

Chapter 7

Parent Counseling in the Internet Age: The Rules & Roles Have Changed

Les R. Schmeltz, AuD

To say that the American family has changed significantly over the last several years would be a gross understatement. The concept of Dad going off to the office while Mom stays home and nurtures the children, cooks an evening meal they all enjoy together, and the family gathers at Grandma’s house on Sunday is as outmoded as dial phones, leisure suits, and lava lamps! Families today are as likely to have one parent as two, dad may be the primary caregiver while mom goes off to work, and parents may be of the same or different sexes. Today’s young children are likely to spend most of their days in child care while one or both parents struggle to make a living. Many of today’s parents have been described as the “helicopter” generation, hovering over their children to be sure they get into the proper schools, sports activities, and social groups. Mobility due to career opportunities or geographic preferences means the extended family may not be readily available for advice and support. Family groups may post on their Facebook page or “tweet” each other rather than gathering at a central location.

Generational differences have not only changed our lifestyle significantly but have a profound effect on the way we prefer to receive and assimilate information. Many of us grew up in situations unlike those experienced by young families in this Internet age. Books, pamphlets, brochures, and informational videos have given way to the Internet, Facebook, Twitter, texting, podcasts, and individualized interactive instruction. Information—both helpful and harmful—is readily available to all. “Google it” has become the byword for accessing the full power of information on the Internet. In early 2012, this author Googled several expressions and received an amazing number of hits. “Auditory verbal therapy” produced 814,000 hits, “infant hearing loss” came in with 3,310,000, “American Sign Language” produced 43,600,000, and “language development” an astounding 68,600,000 hits.

Prior to the 1990s, the average age of identification of hearing loss was 2 1/2 to 5 years, depending on the degree of hearing loss. Due to the success of newborn

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hearing screening and EHDI programs, the average age of identification in many areas is now less than 6 months. There is a significant difference between counseling the parents of a newly identified 3-year-old child and the parents of a 3-week-old infant. By the time a child had reached 3 years of age, parents had adequate time to observe behaviors and develop concerns. Children who weren't speaking, did not respond to verbal commands, and weren't doing well relative to developmental milestones were often labeled as behavior disordered, mentally challenged, or autistic. Typically, parents had expressed concern to multiple caregivers before a hearing evaluation was recommended. Upon being given the diagnosis of hearing loss, many parents expressed relief that a hearing aid and special therapy was all that was required. During this period, the audiologist was the prime source of information regarding hearing and hearing loss.

Parents of the 3-week-old infant, on the other hand, have not had sufficient time to adjust to having a new person in the family. They are still bonding with the infant, have no basis for suspecting hearing loss, and, in most cases, see no physical manifestations that indicate a hearing loss may exist. The professional sharing a diagnosis of hearing loss or recommending a course of habilitation must realize that families require a certain amount of time to accept this new development and be ready to act on recommendations. The sense of urgency conveyed to families about the 1-3-6 (hearing screening by 1 month of age, hearing loss diagnosed by 3 months, and enrollment in early intervention prior to 6 months of age) guidelines may not be compatible with the pace the family is willing (or able) to move through the Early Hearing Detection and Intervention (EHDI) process. The audiologist must be prepared to delicately balance the need for immediate action with the family's ability to proceed.

The initial shock of a diagnosis of hearing loss often leaves parents in an affective,

or emotional, mode for some time. During this time, the ability to retain informational content is dramatically reduced. Audiologists often feel pressured to convey as much information as rapidly as possible—failing to realize that families may need sufficient time to express their feelings before moving on. While it may seem counterproductive to spend valuable professional time encouraging and listening to parents express their “gut reactions” to the situation they now find themselves in, helping families move beyond the affective mode is a critical step along the road to positive progress.

It is absolutely essential that the family implicitly trust the professional before they are willing to accept the information they are being given. As mentioned earlier, there is an abundance of information readily available on the Internet and elsewhere. The role of the audiologist has changed from information provider to information filter—helping to sort the good stuff from the incorrect or unnecessary. It is absolutely essential that the audiologist be familiar with the latest standards of practice, research, and technology. Parents *will* bring information from outside sources and expect the audiologist to be able to intelligently discuss its merits, both positive and negative. Second opinions, as long as they do not represent “diagnosis shopping,” should be actively encouraged. One of the goals of parent counseling is to empower the family to make their own decisions. Timely, accurate information is the first step along the path to family empowerment.

