keeping all of my child's helpers up-to-date. We had five different people helping at one point and I really had to take the lead in coordinating everyone."

How would you rate your ability to help families with the following issues?



Questions? Comments? Your ideas? Thank you!

Please contact us for further information.

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Melinda Marsolek: melinda.marsolek@state.mn.us

Sara Doutre: saradoutre@gmail.com

More El SNAPSHOT presentations:

Tues. 11:35 – How many Ways can a Child get from EHDI to Part C

Tues. 3:45 – Let's hear from Audiologists: El SNAPSHOT Audiology survey

Tues. 4:20 – Continued Challenge of Ensuring Comprehensive SC

