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## **If you want to learn more about hearing loss and about resources for persons with hearing loss...**

then this Resource Guide is for you. Whether you are a parent who has just discovered your child has a hearing loss, a teacher, a school administrator, an audiologist, or someone in the community of persons with hearing loss, this guide can help you.

Please use this guide to:

- Learn more about hearing loss and the effects on child development.
- Explore choices for communication options.
- Find out about helpful books, resources and financial assistance.
- Learn communication tips.
- Interpret the responsibilities of Children's Medical Services Early Steps Program under Part C of the Individuals with Disabilities Education Act (IDEA).
- Assist in developing Individualized Family Support Plans (IFSPs) for children with hearing loss.

As you look through this guide, you may come up with questions and ideas you have not considered before. Remember the options and decisions facing families are theirs alone. There is no one "right" way when it comes to choosing intervention services that will help a child to succeed. The child's needs, as well as the needs of the family, will change with time. It is very important to view your decisions and your child's development as a work in progress. Do not be afraid to remain open to new ideas if your child is not progressing as expected. A communication approach should not be solely based on the degree of hearing loss.

No matter how young your child is:

- Talk, sing and play with him or her. This is fun and provides a solid foundation for turn taking, listening and learning to speak.
- Have your child's hearing thoroughly tested by professionals experienced with infant hearing loss.
- Have your child fitted with hearing aids as soon as possible. Hearing aids will allow your child to become aware of sounds around him or her.

***Discovering what works for your child's development and your family is what makes the choice right.***

*Author's Note: Many of the terms in this guide might be new to you. As you read the guide, turn to the definition section in the back for clarification.*

# FEELINGS



It takes time to move through the feelings you experience when you find out your child has a hearing loss. You cannot rush through the process. Know that the feelings will pass. Gradually you will realize how normal your baby is and accept him or her as he or she is.

- ***Stages of Coping***
  - *Shock*
  - *Recognition*
  - *Recovery*
  
- ***Powerful Feelings Help us Heal, Adjust, Cope and Accept***
  
- ***Parent Testimonials***

## STAGES OF COPING

Most people have little experience with friends or family members who have a hearing loss. Learning that your child has a hearing loss can be frightening. It is common for parents to experience some difficulty in learning to accept their child's hearing loss. Following the diagnosis of hearing impairment, parents generally experience very powerful emotions. Many parents find themselves going through stages of emotions that may include sadness, anxiety, confusion, and depression. These feelings are **NORMAL** and there is no set formula for dealing with such strong emotions.

People handle situations differently. When you lose something that is important to you, such as a loved one, your health, your job, or your dreams of the future, you will naturally experience a sense of loss. By becoming aware of the general stages of grief and learning to recognize what stage you are in, you find it easier to cope with the different feelings you experience.

### **First Stage: Shock**

The first reaction to the discovery that your child has a hearing loss can be shock. Why? Because you now know you have a child who is faced with additional challenges. There is a loss. As the initial shock decreases, you may begin to experience strong emotions such as anger, sadness, and denial. It is common not to want to believe this has happened to you, your child, or your family.

### **Second Stage: Recognition**

During this stage you recognize that your child has a difference that could effect his or her development, potentially causing a delay in the way in which he or she may function throughout his or her life. With early identification of hearing loss, many babies who receive hearing aids, appropriate early intervention services, and have involved parents communicating with them often, will enter school with only limited or no delays in language and learning. However, there are often situations along the way of the child's early development that can cause delays. Every individual is different!

Not everyone experiences all the emotions in the recognition stage. They may include sadness, anxiety, anger, guilt, shame, blame, disappointment, hurt, bewilderment, confusion, helplessness, loneliness, hope, and relief. These feelings are **NORMAL** and eventually decrease in frequency, strength, and the amount of disruption they cause in your life. Sometimes an event will occur that causes some of these feelings to reappear, but they will eventually subside.

**Third Stage: Recovery**

During the recovery stage, you accept your child as a person with a hearing loss. Acceptance does not mean being content with your situation, but it means you are better able to cope with the difficulties and any delays in development that might occur. As you learn to manage the doctor visits, learn what you need to do consistently to enhance his or her development, find good teachers and therapists, and settle into a routine, you will feel less overwhelmed and accept your new role as a parent of a child with impaired hearing. Being aware of your feelings can help you gain more control over them.

**Powerful Feelings Help Us Heal, Adjust, Cope and Accept**

It is important to know that these three stages are not always separated and do not have specific feelings or behaviors associated with them. It is quite normal, at times, to go back through phases of the grieving process. Parents, caregivers, and other family members' reactions to the diagnosis of a physical impairment in a child may differ. You may want to discuss and talk through feelings, while another parent may keep feelings inside and find them difficult to discuss. After time, the feeling of crisis fades and healing starts. This period is the beginning of constructive acceptance. At this time, you learn and practice coping behaviors so you can meet the needs of your child.

Gathering information and talking to family and friends about the situation are healthy ways of coping. It may be necessary to include outside support to help in the coping process. Often, talking with other parents of children with a hearing impairment is very beneficial to a parent of a newly diagnosed child with hearing loss. Sometimes, if feelings encountered in the recognition stage such as frustration, helplessness, and denial do not decrease but continue, it is important for a parent to seek outside support by participating in individual counseling, support groups, or visits to clergy, as a means of finding effective ways to cope.

