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## **Removable File Folder for the Most Recent:**

Hearing Tests
Individualized Family Services Plans
Health Insurance Information
Note Pages

## Acknowledgements

This notebook exists because families with young children who are deaf and hard of hearing, along with professionals who work with these families, asked for it. Committee members have talked with, and more importantly, listened to many families who have struggled with the diagnosis of their child's hearing loss. Through these discussions, it became clear that what families wished for most was clear and unbiased information. It is our hope that families find valuable information included within this notebook. We also hope this book will serve as a place to record and store all the other information important to your child and his/her hearing loss.

Special thanks go to the dedicated parents, who contributed their time, energy, wisdom and experiences. Thanks to the committed group of professionals who helped write, construct and review this resource. These include Kurt Randall, Holly Hyte, Judi Nielsen, Rich Harward, Kathleen Watts, Katie Denter, Nita Jensen, Krysta Behring, Megan Mansfield, Karen Munoz, Todd Houston, and a peer review group of parents, audiologists, and newborn hearing screening hospital coordinators.

Our thanks to the many additional parents who shared stories and photographs of their beautiful children with us and allowed us to display them throughout the notebook.

Particular acknowledgement must go to the following organizations that allowed the reproduction and adaptation of materials already created for families: Mary Pat Moeller and the Boys Town National Research Hospital, the AG Bell Association, and the Wisconsin Children with Special Health Care Needs, Sound Beginnings Program.

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Dear Parents,

Every expectant parent plans on a healthy child and begins building hopes, dreams, and expectations for their new baby. These dreams can be altered when a child is diagnosed with a hearing loss or impairment. Many parents have suggested the diagnosis of their child's hearing loss initiated a mourning process, as well as a new sense of responsibility. With the realization of your child's hearing loss comes the responsibility to gather information, make decisions, and help your baby to develop the best you can.

We understand the dedication, time commitment and sense of overwhelming that comes with this responsibility. The *Interactive Notebook for Families* was created through the collaborative efforts of parents who have been where you are now and professionals who have dedicated their lives to making the “systems” work for you and your child. Utah's Newborn Hearing Screening Program hopes that this resource will help guide you and your family during this emotional and busy time as well as in the years to come. Even though you may not be ready to use all of these resources right away, they are here for you when you are ready.

We are very interested in your thoughts on the usefulness of this resource and how we can continue to make this notebook more helpful to families. We have included a feedback form at the back of the notebook or you may write to the Utah Newborn Hearing Screening Program at:

Utah Department of Health  
Hearing, Speech and Vision Services  
PO Box 144620  
Salt Lake City, UT 84114-4620

Best Wishes,

Utah Department of Health





## Celebrating Your Child Who Is Deaf or Hard of Hearing

This section of the notebook is written for parents who are just discovering their child is deaf or hard of hearing, by parents who have been just where you are. There are resources and technologies available to help you and your child, but those do not ease the immediate response in the heart and minds of parents who are just learning that their child will face difficulties they had not expected. Other parents have been there before you. They understand that it is never easy to accept this information, and it creates many questions for a parent. How will my child learn? Can we communicate fully with our child? How will this affect our family? How will I find the time and money to provide the therapy my child will need? What will my child's life be like? How will I find the strength to cope?

The stories that follow are accounts of how other parents in Utah have coped, and in fact rejoiced in, the life of their child with a hearing loss. They have chosen to share their stories as a means to give you hope, to help you gain confidence, and to help you recognize that you are beginning a special journey with your child.



## Personal Stories of Success

We are the proud parents of two beautiful children who are deaf. Stratten, 4, was diagnosed with profound hearing loss at the age of 11 months. Caroline, 1, was diagnosed with a hearing loss at the age of 5 weeks. By the time she was nine months old, her hearing loss was also profound. We would love to share a few of the lessons we have learned:

1. Our children, and all children born with or who have developed a hearing loss, are amazing! They are perfect. They are “normal”. They play, get into mischief, express themselves, and have the same need for love and acceptance as every other child. We love our children, accept who they are, teach them that their differences (because we are *all* different, after all) are important, and expect the same of them that is expected of every other child.

2. Learning is wonderful! It is challenging. Learning opens doors and minds to new opportunities and ideas. Through this experience we have met new people, learned a new language (American Sign Language), changed the way we view people who are visibly different than we are, and tried in every way to make ourselves experts on raising a child with a hearing loss.

3. Language is the key! With all of the heated debates and fierce opinions among experts and individuals, everyone is really fighting for the same thing---these kids just need an opportunity to access and understand language. Language allows children to think, form memories, communicate, learn, and understand their own feelings. Once we understood this, we decided we would do everything we could to give our children access to language---visual and spoken.



When we found out our first child was deaf, more than anything we wanted to hear the words, "Everything is going to be okay." And now, we would like to tell you . . . "Everything will be more than okay! Everything will be great!" We would not trade our lives, or our children, for any other

experience. This has been an incredible journey, and we can't wait to see what the future holds.

--- Catherine Scott

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When I first learned of our daughter's hearing loss I felt guilty. I wondered what I'd done during the pregnancy to cause the hearing loss. It is completely normal to feel scared, sad, and uncertain. Those feelings don't always remain. I'm quite certain that there will always be moments of frustration - that's normal when raising a child - especially one with extra needs. An important resource for my family was the parent infant program. That program is amazing! The people there gave me many resources including our deaf mentor. The people in these programs are amazing! They helped us to see all her abilities rather than her one "disability."

Having a child with a hearing loss has opened us up to wonderful new experiences, people, and learning. The learning process on hearing loss and deafness has been an incredible ride - the ride of our life. There have been so many emotional ups and downs. Times when we didn't know how to do what our child needed. In the end, with help from wonderful, amazing people - we're still on track.

--- Katie Gardner

---

Taytum is our first child, she is very strong willed, energetic, and adorable. She was healthy, she had 9.9 on her apgars, and we didn't know anything like this would happen. She was just so beautiful.

When we did the newborn hearing screening, the morning after she was born they told us she failed both her hearing tests, and we understood that a lot of children did not pass the first test. The morning we went to take her home from the hospital she did not pass the test again. A gut feeling did tell me that she did have a (hearing) loss. We would stick the phone by her ear and let it ring and she would just sit there.

By the 4<sup>th</sup> test at the hospital, we were sent to PCMC. We found out she had a permanent hearing loss. It was actually more of a relief to know she had a hearing loss. We went to DDI Vantage and the PIP program. It was a great experience for us. They gave us hope that our daughter would be able to hear someday.

When we were sitting up at USDB, and I was holding Taytum at 13 weeks and putting those little earmolds in her ears, and I was thinking wow this is going to be rough, when they put them in and turned them on it was incredible. Her eyes widened and you knew she heard you. To this day it is one of the most memorable experiences.



---Kelli Petersen

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Going through this journey has been a crash course into an unknown abyss. It was a challenge. We were in a completely unfamiliar situation. At first it is hard to know where to begin and what deafness means for the whole family. You just push forward, learning as you go and realize more and more just how amazing your deaf child is. My little son is capable of anything any other child is capable of! His deafness will present him with unique challenges in a hearing world no doubt. There are many successful deaf adults who live full independent lives. My son is going to turn out fine. We just

continue to work at getting him what he needs and facing the challenges that come up. It is an ongoing process and journey. One important thing to remember is you are not alone. Other parents are feeling the same feeling that you are. And your child is not alone either. You as a parent can do this. You are capable of giving your deaf child what they need. There are people and professionals to help you. Much of your role as parent will be to educate family members, friends, neighbors and even doctors about hearing loss and what your child *can* do.

--- Taunya Paxton



When Cole was in the hospital, 5 days old, his natural mother told me there was something wrong with his hearing. His doctor said he didn't pass the hearing test, and at the time I was really surprised that he didn't pass. The doctors explained the test to me but I was really sad because I was going to adopt Cole at the time.

When I took Cole back to the clinic, they ran some tests and they told me he did have a hearing loss in both ears. My husband and I didn't know what to say. We had never had a child with a hearing loss before. I thought maybe he would outgrow it but they told me that was not possible.

I talked to his pediatrician, and he told me that it was a good idea that he would get to try out a hearing aid. He explained to me a lot of things, and helped me work with my audiologist

When the parent advisor came out to check Cole, they really worked with him since he was 6 m old. They suggested a lot of things that I could do with him. They helped me with the paperwork for school.

After I put Cole's hearing aid on, he calms down and he's not aggressive. Other than that he is a very happy boy.

When I first learned of Cole's hearing loss everyone helped me through the process. They really enlighten us on what its like for a child with hearing loss. He didn't really loose out on anything and now he's a smart little boy.

--- Stacy Billie

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We are super happy to have her. We didn't think to much when she didn't pass because she was a couple of weeks early. My husband was a little nervous at first, but the hospital reassured us not to worry and it wasn't something that we took seriously. We returned 2 weeks later, and she failed again and they acted really nervous and they kept repeating the test which made us really nervous.

It took us a month to get into PCMC, where they did an ABR. We didn't know what was happening, they put electrodes on her head. The audiologist just had us hold her still. When the test was all done, we found out that Kembree was profoundly deaf. We did not know anyone who was deaf, we did not have anyone in our family who was deaf. We were devastated. We just looked at this little precious baby and we couldn't believe she couldn't hear us talking. The audiologists reassured us that with all the technology, she would be able to hear and talk someday. That just brightened my whole day.

The hearing aids were so big, it was so funny. They would flop over and Kembree hated them, but we kept them on her. She would try to eat the hearing aids, she hated the left one. The only two sounds she heard with her aids were a fire alarm, and a fire engine. She's beautiful and we love her. We want her to have a high self-esteem. She wasn't getting any benefits from the hearing aids so we began to look at CI. At 15 m she got a CI. Its been amazing to watch her since she got the implant. She hears everything now. She dances and she plays. First thing in the morning when she wakes up, and points to her ear, wanting the implant.

--- Keri Banks

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My first thought after receiving my child's hearing loss diagnosis was, "Ok, what do I do for her? How do I help her? What do I need to learn?" I had important questions about the future such as "What is going to happen at two years old, four years old and so on for the rest of her life? My family's learning process on hearing loss was consuming, enlightening and incredible! I learned to never underestimate a child from birth to three. They have a capacity to learn beyond belief. I want other parents beginning this journey to know the incredible experience that they are embarking on. A child with a hearing loss brings so much love into a home. Because of their unique language needs the family must come together changing the dynamics. Everyone in the family communicates better! There is something special about a child with hearing loss!

--- Greg and Tiffany Maughan





## Family Support

The family of a child who has a hearing loss will seek support from many avenues. Each family must find the support that is best for them. The support system that is in place prior to having a child who is deaf or hard of hearing may change. That is okay. This section will give you many resources for the support you need but certainly you may find other resources as you learn more about what it means to have a child with hearing loss. Make an effort to meet other parents with children who are deaf or hard of hearing. They will understand. Make an effort to meet older children and adults who are deaf and hard of hearing. They will be role models. Make the decisions about the communication approach to follow and treatment required based on the future goals you have for your child. Trust yourself. Be a smart consumer and seek professional support from people who are honest and will provide unbiased information. The information will lead to comfort, confidence and power for you as parents.



## Acceptance

Accepting the news that your child has a hearing loss is perhaps the most difficult challenge that you may face with your child. All kinds of questions go through your mind: Does my child really have a hearing loss? Will it go away, get better? Will my child need hearing aids? How can we afford this? Will my child be made fun of? How will the hearing loss affect my child?

When you are told your child is deaf or hard of hearing, it is normal to experience a variety of emotions. These emotions may include shock, fear, denial, sadness, grief, confusion, anger, guilt, disbelief, surprise and relief.

*“I can’t remember anything they said after the word deaf. I was devastated and shocked. I wasn’t able to get on with my daily activity.”*

*“I was surprised to learn she had a hearing loss and I felt guilty about the possible causes.”*

*“When my daughter’s hearing loss was finally diagnosed I felt such a sense of relief. That might sound odd, but I was so relieved because despite what her doctor and my friends and family had been telling me, I knew something was wrong. Finally getting a diagnosis meant that we had a place to start, we could begin to educate ourselves and try to figure out the next step.”*

The experience of learning that your child has a hearing loss often begins a journey that includes a process of grieving. Dealing with the grief, anger, and pain of such a discovery is difficult but necessary. Grieving is important so you can take actions and make decisions that need to be made for your child. You and your family members may grieve differently. It is a very individual journey and **everyone responds differently.**

*“Make time and space for grieving. Something’s been lost, your hope that your child would have “normal” hearing, so that needs to be mourned and grieved for. Find someone (friend, family, counselor) who will let you talk, cry, shout about this loss without judging you, and telling you to move on. Allowing yourself space and permission to grieve will allow for space to think well about the adjustment you’ll need to make, and how best to help your child.”*

Acceptance as a process:

Most parents describe acceptance as an ongoing process, one that comes and goes over time. When talking about acceptance you are not just talking about accepting the hearing loss itself. You are also talking about the acceptance that life as you know it, has changed. Initially it may feel like everything has changed. You knew how to communicate with your child and suddenly that has changed. Now you may be wondering how to communicate, educate, and interact with your deaf or hard of hearing child. You may question what options are available to you and your child and what the future holds.

Material was adapted from the Boys Town website [www.babyhearing.org](http://www.babyhearing.org) and High Preface.

**With time, you will realize that the hearing loss is just one part of your child:** You will shift from concentrating on the part of your child that is deaf or hard of hearing to seeing the child’s hearing loss as one of the wonderful qualities that makes him or her unique. You will learn to accept your child as a whole, as illustrated by the following story:

Jumbo\* is a little elephant who is ridiculed by his society because his ears are different. When his mother tries to protect him from his tormentors, she is labeled uncontrollable and then separated from him. The scene which impacts most people is when the other animals and their babies were shown in warm, secure embraces while Jumbo and his mother could only touch through prison bars. All because of his ears.

While Jumbo is fictional, we believe the experience is true to life. Many deaf and hard of hearing children are viewed in terms of their ears – ears that don't work, ears that need to be fixed, ears that need testing, amplifying, and maintenance. Ears that result in low language scores. This concentration on ears that need to be made "normal" can interfere with typical, warm, secure embraces, creating a sort of prison barrier within families.

Fortunately, this story has a happy ending. Intervention is provided by a mouse named Timothy who looks at Jumbo's strengths and capitalizes on them. As a result, Jumbo finds success and a sense of self-worth and pride. Jumbo is reunited with his mother and their bond is strengthened. Early intervention can help children and their families be confident and successful if we concentrate on the strengths of the whole unit, not just focus on the ears.

\* This character is known as "Dumbo", the name of the Disney movie. But his mother named him Jumbo, so we used that term.

#### Coping Strategies:

The great majority of children who are identified with a hearing loss are born to hearing parents. Only 5 to 10 % of people with hearing loss are born to deaf parents. In most cases there is no history of hearing loss in the family. Most do not know of any other families in the same situation. This often leaves parents feeling very alone, and many find themselves searching out others who understand what they are going through. During this time parents find themselves being thrust into new and unfamiliar roles. They suddenly feel the need to become experts on the subject of hearing loss in order to make right decisions for their child, as well as become advocates for the services their child needs immediately, and in the years to come. Initially, this task seems overwhelming for most parents. Some helpful coping strategies may be 1) finding out all you can, 2) connecting with other parents and 3) embracing the knowledge that you and your child can be happy and successful together.

