



Guide for parent-professional partnerships in the hearing healthcare setting



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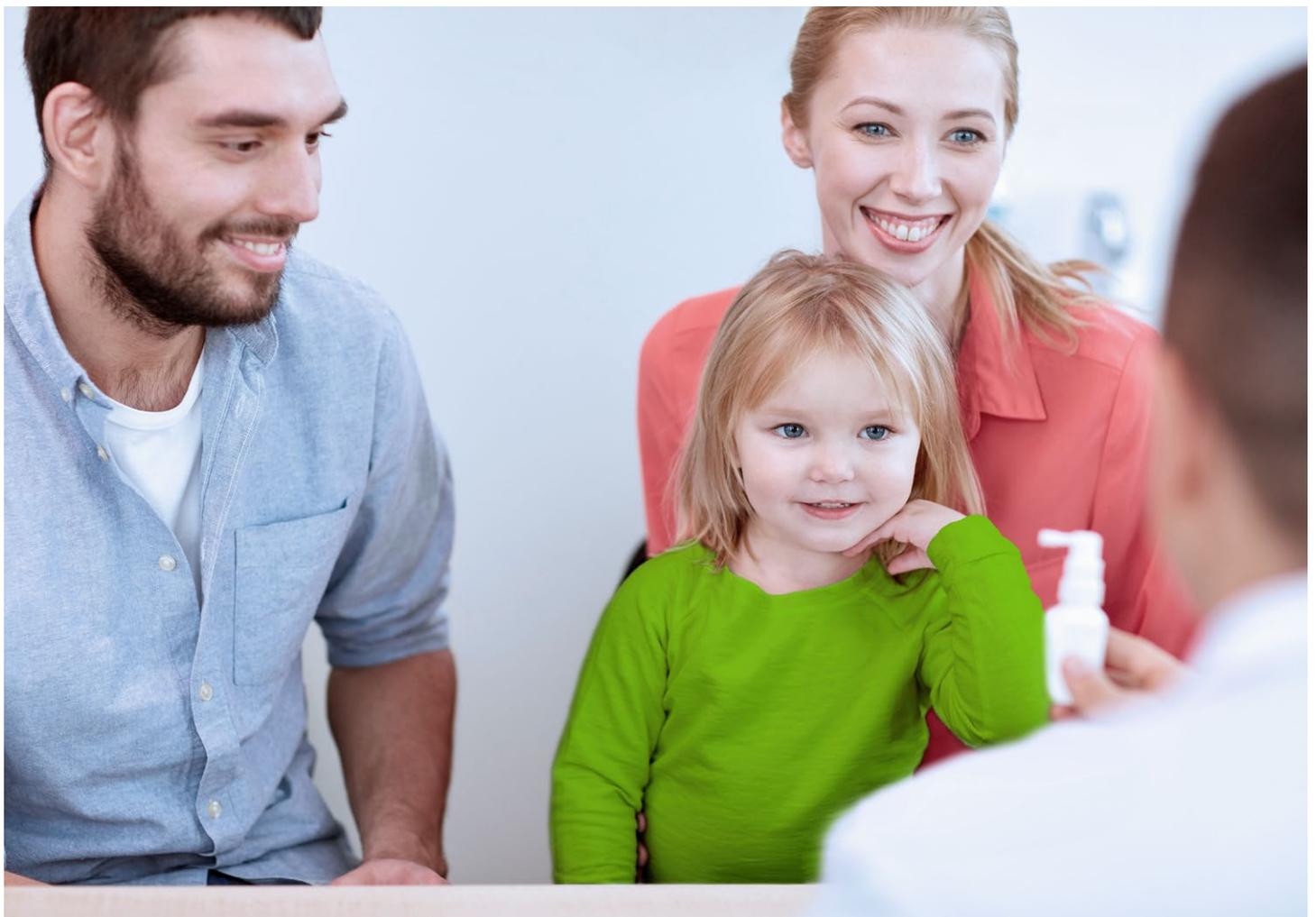
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The importance of working together

The relationship between the family of a child who is deaf or hard of hearing and the child's hearing care provider (HCP) has the potential to be long-term and consequently requires a mutually respectful relationship. Families feel supported by professionals when they perceive the relationship to be a collaborative partnership built on trust¹. This process evolves over time and includes honest and clear communication, understanding, and empathy. Developing active listening skills can help HCPs create these positive connections with families.

Professionals are reported to be a critical source of support for families when a family first learns their child is deaf or hard of hearing². Difficult news needs to be delivered in an empathetic and caring way. Families value HCPs who explain medical and technological options while at the same time appreciating their role as the final decision-makers for their child. This delicate balance can be a challenge for professionals who are trained in the craft of service provision, but not given explicit training in the art of family support. Professionals who can integrate family support and quality service provision into their practice have a structure for success.



Research on coproduction of services

As noted in a **conceptual model of healthcare service coproduction**³, health care services are always coproduced by patients and professionals and should not be viewed as a 'product delivered'. Good outcomes are more likely if the child/family and professional communicate effectively, develop a shared understanding of the problem and generate a mutually acceptable evaluation and management plan. Some of the benefits of using this model include:

- Both HCP and family 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 me".
- When the interactions between HCP and family include the joint creation of services and a plan, generosity grows, and positive relationships form more naturally.

For HCPs working with families, the idea of coproduction requires the idea of partnership from the moment a family walks through the door – from planning and designing a course of action, to co-managing and providing the supports necessary for the child, to monitoring and evaluating progress.

