

HANDS & VOICES  
FAMILY GUIDE TO  
AUDIOLOGY &  
TELEHEALTH



HANDS & VOICES

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“I SUSTAIN MYSELF WITH THE LOVE OF FAMILY.”

- MAYA ANGELOU

## Introduction

Support, love and guidance from family is one of the best indicators of your child’s future success. Whether your child has been referred for testing following a hearing screening or identified as deaf or hard of hearing, naturally you will want to ensure your child gets the right care. However, knowing how to navigate medical systems and becoming knowledgeable about resources and services may be challenging and overwhelming. The goal of this guide is to help you learn about how pediatric audiologists (healthcare professionals who provide care in the prevention, identification, and evidence-based care of hearing and balance issues for young children) may assist your family in your journey and how to access the services and resources available. Ultimately, our hope for this guide is to help you step into your role as a critical member of your child’s team.

## The Importance of Working Together

The relationship between your family and your child who is deaf or hard of hearing (D/HH) with a pediatric audiologist may be long-lasting. Building a strong connection from the start will be helpful. Children benefit when their families and audiologists work to build a trusted partnership for their care. This trust grows over time when communication is clear and honest and when understanding of your family and your values is respected. Developing a relationship with a provider while gaining the confidence to effectively advocate for your child can help create these positive connections with your audiologist.

Professionals are reported to be a critical source of support for families when a family first learns their child is deaf or hard of hearing. <sup>1</sup>Families need news delivered in an empathetic and caring way. Families value audiologists who explain medical and technological options while at the same time can appreciate the family’s role as the final decision-makers for their child. This delicate balance presents a challenge for professionals who are trained in the craft of service provision, but not given explicit training in the art of family support. Your family can ask for information to be shared in a way that helps each family member learn best and is sensitive to your needs. Being an empowered parent sets an example your child will follow, and they too will become empowered.

## Where Families Find Support

Your family already had an existing network of support before you learned your child was deaf or hard of hearing. Your extended family, your coworkers, neighbors, and friends likely do not have experience with deafness, however. For families with members who have been deaf or hard of hearing from birth or a young age, you may have the advantage of built-in role models. For the majority of families, new circles of support may need to be added. The model below shows the variety of resources and opportunities that will increase your skills, strategies, and advocacy tools through building a diverse network of support. Your family should feel confident that you can ask for these services or connections in each area of the chart below to assist your family throughout your child's development into adulthood.

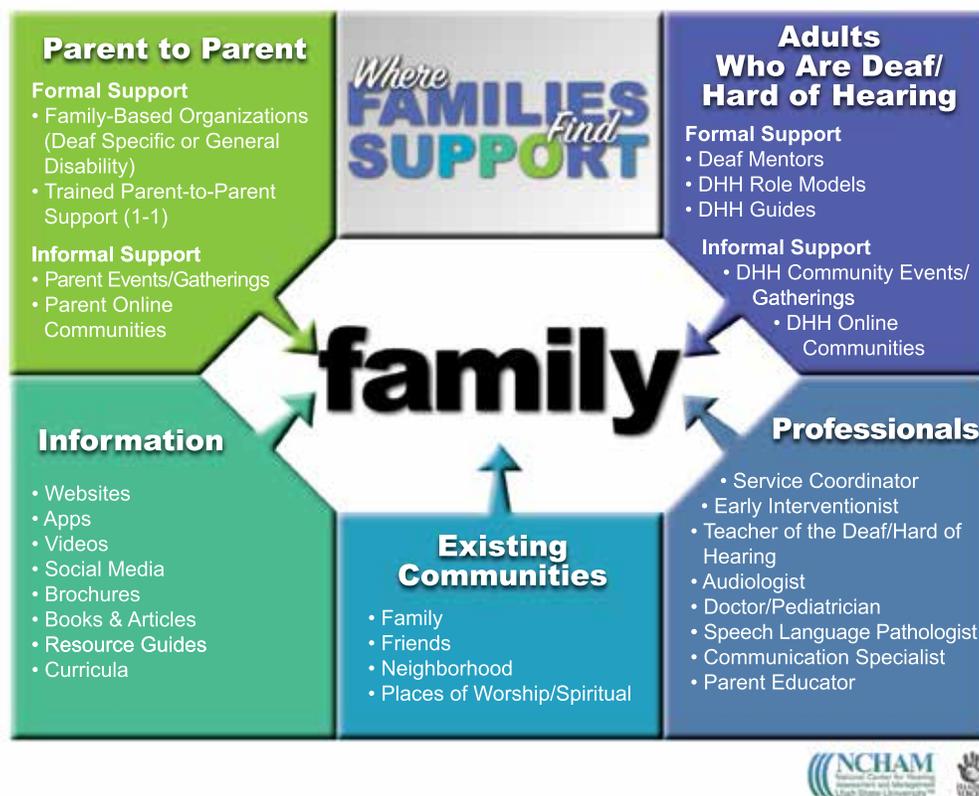


Figure 1 - Where Families of Children who are Deaf and Hard of Hearing Find Support - Hands & Voices HQ & NCHAM

## Parent to Parent Support

“I didn’t know what I didn’t know until I talked to another parent,” is a common response Hands & Voices Guide By Your Side programs receive from new parents. Formal parent support involves parents of D/HH children equipped with training and resources to support other parents, understanding far more than their own child’s unique hearing level and the successful strategies that

families may have used for inclusion and access at school. Informal support is also beneficial, such as meeting other families at D/HH events, online communities, and even in the waiting room at the audiologist, but cannot replace formal parent support programs.

## Deaf/Hard of Hearing Adult Support

Meeting adults who have lived experience and have had an orientation to the realities of today's families can give families a sense of the future for their young child. Whether role models, ASL tutors, or D/HH Guides, these individuals can support a family or a child/young adult in exploring their D/HH identity, understanding their own strengths and needs for access, and inspire a vision for future vocational, recreational and relationship goals. While many D/HH teens want to be football players or models on their career interest surveys, meeting a variety of D/HH adults can give a broader sense of what is possible at work and play. Take advantage of these programs, and if you don't have one in your area, advocate for one! There may also be informal networks that can be tapped into, such as the Hearing Loss Association of America, cochlear implant groups, Deaf associations, state commissions for the Deaf, Deaflympics (Deaf Olympics participants), people who are also consumers of a given audiology clinic, and many more.

## Parent-Professional Partnership

Your family is an extremely important part of your child's ongoing care. In fact, in the “*conceptual model of healthcare service coproduction*,”<sup>22</sup> health care services are always created by both the patient and professional. This replaces the idea that health care services are a ‘product delivered to’ a family or child. Good outcomes are more likely if the child/family and professional communicate effectively, develop a shared understanding of the child's needs and create a plan together focused on the child/family while also helping the professional. Some of the benefits of this approach are:

- Both the family and audiologist feel the benefit of the relationship when they contribute to services together.
- The feeling a parent takes away from the meeting is less “what's the matter with my child”, and more “what matters to our family”.
- When communication between the family and audiologist include the joint creation of services, generosity grows and positive relationships form more naturally.
- Your child learns from watching your interactions with the audiologist how to advocate for their future needs independently both in audiology and with other service providers.