One key to coping for most parents is **finding out all you can** about your child's hearing loss and what it will mean in terms of learning to talk and/or communicate and how it will impact family dynamics, education, and social development. Often, the path to finding out all you can comes through **connecting with other parents!**

*"I had no idea where to begin looking for the info I needed to understand my child's hearing loss...Getting involved with other parents was a life saver. Being able to talk to those who really understood what we were going through helped tremendously. It helped us to relax and find the comfort that we needed as we struggled to figure out what to do for our child. Even more important was being able to see deaf and hard of hearing children older than our own child. We were able to see just how normal they were, and it helped us to realize she was going to be okay."*

Having a child with a hearing loss does not need to be something awful. You and your child can be happy and successful if you can learn to embrace your child and the hearing loss as well as your ability to parent a deaf or hard of hearing child. **You will learn and grow together.**

Material was adapted from the Boys Town website [www.babyhearing.org](http://www.babyhearing.org) and High Preface.



## Impact of Hearing Loss in a Family

There is no doubt about it. Having a child with 'special needs' changes your family. It adds challenges and rewards that can't be imagined when first hearing the words, "your child has a hearing loss."



This is a challenge your entire family is going to face for a lifetime. You and your family will experience a continuum of emotions, which may affect how you bond with your child who has a hearing loss and how you continue to bond with others.

You as a parent will be taking on roles and establishing rights for your child that you may have never considered before learning of your child's diagnosis. You may interact differently with your spouse. One parent may take on more responsibility or change their coping and decision making behaviors. The child's grandparents, siblings, extended family and community members will be affected. They too have to adjust to the news and determine what this will mean for them. Grandparents have added worries. Their concern is not just for the child who is deaf or hard of hearing, but for their son or daughter and his or her spouse, and for the other grandchildren in the family. They may worry about what their responsibilities will be to the child and their family. Help grandparents to know that the best they can do for their new grandchild is to stay connected to the child and keep an open mind about the child's hearing loss. Make sure that your expectations of them are clear. This way they will not feel like they are letting you down or failing to meet your expectations due to a misunderstanding. They may want to help but may not know how. Help them learn what they can do to help you or your child.

The following are descriptions of feelings that any member of your family could experience:

- In the course of finding answers and services, you and your family may need to share personal and private information with professionals and parents. This may feel very uncomfortable for some people.
- You may feel like you are 'on display'.
- You may feel isolated because those close to you don't understand what you are experiencing.
- You may need to alter your communication style and learn a new language. This may be frightening but may also feel exciting.
- You may find your network of friends changing because you feel like you have different opinions, interests and/or priorities now.
- You may feel overwhelmed. This is very likely because there is so much to learn and consider and so many decisions to make.

Although the effect on brothers and sisters will vary, there are some similarities. You as a parent need to be aware that much time and energy will be spent dealing with the hearing loss. Siblings may not get as much attention, causing feelings of 'life isn't fair' and that they are not important. Siblings may need to learn to handle cruelty, insensitivity, and/or ignorance of others towards their brother/sister with a hearing loss. They may begin to see themselves as their sibling's unofficial guardians. These experiences may be very stressful for the other children in a family but can have rewarding results. Siblings often learn an early empathy for others and may appear more mature and independent than other children their age. Be sure to listen to each of your children and seek support on their behalf if you feel it is necessary.

Siblings of deaf and hard of hearing children may learn to understand more about what is happening to their brother or sister by visiting places that you go with the child who is deaf or hard of hearing (i.e., audiologist, therapy room, etc.) They may be interested in

participating in some of these activities. This is an acceptable practice with many professionals if you ask permission before a session.

It is important to be open about hearing loss. Promote education of hearing loss and deafness in your family and community. This will lead to acceptance.

Additional information about the feelings and possible roles that siblings with a brother or sister with special needs can be found at the end of this section on page 23.

This information was adapted from the Sibling Support Project of the Arc of the United States and is not specific only to siblings who are deaf or hard of hearing.



# Parenting the Child Who Is Deaf or Hard of Hearing

*All children need three types of inner resources if they are to become self-regulating people:*

1. *Good feelings about themselves and others.*
2. *An understanding of right and wrong.*
3. *A fund of alternatives for solving problems.*

## **Twelve Strategies for Enhancing the Parent/Child Relationship and Raising Children Who Will Be Self-Regulating and Responsible Adults.**

### **1. Express Love.**

Expressions of love can head off undesirable behavior. When a child feels loved, he/she wants to please their parents. A warm facial expression, a kind tone, a look of admiration and enthusiasm, a hug, all express love in an unmistakable way. Older children, who may be embarrassed by physical expressions, welcome the personal attention of a one-on-one game or special time with mom or dad.



### **2. Be Predictable.**

Children thrive in a predictable environment. Routines and schedules carried out with consistency provide stability and security. This is also true with parenting behavior. Consistent messages and consistent, reasonable consequences result in a child who trusts his/her parents. This can be especially important for some deaf or hard of hearing children who have limited communication skills.

### **3. Communicate Clearly.**

Young children need to be exposed to lots of language in order to learn. It helps when the messages are short and presented slowly. Make sure your words and actions are sending the same message. Words, tone of voice, and facial expression should all “match”. Realize that they need lots of examples to learn. Young children need to have things spelled out

for them. To teach an abstract concept like “sharing,” use examples. If there is a communication challenge because of deafness or hearing loss, acknowledge the need to purposefully develop strategies to close the gap. With a deaf or hard of hearing child, consider creating a ‘quality control’ test to make sure your message was understood as intended, including consequences. Have him/her repeat back what they understood you to say. Role-play to teach productive, appropriate questioning techniques that will be essential at home, at school, and everywhere.

#### **4. Understand Problem Behavior.**

By being good observers, parents can gather information that will help them understand what a child’s problem behavior means. Look for a pattern. What happens before the behavior starts? When, where, and with whom does it occur? Is there a physical cause such as hunger or fatigue? Was the communication experience unsuccessful -- resulting in frustration, anger or lashing out? Does he/she feel threatened, hurried or ignored? Is the child seeking attention in an unappealing way? Is he/she having trouble expressing themselves or projecting their negative energy in a physical way? Which is needed... punishment, or a shoulder to cry on?



#### **5. Catch Your Child Being “Good.”**

It’s easy to take for granted what we approve of and hard to ignore what we don’t. This makes it easy to neglect opportunities to praise good behavior and focus on bad behavior. Let your child feel and see your approval. Turn ‘no’ statements into ‘yes’ statements, i.e. “I love how careful you’re being with our dishes.”

#### **6. Set Up a Safe Environment.**

Children love to explore and thrive in tactile environments where things can be pulled on, climbed over and taken apart. This is their nature. Make their environment safe. The more appropriate things there are available to explore the fewer problems with inappropriate

behavior they will have. Consider how this applies to adolescents and even teenagers. A safe environment is one where the rules and limits are defined and understood. Can they have the car Friday night? Yes, if we know whom they're with, where they're going, and when they'll be back.

### **7. Set Sensible Limits.**

Neither parents nor children want to live in a police-state atmosphere in which there are so many rules it's impossible to avoid breaking them. Generally, very young children can remember only a few rules and a great deal of adult supervision is required to enforce them. Make the language simple and direct, like: "use words" or "no hitting." The limits expand as the child grows older. Going outside established limits is an exercise in trust between parent and child. If your adolescent or teenager demonstrates responsible behavior, they should be rewarded with certain privileges. If they demonstrate a lack of responsibility, the limits may need to be more tightly drawn and defined until trust is built again.



### **8. Defuse Explosion.**

Step in while your child is still calm enough to discuss a problem. Intervene before anger gets out of control. If certain situations are recipes for disaster, talk about them ahead of time and create some plans for coping and resolving. For deaf and hard of hearing kids, not being understood because of a communication mode difference or gap is a common occurrence, and one that lends itself to frustration and anger. Anticipate these kinds of circumstances. Often parents can help children avoid a meltdown by pointing out problem-solving alternatives that can be employed before the problem rises to a crisis state.

### **9. Teach Good Problem Solving Skills.**

There are good solutions to problems, and not-so-good solutions to problems. How do you get your child to know the difference? Start by clearly labeling unacceptable behavior and explain it is unacceptable. Follow up with positive suggestions for what to do next time.

For children under four, it's best to simply state what you want them to do next time. For older kids who can express themselves and think abstractly, ask them what they could do next time that would be better. Suggest additional alternatives. As kids get older and more mature, they'll be able to employ these tactics more successfully if they've been practicing them since childhood. If the problem stems from communication gaps, which is often true for children with deafness or hearing loss, use the same strategies and exploit every opportunity to expand the child's language base around conflict resolution. Knowing how to express themselves and state their position will increase your child's sense of empowerment to successfully solve problems.

#### **10. Don't Overreact.**

Giving lots of attention to problem behavior can create a whole other set of problems. Telling a child to go to a time-out place or removing them from the play area where they misbehaved delivers a consequence for bad behavior without creating an attention-getting incentive to repeat the action again.

#### **11. Seek Professional Help When Needed.**

Most children grow out of common behavioral problems with the patient guidance of parents and other caring adults. However, for a small percentage, approximately 5-15%, the problem behaviors persist and can become severe. Professional help is an excellent resource that can provide support and a constructive plan of action.

#### **12. Be Patient with Your Child and Yourself.**

Misbehavior happens. It's human nature to learn from our mistakes. A key to healthy psychological development lies in the child's ability to do just that. If you follow all 11 steps faithfully and still experience a repeat of bad behaviors, remind yourself that your child is in a learning process called *childhood*. Your consistency, patience and love will provide him or her with the support needed to emerge into mature, independent adulthood.

\*Adapted and excerpted by Leeanne Seaver from Thelma Harms Ph.D., Univ. of North Carolina, Chapel Hill

## What Siblings Would Like Parents and Service Providers to Know

In the United States, there are over six million people who have special health, developmental, and mental health concerns. Most of these people have typically developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:



- These brothers and sisters will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information they can help empower their siblings from childhood through their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and care-giving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True “family-centered” care and services are created when siblings are actively included in agencies’ functional definition of “family.”

The Sibling Support Project facilitated a discussion on SibNet, a listserv for adult siblings of people with special needs, regarding the considerations that siblings want from parents, other family members, and service providers.

For more information about Sibshops, sibling issues, and our workshops, listservs and publications, contact:

**Sibling Support Project of the Arc of the United States**

Don Meyer, Director

6512 23rd Ave NW #213

Seattle, WA 98117

(206) 297-6368

[donmeyer@siblingsupport.org](mailto:donmeyer@siblingsupport.org)

[www.thearc.org/siblingsupport/](http://www.thearc.org/siblingsupport/)



## Communication Possibilities

Decisions. Selections. Choices. Options.... When you discover that your child is deaf or hard of hearing, you are almost instantly faced with all of these. You will have to make decisions about evaluation procedures, selection of hearing technology, speech-language therapy, intervention, providers, and communication options. All of this can feel utterly overwhelming.

In this section we have chosen to call the future decisions you will make *possibilities*. That is what they are. Possibilities are achievable. This section was created to help you better understand the possibilities that exist so that you can feel comfortable about the decisions ahead of you. You will find information about the many different parts of communication. After you have a better sense of the building blocks that make up communication it will be possible to combine them in just about any way to build a communication system that works for your child and family.

You will also find information about the possibilities that exist within the range of hearing technology such as hearing aids, cochlear implants and other assistive listening devices. Information is knowledge, and knowledge is power. Once you learn what possibilities are available, you will have the ability to make decisions for your child and the power to alter those decisions if they are not resulting in positive outcomes.

This section is a place to discover ways to foster a supportive, predictable and responsive world for your child who is deaf or hard of hearing. You will foster your baby's understanding of the world around him and be his guide in finding the best ways for him to tell others his needs and thoughts. The information provided in this section will help you to gather information about and understand many of the ways you and your child can be successful.

## Building Blocks for Communication

Most people think of communication as people talking to one another. However, communication is much more than just talking. It is made up of many different parts working together. The “verbal part” of communication is talking, or speech and language. Yet communication never occurs without the “non-verbal parts.” Those non-verbal parts include eye contact, gestures, head and body movement and facial expressions. Both aspects of communication are natural parts of language development. If you don’t believe it, try to tell someone a story while sitting on your hands, and looking away from them, and using no facial expressions. You may find it nearly impossible.

When you are the parent of a deaf or hard of hearing child, you are almost immediately asked to make decisions about communication. This usually means learning about the variety of options that are available. Before those decisions can be made, you should think carefully about the desired outcomes you want for your child with hearing loss. You must ask yourself *how* you want to communicate with your child. You may also consider which method of communication will be the *best fit* for your child and your family.

There are many different communication possibilities. Once you’ve thought carefully about the desired outcomes and expectations you have for your child and family, you can begin to consider the most appropriate communication method. Regardless of the communication method selected, you will need to be actively involved in developing your child’s language and communication. In this section of the notebook we will explore the six most common communication methods; American Sign Language (ASL), Auditory-Oral, Auditory-Verbal, Cued Speech and Manually Coded English Systems.

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## American Sign Language (ASL)

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### *Description*

ASL is a visual language used by of many culturally Deaf persons in the United States and Canada. It is a distinct language with its own grammar and word order. English is often learned as a second language.

### *Goal*

To teach your child to learn a visual language. Your child will learn to communicate fully through the use of their eyes, hands, facial expressions and body movements.

### *Parent Involvement*

You will also need to learn ASL in order to fully communicate with your child. Opportunities to learn ASL are available through books, videos, interactive ASL classes, the Statewide Deaf Mentor Program and through meeting other Deaf people. See the resources section in this notebook to locate learning opportunities in your area. Through these experiences, parents may also learn more about deaf culture and deaf community resources.

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## Auditory – Oral

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### *Description*

Your child will be taught to make the most of what hearing they have through the use of amplification (hearing aids, FM system) and/or cochlear implantation. Listening skills are encouraged through auditory learning intervention with a therapist or interventionist.

### *Goal*

To teach your child to develop listening and spoken language, through early, consistent and successful use of an amplification system or hearing technology.

### *Parent involvement*

You will need to work closely with the child's therapist or early interventionist to apply listening and spoken language activities in the home and to enhance your child's learning environment. You will also need to ensure full-time use of amplification or hearing technology.



## Auditory – Verbal

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### *Description*

Your child will be taught to make the most of their hearing through the use of amplification (hearing aids, FM system) and/or cochlear implantation. Listening skills are encouraged through parent-centered auditory learning activities that teaches parents how to incorporate language through the child's natural environment. Auditory-Verbal therapy is completed with a specially trained Auditory-Verbal Therapist (AVT). Sign language is not used.

### *Goal*

To teach your child to develop listening and spoken language, through consistent and successful use of an amplification system or hearing technology.

### *Parent Involvement*

With the help of therapists, you will need to incorporate auditory-verbal activities into your child's daily routine and play activities. It is important to provide a language-rich environment and to make hearing a meaningful part of your child's experiences. You will also need to ensure full-time use of amplification or hearing technology.

## Cued Speech

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### *Description*

Cued speech is a sound based system which uses eight hand shapes for consonant groups cued at four locations for the vowel groups. In combination with the lips, all sounds of spoken language look different and are understandable to the child. Cued Speech makes every word of English (or other spoken language) available to a child, regardless of hearing impairment. It is a way for a hearing family to communicate with their deaf/hard of hearing child using the family's native spoken language.

### *Goal*

Your child will learn to speak through the use of amplification, lip-reading and the cues from the hand shape system.

### *Parent Involvement*

You will use hand shape cues when you communicate with your child. Cued speech can be learned through intensive classes taught by trained teachers or therapists. Just like any manual communication system, it takes time and dedication to learn the cues and become proficient in their use.



