

The Family Consultant: Supporting Families from a Non-Clinical Perspective

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Introduction

Helping families find their way back home after the diagnosis of a hearing loss can be difficult. Supporting families through a family-centered care model ensures that families are fully integrated into both the planning and implementation of their child's care. Incorporating non-clinical support can be a bridge between the clinical role of the audiologist and the socio-emotional needs of the family. Non-clinical support in the medical model may include a family consultant, a deaf educator, parent mentors, as well as community resources.

Making the Case for Something Different

What an honor it has been to listen, learn and talk with professionals at the Sound Foundations 2010 conference. I have spent years in audiology appointments. As an audiology "patient," it is a little intimidating and ironic that I am sharing some of those experiences and experiences of the families that I work with as a Family Consultant because I was one of those kids that did not want to go to speech therapy appointments, and I dreaded audiology appointments. I was identified with a severe-to-profound hearing loss at the age of 3, fitted with powerful hearing aids, attended speech therapy through most of my childhood, and in 2006, received a

cochlear implant. It has been a privilege to hear the research and knowledge that has been presented at this conference, and I'd like to speak more about how we can integrate this research and science with the needs of families who have a child newly diagnosed with a hearing loss.

Most families come to us with little understanding of hearing loss. Families may experience shock or disbelief about how and why their baby has been identified as deaf or hard of hearing if no one else in their family has a hearing loss. In our center most parents of newly-identified deaf or hard of hearing children are hearing themselves. These parents may have limited exposure or knowledge of deafness and hearing loss in the pediatric population. Parents may have an older relative with hearing loss; however, hearing loss in children is a difficult concept for families. As one mother said, "The first deaf/hard of hearing child that I ever met was my son." Fortunately, most professionals are aware of how the diagnosis of hearing loss will impact families. As the skills and knowledge among pediatric hearing service providers evolve, the challenge to find and explore appropriate ways to support newly identified families continues.

Beginning with newborn hearing screening, pediatric audiologists are conscientious of helping families move through the stages that follow identification and diagnosis of a hearing loss: helping parents understand technology for their baby, establishing timelines for habilitation, and assisting families in accessing early intervention services. The professionals' goals for effective treatment may not always match with the families' goals, which may lead to appointments that seem disjointed or uncomfortable. The time spent addressing the heartfelt concerns that parents have needs to be as important in these appointments as the time spent on discussing the diagnosis, technology, habilitation and intervention.

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What makes a Hearing Loss Different from other Diagnoses?

Cultural Perspectives

After the diagnosis of a hearing loss families are quick to realize that there are cultural perspectives that make hearing loss different from other disabilities. Professionals tend to shy away from the Deaf community and may be hesitant to direct families to resources that help families understand Deaf culture. If we are aware about what is currently taking place in the Deaf community, perhaps there will be fewer misunderstandings, fears and stereotypes that professionals and families have about the Deaf and the hard of hearing worlds. The goal is to be open and receptive to the differences that Deaf and hard of hearing people have in communicating.

Technology

Parents who deal with the shock of hearing loss must also try to comprehend the technology that is now available for their baby. Most parents have not had the experience of seeing a baby with hearing aids. A mother recently told her audiologist, "I thought you were going to tell me that something was wrong, but I did not think that you were going to tell me that my child will have to wear hearing aids for the rest of her life." This comment, and others that are not always voiced by families, may impact the work that we do with families during the hearing aid fitting appointments.

In our clinic, I frequently draw from my own experiences with a cochlear implant and a new hearing aid to help families understand the benefits of technology. I share how new sounds have become meaningful for me. Some of my personal experiences include hearing the dog's nails clicking in a musical rhythm as she walked across the wood floors, and hearing crickets and realizing that the sound wasn't as pretty as I imagined it to be. I explain that it became easier to differentiate between the "sh" and "ch" sounds in words. Families will hopefully begin to understand that hearing aid technology does not take away from their child's life, but rather enhances it.

While technology has improved a great deal and the new hearing aids are much smaller (and cuter), many parents are focused on what the hearing aids will look like once they are placed on their baby. Be mindful of a parent's body language. Often parents are leaning forward over the table, looking at the new hearing aids and

trying to imagine how the hearing aids will look once on their baby's tiny ears. Pause for a moment and refrain from explaining technical details such as where the microphone is and where the battery goes in. Take a few minutes and assist the parents with putting hearing aids on their child. Let the families have time to see how the hearing aids look once they are on the baby. After that, parents tend to be more open and receptive to what you have to say about the wonderful technology of pediatric hearing aids.

