Breaking the News to Parents

Often the very first information parents receive from a professional is information that may rock their world. How this information is presented and interpreted often sets the stage for all future interactions between the parent and the professionals who will serve their child for many years to come.

Receiving the News

Hopefully when you received the diagnosis, you were told in a sensitive, supportive manner. Perhaps the professionals helped you understand what to do next. Unfortunately, not all parents have a positive experience. If yours was not a positive one, you have the chance to turn a negative experience into an opportunity to educate the professional. In an effort to convey information accurately to parents, professionals sometimes forget that they are dealing with parents who may be receiving devastating news, or at least news that they were not prepared to hear.

Making a Difference for Parents Who Follow

Most professionals strive to provide the best possible services for our children, and input from parents can be very helpful to them. Letting them know how this affected you, and suggestions on how they might better present information to parents may well make a difference to parents who follow you.

A New Role for Parents

You are not "just a parent," you are one of the professionals. You are a key player on the team. Immediately after the diagnosis, a flurry of activity thrusts parents into new roles that are unfamiliar and sometimes intimidating. Until now we knew our child so well, and we were the center of their universe. Often, overnight we find ourselves in the position of having to trust a number of professionals who seem to know more about our child than we do.

You Know Your Child Best

One very important thing to remember during this time is that while you may not understand the hearing loss and all that goes with it, you still know and understand your child better than anyone else in this world. What sets us apart from the professionals is our emotional attachment to our children. While this attachment can sometimes get in the way when we are working with professionals, it is also the force that drives us to settle for nothing but the best and go to any length to figure out what that may be.

Developing the Right Attitude

Go in with a positive attitude. Veteran parents will tell you that your attitude often sets the stage for how professionals perceive you and interact with you. Don't walk in with guns blazing, but go in expecting the best. You will have enough battles to fight in the years to come without having to look for them. Learn to be assertive when you need to be, but don't walk through the door expecting a fight.

Learning To Become an Advocate For Your Child

Learning to become an advocate for our children is one of the most important actions we can take to help them with their hearing loss.

Very quickly, most of us come to understand that we are the ones who will be standing in the gap between our child and the professionals. Because we love our children and want the best possible services for them, this is not something we have to think about doing, we just do it.

Fortunately, many professionals welcome input from parents and are grateful to be able to work with an involved parent to figure out what is best for the child. The hard part comes when we are faced with having to challenge the opinion or advice of a professional. It can be very intimidating to walk into a room full of professionals. An important thing to remember is that you are part of the team and you deserve the respect and consideration of those working with your child.

None of us becomes an advocate overnight. We learn to do this as the need arises. It takes time and effort to reach the point where you are confident enough to walk into a room full of professionals and go head to head with someone who is more educated on the subject than you are. Tapping into the knowledge and experience of "veteran parents" can be an excellent way to learn to advocate effectively for your child. Most are more than willing to share what they have learned over the years.

It is normal to feel a sense of urgency to learn everything you can immediately. While this is an admirable goal, it is not always a realistic one. Most of us have many other things that demand our time and energy, including a spouse, other children, a career, etc.

Permission to 'Just be a Parent'

Begin to do everything you can to educate yourself, but also give yourself permission to 'just be a parent.' It is easy to get lost in the learning and forget to slow down and enjoy your child. The more time you spend with your child, the more you come to know and understand them, and remember that THIS is what makes you such an important part of the team...you know your child better than anyone else!

Educating Yourself

Educating yourself is the key to learning to work with professionals effectively. This education may come in the form of:

- Learning everything you can about your child's hearing loss
- Talking to other parents who have been in the same situations as you are in
- Learning about what services are required to be provided for your child
- Finding out what rights you have as a parent when decisions need to be made concerning your child

Preparing Yourself

It would be nice to think that we could quickly and easily learn everything we need to know before we need to know it. Unfortunately that is not usually the case. There are, however, a number of ways to prepare yourself:

- *Prioritize*: There is so much to learn, so it is often helpful to prioritize the information you feel you need to know. Breaking it down makes it much less overwhelming, and easier to deal with.
- *Identify Resources*: Many resources exist that can help you understand your child's hearing loss, including:
  - Other Parents: Veteran parents are usually eager to share their experience with new parents. Ask the professionals working with your child to put you in contact with other parents.

- Online Resources: Conduct searches that specifically look for information on hearing loss, amplification options, choices in communication and education, etc.
- Local Agencies: Contact local agencies specializing in services for the deaf and hard of hearing. They often have access to classes and public service information that they can share with you.
- Your Local Library: The library is filled with information that can help you understand your child's hearing loss, including books, periodicals, access to the internet, newspaper clippings, and more.

Keep Good Notes

As you find the information you need, print out hard copies, take notes, etc. Many parents find it very helpful to keep a journal or write notes as they think of questions or concerns that they want to address with the professionals who work with their child. It is often hard to digest everything at once, and this allows you to go back and review information when you have some time to yourself. Information that is particularly helpful and good to keep for future use is information on the IFSP (Individual Family Service Plan) and the IEP (Individual Education Plan) process.

Ask Questions

Ask questions and keep asking until you are satisfied that you have gotten the information you need. If your Pediatrician, ENT or Audiologist does not have the answers, ask to be referred to someone who does. Most are very willing to help you find the answers you need, but often do not do so automatically without you requesting it.

babyhearing.org — Supported by the National Institute on Deafness and Other Communication Disorders. Boys Town National Research Hospital.