## Manually Coded English Systems

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### *Description*

There are several signed systems, which modify the signs used in ASL to represent English grammar and word order. These sign systems are not languages but are visual representations of English. The signs are used to support English or to convey tenses, plurals, possessives, and other parts of the English language. Examples of manually coded sign systems are Signed English (a.k.a. Manually Coded English), Seeing Essential English (SEE I), and Signing Exact English (SEE II)

### *Goal*

Your child will learn to use signs as words and learn to sign using the word order and grammar of English. Your child will learn to sign the little words used in English such as “a” and “the” and grammatical endings such as “-ing” and “-ed”

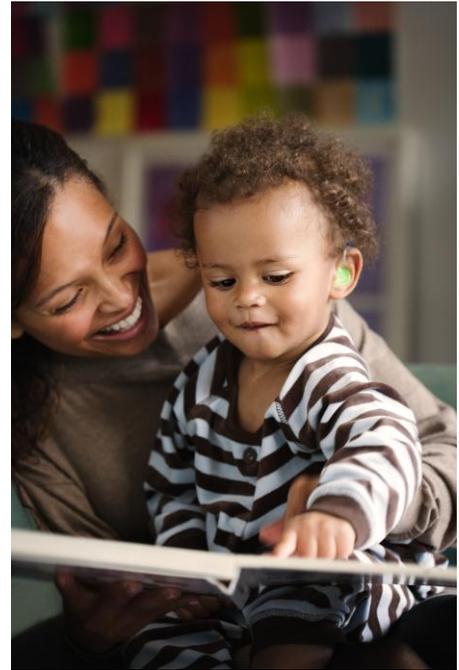
### *Parent Involvement*

You will also need to learn the signed system that you choose for your child and just like any manual communication system, it takes time and dedication to learn the system and become proficient at using it.

When you are choosing a communication method, it is important to remember that no choice is permanent. If you choose an approach that focuses on one building block and does not seem to be working for your child after several months of consistent effort, there is no reason that you cannot try a different approach. The important thing is to communicate in one way or another with your child.

## Early Language and Literacy

Before we start this section, we should make sure that we are talking about the same things when we discuss “early language and literacy”. (The word “emergent” may sometimes be substituted for “early” - meaning “at the very beginning of language and literacy”). You will hear this phrase a lot when talking about your child’s learning, especially since a hearing loss has been identified. The short answer is that “early language and literacy” means everything you do that uses words and/or signs - talking, reading, writing, singing - all the ways that you, as a parent, begin showing your child how to communicate.



Language is more than the words we know and use - it includes our ability to take a thought or feeling, turn the idea or feeling into words, and choose the particular words or signs we want so that a listener understands what we think or feel. “Language” has lots of rules about the order in which words or signs are used. For a child learning to use language, this may be saying one word or using one sign for “milk” to mean “I want more milk in my cup now, Mommy” or “uh-oh, I just dropped the cup and lost all of my milk, but I want more”. As children learn language, they learn how to translate all of their longer and more complicated ideas into messages that people will understand.

What is “literacy”? You will hear this word a lot when talking about the things children learn in the early school years. Let’s start with what it means - it is a term that includes lots of things related to reading and writing. If it is five years away, is it really necessary to talk about now when your child is an infant or toddler? *Yes*, it is, because

reading and writing are linked to listening and talking, singing and signing - communicating! Once children have a handle on basic language and can communicate ideas, we begin to think about teaching reading and writing skills. As you will see, even though we teach reading and writing a lot later, most of the skills they will use can be made stronger when we help them grow their language skills very early, from the time they are infants. Next, let's talk about how we can actually do this - make their emergent or early language and literacy experience really strong.

It is very important that all children, especially children with a hearing loss, learn to enjoy stories and books. Believe it or not, just sharing stories and books with very young children is teaching them language and getting them ready for school - even if that is years later! This is another way to help speech and language develop - in all children. Many studies have shown that children who are read to often early in life do better in learning language, reading and writing later on. You can give your child a head start on communication by reading to them even before they are old enough to talk. We know that children soak up lots of information between six months to one year before they ever show it by saying the words they have heard. So it is never too early to start! Even children three to six months old will love to chew on a board book as you turn the pages, point out and name pictures, using lots of vocal inflection and facial expression. Just hearing you use different voices as you pretend to be a baby bear, mother bear, or great big daddy bear will entertain your child and give them practice using whatever hearing is present. If you have chosen to use sign language to communicate, pairing signs to the pictures during your reading time will have the same benefit in focusing your child on the link between the picture, your sign, and the letters and words in the book. All children are taught to read and write - so all of the exposure to letters, words and books will be useful. Kids will soak up all that they hear and see.

### ***First Books and Stories for Babies (0-6 months)***

So, how do you share stories and books with really young kids? As an infant, begin with board books or vinyl books that are very short and have mostly bright pictures and few, if any, words. You may only keep your child's attention for a couple of minutes – that's fine! Attention grows with age. Just having books as part of your child's toys sets the stage for further reading enjoyment. Getting used to spending a few minutes each day naming pictures, talking or signing early words like "mom", "dad", "grandma" and "grandpa" will get both you and your child into the habit of sharing this quiet time together.

### ***Babies (6-12 months)***

What do kids like at this age? Photos or pictures of other babies, books that they can mouth, chew or cuddle with (like cloth books), and books that have pictures of people they know (mom and dad, brothers or sisters in photo books). If you look in a bookstore, you will see that books for the youngest children have lots of large pictures of the kinds of things the child sees in the world every day. Young kids love the funny sounds that things make – so moo like the cow, oink like the pig – you get the idea! If you are signing, pair the sign while you make your face show the feeling. Hold your own hands over your child's as you turn the page (saying or signing the words as you do this) and naming the pictures.

What else can you do with a baby this age to increase language and literacy? Play pat-a-cake, sing or sign simple songs, wave bye-bye, throw kisses – All of these things help your child to focus on language and play an important role in learning to communicate.

### ***Early Toddler Years (1-2 years)***

If you read with your child often at this age you will find that they begin to have favorite books or stories. At this age, you can do more than just name things – you can read very



short stories, ask your child to locate things “find the duck” “where is the chicken?” or find things with certain qualities (shapes, size, color, etc.) “Can you find the big one? The blue one?” Keep doing all of the things you did when your child was younger – only add more – longer songs that have visual motions (“The Wheels on the Bus”, “Row, Row, Your Boat”) you can do with each other.

### *Late Toddler Years (2-3 years)*

Researchers have studied how parents read to their young children and have some suggestions to make the most of the activity. For older toddlers, you may want to try these suggestions:

1. make simple statements about what you see – objects and activities
2. ask simple “what questions” about the picture or story
3. repeat what your child has said to reinforce them and encourage them to say more
4. try to limit the number of “yes/no” questions that you ask
5. try to limit questions where your child doesn’t talk – like with “pointing” questions (this is great when your child is younger – now you want to get more spontaneous language from your child)

### *Preschoolers (3-5 years old)*

As your child’s language increases, your time together with books can become even more effective. As you use books with words, you can start to point out and name letters and tell your child the sound the letter makes. (“Oh, look! It’s a **dog**! That’s a “d” right there. It says “d” like at the front of “dog”.) Even though you are spending a lot of time on the story, pointing out letters and words is the very beginning of learning to read. We first think of using books, but what else could you use to share stories? Family photos are a great way to start a story. Children at this age love to hear stories about things around them. They especially love hearing stories about themselves. As their language grows, so does their imagination. This is the perfect time to “make up”

short stories with them. Kids love the pattern that stories use – you always begin with “Once upon a time”; there is always a main character in the story (perhaps your family dog); something always happens (the dog got lost); and there is always an ending (mommy found him) complete with “The End”. Just by creating little stories like these, you have shared the main parts of what’s called “narratives” – something they will see a lot of and use often in school.





## Description of the Ear

The ear is made up of three parts:

- Outer ear
- Middle ear
- Inner ear

### Outer Ear

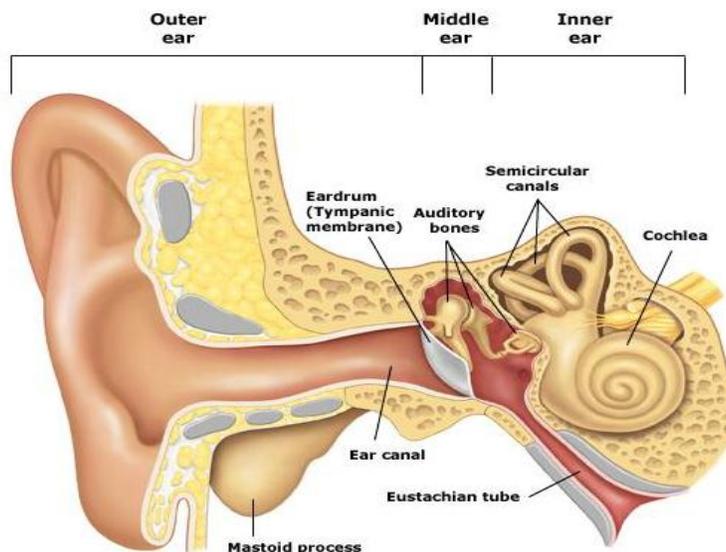
This part of the ear includes the auricle or pinna (visible part of the ear on the outside of the head) and the ear canal. It is also called the external ear. Sound travels through the ear canal and moves or vibrates the eardrum (tympanic membrane).

### Middle Ear

This part of the ear is between the eardrum and the inner ear. The middle ear contains three tiny bones (the ossicles). The eardrum vibrates causing the middle ear bones (ossicles) to move and carry the sound energy through the middle ear to the inner ear. There is also a tube that runs from the middle ear space to the back of the throat called the Eustachian tube. This “tube” provides ventilation (air) to that middle ear space.

### Inner Ear

The inner ear includes the cochlea (snail shaped organ), the semi-circular canals (balance mechanism), and the auditory nerve (8<sup>th</sup> cranial nerve leading from the ear to the brain). When the sound vibrations enter the inner ear from the middle ear, the cochlea changes the vibrations to electrical nerve impulses and sends them to the brain through the auditory nerve. Once the brain receives the impulses, there is a sensation of hearing.



## Treating the Types of Hearing Loss

Hearing loss is categorized by the place in which the hearing loss occurs in the ear, whether it be the outer ear, middle ear, inner ear or a combination.

### **Conductive Hearing Loss:**

This type of hearing loss occurs in the outer ear and/or middle ear. Something is preventing sound waves from reaching the inner ear. This blockage can be partial or complete. Conductive hearing losses do not cause total hearing loss but do cause a loss of loudness. When the sound is made louder, the sound is heard clearly.

Common causes of conductive hearing loss are:

- Non-typical development of the outer ear and/or middle ear
- Blockage of the ear canal (wax or foreign object)
- Damage to the ear drum
- Damage to the three bones in the middle ear
- Failure of the Eustachian tube to let air into the middle ear space
- Infection in the middle ear
- Fluid in the middle ear
- Growth of extra bony material around the three bones in the middle ear
- Cysts (Abnormal tissue growth)

TREATMENT: Most conductive hearing losses can be treated with medication and/or surgery. If the conductive hearing loss is permanent, hearing aids or other amplification devices are used to make sound louder.

### **Sensorineural Hearing Loss:**

This type of hearing loss occurs in the inner ear, with the cochlea, the auditory nerve or the parts of the brain that receive nerve impulses from the auditory nerve.

Sensorineural hearing loss can range from a mild loss to a profound loss (no measurable hearing). Not only is there a loss of loudness but there is also a loss of clarity. Almost all children with this type of loss will have some degree of loudness and/or clarity left. What hearing is left is called residual hearing.

Common causes of sensorineural hearing loss are:

- Faulty development of the inner ear
- Family history of hearing loss
- Damage to the inner ear and/or hearing nerve from illness before birth
- Rubella
- Toxoplasmosis
- Cytomegalovirus (CMV)
- Meningitis
- Lack of oxygen at birth
- Treatment with certain drugs such as streptomycin, kanamycin, garamycin, ethacrynic acid
- Premature birth with NICU admission
- Damage to ear from loud noises
- Head injuries
- High fever
- Rh factors
- Measles



TREATMENT: Depending on the degree of hearing loss hearing aids and/or cochlear implants can provide access to sound. This type of hearing loss cannot be treated by medication or surgery. It is considered permanent because current advancements do not allow nerve cells to grow back or be replaced.

**Mixed Hearing Loss:**

A mixed hearing loss occurs in both the outer/middle ear and in the inner ear. It is a combination of conductive and sensorineural hearing loss.

TREATMENT: Both medical intervention and use of amplification.

**Unilateral Hearing Loss:**

A unilateral hearing loss occurs in only one ear. It can be conductive, sensorineural or mixed. Although a child with this loss has good hearing in one ear, he/she will have difficulty knowing where sound is coming from, hearing in noisy environments, and hearing on the affected side. Most kids perform better in school with the use of amplification.

TREATMENT: Either medical intervention, use of amplification, or both depending on the cause of hearing loss.

**Progressive Hearing Loss:**

A progressive hearing loss occurs when a child's hearing ability decreases over time. A baby may be able to hear at birth but as they grow their hearing ability goes down. It is important to note that just because a baby passes newborn hearing screening *does not* ensure that he/she will always have normal hearing. When a change in hearing is suspected it is important that a hearing evaluation be completed as soon as possible.

TREATMENT: Either medical intervention, use of amplification, or both depending on the cause of hearing loss.

**Fluctuating Hearing Loss:**

This type of loss is one that changes frequently by improving or worsening. Some conductive hearing losses are fluctuating.

An example of this is hearing that worsens when a child has fluid in the middle ear, caused by an ear infection, and the hearing improves when the infection is cleared. When a hearing impaired child acquires a conductive component to the already existing hearing loss, it will make that hearing loss worse as long as the conductive component is present. It is very important that a suspected ear infection is treated immediately.

TREATMENT: Either medical intervention, use of amplification, or both depending on the cause of hearing loss.

### **Syndromic Hearing Loss:**

Sometimes an infant or young child who is deaf or hard of hearing may have other signs or symptoms as well. When multiple congenital malformations appear together, they may be described as a syndrome. This is important because if hearing loss is detected early, then specialists, such as genetic professionals, may be able to test for certain syndromes that may not be physically identifiable by appearance alone. Three examples of such syndromes are:

1. Usher Syndrome which is associated with progressive loss of vision
2. Jervell and Lange-Nielsen Syndrome, which is associated with heart defects
3. Hunter Syndrome which is associated with neurological defects

Early diagnosis of syndromes associated with kidney function can help avoid complications later.

TREATMENT: Either medical intervention, use of amplification, or both depending on the cause of hearing loss.



## Types of Hearing Tests

Hearing testing is done to find out how well a child can hear. Usually a pediatric audiologist will do the testing. The purpose of the testing is to find out the type of hearing loss (conductive, sensorineural, mixed) and the degree of the hearing loss (how severe).

The audiologist and the family will discuss different ways to help the child and family to communicate. When looking for an audiologist, it is important to find one who has experience with infants and children. If you are looking for a pediatric audiologist, contact the Utah Department of Health, Hearing, Speech and Vision Services (801-584-8215 or 800-829-8200, choose option two and then option three). When first contacting an audiologist, ask what experience they have had with young children.

Different hearing tests may be used depending on the age and development of the child as well as the information the audiologist is looking for. The following is a list of tests commonly completed based on age and development. All descriptions of these tests can be found in the back of this book in the glossary.

