

Hearing Loss Diagnosis Provision of Information and Support: Audiologist and Parent Perspectives

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Abstract: When a child is diagnosed with hearing loss, the parents are faced with many decisions that will impact their child's future. This study aimed to obtain data to determine viewpoints on information being provided to parents of children with hearing loss from both audiologist and parent perspectives. Topics of information surveyed included information on modes of communication, Deaf culture, cochlear implants, emotional support, and state resources and laws. A survey was created and shared in Facebook groups for audiologists and parents of Deaf or hard of hearing children. The survey was completed by 91 audiologists and 111 parents. Audiologist and parent survey data were analyzed and compared to look for similarities, differences, and possible biases. The data obtained in the study showed that overall, information on the topics investigated is being provided to parents when their child is initially diagnosed with hearing loss. However, many parents felt that the information that was provided was insufficient; therefore, they did not feel confident in their decision-making process. Audiologists have the responsibility to provide parents with unbiased, extensive information for parents to successfully make informed decisions for their child. Provision of practical, comprehensive information and recommendations may lead to improved parent knowledge and confidence.

Keywords: Children; Hearing Loss; Cochlear Implants; Hearing Aids; Early Intervention; Listening and Spoken Language

Acronyms: ASL = American Sign Language; AV = Auditory Verbal; LSL = Listening and Spoken Language; SEE = Signed Exact English; UNHS = Universal Newborn Hearing Screening

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The introduction of Universal Newborn Hearing Screening (UNHS) protocols drastically improved early detection of hearing loss in infants. Prior to the implementation of these protocols, children were identified with hearing loss at 2 ½ to 3 years old on average, which is a critical period for speech and language development (Eiserman et al., 2007; Walker et al., 2014). When an infant or child is diagnosed with a hearing loss, parents have many decisions to make, including what mode of communication they will choose for their child. Since more than 90% of children who are born Deaf or Hard of Hearing (DHH) are born to hearing parents, many find themselves in a world previously unknown to them (Mitchell & Karchmer, 2004). Decisions on whether to have their child become auditory-verbal via the use of a cochlear implant or implement American Sign Language (ASL) and become immersed in Deaf culture often need to be made sooner rather than later due to the critical age of language development (Chute & Nevins, 2002; Humphries et al., 2012; Li et al., 2003). This early deadline and need to begin early intervention for language development may make parents feel rushed in their decision making (Hyde et al., 2010). Because it

is a choice that will determine their child's path in life, pressure can be felt by parents to make the right decision for their child (Chute & Nevins, 2002). Making effective decisions requires a certain level of confidence (Stewart, 2014). For a parent to be confident in their decision, they must acquire information from a variety of sources and consider all possible modes of communication options and outcomes for their child (Incesulu et al., 2003).

Upon a child's diagnosis of hearing loss, parents are faced with the choice of how they want their child to communicate. Fitzpatrick et al., (2008) identified several areas that parents deemed important following a diagnosis of hearing loss. These included audiological screening and therapy, social support, coordinated services, group support with other parents, and access to pertinent information. There is no right decision on which form of communication the child should use, as it varies from case to case and is based on what works well for the family. The main goal is to provide the child with a form of communication (Li et al., 2003). Research shows there is a critical period for language development, and it is recommended to intervene early so the child can meet

appropriate language milestones. Prolonging the decision of communication modality may result in language delays in children with hearing loss (Hayes et al., 2009). There are five main modes of communication, these include: Auditory Verbal (AV) or Listening and Spoken Language (LSL), Cued Speech, ASL, Signed Exact English (SEE), and Total Communication (Gravel & O’Gara, 2003).

One of the most utilized approaches is AV/LSL. AV is a communication approach that equips parents with the skills to maximize their child’s speech and language development. This approach focuses on using the child’s residual hearing along with having the child wear their amplification devices on a daily basis (Kaipa, 2016). Cued Speech is a communication strategy that uses manual phoneme-based handshapes in combination with mouth movements for speech. The purpose of Cued Speech is to promote understanding using speechreading along with visual cues for the phonemes being verbalized. ASL is often favored among deaf and hard of hearing populations in the United States. ASL is a form of manual communication with unique grammar and syntax, where hand movements and facial expressions play an important role in conveying information (National Institute on Deafness and Other Communication Disorders, 2019). SEE is a form of manual communication that is modeled after the English language. It is the visual form of English, representative of all English vocabulary and grammar. Total communication encompasses all modalities of communication to educate and optimize language development for the deaf and hard of hearing. This includes the use of gestures, fingerspelling, formal signing, body language, listening, lipreading, speech, and facial expressions (Hands & Voices, n. d.). Total communication capitalizes on the unique strengths and needs of each child to find the best modalities for language acquisition. All previously listed communication strategies should be discussed in detail with the child’s parents so they can make informed decisions based on what they think will best serve their child and personal family dynamics.

It is critical that parents know their child’s audiologist is doing everything possible to provide all of the support and information available to best help their child. Gilliver et al., (2013) analyzed 40 parental reports of experiences when their child was diagnosed with hearing loss. The study specifically examined emotional and informational support provided by their child’s audiologist. They found that approximately half of the parents reported “a perceived lack of information provision” (Gilliver et al., 2013). Many parents reported that a single booklet was provided for them by the audiologist, forcing them to seek out additional early intervention and communication options for their child through the internet. Overall, “parents expressed a desire for more information than they have received” (Gilliver et al., 2013).

During their graduate studies, audiologists are trained in counseling; however, research has revealed counseling deficits in audiology. Training variations among different graduate programs can affect the degree to which students are prepared to effectively counsel patients (Muñoz et al., 2017). Research shows that during encounters with

patients, audiologists have been found to dominate conversations, which reduces the opportunity for patients and caretakers to voice concerns and ask questions. Audiologists are using counseling skills such as reflection, assessment of psychological factors, and development of an action plan minimally (Muñoz et al., 2017). Audiologists, especially those that specialize in pediatric audiology, should implement evidence-based counseling services that are patient-centered. This includes providing parents with continuous support and information.

It is the parent’s right to be provided uninfluenced information when they are deciding about their child’s hearing loss. After their child’s diagnosis, parents may be given or need to seek out a vast amount of information regarding the educational, communication, and technological options for their child (Hyde et al., 2010). It is critical that parents are provided a comprehensive understanding of their child’s diagnosis and their options to make decisions that are free from the influence of opinion. Previous research has evaluated the parental decision-making process when choosing modes of communication (Li et al., 2003), and explored the extent to which audiologists provided training and skill support to parents seeking to integrate strategies for communication into their child’s intervention (Munoz et al., 2015). Differentiating the current study from previous research is the surveying of both the audiologist and the parent of the child with hearing loss to look for discrepancies in the information reportedly given by the audiologist and received by the parent. Understanding what information is provided to parents by clinicians may provide insight into how to improve services and counseling, promoting successful patient outcomes.

The purpose of this study was to survey perspectives of parents of children diagnosed as Deaf or Hard of Hearing (DHH) as well as survey perspectives of audiologists who diagnose children as DHH. Information from the survey obtained data views on what information is being provided to parents from the audiologist perspective as well as the parent perspective regarding their child’s hearing loss, Deaf culture, and available communication options. The hypothesis proposed that audiologists would overestimate the number of resources they provided to parents, while parents would report not feeling like they were provided with enough information and support from their audiologist.