Partnership defined as a continuum

Partnership is a term that is used to describe the process of working together. A continuum of partnering is perhaps more useful to think about than a single definition of partnership. This continuum may range from coexistence, to networking, to cooperation, to collaboration, to true partnership with a variety of points in between.

Programs and systems are best created by partnering with families impacted by the policies, systems and services they touch. The partnership should exist at all levels, working together in the best interest of children and their families.

What has become clear is that partnership is not a state of being or a static thing. It's not a stand-alone agreement signed at a certain point in time. It is more about a process or way of doing things.

How HCPs benefit from partnering with families

Parents have a daunting amount of information to learn in order to make informed decisions and support their child who is deaf or hard of hearing. From understanding their child's hearing loss, to becoming adept at handling hearing technology, to explaining the impact of hearing loss to family and friends, it is understandable that families may become overwhelmed. Affording parents time to process information and providing opportunities for the family to engage in a safe, honest question/answer exchange will build trust and knowledge. The provider will also have a family who is better engaged and prepared to support their child.

By partnering with families, the HCP will gain insight into the real-life experiences of families and children beyond the walls of the sound booth, including work done by other care team members. Building a trusting relationship with a family requires time but will result in better outcomes for the child and ultimately, create a more rewarding professional experience for the provider. Each successful encounter with a family increases the HCP's confidence and skills, which means approaching the next family interaction with a wider array of strategies and experience.

Benefits of partnership:

- Insight into real-life experiences of children and families
- Knowledge from other members on the child's care team
- Deeper parent and child engagement
- Expanded strategies for building relationships with other families
- Better outcomes for the child
- More rewarding professional experience

Tips from the trenches

Talk directly to your young patients (even the itty-bitty babies) throughout the appointment. Children are often excluded from conversations and an audiology appointment should be a fully inclusive experience.

What parents say about partnering with providers

In 2004 (and updated in 2009), Hands & Voices organization developed a training tool for audiologists entitled, **"A Parents Wish List for Audiologists: The Parent Perspective"**. In this list, parents expressed their want for partnership, honesty, information, amplification options and communication choices. Here is a sampling of the input⁴:

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 and our values.

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 specific field.
- When we ask for your professional opinion, don't be afraid to give it, but please don't deliver your opinion in 'absolutes'.

Information

- 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.

Communication choices

- Deafness is not about hearing and methodology, but about communication.
- Finding the right communication mode is a combination of family choice, ongoing assessment of a child, resources in the community in which you live, and resources within your own family.



Considerations for understanding and supporting families

"I always forget that the family that shows up is never the same family in my head."

Quote from a TV comedian

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

Taking additional time in the beginning to get to know the qualities of the family as well as considering how the family learns best will assist HCPs in meeting each family's unique needs. It is their responsibility to deliver information to the family in the way individual family members learn best. This may vary within the same family so asking all caregivers is important.

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. The information the HCP shares with families is often new and unfamiliar. Acknowledging this will demonstrate support and asking the family how information can be delivered based on how they learn best will show respect for the new journey they are embarking on.

Families can be further supported through:

- Passive communication (e.g. parent welcome letters, resource guides, websites, newsletters)
- Group interactions (e.g. social events, educational workshops, retreats, Facebook)
- Anonymous interactions (e.g. on-line chat rooms, list serves, blogs)
- One-on-one communication (e.g. phone or email communications, in-person meetings)

Impact of life experiences

Every family member the HCP encounters comes with a variety of life experiences that can impact how information is received, how their child's hearing abilities are perceived and how they engage in their child's care. Family members may not have had previous experience with anyone who is deaf or hard of hearing, other than older adults. Additionally, parents may have reasons to be wary of medical professionals, sensitive to news that may feel traumatic, and/or have strong emotions about having a child who has health issues.

Approaching each family member as an individual and refraining from making any assumptions about how a family may react to the identification of hearing loss or how they may engage in their child's care is advised. Asking open-ended questions to gain a better sense of the frame of reference and feelings about the child's hearing loss would also be helpful.

Consider this story.

A father of a child who is hard of hearing appeared to resist taking next steps to fit his son with hearing aids, even though he said he wanted him to use listening and spoken language. The HCP sought advice from a parent-to-parent support organization who advised digging deeper into the father's own history.

At the next appointment, the father shared that he had an older sibling with special needs who still lived at home with his elderly parents. He harbored resentment for the responsibility of caring for his sibling as well as how he felt his parents limited his sibling's life. He approached his own son's hearing loss with deep sensitivity to how his young life may be limited. This conversation allowed the provider to explain how current technology had good potential to enable his son to acquire spoken language. The father was then able to move forward, and the child became a successful hearing aid user.

Cultural sensitivity

To provide better service, HCPs benefit from understanding and respecting a family's cultural background. The professional-parent relationship is one in which important and delicate information must be discussed with confidence and cultural differences can get in the way. With the diversity of the general population dramatically increasing, there is a need for increasing awareness of other cultures.

It is important to keep in mind the challenges some families with children who are deaf and hard of hearing may face that differ from other subpopulations (e.g., parental citizenship status, language barriers, and economic stress). These families will require more effort by their providers to deliver helpful, useful information and resources. It is crucial for all HCPs to identify specific considerations when building relationships with families of diverse backgrounds.