Finally, the period of time spent in one stage or another varies from individual to individual. What is important to understand is that the rate you go through this process can differ from others around you. You may experience frustration from time to time. Being aware of this feeling will help guide you so you will not act for the wrong reasons. Each time your child comes to a major life milestone, it may impact you in a new way, and you may experience the range of emotions again.

Acceptance of your child's hearing loss means you understand and accept the reality that your child is and always will have a hearing loss. But your life need not center on this aspect. Having a hearing loss means that there will be situations that are more challenging for your child than for children without a hearing loss. This can be an accepted part of the child's life.

*Excerpted and adapted from: John W. Adams (1988) You and Your Hearing-Impaired Child: A Self-Instructional Guide for Parents, Gallaudet University Press, Washington, DC*

## **Parent Testimonials**

### ***Child Who Benefited from Early Intervention***      By Ann Filloon

My husband and I are the proud parents of two incredible children, both with hearing loss. Unfortunately our state did not have newborn hearing screening when they were born. The similarities between our children are they both use cochlear implants to hear and are siblings. Their paths to this point are remarkably different. My son's hearing loss wasn't identified until he was about 22 months old. He was initially fitted with a hearing aid in his better ear and the second aid 4 months later. At 2 ½, his hearing loss was mild to severe. He began speech therapy and slowly gained language skills. Since our educational backgrounds were not in the medical field, we listened to the medical experts, and followed all their advice.

When our daughter was born, we tested her hearing at 3 months on the advice of our ENT. She was born profoundly deaf! After the initial shock wore off and we worked through the emotional turmoil, we felt prepared to help her by whatever means necessary. She began wearing hearing aids at 4 months and speech therapy at 5 months. I began reading, researching and meeting other families with deaf children. I discovered that the services my son was receiving were not at all appropriate for a child with hearing loss. We lost critical time and wasted over a year of speech services!

It wasn't until my son received digital aids that he was amplified in all frequencies within the speech range. He was 5 years when he heard high frequency sounds for the first time! His hearing loss began to fluctuate and became progressively worse. Eventually he qualified for a cochlear implant at 7 ½ years.

Once we found an appropriate center to work with our family for speech therapy, my son's language skills took off. He closed his 2-year language gap in 7 months and advanced an additional 2 years within the next 8 months! His progress was incredible!

Although my son only had a mild to severe loss, which eventually progressed to profound, he experienced a 2-year language gap. His sister who was born with a profound loss, had the advantage of early intervention services, appropriate speech and language services, appropriate amplification, ultimately a cochlear implant at an early age, never had a language gap of more than 12 months! Her language skills developed similarly to those of hearing children. By the age of 4 ½, she closed her language gap. She is now fully mainstreamed in Kindergarten, is learning to read, plays the piano, dances and has an incredible social life for a Kindergartener. Our son is a 3<sup>rd</sup> grader with a sense of humor who plays tennis and baseball, participates in cub scouting, plays the piano and is a typical boy.

By becoming informed parents of services for the deaf, we searched and found the services that best met the needs of our family. It was a long long road to where we are today, but worth every minute and experience. Our children are children first, who happen to hear differently than we do.

*Ann Filloon is the Lead Follow-up Coordinator with Florida's Children's Medical Services, Newborn Screening Program.*

***Child Who Benefited from a Cochlear Implant*** By Sherra Payne

Nine years ago our first child was welcomed into our family with great joy and excitement. My husband and I were thrilled with our perfect baby boy. As the days went by we marveled at what a good sleeper he was since he could sleep through anything if he was tired. Much to our dismay, when he was seven months old we found out that the reason he didn't startle to noise was because he didn't hear the noise. In March of 1993, he was diagnosed with a profound sensory neural hearing loss. As first time parents, we didn't have many clues early on and although the news was not a total shock it set us into a tailspin of what's, why's, how's, and where do we go from here.

For the next several years we continued to search for the best opportunities for our son and our family, we chose oral communication as our method and worked endlessly to help Austin discover sounds and the spoken word. Much of our effort was to no avail and after several years of intense Auditory Verbal Therapy and using the best hearing aids available, we started to consider the Cochlear Implant, which at the time was not tried and true for children. On May 14<sup>th</sup>, 1996 at 7:00 AM we began the long road down the Cochlear Implant path.

One month later Austin received his external processor and heard his first sound. That day remains a blur in my mind but the months and years that have followed are like snapshots in time. The first time he heard a toilet flush in a public bathroom, the first time he heard his brother cry and we were at the other end of the house, the night he kissed his brother goodnight and when Tristan said "I love you with all my heart" and Austin replied "I love you my heart", the soft whispers goodnight after the lights are out to which he responds "goodnight, I love you". The day his teacher told me that he was the best listener in class and all the other kids wanted to sit next to him during dictation tests since he repeats the sentence quietly while he writes it out.

Today, he is thriving in a mainstream school with no support services. We no longer attend therapy sessions several times a week. He prides himself on getting 100% on his spelling pretests and being in the challenge spelling group each week. Just recently he got two A+s on Spanish dictation tests. Now he is just one of the guys on the playground and at baseball camp. He is happy, loving and carefree. People who don't know him ask why he is wearing that hearing aid and assume that he has normal hearing in one ear. When people ask, he so accurately states, "I wear my hearing on the outside!"

These are all miracles made possible for Austin through the use of a Cochlear Implant and the support of the Implant Team. When Austin was first diagnosed with a hearing loss 9 years ago I was the parent of a "hearing impaired" child...today I am the parent of a child with impaired hearing. That may not seem like much of a difference, but as a parent I can tell you that the difference is significant. The loss of hearing which at one time was the focus of our lives is now just a small part of our daily routine.