For families, the idea of “coproduction” requires the idea of partnership from the moment you first meet your child's audiologist--from planning and designing an action plan, to co-managing and providing the supports necessary for your child, to monitoring and evaluating your child's progress. Your family is vital to your child's success, so having the confidence to make a plan that is truly best for your family's unique needs is critical.

## Who's Who on Your Audiology Team?

Having a strong team working together to help your child achieve their goals is important. Often, the responsibility to connect all the members falls on us, the family. So, understanding the role of each of your child's team members and recognizing when someone is missing from your child's team are important. Below are some definitions of the audiology-related professionals on your team. (See "Early Intervention" and the Hands & Voices Virtual Waiting Room site for other important members on your team.)

**Clinical audiologists** (sometimes called "private audiologists") work in a variety of settings and can specialize in working with children (pediatrics), older adults, balance, cochlear implants, hearing aids, tinnitus and auditory processing, among other issues. They provide a number of services including evaluating hearing and counseling patients and their families and caregivers on options for amplification. Some may also fit amplification, such as hearing aids, and help with assistive technology, such as personal FM systems.

Audiologists tend to specialize in certain equipment fitting, such as a "mapping" audiologist (those who work with cochlear implants) and may have specialties in bone conduction hearing systems typical for children with conductive hearing loss. An "Au.D." signifies the top certification for audiologists as a doctorate of audiology. Parents will want to ensure that their clinical audiologist is a pediatric specialist, having both the expertise and the equipment to work with babies and children.<sup>3</sup>

**Educational audiologists** are hearing healthcare professionals who work in schools with children who are deaf and hard of hearing to make sure they receive appropriate support in the classroom. They may assess a child's functional listening skills, troubleshoot equipment, manage classroom acoustics to eliminate background noise, teach the child and staff how to use assistive listening technology appropriately, and advocate for classroom accommodations for a child.

**An ENT or otolaryngologist** is a doctor who specializes in conditions involving the ear, nose and throat, and evaluate and treat these conditions through prescribing medications, performing sur-



### Tips from the Trenches

Pediatric audiologists who specialize in working with children who are deaf and hard of hearing are recommended over audiologists who work exclusively with adults. This may mean traveling a greater distance for in-person appointments or utilizing telehealth or remote access to a professional, as needed.

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gery, and referring to audiology or other service providers. (Patients seek treatment from an otorhinolaryngologist for diseases of the ear, nose, throat, base of the skull, and for the surgical management of cancers and benign tumors of the head and neck.)

**An otologist/neurotologist** is a board-certified otolaryngologist (see above) who specializes in the medical and surgical care of patients, both adult and pediatric, with diseases that affect the ears, balance system, temporal bone, skull base, and related structures of the head and neck.

The neurotologist knows the basic sciences of hearing, balance, nerve function, infectious disease, and anatomy of head and neck.

### **Their diagnostic, medical, and surgical skills include:**

- Treatment of hearing loss and tinnitus
- Dizziness
- Infectious and inflammatory diseases of the ear
- Facial nerve disorders
- Congenital malformations of the ear
- Tumors of the ear, hearing nerve and skull base

## What Parents Say about Partnering with Audiologists

Hands & Voices developed a training tool for audiologists called “A Parent’s Wishlist for Audiologists”. In this list, parents expressed their desire for partnership, honesty, information, amplification options and communication choices. Here is just a sampling of the input.<sup>4</sup>

### **Partnership**

- As a professional, you bring to the process: education, experience, expertise, dedication.
- We as parents bring to the process: lifelong commitment and responsibility, seeing our whole child, the right to make choices for our child, a parent’s love, family priorities, culture and values.
- Please take a longer view beyond birth to three. What perspectives are needed as we consider our child as a future student, adult, and accepted member of society?
- Working at being nonbiased allows both the audiologist and family members freedom to explore options, increases trust, and increases hope.

### Honesty

- If you don't have experience in working with infants/children, refer us to someone who does. Explain to us the fact that "Infant/Pediatric Audiology" is a specialty area.
- Give your professional opinion, but please don't deliver your opinion in 'absolutes'.

### Information

- Provide us with family-friendly information to make well-informed decisions. For example, give us research about progressive hearing loss; or explain the reason for and type of hearing loss so we can educate others, etc.
- Give information in writing. Don't decide for us when you think we are ready. Give us pamphlets and phone numbers, websites and parent groups. Give us questions to ask audiologists and early interventionists.
- As children and parents grow, their choices and need for information grows and changes.
- Respect the choices that families make. Let us, the parents, make the final decision.



### Amplification Options

- Tell us of other brands on the market, even if you don't distribute them as a dealer.
- Please be patient and willing to test children with as many different types of aids until the best possible results are achieved.
- Tell us about funding options, or lack thereof if that is the case.

### Communication Choices

- Deafness is not about hearing, but about communication and language.
- Finding the right communication option(s) is a combination of family choice, careful and ongoing assessment, resources in the community in which you live, and resources within your own family.

## Considerations for Learning and Understanding

Every family has unique traits, and each family member is as distinct as their own fingerprints. Audiologists benefit from understanding the elements of diversity that influence the uniqueness of our family/family members such as: values, culture, family dynamics, priorities, and access to support.

The information the audiologist shares with families is often new and unfamiliar to a family who has not experienced childhood hearing loss before. How parents and children prefer to receive information may include visual information such as diagrams or videos. It may include auditory instructions such as a verbal explanation of how to clean a hearing aid or listening to a hearing loss simulation of a specific level of hearing loss. For a parent or child who prefers written material, a brochure or website may be helpful, while a kinesthetic learner may prefer to take the hearing aid battery out and replace it while in the office.



### Tips from the Trenches

Let your audiologist know how you prefer to receive information. Sometimes, a moment to digest what you have learned is important. Asking questions shows your commitment to understanding how to help your child. Ultimately, an informed family member becomes the best encouragement for a child to feel confident and share what their own needs are. That is the ultimate goal.

## Finding a Match for You and Your Child

Finding a pediatric audiologist (like any healthcare provider) who understands your family's unique needs is critical. If you are lucky, the first audiologist you work with clicks with your family, and may continue to work with you and your child for a long time. For other families, it may be necessary to visit several audiologists to find the right match. You can feel assured that asking questions and sharing your goals for your child is not only appropriate but will help your child's audiologist provide better care.

Consider using existing checklists to create a list of questions you would like your child's audiologist to answer, such as the Center for Disease Control (CDC) resource, "[Questions You May Want to Ask Your Child's Audiologist](#)" (pictured on next page, and referenced in Resources for Parents). The answers to your questions



# Questions you May Want to Ask Your Child's Audiologist



Names of Audiologist: \_\_\_\_\_

Phone/Contact Information: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

Hearing Test Name: \_\_\_\_\_

**An audiologist is a person  
who is trained to test hearing.**

Audiologists can test a child for hearing loss. They can describe the test results and help you consider if amplification (am-ply-fi-kay-shun) devices will help your child. An amplification device, such as a hearing aid, helps people hear better. An audiologist will be able to give you suggestions about hearing aids and some may sell and fit hearing aids for children. Some audiologists can also provide you with information on auditory/hearing training and different options to communicate with children with hearing loss.