Communication Choices

The wide range of communication modes makes a hearing loss different from other disabilities. While audiologists are committed to providing children with access to sound, parents should be reminded that the choice is ultimately theirs to make and that the parents are the experts on their child.

Both families and professionals benefit from connections with deaf and/or hard of hearing mentors who have diverse life experiences and diverse communication modes. Parents will begin to see that hearing loss or deafness is not a learning issue. It is an access issue. It is not a question of how a child will best understand the language, but how a child will best access the language. We need to remind families of the difference between speech and language, and assure parents that all children want communication, whether it occurs verbally or non-verbally. Unintended biases may occur and families may mistakenly correlate speech intelligibility and intelligence, or equate the severity of the hearing loss with the intelligence of their child. Parents need opportunities to meet or learn about successful deaf professionals that may also have a severe to profound hearing loss and have chosen various communication options.

Identity of the Family

The diagnosis of a hearing loss may change the identity of the family. What seems unfamiliar at first eventually becomes typical for families in their day-to-day lives. Audiologists are in a unique position to assist families in becoming more comfortable with their new identity.

My husband and three children are hearing. That said, they have some traits and habits that are different from their peers due to growing up and living with a person with a hearing loss. For example, when my husband and I drove our children around in the car, they would reach up and turn on the light above them so that I could

see what they were saying (as soon as their arms were long enough). To this day, they watch TV with the subtitles on out of habit. Adapting to my hearing loss became a part of their day-to-day life and became natural to them. I know this will eventually happen with newly diagnosed families. Access to communication takes place in a variety of ways, and we want to help families understand that while it may not be their usual way to communicate, it will become comfortable and normal for them.

Navigating with Families: Finding their Way Back Home after the Diagnosis

Because of newborn hearing screening, families struggle to understand the implications of their child's hearing loss and what their baby can or cannot hear. Parents of newly identified babies find the diagnosis of hearing loss implausible. When I began my job as a Family Consultant, a mother shared with me that she felt uncomfortable even driving home after she found out about her baby's hearing loss, saying "I couldn't even think. I wasn't sure what to do with this new information." How can we help families navigate their way back home after the diagnosis?

Families need to get back home after this difficult diagnosis not just in their car but in their heart. Fortunately, we have come a great distance with universal newborn screening and diagnosing hearing loss, technology, and establishing timelines for habilitation and early intervention. Professionals must acknowledge, allow, and accept where families are and allow them to move through this journey in a way that works best for them. During this process, all emotions, including grief, need to be honored.

Primarily, we want to preserve the relationship between the baby and the family. After all, babies are not clinical beings; they are human beings in a family system. The diagnosis that the audiologist gives to families is about the facts of the child's hearing loss. It is not about feelings. The diagnosis will tell the family what the child has, not where the child is going. The manner in which families process the information about their child's hearing loss shapes the work that is to come.

The impact of the diagnosis may include the extended family as well. Grandparents are often shocked that their grandchild has a hearing loss and to find out that hearing aids are not just for older people. As I walked a grandfather out of an appointment with his new grandbaby, the grandfather shared that the diagnosis of

hearing loss was difficult. "As grandparents," he said, "we grieve for our child and what they must go through as new parents. We also grieve for our grandchild and what his life will be like with a hearing loss."

It is important to remember that while the perspective of the family has changed, the infant has not. I had the privilege of working with a psychiatrist, Jules Klueger, who frequently said that the job of infants is to give their parents joy and it is the parents' job to accept that joy. Parents may need your help to not lose sight of their babies as babies and to see their baby as more than just a hearing loss. I recently spoke with a family by phone after their child was newly diagnosed with a hearing loss. The parents expressed shock and disbelief at their son's hearing loss. I shared with the family that although the news may be overwhelming for them, we have a team of people in place to help them navigate this process, and I reminded them to take time to enjoy their baby and their new family over the holiday weekend. Several months later during an audiology appointment, the parents expressed their gratitude that they were reminded in the phone call to enjoy their new baby. The father commented that while it was hard to not focus only on the hearing loss, the family was able to briefly forget about the difficult news that they had received and enjoy the holiday weekend with their baby.

Often I am able to get a sense of how families are processing their child's hearing loss by the questions that they ask me. A question that I frequently receive from parents is, "Do your children have a hearing loss?" I typically answer that I have three children and they do not have a hearing loss. Many times families will respond with, "You are so lucky. You must feel so thankful that they don't have a hearing loss." Comments such as these may indicate where the family is in regards to the comprehension of their child's diagnosis and how they view hearing loss as a whole. In situations like this, I typically state that regardless of whether or not my children have a hearing loss, I am lucky to be the mother of my children and to have them in my life. It is my hope that families will recognize that a diagnosis of a hearing loss or the technology that may follow does not define the child.