It is extremely important to realize that parents do not retain all the information they hear in a counseling session. As a matter of fact, depending on conditions, 40 to 80% of the information provided may be forgotten immediately. In addition, of the information parents do recall, they remember about half incorrectly (Margolis, 2004). When these facts are taken into account, the need for frequent repetition and verification of understanding becomes quite obvious.

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Audiologists must be prepared to present information in several different ways and multiple times before expecting parents to have more than a passing understanding of what is being said.

Parents are often put in the role of providing information to others in their family and support circle. Explaining hearing loss, amplification, educational activities, and other matters related to EHDI can be difficult for those with very limited or inaccurate information of their own. Inviting the parent(s) to include others in counseling sessions can be extremely helpful in gaining the support and assistance so necessary for a deaf or hard-of-hearing child to achieve success. Providing information for families to share is another way to lighten the load of the parents. There are excellent materials suitable for sharing with extended family and support groups. Links to many of these materials may be found on the National Center for Hearing Assessment and Management (NCHAM) website: www.infanthearing.org; and the Boy's Town website: www.babyhearing.org

As a young audiologist, I (of course) knew all there was to know about hearing loss and took every opportunity to share my wisdom with any and all who would listen. Parents were forced to sit through a detailed explanation of the audiogram before being given any information about their child's hearing loss. I would provide them with an impressive stack of literature, expecting them to have read and digested all the material prior to our next visit. We would talk about hearing aids in terms I suspect they never understood. Since they didn't question my recommendations, I assumed they had somehow understood all the information I supplied during our previous visit. When it came to educational recommendations, I deferred to our resident expert who happened to be a gifted teacher of the deaf and hard of hearing.

You can imagine how quickly deflated my pompous ego became the first time I sat in on one of her parent counseling sessions. She talked about seaweed, snails, ocean waves, and many other decidedly unscientific things in describing the process of hearing and hearing loss to parents—and they actually understood exactly what she was saying. None of those glazed-over expressions; no obligatory “uh-huhs;” just warm, open, and honest communication. Barb could reduce a hearing aid to simple, understandable terms and had no problem making meaningful educational recommendations that the parents welcomed enthusiastically. Not only were the parents understanding her, but they were asking questions that indicated to me they were fully committed to the educational process upon which they were embarking.

It did not take long to realize that parents really didn't care how much I knew; they needed to know how much I cared. They needed someone to cry with them, to help them gently along the road, and someone to lean on when the going got tough. They needed to know that I was capable of doing what needed to be done, but also to help them understand what we all needed to be doing. They needed reassurance



Photo courtesy of Phonak

that their feelings were being considered despite the radical changes that hearing loss made in their family dynamics. They needed someone to understand that grief for the perfect child they lost and acceptance for the child they actually received is not a simple, linear process. Families learn to deal with adversity over time but still revisit old concerns and experience old feelings, hopefully with better coping skills and much greater cognitive awareness. Grief is chronic and continues to be triggered by unexpected events and at different times. Parents may also have to deal with feelings of guilt caused by the fear that something they did, or neglected to do, caused their child to have a hearing loss.

Despite my knowledge and expertise, I was the person this family never wanted to have to meet. I was telling them something they really didn't want to hear at a time they were not prepared to hear it. Maybe if they ignored the message, the problem would go away. What I wrongly interpreted as indifference was really a family crying out for support and time to adjust to the terrible news I was trying to tell them. Thank heavens for Barb, our teacher, who was willing to help me realize that parent counseling is NOT just telling the parents about the audiogram and dB level results. One of her favorite expressions was, "God gave us two ears and one mouth for a reason. Shut up and listen to what families are trying to tell you!"

Everyone learns differently. One of the most essential pieces of information a professional can gather during a case history is about the learning style of the parents. Although it may seem a bit unusual, ask parents a question like, "You have installed a new program on your computer. How would you learn to use that new program?" Some parents prefer a hands-on approach and jump in and do it by trial and error. Others will read the manual from cover to cover before attempting to use the program. Still others will review the basic facts and then begin to experiment. Some parents will listen, discuss, and consult with others before

trying to use the program. The answers to this simple question will help tremendously in guiding the counseling process.