### *Ages 0-6 months*

Otoscopy  
Tympanometry with 1000 Hz tone  
Otoacoustic Emissions  
Auditory Brainstem Response with click and tone burst stimuli  
Behavioral Observation Audiometry



### *Ages 6 months-2 1/2 years*

Otoscopy  
Tympanometry with 226 Hz tone  
Acoustic Reflex  
Otoacoustic emissions  
Visual Reinforcement Audiometry  
Speech Audiometry



*Ages 2 ½ years- 5 years*

Otoscopy  
Tympanometry with 226 Hz probe tone  
Acoustic Reflex  
Otoacoustic emissions  
Conditioned Play Audiometry  
Speech Audiometry

*Ages greater than 5 years*

Otoscopy  
Tympanometry with 226 Hz probe tone  
Otoacoustic emissions  
Acoustic Reflex testing  
Pure Tone Audiometry  
Speech Audiometry



## What Is an Audiogram?

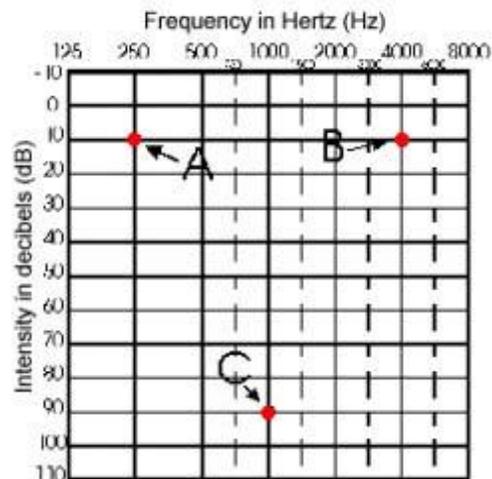
An audiogram is a graph of the softest levels at which your child can hear sound. It is a 'picture' of the results of a test that is done by the audiologist. Your child's audiogram will often be used to describe the hearing loss.

The audiogram shows two things: loudness and frequency. Loudness (intensity) is measured in decibels (dB). Loudness levels are located beside the horizontal lines on the audiogram. Intensities usually go from 0 dB to 110 dB; with 0 dB being very quiet and 110 dB being very loud. Frequency, which is another word for pitch, is measured in Hertz (Hz). The different pitches are found above the vertical lines on the audiogram. Pitches range from 125 Hz to 8000 Hz. 125 Hz is a very low pitched sound and 8000 Hz is a very high pitched sound.

### What does an audiogram look like?

Every point on an audiogram represents a different sound. For example, point A on the audiogram to the right represents a soft low-pitch sound and point B represents a soft high-pitch sound. Point C represents a loud mid-pitch sound.

As the pediatric audiologist tests your child's hearing, he/she will use different symbols on the audiogram that represent the softest levels at which your child is aware of sound. This softest level of sound awareness is called the minimal response level or threshold. By looking at the point where the pitch and loudness lines cross and the mark is made, you can see the loudness levels which the child can detect at various pitches.



## What do the symbols and drawn lines mean on the audiogram?

If your child is tested with earphones or inserts, it is called air conduction testing. Because sound is presented to each individual ear, information can be gathered about the hearing in each ear, separately. The symbols used to represent air conduction testing are an X for the left ear and an O for the right ear.

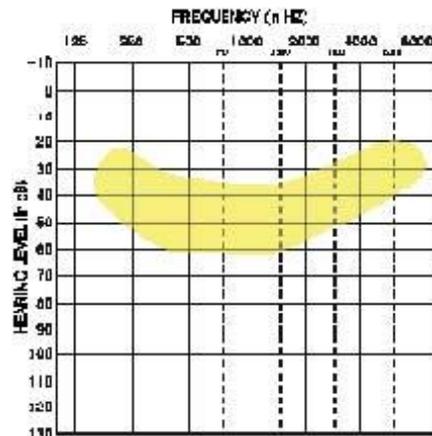
Typically colors are used for the different symbols: red for the right and blue for the left.

If your child is tested using bone conduction, (a vibrating piece of plastic that is placed behind his ear rather than on or in it) different symbols will be used. A right arrow symbol (>) is used to show the left ear results and a left arrow symbol (<) is used to show results for the right ear.



After the audiologist has information about various pitches, he will connect the symbols to make a line on the graph for each ear. This line is the configuration of the audiogram. Configurations vary due to each child's individual hearing loss. Some configurations go somewhat straight across. These are called flat hearing losses. Some configurations will angle downward; either gently or sharply. These are called sloping losses. Professionals may use configurations and terms such as "flat" or "sloping" to describe your child's hearing loss.

Many of the speech sounds are made in the pitches between 250 and 5000 Hz and are spoken at a loudness level of 20 dB to 60 dB. Sometimes an audiogram will have shading on it that resembles the outline of a banana and falls in



between the pitch and loudness levels mentioned above. This is put on the audiogram to show where speech sounds typically occur and is often referred to as the speech banana. If the audiologist fits a hearing aid on your child, they will try to make sure that your child can hear sounds in this area.

### **What can you find out from an audiogram?**

Although your child's audiogram will be referred to often through the years and may even be used to describe your child's hearing loss; it is **not** a predictive measure. An audiogram can be compared to a growth chart. A growth chart will give you some indication as to how big the child may become as an adult; but it is not a precise indicator of who that child will become. An audiogram can give you an idea of what that child's usable hearing (residual hearing) is, but it is not a precise indicator of how your child will use their hearing to learn speech or how your child will process sound.



## Degrees of Hearing Loss and Potential Effects

The following chart describes what sounds your child may and may not hear without amplification based on the degree of hearing loss. It identifies how amplification may help your child and the potential effects the hearing loss might have on your child's ability to hear and recognize spoken conversation and environmental sounds. However, this is only a guide. Each child has unique potential and uses that potential differently. Only time and hard work will tell how your child will use his hearing potential and how he may or may not benefit from use of amplification.

<b>Degree of Loss</b>	<b>Decibels</b>	<b>Potential Effects</b>
Slight Hearing Loss	15-25 dB	A minimal loss of some sounds. May have difficulty hearing quiet or distant conversations especially in noisy environments.
Mild Hearing Loss	25-30 dB	Without amplification, the child can hear most conversations up close and in quiet environments, but is likely to miss parts of words. The child may appear to be "hearing when she wants to." Amplification and speech-reading may supplement understanding of what is said.
Moderate Hearing Loss	30-50 dB	Without amplification, the child will have difficulty hearing spoken conversation. Proper amplification and intervention should enable the child to hear and recognize all sounds.
Severe Hearing Loss	50-70 dB	Without amplification, the child may hear loud voices and sounds close to the ear. With early and consistent use of hearing aids, many children will be able to detect sounds such as speech. Most children will use visual cues along with amplification to aid in communication.
Profound Hearing Loss	70 dB or higher	Without amplification, the child will be more aware of sounds as vibrations. Visual cues become an important element, along with amplification, to effectively communicate. Where little benefit is observed in use of appropriate amplification, consideration for an alternative source of acoustic information should be sought (i.e., cochlear implant) for the development of spoken language.

## Types of Assistive Listening Devices

1. **Hearing Aid** – Used to amplify (make louder) speech sounds to the level of hearing for the user. The most efficient and most commonly used today would be a digital hearing aid because of its flexibility and ability to process the speech signal.
2. **Cochlear Implant** – Used with patients who are not able to obtain benefit from hearing aid amplification. Cochlear implants involve surgery but have often shown to be effective when used at an early age with dedicated training
3. **FM system** – Most often used to reduce the effects of distance from the speaker (teacher) and other background noise that may affect the ability to understand speech.





## Hearing Aid Styles

Hearing aids come in different sizes. The style used for infants and children is the behind-the-ear (BTE). Other styles include completely-in-the-canal (CIC) and custom in-the-ear (ITE); which can be used once children are in their teens



BTE



CIC



ITE

### *BTE hearing aid*

Behind-the-ear hearing aids are recommended for children. They can be used for all degrees of hearing loss from slight to profound. A BTE consists of a plastic casing containing the hearing aid's electronic parts that rests behind the ear. The casing is

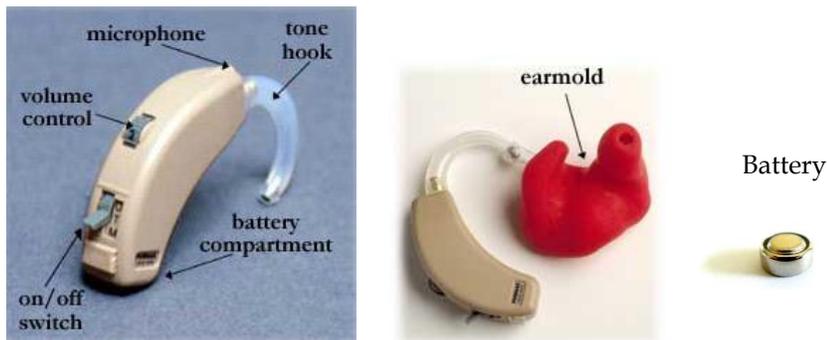


attached by a tube to a custom made earpiece that fits inside the concha or the bowl of the ear and a small part of the outer ear canal. This custom made piece is called an earmold. The casing portion of the hearing aid is often

able to be ordered in a variety of colors which when a child reaches an appropriate age, allows them to make their own decisions about their hearing aid and may increase acceptance of the process.

## Parts of the Behind the Ear Hearing Aid

Not all behind the ear hearing aids will have the same parts or features. Generally the more additional features a hearing aid has the more expensive it is to purchase. Your audiologist should discuss with you the features important for your child based on their individual needs. During an orientation to your child's hearing aid the audiologist should show you all the parts of your child's hearing aid and their function. The parts described below are to give you an idea of what your child's hearing aid may contain. Be sure to ask the audiologist about things you do not understand or need explained again.



### **Battery**

Hearing aids run on battery power. The size of the battery however differs with the type of hearing aid used. Although hearing aid batteries need to be changed often, the amount of battery life is dependent on the size of the battery, the amount of drain of the hearing aid and the number of hours the hearing aid is used. The life of a battery can vary from a few days to three weeks. The best batteries for hearing aids are called Zinc Air. This type of battery has a longer life because it is not activated until a paper tab is removed from the back of the battery before it is used.

How to correctly insert a battery into a hearing aid will be shown to you by your child's audiologist when you receive the hearing aid.

Hearing aid batteries are small and therefore can be a hazard if swallowed by a child. Therefore, children's hearing aids should have tamper proof battery doors. Batteries should be kept out of reach of children and pets. If a child swallows a battery they should immediately be taken to the emergency room or local hospital.

### **Switch**

A switch may be located on the outside of your child's hearing aid. This switch allows you to turn the hearing aid on and off and change the settings. Some switches are labeled "M" for the microphone, "O" to turn the hearing aid off, "T" for a telephone setting and "MT" for the microphone and telephone to work together. Digital hearing aids often have a button in place of switch you can push to change programs.

### **Volume Control**

The volume control setting allows the overall loudness of the hearing aid to be turned up or down. It is a feature that may or may not be included on the outside of your child's hearing aid. If volume control is available, your audiologist will discuss with you the appropriate volume setting for you child.

### **Microphone**

The microphone is the part of the hearing aid that picks up sound. When a sound enters the hearing aid it is changed into electrical energy and the sound is made louder. There are two types of microphones, omni directional and directional. An omni directional microphone picks up sound from all directions equally. If a person talking in front of your child is the same distance away as a person talking behind your child, the microphone picks up both sounds equally. An omni directional microphone is necessary for young children as they are often not looking at the person speaking. The speech a child overhears aids greatly in their development of language and therefore, requires an omnidirectional microphone to pick up sounds in all directions.

A directional microphone turns up the sounds coming from in front of your child more than other surrounding sounds. Directional microphones may help improve your child's ability to understand speech when background noise is present. For example, when a child enters school and background noise is prevalent, a directional microphone might help him/her to hear the teacher better. Therefore a directional microphone should be considered when selecting a hearing aid for your child.

### **Earmold**

The earmold is the custom piece an audiologist makes to help secure the hearing aid in the ear. After a sound goes through the earhook it will travel through the earmold to reach the ear canal. Earmolds should be made of a soft material and fit snugly in the ear canal to prevent feedback. Since this piece of the earmold is custom made, it must be remade often as your child grows. Earmolds will need to be replaced frequently, approximately every 6-8 weeks, during the first year of life due to your child's rapid growth. As your child grows the earmold fit becomes loose. This allows amplified sound to leak back to the microphone and cause feedback (a squealing or whistling sound). A snug earmold fit is important for your child to maintain adequate access to sound. As your child gets older the length of time the earmold will last gradually increases.

### **Earhook**

The earhook is the clear plastic part of the hearing aid that fits over the top of the ear. It helps to direct sound into the hearing aid and protects the microphone and receiver. Sometimes a filter will be used in an earhook. A filter helps shape or change the sound signal entering the ear. Be aware that the filter may look like debris in your child's earhook. Do not remove or clean the earhook without checking with your audiologist first.

## DAI

Direct Audio Input (DAI) sends sounds from other sources directly to your child's hearing aid. This allows for the use of an FM system (mentioned at the beginning of the It's All About Hearing section). This is an important capability for a child's hearing aid for future situations where a child would need a signal louder because of distance. *Every* child's hearing aid should include Direct Audio Input.

## Telecoil

A telecoil is a magnetic loop that works with some phones to receive and amplify the electromagnetic signal from the telephone and increase the quality of phone use. The telecoil program is sometimes turned on by a switch or button found on the outside of a hearing aid marked by a "T". The telecoil may also allow for the use of other assistive listening devices.



## Receiving a Hearing Aid

Following diagnosis of hearing loss and determination that your child is a candidate for hearing aids the process of obtaining and fitting hearing aids begins and includes five steps.

### **First Step:** Medical Clearance

Children under 18 years of age are required by law to have written medical clearance for use of amplification from their physician, preferably an otolaryngologist, before hearing aids are fit.

### **Second Step:** Selection of Hearing Aids

Selection of hearing aids involves making decisions on specific features and functional needs of the hearing aid, such as requesting a tamper resistant battery door, direct audio input, and selecting colors for the hearing aids and earmolds.

Impressions are made of your child's ears at this time and custom earmolds are ordered. It is important to remember that your child is growing rapidly, therefore the earmolds and hearing aids need to be fit as soon as possible, preferably within one week. The longer the period between when the impressions are taken and the fitting, the less time the earmolds will last before replacement is needed.



### **Third Step:** Hearing Aid Fitting

Once the hearing aids and earmolds are ordered an appointment to fit the hearing aids is scheduled. At this appointment the audiologist will check that the earmolds fit well and will customize the programmed settings of the hearing aids to ensure that your child receives adequate access to sound. This is done by taking a special measurement of your child's ear called real-ear-to-coupler-difference (RECD). This quick test measures

unique characteristics of your child's ear with the custom earmold in place and allows the audiologist to account for the large physical variability that exists between children, even of the same age, in order to individualize the hearing aid settings to best meet your child's needs. The values from the RECD measurement along with your child's hearing test results are then used to precisely program the hearing aids. To do this, the audiologist performs additional measures in a test box (while you and your child relax) that simulates how well the hearing aid settings will allow your child to hear soft, average, and loud speech sounds, and also to make sure loud sounds will not be too loud. The audiologist will fine tune the settings during this test based on the results to make sure the hearing aids are set appropriately for your child.

#### **Fourth Step: Orientation to the Hearing Aids**

Orientation to the hearing aids begins at the hearing aid fitting appointment and is ongoing as you learn how to manage the daily function of the hearing aids and become comfortable with the process. The orientation includes training in the following:

- Caring for and cleaning hearing aids
- When the hearing aids should be worn
- How to keep the hearing aids on the ears
- Insertion
- Removal
- Overnight storage (including how to turn off the hearing aids)
- Insertion and removal of batteries
- Information on battery life, storage, disposal, toxicity
- Basic steps to try when problems occur with batteries, feedback, plugged earmold and/or receiver
- How to use a hearing aid with a telephone (if appropriate)
- How to use an assistive listening device with a hearing aid
- Moisture solutions
- Tools to help take care of hearing aids (e.g., battery tester, listening stethoscope)
- Issues dealing with loss of hearing aids (including spare hearing aids and any loaner program)
- Recommended follow-up appointments to monitor how hearing aids are working.