Method

Participants

Audiologists and parents of children who are DHH were surveyed about their respective experiences involving information about modes of communication. These participants were recruited from active members in social media groups for audiologists and parents of children who are DHH. Specific social media groups on Facebook where the survey was shared included: Audiology Happy Hour; Audiology Antics and Anecdotes—for All Hearing Professionals, Pediatric Educational Audiologists: AKA—Freakin’ Miracle Workers; National Hands and Voices Chapter; Alabama Hands and Voices Chapter; and

Support Group for Parents of Kids with Hearing Loss. Participant inclusion criteria was broad and included any parent of a child diagnosed as DHH or an audiologist who diagnosed children as DHH.

Survey

A survey was prepared using Qualtrics software (Qualtrics, Provo, Utah). The invitation to complete the survey included a brief introduction about the study, consent information, and a link to the online study. The survey was voluntary, anonymous, took approximately 10 minutes to complete, and no Personal Health Information (PHI) data was obtained in the process. At any time before submission of the survey, participants were able to withdraw from participation without penalty. The total number of surveys completed by audiologists was 91 and the total number of surveys completed by parents was 111.

The data collected pertained to the information being provided by audiologists to parents concerning various modes of communication and other educational information regarding hearing loss and options for amplification. Both audiologists and parents' experiences were measured by the survey. Several questions were administered to pinpoint the type and extent of information that was provided at the time of diagnosis.

Audiologist Survey

At the beginning of the survey, the participant was asked to identify as an audiologist or a parent. The answer to this question determined which set of questions the participant would be asked. If the individual selected *Audiologist*, they would be led to a survey of eight questions. Five of the questions allowed the audiologist to choose more than one answer (unlimited choice), and three questions required the audiologist to choose one answer (multiple choice). The unlimited choice questions all had an *Other* option and were followed by a comment section to explain and elaborate on the survey data. The multiple-choice questions gave a comment section for the audiologist to elaborate if they responded *No* or *Other* to the question. For reference, a complete listing of the audiologist survey questions can be found in Appendix A.

Parent Survey

If the individual selected *Parent*, they would be led to a set of thirteen questions. Five of the questions allowed the parent to choose more than one answer (unlimited choice). The unlimited choice questions all had an *Other* option and were followed by a comment section to explain and elaborate on the survey data. Six of the questions allowed the parent to choose one answer (multiple choice), and two of the questions were rating scales. The first rating scale had parents rate the information they received about each communication option listed by selecting either *Excellent*, *Good*, *Fair*, or *Poor*. The second rating scale had six individual statements concerning their personal experience with information on early intervention, communication modes, emotional support, and audiologist bias/pressure. The parent was asked to rate each statement with *Strongly Agree*, *Agree*, *Somewhat Agree*,

Neither Agree or Disagree, *Somewhat Disagree*, *Disagree*, or *Strongly Disagree*. For reference, a complete listing of the parent survey questions can be found in Appendix B.

Results

Demographics

Out of the 91 audiologists who completed the survey, 39.13% of participants worked at a hospital, 10.14% worked at a university, 8.70% at a private practice, and 8.70% for an Ear, Nose, and Throat (ENT) practice. One third of the participants (33.33%) worked at other settings such as educational audiologists, non-profit, and state agencies (see Figure 1 for results and Table 1 for comments). Audiologists that had been practicing for less than 5 years accounted for 31.88%, 17.39% had been practicing 5 to 10 years, 23.19% for 10 to 15 years, 7.25% for 15 to 20 years, and 20.29% for more than 20 years. See Figure 2 for results.

Figure 1

Workplace Setting: Audiologist

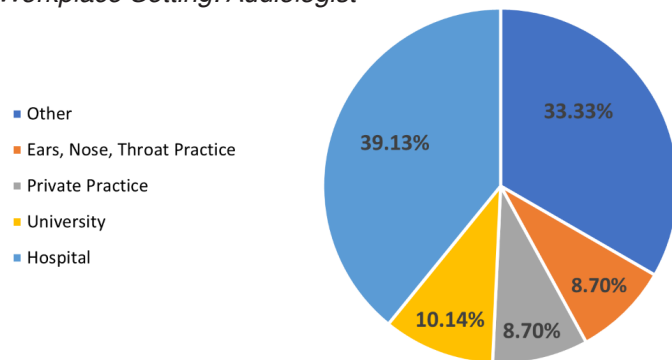


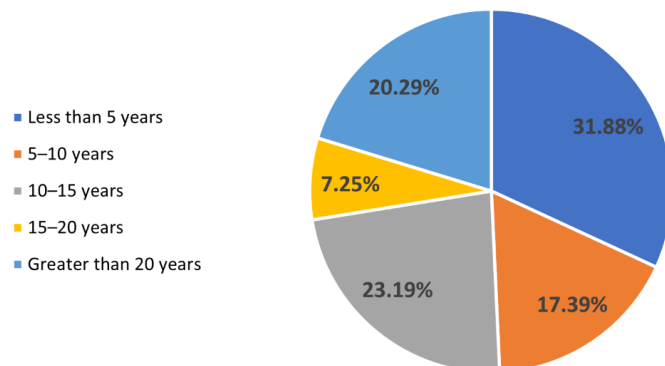
Table 1

Workplace Setting: Audiologist

Q1: What best describes your work setting?	Audiologist Comments
	<ul style="list-style-type: none"> ● State Agency ● Private Non-Profit ● Early Interventionist ● Educational Audiology ● Multispecialty Pediatric Clinic ● Contract Audiologist

Figure 2

Years Practicing: Audiologists



Out of the 111 parents who completed the survey, none of the participants responded that they were deaf, 6.25% indicated that they were hard of hearing, and 93.75% were individuals with normal hearing. Parents that reported their child was diagnosed as DHH from birth to 3 months of age accounted for 47.56%, 2.44% from 4 to 6 months of age, 1.22% from 7 to 12 months of age, 7.32% from 1 to 2 years old, 10.98% at 2 to 3 years old, and 30.49% over the age of 3 (see Figure 3). According to parental participant report, 24.69% of children were part of the Deaf Culture and 75.31% were not. Parents reported their child was fit with hearing aids in 77.46% of cases, and 22.54% reported their child was fit with a cochlear implant.

Figure 3
Child's Age of Diagnosis: Parents

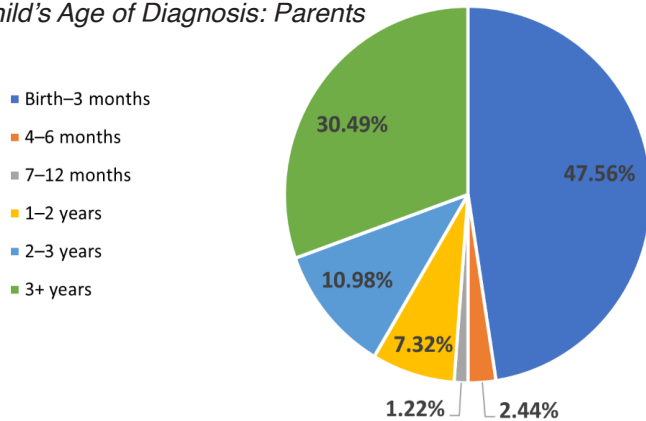


Figure 4a
Sources of Information/Materials: Audiologists

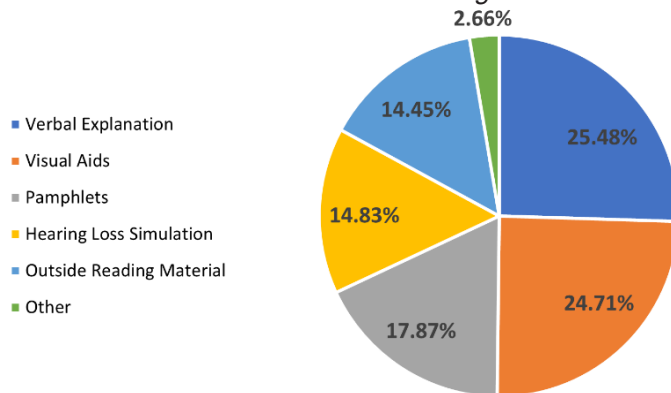


Table 2a
Sources of Information/Materials: Audiologists

Q3: What materials did you use in order to explain the child's hearing loss to the parents?	<p>Audiologist Comments</p> <ul style="list-style-type: none"> ● Informational videos, social media, etc. ● Audiogram, speech banana, other parents, etc. ● Hands and Voices Resource Guide ● I ask parents how they would like the information presented; everyone has different learning styles. ● Materials from Beginnings are excellent.
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Figure 4b
Sources of Information/Materials: Parents