HCPs should be aware that the diversity of cultures and family dynamics also differ from one family to another. They should recognize the importance of developing cross-cultural competence and utilize techniques that will maintain a positive relationship with the families they serve. Cultural sensitivity is not only the ability to understand other cultures, but also acknowledging self-bias to effectively communicate with parents about their child's hearing healthcare needs and options.

Being present, inclusive and respectful demonstrates an interest in the family's well-being and overall outcomes. This requires providers set aside their assumptions of what is important in life and beliefs which are what is accepted, considered to be true, or held as an opinion⁵. Assumptions and beliefs frequently influence the care of families before providers meet the family. Assumptions may stem from information gathered prior to the family's appointment such as name, address, ethnicity, type of insurance or other health considerations/information.

One family shared this experience when their second child was identified as hard of hearing.

Their provider quickly reassured them that the process would be easier the second time around since they had already been through this with their first-born child. They shared that this was not the case. The second time was harder for them than the first time.

Assumptions and beliefs interfered with the provider's ability to be inclusive and respectful of the family. Being present, finding common ground and cultural responsiveness strategies will pave the way for meaningful involvement and informed families.



Deaf culture considerations

Ten percent of deaf and hard of hearing babies are born to one or both parents who are also deaf/hard of hearing. The diversity of experiences among parents who are deaf/hard of hearing should be taken into consideration during and after the newborn hearing screening process. It is important for the HCP to refrain from making assumptions based on hearing loss or communication modes. For some parents, it is a celebratory experience to have a child with similar hearing loss. For others, there may be a mixed reaction or grief. Allow the parents to lead the way in sharing from their perspective. Every family, every deaf/hard of hearing person is different. When in doubt, ask for their perspective. Choose compassion, kindness, and empathy to guide you.

For deaf/hard of hearing parents, communication access needs to be taken into consideration. Connect with the parents to ask their preferred mode of communication access prior to the first appointment. After the appointment has concluded, obtain feedback about the communication access and adjust for future appointments.

Tips from the trenches

Train your entire staff to get comfortable with deafness. Most are comfortable with 'hearing loss' but that is not always the case with culturally Deaf families and patients and families who incorporate ASL Deaf culture into their child's life.

- Ask family members who are deaf and hard of hearing, how they prefer to communicate.
- Consider your environment and how you move through it. Walk side by side, maintain eye contact or wait until you get to the room to have conversations, especially if using an interpreter.
- Train your office staff to know how to use interpreters, captioning devices, and to talk naturally.

Other health considerations

Children who are deaf and hard of hearing may also have additional health concerns such as autism, vision loss, cerebral palsy, or mental health issues, sometimes termed Deaf/Hard of Hearing Plus (D/HH Plus). Forty percent of 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. Family members may have many healthcare providers involved and many medical appointments which may also impact their ability to manage all their child's needs.

Understanding the family's challenges carefully balanced with providing information for the parent to understand the potential impact of the child's hearing loss on other areas of the child's development is a needed skill. The HCP might find it beneficial to ask the parent for a release of information in

order to consult or share reports with other members of the child's care team. As much as the HCP can learn from other providers, the other care team members will benefit from understanding the child's hearing loss and technology. Maximizing the child's ability to effectively communicate is possibly an even bigger need for children who are D/HH Plus; therefore, welcoming the input of family members as well as other care team members is important.

A potential danger for the provider is to allow the expectations for the child to be reduced due to the addition of medical and developmental challenges. Families of children who are D/HH Plus benefit most when the professionals they work with have a positive outlook of the child while incorporating additional creative strategies as they are needed.



Challenging-to-engage families

Each family will demonstrate involvement in different ways. It is important for professionals not to judge families for a perceived 'lack of involvement' but to work on strategies for bringing families along the continuum of involvement. Additional factors may contribute to a parent's ability to be involved and may need to be addressed. These may include:

- Emotional resources and acceptance level of the hearing loss
- Confidence level in decision making and parenting ability
- Understanding and perception of the impact of hearing loss
- Confidence and trust in the HCP
- Individual family capacity due to life stressors (e.g., time constraints, money, illness)

Identifying the obstacles for both the parents and professional is essential to meeting the needs and expectations of the child.



Role of telehealth

Telehealth continues to grow as a unique service provision method for families, particularly those living in rural areas without easy access to early intervention experts. Telehealth (also called telepractice or tele-intervention) 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 when intervention visits could otherwise occur as scheduled.

Considerations for providing telehealth include available internet, connectivity, and parent comfortability and capacity. The technology concerns are well-covered in the resources below. Some parents will be hesitant about accepting or fully participating in live video visits if not already comfortable with technology or if they have not established a relationship with the HCP. Unfortunately, families in remote areas who would most benefit from telehealth often live in areas with the least reliable internet.

A parent's past experience with poor audio or video, the sense that the home visit would be impersonal or ineffective, or anxiety over unfamiliarity with intervention at all (let alone intervention over a remote connection) can all impact parent consent. A relationship built through engagement and trust may need to be established in person with trial sessions and motivational interviewing/teaching techniques to ease parents into engagement with the provider.

Parents may also worry that a baby or toddler with hearing loss will not respond as well to tele-intervention. Providers would be wise to orient parents carefully to the idea that the provider is coaching the adult and not working with a baby or toddler directly; but still, frequent soundchecks should happen during telehealth care. Not all microphones/speakers/hardware are created equal. Many parents find that this model creates more parent-led opportunities and coaching potential than with in-person visits, which can

tend to be more professionally-directed particularly among providers with less skill or experience.