Dynamic learners—the ones who prefer hands-on—will want to learn by doing. This is the group unafraid to tackle new techniques and technologies, but give them plenty of time to experiment. The analytic learner, who will read the manual from cover to cover, would be thrilled to have a large stack of brochures and literature to study before your next visit. The commonsense learner, on the other hand, wants just the facts before beginning to experiment. The imaginative learner, who would listen, discuss, and consult with others, is the social being of the group. This person requires family-to-family contact immediately and would like to meet other parents and professionals who can share information.

It is equally important that professionals be aware of their own learning style and be willing to adapt their informational counseling to better suit the style of the family. The quality of your interactions with the family will be largely determined by how responsive you are to their needs for information and how effectively you help them reach decisions most relevant to their child. If you are an analytic learner, for example, your inclination would be to provide the parents with lots of information to study—which is fine if the parent(s) happen to have the same learning style. If you are dealing with a dynamic learner, your stack of literature would go unread, and the parent would be frustrated that you did not provide the means to experiment and learn.

To assist audiologists and other professionals in the area of counseling families, the [American Speech-Language-Hearing Association](#) (ASHA) has developed *Guidelines for Audiologists Providing Informational and Adjustment Counseling to Families of Infants and Young Children with Hearing Loss Birth to 5 Years of Age* (ASHA, 2008). Throughout the balance of this chapter, they will be referred to as the ASHA guidelines.

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Quotes from the ASHA (2008) guidelines:

“Providing unbiased information requires a recognition and revelation of one’s own biases and opinions, fully disclosing any biases to families and stating the same and then providing a basis for the opinion.”

“The desires and needs of the family must be acknowledged and supported and given equally high priority as any public or institutional policy, keeping in mind that families are their children’s primary decision-makers and change agents. Any system must honor racial, ethnic, cultural, and social economic diversity of families.”

The ASHA guidelines differentiate between informational counseling and adjustment counseling as follows:

Informational counseling refers to “the imparting of information to families about a broad range of topics throughout childhood.”

Adjustment to hearing loss counseling refers to “the support provided by audiologists to families as they learn of their child’s hearing loss and to recognize, acknowledge, and understand the realities of having a child with hearing loss” (ASHA, 2008).

EHDI has compressed the timeframe for intervention, much to the frustration of some parents and professionals. Ample evidence has demonstrated the benefits of early intervention for deaf or hard-of-hearing children. The national goals for EHDI call for infants to have their hearing loss diagnosed by 3 months and to be enrolled in early intervention before 6 months of age. Moving families from initial diagnosis of a hearing loss to enrollment in early intervention services rapidly calls for an expansive set of counseling skills on the part of the audiologist. The difficulties in dealing with this newly compressed timeframe are addressed in the ASHA guidelines, “Family-focused service provision attempts to balance the system and technology-driven approach and recognizes that not all families can or will follow through with recommended benchmarks” (ASHA, 2008).

When families are ready to make informed decisions about desired outcomes, audiologists and other professionals are obligated to inform them how best to achieve those outcomes. As professionals, it is important that information provided be as unbiased as possible. Unbiased information provided to the family must be delivered in a straightforward manner without hidden agendas. This does not, however, imply that audiologists cannot or should not offer their expert opinions to families.

Honoring the racial, ethnic, cultural, and socioeconomic diversity of families may be easier said than done in many cases. Often, it is incorrectly assumed that having an interpreter present ensures effective communication across language barriers. Just knowing a language does not necessarily mean an interpreter will be able to handle the responsibilities of conveying emotion and the nuances so vital to effective counseling. Unless you use terms easily understood by the interpreter, getting the proper information to the family may be impossible. It is always best when using an interpreter to spend extra time getting acquainted in order to gauge the interpreter’s rapport with the family.

Avoiding cultural stereotypes is essential in dealing effectively with families. Often, it is assumed that some cultures prefer to have children who are “seen and not heard.” The father in some families is the absolute authority figure, while mother “rules the roost” in others. Certain procedures may be unacceptable to some religious groups, while prayer is expected to resolve the problem in others. While you may find these assumptions true in some cases, you are just as likely to be wrong in others. Preconceived notions of family dynamics based on racial, cultural, or religious stereotypes are counterproductive and downright insulting to most parents.

