



**FAMILY NEEDS ASSESSMENT**  
**SUCCESSES AND CHALLENGES**  
**LISTENING TO THEIR VOICES**

A Survey by the Alexander Graham Bell  
Association for the Deaf and Hard of Hearing

*Alexander Graham Bell*

ALEXANDER GRAHAM BELL  
ASSOCIATION FOR THE DEAF AND HARD OF HEARING

# Presenters



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# Learning Objectives

- **Describe at least two critical elements that impacted families' access to early intervention services.**
- **List three major findings that describe what families are experiencing in delivery of early intervention services to support language development.**
- **Describe both positive and negative characteristics of professionals who deliver information as identified by families of children with hearing loss.**



# The Sky is the Limit!





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# Methodology

## Goal

To understand the core needs of families as they progress through the major phases of their child's journey, including newborn screening, diagnosis, connecting with Early Intervention, amplification, and the transitions faced by families as their child progresses from Early Intervention to preschool, school and eventually adulthood.

## Process:

The Family Needs Assessment was developed in concert with experts in the field, AG Bell staff and a consulting firm specializing in developing surveys. The main topics were identified based on trends in the literature and in consideration of the Association's strategic pillars. The questions were designed to allow AG Bell to be able to understand the breadth of the issues that families face today.





# Methodology

## Topics Addressed:

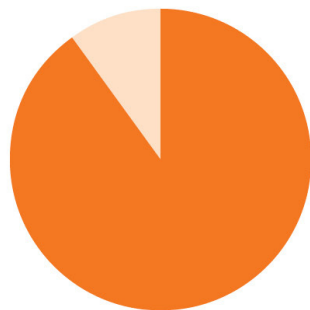
- Access to quality information
- Emotional and support service provision
- IFSP and IEP development
- School options
- Financial impacts and barriers

## Target Audience:

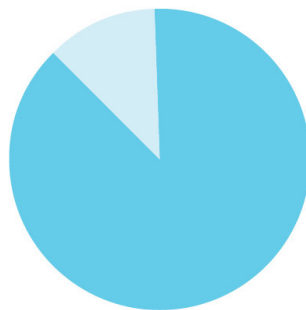
Families of children who are deaf and hard of hearing in the post-EHDI era (younger than 15) and who had chosen a listening and spoken language outcome. More than 1,000 families opened and responded to the survey. Of those, about 80% fit this criteria and those responses are included in this presentation.

# Respondent Demographics

Respondent Demographics



Male 10%  
Female 90%



Single-Parent Household 12%  
Dual-Parent Household 88%

## Considerations:

- **Geography and local support availability are important drivers of parents' experience.**

Enormous variability exists both across and within states in terms of access to information, services, etc. Responses came from every state in the country.

- **In response to almost every question on the survey, responses were highly polarized.**

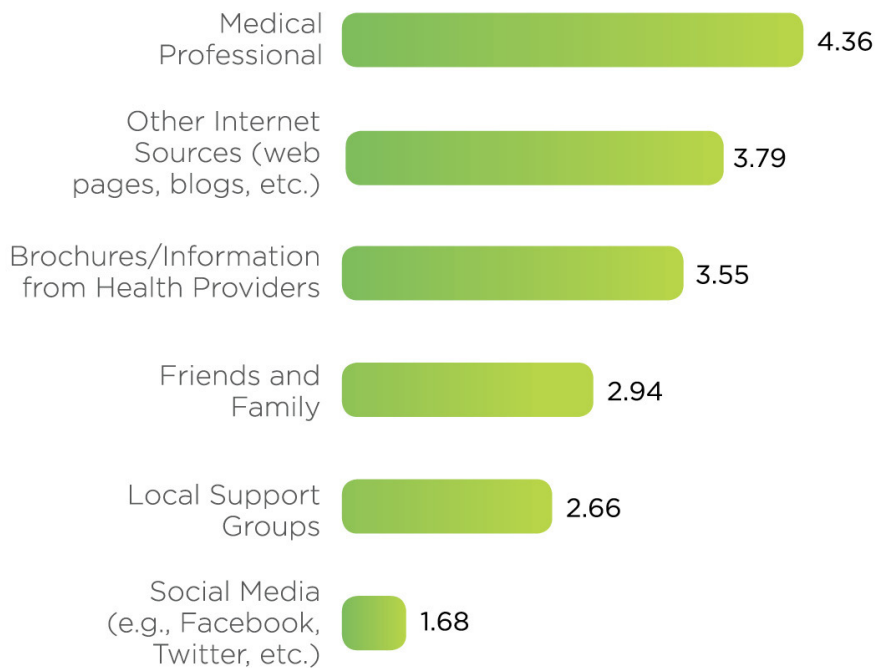
In other words, while an average quality or satisfaction rating might be positive, those families that had a negative experience typically had a highly negative experience.