Tele-intervention should not add to the isolation that most families experience. Offer to connect a new family with a veteran parent who has experienced tele-intervention through a local parent support organization. Include siblings and extended family and friends and/or incorporate the expertise of Deaf/hard of hearing mentors, consultants regarding visual language, behavior, listening/spoken language or needed interpreters/translators without asking the family to travel to another location.

For families with babies and toddlers, remember to consult your area's rules for birth to three services before offering tele-intervention.

Empowering families

Decisions facing any family are theirs alone to make, with information, options and support from professionals and other parents. There is no one 'right' way when it comes to empowering a child to succeed. His or her needs, as well as the needs of the family, will change with time, and both the child and the parent will learn and grow. It is very important to see this all as a work-in-progress. Don't be afraid to remain open to new ideas, and even change your approach if necessary. And remember, research clearly shows that a communication choice should not be solely based on the degree of hearing loss. (Resource Guide, Colorado Hands & Voices, www.cohandsandvoices.org).

Providers need to be confident in their expertise and become comfortable with their limitations. The ability to know when and where to refer a 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 the child's expressive/receptive understanding of language. Does the family feel connected to their child and the language that they are using as a family? How does the family understand and meet their child's daily needs? What additional support or collaborative services may enhance the child's access to language? When given the right information, families will make the best decision for their child.



Practical strategies for partnering with parents/families

HCPs can incorporate simple strategies into their visits with families to show a sincere effort to maximize communication and strengthen the relationship. Consider these suggestions:

1. Prepare for the appointment

- Verify family members' names and what they prefer to be called.
- Verify the language that will be used during the appointment (i.e. languages other than spoken English). If needed, ensure that appropriate interpreting services have been arranged. Know the policies that govern your practice. Inform the family of the purpose of the appointment.
- Ascertain family's priorities for this appointment (consider the family's perspective regarding their child's needs).
- Inform the family of what they will need to bring to their appointment.
- Review information from the previous appointment (if applicable) and follow up on any requests the family has made.
- Suggest the family bring a spouse/friend/team member for support at this meeting, as appropriate.
- Ensure time allocated is appropriate in terms of what needs to happen at the visit.
- Obtain written resources for the family on the content areas to be covered (e.g., technology, educational opportunities, parent to parent/peer to peer support, referrals, medical resources, local resources).
- Gather the information and referral sources needed to make comprehensive, unbiased resources available to the family about language and communication.

2. Enhance communication with families

Several strategies have been proven to be effective for enhancing communication with families, including **'teach-back'** and **'motivational interviewing'**.

Teach-back is a research-based health literacy intervention that promotes adherence, quality, and patient safety. It is described as a method that:

- Involves asking a child or family member to explain in their own words what they need to know or do.
- Makes sure the HCP explained information clearly; it is not a test or quiz.
- Checks for understanding (can be re-explained and checked again if needed).

HCPs could be trained in the teach-back method as part of their initial training, as well as part of ongoing professional training. Examples of topics to implement teach-back with parents (and when appropriate, the child) could be:

- Explaining the child's audiogram and hearing status
- Changing batteries/programs on technology
- Pairing hearing technology with assistive technology
- Troubleshooting hearing technology problems

Another effective counseling strategy is motivational interviewing (MI). It is described as an approach that "influences the decision-making process by actively engaging clients in an evaluation of their behavior, and likely promotes an evaluation of one's behavior that changes the balance between the positive and negative aspects of change". This varies significantly from traditional approaches that focus on advice given by the professional, in which facts and their interpretation are combined in a single message. Traditional approaches put the HCP in the 'expert' role and place the parents in the position of accepting the advice being imparted or resisting it either directly or indirectly through lack of adherence to the recommendations. In contrast, the MI approach places the family in the role of expert, in that they must decide how to interpret and integrate the information that is received, and whether or not it is relevant for their own situation."

Motivational interviewing could be a useful training tool for new HCPs and a topic of role playing as part of ongoing professional development. MI promotes the idea of assisting the child and family in understanding what their goals are and then helping them determine the steps they must take in order to achieve those goals. This reinforces the important role that the family members and child play by allowing them to:

- determine their desired outcome
- take an active role in achieving that outcome
- see the HCP in a supportive role to reaching the outcome

Tips from the trenches

Learn to **become comfortable with being uncomfortable**. It's part of being human and being able to grow. Sadness, grief or discomfort. Sometimes it just is that way in an appointment 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.

3. On-board new patients and offer goal setting with child/family

Relationship-building is a critical component of the initial meeting between family members and the HCP. To set the tone for how the provider and family members will be equal partners in delivery of services, the HCP could ask for the family's input while completing initial new client information. Adding a question before an initial appointment (and before subsequent appointments) can be a simple way to ensure their needs are being met. An example question could be, "Please let me know questions you would like to have answered during your appointment." Or "What are the most important questions you would like to have answered today?"

During the appointment, the HCP can be trained to read the questions, make affirming statements about the questions, and then answer them, checking for confirmation that the parents and child have understood.

At the end of the appointment, the provider can invite the parents and child to set goals to be accomplished before their next meeting. The provider can also outline what follow-up activities will be done before the next appointment and both sets of goals can be documented in the case notes and provided to the family before they leave.