For more information about children's hearing visit [www.cdc.gov/ncbddd/hearingloss](http://www.cdc.gov/ncbddd/hearingloss)



The audiologist may work with your family and a team of professionals, such as a speech-language pathologist, ENT (ear, nose, and throat doctor), early intervention specialist, and teacher of the deaf, to provide you and your child with the services you need. Please see some of our other tip cards for information about some of the other professionals.

**Among audiologists, one who has training and  
experience in testing and providing services for  
infants and young children will offer the best  
care for your baby.**



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

Revised: November 2012 CS235978B

### Questions about my child's hearing loss:

1. How much hearing loss does my child have? Please explain the terms: sensorineural, conductive, mixed, mild, moderate, severe, profound, and auditory neuropathy.
2. Is the loss permanent? Does my child need more testing? How often should my child's hearing be tested?
3. Can you tell me if my child's hearing loss will change or get worse?
4. Do both ears have the same hearing loss?
5. How will the hearing loss affect my child's speech and language development?
6. What could have caused my child's hearing loss?
7. Would you suggest genetic counseling for our family?
8. Please explain the audiogram or the report.
9. May I have a copy of the hearing test results?

### Questions about hearing aids and cochlear implants (an electronic device placed under the skin behind the ear):

1. Does my child need a hearing aid? What are my choices? Should he or she have a hearing aid in both ears?
2. How much do hearing aids cost? Where can I get help to pay for the hearing aids?
3. Can you help me contact a program that can lend me hearing aids?
4. What can my child hear with the hearing aids? How do you test if the hearing aids are working just right for my child?
5. How many hours should my child wear the hearing aids?
6. Should my child wear the hearing aids when playing sport activities?
7. What should I do if my child loses his/her hearing aids?
8. What should I do if my child does not want to wear the hearing aid?
9. How often do you need to check or adjust the hearing aids?
10. How often will my child need new hearing aids?
11. Which part of a hearing aid (such as the earmold and tubing) will need to be replaced regularly?
12. What is the difference between a hearing aid and a cochlear implant?
13. Should I consider a cochlear implant (an electronic device placed under the skin behind the ear)? Where can I get more information?

### Questions about communication options and education:

1. What are communication options (such as total or oral communication, sign language)?
2. When should I begin early intervention, speech or other therapy? What is available in my area?

### Questions about support:

1. Is there a parent group in my area? And who should I contact?
2. Can you help me meet another parent with a child who has a hearing loss similar to my child's?
3. Where can I look up more information about hearing loss?
4. How do I describe the hearing test result to my family?
5. Do you have tips for my family about how to communicate with my child at home?

## AUDIOLOGIST QUESTIONS

may help you determine who might be the right match for your family, based on your goals for your child and the needs of your family. Through open communication, you can share any concerns, so the audiologist has an opportunity to clarify information or to recommend a colleague with more experience in a certain area.

Another option is the “*What Else Checklist*,” written for both audiologists and adapted for families to make the most of the appointment time together.

If you are a parent who is deaf or hard of hearing yourself, you can be encouraged to share your preference for the quality of communication access and sensitivity of the providers to your family choices, so adjustments can be made for future appointments. And as your child grows, your child will need to learn to be assertive about their communication access needs as well.

## Engaged Families Equals Empowered Families

Decisions we face in our family are ours alone to make, with ample accurate information, options and support, experience from professionals and insight from other parents and adults who are D/HH. There is no one ‘right’ way when it comes to empowering your child to succeed. His or her needs, as well as the needs of your family, will change with time, and both you and your child will learn and grow. It is very important to see this all as a work in progress. Do not be afraid to remain open to new ideas, and even change your approach if necessary. And remember, communication choice should not be solely based on the degree of hearing loss.

Providers need to be confident in their expertise and also be aware of their limitations. The ability to know when and where to refer your family for additional information or services is crucial for best outcomes. This topic frequently surfaces during discussions about communication and language options and the progression of your child’s expressive/receptive understanding of language. Does your child and your family feel connected to your child and the language that you are using as a family? How does your family understand and meet your child’s daily needs? What additional support or collaborative services may enhance your child’s access to language? When given the adequate information and assessments of your child’s progress, your family will make the best decision for your child. And ultimately, your child will make decisions about their own needs, as they grow.



### Tips from the Trenches

We may have mixed feelings about our connection to our audiologist. Like all relationships, the one with our audiologist can be a work in progress. We may seek out second opinions, meet with different providers, explore communication choices and ask tough questions. We may take those first steps in trusting our intuition in advocating for ourselves or our child.

## Other Health Considerations: D/HH Plus

Children who are deaf and hard of hearing may also have additional health concerns such as intellectual disability, Down syndrome, cerebral palsy, vision impairment or deafblindness, attention deficit disorder, autism spectrum disorder, or mental health issues. A child with any additional condition(s) may sometimes be referred to as Deaf/Hard of Hearing Plus (D/HH Plus). Forty percent of D/HH children are estimated to have medical or developmental challenges and some of these may have an impact on the assessment of the child's hearing abilities or management of technology. If your child has additional health issues, it is helpful to know if your child's audiologist has experience working with children with similar challenges. If not, you may wish to find someone who does or encourage your child's audiologist to consult with an experienced colleague if testing becomes challenging. Different strategies may be required, such as longer wait times for a child to respond, or a different timeline for progress than typically used. Regardless, all children can communicate at some level. Additionally, a child may be gifted in some areas difficult to see because of other complexities present.



### Tips from the Trenches

Your team should hold high expectations for your child in keeping with any medical and developmental challenges. Your child who is D/HH “Plus” benefits most when the professionals they work with have a positive outlook of your child, have high expectations while incorporating additional creative strategies as they are needed. You will be an important person to relay critical information and progress from other areas of your child's life to keep those expectations high. Consider connecting with D/HH Plus communities for this reason! One active group is the Hands & Voices D/HH Plus private parent Facebook group.

It is helpful for your child's audiologist to understand your child's other healthcare issues so they can help you understand the potential impact of your child's hearing on other areas of their development. It is beneficial to sign a release of information so your audiologist can consult or share reports with other members of your child's care team. As much as the audiologist can learn from other providers, the other care team members will benefit from understanding your child's hearing loss and technology. Maximizing your child's ability to effectively communicate is possibly an even bigger need for children who are D/HH Plus; therefore, providing your input and that of family members as well as other care team members is important. Discussions with your child's audiologist may lead to exploring other technologies, communication tools and/or augmentative communication devices to further communication and language.

## Telehealth: Technology and the Art of the Audiology Visit

Telehealth continues to grow as a unique service provision method for families, particularly those living in rural areas without easy access to qualified professionals in pediatric audiology or even early intervention. For families who live far from audiology clinics or speak a language other than English, access to professionals with knowledge and experience in childhood deafness is even more limited. Telehealth (also called telepractice or teleintervention) can include remote services by pediatric speech-language pathologists, audiologists or teachers of the deaf/hard of hearing through live video visits with families over an internet connection and videoconference software. In addition, telehealth may be used as a 'safety net' due to inclement weather, travel or illness, or public health crises like COVID-19. Are these benefits that would work for your family?