# Information sources

## Information Sources Most Utilized

Weighted Average Rating (1-5)



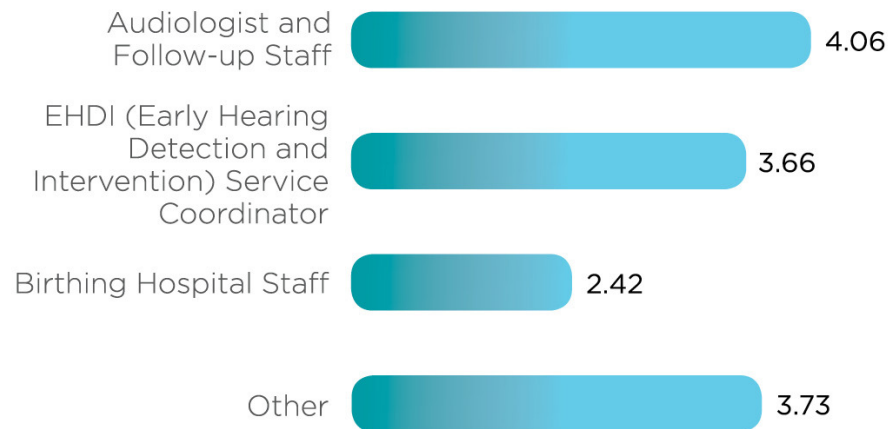
## Considerations

- Internet sources are fast becoming the standard for information gathering, particularly static content.
- Blogs and personal or community-based online sources were often seen more positively than sites with pure facts and static content.
- Although social media rated the lowest as a source of information, its use is increasing over time. Parents with children under the age of 5 rate the use of social media significantly higher than parents of children age 6 and older.

# Quality of Information by Provider

## Quality of Information by Provider

Weighted Average Rating (1-5)



## Considerations

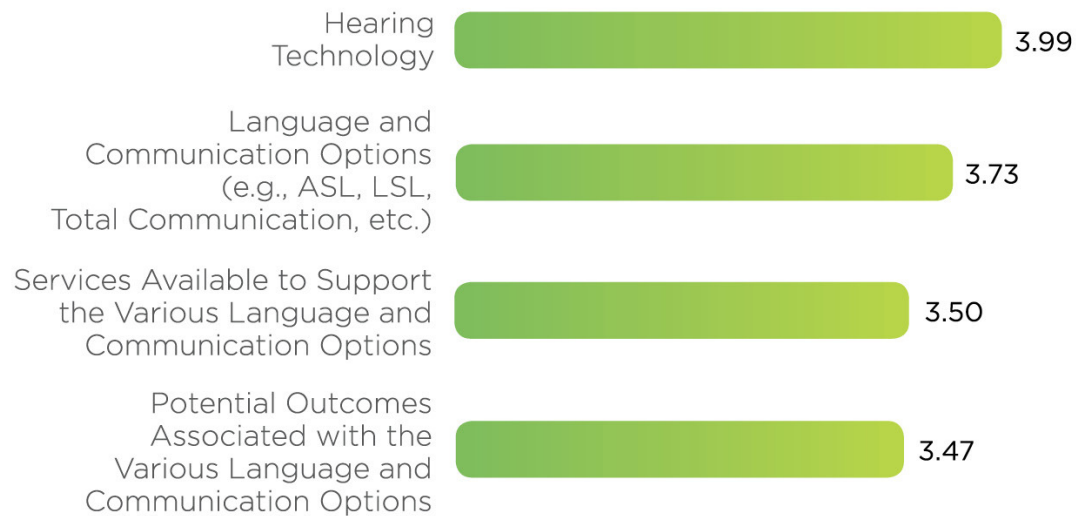
- **Audiologists were seen as providing the highest quality of information to parents in the first six months after a diagnosis.**
- **Birthing hospitals were a noted challenge, with well over 50% of parents describing the quality of information from this group as poor to average.**



# Quality of Information by Topic

## Quality of Parent's Experience in Getting information by Topic

Weighted Average Rating (1-5)