Tips from the trenches

Be aware of your desire to take notes and write continuously during the appointment. Children and parents may feel concerned when an audiologist is writing a lot of notes. **To ease concerns, tell them what you are writing.** For example, a favorite pediatric CI audiologist will say out loud to the kids during their mapping appointments "I am writing these numbers down to help me create a good program for you."

4. Provide services during appointment

- Review family questions about last appointment and/or information that was provided.
- Describe the child's hearing loss in a variety of ways to the family (beyond the audiogram)
- Use layman's terms to discuss today's information. Check with the family to see if they understand the terminology/jargon used today.
- Assist the family in accessing information and referral sources to continue the conversation and make informed decisions about language and communication.
- Ask the family, "Are you getting too much or too little information?" Wait for the answer.
- Ensure the family has sufficient understanding to enable them to describe their child's hearing loss and communication needs to others (e.g., extended family, friends, educators, community members).
- Ask open-ended questions for answers that demonstrate understanding.
- Check in on the emotional state of the family and consider referrals to counseling, as needed. Listen to what the family is REALLY asking.
- Explain to the family the types of referrals you will be making (refer to the "What else Checklist").
- Address the family's perspective regarding their child's needs.
- Provide the family with written instructions to guide them in their next steps.
- Provide the information and referral sources that you need to make comprehensive, unbiased resources available to the family about language and communication. Provide parents with resources based on the visit's conversation.

5. Provide services after the appointment

- Note what written information and resources were given to the family.
- Document what was discussed.
- Reflect on the following questions: Did I allow the parent to guide what they needed today? Have I considered the family's perspective regarding their child's needs?, Have I considered the family's priorities in our discussions?, Did I talk about this experience in a 'non-medical' way?
- Think about family support during the appointment. Provide copies of reports to the family in a timely manner.
- Document your next steps for the family.

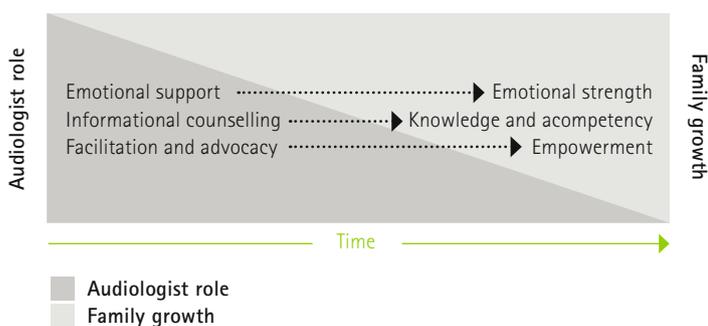
Tips from the trenches

"The moment has arrived to put hearing aids on our child for the first time. Let us see what our baby looks like with his hearing aids on before showing us how the hearing aid works and how to open the battery door. Do that after we see our baby with his first hearing aids on his little ears." Remember to hold space for parents.

Other considerations for supporting families

Tools in decision making

In addition to identifying hearing loss, HCPs must ensure families get the information and support they need to support the language development and communication access of their children. This includes: supporting the family with the information they need to make informed decisions, affording time to meet these needs, providing additional resources beyond the office that will help the family (e.g., community, family-to-family support), and supporting the family emotionally.



Guidelines for Audiologists Providing Informational and Adjustment Counseling to Families of Infants and Young Children With Hearing Loss Birth to 5 Years of Age (<http://www.asha.org/docs/html/GL2008-00289.html>).
Used with permission.

Decision-making can be stressful for a family, especially when considering all of the new information they will be receiving, and ensuring that they do receive comprehensive, timely, accurate information about all of their options and choices. Making sense of the information and determining what is relevant to their unique child and their family's own experience may (and usually does) lead to decreased confidence in making timely decisions for their child.

The HCP might guide a family through the decision-making process by: 1) finding a starting point, 2) identifying and exploring the individual family's needs, and 3) planning the next steps.

Challenges in making decisions may be due to:

- Suddenness of new information
- Major shift in preconceived image of their child's future
- High stakes
- Complicated science
- No previous experience
- Time pressure

As individuals, we insist on the freedom to choose even if the choice is difficult or if we may be worse off because of a decision. Reason and emotion play an important role in a play in a families' decisions. Helping a parent use reason as they begin this process can help avoid biases and is often best in new situations when they don't have any previous experience. Families can easily become overloaded with multiple options and must be able to determine what factors are most relevant. Emotionally, they can handle more information because they are able to draw on their experience (however limited) to build wisdom over time.

When providing multiple options of intervention, technology and communication choices, help the family determine their preferences and make their own informed choices. When some families have 'good' information they may have a limited number of important criteria and then select the first option that meets their standards. Other families may want to compare their options using multiple variables and then choose what they deem the 'best'. It's important to respect each family's process and offer different ways that will empower them to address the unique and specific needs/ desires of their family.

Understand that several factors may add to the difficulty of making decisions for their child who is deaf or hard of hearing. For example, there are too many options, options may appear too similar, options are equally appealing, or all options may be undesirable. Some strategies the HCP can use to help reduce this difficulty for families may include providing professional assistance in helping them reduce options, evaluating the reality of services that are available (due to geography, money, etc.), or allowing the family to admit their 'best' option, even if they must choose another option now.