Although a comprehensive treatise on dealing with racial, ethnic, cultural, socioeconomic, or religious diversity is beyond the scope of this chapter, here are a few suggestions based on many years of experience:

- When dealing with families, always err on the side of cultural caution.
- If in doubt, ask! Families often appreciate the consideration and are more than happy to explain their beliefs or situation.
- Be cautious when using an interpreter, particularly other family members. Always talk to the family not the interpreter.

- Maintain eye contact with the family and let your body language suggest you are interested in what they have to say.
- Silence may not indicate understanding or lack of understanding. Periods of silence may be necessary for the family to assimilate the information you are trying to convey or may indicate confusion about what is being conveyed.
- Solicit feedback often to be sure the family understands what you are trying to convey, why it is important, who is responsible, and when and where the next step is to take place.
- DO NOT dismiss legitimate concerns or objections. Instead, seek to understand the basis for them and deal with each as it is expressed.

One of the most critical periods for effective counseling in the EHDI process is informing parents of results of newborn hearing screening. Often, this chore is relegated to a relatively untrained screening technician who may minimize the importance of results or fail to communicate clearly to parents the required next steps in the process. In an informal survey conducted in Iowa several years ago, one of the most frequently mentioned reasons by parents for not following up on hearing screening failures was their perception that many normal hearing children don't pass the screening, and, therefore, they shouldn't be concerned about the results. Fortunately, some hospital personnel have received a considerable amount of training in this area. Many programs have a script for screeners to follow when conveying information to parents. It is vital that screening programs pay close attention to how, by whom, and when this information is conveyed to parents.

It falls to the audiologist to inform parents of the presence or absence of a hearing loss following a diagnostic evaluation. The audiologist is responsible for describing the hearing loss and its implications to the family. Initially, it is best to describe

audiometric results to the family in functional terms. Detailed explanation of the audiogram should not be attempted until the parents indicate a desire to have that technical information. It is important to realize that some families may *never* really understand the fine points of an audiogram. Most families will not have a clue what "moderate to moderately severe, sloping, sensorineural hearing loss" means, but will readily understand "your child will not be able to hear conversational speech without the assistance of amplification." During this interchange, parents' questions and comments and their learning styles must guide the quantity of information and the level of detail provided. It is critical at this stage to make genuine, heartfelt contact with the family and avoid the perception of maintaining an uncaring professional distance.

Regarding early intervention and habilitation, "Audiologists are responsible for providing families with unbiased information, recommendations, and appropriate educational and communication options based on family decisions and informed choices. As such, audiologists are responsible *to* families, not *for* families" (ASHA, 2008).

In reality, it is impossible to separate informational from adjustment counseling. We must realize that we are delivering unsolicited information about the EHDI program and about their infant's hearing to parents at a sensitive and potentially vulnerable time. To provide a smooth and timely transition from screening to the diagnostic and early intervention process, we must provide appropriate and timely adjustment counseling for every family. It is critically important to remember that we must listen to the fears and concerns expressed by families and be prepared to support whatever decisions the family makes regarding the process. We must also recognize that our manner of delivering information may significantly interfere with parent-child bonding.

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While preparing for family counseling, we must recognize the family's fragility during the EHDI process and the impact the diagnosis of hearing loss has on the entire family, including the extended family. The family will need to identify and seek the assistance of many supports outside the audiological community and will need continuing emotional support throughout the child's lifetime.

Audiologists need not be afraid of periods of silence, tears, or expressions of anger. Silence may be a time when parents are attempting to integrate and think about their feelings; therefore, it is important that this silence not be interrupted. It is critical, however, that audiologists recognize signs of clinical depression or other serious issues within the family and initiate appropriate referral to a mental health professional, where indicated.

The transition from diagnosis and amplification to early intervention can be difficult for many parents. Audiologists are often the determining factor in how well parents accept recommendations for early intervention and participate in the design of an early intervention plan. The audiologist must facilitate the parents' knowledge of options and opportunities to send a message of optimism and prevent feelings of fear or isolation. Family-to-family support (as detailed in another chapter of this publication) is critical to reducing isolation and putting hearing loss in a proper perspective. The audiologist may be a facilitator of the parent-to-parent support process but must be ready to step back and let the dynamics of the parent-to-parent interaction take place without undue interference.