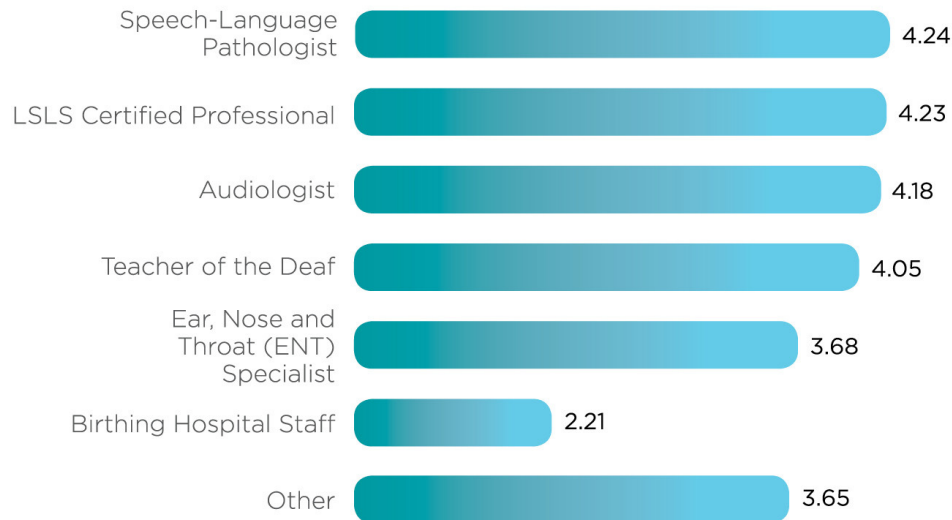
## Considerations

Parents noted the need to make decisions early in a child's life, and it was noted that this is often without a clear roadmap for what services will be offered in the future.

# Who Answered Questions and Provided Guidance?

## Who Explained the Issues, Answered Questions and Guided us in Our Journey?

Weighted Average Rating (1-5)



## Considerations

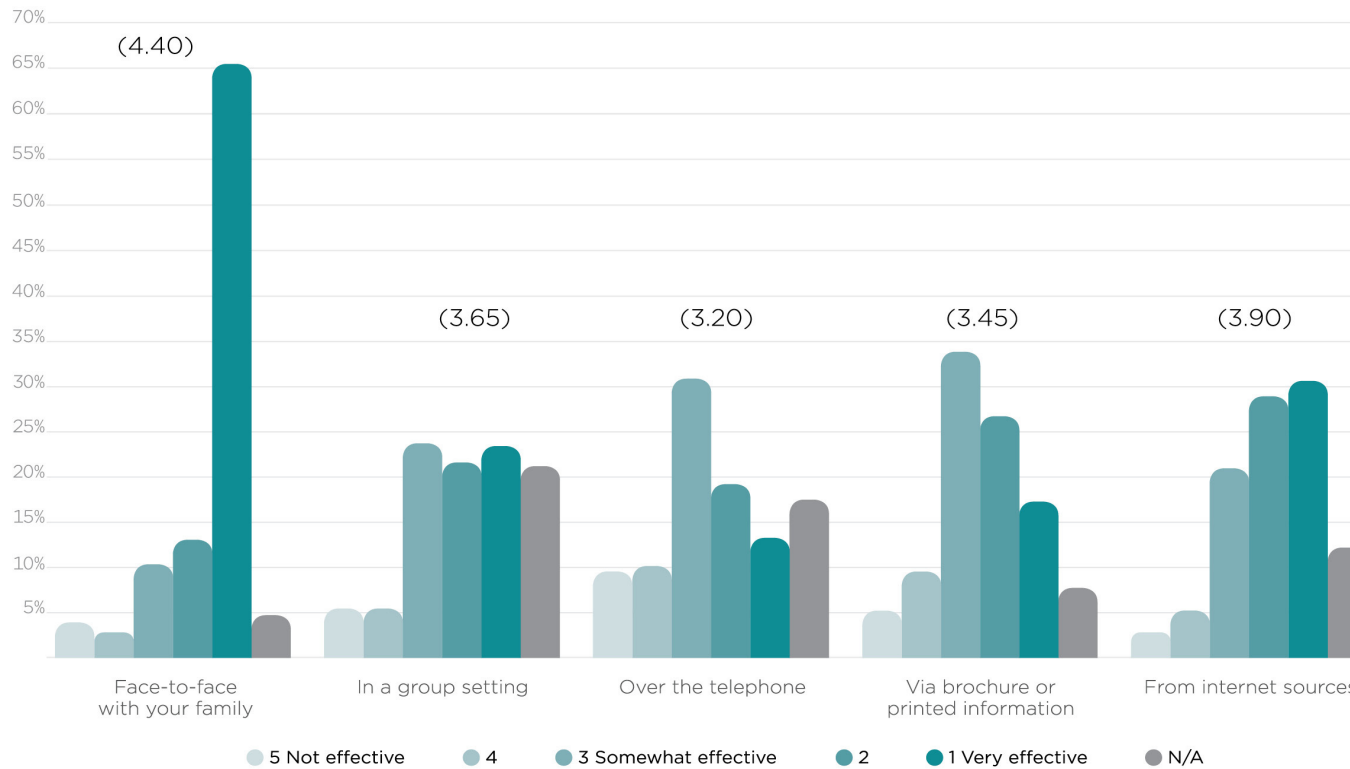
- Where available, LSLS certified professionals were rated second highest in terms of effectively explaining issues and helping parents on the path to developing LSL for their child.
- However, “Auditory Verbal Therapists” were the most commonly noted other professional that provided guidance.