We are so thankful for the opportunities available to us today that allow us to make the choices that are best for our family. Each family is different, just as each child is different but the one common factor is that the choice is ours. Once we make a decision it is very important that we follow that path and give it 100% effort. By doing that, our children will achieve their full potential and have the opportunity too reach any goals they set. For those parents who are just starting down the road, good luck and follow your heart.

*Sherra Payne is a parent living in Florida*

***Choices in Deafness:***

By Michele Love

In 1989 my husband and I had our first child, Kenneth. Named after his great grandfather he arrived to change us from a couple to a family, and we were thrilled. Ken was a wonderful baby who slept well, never cried much, was very alert and visually attune. Others would always comment how good he was, and I remember being at a restaurant with him and a business partner of my husband's commenting "Look at that, he didn't even wake up" after a server dropped an entire tray of food right next to our table. It was about that time that my husband and I began to have concerns about Ken's hearing and at 12 months of age he was officially diagnosed with a severe to profound hearing loss.

This came as a tragedy to our family. Having no knowledge of deafness and no family history of deafness, we had no idea what to expect and it felt like we had been dealt a devastating blow. I was also 2 months pregnant with our second child and had to undergo tests to make sure that I had not contracted CMV. Had CMV been the cause Ken's deafness, it could have a serious impact on the child I was carrying, with hearing loss being one of the milder affects of the virus. Although we dealt a lot those first few months after Ken's diagnosis, we also got quite an education into the world of disabilities. As things turned out, Ken was fitted with hearing aids and our second child, Ellen, was born with normal hearing.

I never imagined that there were so many choices in modes of communication, and philosophies to do with deafness and hearing loss. In 1989 when Ken was born, there was not a standardized procedure for testing children for hearing loss at birth, and that is the most positive change that has occurred since our experience. Secondly, I have since learned that not all professionals with whom you will come into contact, are to be viewed as being all-knowing and unbiased within their field. Our road has been a long one, but I feel that we have been blessed with an opportunity that we would never have experienced had Ken been born with normal hearing. Of course, things did not seem so wonderful and fair at that time.

I was given information regarding services in our area one of which being a center that specialized in Auditory Verbal training. This is an option for parents that stresses using a child's residual hearing to train him to speak through much training and exercise both professionally and reinforced on a daily basis at home. Of course, this sounded like the perfect choice for us! I called the center, paid them a visit, and was explained that through proper training, my child would be able to hear and speak using his hearing aids. This is a strict program where no visual cues are given to the child, and one's hand usually covers the mouth to avoid lip-reading dependence. We attended this program for two years, driving about 45 minutes each way two to three times a week. We also began receiving services from the county's early intervention program and several times a week a specialist would come to our home and work with our family.

At age 3 Ken was still not making much progress and only saying a few words. I learned of a program through our school system, which took an Auditory Oral approach. This mode of teaching including Auditory training, but allowed for some visual cues to be included as well. We decided to change gears and give this program a try hoping that with some visual prompts Ken's ability to speak would improve. We had a wonderful teacher who was very patient and kind with Ken, and very helpful to our family.

We stayed with the oral program until age four, when Ken was still not speaking or showing much progress. By that time we knew that he was a very bright child, but he was not showing any inclination to speak. We were in intensive private speech therapy both privately and through

the school program. The changing point for us happened when the speech therapist from the school called to talk to me. She said that day in speech; Ken wanted to play with a toy dog that was high up on a shelf. To let her know what he wanted, he got on his hands and knees to imitate a dog. It crushed me that he was unable to communicate his needs. Prior to this time, other school personnel had begun to mention that perhaps we should switch Ken to the Total Communication class at school where he would learn sign language and speech at the same time. I had held fast to the dream that he would speak, convincing myself he would be just like other children, but with hearing aids and to finally come to terms with the thought that he would never be like a “normal” child was awful. We decided to move him to the Total Communication program and looking back, I feel that this was the first time that I ever really saw Ken as “deaf”. My husband and I both had a lot of feelings to deal with that we had pushed aside in our efforts to make him a hearing child.

Ken began to blossom in the Total Communication program. All of the things that never had labels or names before began to all make sense to him. He began expressing himself and his wants and desires to us. I began to take sign language classes and we worked as a family, even grandparents and aunts and uncles, taking sign classes. In less than a year Kenny was signing quite well and I could see his frustration level with communication improve dramatically. Still no speech, but slowly I was coming to grasp the idea that that would be okay.

Today, Ken is a 6<sup>th</sup> grader at the Florida School for the Deaf and the Blind and is in the top of his class. He mainstreams to the local public school for math, which has been a good experience for him. He swims and runs track at school, and has many friends here as well. While he is a very vocal child, he still does not have great speech, but I’ve come to decide that he’s his own person, no matter how we communicate.

I have no regrets with the road that we took to get here, nor do I have any regrets with coming to use sign language as our choice of communication. It is who he is, and he is happy, well adjusted and would you know, a normal sixth grade boy. I would not change the way we came to this place, because it was such a growing process and an education for us. We have met a lot of wonderful people along the way, and I hope that any parent with a newly identified child will take the time to explore all of your options and learn as much as you can! Communication is the key in no matter what choice your family makes. It is so important that you and your child are able to communicate freely regardless of the method and road you choose to get there!