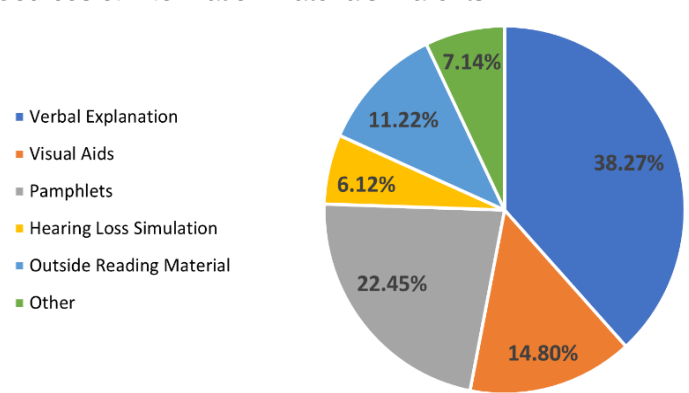


Table 2b
Sources of Information/Materials: Parents

Q5: What materials were you provided by an audiologist in order to explain your child's hearing loss?	<p>Parents Comments</p> <ul style="list-style-type: none"> ● Contacts with School for the Deaf and families with similar experiences ● Information on FM systems ● Resource binder on deaf issues, culture and assorted information explaining topics ● Just test results (Auditory Brainstem Response [ABR], audiogram, etc.) ● None ● A resource binder on deaf issues, culture and assorted information explaining different things. Also had different organizations contact info.
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Sources of Information and Materials

Audiologists were asked to report what materials they used to explain the hearing loss to parents. Audiologists were given the option to select multiple answers and the reported percentages reflect the total responses selected for that category. The most frequently reported was Verbal Explanation (25.48%), then Visual Aids (24.71%), Pamphlets (17.87%), Hearing Loss Simulation (14.83%), Outside Reading Materials (14.45%), and Other (2.66%). Further analysis of the responses found that 24.00% of audiologists chose not to answer this question, while the other audiologists (76.00%) reported they used a combination of these materials when explaining hearing loss to parents. The comment section was used by respondents to express other responses and more detailed information. Results can be found in Figure 4a, and comments can be found in Table 2a.

Parents were asked what materials were provided by an audiologist to further explain their child's hearing loss. The parent was able to select multiple answers and the reported percentages reflect the total responses selected for that category. The most frequently reported was Verbal Explanation (38.27%), then Pamphlets (22.45%), Visual Aids (14.8%), Outside Reading Materials (11.22%), Hearing Loss Simulation (6.12%), and Other (7.14%). Further analysis of the responses found that 27.00% of the parents chose not to answer this question,

while 21.60% of parents reported that only one type of material was used in explaining their child's hearing loss with Verbal Explanation (16.20%) being the most frequent method. The other parents (51.32%) reported that the results were explained with two or more types of materials. Results can be found in Figure 4b, and comments can be found in Table 2b.

Cochlear Implant and Deaf Culture Information

Audiologists were asked if they provided parents with information on both cochlear implants and Deaf Culture. It was found that 77.94% of audiologists reported providing both information on cochlear implants and Deaf culture, while 22.06% of audiologists reported not providing this information. Results can be found in Figure 5a, and comments on why they did not provide both can be

found in Table 3a. When parents were asked if they were provided information on both cochlear implants and Deaf Culture, 71.95% of parents reported *No*, 12.20% reported *Yes*, and 15.85% reported *Other*. Results can be found in Figure 5b, and comments can be found in Table 3b. A stark contrast is seen in the materials reportedly given by the audiologist and those reported being received by the parent. Although this numerical difference does represent a breakdown in relaying of information from the professional to the parent, it has also been influenced by factors such as (a) setting of the audiologist, (b) parental inquiry and wants for their child, and (c) the severity of the child's hearing loss not necessitating these conversations (see Table 3a and 3b).

Figure 5a

Cochlear Implant and Deaf Culture Information: Audiologists

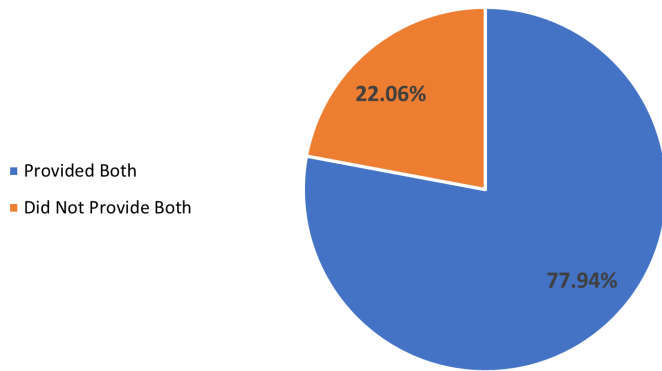


Figure 5b

Cochlear Implant and Deaf Culture Information: Parents

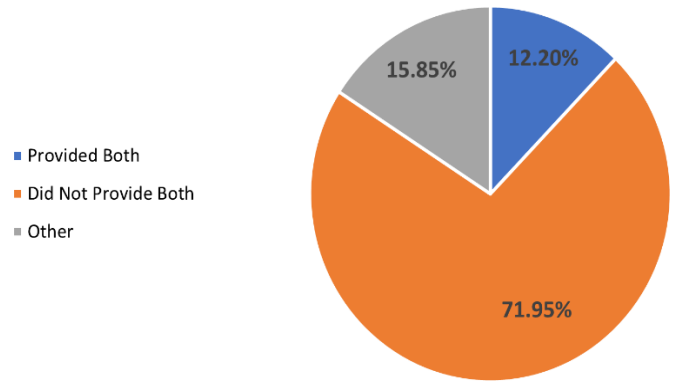


Table 3a

Cochlear Implants and Deaf Culture Information: Audiologists

<p>Q4: Did you provide the parents with information on both cochlear implants AND Deaf Culture?</p>	<p>Audiologist Comments</p> <ul style="list-style-type: none"> • All parents I've seen want their child to be hearing • I do not do cochlear implants, so I generally do not discuss them at length. I refer ALL newly diagnosed children and their parents to Parent Support services, which include Guide By Your Side, unbiased support from parents of both aided/implanted children and children using ASL. I do not feel I am enough of an expert on either to provide an opinion. • We provide information on ALL communication options. So, yes, but this question could be expanded on. Also, we only discuss CIs if applicable. CI candidates referred to another AuD • I would not choose either yes or no, but rather, "it depends." I allow the parents'/family's questions to guide the information provided, especially in the early stages. In general, I think audiologists talk too much and listen too little. What I do consistently encourage is that the family develop an action plan- as quickly as their unique circumstances permit. • In our team if we newly identify a profound hearing loss we send it to audiologists that work either CIs for confirmation and discussion of hearing aids CI and Deaf culture. I usually ask about whether the parents' goal is for their child to use hearing/speech to communicate and only provide info on Deaf Culture if parents ask about other options. • We are an LSL preschool. By the time families reach us they are implanted (or on the way) and have already chosen communication method • If I see a child who has significant hearing impairment, I refer them to the ENTs who perform cochlear implants and have audiologists who deal almost exclusively with kids. They are plugged in to all the local resources for these kids. • I provide info on learning ASL but not on Deaf culture. They are not the same, so I chose no.
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Note. ASL = American Sign Language; CI = cochlear implant; ENT = Ear, Nose, and Throat doctor; LSL = listening and spoken language