# Preferred Communication Channels

## Effectiveness of Communication Channel

Weighted Average Rating (1-5)

Bars indicate percentage of respondents for each response option.





# Would parents change how they received information or would they change the information they received?

Most parents indicated they did feel fully informed prior to making decisions about communication and language options – an average weighted rating of 3.88 (on a scale of 1 to 5 with five being the highest)

## Summary of Comments

- Desire for unbiased information and a full description of all options (42% of comments)
- Feeling alone (35% of comments)
- Would like a roadmap, including longer-term expectation setting around service availability and outcomes (28% of comments)

### Sample comment:

“...It was very confusing and I did not know who to believe. The advice and information was conflicting and there was no real evidence to support to refute any of the information I received. The reality is that until your child begins communicating, you have no idea which mode of communication will work best. Because opinions are so strong on both sides about LSL or ASL approaches, the information received from either side seems biased.”

# Would parents change how they received information or would they change the information they received?

*“We had to make immediate decisions with maybe not quite enough information, but I was so overloaded with new information while at the same time grieving the reasons I needed this information that I ended up making decisions as best I could.”*

*“I would have changed the actual information received to encompass the entire journey and possible issues – not just issues that we are facing and would face in the immediate future, but down the road as well.”*

*“I felt like the information wasn't given to me in a format that I could process. I got a little information at a time, but not whole-picture information. I never had all the options explained to me in a way that I felt I was making a holistic decision instead of a million one-off decisions. Had someone explained my options and outcomes in one sitting, it would have made a difficult time a little less difficult.”*

# Emotional and Support Resources

Families Choosing to Use Support Resources  
% of Respondents



## Considerations

- Even when local support services were available, many parents noted that in the early years they often felt overwhelmed with the amount of time required to provide adequate support to their child, and the effort required to connect with support groups was a barrier.
- Parents noted a wide range of services were available, including school-based groups, general support groups, connections with local parents, AG Bell and other similar organizations, online groups, therapists and hearing loss-oriented centers.



# Benefits of Emotional and Support Resources

## Parent Quotes

*“Speaking with parents of children older than my own gave a glimpse into what we could expect and provided hope for the future.”*

*“Being able to meet and talk to other parents who had gone through or were going through similar experiences that we were was tremendous for us. We stopped feeling like we were alone.”*



# Benefits of Emotional and Support Resources

## Parent Quotes

*“My daughter loved seeing other children with hearing aids and CIs.”*

*“The group we attended provided parent-to-parent support and more importantly an instant community of people sharing a common experience. It was a safe place to grieve and feel sad with people who really understood, and it was a safe place to not be judged about the choices we made for our children.”*



# Benefits of Emotional and Support Resources



## Parent Quote & Tip for Professionals

*“Our SLP purposefully overlapped her appointments, so when we came in, another family would be leaving, we would all sit and talk for about 15 minutes before we started our session with her. I cannot thank her enough for how much meeting other parents meant to me.”*