As part of the orientation process you will be instructed on how to perform a listening check on the hearing aids. Each day before putting the hearing aids on your child, inspect the earmolds and hearing aids for any problems, such as cracks or broken parts. A listening check can then be performed to check the sound quality of the hearing aids and to make sure they are functioning. As part of the fitting you should receive a listening stethoscope and a hearing aid care kit from your audiologist.

**Fifth Step: Validation of Benefit**

To determine the benefit your child is receiving from the hearing aids, you will be asked to observe your child during typical daily activities. You should be provided with a questionnaire to help you assess how well your child is hearing in different situations. This information is valuable and is used by your audiologist to help determine if any changes in the hearing aid settings are needed. It also helps to guide other intervention decisions, such as whether or not an FM system should be considered.





## FM Systems

An FM system is a type of assistive listening device that can help your child hear a single talker in noisy situations. Examples of some of these situations may be the car or classroom where hearing aids alone may not be enough for your child to understand what is being said.

### **How do FM systems work?**

An FM system relies on the wireless transmission of a sound sent directly from the speaker's mouth to the listener's hearing aid. This is possible when the speaker wearing a microphone and transmitter and the listener wears the receiver.

### **Why is an FM System Needed?**

Hearing aids and cochlear implants cannot provide optimal listening in all situations. There are three factors that make it difficult to hear: listening in background noise, distance from the speaker, and reverberation. An FM system helps to overcome these challenges to improve speech understanding in difficult to listen environments.

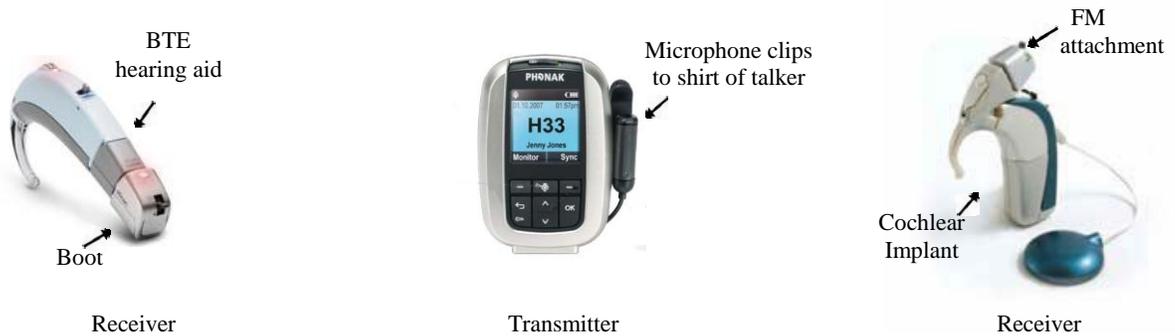
Background noise interferes with your child's ability to hear the person speaking. The level of the background noise compared to the level of the speaker's voice is referred to as signal-to-noise ratio (SNR). For example, if the level of your voice is 50 decibels (dB) and the level of the surrounding noise is 35 dB, the SNR would be +15 dB because the speech is 15 dB louder than the noise. A SNR of 0 dB would mean that the level of the speech and the noise is the same. At a SNR of -15 dB none of the speech would be audible to your child. Children with a hearing loss need a higher SNR to understand and learn speech than do children who have normal hearing.

Two additional factors affect how well your child will hear in noise, distance and reverberation. The farther away your child is from the speaker, the more difficult it is to hear. For maximum speech understanding, your child should be no more than 3-6 feet

away from the speaker. Reverberation refers to how long a sound echoes in a room. A room with hard surfaces will have more reverberation than a room with surfaces that absorb sound, such as carpeting and acoustic ceiling tiles. Children with hearing loss have difficulty separating speech from noise and filling in communication gaps. An FM system can help your child overcome these difficulties in difficult listening environments.

### FM Styles

There are a few styles of FM systems available. The most common type is one worn at the ear level that connects to the child’s BTE hearing aid using an adapter called a “boot”. Your child’s hearing aids should have direct audio input capability to be compatible with an FM system. Children with cochlear implants can also obtain additional accessories to use FM systems.



A FM system can also be ordered as a body worn, which has ear or head phones that plug into a small box that clips to the child’s waist or belt. This type of FM system can stand alone without the use of hearing aids. It can help children with mild high frequency losses or those with auditory processing problems.



FM transmitter can be worn in a pocket or clipped to the waist/belt

Another style of FM system is a sound field system. This type of system is most often used in classrooms and involves a microphone worn by the talker/teacher with speakers strategically placed around the classroom. Although personal FM systems are recommended for children who wear hearing aids and cochlear implants, a sound field system that makes the teacher's voice louder regardless of where she stands in the classroom have been show to be beneficial in the classroom.



Sound field FM system

It is important to discuss with your audiologist the benefits of FM systems and what style is most appropriate for your child. In addition, when an FM system is chosen and purchased, it is important to monitor the use of that FM system. This involves the training of all individuals who use the system to understand how to operate the FM system and monitor it daily. In some cases, an educational audiologist may be available to help in monitoring the system and it's use. Otherwise parents and teachers need to take an advocating role since the FM system is only beneficial when it is functioning properly and used appropriately.





## What is a Cochlear Implant?

A cochlear implant is an electronic device designed to provide enhanced sound detection and potentially greater speech understanding for children with severe to profound hearing loss who obtain minimal benefit from hearing aids. As opposed to a hearing aid, a cochlear implant converts speech, music, and environmental sounds into electrical



signals and sends these signals directly to the hearing nerve, where the signals are interpreted as sound by the brain. Cochlear implants have been approved for use in children since June 1990. Currently three cochlear implant systems are approved for sale by the Food and Drug Administration (FDA) in the United States (Advanced Bionics, Cochlear and Med-El).

### **How Do Cochlear Implants Work?**

A cochlear implant works in this way:

1. Sound (signals) are received by the microphone.
2. Electrical pulses that represent the energy contained in the sound signals are sent from the microphone to the speech processor.
3. The speech processor selects and codes the most useful portions of the sound signals.
4. This code and information is sent to the transmitter.
5. The transmitter sends the code across skin to the receiver/stimulator
6. The receiver/stimulator converts the code to electrical signals.
7. Electrical signals are sent to an electrode array in the cochlea to stimulate the hearing nerve fibers.
8. Signals are recognized as sounds by the brain.

All cochlear implant systems consist of internal and external components. The external components consist of:

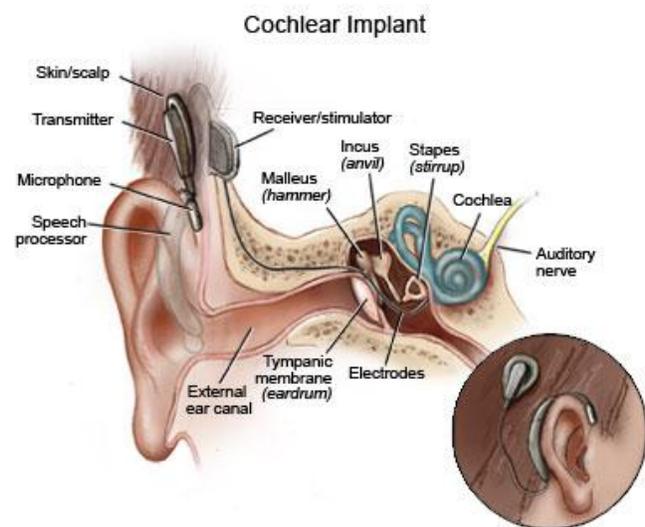
- a microphone (to pick up the sound and transmit it to the speech processor),
- a speech processor (which selects and codes useful sound)
- a transmitter with a magnet (which sends the code to the receiver).

Information on Cochlear Implants adapted and included with permission from AG Bell. For more information about Cochlear Implants go to [www.agbell.org](http://www.agbell.org).

The transmitter is placed on top of the skin behind the ear. A cord connects the transmitter to the speech processor, which is worn behind the ear like a hearing aid, in a pocket or clipped to a belt.

The internal components consist of a receiver coil and an electrode array. A

small receiver coil with an enclosed magnet is surgically placed under the skin behind the ear and serves to convert the coded sound into electronic signals. Electrical contacts, in the form of an electrode array, are inserted into the inner ear and stimulate the hearing nerve fibers to send these signals to the brain where they are recognized as sound.



### **How Do I Know if My Child Is a Candidate for a Cochlear Implant?**

Children who are candidates for a cochlear implant must:

- Have a profound sensorineural hearing loss in both ears if the child is under two years old and a severe to profound hearing loss if the child is over two years of age.
- Receive little or no benefit from hearing aids (usually determined through a trial

period of using two hearing aids) as indicated by whether age-appropriate communication skills are developing.

- Have an intact auditory nerve as indicated by CT or MRI scans.
- Be healthy enough to tolerate surgery (typically an outpatient procedure).
- Have no uncontrolled infections present

Additionally, their families must possess a clear understanding of the benefits and limitations of a cochlear implant, and demonstrate commitment to the cochlear implant process by accommodating pre-implant evaluations and postoperative follow-up services. Children undergo audiological, medical, and psychological procedures to determine implant candidacy. The time involved in completing these procedures varies with the age and abilities of the child.

Since the purpose of obtaining a cochlear implant is to use hearing, some centers require assurance from the family that the child's home and educational environment will rely on spoken language (an oral approach) to ensure the best possible outcomes from the implant.

Most cochlear implant centers take a team approach to determine implant candidacy. In addition to the family, the following professionals are typically involved in the decision:

- Pediatric audiologist
- Surgeon (Otologist, Otolaryngologist, Otorhinolaryngologist)
- Speech-language pathologist and/or therapist—to assess the child's overall communication abilities
- Educator—to review child's abilities in the school setting
- Psychologist—to evaluate child's cognitive, social, and emotional development before, during, and after the procedure

A team approach enables the candidacy process to move forward more efficiently because it considers the whole child and the family while screening for any potential issues that might affect the child's ability to learn language with an implant.

### **How to Select a Cochlear Implant Center**

Cochlear implant manufacturers maintain a list of implant centers worldwide. To select the right center for you and your child, consider the following factors:

1. Is the center located close enough to your home so that you can accommodate frequent visits?
2. Who is on the implant team? Do they have experience with children?
3. Is the audiologist sufficiently trained and skilled in programming for children?
4. How many cochlear implant surgeries has the center done? How many have been performed on children?
5. If you have used sign language with your child, is there someone at the implant center who can communicate with him or her?
6. What are the center's facilities for cochlear implant (re)habilitation? What is the team audiologist's experience with (re)habilitation?
7. Is the implant team sensitive and responsive to your questions? To your child's questions?

It is also recommended that parents talk with other parents of children who have been implanted at the center. Obtain parent referrals from the center so that you can hear others' experiences and ideas. Take advantage, also, of the center's in-house library. The team should be able to provide you with information, books, brochures, and videotapes about cochlear implants. Read, watch, and ask all you can.

## What Does Implantation Involve?

### *Surgery*

Cochlear implant surgery is typically performed under general anesthesia and lasts for approximately 2 1/2 hours. The procedure can be performed in either an inpatient or outpatient setting and carries the typical risks of major surgery requiring general anesthesia. The surgeon exposes the mastoid bone behind the ear canal and drills open a channel to the inner ear. The electrodes are threaded into the inner ear and the receiver coil is placed in the bone behind the ear. The skin is closed over the receiver-stimulator. A pressure bandage is placed to reduce swelling around the incision. Most children go home the same day or spend no more than one night in the hospital.

### *Device Fitting*

After four to six weeks of healing around the surgical site, the process of “fitting” the external parts takes place, often known as the “hook-up” or “initial fitting.” During the fitting session, the headpiece and microphone are placed over the implant. The speech processor is connected to the headpiece and the audiologists’ computer. Measurements are used to program the speech processor for



the individual child. The speech processor is disconnected from the audiologist’s computer and rechargeable or disposable batteries are then inserted. The child can then take the implant system home. Accurate programming is critical during the first months of implant use. Fewer visits are required on a less frequent basis thereafter.

### *Follow-Up Services*

Once the speech processor has been programmed the child requires intensive auditory and speech training. Children with implants require this communication training to help

them jumpstart their language and listening skills, which they were not able to fully develop prior to the implant. Long-term (re)habilitation should include training that focuses on communication behaviors, listening skills, speech production, and expanding a child's spoken language. These services can be provided by staff at an implant center or at the child's school if that setting has qualified personnel. In addition, children should return to the implant center at least every three to six months for monitoring and program adjustments of the speech processor. After a few years of implant use, follow-ups will generally occur on an annual basis.

### **What Are the Potential Benefits Associated with Cochlear Implants?**

Although there is a wide range of performance in children using cochlear implants, the benefits for most users include sound awareness, environmental sound recognition, enhanced lip-reading abilities, speech recognition (understanding the speech of others without lip-reading), and improved speech production. Today, advances in implant technology enable more children to maximize these benefits and develop appropriate spoken language skills.

Even though thousands of children have received cochlear implants, surgeons and audiologists are currently unable to predict before surgery the degree of benefit an individual child will receive from an implant. Some factors that are known to affect implant performance include:

- Age at implantation and whether the child has had some experience with effective hearing previously
- Postoperative (re)habilitation
- Primary mode of communication (e.g. sign language versus spoken language)
- Educational setting (does it support the use of a cochlear implant and does it promote spoken language development)
- Length of implant use

Research suggests that implantation works best for children who are implanted at the earliest possible age. Of special importance when considering implantation is the critical period for speech and language development (0-6 years old). Before becoming a candidate for an implant, children must complete a trial period with hearing aids to see whether or not this technology can provide them with satisfactory sound. Children may be considered candidates for an implant if the hearing aid trial period has failed to promote more age-appropriate listening and speaking.

Currently, the minimum age for implantation is twelve months. However, the promising results demonstrated by children implanted at an early age has promoted the trend to lower the age of implantation, with some centers implanting under the age of twelve months. Due to a national focus on early identification of hearing loss, many more children are being identified with hearing loss soon after birth. It is likely, as a result, that as the age of identification decreases, so too will the age of implantation in an effort to tap natural language learning abilities that are maximal during a child's first six-year "critical period".

### **How Much Do Cochlear Implants Cost?**

Cochlear implants are covered benefits in some medical insurance policies and in most states' Medicaid plans. Currently, the cost for evaluation, implantation, and follow-up programs and (re)habilitation is between approximately \$40,000 and \$60,000. Included in these costs are audiological testing, medical examinations, surgical fees, anesthesiologist, operating room and hospital charges, and follow-up programs. Auditory and speech training is sometimes not covered by medical insurance.

Follow-up care after the first year includes testing and monitoring and routine reprogramming of the device. Like any child with a hearing loss, children with cochlear implants will need ongoing therapy to ensure maximum listening and speech skills.

## **What Type of School is Best for my Child with a Cochlear Implant?**

Making the decision regarding educational placement for a child with hearing loss is often confusing. For a child with a cochlear implant, the decision can impact his or her progress with the technology. Research has shown that for children to make significant progress learning to listen and speak with a cochlear implant, their homes and schools must be primarily auditory environments. Meaning those that provide lots of opportunities for children to listen and use their own voices.