It is crucial to communicate to the family, that however they may want to defer deciding, some choice is better than no choice regarding intervention and communication for their child who is D/HH. This however does not imply or require a family to justify a decision or their choice which may only change their choice or increase regret and reduced satisfaction later, while lowering the parents' trust in self and their 'gut reaction' because parents may trust the professionals who know more about hearing.

Empowering a family to trust their decisions is vital, because this new situation is novel which makes it difficult to determine the immediate cost vs. future benefit, especially emotional benefit. Families often overestimate the duration of their emotional responses, and under-estimate their own resilience. When there are multiple decision makers, there is the stress of sharing this process with a partner or others with different decision-making approaches.

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. **Be prepared to step aside as we seek out second opinions, meet with different providers, explore communication choices and ask tough questions of you.** It may be the first step in advocacy for ourselves or our child.

What can you do as an HCP to help families?

- Make information more comprehensible
- Allow family to delay decision, or at least delay the 'perfect' decision
- Understand that communication decisions may be separate from technology decisions
- Allow the family to process the situation and develop knowledge of their child
- Understand that it may be hard for a family to articulate/ express themselves clearly
- Ensure all criteria are equally weighted
- Help the family to identify a few of the most salient criteria
- Obtain and share factual information about each option/choice using salient criteria
- Help the family imagine living with different options/choices
- Encourage the family to pause and 'sleep on' alternatives
- Acknowledge/accept that the family will choose the option that feels right, without providing rationale

How families process research and evidence-based information

As scientifically-based instructional practices more often drive early intervention, it is important for families to understand which research findings may apply to their particular child. Families use a variety of sources of information to guide their decisions. These include findings from research, but also subjective 'gut instincts', parental preference, child preference, and available resources in a community. These findings can help a parent sift through options in hearing technology, communication and language development in order to increase their knowledge base for making decisions.

While research is very valuable in finding evidence for decision making beyond people's opinions, at the end of the day, it is a parent's right and responsibility to make decisions for their child in context to both subjective and objective information, as well as cultural and family considerations.

Utilizing assessments

When providing family-centered care, parents can participate meaningfully as engaged partners in the assessment process. Raising a successful child who is deaf or hard of hearing is a complex, individualized journey for each family. Parents rely on both subjective and objective information to make decisions and provide for their child's success. This requires a parent's ability to collate facts, feelings, and data across a variety of domains in a child's development to set goals towards positive achievement.

Parents can participate meaningfully as engaged partners in the assessment process. Assessment and evaluation of the child provide essential 'data' that play into every decision about unique needs and whether the hearing healthcare needs of the child are being met.

Tips from the trenches

Inquire about the life of the child. Ask about personalities, social-emotional growth and daily functioning rather than focusing solely on testing, verification and devices. Ask about family life, school, sports or leisure activities, friends and advocacy. 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."

For parents to use data, they must also understand the nature of their child's hearing loss and/or learning problems, their child's strengths and challenges, how all this should be addressed, and how progress should be monitored. HCPs can support this process by ensuring a family understands and participates in assessing their child's development through audiologic testing results and other language/communication assessments.

Other support families need

Early intervention: Providers need to take the time to have comfortable conversations with the family regarding follow-up appointments, outside providers and referrals. Aiming for team work and consistent referrals to early intervention services will increase follow through. Families desire to do what is best for their child through the NBHS and EI process may require multiple phone calls and appointments, which can be challenging for families with a new baby.

How HCPs can support families during early intervention:

- Inquire about upcoming appointments with the pediatrician and early intervention services.
- Ensure parents are aware of the next steps in follow up
- Discuss possible obstacles for families with the follow-up appointments (scheduling, transportation, location of services, child care for other siblings)
- Ask if there is a second point of contact (relative or friend) for family support or to attend appointments
- Inquire if there is discomfort, fear or emotions connected to follow up appointment

Tips from the trenches

Help families **build a team and increase resources**. Connect them to other parents, groups, Deaf/HH guides, mentors and programs. Offer this support frequently and throughout the years. Once is not enough.



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)⁶. 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
- Safe place to brainstorm and express feelings
- 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

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.

These 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 driven⁷.

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 D/HH 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.

The importance of Deaf Mentor programs was demonstrated in a study by Jackson (2011)⁸. Through a survey of 456 parents of children who were deaf or hard of hearing, 56.2% indicated that deaf role models and mentors were very important, while 27.9% more indicated that it was moderately important; 47.9% indicated that access to adults who are deaf or hard of hearing was very important, and an additional 27.1% indicated that it was moderately important.

In August 2016, Wilder Research released a report entitled, "Lifetrack's Deaf Mentor Family Program: An Evaluation of the Experiences and Outcomes for Participating Families" (Peterson, 2016) to evaluate the Minnesota Lifetrack Deaf Mentor Family Program⁹. The program matches families with young children who are deaf and hard of hearing with an adult who is deaf (called a "Deaf Mentor"). Key findings included: A majority (85%) of families felt their child's quality of life had "improved" as a result of participating in the deaf Mentor Family Program; Two-thirds of respondents (68%) said that communication with their child had "gotten much better."; Nearly all (96%) received information on Deaf culture or the Deaf community during their sessions with their Deaf Mentor; of those, three-quarters (76%) found the information "very helpful." The study went on to say that families desired more diversity in adult role models, including those who use listening and spoken language and cued speech.

HCPs can seek out and connect families with deaf and hard of hearing adults, especially those trained to work with families in the early intervention and educational system.