*Michele Love is a parent living in Florida*

***For the Sake of Joy***

By Janet DesGeorges

My baby girl never heard me tell her I loved her the first two years of her life. It wasn't that I didn't love her, or that I didn't tell her everyday, but rather that she had a hearing loss that went undetected for those two years, and was unable to hear any speech. There was no newborn hearing screening process in the hospital where she was born.

I remember the signs along the way. As a toddler, my daughter Sara would walk up to the TV and put her ear up to the speaker. If I entered her room, and she was looking away from me, she wouldn't turn to me, even if I had said "hello." I did the pan banging behind her head, and when she turned her head to that, my fears would be alleviated for a while. When I thought of deafness, I understood it to be all or nothing. I didn't realize Sara could have a hearing loss and still be able to hear some noise, but not speech. I think there is an assumption by some people that if a child has a hearing loss, a parent will pick up on it right away, and seek out help for their child. It took several months for me to be able to follow through on my intuition that something was not quite right. I don't even understand why I wasn't able to seek help for my daughter the first time I questioned her ability to hear. I guess it was the hope that if I just waited, everything would turn out fine.

During that time in my daughter's life, I remember the frustration of not being able to communicate with Sara, and not understanding why. As a mother of three, and a daycare provider for fifteen years, I had a lot of confidence in my parenting skills. So the inability for me to understand Sara when she wanted something was a mystery to me. And her inability to follow even the simplest directions was a very frustrating time in our lives.

When I think of those first two years of my daughter's life, there is a myriad of emotions that still flood my heart to this day: Self-reproach for not having the insight to follow up on the questions that came up about Sara. Sorrow for my daughter not having a language to use during that critical time of development. Anger over the fact that the hospital where Sara was born did not do a simple test that could have changed the life of our family, and perhaps the future of my daughter's life. By having the knowledge of a difference in our daughter from the start, we could have intervened on her behalf to facilitate communication from the start. I'm sure some of the frustrations that occurred over the span of those two years, having intervened, would not have happened.

When my daughter was finally identified, the help our family received from early intervention helped to set the framework for our attitudes. We also received much unbiased information to help us set a course for our daughter's education and the tools we needed to help her succeed in life. We are very thankful for the people who were able to provide their professional expertise, yet also gave us the respect, as a family to make the choices we felt were appropriate.

I guess most of all, when you discover you have a child who is deaf, you come to discover that it is not an awful thing. It is just a part of who your child is. It does not change the way you love or accept your child. It does not change the hopes and dreams you have for your child, and who they will become. You just open your heart to a different way of interacting in the world around you. There is a joy in discovering your child as they grow, and I just wish that opportunity to know my child, a child with a hearing loss, had been there for me from the start. For the sake of joy, let's identify all children who are deaf or hard of hearing from birth, so families and communities can learn from the beginning how to get the message across..."I love you."

*Janet DesGeorges is the Parent Consultant to the Colorado Children's Hearing Impaired Program [www.handsandvoices.org](http://www.handsandvoices.org)*

# GETTING STARTED



A reaction many parents have to the news that their child has a hearing loss is to stop speaking, singing and cooing to him or her. This is a normal reaction, but a child with a hearing loss needs everything a child with normal hearing needs. Your child needs your smile, gestures, talking, playing, and responding to his or her moods, actions and noises. Children with hearing loss actually need to be surrounded by additional language and sound so they can eventually make sense of it. **Remember that your child is a child who happens to have a hearing loss.**

- *Early Identification and Diagnosis is Essential*
- *Who Can Help?*
- *Responses of Children with Hearing Loss to Sound*
- *Does Your Child...*

***Early Identification and diagnosis is essential.***

All babies born in Florida hospitals are required by law to have their hearing screened. This test is painless and performed while a baby is sleeping. It checks whether each ear is functioning properly. If a baby fails the newborn hearing screening, he or she will need to have a complete hearing evaluation by a pediatric audiologist (hearing doctor). This will confirm or rule out a hearing loss. The type and degree of loss will be measured.

**Who can Help?**

It is important to choose professionals carefully. Babies as young as 3 weeks old can be fit with hearing aids. Services to help you understand your baby's needs can begin within 6 weeks of referral. Do not wait. It is important that you are comfortable working with the professionals you choose, since they will be part of your team for many years. It is all right to ask them questions and expect the answers to be understandable. **The following list of professionals may work with you and make up your intervention team. One person may fill multiple roles on the team.**

**Pediatric Audiologist (Hearing doctor)**

1. Specializes in working with infants and young children and evaluates their hearing in each ear at a range of frequencies.
2. Makes the referral to the Children's Medical Services Early Steps Program.
3. Arranges to fit hearing aids on your child and may provide them on a trial basis.
4. Makes earmold impressions and keeps child with well-fitting earmolds.
5. Has loaner hearing aids available.
6. Has the resources to repair hearing aids in a timely manner.
7. Reviews the results of the audiogram with your family at the time of each evaluation.
8. Provides a comprehensive written report, with a copy of the audiogram, to your child's doctor and with your consent, Early Steps.
9. Tests your child while wearing amplification and questions parents about child's responses to sound at home.
10. Is familiar with procedures for Individualized Family Support Plan (IFSP) development and for paying for hearing aids or assistive technology.
11. Works on the intervention team with you and early intervention specialists to monitor and maintain your child's amplification systems (hearing aids, FM systems, cochlear implants).

