

Chapter 12

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

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means the extended family may not be readily available for advice and support. Family groups may post on their Facebook page, "tweet," "facetime," or "skype" each other rather than gathering in person at a central location.

We now live in the information age and all that it entails. No longer do we have to wait for the textbook, magazine, or newspaper to tell us what's happening in the world around us. Most of us are totally dependent on our electronic gadgets and the instant information they are capable of providing. Television and Internet news sources provide almost instantaneous coverage of everything worth reporting, and unfortunately many things that aren't. If we need specific kinds of information, the byword is "Google it." Typing or even just saying a keyword or phrase brings up an immense amount of information from which to choose.

New parents are part of this age. They likely do not remember waiting for information, studying it carefully, and forming their own conclusions. Having grown up with cell phones, computers, the Internet, and instant information, this group presents a challenge to those of us who may not have had the same experience. As professionals, we are challenged with providing meaningful and relevant information to young families who do not particularly want to hear what we have to say.

The arrival of an infant evokes a multitude of emotions in parents and the rest of the family. If the infant is the first child, drastic changes in lifestyle are mandatory. No longer are the parents free to come and go as they please. The new baby demands almost constant attention—usually at the most inconvenient times. Conducting and arranging childcare becomes a major issue in daily life. Financial obligations certainly change with frightening speed. New mothers particularly often experience what is commonly known as the “baby blues.” Parents and extended family may be unable to share the burdens due to the limitations of geography or lifestyle.

In addition to all their other functions and responsibilities, it is necessary for the parents to take the first steps to investigate any possible disability. If the new arrival is found to have a disability, a whole new set of variables is introduced into the family dynamic. It is often a difficult transition to realize that the infant parents hoped to be perfect is just not what they expected. It can be a traumatic experience to accept the baby you received instead of the one you wished for. If you are not familiar with an essay called “Welcome to Holland” by Emily Pearl Kingsley, Google it and gain some insight about dealing with the emotional issues of raising a child with a disability.

If the infant is deaf or hard of hearing, the family has a whole new set of professionals to deal with. Often the audiologist is the first such professional that the family encounters and is faced with the responsibility of delivering a diagnosis

that may be frightening and confusing for the family. If the audiologist is insensitive to the emotions being experienced by the family and concentrates on delivering only factual information, the family may withdraw from the entire process until such time as they have been able to integrate their emotions with the diagnosis. In some cases, the audiologist may represent a second, third, or fourth opinion for a family reluctant to accept an initial diagnosis. As professionals, we understand the importance of early diagnosis and intervention and convey a sense of urgency to initiate actions that the family may not be prepared to handle. It is absolutely essential that the family implicitly trust the professional before they are willing to accept any information they are being given.

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 totally unlike those experienced by young families in the information age. The Internet offers a huge source of information regarding almost everything. In early 2016, this author Googled several terms related to hearing loss. Hearing loss returned 30,600,000 hits, deafness 8,550,000 hits, cochlear implants 1,100,000 hits, early intervention 21,400,000 hits, and American Sign Language 539,000,000 hits. Contained in this astounding number of hits is a great deal of excellent information, probably an equal amount of inaccurate information, and a significant amount of downright bad information. The problem, of course, is separating the wheat from the chaff as far as relevant information is concerned.

The role of the professional has changed from information provider to information filter—helping to sort the good stuff from the incorrect or harmful. Parents will bring information from outside sources and expect the professional to be able to intelligently discuss the merits of each piece. Here are some suggestions for helping families to deal with outside information:

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- Know the source. Information that sounds too good to be true usually is. Anyone can post information on the internet or social media. Look carefully at the qualifications of the author and, if possible, any affiliations they may have with organizations.
- Ask a lot of questions. Why is this information posted? What is the experience that caused the author to write about a specific topic?
- Do not believe everything you see or read. Just because it's posted on the Internet or printed somewhere does not necessarily make it true. Be skeptical!
- Whether information is being presented to you in a one-on-one professional situation, in social media, or on the Internet, don't be afraid to question and have it explained again and again until you understand what is being said.

Second opinions, as long as they do not represent "diagnosis shopping," should be actively encouraged. One of the goals of parent counseling is to

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It is extremely important to realize that parents do not retain all the information they hear in a counseling session or see on the Internet. As a matter of fact, depending on conditions, 40 to 80% of the information they receive 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.

We must also realize that 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 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

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



Photo courtesy of Phonak

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 systems must honor racial, ethnic, cultural, and social economic diversity of families.”

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 remember they may need plenty of time to experiment. The analytic learner, who will read the manual from cover to cover, would be thrilled to be provided with 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.

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 the 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 all of the professionals involved. This is often a time when families need the support of other families. 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

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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.

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. Fortunately, most 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 be delayed until the parents are ready for that technical information. 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. Consideration for family circumstances, cultural values, and preferences must be demonstrated at every step of the counseling process.

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. In order 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 decision the family makes regarding the process. We must also recognize that our manner of delivering information may significantly interfere with parent-child bonding.

While preparing for family counseling, we must recognize the family’s fragility during



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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.

Professionals 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 professionals 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 professionals. Often their first audiologist is the person 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 audiologic 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 any opportunities to gain this valuable experience.

Counseling families, especially families of infants who are deaf or hard of hearing, is an extremely difficult skill for new professionals to develop. The ASHA guidelines provide helpful information

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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. Another extremely helpful resource for improving parent counseling skills is the CARE Project. I would highly recommend you visit their website (www.thecareproject.com) for additional information on the materials and training they offer.

While the major emphasis of this chapter has been on counseling by audiologists, the principles are equally applicable to everyone involved in EHDI. Early interventionists, speech-language pathologists, EHDI program personnel, therapists, deaf mentors, and any other professionals that provide services must realize the importance of appropriate and effective family counseling. All too often we hear reports of a family “turning off” to a program or service simply because of inappropriate or inadequate comments made by an insensitive or poorly trained professional.

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.



Photo courtesy of NCHAM

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