### What Do I Need to Get Started in Telehealth?

Considerations for providing telehealth include:

- available high-speed internet



### Tips from the Trenches

Family members of a child who is D/HH Plus may need to watch for their child's nonverbal behavior as signs their child is communicating a need. Audiologists with experience with children who are D/HH Plus can be very helpful in looking for or interpreting a child's behavior. Any change in behavior should be considered communication, and it takes some problem-solving to figure out what the child is communicating. Consider these behaviors:

- Continually tugging on an ear to indicate wax build up or discomfort with an ear mold.
- After adjusting to technology, refusing to wear technology or crying when technology is turned on may indicate a new issue.
- Child's eyes blinking repeatedly when this is not typical may mean an adjustment is needed.

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- connectivity directly to the router
- parent comfort with live video communication
- audiologist clinic capacity

Some parents may be hesitant to participate in video visits if they are not comfortable with the hearing technology or the connection to the internet, or if they have not established a strong working relationship with the audiologist. Unfortunately, families in remote areas furthest from pediatric audiologists who would most benefit from telehealth often live in areas with the least reliable internet.

If you have had a negative experience, such as poor audio or video, you may worry that your visit could be impersonal or ineffective. You may be anxious about telehealth in general. Consider reaching out to your audiologist, asking for an initial in-person appointment or a trial session to ease your concerns.

### What about my child's privacy?

You may also have a concern about confidentiality. Check with your provider about how the practice insures a secure internet connection and other protections under the privacy regulations. HIPAA, or the Health Insurance Portability and Accountability Act of 1996, requires three types of safeguards to your child's private health information: administrative, physical and technical requirements imposed on health care providers, nothing should be shared or recorded without your prior written consent.

### Tips for successful visits

Parents may worry that a baby or toddler with hearing loss will not respond as well to teleaudiology or other services. Parents have shared these tips about successful visits:

1. Know what to expect at each visit. A plan is mapped out before the first visit with a trial to troubleshoot technology and manage expectations with the parent/child/audiologist. In following appointments, expect to share any concerns about speech comprehension or intelligibility, the latest response to Ling sounds\* and any new concerns with listening and amplification, hearing aid use and function. Children are encouraged to share their questions, comments and concerns as early as possible as the true "consumer" of audiology services. (\*See more on "Ling sounds" at the end of this section.)
2. Prepare young children for the visit with a knowledge about what to expect. The hearing aid or implant will be plugged into a device for programming. The child will wear the aid again and recheck the sound quality. If the audiologist uses a visual chart to show sounds from soft to comfortable to loud, you should have that handy. Share a picture of the audiologist ahead of time. Plan a fun activity when the visit is over. Bonus: older kids appreciate not having to take half a day or more from school and other activities to travel to the audiologist so may be even more motivated to participate.
3. Know that you will be coached by the provider through the visit. The provider will not be working with a very young child directly. This is a good opportunity to ask what you should be doing

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between visits, such as frequent soundchecks and cleaning/checking hearing aids and processors during telehealth.

4. Understand your state/territory may have restrictions about telehealth visits by audiology or early intervention. A training program may be required first. Insurance approval may need to be granted.
5. Embrace your increased role. Many parents find that this model creates more opportunities for parents to play a bigger part and to be coached, as compared to in-person visits, which can tend to be more professionally directed particularly from providers with less skill or experience.

### What happens before and during a teleaudiology visit?

- Equipment to connect devices and a tablet are sent to the family's home prior to the appointment with instructions for connecting.
- Plan on creating a quiet environment, like you might do with any new learning situation.
- Provide for good lighting.
- Directly connect to a router for the best video and sound connection.
- A microphone is helpful to decrease unexpected background noise.

After set-up, the visit is much like any other visit: greetings and a shared plan for the appointment discussed, any concerns by the parents or child addressed, determining the programming or implant mapping needed through frequency testing, and some kind of speech intelligibility measure is given routinely. The audiologist is able to track how often the child uses hearing technology. If your child is having difficulty wearing technology “all waking hours”, share your concerns with your audiologist. Telehealth on its own should not impact the quality of your child's listening experiences and working with the audiologist, but rather have significant benefits when needed for greater access to services.

Telehealth should not add to the isolation you may be experiencing. Your audiologist should offer to connect you with a parent-to-parent support organization, and offer to connect your family with a veteran parent who has experienced telehealth before. Siblings and extended family/friends closely involved in the child's life may also observe sessions to gain a better understanding how your child experiences the use of equipment. Children should have an opportunity to speak with the audiologist privately, if desired.



# One Family's Story

### Tips from the Trenches

Maine Hands & Voices leader Amber Woodcock normally had to travel with her young son for six hours roundtrip to visit a pediatric audiology clinic at Boston Children's Hospital, the closest one to her home. During COVID-19, this was made more difficult by the inability of the clinic to accommodate her other children attending, but even worse, the necessity to quarantine when traveling out of state. When the pediatric audiologist offered cochlear implant mapping via tele-audiology, the family was thrilled with the results.

"This gives me hope for our families in Maine, some who have to travel eight hours one way. It was an easy, streamlined process that the staff walked me through. I received the Microsoft Surface computer and cords to charge it and connect to my son's equipment, and all I had to do was place it in the Fedex drop-off to return. You can see from his picture how happy he was to have his appointment this way. He had to turn around to avoid seeing the sound stimulus occurring, but at other times in the appointment he really enjoyed seeing the audiologist's screen. I was nervous about it, but the appointment went very well and we are so excited for this option."

Teleaudiology currently includes options for newborn screening, diagnostics, and ongoing audiology visits for programming and troubleshooting equipment. These include hearing aids, cochlear implants, and other devices. While not available in every region, providers are working towards expanding these services.

Teleintervention (or birth to three supports) provides opportunities to include important family members, caregivers, and or incorporate the expertise of Deaf/hard of hearing mentors, consultants regarding visual language, behavior, listening/spoken language or needed interpreters/translators during home visits for the benefit of engaging the whole family. While not always ideal, these services can be brought into your home through video calls without a huge effort on your part to travel to another location.

## References

NCHAM's web page is dedicated to resources, procedures, presentations and research on building parent-provider partnerships through telehealth. <https://www.infanthearing.org/telehealth/index.html>

Training on telehealth for providers, parents and administrators can be found at: <https://www.infanthearing.org/ti101/>

The American Speech Language Hearing Association (ASHA) site for speech/ language and audiology services delivery through telepractice: <https://www.asha.org/practice-portal/professional-issues/telepractice/>

Telehealth Resource Centers (TRCs) assist in implementing telehealth programs. <http://www.telehealthresourcecenters.org>

Video about Tele-intervention by three early interventionists: In this video, four therapists share how the move to tele-intervention has changed their interaction with families. While intended for therapists, families can watch this to learn more about the therapist's view important factors to discuss with your therapist or audiologist: changes in your daily routines, what is working and not working in terms of needs/strategies tried at home, and changes in your family life (job loss, emotional stressors, etc.) so they can grasp a better picture of what is going on at home. For this video and other resources, visit: <https://ectacenter.org/topics/disaster/ti-service.asp>