**Pediatrician/Family Practitioner**

1. Makes sure your child has received a hearing evaluation or follow up hearing screening before 3 months of age if he or she failed newborn hearing screening.
2. Refers you to an audiologist skilled in testing the hearing of infants and toddlers when you express concern about your child's hearing.
3. Answers your questions about medical or surgical treatment of different types of hearing loss.
4. Confirms the need for prompt action involving amplification and early intervention once your child has been diagnosed with hearing loss.

5. Treats or refers your child to medical ear specialists when your child has middle ear disease.
6. Makes a referral to the Early Steps Program, or assures that a referral has been made, so support services can begin.

### **Otolaryngologist or Ear, Nose, Throat (ENT) Physician**

1. Confirms whether or not there is a medically treatable condition in your child's outer ear or middle ear that is causing the hearing loss.
2. Answers your questions about medical or surgical treatment of different types of hearing loss.
3. Signs a form authorizing use of hearing aids with your child (required by law before hearing aids can be fit on a child).
4. Places ventilation, or PE tubes in your child's eardrums if he or she has chronic middle ear disease that is not cleared up by antibiotics. Also prescribes antibiotics and performs other ear, nose and throat surgeries.

### **Serving Hearing Impaired Newborns Effectively Service (SHINE) – Hearing Specialist**

1. Meets with your family to provide initial information about hearing loss.
2. Helps you begin to understand hearing loss, works with you to determine the size of your child's listening bubble, and discusses the meaning of the audiogram.
3. Helps you obtain, understand and do daily checks on the function of the hearing aids.
4. Provides information on development of effective parent-child interaction.
5. Explores communication options with your family in an unbiased manner.
6. Helps you complete a Communication Plan once you know how you would like to communicate with your child
7. Assists you with obtaining appropriate early intervention services.
8. Provides understanding and support to the family.
9. Works with you to monitor your child's progress in developing language and auditory skills at least every 6 months.

### **Early Intervention Service Provider – Hearing Specialist**

1. Provides information about hearing loss, audiograms, auditory development, amplification, communication options and developmental issues.
2. Works on the intervention team with you to develop the intervention plan for your family.
3. Provides ongoing support to your family, helping you to learn how to best assist your baby's communication development and overall learning.
4. Helps you access services and identify resources that may be helpful.

### **Speech Language Pathologist (SLP)**

1. Works on the Early Steps intervention team to develop family centered strategies that address your child's early communication, language, and speech needs.
2. Gives you a time line when services will begin and end.

3. Describes how your family will be involved in developing communication skills with your child. Defines your role in communication skill development and expectations about your family's participation.
4. Provides you with high-quality instruction, demonstration and coaching in communication skill development for your child.
5. Helps you learn how to help your child listen during everyday activities and routines while wearing hearing aids all waking hours.
6. Answers your questions about your child's hearing loss.
7. Helps you stimulate spoken language development.
8. Listens to your observations and concerns about your child and discusses these with you.
9. Works with the audiologist to help your child learn to use amplification and make sure your child's hearing aids function properly.
10. Keeps records of your child's progress in developing communication skills.
11. Communicates with other members of your child's Early Steps team

### **Auditory-Verbal Therapist**

Should be comfortable doing all the items a speech and language pathologist does plus the following:

1. Uses an auditory verbal treatment plan for developing speech and language for children with hearing loss through maximum use of amplified hearing.
2. Works directly with your child and family while teaching you auditory verbal techniques to support your child's growth of auditory, speech, language, and cognitive skills.

### **Teacher of the Hearing Impaired (Deaf)**

1. Develops family-centered strategies and trains parents to address the child's communication, listening, language, and speech development.
2. Provides links to people in the community with hearing loss and support services.
3. Provides information on hearing loss and its effects on learning and teaching strategies.

### **Other Parents of Children Who Have a Hearing Loss**

1. Share experiences they have had with professionals and early intervention programs.
2. Tell you about people and information sources they have found useful.
3. Listen to you.
4. Share with you their feelings related to parenting a child with hearing loss and how their feelings have changed over time.
5. Tell you about their child's achievements.
6. Get together with you so your children can play together.

### **Your Family**

1. Helps your child develop communication and social skills by engaging your child in natural everyday routines.

2. Models natural language for your child.
3. Allows you to take a needed break for yourself.
4. Listens to you, provides support and understanding.

**Responses of Children with Hearing Loss to Sound**

Some children will not be identified through the hearing screening in the hospital and will develop a hearing loss at a later time. The following is a list of behaviors that sometimes indicate there is a problem with a child’s hearing. If the answer is "no" to any of the following questions, and the child has not had a complete audiological evaluation in the last few months, you should promptly speak with your child’s doctor about having your child’s hearing tested by a pediatric audiologist. Hearing ability can change!

Even a mild hearing loss or a hearing loss in only one ear will typically affect speech and language development.