It is important during audiology appointments to encourage parents to share information about their child. Their child's likes, dislikes, favorite foods, toys, personality traits are all important and must be acknowledged throughout the appointment. This helps remind parents that there is more to their child than the hearing loss itself. It is a pleasure to later meet families during appoint-

ments and listen as they share something about their child and then discuss their child's hearing loss and or technology.

Incorporating Non-Clinical Support into the Medical Model

Family Centered Care allows parents to focus on being the best parent that they can be by becoming partners in their child's care and treatment. We must remember that parents are not required to become a medical expert, speech-language pathologist or audiologist for their child. Hopefully parents will have those people on their team working with them and establishing the validity of the team's perspectives. Families will make informed decisions given the full range of choices available. When professionals honor the family and place a sense of trust in them, the trust that the family places in the professional will also increase. Constructing strength-based support systems ensures that children receive optimal care and outcomes.

In 2005, Dr. Deborah Hayes, Director of the Bill Daniels Center for Children's Hearing at The Children's Hospital of Colorado, built a multi-disciplinary team to better serve families with children who have a hearing loss. The team now consists of:

- Pediatric Otolaryngologists
- Genetics Counselor
- Pediatric Audiologists
- Pediatric Cochlear Implant Team
- Speech-Language Pathologists with deaf and hard of hearing expertise
- Social Worker
- Deaf Educator
- Family Consultant
- Family Advisory Council
- Community Resources

While the pediatric audiologists maintain strong connections with families after a diagnosis, they are often limited by amount of time that can be spent with families during appointments. Non-clinical support roles were added to work alongside the audiology team in a medical setting. The deaf educator works with speech pathologists overseeing toddler/parent groups that take place at the hospital. She is available to assist families as they transition from early intervention services to the educational services and review Individual Educational Plans (IEPs). Families who choose private

schools for their children may not have full access to accommodations and seek the services of the deaf educator to help advocate for their child. The deaf educator participates in workshops to train teachers and introduce hearing loss to classrooms with a student that has a hearing loss. Families cherish the connection and support of the deaf educator since she often has been with families from the time their child was identified to the time their child enters the school system.

The clinical social worker has expertise with families and children who have hearing loss. She is available to meet with families in groups and individually as requested. She also works with the cochlear implant team and the cleft palate team.

The Family Advisory Council is made of six to seven families that meet at the hospital approximately four times a year and give feedback to the Audiology, Speech Pathology, and Learning Services department. The parent perspective on how our services can better meet the needs of families has been enlightening. This type of parent support can be incorporated into a variety of audiology practices. With the guidance of the Family Advisory Council, we searched for ways that families could better access the services that the team and the hospital as a whole provide to families. The Video Relay phone was recently added and is available to families to use for scheduling appointments and to stay connected to their families while in the hospital.

Another system provides certified medical sign language interpreters 24 hours a day, seven days a week. When a sign language interpreter cannot be accessed immediately, the video network can be used until the interpreter arrives. The family does not have to spend additional time waiting for an interpreter, and the audiologist can continue with the scheduled appointment without delays. Parents sometimes assume the role of interpreting for their young child and may not request an interpreter. Pediatric patients who use sign language deserve and enjoy full access to their appointments in the clinic. During the evenings and weekends the sign language video system is kept in the emergency department so that a family in an emergency situation does not need to be kept waiting for an interpreter.

The Family Advisory Council has expressed a desire to host a workshop with our audiologists on hearing aid technology, assistive listening devices and upcoming technology. A parent on the Family Advisory Council shared, "I need more information about technology than our audiology appointment time could ever allow. Even with additional phone calls and emails to our audiolo-

gist, there is more that I need to know so that my son will know what to advocate for as he gets older. We want to know how our children can hear better at the movies, in museums or traveling.” Parents have also asked for additional support outside of their audiology appointments on being better prepared for transitions in their child’s life, such as moving from elementary school to middle school or learning to drive. Families are eager for their children to be able to use their hearing aid to its full capacity as they move from out of their appointment and into the practical day-to-day issues of a hearing loss.

Several of the Family Advisory Council members have spoken with students in the pediatric audiology course, giving a parent perspective on diagnostic and management of hearing loss in infants and children. Members have also served as parent mentors for families in the clinic that may desire a connection with other parents. As professionals, we may be hesitant to connect parents because we may not be able “match up” families with similar diagnoses. What all of these parents share is the experience of hearing loss in a child, the heartaches they have had and the process of accepting their child’s diagnosis.