Ling sounds: This is an easy-to-use tool that helps you know how well a child is hearing with their equipment. It uses six simple sounds that can be used daily, or any time you are not sure if a child is hearing well. It is regularly used at school. Ahh, eee, ooo, mmm, shh, and sss are sounds that cover the speech range in low, mid and high frequency ranges. See more about this behavioral test here: <https://advancedbionics.com/content/dam/advancedbionics/Documents/libraries/Tools-for-Toddlers/tools-for-parents/The-Ling-Six-Sound-Check.pdf>

## Practical Strategies for Partnering with Audiologists

Families benefit from the positive relationships built when we show a sincere effort to proactively communicate with the audiologist. Consider these suggestions from parents:

### 1. Prepare for the appointment

- Consider what you will need to bring to the appointment, including any questions that may have come up since you last met, hearing devices, assistive technology, batteries, etc.
- Ask your child to describe how they have been hearing and specifics about how their technology has been working.
- Have an honest discussion with other family members, day care providers, grandparents who care for your child, etc. about how much time the child is wearing technology or using assistive technology. Bring tracking sheet if used.
- Check in with your child's early interventionist and/or educational audiologist to see if they have any observations or concerns to pass on.



### Tips from the Trenches

Learn to become comfortable with being uncomfortable. Being uncomfortable is part of being human and growth. Sadness, grief or discomfort is present at appointments, just like “in real life” and that's okay. Have the courage to begin uncomfortable and honest conversations when things aren't going well. For example, when there is progressive hearing loss, language gaps or other challenges, take a deep breath, and start a conversation for your child's sake.

- Review information from the previous appointment like notes, test results (if applicable) and follow up on any requests the audiologist has made. If you have access to an online portal, review information there. If not set up already, establish access.
- Bring a spouse/friend/team member for support at this meeting, when possible. (It is hard to have to explain everything to the rest of your circle!)
- Set a goal for this appointment and write down your questions. What you hope to accomplish?
- Plan out your day so you can be on time and take full advantage of your provider's time.
- Ask ahead for access services if needed (American Sign Language, Cued Speech, foreign language, tactile sign, captioning, etc.)
- If a parent/caregiver or support person is not available in person but could be brought in remotely, request this ahead of time.



### Tips from the Trenches

Moments when you learn the diagnosis or when you see your baby with those first hearing aids on his little ears can generate some emotion. Give yourself the space and grace to adjust. You may want to remind your audiologist of this.

## 2. Making the most of your appointment

- Share with the audiologist your goal for this appointment. Share your most pressing questions.
- Describe how your child is doing in a variety of settings, including use of technology throughout the day. As your child grows, your child should be encouraged to share this.
- Ask the audiologist to slow down when you need them to, share examples, or give additional resources to help ensure you understand the information they are sharing.
- Write down answers to your questions and ask for a summary/notes.
- Repeat back any instructions you are given to check if you have understood.
- Ask for next steps in writing. A visit summary and audiogram are often given. Will this also be shared with your early interventionist?
- Inquire about additional resources or tools to help your child.
- If you are unsure about a recommendation, let the audiologist know why you are not sure. Give them time to explain.
- Express appreciation for what has been helpful during this appointment. As your child grows, your child can share their appreciation and feedback.
- If a second opinion about any recommendations is needed, let the audiologist know you want to explore other options. Follow up afterwards.

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- Ideally, set up the next appointment in advance, with access requests like interpreter/transliterator for child or parents. It is easier to cancel than to get something scheduled quickly!
- Ask about new earmolds and potential repairs. Earmolds can often be fit with a brief visit. Your child's earmolds can be mailed to you, and you should receive instructions for cutting the tubing to fit. If not, contact your audiologist before cutting. Request tube stoppers to prevent tubes from pulling out of earmolds.

### 3. After the appointment

- Review your notes and any provided by the audiologist.
- Follow up on recommendations.
- Observe any changes in your child's use of technology and make note of it for the next appointment (or sooner communication if needed.) Ask your child for feedback, whenever able.
- Continue to do sound checks with the Ling sounds and report any changes.
- Explore the resources, organizations and tools the audiologist shared.

## Processing information

It is important for your family to understand how individual assessments of your child's progress and general research about hearing loss will help you make decisions for your child. These may include speech-in-noise testing to see how well a child is understanding in noise or an auditory skills development checklist to help determine next steps in therapy. Comparing hearing tests over time can highlight a progressive loss, if present. These findings can guide you as you sift through options in hearing technology, communication and supports for language development. With input from your audiologist, early intervention staff and other educators, your family will ultimately make decisions that fit your child and family. Your active participation and discussion about ongoing assessments will be key to knowing if the strategies you are using are helping your child or if additional supports are needed.

### Assessment Checklist

- Understand how often the assessment will be done and what it measures.
- Share any questions you have about how the assessment was done.
- If your child has additional health or learning challenges, ask if the audiologist for their opinion of how these may factor into the results.
- Inquire about what are tips you can use to improve your child's progress.
- Ask for a copy of the report and suggestions. If this is needed in a different format or language, advocate for that.

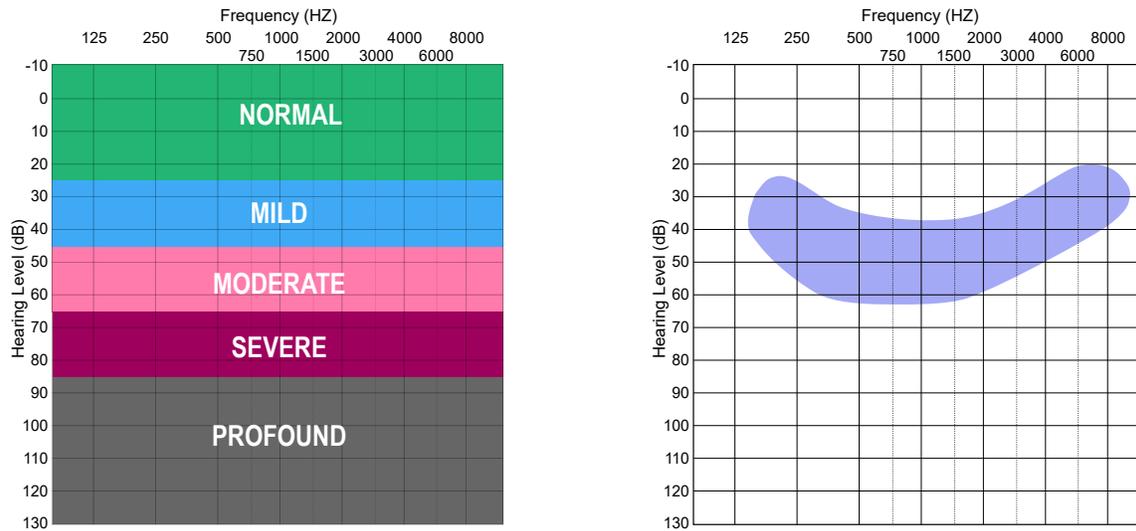


Figure 2 - Audiograms Showing Levels of Hearing Loss and Where Speech is Audible – babyhearing.org

## About Audiograms, Functional Assessments, and Acronyms

The audiogram shows the quietest level of sound your baby can hear. The graph shows each frequency (pitch) from very low to very high across the top. Along the side of the chart, sound volume, increases from very soft to very loud (measured in decibels). Loudness or intensity increases lower in the chart. Responses for the left ear are recorded as “X”, and responses for the right ear as O.