**DOES YOUR CHILD...**

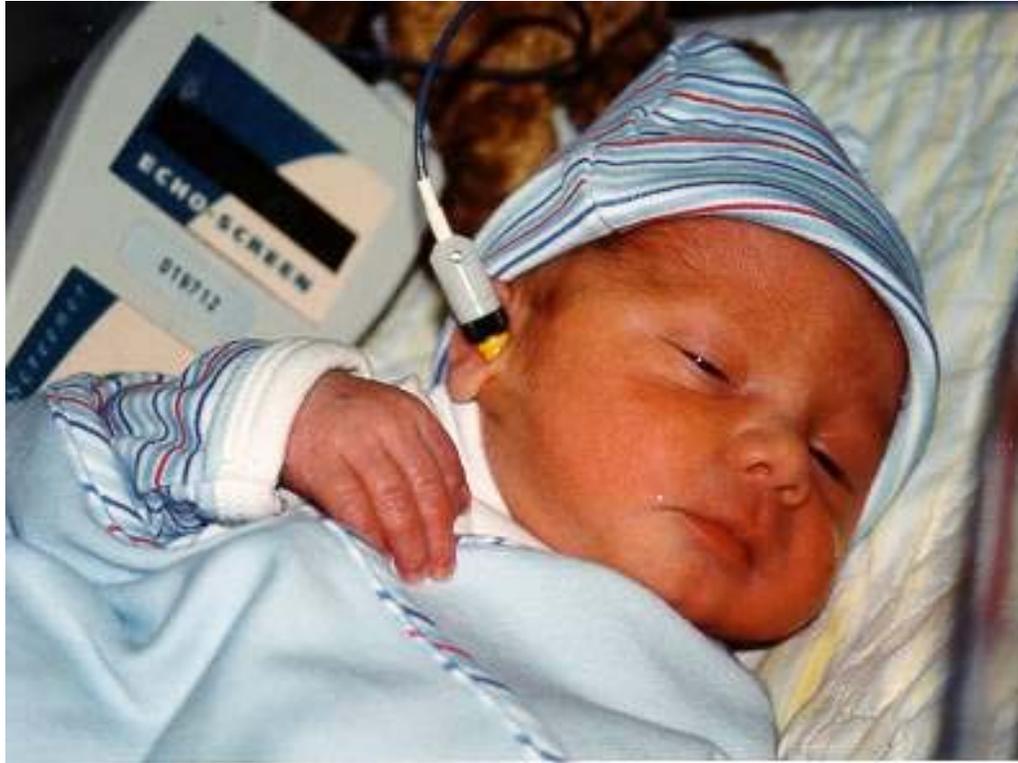
**If no problems, at least 2 of the 3 items in the child’s (adjusted) age group should be checked.**

AGE		YES	NO
1-2 mo	Startle to loud sounds (throws arms out)?		
1-2 mo	Move arms or legs in time to speech patterns?		
2-3 mo	Quiet when he is upset and hears your voice?		
3 mo	Look around to see what is making a new sound?		
3 mo	Look at toys or objects when they make sound?		
3 mo	Imitate vowel sounds like oo, ee, ah?		
4-6 mo	React to a change in the tone of your voice? (i.e. happy, mad)		
4-6 mo	Quiet when talked to with a soothing voice?		
4-6 mo	Move eyes toward the direction of sounds heard from the side?		
6-9 mo	By 7 months look down if a sound occurs from below?		
6-9 mo	Aware of parent’s voice when heard from a distance (next room)?		
6-9 mo	By 9 months looks up for a sound from above?		
9-12 mo	Watch TV for a short time (i.e., reacts to songs, rhymes, etc.)?		
9-12 mo	Turn or look when you say his name?		
9-12 mo	Babble using a variety of sounds like baba, geegoo?		

AGE		YES	NO
12-18 mo	Turn head quickly to locate sound from any direction?		
12-18 mo	React to or show pleasure at new or unusual sounds (whistle, buzzer)?		
12-18 mo	Respond to a simple command with no gestures (“Come here” “Sit down”)		
18-24 mo	“Dance” to music?		
18-24 mo	Let you know what he wants or needs by using his voice?		
18-24 mo	Consistently use 20 or more words?		
24 mo	Point to some body parts when asked (“Where’s your nose”)?		
24 mo	Enjoy listening to stories?		
24 mo	Understand many words (200+)?		
30-36 mo	Notice and identify different sounds (phone, doorbell)?		
30-36 mo	Listen to stories in a group of others?		
30-36 mo	Understand most things said to him?		

RED FLAG HEARING QUESTIONS-HEARING	AGE	YES	NO
Does your child often fail to respond to typical sounds in the environment? (i.e., dog bark, door bell, item dropped behind)?	3+ months		
Does your child often fail to respond to his name or a noise that you would expect him to hear? (i.e. pan dropping)	3+ months		
Does your child seem to respond less to sound now than when he/she was younger?	6+ months		
Does your child seem to turn more to one side than the other when sounds occur?	7-9+ months		
Does your child often seem to watch your lips while you speak?	12+ months		

# HEARING TESTS



It is important to have your child's hearing tested as soon as possible. No child is too young! Find an audiologist who has experience working with infants and children. Go to [http://www.doh.state.fl.us/Cms/NewbornScreening/CMS\\_APPROVED\\_PEDIATRIC\\_AUDILOGISTS.pdf](http://www.doh.state.fl.us/Cms/NewbornScreening/CMS_APPROVED_PEDIATRIC_AUDILOGISTS.pdf) for a list of pediatric audiologists. Since most children over 3 months of age will not tolerate having all tests done at one time, a few visits may be necessary to complete testing. Some children may need to be sedated for testing. Evaluation under 3 months of age usually avoids the need for sedation to diagnose hearing ability. Feel free to ask questions about what the tests measure, how the tests work, what they expect to find, and how to read the test results.