In theory, children's special education services are supposed to be tailored to their needs. In practice, children are apt to receive a generic set of services based on their disability, rather than on their individual strengths and weaknesses. As a result, parents must be aggressive in requesting accommodation for their child. However, unlike general education, special education allows parents to have some say in their child's educational programming and supplementary services. The foundation of your child's education is the Individualized Education Plan, known as the IEP. An IEP is a legal, written plan that specifies the special education and related services necessary to meet the individualized needs of a student with a disability.

After your child receives a cochlear implant, parents should revisit their children's IEP goals and determine whether these goals are still relevant, or should be modified to better address their children's needs. Questions to consider include:

- What are realistic language development goals for my child post-implant?
- What are realistic speech production and speech perception goals for my child post-implant?
- How does the school district plan to reach those goals? How will these goals be integrated with academic objectives?
- What responsibility does the school district take for cochlear implant (re)habilitation? What experience does the school have in this area?
- Will the school district provide auditory support or technology to assist my child

in the classroom, such as personal FM system or FM sound-field system, if not already in use? If the school district pledges to provide support in this area, be sure to get its commitment in writing.

Information on Cochlear Implants adapted and included with permission from AGBell. For more information about Cochlear Implants go to [www.agbell.org](http://www.agbell.org).





## Advocating for Your Child

The purpose of this section is to prepare your family for the rewards and challenges of transitioning out of the birth-to-three stage and entering a new phase of your child's life, which may include transitioning out of county services

and into school services. Parents often need to advocate for their child by making decisions concerning their child's placement and services. Resources in this section will help you understand what is to come, what actions you may need to take and when to anticipate these changes.

Each parent will assess their child's future at their own pace. If your baby is very young, this might seem like the farthest thing from your mind or you might already be considering plans for this child's college career. Whatever your case may be this information is here for you when you are ready.

## Eligibility for Hearing Services

Receiving early intervention and school age services will depend on your child's eligibility. Eligibility for services is determined on how a child qualifies according to the criteria described below.

### **Birth to Three Qualifying Hearing Loss**

Most common hearing disorders which qualify an infant/toddler for services from an Early Intervention Hearing Consultant with the Utah Schools for the Deaf and Blind (USDB) Parent Infant Program (PIP):

- A. Sensorineural Hearing Loss
  - 1. Bilateral mild to profound
  - 2. Unilateral mild to profound

- B. Conductive Hearing Loss
  - 1. Chronic ear infections with resulting language delay
  - 2. Structural anomalies
  
- C. Mixed Hearing Loss
  - 1. Bilateral mild to profound
  - 2. Unilateral mild to profound

### **School-Age Qualifying Hearing Loss**

Criteria required for a child with a hearing loss to qualify for services after leaving the birth-to-three stage.

- A. School-Age Hearing Loss: a hearing impairment which adversely affects the student's educational performance
  
- B. Eligibility Criteria:
  - 1. The hearing impairment **MUST** adversely affect the student's educational performance.
  - 2. The student must require special education and related services.
  - 3. The IEP team must determine the hearing impairment is the primary disability.
  - 4. Measurements in terms of decibels, percentages, etc., serve only as guidelines in the eligibility process.
  
- C. Evaluation - Multiple measures (formal and informal) are required for a student suspected of having a hearing impairment.
  - 1. Audiological evaluation including audiometric testing, auditory functioning, language development, speech evaluation, and academic achievement.
  - 2. Other areas of evaluation, as appropriate, may include intellectual ability and adaptive behavior.

## The Transition Process

As a child leaves the birth-to-three stage and nears the time he/she will begin to receive school services there are three essential meetings that need to take place for your child and family. These include:

- Individualized Family Service Plan (IFSP)
- 120 Day Transition meeting
- Individualized Education Plan (IEP) meeting.



## IFSP Meeting

An Individualized Family Service Plan (IFSP) documents and guides the early intervention process for children with disabilities and their families. Through the IFSP process, family members and service providers work as a team to plan, implement, and evaluate services specific to the family's unique concerns, priorities, and resources.

- At the IFSP meeting closest to the child's 2<sup>nd</sup> birthday, issues relating to the child's transition to the next educational environment will be discussed.
- Discuss the preparation for preschool readiness that needs to take place before the child turns three.
- Discuss differences between early intervention programs and preschool early childhood special education programs; how services may be delivered differently.
- Need for a Release of Information to exchange information with the local education agency.
- Differences in eligibility exist between early intervention and preschool (children with a unilateral loss or a temporary conductive hearing loss may not qualify for the district preschool program).
- Identify needs and concerns to prepare the child and family for the preschool process.

### **Hearing Loss Issues to Address between the Child's 2<sup>nd</sup> and 3<sup>rd</sup> Birthdays:**

- Have all appropriate communication modes been explored to meet the child and family's current and future needs?
- Are there issues related to hearing aid use in future environments?
- Is an FM system appropriate to assist the child in listening activities and language acquisition through hearing?
- Is there a need for intervention to further enhance the child's listening and auditory skills?
- If spoken language is the goal, is there appropriate speech-language intervention available?
- Would Deaf Mentor services assist the child and family in building skills with signed communication through American Sign Language?

## 120 Day Transition Meeting

- This meeting is held at least 90 days, and preferably 120 days prior to the child's 3rd birthday.
- Early intervention, district preschool, USDB PIP and USDB preschool personnel are present.
- The purpose of the meeting is to finalize a transition plan facilitating a smooth transition into preschool.
- Discuss the array of service delivery options available at age three.
- Identify needs to complete child and family preparation for the preschool process.
- Discuss communication modes used by the child and family.
- Transition plan may include visits to the USDB, as well as visits to local preschool programs, as identified during the Transition Meeting.
- Review current audiological reports and other assessments.

## IEP Meeting

- This is the third and final meeting in the transition process.
- Each public school child who receives special education and related services must have an Individualized Education Plan (IEP); which is designated for that one specific student and is individualized to his or her needs.
- The purposes of this meeting are to determine eligibility for preschool, develop the IEP document, and to determine the preschool placement.
- The IEP must be in effect on or before the child's 3<sup>rd</sup> birthday.
- Early intervention, district preschool, USDB PIP and USDB preschool personnel should be present, along with a regular education teacher. Others, such as therapists, etc. may attend, if their services are needed.
- A review of assessment information, including audiological reports, speech and language evaluations, listening assessments, overall developmental assessments, etc., is completed to determine eligibility. The hearing loss *must* adversely affect the child's educational performance for the child to be eligible.
- Once eligibility has been determined, the IEP can be developed. Discuss the child's strengths and needs to determine goals and objectives for the IEP.
- Identify the related services, program modifications, and/or supports needed in assisting the child to accomplish the goals and objectives. Remember to include those related to the hearing loss.
- Discuss the extent to which the child will NOT participate with non-disabled children in regular classes and activities.
- Select a date when the services will begin.
- Decide on the frequency, duration, and location of these services. (Location, in this case, refers to the type of environment that is appropriate for the provision of these services, NOT a specific placement or address location.)
- Discussion must specify how the parents will be informed of their child's progress.
- Assistive technology devices, such as FM systems, may also be considered.

- The final step of the meeting is to determine appropriate placement to meet the previous items discussed. Options should be considered from both the local school district and the Utah Schools for the Deaf and the Blind (USDB), including USDB support to a district program. Placement should reflect the child's needs, rather than the desire for a particular location or type of service delivery.



## Exploring School Placement Options

If the child meets the eligibility criteria for special education services, an Individual Education Plan (IEP) is created which contains goals and objectives as well as a listing of supplementary aids and services for the child and supports for school staff. Based on these, an appropriate placement is chosen.

Before this is done, however, families may want to consider what types of appropriate placements or school options are available. Some options within the state that have been used are:

- Placement in a regular preschool with services provided there.
- Placement in a self-contained classroom for deaf and hard of hearing students and taught by a teacher for the deaf and hard of hearing with additional services provided as recommended by the IEP team.
- Placement in an Early Childhood room with additional services provided as recommended by the IEP team.
- Placement in an Early Childhood room, which is team-taught by a teacher for the deaf and hard of hearing and an Early Childhood teacher.
- Placement at home and/or daycare setting with services provided there.

These are just some of the placement options. Some placements are combined and/or altered slightly to reflect the needs and strengths of the child, the preference of the family and resources of the local school district. The modifications or adaptations that are made to a program are only limited by the team's creativity and flexibility. Furthermore, different programs and related services can be added and utilized in different ways.

A certified speech-language pathologist understands how to promote communication and develop language and therefore should be involved in working with your child from the beginning. It is necessary that this person have previous experience working

with children who have a hearing loss. The SLP should have experience with whatever communication system the child is using including cochlear implants, Auditory-Verbal therapy, American Sign Language, signed system, Cued Speech, etc.

Educational audiology is a related service. An educational audiologist can ensure that the correct amplification is in place and oversee the child's auditory skill development. In addition, they can assess the acoustic environment and determine the child's hearing with and without assistive listening devices. The educational audiologist can also work as the connection to the classroom teacher.

If your family has chosen sign language for communication, educational interpreting may be involved in the child's programming. Although most young children who are deaf or hard of hearing and rely on a signed language to communicate are not developmentally ready to use an interpreter, there are a variety of ways that such a person could be used:

- To develop the child's use of an interpreter. Eventually the child, who is using signed language, will likely need an interpreter in some environments. There are activities that can be used to develop skills in using an interpreter.
- To provide information about signed languages and deafness to those who are unfamiliar with it. In doing this, the interpreter could relate his/her experiences and suggest resources on general topics relating to hearing loss.
- To foster the child's participation in group activities.
- To promote an expanded communication environment for the child.
- To be a member of the child's team, including development and implementation of the IEP.

Interpreters should not be used to teach the child. Although interpreters are trained in the use of signed language, they are not trained to teach language to young children. They are usually not trained to work with young children or families. A child needs

interaction, language modeling and experiences paired with language before benefiting from interpreting services. In addition, interpreters should not become the child's constant companion. It is not appropriate to expect the interpreter to function as the child's only language resource. Interpreters should not be expected to resolve all communication needs within the classroom. Interaction with peers can become frustrating and incomplete to young children who are deaf or hard of hearing if they are continually through the use of the interpreter.

A deaf or hard of hearing person functioning in some capacity with the school environment is a valuable resource to the child and the staff. This person could provide first hand experiences to the staff on hearing loss as well as promote a near optimal communication environment for the child. Providing non-disabled hearing peers for young deaf and hard of hearing children whether in a self-contained classroom for the deaf and hard of hearing or in an Early Childhood classroom setting is particularly worthwhile. This is essential if speaking options are being promoted for the child.

While considering a placement, families may want to answer these questions about different options:

- Does the staff have training in working with young children? Are they aware of developmentally appropriate practices?
- What is done in the setting to promote communication?
- Does this particular setting meet the goals I have for my child?
- If the child is using a signed language, what is the signing ability of the staff?
- Does the staff have specific knowledge and skill in working with children who have a hearing loss?
- Does the staff have knowledge on auditory skill development and the technology used to develop auditory skills?
- What will the transportation be for my child? How will my child get to and from the school? Will the drivers have some knowledge of how to communicate with a

deaf or hard of hearing child?

- What is the acoustic environment like?

Making a decision of where the child will attend school or what kind of placements the child needs may be very difficult. When making such a decision it is important for families to keep the goals they have for the child in mind foremost. In addition they many want to:

- Gain background information on what is the best practice in educating children who are deaf or hard of hearing.
- Visit different programs that serve young children who are deaf or hard of hearing.
- List what the available options are (be creative and inclusive).
- Talk with other families who have children who are deaf or hard of hearing. Ask them about their decisions and how they made them.
- List advantages and disadvantages of each available option listed.
- Consider what transportation might be involved.

It is important to know that **no decision about placement is final** and parents have the right at any time to question or re-evaluate their child's placement.





## Keeping Track



The Keeping Track section is intended to provide you with a place to keep all of the information you are gathering about your child. In this section, you will find:

- A plastic business card holder to keep the cards of professionals that are becoming part of your child's life. Many times the business cards also have appointment dates and times on them.
- Information Providers May Request From You - organizes the information regularly needed by medical providers, child care providers, family members and so on. You may want to make extra copies of this form rather than re-writing this information over and over again.
- Removable File Folder - provided for you to store your child's most recent hearing tests, IFSP's and IEP's. This folder is also available for health insurance information to be stored and easily located when needed.
- Note Pages - sometimes professionals may ask you to carry a message to another professional. Other times professionals may wish to keep a running dialog with one another. For example, the audiologist and the early intervention providers may want to communicate about how your child is using his/her hearing instrument. Blank pages are provided for you or the professionals you work with to record notes.

**You may find that all of the organizational tools provided are useful just the way they are or you may wish to change them to better fit your style. They are meant to make life a little simpler. Don't forget to make photocopies of pages you find particularly useful.**

## Information Providers May Request From You

### Child's Insurance Information

Name of Insurance	Group/Policy #	Child's Social Security number	Phone Number
			( )
			( )

### Child's Medical Information

Title	Name	Address	Phone Number
Primary Care Provider			( )
Audiologist			( )
ENT			( )
Other			( )
Other			( )
Other			( )

### Child's Early Intervention Information

Title	Name	Address	Phone Number
Service Coordinator			( )
Therapist			( )
Other			( )
Other			( )

### Child's Amplification Information

Type of Amplification (Hearing Aids, Cochlear Implant, FM System)	Right Side	Left Side
Make and Model		
Serial Number		
Date of Purchase		
Date Warranty or Guarantee Expires		

**Child's Amplification Information** (continued)

	Right ear	Left ear
Date Service Plan (if any) Expires		
Earmold Material and Style		
Date most recent earmolds were fit		
Type of Cord (if applicable)		
Accessories (if applicable)		

Amplification Contacts	Name	Address	Phone Number
for repair			( )
for programming			( )
for batteries			( )
for insurance			( )

**Special Concerns or Additional Information**

\_\_\_\_\_

Parent/Guardian Signature

\_\_\_\_\_

Date







## Resources for Families of Children who are Deaf and Hard of Hearing

There are thousands of resources for parents of children who are deaf and hard of hearing. It's easy to feel overwhelmed by it all! We have tried to help sort through them to compile a listing of major national and statewide organizations for deaf and hard of hearing topics. These organizations provide information about books to read, materials to try, parents to meet, information to learn, and much more. We have not listed any specific materials in this section, as we strongly feel that the age of your child, the mode of communication chosen, the level of your child's hearing loss, and the child's other siblings are all factors that will affect which materials are helpful and relevant to you.

### National Resources

#### **Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G. Bell)**

(202) 337-5220

<http://www.agbell.org>

A membership organization and information center focusing specifically on children with hearing loss and the auditory approach.

Provides newsletters, journals, and information relating to oral education and the use of technology. Financial aid programs available for children with hearing loss.

#### **American Academy of Audiology (AAA)**

(800) AAA-2336 Toll Free

(703) 790-8466 Voice

<http://www.audiology.org>

A professional organization dedicated to providing quality-hearing care to the public.

Offers professional development, education, research, and increased public awareness of hearing disorders and audiologic services.

#### **American Society for Deaf Children**

(800) 942-2732 Parent Hotline

<http://www.deafchildren.org>

A non-profit, parent organization that provides information about signing and Deaf culture. It also provides support and encouragement to parents and families with children who are deaf or hard of hearing. Publishes "Endeavor", a publication free to families for one year.

**ASL University**

[www.lifeprint.com/asl101](http://www.lifeprint.com/asl101)

An online curriculum resource for American Sign Language (ASL) students, instructors, interpreters, and parents of deaf children.