See more about the audiogram and normal, mild, moderate, and severe hearing configurations at <https://www.babyhearing.org/professional-resources/Documents/WhatIsAnAudiogram.pdf>, used with permission.

You can learn more about the typical tests used for hearing in all systems of the ear at babyhearing.org. Some hearing types are more common than others. For example, children with auditory neuropathy, (ANSD or Auditory Neuropathy Spectrum Disorder) or congenital Cytomegalovirus (CMV) can have more complex hearing systems or challenges than the more typical sensorineural (function of the ear called the cochlea) hearing loss, whether in one ear or both. You have a right to seek out a



### Tips from the Trenches

Share about your child/family. Describe your child’s personality, social-emotional growth and daily functioning in addition to technology use and language development. Share relevant information about your family life, your child’s teacher/school, activities, and friends and independence. One parent said, “Everyone seems to have goals for our child or for us as patients. Ask about our own goals for our child or ourselves.”

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professional who has more experience with your child's specific needs.

You will see many acronyms and terms in audiology and early intervention. For example, IFSP refers to the Individualized Family Service Plan, created by a team of multidisciplinary (more than one) providers with the family every six months during the early intervention period from birth to age three for children who qualify for early intervention in their state or region. Don't be afraid to ask about what these terms mean. It is important to understand the language for your child's sake.

The following are two comprehensive definition and acronym lists: <https://www.cdc.gov/ncbddd/hearingloss/parentsguide/glossary.html>

<https://www.babyhearing.org/glossary>

### Early Intervention: Who Qualifies for Birth to Three Supports?

Children who have hearing differences are generally eligible for early intervention services because bilateral hearing loss is a known risk factor in language and communication development. Sometimes, a child with a unilateral hearing difference is not eligible for direct services, and if so, inquire about what is available to your child. Developmental surveys are often shared to ensure your child is on track with milestones. If there is a delay, you can request an evaluation through your local early intervention agency at any time. The purpose of early intervention is to give your family time to explore and implement actions that will keep your child on target for development and entry to school.

If eligible, services are provided in the home or places your family goes regularly, such as childcare settings. Providers are professionals who have additional expertise in assisting families in developing a child's language, communication, and other skills that will assist in meeting developmental milestones for babies and toddlers ending at three years of age. You will hear terms like "Part C", the section in the Individuals with Disabili-



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ties Education Act (IDEA) that explains these services, and where the origin of the IFSP process is found.

Families often develop very close relationships with early interventionists. These are often the first people you might meet after your child is identified, and they come to your house to coach you through the learning curve of understanding hearing and through strategies to increase your child's language and communication.

You should expect your audiologist to make a referral to early intervention right after any level of hearing loss is confirmed. The pediatric audiologist and your early interventionists should work closely together with you in understanding hearing, equipment if chosen, and using careful assessment to determine best equipment programming.

Each state and community set their own guidelines for early intervention. Some providers are specialists with advanced degrees in infant hearing, some are trained in specific approaches, such as American Sign Language (ASL) or Listening and Spoken Language therapy (LSL), and others are generalists or developmental interventionists. They have a timeline to follow to assist you with a transition to school age services (Part B) which might include preschool programs if your child is eligible at age three.

### What is EHDI? What are the EHDI Timelines?

These are milestones in the Early Hearing Detection and Intervention (EHDI) system called EHDI 1:3:6. Hearing screening completed before one month of age, identification of hearing loss before three months by pediatric audiologists, and entrance into early intervention before six months of age are the national goals for each Early Hearing Detection and Intervention (EHDI) programs:

Families should know these steps in the EHDI system: (See graphic at <https://handsandvoices.org/resources/pubs/1-3-6-ehdi-Jul2019-info-graphic.pdf>)

- After a “did not pass” on the newborn hearing screen, arrange for a follow up screening. These often occur at the hospital or birth center. Inquire from your midwife where to go for screening following a homebirth. A follow-up screen should be done by one month for both ears to maximize your time in early intervention.



### Tips from the Trenches

Families are the constant in a child's life. We need to build a team and increase resources for our babies and toddlers. In addition to professionals as a source of information, experienced parents and D/HH mentors can share about fully including your child with a hearing difference into family life, connecting to other parents, Deaf culture, and more. What your child needs as a baby will be different than what they need as an older teen and young adult. Building your network will pay off in the long run, for fielding questions like keeping equipment on your busy toddler, or later, transitioning from high school.

# Count 1-3-6 Steps to Open the Door to Your Child's Language and Early Learning



## By 1 Month

### Newborn Hearing Screening

#### Can your baby hear every sound?

- Newborns should receive several screenings to rule out serious conditions at birth.
- Can your baby hear well? Ask for a *hearing screening* at birth. The screening will show if your baby's ears are receiving all sounds.
- Most babies sleep right through the fast screening process.
- *Use ELDI-PALS to find local facilities for hearing tests.*

## By 3 Months

### Know for Sure - Diagnostics

#### Complete testing with a Pediatric Audiologist

- If your baby doesn't pass the screening in one or both ears, get a full hearing test by someone with special training & equipment who works with babies by three months of age. (Pediatric Audiologist)
- Why the hurry? Babies can avoid sedation with early testing and you'll be helping your baby in a period of rapid brain growth.
- *This is a great time to connect with other parents who have children who are deaf/hard of hearing and meet Deaf/hard of hearing adults.*



## By 6 Months

### Begin Early Intervention-The Key

#### Qualified experts in early childhood hearing loss

- All babies identified with hearing loss in one or both ears should receive critical language and developmental services by 6 months of age.
- "EI" support from birth to age three can help a child enter school with skills on track with typically hearing children.
- Families can enroll as soon as a hearing loss is identified.
- Signing a release of information helps professionals support you in getting your baby to the next step.
- *Contact your local EI Coordinator (at the link below) and ask for experienced birth-to-three providers in your area.*

"Early intervention changed our daughter's life. We are grateful for the early identification and the team who surrounded our family." *A parent of a child with hearing loss*

- Find more information at [www.handsandvoices.org](http://www.handsandvoices.org)
- Find ELDI-PALS here: <http://ehdipals.org/>
- Early Intervention at <http://ectacenter.org/contact/ptccoord.asp>
- Connect with experienced parents at [parentadvocate@handsandvoices.org](mailto:parentadvocate@handsandvoices.org)
- Find your local ELDI program at <http://www.infanthearing.org/states/index.html>
- Data Questions? Contact the Centers for Disease Control site at <http://www.cdc.gov/ncbddd/hearingloss>
- *Giving consent to share data will assist ELDI programs in getting you to the services you need.*

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- Complete your first visits with a pediatrician or family practice, and consider any medical advice related to risk factors, genetic, vision, or other testing.
- Make an appointment with a pediatric audiologist for a full testing of all parts of the ear and hearing system.
- Connect with your local EHDI system<sup>5</sup>, local Hands & Voices Chapter,<sup>6</sup> and other other parent organizations.<sup>7</sup>
- Discuss possible obstacles you face with follow-up appointments (scheduling, transportation, location of services, childcare for other siblings, payment concerns, or other questions.)
- Ask if a partner, relative or friend can attend appointments as a support to you. Some audiologists also have experienced parents or D/HH mentors you can access. Share any concerns, fears, or emotions connected to the follow up appointment.
- Connect with Early Intervention specific to deaf/hard of hearing babies and toddlers, with specific expertise related to your child's identification. This is usually provided through a state agency with a local service coordinator serving children birth to three. A private clinic may also provide early therapies, and teleaudiology or teleintervention may be available.
- Research shows that timely early identification and early intervention with qualified staff give your child the best outcomes.
- For those of us with children who are late-identified, be encouraged that your child can still make good progress! Strong family engagement and parental communication skills is a significant predictor of language development and academic performance.