Table 3b

Cochlear Implants and Deaf Culture Information: Parents

<p>Q6: Were you provided with information on both cochlear implants AND Deaf culture by an Audiologist?</p>	<p>Parents Comments</p> <ul style="list-style-type: none"> ● CI but told that child would be a good candidate if needed later ● Little information ● “They told me cochlear implants were the only thing that could help my son learn. They completely ignored that there should always be a trial of hearing aids first and they were incredibly rude about deaf culture” ● Neither ● No, but only because we did not need these
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Note. CI = cochlear implant.

Modes of Communication

Audiologists were asked to indicate what modes of communication they used to provide information to parents. They could respond by selecting all modes that they have provided, and the reported percentages reflect the total responses selected for that mode of communication. The most frequently reported was American Sign Language (25.11%), Auditory Verbal

(24.67%), Total Communication (23.35%), Bilingual Approach (14.54%), Signed Exact English (6.17%), Cued Speech (4.41%), and Other (1.76%). Additional analysis found that 31.87% of audiologists chose not to answer this question, while 50.55% of audiologists reported giving parents information on three or more modes of communication with auditory verbal and ASL being the two most often recommended approaches. Results can be found in Figure 6a, and comments can be found in Table 4a. Parents were asked what information on modes of communication they were provided and could select multiple answers. The reported percentages reflect the total responses selected for that mode of communication. The majority reported receiving information on Auditory Verbal (43.59%). Information for other modes of communication were ASL (23.08%), Total Communication (11.54%), Cued Speech (10.26%), Other (5.13%), Bilingual Approach (3.85%), and Signed Exact English (2.56%). Additional analysis found that 63.96% of parents chose not to answer this question, while 21.62% of parents reported getting on one mode of communication with auditory verbal being the most often recommended approach. Parents reported 9.00% of the time they were given information on two modes of communication and 5.41% of the time they were given information on three or more modes of communication with auditory verbal and ASL being the most often recommended approaches. Results can be found in Figure 6b, and comments can be found in Table 4b.

Figure 6a

Modes of Communication: Audiologists

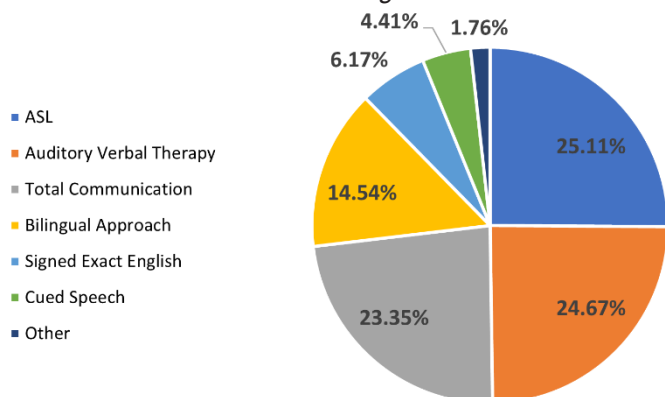
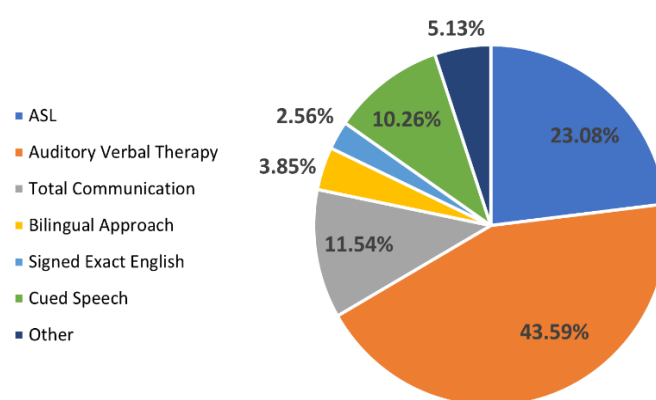


Figure 6b

Modes of Communication: Parents



Note. ASL = American Sign Language.

Table 4a

Modes of Communication: Audiologists

<p>Q5: Which of the following did you provide information regarding modes of communication?</p>	<p>Audiologists Comments</p> <ul style="list-style-type: none"> ● I would argue that AVT and TC are not modes of communication but are teaching methods ● As I said above, I do not feel I am enough of an expert on any of these methods of communication to guide the parent of a profoundly hearing-impaired child. When I initially diagnose a child with a profound hearing impairment, I refer these parents to agencies in our state who provide excellent, unbiased information on many of these methods of communication. Again, really depends on the degree of hearing loss. ● Parents are provided with information that allows them to access information about all treatment options so they can be make informed decisions for their child and take the lead.
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Note. AVT = auditory verbal therapy; TC = total communication.

Table 4b

Modes of Communication: Parents

<p>Q7: Did an audiologist provide you with any of the following information regarding modes of communication?</p>	<p>Parents Comments</p> <ul style="list-style-type: none"> • Information came more from EI • Not our initial audiologist • Child already speaking
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Note. EI = early intervention.

Emotional Support Information

Provision of emotional support materials was also evaluated. Audiologists were given the option to select multiple answers. The reported percentages reflect the total responses selected for that category. The most frequently reported were Family Support Groups (36.77%), Blogs/Social Media Groups (25.16%), Deaf Mentors (16.77%), Family Counseling Services (16.77%), and Other (4.52%). Additional analysis found that 30.77% of audiologists chose

not to answer this question, while 31.87% of audiologists reported giving three or more supports with the same frequently reported categories listed above. Information on one support was reportedly given by 13.19% of audiologists, while 24.18% reported giving information of two supports. Results can be found in Figure 7a, and comments can be found in Table 5a. Parents were asked what information the audiologist provided on emotional support materials and were also given the option to select multiple answers. The reported percentages reflect the total responses selected for that category. The most frequently reported answers for parents were Family Support Groups (46.67%), Blogs/Social Media Groups (18.33%), Deaf Mentors (16.67%), Family Counseling Services (8.33%), and Other (10%). Additional analysis found that 63.10% of parents chose not to answer this question, while 24.32% of parents reported getting information on one support, 5.40% on two supports, and 5.41% on three or more supports with the same frequently reported categories listed above. Results can be found in Figure 7b, and comments can be found in Table 5b.