Next steps for HCP/parents/child

Establishment of schedule of care

The family would benefit from having a written outline of the projected schedule for on-going care. The plan can be updated as the child's/family's needs change, but a general forecast of what typically is expected for on-going care can provide the family a roadmap of next steps and points where decisions need to be made. Preferably, the care plan is written in the native language of the family.

Tips from the trenches

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

Reminder appointment call/postcard also reminds of 'next steps'

The family and child will have greater success in achieving their goals if they are reminded of the goals they set at the previous appointment. When family is contacted with an appointment reminder, staff can mention the date/time/location as well as remind the family to consult their care plan notes for their goals from the previous visit.

Case conferencing with other colleagues about strategies to help client

Another beneficial practice is providing hearing healthcare staff opportunities for care conferencing. Bringing cases of successes and challenges to other providers can allow professionals to get input from different perspectives and learn from colleagues with more experience.



Evaluation of effectiveness of partnership skills with families

There are many ways to periodically assess and provide input to partnerships with families to ensure they are as effective as they can be. Whether it be through parent satisfaction surveys (quantitatively), focus groups, or engaging parents in advisory councils, evaluation can help identify areas for improvement and help HCPs realize goals more efficiently. Evaluation is a process that involves collecting and analyzing information about a program's activities, characteristics, and outcomes. Its purpose is to make judgments about a program or services provided, to improve its effectiveness, and/or to inform programming decisions.

Making evaluation an integral part of a hearing healthcare practice or program means evaluation is a part of everything you do. It is important to design the program with evaluation in mind, collect data on an on-going basis, and use these data to continuously improve the program. Developing and implementing such an evaluation system has many benefits including helping to:

- better understand parent/family needs and how to meet these needs
- design objectives that are more achievable and measurable
- monitor progress toward objectives more effectively and efficiently
- learn more from evaluation
- increase program's productivity and effectiveness

Focus groups are another way to gather information from a diverse group of people using a guided discussion to gather reactions about perceptions, opinions, beliefs and attitudes towards a service. These groups enable members to interact and influence each other during discussion and consideration of new ideas and perspectives. By conducting several focus groups using consistent content (or questions for discussion) with different participants, HCPs can get an understanding of a family's needs and wants and smooth out any differences that might pop up.

Once evaluation data has been gathered and analyzed, it is time to document steps to improve on areas identified.

Other references/resources:

- **Family Engagement Guide** from the National Institute for Children's Health Quality (NICHQ). This guide has a section with information about how to evaluate, sustain and improve family engagement.



https://www.nichq.org/sites/default/files/resource-file/Family_Engagement_Guide_FINAL.pdf

- **Improving Follow-up after Newborn Hearing Screening; An Action Kit for Audiologists** from the National Institute for Children's Health Quality (NICHQ). This Action Kit is specific to helping audiology practices provide more reliable follow-up care after newborn hearing screening.



<http://trigonroad.com/ak/Improving%20Follow%20Up%20Audiology%20Guide%20-%20Final%20Draft%20to%20Editor%201.20.pdf>

Parent advisory councils

Many medical facilities (clinics and hospitals) have incorporated the use of parent advisory councils to give input to the practices and to integrate the parent voice within service delivery. These facilities do not only develop the individual partnerships between healthcare staff and an individual family, but to provide a more overall clinical input from the parent perspective into the practices and policies of a hearing healthcare setting. The following link provides a more in-depth look at this practice:



<https://www.nichq.org/sites/default/files/resource-file/PFAC%20Toolkit.pdf>

Professional self-reflection

The importance of self-reflection for HCPs concerning their own attitudes and assumptions is often the first step towards helping families move towards more effective involvement. The attitude of a professional is often the basis for the relationship with a family, and families who establish a sense of trust and acceptance are far more likely to follow through with treatment recommendations.

Conclusion

The relationship between families with children who are deaf and hard of hearing and their HCP is best built on trust, partnership, mutual respect, honesty, and willingness to be flexible as the families' needs change and new technologies/opportunities arise. Parents value the experience and patience HCPs afford them as they move through various phases of their child's life experiences, from periods of adjustment and discovery to transitioning responsibilities to the child. Hearing healthcare is an ever-evolving and sometimes challenging field and pediatric care requires a lot of counseling accompanied by technical skill. Families appreciate the extra time and sensitivity needed to address their family's unique needs. The result is better family and child engagement and commitment, and hopefully, greater satisfaction for the HCP.

Resources for parents:

1. The "What Else" Checklist. National Center on Birth Defects and Developmental Disabilities: Division of Human Development and Disability. Retrieved from <https://www.cdc.gov/ncbddd/hearingloss/freematerials/Checklist.pdf>
2. Decision Guide to Communication Choices. Hands & Voices. Retrieved from http://www.handsandvoices.org/articles/GoOn/V13-3_cdc-decisionguide.html
3. A Parent's Guide to Deaf and Hard of Hearing Early Intervention Recommendations. Hands & Voices. Retrieved from <http://www.handsandvoices.org/resources/jcih-parent-guide.html>
4. Communication Considerations A-Z™. Hands & Voices. Retrieved from <http://handsandvoices.org/comcon/index.html>
5. We are Hands & Voices; Stories for families raising children who are deaf/ hard of hearing. Hands & Voices. Retrieved from <http://www.handsandvoices.org/resources/products.html>
6. Book of Choice. Hands & Voices. Retrieved from <http://handsandvoices.org/resources/products.htm#boc>
7. English, K., Walker, E., Farah, K., Munoz, K., Pelosi, A., Scarinci, N., DesGeorges, J., August, H., Madell, J., Moeller, M.P., Marriage, J., Flexer, C., & Jones, C. (2017) Implementing family-centered care in early intervention for children with hearing loss: Engaging parents with a question prompt list (QPL). *Hearing Review*. 2017;24(11):12-18.