### Family-to-Family Support

The family is the social context into which children who are deaf or hard of hearing are born. The impact of a child's hearing loss affects not only the child, but the parents, siblings, extended family, and community as well. When this experience 'happens' to a family, everyone is impacted. No one quite understands this as well as other families who also have a child who is deaf or hard of hearing.

On reflection of the early intervention years, families rank parent-to-parent support as one of the strongest measures of family support (Jackson, 2009). There is something incredibly unique and important in receiving support from other parents and families who have children that are deaf or hard of hearing and have 'been there'.

There is a sense of an equitable relationship between the experienced parent and the referred parent (Ainbinder et al., 1998). Because of the low incidence of hearing loss, families of children who are deaf or hard of hearing often feel isolated from each other and do not typically have support opportunities in their already-established community. Meaningful parent-to-parent or family-to-family contact offers the following:

- Forum for sharing information

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- A safe place to brainstorm and express feelings and ask questions. Families may not feel comfortable sharing financial hardships, difficulties with acceptance and follow-through or barriers they are experiencing with professionals.
- Opportunity to validate feelings
- Increased sense of confidence and empowerment
- Increased acceptance of the situation and hope for the future
- Increased capacity to cope
- Means of learning practical parenting skills
- Learning more about protective factors and proactive actions that can keep your child safe as they grow. See the O.U.R. Children’s Safety Toolkit at: <https://www.handsand-voices.org/resources/OUR/>

Whether parents/family members can speak one-on-one, chat online, or attend support groups or other activities, communicating with other parents and families is a valuable component of the circle of support. National organizations, such as Hands & Voices (and the Hands & Voices Guide by Your Side Program), Alexander Graham Bell Association, Family Voices, and American Society for Deaf Children have models for providing parent-to-parent support.

Support models range from formalized programs—where trained parents embedded in the system provide systematic, knowledgeable support—to the informal matching of families in a given community by professionals who know other families with a similar story. The most successful models of parent-to-parent support are programs that are parent-led and driven.<sup>8</sup>

### Access to D/HH Adult Role Models

Adults who are deaf and hard of hearing (D/HH) play an important role in the journey of families with children who are D/HH. Such individuals are typically trained adults who interact with the family and provide mentoring, modeling, and information through one-on-one interaction. A variety of terms are used to describe such individuals: deaf mentors, deaf guides, role models and partners.

In an interview between Janet DesGeorges and Karen Putz, they discuss the impact of deaf/hard of hearing adults on the family journey: <https://vimeo.com/230043030>

For many parents, the first time they had a conversation with a deaf or hard of hearing adult, especially one who has received training on supporting families with young children who are deaf/hard of hearing, was a welcome revelation. Suddenly, parents received a much better idea about what life might be like for their child in the years to come. When parents are introduced to deaf and hard of hearing adults—in all kinds of professions, trades, jobs, and all walks of life—this leads parents to new visions of hope and possibilities for their baby/young child. For example, it can inspire parents to know that



### Tips from the Trenches

Celebrate the little victories. What seems insignificant to others can be huge for your child and family, such as increasing the time hearing technology is worn from one hour to several hours.

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there are over 600 doctors, attorneys, and small-plane pilots. Having the opportunity to meet and get to know deaf and hard of hearing adults can shape the family's journey to be a positive one.

The importance of Deaf Mentor programs was demonstrated in a study by Jackson (2011) and by Wilder Research in 2016. Families surveyed felt that their child's quality of life had improved and information shared was very helpful. Studies share that families desire diversity in adult role models, including those who use listening and spoken language, cued speech and have unilateral hearing loss.

Ask your audiologist and early interventionists about connecting with other families with deaf and hard of hearing adults, especially those trained to work with families in the early intervention and educational system.

### Providing Feedback

Many medical facilities (clinics and hospitals) have created ways for families to provide input about the care they are receiving. Here are several options for giving praise and constructive feedback to your audiologist and clinic:

- Direct feedback to your audiologist: Through whatever communication method you have set up with your audiologist, you can feel empowered to call, email, message through a patient electronic portal or in-person, provide your input about what works and does not work in caring for your child's audiological needs.
- Feedback to a clinic manager: You can contact your clinic's supervisor to share your gratitude, suggestions or concerns. Recognizing excellence is just as important as giving corrective feedback.
- Parent satisfaction surveys: Your clinic may send out periodic surveys so you can share your thoughts about how the services are working for your family.
- Advisory Councils: Some clinics have established parent advisory councils so parents can give input to the practices at their facilities. This allows not only development of individual partnerships between healthcare staff and an individual family, but to provide general input from your parent perspective into the practices and policies of your health-care facility. The following link provides a more in-depth look at this practice: <https://www.nichq.org/sites/default/files/resource-file/PFAC%20Toolkit.pdf>

### Self-reflection

Are audiology appointments productive for your child and for you? Are you learning more each time, especially in those early years? Are you bringing questions and concerns to the appointment or encouraging your child to do so? Self-reflection is often the first step towards creating an effective team approach with your audiologist. If the answer to these questions is no, consider whether talking to the audiologist privately about the quality of your interactions or even seeking a second opinion to see if there is a better fit for you and your growing child. Families who establish a sense of trust and acceptance with their audiologist are far more likely to see success with recommendations within this long-term relationship.

# Conclusion

The relationship between families with children who are deaf and hard of hearing and their audiologist is best built on trust, partnership, mutual respect, honesty, and willingness to be flexible. As a family, you should feel comfortable sharing your changing needs and asking questions, while your audiologist should anticipate your child's growth and suggest new technology/opportunities as they become available. Parents and growing kids value the expertise of audiologists as they move through various phases of their child's life experiences, from periods of adjustment and discovery to transitioning responsibilities to the child. Audiology is an ever-evolving and sometimes challenging field. Pediatric care requires a balance of people skills, counseling and technical expertise. Families like ours appreciate the extra time and sensitivity needed to address our family's unique needs and seeing our child holistically: a child within a family, a student within a school, a future employee or citizen within the community who has a right to communication access, no matter what choices have been made in that regard. Teamwork results in better family and child engagement and commitment of the audiologist in "just-in-time" support at each phase of the child's journey.