Figure 7a

Emotional Support Information Provided: Audiologists

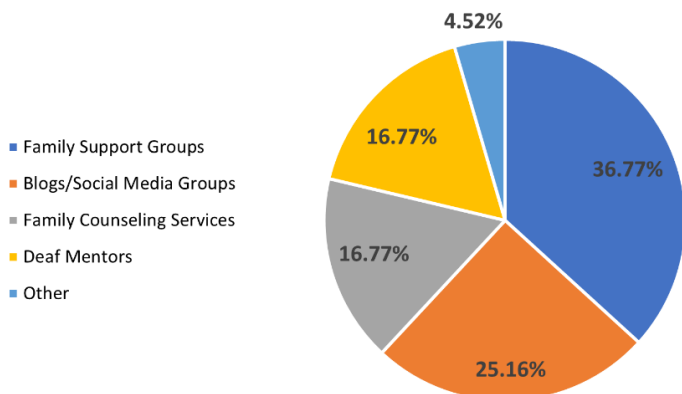


Figure 7b

Emotional Support Information Provided: Parents

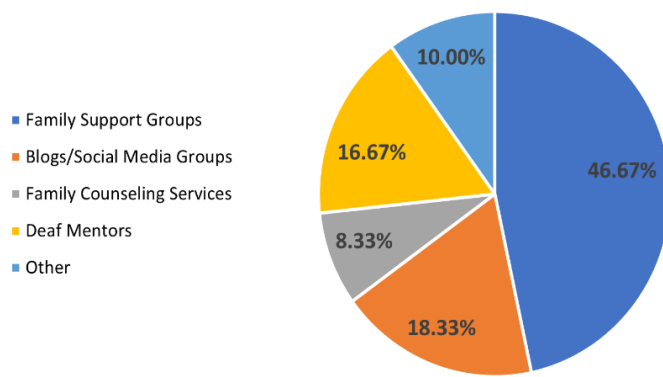


Table 5a

Emotional Support Information Provided: Audiologists

<p>Q6: Which of the following did you provide information on regarding emotional support?</p>	<p>Audiologists Comments</p> <ul style="list-style-type: none"> • Hands & Voices, CRS Parent Consultant, Family Voices • Summer camps in our state, semi-annual family events available through the school district • Again, this is unique to each family, but on the whole, Hands and Voices Guide by Your Side program is an excellent resource as is making family to family links where appropriate. Each family's circumstances are unique. Every effort is made to support parent choice at every stage. • Other parents who have children with hearing loss. • EI/Beginnings • Educational Support Groups
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Note. CRS = Children's Rehabilitation Services; EI = early intervention.

Table 5b

Emotional Support Information Provided: Parents

<p>Q8: Did an audiologist provide you with any of the following information concerning emotional support?</p>	<p>Parents Comments</p> <ul style="list-style-type: none"> • Early Intervention • Beginnings • Phone number of a family in our town who's now grown kids have CIs and spoken language • Referral to early intervention and schools for the deaf who connected us to families, deaf adults, and support groups
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Note. CI = cochlear implant.

State Resources

Audiologists were asked to indicate what state resources they recommended to parents and were given the option to select multiple answers. The reported percentages reflect the total responses selected for that category. The most frequently provided responses were Early Intervention (52.42%), Hands and Voices Chapter (38.71%) and Other (8.87%). Additional analysis found that 25.27% of audiologists chose not to answer this question, while 28.57% of audiologists gave information to parents on both Early Intervention and Hands and Voices Chapter. Audiologists gave parents information on Early Intervention in 6.59% of cases and in 8.79% of cases a combination of state resources was given. Results can be found in Figure

8a, and comments can be found in Table 6a. Parents were asked what information they received from audiologists on state resources, and they were given the option to select multiple answers. The reported percentages reflect the total responses selected for that category. The most frequently reported responses were Early Intervention (55.56%), Hands and Voices Chapter (23.33%), and Other (21.11%). Additional analysis found that 36.03% of parents chose not to answer this question, while 32.43% of parents were given information on only one state resource (most often Early Intervention and Hands and Voices) and 17.12% of parents reported receiving information on two state resources (most often Early Intervention). Results can be found in Figure 8b, and comments can be found in Table 6b.

Figure 8a

State Resources: Audiologists

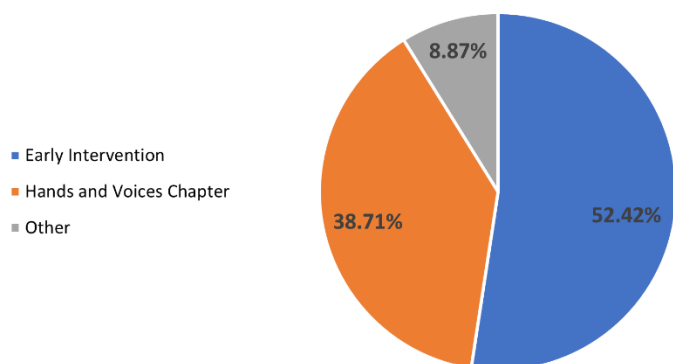


Figure 8b

State Resources: Parents

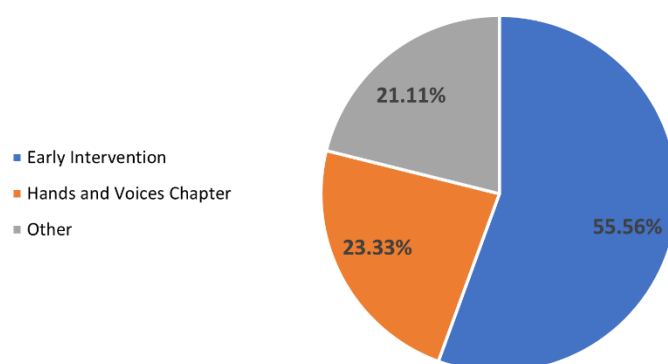


Table 6a

State Resources: Audiologists

<p>Q7: Which of the following state resources did you recommend to the parents?</p>	<p>Audiologists Comments</p> <ul style="list-style-type: none"> Public health nursing Offer to sponsor online sign classes and John Tracy clinic Children's Rehabilitation Services for hearing aids (Medicaid) Colorado Home Intervention Program (CHIP) providing home-based early intervention support and services from birth to age 3 years. I have reservations about our state EI services. The intensity and frequency of intervention is insufficient to support positive outcomes. Referrals to private providers or the school for the deaf (depending on chosen communication mode) is always required. In our state, Hands and Voices is not a "state resource," but I think it would be beneficial if it was. Guide by your side program AG Bell Chapter
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Note. EI = Early Intervention.

Table 6b

State Resources: Parents

<p>Q9: Which of the following state resources were recommended by your audiologist?</p>	<p>Parents Comments</p> <ul style="list-style-type: none"> None Really nothing like this was offered/available Our audiologist never recommended any resources. I had to research them myself. Eventually we connected to Hands and Voices, but not until a few years after diagnosis. Already in EI School for Deaf and Blind
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Note. EI = Early Intervention.

Legislative Materials

Provision of information on legislation regarding the Deaf and hard of hearing was also evaluated. Given the option to select multiple answers, the reported percentages reflect the total responses selected for that category. Audiologists most frequently reported providing information on the Individualized Family Service Plan/Individualized Education Plan (27.94%), Individuals with Disabilities Act (22.06%), Section 504 of the Rehabilitation Act of 1973 (21.32%), American Disabilities Act of 1990 (8.09%), and Other (3.68%). Additional analysis found that 29.67% of audiologists chose not to answer this question, while 26.37% indicated they did not give information on any of

the choices listed or they gave information indicated as Other. Most of the audiologists (37.36%) reported giving information on a combination of the listed laws. Results can be found in Figure 9a, and comments can be found in Table 7a. Parents were given the choice to select multiple answers and the reported percentages reflect the total responses selected for that category. Most frequently reported responses were Family Service Plan/Individualized Education Plan (36.36%), Individuals with Disabilities

Education Act (27.73%), Section 504 of the Rehabilitation Act of 1973 (15.91%), American Disabilities Act of 1990 (13.64%), and Other (9.09%). Additional analysis found that 25.23% of parents chose not to answer this question, while 13.51% of parents were given information on only one law, 4.50% of parents reported receiving information on two laws, and 4.50% of parents reported receiving information on three or more laws. Results can be found in Figure 9b, and comments can be found in Table 7b.