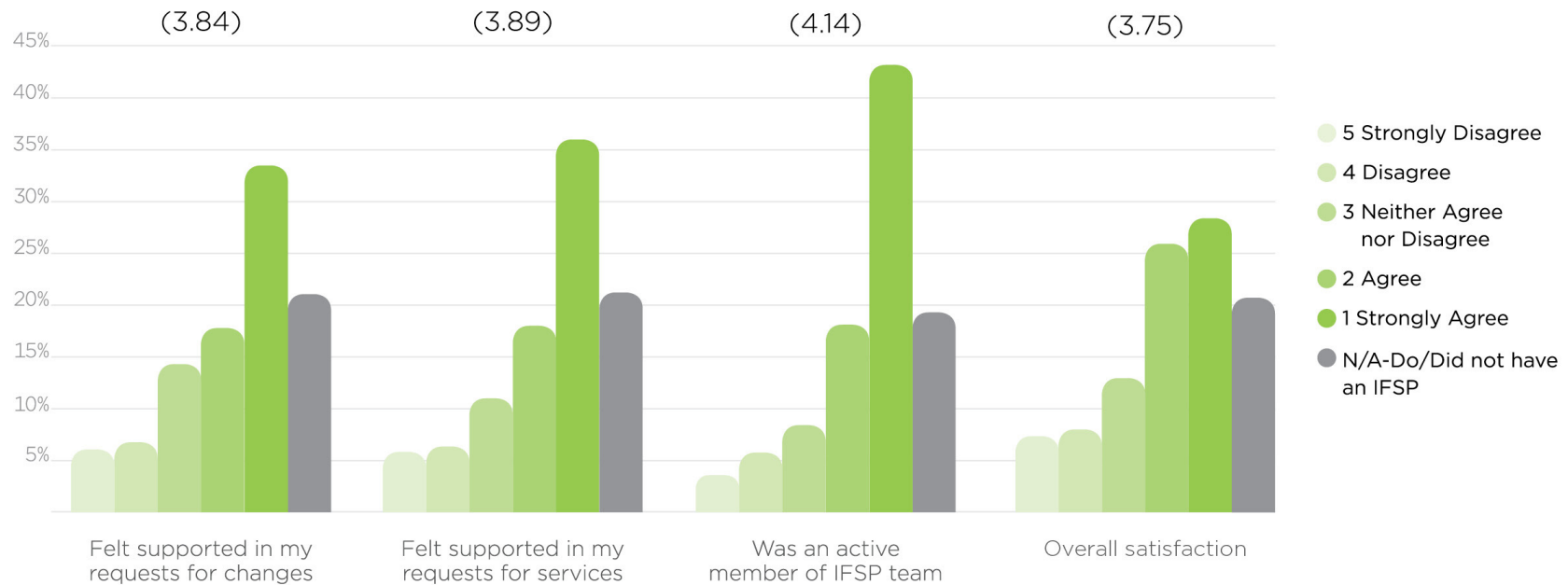


# IFSP Development and Fulfillment

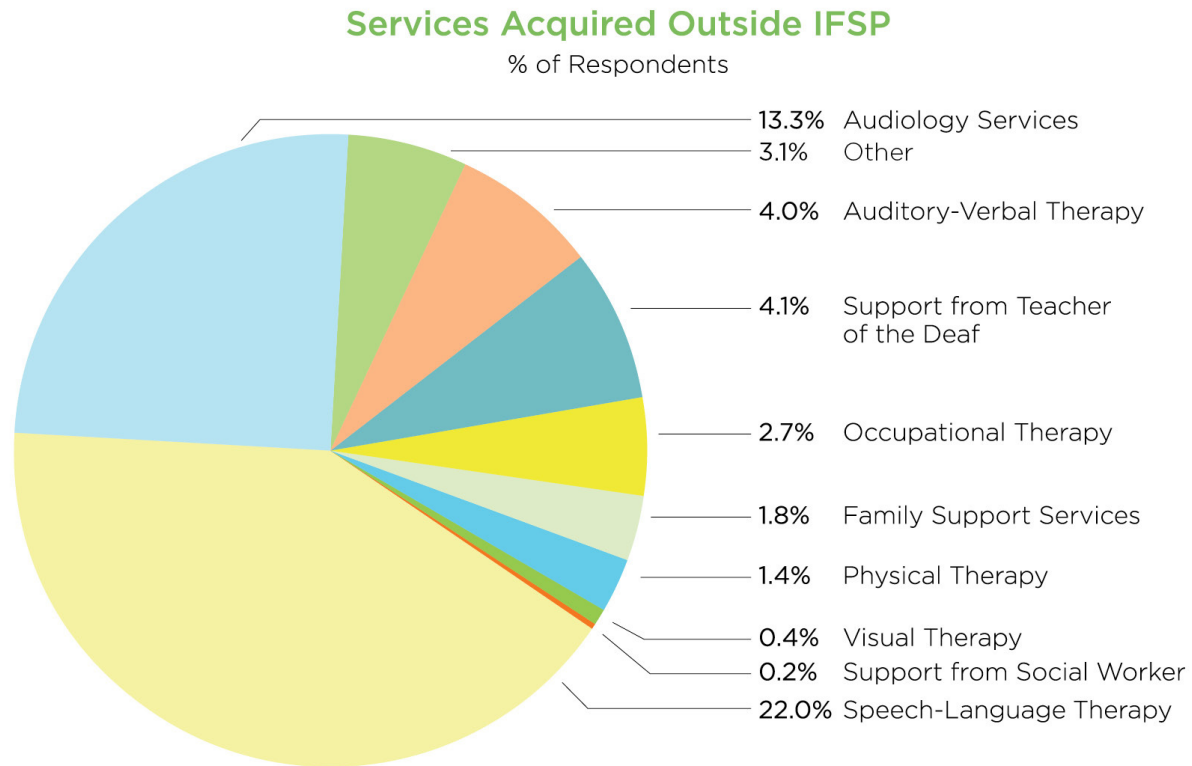
## IFSP Development Rankings

Weighted Average Rating (1-5)

Bars indicate percentage of respondents for each response option.