**Boys Town Nation Research Hospital**

Center for Childhood Deafness

(402) 498-6521

<http://www.babyhearing.org>

Boys Town is a research center on hearing loss and related disorders. Provides educational materials for families of deaf and hard of hearing children.

**Cochlear Implant Association, Inc.**

(202) 895-2781

<http://www.cici.org>

Provides information and support to cochlear implant users, their families, and professionals.

**Families for Hands and Voices**

(303) 300-9763

(866) 422-0422 Toll Free

<http://www.handsandvoices.org>

Hands & Voices is a parent driven, non-profit organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing. Their goal is to connect families with resources and information to facilitate informed decisions around the issues of deafness and hearing loss.

**Hear and Now**

National Center for Hearing  
Assessment and Management

Utah State University

[www.hearandnow.org](http://www.hearandnow.org)

Hear and Now provides information for parents about the newborn hearing screening process, testing, and diagnostics. Information for Health Care Providers is also included.

**Laurent Clerc National Deaf Education Center**

(202) 651-5051

<http://clerccenter.gallaudet.edu/>

Gallaudet is the only four-year liberal arts university for students who are deaf or hard of hearing. Centralized source of information on topics dealing with deafness and hearing loss.

**John Tracy Clinic**

(800) 522-4582 Toll Free

<http://www.jtc.org>

<http://www.jtc.org/corres/>

Provides parent-centered services to families of children birth through five years who have diagnosed hearing losses.

**National Cued Speech Association**

(800) 459-3529

[www.cuedspeech.org](http://www.cuedspeech.org)

The National Cued Speech Association supports effective spoken communication, language development and literacy through the use of Cued Speech (visual cueing using manual signs).

**National Institute of Deafness and Other Communication Disorders**

National Institutes of Health

(800) 241-1044

[http://www.nidcd.nih.gov/  
health/hearing/](http://www.nidcd.nih.gov/health/hearing/)

NIDCD supports biomedical and behavioral research and research training in the processes of hearing, balance, smell, taste, voice, speech, and language. The Institute also conducts and supports research and research training associated with people who have communication impairments or disorders.

## State of Utah Resources

### **2-1-1**

[www.informationandreferral.org](http://www.informationandreferral.org)

1-888-826-9790 or 211

211 Info Bank, a program of Community Services Council, is a free information and referral line for health, human and community services.

### **AG Bell, Utah Chapter**

(801) 765-1096

<http://www.agbell-utah.org/>

A membership organization and information center focusing specifically on children with hearing loss through the auditory approach. Provides newsletters, journals, and information relating to oral education and the use of technology. Financial aid programs available for children with hearing loss.

### **Baby Watch Early Intervention Programs**

(801) 584-8226 or (800) 961-4226

[www.utahbabywatch.org](http://www.utahbabywatch.org)

Provides early identification and developmental services for families of infants and toddlers, ages birth to three. Some of the services offered include:

- A full assessment of a child's current health and development status
- Service coordination among providers, programs and agencies
- Strategies to build on family concerns, priorities, and resources
- Developmental services: occupational therapy, physical therapy, speech language therapy.

These services are provided through the coordinated effort of parents, community agencies, and a variety of professionals. There are 16 local programs in Utah that provide public Early Intervention Services.

### **Primary Children's Medical Center, Audiology**

(801) 662-4949

<http://intermountainhealthcare.org/hospitals/primarychildrens/services/pages/Service.aspx?index=Audiology%20Services,%20Outpatient>

**Primary Children's Medical Center, Pediatric Genetics**

(801) 581-4983

<http://intermountainhealthcare.org/hospitals/primarychildrens/services/pages/Service.aspx?index=Genetics>

**Primary Children's Medical Center, Pediatric Otolaryngology**

(801) 662-1740

[http://intermountainhealthcare.org/hospitals/primarychildrens/services/pages/Service.aspx?index=Otolaryngology%20\(ENT\)%20/%20Head%20and%20Neck%20Surgery](http://intermountainhealthcare.org/hospitals/primarychildrens/services/pages/Service.aspx?index=Otolaryngology%20(ENT)%20/%20Head%20and%20Neck%20Surgery)

**Relay Utah**

(801) 530-6769 (V/TTY)

[www.relayutah.gov](http://www.relayutah.gov)

Relay Utah provides access to hearing assistive equipment and telephone relay services, to allow Utah citizens who are deaf, hard of hearing or speech disabled more efficient communication.

**Sound Beginnings of Cache Valley, Utah State University**

(435) 797-2613

[www.soundbeginnings.usu.edu](http://www.soundbeginnings.usu.edu)

Sound Beginnings of Cache Valley is an early education program that provides home and center based services to children with hearing loss whose families want their children to learn to listen and talk.

**Utah Association for the Deaf**

(801) 288-2159

[www.uad.org](http://www.uad.org)

A non-profit organization dedicated to the educational, social, and economic welfare of the Deaf in the State of Utah.

**Utah Department of Health, Children with Special Health Care Needs**

(801) 584-8284

<http://health.utah.gov/cshcn/>

Utah Children with Special Health Care Needs is a bureau within the Utah Department of Health, that provides services for children who "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally".

**Utah Family Voices**

(801) 584-8236

[www.utahfamilyvoices.org](http://www.utahfamilyvoices.org)

The regional affiliate of a national advocacy group organized and operated by parents of children with special health care needs.

**Utah Hands and Voices**

(810) 266-5272

[www.utahhandsandvoices.org](http://www.utahhandsandvoices.org)

Hands and Voices is a nationwide non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them. This is a parent-driven, parent/professional collaborative group that is unbiased towards communication modes and methods.

**Utah Parent Center**

(801) 272-1051, (800) 468-1160

Espanol: (801) 272-1067

[www.utahparentcenter.org](http://www.utahparentcenter.org)

The mission of the Utah Parent Center (UPC) is to help parents help their children with disabilities to live included, productive lives as members of the community.

**Utah Parent Infant Program**

(801) 464-2028, (800) 990-9328

[www.usdb.org/pip/deafpip](http://www.usdb.org/pip/deafpip)

Coordinated through Utah Schools for the Deaf and the Blind, the Primary goals of PIP are to: Expose families to the various aspects of hearing loss. Facilitate families in learning essential skills for early communication with their child. Through play, provide opportunities for a child to experience activities for optimum development. Prepare families with information for smooth transition at the age of three.

**Utah Schools for the Deaf and Blind**

(801) 629-4700, (800) 990-9328

[www.usdb.org](http://www.usdb.org)

The Mission of USDB is to provide resources and information in order to foster the spirit of understanding and collaboration between Utah Schools for the Deaf and the Blind and the community so that they may work together to provide quality educational services to children with sensory impairments throughout the state of Utah.

**Utah Services for the Deaf and Hard of Hearing**

(801) 263-4861, (877) 860-4861

[www.deafservices.utah.gov](http://www.deafservices.utah.gov)

Offers a full range of services for seniors, youth, family, and people with multiple disabilities.

## Funding Sources

Supporting the needs of a child who is deaf or hard of hearing can be very expensive. The following resources have been provided to help you look into funding opportunities.

### **Children's Hearing Aid Loaner Programs**

[www.infanthearing.org/HA-loaner](http://www.infanthearing.org/HA-loaner)

### **Funding Assistance for Audiology Services**

[www.asha.org/familyfunding](http://www.asha.org/familyfunding)

### **HARP (Hearing Aid Recycling Program)**

<http://www.health.utah.gov/cshcn/HSVS/harp.html>

(801) 584-8215

### **Hear Now**

9745 East Hampden Ave. Suite 300

Denver, CO 80231-4923

(800) 648-HEAR

### **or Hear Now**

4248 Park Glen Road

Minneapolis, MN 55416

(800) 648-4327

### **The Hearing Impaired Kids Endowment (Hike) Fund, International Center for Job's Daughters**

(402) 592-7987

### **Sertoma Club**

(608) 221-3029

### **Starkey Hearing Foundation**

(952) 941-6401

### **Utah Assistive Technology Foundation**

(435) 797-3824

[www.uatpat.org](http://www.uatpat.org)

### **Utah Department of Health, Children with Special Health Care Needs**

(801) 584-8284, (800) 829-8200

<http://health.utah.gov/cshcn/>



## Glossary

### **Acoustic Feedback:**

A whistling sound produced by a hearing aid. The amplified signal generated by the receiver of the hearing aid leaks outside, is picked up by the microphone, and is then re-amplified.

### **Acquired Deafness:**

A loss of hearing that occurs or develops some time during a person's life but is not present at birth.

### **Aided Thresholds**

The softest level that a given sound can be heard with the hearing aids on and the gain set at a pre-selected level.

### **Air Conduction (AC):**

The process by which sound is sent (conducted) to the inner ear through the external ear canal, middle ear and into the inner ear. Air-conduction testing is performed by sending sounds to the ear through an earphone or loudspeaker.

### **Air-Bone Gap:**

A difference between hearing responses for earphone or loudspeaker (air conduction) versus bone vibrator (bone-conduction) stimulation. A gap or difference between air-conduction and bone-conduction responses indicates conductive hearing loss due to problems in the middle ear.

### **Americans with Disabilities Act (ADA):**

Signed into law in 1990, this is a "civil rights act" for persons with disabilities. The ADA requires public services and buildings to make reasonable accommodations to allow access to persons with disabilities, including hearing loss.

### **American Sign Language (ASL):**

A manual language with its own word order and grammar, used primarily by people who are deaf.

### **Amplifier:**

An electronic device for increasing the strength or gain of an electrical signal.

### **Amplification:**

Used as a general term to refer to whatever device is being used to amplify sound (i.e., hearing aids, cochlear implants, FM systems).

**Assistive Listening Device (ALD):**

Devices, other than hearing aids, that improve listening for individuals with hearing loss. Some systems improve hearing in noisy situations by positioning the microphone closer to the sound source, or improve the quality of amplified speech or music. Includes FM systems and infrared systems.

**Atresia (aural):**

An ear malformation in which there is an absence of the external ear canal, usually with abnormalities of the outer ear, and/or middle ear space.

**Audiogram:**

A graphic representation of hearing loss, showing the amount of hearing loss (in decibels or dB ) at different frequencies (250 - 8000 Hertz or Hz).

**Audiologist:**

A health care professional who is trained to evaluate hearing loss and related disorders, including balance (vestibular) disorders and tinnitus, and to rehabilitate individuals with hearing loss and related disorders. An audiologist uses a variety of tests and procedures to assess hearing and balance function and to fit and dispense hearing aids and other assistive devices. The minimum academic degree is a Doctorate. State licensure is required to practice audiology in Utah.

**Audiology:**

The study of hearing; the profession is concerned with measurement and rehabilitation of auditory and communication problems.

**Audiometer:**

A device for presenting precisely measured tones of specific frequencies (or speech and recorded signals) and intensity levels in order to obtain an audiogram.

**Auditory Brainstem Response (ABR) test:**

A test that can be used to assess auditory function in infants and young children using electrodes on the head to record electrical activity from the hearing nerve. Other terms are: Brainstem Evoked Response (BSER), Brainstem Auditory Evoked Potential (BAEP), and Brainstem Auditory Evoked Response (BAER).

**Auditory Neuropathy/Dysynchrony:**

A term that describes a pattern of abnormal findings for a number of audiometric measures, e.g., auditory brain stem response (ABR), pure-tone and speech audiometry, and/or acoustic reflexes, yet normal findings for otoacoustic emissions (OAE). The most common pattern is the absence of an ABR with normal OAE.

**Auditory Nerve:**

The cranial nerve (VIII) that carries nerve impulses from the inner ear to the brain.

**Auditory Training:**

The process of training a person to use their hearing abilities by listening to environmental sounds, music and speech and then practicing recognizing and understanding what has been heard.

**Aural (re)habilitation:**

Specialized training for people with hearing loss to help them learn spoken communication skills through speech reading and auditory training.

**Auricle:** the visible portion of the external ear; also known as the pinna

**Balance:**

The biological system that enables individuals to know where their bodies are in the environment and to maintain a desired position. Normal balance depends on information from the labyrinth or vestibular system in the inner ear and from other senses such as sight and touch.

**Balance Disorder:**

A disruption in the labyrinth, the inner ear organ that controls the balance system, which allows individuals to know where their bodies are in the environment. The labyrinth works with other systems in the body, such as the visual and skeletal systems, to maintain posture.

**Behavioral Observation Audiometry (BOA):**

A pediatric audiometric procedure in which behavioral responses to sounds (e.g., eye opening, head turning) are detected by an observer. This procedure has been shown to be unreliable and affected by observer bias. It has been replaced by newer test methods (see Auditory Brainstem Response, Visual Reinforcement Audiometry).

**Behind-the-Ear (BTE) Hearing Instrument:**

A style of hearing instrument that has the electronic components in a case that sits behind the top of the ear. It is then held in place by a custom made earmold.

**Bicultural:**

To be a part of two cultures, such as deaf culture and hearing culture.

**Bilateral Hearing Loss:**

A hearing loss in both ears.

**Bilingual:**

To be fluent in two languages. When talking about children who are deaf or hard of hearing it generally means the proficient use of both English and ASL.

**Bilingual-Bicultural:**

Bilingual-Bicultural education of deaf and hard-of-hearing children encourages children to use American Sign Language as their first language and English as their second.

**Binaural:**

Refers to both ears.

**Baby Watch/Early Intervention:**

This early intervention program serves children ages birth to three years of age in Utah who have developmental delays or conditions known to result in a developmental delay.

**Bone Conduction:**

The transmission of sound (mechanical vibrations) through the bones of the skull to the inner ear. Bone conduction testing is completed using a bone oscillator (vibrator) that is placed on the mastoid bone behind the ear or on the forehead.

**Bone-conduction Hearing Aid:**

A hearing aid in which the amplified signal directly stimulates the inner ear via a bone vibrator placed on the mastoid bone behind the ear. This type of hearing aid typically is used for individuals with atresia or chronic ear drainage.

**Boot:** an electronic device that attaches to a hearing aid or cochlear implant to allow the use of an FM system and the wireless transmission of sound

**Captioning:**

A text display of spoken words, presented on a television or a movie screen that allows a deaf or hard-of-hearing viewer to follow the dialogue and the action of a program simultaneously.

**Central Auditory Processing Disorder (CAPD):**

A language disorder that involves the perception and processing of information that has been heard. Children with CAPD have problems following spoken instructions and usually show other language-learning problems, even though the inner ear is functioning normally.

**Cerumen:**

Ear wax.

**Cochlea:**

Also called the “inner ear.” A snail-shaped structure that contains the sensory organ of hearing and changes sound vibrations to nerve impulses. The impulses are carried to the brain along the VIII nerve, or auditory nerve.

**Cochlear Implant:**

A medical device that is surgically implanted and bypasses damaged inner ear structures and directly stimulates the auditory nerve, helping individuals who have severe to profound hearing loss to interpret sounds and speech.

**Completely-in-the-Canal (CIC) hearing aid:**

Hearing aids that are molded to fit inside the ear canal. This is the smallest type of hearing aid and is *not* appropriate for children.

**Concha:**

The bowl-shaped cavity at the entrance of the ear canal

**Conditioned Play Audiometry (CPA):**

A type of hearing test in which the audiologist teaches the child to respond when a sound is heard by playing some type of game. For example, the child puts a peg in a hole or a block in a bucket every time a sound is heard.

**Conductive Hearing Loss:**

A loss of sensitivity to sound, resulting from an abnormality or blockage of the outer ear or the middle ear. The most common cause of conductive hearing loss is middle ear fluid or infection. Other causes include wax buildup in the ear canal, a hole in the eardrum, or damage to the tiny bones of the middle ear.