Figure 9a
Legislative Materials: Audiologists

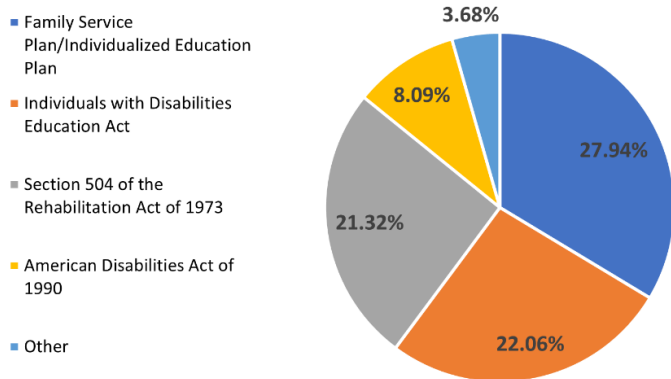


Figure 9b
Legislative Materials: Parents

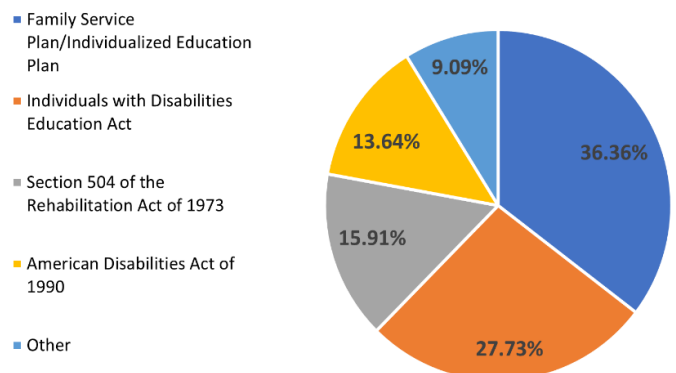


Table 7a
Legislative Materials: Audiologists

<p>Q8: Which of the following laws did you provide information on to the parents?</p>	<p>Audiologists Comments</p> <ul style="list-style-type: none"> • There is SO MUCH information being provided when a child is initially diagnosed with hearing loss, I don't feel that particular time is the best to discuss laws and advocacy for the child. I generally provide age appropriate information at follow-up appointments and guide the parents with the appropriate channels to contact re: obtaining an IFSP/IEP or 504. Unfortunately, in the city I live in, many of the parents are not very motivated despite being educated about their child's hearing impairment to advocate for their child and many, many of the schools do not comply with IDEA, so the children do not get the accommodations they need. It is extremely difficult to empower some parents while they are grieving the loss of their "perfect" child. Then you have others who take it and run with it. It is the nature of our business :-) • I talk about school laws when children get close to school age. Also, IEPs are part of IDEA • ...but not at initial diagnosis! Families need space and time to process. This information can come later. • Our EI/Beginnings does this
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Note. EI = Early Intervention; IDEA = Individuals with Disabilities Education Act; IEP = Individualized Education Plan; IFSP = Individual and Family Service Plan; 504 = Section 504 of the Rehabilitation Act of 1973.

Table 7b
Legislative Materials: Parents

<p>Q10: Which of the following laws were you provided information on by the audiologist?</p>	<p>Parents Comments</p> <ul style="list-style-type: none"> • We live abroad • None (4 responses)
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parent comments. Parents were then asked to rate the information (using *Excellent, Good, Fair, or Poor*) they received about each of the communication options when their child was diagnosed. See Table 9 for results. Finally, they were given a list of questions and asked how much they agree or disagree with each of the statements (i.e., *Strongly Agree, Agree, Somewhat Agree, Neither Agree or Disagree, Somewhat Disagree, Disagree, or Strongly Disagree*). The majority of parents agreed with the following statements:

Parent Perspective

When asked if they felt their audiologist provided them with unbiased, extensive information on intervention for their child's hearing loss, 47.56% of parents said *Yes*, 43.90% said *No*, and 8.54% said *Other*. See Table 8 for

- "It was easy for me to get information regarding early intervention options for my child."
- "It was easy for me to obtain information regarding different modes of communication for my child."

- “I feel that my audiologist’s goal was to provide me with unbiased options in order for me to make the best decisions for my child.”
- “I understand and utilize the public laws that seek to help the Deaf population.”

On the other hand, most parents surveyed disagreed with the following statements:

- “I was provided with extensive information regarding emotional support after my child’s diagnosis.”
- “I felt pressured by my audiologist to choose one communication option over others.”
- “I feel as though I do not understand my child’s hearing loss and its effects.”
- “I felt as though my audiologist did not have enough time to explain important concepts thoroughly.”

Nearly equal numbers of parents agreed and disagreed with the statement, “I often felt frustrated and confused regarding what decisions to make.” See Table 10 for detailed results.

Discussion

The findings of the survey demonstrated that the information that audiologists reported providing was consistent with what parents reported receiving. Although the intended goal of the study was to compare audiologist and parent perspectives on the information and support provided when a child is deaf or hard of hearing, the study also analyzed the parent’s opinion of their overall experience in working with an audiologist and the quality of the information they received about their child’s hearing loss. When comparing what audiologists reported providing to what parents reported receiving, survey data revealed much consensus concerning types of information provided. This includes types of materials provided, emotional support, state resources, and related legislation. The responses indicated that audiologists are providing this information to parents; however, there is questionable value and ability to apply the information for parents, as seen in the parent perspective rating questions.

Table 8
Comments on Quality of Information about Hearing Loss Intervention

<p>Q11: Do you feel that your audiologist provided you with unbiased, extensive information regarding intervention for your child’s hearing loss?</p>	<p>Parents Comments</p> <ul style="list-style-type: none"> • Unbiased, but not extensive • Somewhat • “I’m not sure if it was unbiased but we planned to choose spoken language for our child and the audiologist may have perceived that” • “She was definitely biased towards implants and one size fits all for individuals with hearing loss”
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Table 9
Communication Option Information Intervention

	Excellent	Good	Fair	Poor
Auditory Verbal Therapy	26.76%	14.08%	16.90%	42.25%
Cued Speech	2.84%	8.82%	17.65%	70.59%
American Sign Language	9.09%	12.12%	19.70%	59.09%
Signed Exact English	0%	6.15%	15.38%	78.46%
Total Communication	9.09%	13.64%	18.18%	59.09%
Bilingual Approach	1.54%	7.69%	10.77%	80%

For the rating scale questions, a discrepancy was found between reported provision of Deaf culture and cochlear implant information. This could be attributed to the chance that the child did not meet candidacy requirements, and the audiologist did not present this information because they knew the child was not a candidate. Therefore, the discrepancy does not mean that audiologists are not providing information on both because of their personal biases, but possibly that the choices are not applicable for the child’s specific loss. However, one parent participant left a comment that their audiologist told them, “Cochlear implants were the only thing that could help my son learn. They completely ignored that there should always be a trial of hearing aids first, and they were incredibly rude about Deaf culture.” One audiologist participant commented, “I usually ask about whether the parents’ goal is for their child to use hearing/speech to communicate and only provide info on Deaf culture if parents ask about other options.” When parents were asked if they felt that their audiologist provided them with unbiased, extensive information regarding intervention for their child’s hearing loss, nearly half of respondents reported that they did not believe that they received unbiased, extensive information. Participants could elaborate further on this question in the comment section. One participant stated, “The information was unbiased, but not extensive.” Another participant stated, “She was definitely biased towards implants and a one size fits all for individuals with hearing loss.” Based on evidence from the survey data obtained, there is an indication that biased information could be being presented to parents. According to American Speech-Language-Hearing Association (ASHA), audiologists help facilitate decision making with families regarding their child’s hearing loss by the information they provide at the time of diagnosis. When counseling families, it is the clinician’s responsibility to remove their own biased opinions from their professional delivery of up-to-date, relevant information. When the family is ready to make an

