



Family Needs Assessment Highlights

The Alexander Graham Bell Association for the Deaf and Hard of Hearing commissioned the Family Needs Assessment survey in an effort to gain insight on the perceptions of families with children who are deaf and hard of hearing about the quality and availability of services received. The survey was developed to assess the core needs of families as they progress through the major phases of their child's journey.

This paints a picture of hope and encouragement, suggesting that many families have access to key services needed to help their children succeed in life. Many other families, however, have a clear and present need for information, advocacy, emotional support and financial help across the full range of issues explored in the survey. The Family Needs Assessment survey provides vital data that can be used by professionals, policymakers, media and others to transform the future of people living with hearing loss.

Overall Highlights

- Geography and local support availability are important drivers of parents' experience.
- Responses to nearly every question on the survey were quite polarized, indicating that parents had either a strong positive or a strong negative experience.
- The period of early intervention (IFSP) was the most positive for families.
- The timeframe when the child is 3-5 years of age is the most difficult for families.
- The schism between Listening and Spoken Language and American Sign Language (ASL) added to families' anxiety and difficulty in the early stages of decision making.
- The costs of listening and spoken language services is a significant barrier for many families.
- Limited access to qualified professionals and services is a challenge for many families.
- A single individual or organization often made the difference between a family feeling lost and feeling on-track.

Highlights by Topics in the Survey

Access to Information

- Families overwhelmingly prefer face-to-face interaction as the most effective communication method.
- Internet sources are 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 was 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.
- While most parents indicated that they did feel fully informed prior to making decisions about communication and language options, about 45% of parents commented on ways they would have changed either what information they received or how they received it.

Summary of comments on this question:

- 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)



Emotional and Support Resources

- Availability of emotional, counseling and support resources in the area local to families varied widely. More than 25 percent of respondents noted a challenge associated with the availability of such resources.
 - Only two-thirds of respondents chose to use these resources if they were available to them at the time, and 61 percent of those who used services rated them favorably.
- 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.

Early Intervention Services

- The IFSP process was the most positively rated experience on the survey. Parents largely felt included and heard in the process.
- More than half of respondents (53%) said they acquired services outside of their IFSP. Families obtained a mixture of services provided by public services and additional or supplemental services.

School-age Years

- Satisfaction with **preschool** placement options showed the most polarized responses on the survey. Nearly one-third of respondents STRONGLY DISAGREE with the statement: "The public school system fully offered the preschool placement that my family desired for my child."
- **Elementary** school placement options were rated higher, though still 20% of respondents disagreed with the statement: "The public school system fully offered the elementary school placement that my family desired for my child."
- Families noted the following as the most common challenges with IEP development:
 - A perception of a lack of flexibility 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
- In terms of the types of supports provided for school-age children, parents indicated that more than 90% of children were in schools that supplied assistive listening devices, such as FM systems. Preferential seating and acoustically-friendly classrooms were rated the second and third most available, with 64% and 40.7 % respectively.

Self-Advocacy

- While self-advocacy was rated as necessary at all age levels, the transition points at elementary, middle and high school represented a jump in the need for these skills.
- Parents noted the need, particularly in younger children, to develop self-advocacy skills for activities outside of school, where the structure and experience of teachers and therapists cannot be relied upon.

Financial Impacts and Barriers

- Auditory/speech-language therapy services, hearing aid purchases and auditory devices such as FM devices were the three items parents rated as being areas where financial assistance would be most valuable. The costs associated with implantation and maintenance were also rated highly.
- 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.
- Of the topics explored in the survey, families noted the cost of listening and spoken language services, and public school options as the most significant barriers. Second to that was access to quality listening and spoken language services available locally