# Services Acquired Outside of the IFSP



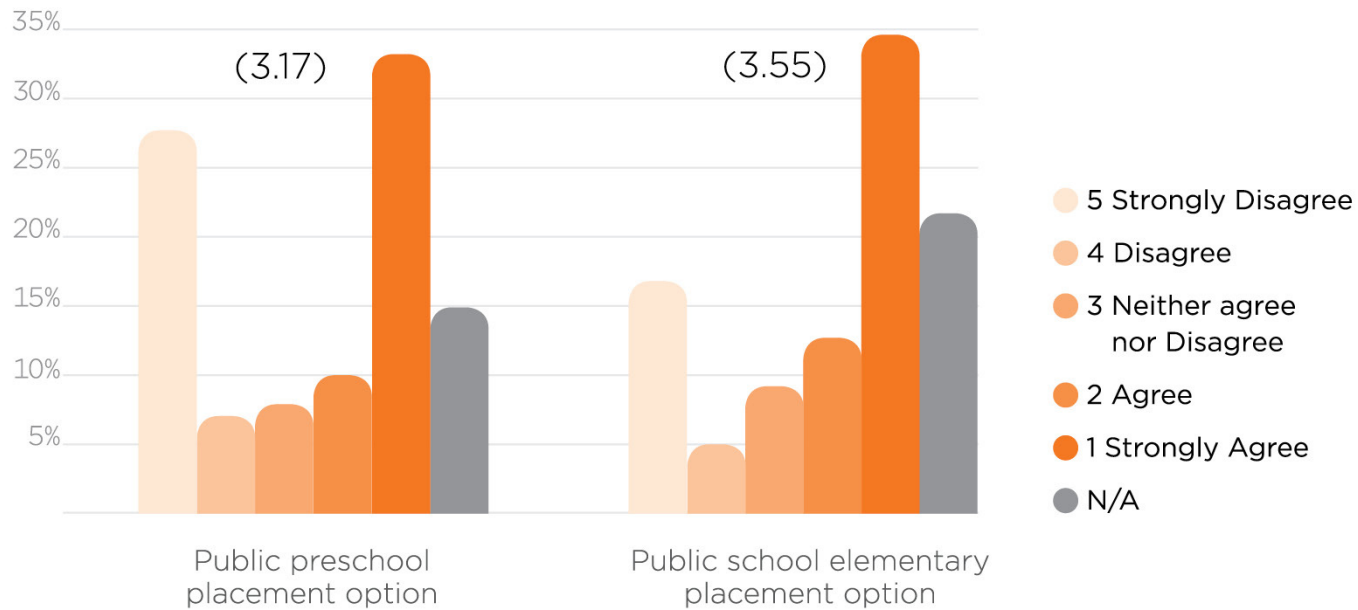
This chart represents 53% of respondents who received services outside the IFSP. The remainder of respondents did not receive services outside the IFSP.

# The School Years

## Public School Provision of Desired Placement Option

Weighted Average Rating (1-5)

Bars indicate percentage of respondents for each response option.





# The School Years

*“Our public school agreed immediately to send her out of district. They had no program to offer her nor did they pretend to.”*

*“Preschool placement was a horrible process and very difficult time for us. The preschool that was offered was not appropriate so we had to privately send him to preschool.”*

*“We send our son to a private school and have since nursery school. We feel the smaller classroom size was more beneficial.”*

*“We moved cross country for a better placement.”*

*“The goal for my son was to be mainstreamed and they have respected that with both modifications & accommodations.”*

# The School Years

## Top Three Supports Provided by the School

**Assistive Listening Devices such as FM  
Systems – 90%**

**Preferential Seating – 64%**

**Acoustically Friendly Classrooms – 40.7%**

## Challenges

In comments, families noted these as the three most common challenges with IEP development:

- a rigid position from the school district on an appropriate IEP
- a sense of not having appropriate support from experts on the IEP team
- a need to justify an IEP when a child is performing at grade level in mainstream classes