Table 10
Statements Regarding Information Given to Parents

	Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
It was easy for me to get information regarding early intervention options for my child.	19.75%	19.75%	18.52%	9.88%	12.35%	9.88%	9.88%
It was easy for me to obtain information regarding different modes of communication for my child.	7.50%	23.75%	21.25%	12.50%	12.50%	12.50%	10.00%
I was provided with extensive information regarding emotional support after my child's diagnosis.	4.88%	12.20%	10.98%	4.88%	13.41%	28.05%	25.61%
I feel that my audiologist's goal was to provide me with unbiased options in order for me to make the best decisions for my child.	14.63%	19.51%	15.85%	23.17%	15.85%	4.88%	6.10%
I felt pressured by my audiologist to choose one communication option over others.	9.88%	9.88%	7.41%	11.11%	8.64%	30.86%	22.22%
I understand and utilize the public laws that seek to help the Deaf population.	8.64%	18.52%	18.52%	18.52%	7.41%	14.81%	13.58%
I feel as though I do not understand my child's hearing loss and its effects.	2.47%	9.88%	9.88%	9.88%	13.58%	24.69%	29.63%
I often felt frustrated and confused regarding what decisions to make.	13.58%	17.28%	14.81%	8.64%	12.35%	22.22%	11.11%
I felt as though my audiologist did not have enough time to explain important concepts thoroughly.	10%	8.85%	16.25%	12.5%	6.25%	22.5%	23.75%

informed decision about the desired outcomes for their child, audiologists are then obligated to advise families on how best to achieve those outcomes (ASHA, 2008).

Many parents reported confidence in the ability to obtain information on early intervention services for their child and information on modes of communication. In addition, parents felt they were not pressured by their audiologist to choose a certain mode of communication and that their audiologist's goal was to provide them with unbiased options for their child. Approximately one half of parent respondents reported feeling frustrated and confused on what decision to make about their child's hearing loss. Furthermore, ASHA reports that it is the audiologist's responsibility to provide sufficient and concise information to assist families in their decision making. Audiologists should refrain from using terminology that confuses parents and recognize that every family does not process or accept new information in the same manner and pace (ASHA, 2008).

Parent perspective survey questions yielded evidence that many parents felt they were not provided with extensive information regarding emotional support after their child's diagnosis. Stress and grief may occur in parents due to the diagnosis of their child's hearing loss, which can slow down the intervention process. Once the parent's

emotional needs are addressed, they become more receptive to new information for making informed decisions concerning their child. It is critical that audiologists are making the appropriate recommendations for emotional support including family counseling, support groups, and connecting with other families with similar experiences (ASHA, 2008).

Data analysis also found most parents felt that they did not fully understand their child's hearing loss and its effects. Only a few audiologists and parents reported using and/or observing hearing loss simulation to further understand hearing loss and its ramifications to the understanding of speech. Research shows that hearing loss simulation is an excellent tool to provide parents with a realistic demonstration of the communicative and psychosocial effects of their child's hearing loss. Through hearing loss simulation, family members can recognize the importance of effective communication strategies, such as lipreading and speaking clearly. Moreover, hearing loss simulation gives parents realistic expectations concerning amplification (Zurek & Desloge, 2007).

Workplace variations can place certain limitations on the audiologist's ability to counsel parents effectively. These limitations may include, but are not limited to, the amount of time the audiologist has available to spend with patients,

how often they see the pediatric population, if their setting provides various amplification options, and limitations to accessing necessary supplies for parent education. More than one-third of audiologists that participated in the survey reported working in a hospital. According to Severn and colleagues (2012), audiologists that reported the highest stress levels were working in public hospitals. This is a notably difficult work environment due to busy caseloads that may limit quality interaction with patients and dealing with grief reactions of patients, parents, or family members (Severn et al., 2012). Although this theory cannot be proven by the current study, audiologists may not have been able to provide as extensive information to parents as they would have liked due to workplace limitations. This possibility could influence the results obtained on audiologist provision of information. Another possible factor that could have influenced results was the number of years the audiologist had practiced. Nearly one-third of audiologist respondents reported only working clinically for less than 5 years. Work experience, self-confidence, and clinical maturity can play a large role in knowledge and the ability to effectively counsel and provide appropriate and extensive recommendations.

Nearly half of the parent respondents reported their child was diagnosed anywhere from birth to 3 months of age. As previous research shows, children that are fit with amplification earlier are more likely to have better language and learning outcomes than children who are fit later in life (Moeller & Tomblin, 2015). Since nearly half of the respondents reported early diagnosis, this could have yielded a possible positive effect on the survey data. An early diagnosis could have led to better parent perspectives and overall ratings on the information they received. Those with early diagnoses may have had more time to make decisions and experienced less stress when it came to the timeline of their child's acquisition of language. Nearly one-third of parents reported their child was diagnosed over 3 years of age, which may have yielded a more negative experience with their audiologist; however, there is no evidence as to how older ages of diagnoses affected the survey data obtained.

Population Considerations

Although most parents reported their child was fit with hearing aids, several parents reported their child was fit with a cochlear implant. Additionally, there was a reasonable number of parents whose child was a part of Deaf Culture. The survey obtained information from a diverse population, with participants in both hearing and Deaf Culture along with considerable variations in amplification use. This provided a wide range of responses for data analysis. Overall, there were 91 audiologists and 111 parents who participated in the survey. The large and comparable audiologist and parent sample sizes allowed the authors to analyze population data and receive a wide array of participant comments. Of the 91 audiologists and 111 parents who participated in this study, there were surveys from both parties that were not fully completed. Therefore, these surveys

were only considered in part of the data analysis, which affected the sample size. As the dissemination approach allowed participants to self-select, the authors suspect that rather than the length of the survey, possible reasons for incompletes may have included loss of cell phone power or service, outside distractions (e.g., work duties, obligations in the home environment), accidental closing of the browser, and/or compatibility across mobile devices for the charts.

Limitations

There are a few factors that limit the application of results from this study. First, it must be considered that audiologists who participated in this survey did not work directly with the parent participants within the survey. Therefore, this survey data does not reflect direct clinician to patient comparisons on counseling, services, and quality of information and recommendations provided. Additional limitations include the possibility that the audiologists surveyed may not have a large pediatric caseload at their workplace and may have depended more on previous experience and education rather than on current patient encounters to answer survey questions. In addition, an audiologist participant commented, "We rarely see children, and if we do, we typically get mild to moderate hearing losses." The intended target population may not have been fully obtained due to limited author control over specific pediatric clinical experience of the audiologists that participated in the survey. Extensive clinical experience with the pediatric population can affect the audiologists' confidence level and ability to effectively counsel parents and provide appropriate and extensive recommendations. Additionally, it is possible that parents who were surveyed may not have been counseled or given information on "cochlear implants and Deaf culture" (Parent Survey-Question 6) due to the degree of their child's hearing loss obviating the need for those conversations with their audiologist. Therefore, this may have directly affected the survey responses obtained. More specific instructions could have been given to the parents to assist them in thinking about their personal experiences and how that could potentially influence their answers.