# Resources for Parents

1. CDC "Questions You May Want to Ask Your Child's Audiologist" [https://www.cdc.gov/ncbddd/hearingloss/freematerials/Audiologist\\_Questions\\_ENG.pdf](https://www.cdc.gov/ncbddd/hearingloss/freematerials/Audiologist_Questions_ENG.pdf)
2. The "What Else" Checklist: <https://www.cdc.gov/ncbddd/hearingloss/freematerials/Checklist.pdf>
3. Decision Guide to Communication Choices (H&V): [https://www.handsandvoices.org/articles/GoOn/V13-3\\_cdc-decisionguide.htm](https://www.handsandvoices.org/articles/GoOn/V13-3_cdc-decisionguide.htm)
4. A Parent's Guide to Deaf and Hard of Hearing Early Intervention Recommendations (H&V): <https://www.handsandvoices.org/resources/jcih-parent-guide.html>
5. Communication Considerations A-Z™ (H&V): <https://handsandvoices.org/comcon/>
6. We Are Hands & Voices; Stories for families raising children who are deaf/ hard of hearing (H&V): <https://www.handsandvoices.org/resources/products.htm>
7. Book of Choice (H&V): <https://handsandvoices.org/resources/products.htm>
8. Implementing Family-Centered Care in Early Intervention for Children with Hearing Loss: Engaging Parents with a Question Prompt List (QPL): <https://www.hearingreview.com/2017/10/implementing-family-centered-care-early-intervention-children-hearing-loss-engaging-parents-question-prompt-list-qpl/>

9. Guide for Understanding Best Practice Recommendations for Children with Unilateral Hearing Loss: <https://www.handsandvoices.org/resources/uhl-considerations/>

## Resources for Audiologists

1. The “What Else” Checklist:  
<https://www.cdc.gov/ncbddd/hearingloss/freematerials/Checklist.pdf>
2. The Three P’s: Enhancing a Student’s Education through Private Audiology Services, Public Education, Audiology, and Parents (DesGeorges, Johnson) <https://www.audiologyonline.com/articles/three-p-s-enhancing-student-11868>
3. Implementing Family-Centered Care in Early Intervention for Children with Hearing Loss: Engaging Parents with a Question Prompt List (QPL):  
<https://www.hearingreview.com/2017/10/implementing-family-centered-care-early-intervention-children-hearing-loss-engaging-parents-question-prompt-list-qpl/>
4. Motivational Interviewing: Practical Strategies for Speech-Language Pathologists and Audiologists, McFarlane, Canadian Journal of Speech-Language Pathology and Audiology, Vol 36, No. 1, Spring 2012.  
[www.cjslpa.ca](http://www.cjslpa.ca) › download › McFarlane\_CJSLPA\_2012. Also, <https://www.centerforebp.case.edu/practices/mi>
5. Welcome to the Always Use Teach Back Training toolkit: Welcome to the Always Use Teach-Back! Training toolkit: <http://www.teachbacktraining.org/>
6. The Family-Centered Consultation Model:  
<https://www.babyhearing.org/resources/family-centered-consultation-model>
7. Chapter 6, Children Who Are Deaf or Hard of Hearing PLUS:  
[https://infanthearing.org/ehdi-ebook/2018\\_ebook/6%20Chapter6ChildrenPLUS2018.pdf](https://infanthearing.org/ehdi-ebook/2018_ebook/6%20Chapter6ChildrenPLUS2018.pdf)
8. Children’s Home Inventory for Listening Difficulties (C.H.I.L.L.D.):  
[https://successforkidswithhearingloss.com/wp-content/uploads/2017/09/child\\_questionnaire.pdf](https://successforkidswithhearingloss.com/wp-content/uploads/2017/09/child_questionnaire.pdf)
9. How We Decide, Jonah Lehrer (Mariner © 2009)
10. Nudge: Improving Decisions about Health, Wealth, and Happiness, Richard. H. Thaler and Cass R. Sunstein (Penguin © 2008)
11. Telehealth and EHDI Systems (NCHAM): <https://www.infanthearing.org/telehealth/index.html>
12. Telehealth Learning courses (NCHAM):  
<https://www.infanthearing.org/ti101/>

13. Telepractice Information (American Speech Language Hearing Association):  
<https://www.asha.org/practice-portal/professional-issues/telepractice/>
14. Telehealth Resource Centers (TRCs):  
<https://www.telehealthresourcecenters.org>

## About This Guide

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This guide was derived from the Guide for Parent-Professional Partnerships in the Hearing Health-care Setting in partnership with Phonak.

Hands & Voices is a parent-driven, professionally collaborative family support organization which provides support to families who have children who are Deaf/Hard of Hearing (D/HH). Hands & Voices has over twenty years of experience representing the needs of parents with children who are D/HH. It has been successful in the establishment of Hands & Voices chapters and programs across the U.S. and Canada, as well as international collaborations with other parent-driven organizations. We seek to share our experience and expertise with professionals who wish to deepen partnerships with families in the coproduction of health care services.

### **A parent speaks out about the professionals who served them:**

“What really pulled our family through our son’s initial diagnosis was the amazingly dedicated individuals in our early intervention system and medical profession that greeted us with smiles, information, and encouragement. An audiologist who so kindly greeted us, and embraced our child, and then walked us through the process of what we could do for our deaf child; a Service Coordinator and therapist who, not only ‘worked’ with our child, but listened to us and our needs. Finally, a team of individuals following the standards and regulations, set by the law, who empowered us to do for our child and our family what we were so afraid we would never be able to do.”

– *A parent from Georgia*

# Endnotes

- 1 Jackson, C. W. (2011). Family Supports and Resources for Parents of Children Who are Deaf or Hard of Hearing. *American Annals of the Deaf*. 156(4), 343-362 <https://muse.jhu.edu/article/457041>
- 2 Coproduction of healthcare service, Armstrong, Lisa et al. *BMJ Qual Saf* published online September 16, 2015 <https://qualitysafety.bmj.com/content/early/2015/09/16/bmjqs-2015-004315.abstract>
- 3 <https://infanthearing.org/audiology/index.html>
- 4 [https://www.handsandvoices.org/articles/parent\\_pro\\_collab/wish\\_list.html](https://www.handsandvoices.org/articles/parent_pro_collab/wish_list.html)
- 5 National Center for Hearing Assessment and Management Early Hearing Detection and Intervention contacts: <https://www.infanthearing.org/status/cnhs.php>
- 6 Hands & Voices Chapter Contacts: <https://handsandvoices.org/chapters/starts.htm>
- 7 Parental Involvement in Deaf Children's Education Programs as a Predictor of Child's Language, Early Reading, and Social-Emotional Development, <https://pubmed.ncbi.nlm.nih.gov/15454509/>, Parent Engagement in Audiologic Habilitation. Increasing Positive Outcomes for Children with Hearing Loss, <https://leader.pubs.asha.org/doi/full/10.1044/leader.FTR4.16082011.5>
- 8 National Center for Hearing Assessment and Management (NCHAM) eBook: Family Support & Cultural Competence: [https://infanthearing.org/ehdi-ebook/2018\\_ebook/13%20Chapter13FamilySupport2018.pdf](https://infanthearing.org/ehdi-ebook/2018_ebook/13%20Chapter13FamilySupport2018.pdf)