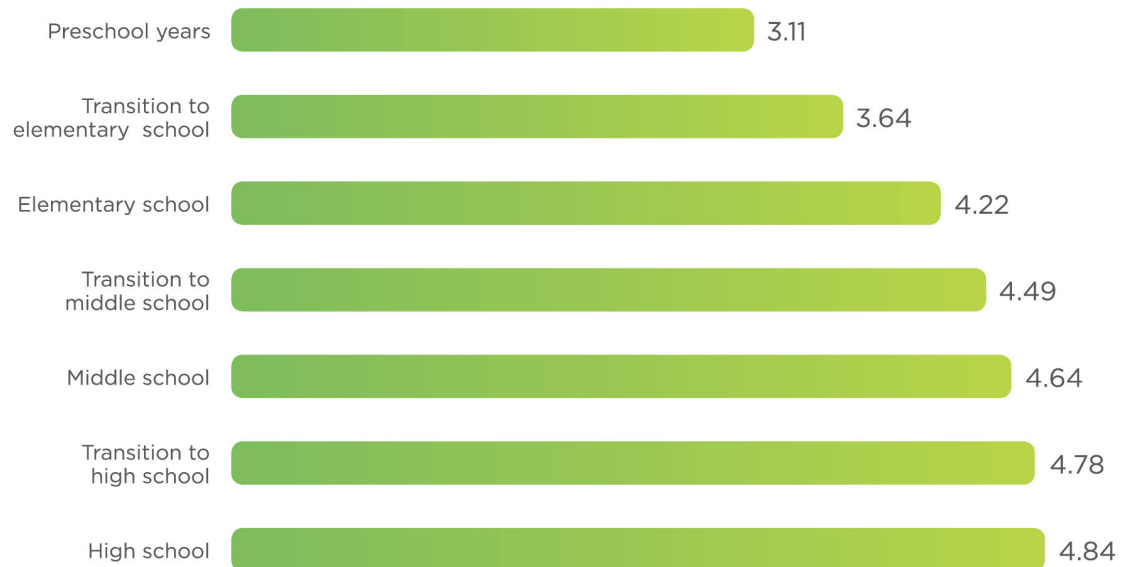
# The Need for Self-Advocacy Skills





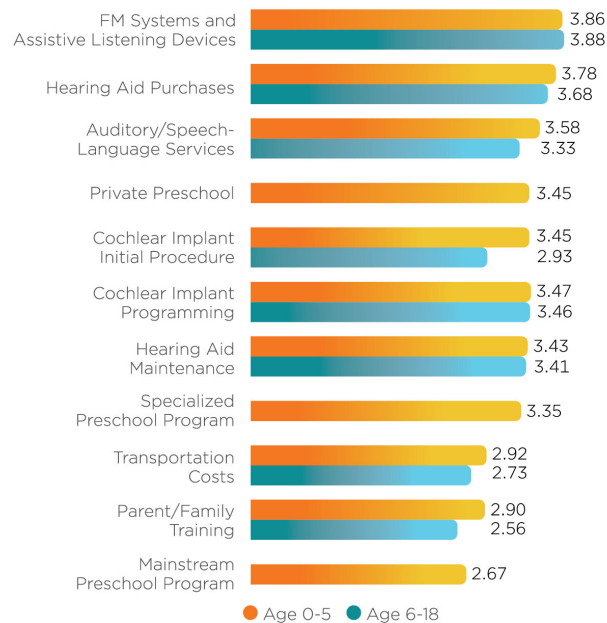
# The Need for Self-Advocacy Skills

Stage Where Self-Advocacy Skills are Most Necessary  
Weighted Average Rating (1-5)



# Financial Impact and Support

**Financial Assistance**  
Weighted Average Rating (1-5)



**FIGURE KEY**  
1 = Do not need financial assistance, 2 = financial assistance would be slightly valuable, and 5 = financial assistance would be extremely valuable

## Considerations

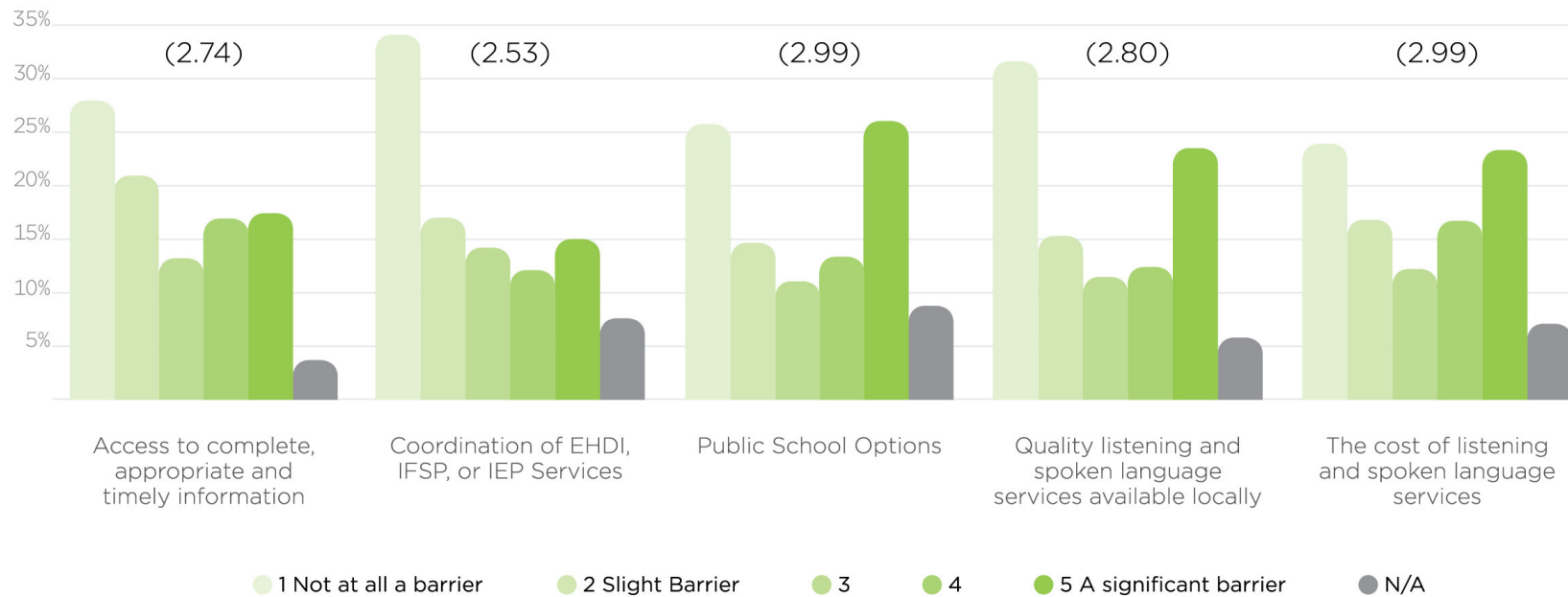
- The years when a child is aged 4 to 6, followed by elementary school years were noted as the most financially challenging periods for families.
- Insurance coverage ranged widely.