Lastly, the dissemination approach of using social media platforms and the lack of ability to adequately quantify the response rates from individuals in the survey was problematic. Despite this, the results revealed clear patterns related to the information provided to parents from audiologists in a variety of work settings. Since the survey was exclusively distributed through social media platforms, the survey was not able to accommodate participants from populations who are not on social media and/or do not have access to computers, smartphones, internet access, et cetera. The data showed that nearly one third of the audiologists surveyed had practiced for less than 5 years. This population trend of younger and less experienced audiologists may be because younger generation audiologists may have more access and comfort with the use of social media platforms.

Conclusion

The data showed that in many aspects, adequate information is being provided to parents when their child is diagnosed with hearing loss; however, it also showed that information in many areas was insufficient, and parents did not feel confident in their ability to make decisions for their child. Within the parent survey, 93.75% of parent respondents reported that they were hearing individuals with a child with hearing loss. Research shows this is a common occurrence, and parents who have no previous experience in this realm will need more guidance and information about making decisions for their child. Due to the short time window for intervention, the decisions made at this time are of high priority. It is critical to provide parents with reliable guidance and support during this time to make properly informed decisions for their child (Kushalnagar et al., 2010).

This makes the decision-making process considerably more difficult, as they are navigating unknown waters. Audiologists have the responsibility to provide parents with unbiased, extensive information for parents to successfully make informed decisions for their child. Provision of practical, comprehensive information and recommendations may lead to improved parent knowledge and confidence. Ample time should be allotted by audiologists when scheduling appointments with parents of children who are deaf or hard of hearing; this will allow time for the audiologist to fully educate, counsel, and support the parents who are also processing their emotions. Audiologists also should be vigilant in providing evidence-based practice and in maintaining education of current state and local resources, as well as emotional support available to help families after a diagnosis of hearing loss. To expand on this research, a study could examine parent perspectives on what information and audiological services would have been or were most beneficial while making decisions for their child. This may, in turn, provide clearer information on what audiologists can do to further assist parents during a demanding, yet rewarding time.

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Appendix A
Audiologist Survey Questions

1. What best describes your work setting?
 - a. Hospital
 - b. University
 - c. Private Practice
 - d. ENT
 - e. Other—comments were accepted

2. How many years have you been practicing?
 - a. Less than 5 years
 - b. 5–10 years
 - c. 10–15 years
 - d. 15–20 years
 - e. Greater than 20 years

3. What materials did you use in order to explain the child's hearing loss to the parents? Check all that apply
 - a. Pamphlets
 - b. Verbal Explanation
 - c. Visual Aids
 - d. Hearing Loss Simulation
 - e. Outside Reading Materials (i.e., online articles, books, etc.)
 - f. Other—comments were accepted

4. Did you provide parents with information on both cochlear implants AND Deaf culture?
 - a. Yes
 - b. No (if no, why?)- comments were accepted

5. Which of the following did you provide information on regarding modes of communication? Please select all that apply.
 - a. Auditory Verbal
 - b. Cued Speech
 - c. American Sign Language
 - d. Signed Exact English
 - e. Total Communication
 - f. Bilingual Approach
 - g. None of the above
 - h. Other—comments were accepted

6. Which of the following did you provide information regarding emotional support? Please select all that apply.
 - a. Deaf Mentors
 - b. Family Support Groups
 - c. Family Counseling
 - d. Blogs/Social Media Groups
 - e. None of the above
 - f. Other—comments were accepted

7. Which of the following state resources did you recommend to the parents? Please select all that apply.
 - a. Early Intervention
 - b. Hands and Voices Chapter
 - c. Other—comments were accepted

8. Which of the following laws did you provide information on to the parents? Please select all that apply.
 - a. Individuals with Disabilities Education Act
 - b. Individualized Family Service Plan/Individualized Education Plan
 - c. Section 504 of the Rehabilitation Act of 1974
 - d. American Disabilities Act of 1990
 - e. Other—comments were accepted

Appendix B
Parent Survey Questions

1. Are you
 - a. Deaf
 - b. Hard of Hearing
 - c. Hearing
2. How old was your child when they were diagnosed as Deaf/Hard of Hearing?
 - a. Birth–3 months
 - b. 4–6 months
 - c. 7–12 months
 - d. 1–2 years
 - e. 2–3 years
 - f. Over 3 years
3. Is your child a part of Deaf Culture?
 - a. Yes
 - b. No
4. Does your child wear
 - a. Hearing Aids
 - b. Cochlear Implants
 - c. None of the above
5. What materials were you provided by an audiologist in order to explain your child's hearing loss? Please select all that apply.
 - a. Pamphlets
 - b. Verbal Explanation
 - c. Visual Aids
 - d. Hearing Loss Simulation
 - e. Outside Reading Materials (i.e. online articles, books, etc.)
 - f. Other—comments accepted
6. Were you provided with information on both cochlear implants AND Deaf culture by an Audiologist?
 - a. Yes
 - b. No
 - c. Other—comments accepted
7. Did an audiologist provide you with any of the following information regarding modes of communication? Please select all that apply.
 - a. Auditory Verbal Therapy
 - b. Cued Speech
 - c. American Sign Language
 - d. Signed Exact English
 - e. Total Communication
 - f. Bilingual Approach
 - g. None of the above
 - h. Other—comments accepted
8. Did an audiologist provide you with any of the following information concerning emotional support? Please select all that apply.
 - a. Deaf Mentors
 - b. Family Support Groups
 - c. Family Counseling
 - d. Blogs/Social Media Support Groups
 - e. None of the above
 - f. Other—comments accepted
9. Which of the following state resources were recommended by your audiologist? Please select all that apply.
 - a. Early Intervention
 - b. Hands and Voices Chapter
 - c. Other—comments accepted

10. Which of the following laws were you provided information on by the audiologist? Please select all that apply.
- Individuals with Disabilities Education Act
 - Individualized Family Service Plan/Individualized Education Plan
 - Section 504 of the Rehabilitation Act of 1974
 - American Disabilities Act of 1990
 - Other—comments accepted
11. Do you feel that your audiologist provided you with unbiased, extensive information regarding intervention for your child's hearing loss?
- Yes
 - No
 - Other—comments accepted
12. Rate the information you received about each of the following communication options when your child was first diagnosed. Parents were asked to choose one of the following for each communication option listed below: *Excellent*, *Good*, *Fair*, and *Poor*.
- Auditory Verbal
 - Cued Speech
 - American Sign Language
 - Signed Exact English
 - Total Communication
 - Bilingual Approach
13. How much do you agree with the following statements? Parents were asked to rate each statement below as one of the following: *Strongly Agree*, *Agree*, *Somewhat Agree*, *Neither Agree or Disagree*, *Somewhat Disagree*, *Disagree*, and *Strongly Disagree*.
- It was easy for me to get information regarding early intervention options for my child.
 - It was easy for me to obtain information regarding different modes of communication for my child.
 - I was provided with extensive information regarding emotional support after my child's diagnosis.
 - I feel that my audiologist's goal was to provide me with unbiased options in order for me to make the best decisions for my child.
 - I felt pressured by my audiologist to choose one communication option over others.
 - I feel as though I do not understand my child's hearing loss and its effects.
 - I often felt frustrated and confused regarding what decisions to make.
 - I felt as though my audiologist did not have enough time to explain important concepts thoroughly.