A young father recently shared with an Advisory Council member that he had shared custody of his son and said that when his son stayed at his house, the boy did not need to wear hearing aids, saying, “My son needs to learn to be man when he is with me.” The father on our council replied, “It’s hard to be a man when you can’t hear or communicate.” We as professionals need to consider how to present parents with opportunities to learn from and support each other.

The Role of the Family Consultant

Supporting families outside of their audiology appointments will strengthen the professional’s audiology practice. Building strong ties to communities, establishing parent support organizations and exploring the use of non-clinical support in your practice will reduce work stress and prevent burnout for professionals. The Family Consultant role is used to enhance the medical model by focusing on family centered care and supporting both families and the professional. This connection to families can address anxiety and demonstrate new ways of communicating while beginning to build a relationship with the person that parents imagined that they had lost. Parents that are able to see deaf and hard of hearing adults as valuable members of their team are better able to understand and see the potential in their child. Fam-

ilies begin to learn that they don’t have to figure all this out on their own.

In this model, families are given the opportunity to connect with the Family Consultant through their regular audiology appointments, which saves making an additional appointment. Families do not need to be in a crisis mode to benefit from visiting with the Family Consultant. Developing a relationship with families alongside the audiologist gives families multiple opportunities understand the differences, hardships, and joys in parenting a child with a hearing loss. As a third person in the visit, next to the audiologist and the parent, the Family Consultant can assist in clarification and comprehension of information. This is important, as emotions and stress can affect comprehension. Recently a mother shared that she found it difficult to talk about her daughter’s hearing loss during the audiology appointment because whenever she said something, the audiologist frantically wrote down what was just said. The discomfort was also evident in the mother’s body language. We want families to feel comfortable in their appointments and not that they are only there to be part of a report. It is important to articulate to parents what is being written down by simply saying something like, “That is a good point. Let me write that down so I can remember that when I program the hearing aids.” We may reassure parents how valuable their input is to the audiologist. We may also use the opportunity to clarify the purpose of any note-taking and that it allows the parent to be a partner in the process. We might ask the audiologist if there anything else that the parent could share that would be helpful. These questions and comments may also serve as a gentle reminder to the audiologist that listening to the parent is as important as documenting what is being said.

Recently a parent discussed the stress that she felt during their child’s hearing aid fitting because she saw that the audiologist would periodically check her watch. The parent felt that the audiologist had to be thinking about how long it was taking to get the hearing aid in the child’s ears and that audiologist needed to end the appointment. The audiologist was actually looking at her watch to figure out how to restructure the appointment so that more time could be spent getting a better and more comfortable fit with the hearing aid. It is important to work with the audiologist and the parents to ensure that miscommunications like this are addressed.

Parents with infants who were recently identified with hearing loss may appreciate opportunities to ask the Family Consultant about immediate concerns of the heart; questions that they may not ask their ENT or au-

diologist. A family member once asked me, “How can you be romantic or intimate with a cochlear implant/hearing aid in your ears?” I laughed and thought to myself, “We do it the same way you do.” I have to wonder why they didn’t ask their ENT or audiologist that question! However, I did understand where the family was going with this question. Parents without prior experience or exposure to deaf and/or hard of hearing people tend to view normal hearing as a precursor to successful relationships. Questions like these often hint at deeper fears and worries, and I tend to acknowledge the question, as well as the question beneath it, by responding, “I think what you are wondering is who your child will have a relationship with when they get older. Your child will be with the person that he or she meets and wants to spend the rest of their life with, and it won’t matter if they are deaf, hard of hearing or hearing.”

All relationships are built on communication, and an important relationship the family must build is with their audiologist. We had a family in one of our toddler groups that said, “In the beginning of this process, we got our strength from our audiologist and the people involved with our daughter’s life.” Often, this strength comes from within when a family feels that they have been listened to and their concerns addressed. Families should be given multiple opportunities to review their child’s audiogram and ask questions. Treatment choices and decisions may change as the child grows. Opinions may differ within the family and the audiologist may need to be a sounding board for the family. Effective counseling skills and the use of multiple support systems in your practice may guide families as they seek to gain knowledge about the choices that need to be made.

Families are surprised and somewhat relieved that the “basics” of parenting hold true whether their child has typical hearing or not. Families appreciate the reminder to continue singing, humming, cooing and reading to their baby and to do all things that they dreamt of doing for their little ones before the diagnosis of a hearing loss. Families have expressed gratitude for the reminder, saying that before knowing this, they simply stopped talking and singing to their brand new baby because they were not sure what their baby could or could not hear.