**Configuration**

The term used to describe the severity of the hearing loss and the shape of the audiogram.

**Congenital Hearing Loss:**

A hearing loss that is present from birth and which may or may not be hereditary.

**Congenital Malformation**

Any deformity of the face, body, or organs that is present at birth.

**Cued Speech:**

Cued Speech is a communication method, which uses hand shapes and positions to represent the essential sounds of spoken language.

**Cytomegalovirus (CMV):**

One group of herpes viruses that infects humans and can cause a variety of symptoms, including deafness or hearing impairment. A child may be infected with the virus before, at or after birth.

**Deaf:**

A term used to describe persons who have a hearing loss greater than 90 dB HL. It also may be used to refer to those who consider themselves part of the Deaf community or culture and choose to communicate using American Sign Language instead of spoken communication.

**Decibel (dB):**

The unit that measures the intensity or volume of sound.

**Degree (of hearing loss):**

Refers to the severity of hearing loss. The degree is described by categories of normal, slight, mild, moderate, moderately-sever, severe and profound.

**Direct Audio Input:**

The capability of connecting a sound source, such as a TV or tape recorder, directly into a hearing aid. Also refers to the connection of an FM auditory trainer directly into a Behind-the-ear hearing aid.

**Directional microphone:**

A microphone that pulls sound from one direction at a time, usually from the front of the listener while blocking out sounds from behind

**Dizziness:**

A physical unsteadiness, imbalance, and lightheadedness associated with balance disorders. See vertigo.

**Dynamic Range:**

The difference between the softest sounds a person can hear and the loudest sounds they can tolerate.

**Ear Canal:**

The passageway from the outer ear to the eardrum.

**Eardrum:**

Also called the tympanic membrane; the eardrum separates the outer ear from the middle ear and is important in conducting sound to the middle ear and inner ear.

**Earhook:**

A piece of plastic attached to the behind-the-ear hearing aid that allows for the tubing to be attached to the hearing aid component that sits behind the ear.

**Ear Infection:**

Also called Otitis Media; the presence and growth of bacteria or viruses in the ear.

**Earmold:**

A custom-made earmold used with a behind-the-ear hearing aids and delivers amplified sounds into the ear. The earmold helps to hold the hearing aid in the ear and directs sound from the hearing aid into the ear canal. Earmolds are made from soft materials after an impression is taken of the ear. They are made individually for each person.

**Earphone:**

A device for presenting sounds to the ear. Earphones may fit over the external ear or fit into the ear canal.

**Ear Wax (cerumen):**

A normal secretion from glands in the outer ear that keeps the skin of the ear dry and protected from infection.

**Educational Audiologist:**

An audiologist with special training and experience to provide auditory rehabilitation services to children in school settings.

**ENT physician:**

A doctor that concentrates on problems with the ear, nose, and throat.

**Eustachian Tube:**

A small passageway from the back of the throat to the middle ear that allows air into the middle ear.

**External Ear:**

The outer portion of the ear that is normally visible. Components of the external or outer ear include the pinna and the external ear canal.

**Feedback:**

The shrill whistling sound made when amplified sound from the hearing aid receiver goes back into the microphone of the hearing aid. Feedback can be caused by an earmold that does not fit properly or a damaged hearing aid.

**Filter:**

A material placed in the tone hook of the hearing aid to “damp” certain pitches transmitted by the hearing aid and decrease the output of the hearing aid

**Flat hearing loss:**

A hearing loss which shows up as a relatively flat (but lowered) line on the audiogram. A flat hearing loss means that the hearing level is diminished approximately the same amount across all frequencies.

**Fluctuating Hearing Loss**

A hearing loss that changes unpredictably in severity. Sometimes conductive losses associated with the onset of middle ear infections are called fluctuating hearing losses.

**FM System:**

An assistive listening device that improves listening in noise. Signals are transmitted from a talker through a microphone to the listener by FM radio waves that are directly imputed into the child’s hearing instrument.

**Frequency:**

The unit of measurement related to the pitch of a sound. Frequency is expressed in Hz (Hertz) or cps (cycles per second). The more cycles per second, the higher the pitch.

**Functional Gain:**

The difference in a person’s responses between aided and unaided threshold measures. Functional gain is less reliable and valid than other methods of testing aided benefit.

**Gain:**

An increase in the amplitude or energy of an electrical signal with amplification. Gain is the difference between the input signal and the output signal. It is a characteristic that hearing specialists look at when choosing a hearing instrument.

**Genetic Professionals:**

Consists of Clinical Geneticists (physicians) and Genetic Counselors who will work together to provide a genetic evaluation.

**Genetic Testing:**

May be able to provide information about the cause of hearing loss, possible associated medical conditions, and the risk of hearing loss for other family members through methods, which may include a review of family and medical history, a physical examination, discussion about laboratory tests such as DNA or chromosome testing, and discussion about ongoing care.

**Hair Cells:**

The hair-like structures in the inner ear that transform the mechanical energy of sound waves into nerve impulses.

**Hard of Hearing:**

The term to describe those with mild to severe hearing loss.

**Hearing Aid:**

Also known as hearing instrument; an electronic device that brings amplified sound to the ear. A hearing aid usually consists of a microphone, amplifier, and receiver.

**Hearing Aid Dispenser (Dealer):**

Is a professional who is licensed to test hearing in adults for the purpose of fitting hearing aids. In Utah, a hearing aid dispenser is not licensed to test children's hearing but may dispense a hearing aid prescribed by an audiologist.

**Hearing Aid Evaluation (HAE):**

The process of selecting an appropriate hearing aid. The audiologist will evaluate different types of hearing aids to determine which is best suited to a particular hearing loss.

**Hearing Disorder:**

A disruption in the normal hearing process that may occur in the outer, middle, inner ear or the nerves to the brain.

**Hearing Loss (or impairment):**

A problem with hearing that is characterized by decreased sensitivity to sound in comparison to normal hearing. See conductive, sensorineural, and mixed hearing loss.

**Hearing Threshold Level (HTL):**

The softest intensity level (volume) measured in dB hearing level that a person can hear a sound of a particular test pitch. A completely normal HTL is 0 dB. Also known as HL.

**Hereditary Hearing Impairment:**

Hearing loss passed down through generations of a family.

**Hertz (Hz):**

Cycles per second. Frequency is denoted in Hz.

**Impressions:**

A blueprint taken of the ear by putting soft material in the ear canal and allowing it to harden before removing it. This 'impression' of the ear is sent to the manufacturer for custom hearing aid products.

**In-the-Ear (ITE) hearing aid:**

ITE hearing aids come in plastic cases that fill most of the concha, or bowl, of the ear.

**Individualized Education Program (IEP):**

A written statement for a child with a disability (between the ages of 3 and 21) that is developed, reviewed, and revised by a team that is composed of the child's parents, regular education teacher, special education teacher, and a representative of the local education agency. Other people who have knowledge or expertise about the child or the particular disability may be invited to be part of the team.

**Individualized Family Services Plan (IFSP):**

A team-developed, written plan for infants and toddlers birth to 36 months and their families, which addresses: 1) assessment of strengths and needs and identification of services to meet such needs; 2) assessment of family resources and priorities, and the identification of supports and services necessary to enhance the capacity of the family to meet the developmental needs of the child.

**Inner Ear:**

The part of the ear that contains both the organ of hearing (the cochlea) and the organ of balance (the labyrinth).

**Jervell and Lange-Nielsen Syndrome**

A disorder made up of the following symptoms: endogenous, sensorineural hearing loss present at birth accompanied by a congenital heritable defect of the heart. Clinical feature includes fainting episodes.

**Lip-reading:**

Also known as speech-reading; a communication strategy that understands spoken language by interpreting lip movements, facial expressions, and postures.

**Listening stethoscope:**

A device which allows someone to listen to a hearing aid to ensure it's working properly.

**Localization:**

The ability to determine the direction of a sound source.

**Mastoid Bone:**

A portion of the temporal bone located behind the external ear. Bone-conduction stimulation often is applied to the mastoid bone.

**Microtia:**

Abnormal growth of the outer ear. Severity varies from minor skin tags or differences in

ear shape to complete absence of the outer ear.

**Microphone:**

The part of the hearing aid that picks up a sound and converts it from an acoustic signal into an electrical signal.

**Middle Ear:**

The part of the ear that includes the eardrum and three tiny bones (ossicles) of the middle ear, ending at the round window that leads to the inner ear.

**Minimal Response Level:**

The softest level a patient responds 50% of the time; also known as threshold

**Mixed Hearing Loss:**

A hearing loss with both conductive (middle ear pathology) and sensory (cochlear or VIIIth nerve pathology) components. The audiogram shows a bone-conduction hearing deficit plus a gap between earphone and bone-conduction responses.

**Multimemory:**

Hearing aids that have the ability to store different listening programs or settings that amplify sound according to particular listening environments and may be accessed by the user.

**Nonsyndromic Hereditary Hearing Impairment:**

A hearing loss or deafness that is inherited and is not associated with other inherited physical characteristics.

**Omnidirectional microphone:**

A microphone that picks up sound in all directions.

**Ossicles:**

The chain of three tiny bones in the middle ear (malleus, incus, stapes). Sometimes these bones are called the hammer, anvil and stirrup in common terms.

**Otitis Externa:**

An inflammation of the outer part of the ear and sometimes in the auditory canal.

**Otitis Media:**

An inflammation of the middle ear caused by infection.

**Otitis Media with Effusion (OME):**

Otitis media with abnormal fluid in the middle ear.

**Otoacoustic Emissions (OAE):**

Low-intensity sounds produced by the inner ear that can be measured with a sensitive microphone placed in the ear canal. It is also a test used to detect hearing loss.

**Otolaryngologist:**

Also known as an ENT; a physician/surgeon who specializes in diseases of the ear, nose, throat, head and neck.

**Otologist:**

A physician/surgeon who specializes in the treatment of ear problems.

**Otology:**

The branch of medicine that specializes on the ear.

**Otoscopy:**

A visual exam that looks at the structures inside the ear. It can detect ear wax, foreign bodies, and problems with the ear canal skin.

**Outer Ear:**

The external portion of the ear that collects sound waves and directs them into the ear. The outer ear consists of the pinna and the ear canal.

**Pinna:**

The outer part of the ear; also called the auricle

**Postlingually Deafened:**

The process of becoming deaf after a person has acquired language.

**Pressure-Equalizing (PE) Tube:**

Also called a tympanostomy tube; a tube that is inserted in the eardrum to equalize the pressure between the middle ear and the ear canal and to permit drainage.

**Prelingually Deafened:**

An individual who is either born deaf or who lost his or her hearing early in childhood, before acquiring language.

**Probe Microphone:**

A tiny microphone attached to a soft, small tube. The probe microphone is placed in the ear canal and is used to measure a variety of sounds during a hearing aid evaluation.

**Progressive Hearing Loss:**

A hearing loss that becomes increasingly worse over time.

**Pure Tone Audiometry:**

The main test used by audiologists to evaluate hearing loss. This test uses frequency specific pure tones for responses so that the configuration ('shape') of a hearing loss can be identified.

**Real-Ear-to-Coupler Difference (RECD):**

The difference, in decibels and across frequencies, between the response of a hearing aid measured in a real ear versus a standard coupler. The RECD is a measure that allows the audiologist to accurately specify the sound levels delivered to the ears of infants and young children.

**Real Ear Measurement:**

A test technique used to measure the sound levels in the ear canal produced by a hearing aid. A probe microphone is placed in the ear canal alongside the hearing aid.

**Residual Hearing:**

The amount of measurable, usable hearing.

**Reverberation:**

The reflection of a sound off a hard surface causing it to persist after the sound source has been stopped.

**Sensorineural Loss:**

A hearing loss caused by damage to the inner ear (cochlea) and/or the hearing nerve.

**Sign Language:**

A method of communication used primarily by people who are deaf or hard of hearing in which hand movements, gestures, and facial expressions convey grammatical structure and meaning.

**Signal-to-Noise Ratio:**

The difference between the signal compared to the background noise level.

**Sloping hearing loss:**

Refers to a hearing loss that gets progressively worse as the pitch is raised from low to high. On the audiogram the line appears to "slope" or drop off as the line moves from the left to the right.

**Speech Audiometry:**

Used to determine the weakest intensity at which a person can recognize words, or to measure the clarity of words when they are heard at a comfortable loudness.

**Speech Awareness Threshold (SAT):**

The lowest hearing level in dB at which a person can detect the presence of a speech signal, also known as the speech detection threshold (SDT).

**Speech Banana:**

All the sounds necessary for speech graphed on an audiogram. When a line is drawn around these sounds the shape resembles a banana and hence, "speech banana" is a term used to describe the range of conversational speech.

**Speech Frequencies:**

The frequencies within the 500 to 4000 Hz region, which are most important for hearing and understanding of speech.

**Speech Detection Threshold**

The softest level a person can perceive the presence of a speech signal.

**Speech Reception Threshold (SRT):**

The lowest hearing level in dB at which 50 percent of two-syllable (spondee) words can be identified correctly. Also known as the ST (speech threshold or spondee threshold).

**Speech-Language Pathologist:**

A professional who evaluates and provides treatment for speech, language, cognitive-communication, and swallowing problems of children and adults. Speech and language delays are frequently seen in children with hearing impairments. Minimum academic degree is a Master's degree. State licensure is required to practice speech-language pathology in many states.

**Sudden Deafness:**

The loss of hearing that occurs quickly due to such causes as an explosion, a viral infection, or the use of some drugs.

**Syndromic Hearing Impairment:**

A hearing loss that is accompanied by additional physical characteristics (e.g., blindness, mental retardation or involvement of other organs).

**Telecoil:**

A wire coil contained within a hearing aid that picks up magnetic energy available from telephones or other assistive listening devices.

**Threshold:**

See also Hearing Threshold Level; the softest level at which a sound can be heard 50 percent of the time. The term is used for both speech and pure tone testing.

**Tinnitus:**

A sensation of ringing, roaring, or buzzing sound in the ears or head. It is often associated with hearing impairment and/or noise exposure.

**Toxoplasmosis**

A common disease found in birds, cats, and mammals across North America. The infection is caused by a parasite called toxoplasma gondi and affects 10 to 20 out of every 100 people in North America by the time they are adults. If a mother is infected while she is pregnant, her baby could be born with hearing loss.

**TTY/TTD:**

A device for severely or profoundly hearing-impaired persons to send or receive written messages transmitted via telephone lines.

**Tympanic Membrane:**

Eardrum.

**Tympanogram:**

A measure of tympanic membrane (eardrum) mobility.

**Tympanometry:**

A test used to measure the condition of the middle ear and the movement of the eardrum.

**Tympanostomy Tube:**

See Pressure-Equalizing tube.

**Unilateral Hearing Loss:**

A hearing loss in one ear only.

**Usher's Syndrome**

Hereditary disease that affects hearing and vision and sometimes balance.

**Vertigo:**

A spinning sensation, sometimes occurring with nausea and/or vomiting.

**Vestibular System:**

The system in the body that is responsible for maintaining balance, posture, and the body's orientation in space. This system also regulates body movement and keeps objects in visual focus as the body moves.

**Volume Control:**

A device for increasing or decreasing the gain or volume of a hearing instrument.

**Visual Reinforcement Audiometry (VRA):**

A pediatric hearing test procedure in which the child's responses to sound are reinforced with a visual event (e.g., a moving toy). This procedure is most appropriate for children in the 6 month to 3-year age range.

**Wide Dynamic Range Compression:**

A special type of hearing aid or amplification device that compresses a wide range of sounds into a narrower range. This makes soft sounds easier to hear and makes loud sounds more comfortable for listening.