- *Types of Hearing Tests*

**Types of Hearing Tests**

<i>Name of Test</i>	<i>Procedure</i>	<i>Format of Results</i>	<i>Age Appropriate</i>
Auditory (Brainstem) Evoked Response (called ABR or AER) or Auditory Steady State Response (ASSR)	<ul style="list-style-type: none"> <li>• Requires no voluntary response from child</li> <li>• Response is measured by electrodes on scalp</li> <li>• Sounds are presented through earphones</li> <li>• Estimate of hearing level by determining the softest sounds that produce measurable brain response</li> </ul>	Wave form that indicates response of the auditory nerve (CN VIII)	<ul style="list-style-type: none"> <li>• Infants under 3 months without sedation</li> <li>• Infants and toddlers over 3 months, sedation is typically used</li> </ul>
Otoacoustic Emissions (OAE)	<ul style="list-style-type: none"> <li>• Requires no voluntary response from child</li> <li>• Response is measured by a small probe in the ear canal</li> <li>• Sounds are presented through the same probe</li> <li>• Does not determine severity of hearing loss</li> <li>• Does confirm presence of permanent hearing loss</li> </ul>	Graph displaying response of inner ear	<ul style="list-style-type: none"> <li>• Newborns, infants, toddlers, older children. No sedation is required</li> <li>• Child must be still &amp; quiet for up to one minute</li> </ul>
Immittance Measures	<ul style="list-style-type: none"> <li>• No response is required from the child</li> <li>• Response is measured by a probe placed in child's ear canal</li> <li>• Sounds are presented through the same probe</li> <li>• A computer measures how the eardrum responds to different air pressures</li> <li>• Does not measure hearing loss-indicates if infection or middle ear fluid behind the eardrum may be present</li> </ul>	Graph of response of eardrum to changes in air pressure	<ul style="list-style-type: none"> <li>• Infants (at least 5 months old), toddlers, and older children. No sedation is required</li> <li>• Infants under 5 months old only if high frequency sound is used</li> </ul>

<i>Name of Test</i>	<i>Procedure</i>	<i>Format of Results</i>	<i>Age Appropriate</i>
Behavioral Observation Audiometry (BOA)	<ul style="list-style-type: none"> <li>• Requires an unconditioned response from a child -- eye widening; sucking start or stop</li> <li>• Conducted in a soundproof booth</li> <li>• Sounds from an audiometer are presented through insert earphones or loud speakers (tones of varied pitch and loudness, speech, etc.)</li> <li>• Estimates the degree of hearing loss</li> </ul>	Audiogram -- quietest levels at which child appears to detect sounds at the different pitches tested	<ul style="list-style-type: none"> <li>• Younger than 6 months of age. Should be used in conjunction with ABR, OAE and Immittance Measures to verify a hearing loss is present</li> </ul>
Visual Reinforcement Audiometry (VRA)	<ul style="list-style-type: none"> <li>• Requires a conditioned response (looking at a lighted toy)</li> <li>• Conducted in a soundproof booth</li> <li>• Sounds presented via loudspeakers, insert earphones, or a small vibrator on the skull bone are varied in loudness and pitch by an audiometer</li> <li>• Degree of hearing loss is determined</li> </ul>	Audiogram -- softest levels at which child responds to different pitches	<ul style="list-style-type: none"> <li>• 6-30 months</li> </ul>
Conditioned Play Audiometry (CPA)	<ul style="list-style-type: none"> <li>• Requires a conditioned response (throw a ball in a bucket)</li> <li>• Conducted in a soundproof booth</li> <li>• Sounds presented via loudspeakers, insert phones, earphones, or small vibrator on the skull bone are varied in loudness and pitch by an audiometer</li> <li>• Degree of hearing loss is determined</li> </ul>	Audiogram - softest levels at which child responds to different pitches	<ul style="list-style-type: none"> <li>• At least 18 months</li> </ul>

# HEARING LOSS



Testing a child's hearing and fitting him or her with hearing aids is a process, not a one-time event. Useful information will come from your observations of your child's response to sound while wearing hearing aids. Take notes and share this information with your audiologist. Understanding the type and degree of hearing loss allows your child to wear the hearing aids that work best for him or her.

- *How We Hear*
- *Learning about Hearing Loss*
- *Degree of Hearing Loss and Potential Effects*

## How We Hear

Sound travels through the air in the form of waves of varying frequencies. The frequencies of these waves determines the pitches of the sound we hear. Sound waves enter the outer ear (Refer to Diagram of Ear) through the external ear canal (#1) and are transmitted to the middle ear. Sound is directed to the eardrum (#2). The movement of the sound waves causes the eardrum to vibrate. This vibration causes three tiny bones to move back and forth in the middle ear. This

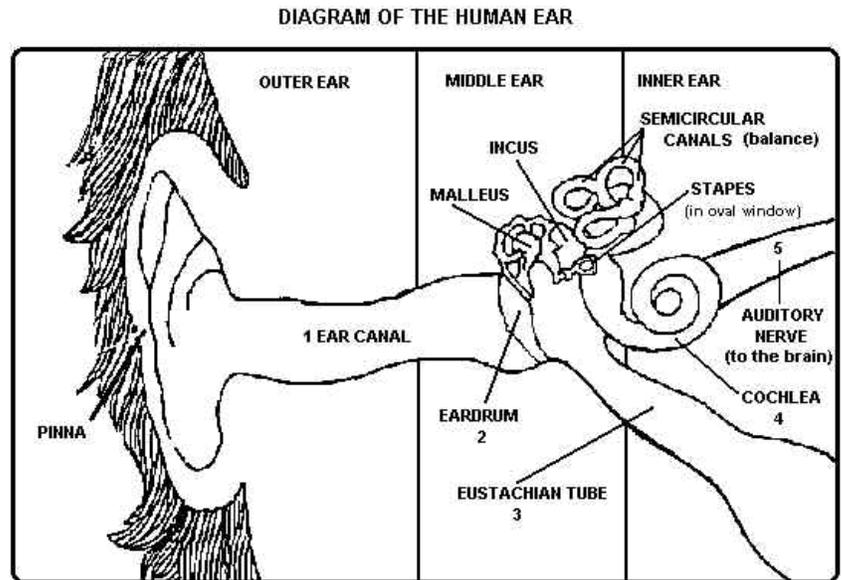
mechanical vibration is then directed into the inner ear, the cochlea (#4). The cochlea is lined with a membrane that has thousands of hair cells on it. The purpose of the hair cells in the cochlea is to code them into an electrical signal that the brain can recognize. The hair cells have nerve fibers from the Auditory Nerve (#5) in them that change the mechanical energy of the sound wave into electrical energy. This electrical energy stimulates the nerve and sends a signal representing the sound wave into the brain.