Parents often form a deep bond with their first audiologist and continue to consult that audiologist long after transition to other professionals has been made. Audiologists must be prepared to provide continuing support to families throughout the active parenting years. Families may fear additional bad news with each subsequent evaluation and

need additional emotional support if the hearing loss progresses. It has been this author's experience that parents will often seek a second opinion regarding recommendations made by other audiologists or professionals. Often, their first audiologist is the professional they prefer to call.

"Counseling in audiology has historically employed a medical model with an emphasis on providing content/informational counseling and rarely providing emotional support" (ASHA, 2008). The entire EHDI system has employed a medical model of providing information on newborn hearing screening, diagnosis, and intervention of hearing loss within the first 6 months of life. We've been very good at providing the necessary information, but sorely lacking in the emotional support necessary to carry families through the process. Sensitivity to the cultural and emotional issues of families may require modification of the EHDI timelines in some cases. "... achieving benchmarks (i.e., positive language outcomes) in early detection is facilitated when family counseling and emotional support are actively infused into audiology care with the systems driven paradigm" (ASHA, 2008).

Audiologists and other EHDI professionals receive a great deal of training regarding informational counseling. From the very beginning of our training, we are taught to give parents and other professionals the facts regarding our findings. It is a rare program indeed that provides professionals with the skills necessary to do an adequate job of emotional and adjustment counseling. Many audiologists have had limited exposure and experience in dealing with infants. The emotional and informational needs of families of very young children are significantly different than those of older children and hearing-impaired adults. It is incumbent on the professional to avail him or herself of every opportunity to gain this valuable experience.

If there is one key concept to be learned regarding counseling, it would be to listen to what families are trying to tell you.

Table 1 lists a few of the counseling styles I have observed over the years. Hopefully, you do not recognize yourself on the list. Counseling families, especially families of infants who are deaf or hard of hearing, is an extremely difficult skill for professionals to develop. The ASHA guidelines provide helpful information for anyone interested in learning more about the topic, but certainly do not provide a cookbook of techniques that will be effective in every situation.

If there is one key concept to be learned regarding counseling, it would be to listen to what families are trying to tell you. By listening more, talking less, and being sensitive to the emotions and needs expressed, you will make giant strides along the path to becoming a more effective resource for infants and their families.

Table 1

Counseling Styles

Overwhelm them with the facts.

Professionals who utilize this approach—typically analytical learners—feel that every parent would like to leave the office with an armful of pamphlets and other information. Counseling sessions tend to be quite one-sided, with the professional using every opportunity to “share” knowledge with parents.

Hit-and-run professionals.

These professionals are extremely busy and don’t hesitate to inform families of that fact. Brevity is the key word in their presentations, which are quite one-sided. Families don’t get to have their questions addressed and often leave wondering what it was they were just told. Often the hit-and-run professional is very uncomfortable in emotional situations and escapes before these emotions surface.

The busybody counseling style.

This professional gives parents a long list of things that must be accomplished, under the assumption that keeping them busy will ease their pain. This professional will provide parents with a checklist of things to do, places to go, people to contact, and activities to begin without realizing that parents may not be prepared to do anything but digest the information they were just given.

Sympathy, not empathy.

These professionals do not hesitate to cry with parents and offer their deepest sympathies at the information they have to share. Somehow, doom and gloom seem to accompany most diagnoses and prognoses. While this person may initially be very comforting to the family, they rapidly discover that they are getting nowhere.

The canned presentation professional.

This professional has an agenda and information that must be presented no matter what. For each diagnosis, information is prepared and presented exactly the same to every family. Sometimes under the guise of not forgetting anything significant, professionals prepare presentations that can be rapidly retrieved from their memory bank.

The nonstop talker.

Some professionals prefer to talk, so they don’t have to listen or experience awkward periods of silence. It’s much more comforting to be in total control of the situation and not have to spend time listening. When they appear to be listening, these professionals are typically formulating their next thought.

The “don’t worry, we can fix it” style.

This professional tends to minimize the impact of a diagnosis by reassuring the parents that technology is available to cure most of the problems a deaf or hard-of-hearing child is likely to experience. In trying to minimize the effects of a diagnosis, this professional often inadvertently encourages unrealistic expectations and inappropriate intervention decisions.



Photo courtesy of NCHAM

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