An effective pediatric audiologic evaluation process may require that the parent and child spend several appointments being tested throughout the year. Going into the booth can increase the anxiety of the parent and child. There is a natural desire to want to perform and to

do well on a test. For some parents the annual hearing test may be a reminder of their child’s first hearing test and all of the emotions that accompanied it. I was in the booth with a mother who was stressed about her daughter’s hearing test. When I asked the mother, “What is it? What is it that you are hoping for?” She responded that she wanted her daughter to do the best that she could and for us to see how well her daughter really was doing. Families need to be reassured of the purpose of frequent testing. In your own testing, keep the child engaged and the toys fun. As a child, I remember several years of testing with the same wooden puzzle of a cat. This repetitive testing was made worse by the fact that the cat puzzle was missing a paw, and was missing it for years. Remember that with testing, it is important that all of the pieces of the puzzle fall into place for both the child and the parent.

One of the puzzle pieces that must fall into place for the child is self-advocacy. My favorite time as a Family Consultant is to assist in the booth. There are times when the children find it reassuring that someone else can’t hear either. I recently played (assisted) with a five year old girl with bilateral cochlear implants. The tones were coming at an intensity that was difficult for both us to hear. This little girl wasn’t hearing the tones and she looked over at me for verification that something was happening. Again, there was a moment where the sound was too soft for her to hear, and she looked at me again and I shrugged my shoulders. I didn’t hear anything either. Finally she popped out of her chair and yelled through the window to the audiologist, “We can’t hear you!” What beautiful self advocacy skills this little girl demonstrated! Always ask yourself: how can we use the time that we spend with families in audiology appointments to develop and further advocacy skills? The social worker, deaf educator and family consultant on the team are available to the audiologist to assist the child or families with this important life skill.

Connecting the Family and the Home Community

Families may leave their audiology appointments carrying an overwhelming sense of accountability to the audiologist for the amount of time that their baby needs to spend wearing hearing aids. New data logging technology, which calculates and averages the number of hours that hearing aids are on, should be discussed with families at the initial hearing aid fitting. Families have commented that due to the number of times per day that they put their child’s hearing aids back on, it feels as if

their child is wearing them for a larger portion of the day. They are often surprised when the audiologist shares with them the number hours that the data logging hearing aids have tracked, as these hours can be considerably less than what the parent reports. Data logging should not be used to “check” on parents, but rather it can provide a segue for discussing strategies and support for keeping hearing aids on the pediatric population. Parents need to learn how to mesh babies and their new hearing aids into the family life as a whole. Once a mother whispered to me that they did not take their daughter’s hearing aids with them on vacation to the beach. She smiled and reminisced about the wonderful vacation and the freedom they enjoyed without having to worry about hearing aids. When I asked why she was whispering, she replied she would not want the audiologist to hear, but that it was the most fun that the family had since the diagnosis of their daughter’s hearing loss. Families may need breaks and opportunities to reconnect, especially if they feel that the hearing aids are at the forefront of their relationship with their child. Perhaps a few hearing aid breaks in the beginning would have helped this family. With the audiologist’s permission, I may let a family know that it is okay to take short hearing aid breaks. The important message is that breaks may be beneficial, provided the hearing aids go back on the child after these breaks and the hearing aids don’t start to feel like an ongoing battle.

Other families may struggle with their baby wearing hearing aids when they are in their community in their day to day life. Parents want to go to the grocery store and not have to explain to strangers why their baby has hearing aids. Sometimes it’s hard for families to go out knowing they will have to respond to questions from the public. Often I will work with families on gauging their comfort level and how much information is appropriate for them to share. Learning how to respond with confidence to questions about their child’s hearing loss mirrors how the child will eventually respond. This is a great tool to give a family.

The use of non-clinical roles can support the audiologist in teaching families the value of incidental learning and inclusion, which occur primarily through overhearing. These subtle yet rich messages that occur in our daily life lead to a sense of belonging. Family traditions and beliefs give meaning and purpose to familial interactions, and it is important that the child with a hearing loss has access to those family connections. When children with hearing loss feel worthy in their family, peer group, and in their school, they become confident

in their ability to retrieve missed information and begin to advocate for themselves. From early identification to childhood and adolescence, audiology appointments can be a safe place for parents to share their concerns, their fears and the hopes that they have for their child. Incorporating non-clinical support into audiology practices can be used as a bridge between the clinical model and the socio-emotional needs of the family to ensure that the child has access to these family connections.