# Barriers and Challenges

## Barriers

Weighted Average Rating (1-5)

Bars indicate percentage of respondents for each response option.



# Considerations for Professionals Who Serve Families

- **Needs continue to exist in all areas**

Families continue to struggle with access to appropriate information, appropriate delivery of that information, the complex nature of IFSP and IEP development, self-advocacy (both parents and children), along with the financial pressures associated with these issues.

- **Guides and gatekeepers**

Families tend to find a “home” upon which they rely heavily for information and insight. These people or institutions can be seen both as guides and gatekeepers. They hold significant influence. Parents can quickly feel “lost,” as was often mentioned. This is exacerbated by an onslaught of potentially biased information immediately after a failed screening.

- **Access to advocates**

The story of parents feeling alone and navigating a complex system of regulations, institutions and financial challenges is revealed quite clearly in the survey data. Providing expertise, and more importantly, family advocates during decision-making phases and IFSP and IEP development could help alleviate families’ sense of “going it alone.”



# Considerations for Professionals Who Serve Families, *continued*

- **Geographic Breadth**

An imbalance of service availability was a noted challenge across many of the survey topics. Providing support to under-represented areas is key to improving the experience for families. While rural areas can clearly be a challenge, a number of respondents from major cities noted a lack of local support as well. Because of the various pieces of the experience and process, it can be difficult to identify specific drivers across large regions. Families' experiences are often based on local actors, for example school districts, so having more dynamic resources such as web-based tools, traveling resources, and local models that don't require highly-trained and difficult-to-find experts prove beneficial.

- **Access to trained professionals**

Whether through continued advocacy or the increased adoption of LSLS certification, improving access to appropriately trained professionals is essential to improve the dramatic variance of family experience

- **Accessible personal and emotional support resources**

Programs that provide parent-to-parent communication and support in an accessible way are very important. This is reinforced by parents' desire to have face-to-face and connected discussion as well as the fact that availability (in terms of both time and geography) was the greatest barrier to utilizing these resources.

# Considerations for Professionals Who Serve Families, *continued*

- **Industry-wide schisms**

One of the major undercurrents in many comments on the survey was the pervasive struggle around the topics of ASL “vs.” LSL and whether to integrate total communication. The pointed nature of the struggle creates a lack of trust, and exacerbates parents’ sense of loneliness. This is a challenge for families and for the professionals who serve them.

- **Simple yet thorough information**

Parents identified two challenges with the information provided in the early years: feeling overloaded by noise and feeling like they don’t have full information.

- **Unbiased information**

There are two potentially contradictory voices in the responses. On the one hand, some families felt prompted into LSL choices, while others feel like the LSL option wasn’t presented strongly enough. This brings into focus the discussion of consistent presentation of outcomes. EHDI programs struggle to provide consistent messaging around outcomes.



# Summary

## To address the needs of families, AG Bell is working to increase:

- States with insurance coverage for hearing health technology.
- Availability of culturally relevant and sensitive materials for families and children who are deaf and hard of hearing.
- Timely, complete, and accurate information at diagnosis and transitions throughout life.
- Access to LSLS-certified professionals along with pediatric and educational audiologists.
- Advocacy for access to services through the Individuals with Disabilities Education Act and the Americans with Disabilities Act.

## Additional Resources

- **Family Needs Assessment on the web**  
[ListeningandSpokenLanguage.org/FamilyNeedsAssessment/](http://ListeningandSpokenLanguage.org/FamilyNeedsAssessment/)
- **Family Needs Assessment Booklet (PDF)**  
[ListeningandSpokenLanguage.org/WorkArea/DownloadAsset.aspx?id=2323](http://ListeningandSpokenLanguage.org/WorkArea/DownloadAsset.aspx?id=2323)
- **AG Bell Strategic Plan**  
[ListeningandSpokenLanguage.org/StrategicPlan/](http://ListeningandSpokenLanguage.org/StrategicPlan/)





**Questions??**