Resources for HCPs:

8. The "What Else" Checklist. National Center on Birth Defects and Developmental Disabilities: Division of Human Development and Disability. Retrieved from <https://www.cdc.gov/ncbddd/hearingloss/freematerials/Checklist.pdf>
9. DesGeorges, J. (2013). The Three P's: Enhancing a student's education through private audiology services, public education audiology, and parents. *AudiologyOnline*. Retrieved from <http://www.audiologyonline.com/>.
10. English, K., Walker, E., Farah, K., Munoz, K., Pelosi, A., Scarinci, N., DesGeorges, J, Angust, H., Madell, J., Moeller, M.P., Marriage, J., Flexer, C., & Jones, C. (2017) Implementing family-centered care in early intervention for children with hearing loss: Engaging parents with a question prompt list (QPL). *Hearing Review*. 2017;24(11):12-18.
11. Motivational Interviewing. Center for Evidence-Based Practices at Case Western Reserve University. Retrieved from <https://www.centerforebp.case.edu/practices/mi>
12. Always Use Teach-back! training toolkit. UnityPoint Health. Retrieved from <http://www.teachbacktraining.org/>
13. The Family-Centered Consultation Model. My Baby's Hearing: Boys Town National Research Hospital. Retrieved from <https://www.babyhearing.org/resources/family-centered-consultation-model>
14. Wiley, S., St. John, R., & Lindow-Davies, C., (2018). Chapter 6: Children Who Are Deaf or Hard of Hearing PLUS: A Resource guide for early hearing detection and intervention. *National Center for Hearing Assessment and Management*. Retrieved from http://infanthearing.org/ehdi-ebook/2018_ebook/6%20Chapter6ChildrenPLUS2018.pdf
15. Anderson, K., Joseph, J. & Smaldino, L. (n.d.). Children's Home Inventory for Listening Difficulties (C.H.I.L.D.). Retrieved from https://successforkidswithhearingloss.com/wp-content/uploads/2017/09/child_questionnaire.pdf
16. Lehrer, J. (2009). *How we decide*. Houghton Mifflin: Boston, MA.
17. Thaler, R. H., & Sunstein, C. (2008). *Nudge - Improving Decisions About Health, Wealth and Happiness*. London: Penguin Books. doi:10.1017/S1474747209990175
18. Telehealth and EHDI Systems. National Center for Hearing Assessment and Management. Retrieved from <http://www.infanthearing.org/telehealth/index.html>
19. Telehealth Learning Courses. National Center for Hearing Assessment and Management. Retrieved from <http://www.infanthearing.org/ti101/>
20. Telepractice for SLPs and Audiologists. American Speech-Language Hearing Association. Retrieved from <http://www.asha.org/practice/telepractice>
21. Telehealth Resources. National Consortium of Telehealth Resource Centers. Retrieved from <http://www.telehealthresourcecenters.org>

About this guide

This guide was created by Hands & Voices 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

References

- 1 Stonestreet, R., Johnston, R., & Shuckie J. (1991). Guidelines for real partnerships with parents. *The Transdisciplinary Journal*, 1(1), 37-46.
- 2 Jackson, C., Wegner, J., Turnbull, A. (2010). Family life following early identification of deafness. *Language, Speech, and Hearing Services in Schools*, Vol. 41, 194-205. doi:10.1044/0161-1461(2009/07-0093)
- 3 Batalden M, Batalden P, Margolis P, Seid, M., Armstrong, G., Opari-Arrigan, L., & Hartung, H. (2015). Coproduction of healthcare service. *BMJ Quality and Safety*. Retrieved from <http://qualitysafety.bmj.com/content/early/2015/09/16/bmjqs-2015-004315.abstract>
- 4 DesGeorges, Janet (2014). A Parent's Wish List for Audiologists: The Parent Perspective. *Hands & Voices*. Retrieved from http://www.handsandvoices.org/articles/parent_pro_collab/wish_list.html
- 5 Merriam-Webster's collegiate dictionary (10th ed.). (1999). Springfield, MA: Merriam-Webster Incorporated.
- 6 Ainbinder, J.G., Blanchard, L.W., Singer, G.H., Sullivan, M.E., Powers, L.K., Marquis, J.G., Santelli, B., & the Consortium to Evaluate Parent to Parent. (1998). A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology*, 23, 99-109.
- 7 DesGeorges, Janet (2018). Family Support and Cultural Competence. The National Center for Hearing Assessment and Management eBook: A resource guide for early detection and intervention (EHDI). Retrieved from http://infantheating.org/ehdi-ebook/2018_ebook/13%20Chapter13FamilySupport2018.pdf
- 8 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.
- 9 Petersen, A., Kinoglu, S., Gozali-Lee, E., & Martin Rogers, N. (2016). Lifetrack's Deaf Mentor Family Program: An Evaluation of the Experiences and Outcomes for Participating Families. *Wilder Research*. Retrieved from https://www.wilder.org/sites/default/files/imports/LifetrackDeafMentorProgram_8-16.pdf

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