The normally functioning ear responds to a wide range of frequencies (pitches) and intensities (loudness). Hearing loss generally reduces the intensity of a sound and can affect different frequency ranges, depending on the type and degree of hearing loss.

## Learning about Hearing Loss

***Your intervention team should assist you in learning about the nature of your child's hearing loss.***

There are different kinds of hearing loss. A child may have a conductive hearing loss, a sensorineural hearing loss, or a mixed hearing loss. All types of hearing loss reduce loudness of some sounds or eliminate the ability to hear different pitches or to hear speech clearly. The hearing loss may be in one ear (unilateral loss) or in both ears (bilateral loss). Conductive loss may be temporary; sensorineural loss is permanent. Another kind of hearing problem is called auditory dyssynchrony or auditory neuropathy in which the cochlea, middle and outer ear may be normal, but the brain does not process sound normally.



**Conductive Hearing Loss**

A conductive hearing loss occurs when there is a problem in the outer or middle ear. The most common cause of conductive hearing loss in young children is a middle ear infection called otitis media. Otitis media is defined as inflammation of the middle ear, usually with fluid, which may or may not be infected. The condition is very common in young children and is the reason for many visits to the pediatrician. It is important that ear infections be treated by a physician as quickly as possible to reduce potential hearing loss. Most children will experience some occurrences of middle ear infection. However, significant problems result from infections that last for several months, despite medical treatment.

There are also other types of conductive hearing loss in young children. Some children are born with a physical abnormality of the outer or middle ear. This may not be surgically treated until the age of 5-6 or later, leaving these children with a hearing loss until the surgery.

**Sensorineural Hearing Loss**

Sensorineural hearing loss occurs when the inner ear (cochlea) or the auditory nerve is malformed or has been damaged. There are many early causes of sensorineural hearing loss including loss of oxygen during birth, extremely low birth weight, inheritance, and maternal viruses or drug use (particularly in the first twelve weeks of pregnancy). A child may be born with normal hearing and acquire a loss due to a viral disease such as meningitis or exposure to certain drugs or for no identifiable reason. There are also some inherited conditions that are associated with progressive sensorineural hearing loss (loss of more hearing over time). Children with sensorineural hearing loss need to receive appropriate amplification and audiological management as soon as the hearing loss is identified. Regardless of the degree of hearing loss, or if the hearing loss is present in only one ear, audiological management should include ongoing auditory testing and follow up, referral for related medical follow-up, fitting and trial of hearing aids, and monitoring of the effectiveness of amplification and communication development.

**Mixed Hearing Loss**

When a child has both a conductive and a sensorineural loss in the same ear, it is called a mixed hearing loss. Children with permanent sensorineural hearing loss are as susceptible to middle ear infections as children with normal hearing and may add a conductive hearing loss to their existing sensorineural hearing loss. A child's pediatric audiologist should regularly test all kinds of hearing loss as part of the child's ongoing audiological management.

Research clearly shows that a communication choice should not be based only on the degree of hearing loss.

## Degree of Hearing Loss and Potential Effects

<b>DEGREE OF LOSS</b>	<b>POTENTIAL EFFECTS</b>
<b>26–40 dB</b>	May have difficulty hearing faint or distant speech. A child with a mild loss may miss up to 10% of the speech signal when the speaker is at a distance greater than three feet, or if the environment is noisy. Likely to experience some difficulty in communication and educational settings. Consider need for hearing aids and intervention.
<b>41-55 dB</b>	Understands conversational speech at a distance of 3-5 feet. Amplification may enable listener to hear and discriminate all sounds. Without amplification, 50% to 100% of the speech signal may be missed. Intelligibility of speech may be affected unless optimally amplified.
<b>56-70 dB</b>	Conversation must be very loud to be heard without amplification. A 55 dB loss can mean 100% of the speech signal is missed in a typical conversational situation. When amplified, may have difficulty in settings requiring verbal communication, especially in large groups. Delays in spoken language and reduced speech intelligibility expected without intervention and amplification.
<b>71-90 dB</b>	If loss is pre-lingual, spoken language and speech may not develop spontaneously, or could be severely delayed. Without amplification, is aware of loud voices about one foot from the ear and is likely to rely on vision for communication. With consistent use of amplification, parent attention to communication strategies, and an effective communication environment, language development and speech may develop to be normal or near normal.
<b>91 dB or greater</b>	If loss is pre-lingual, spoken language and speech will not develop spontaneously. Without amplification, relies on vision rather than hearing for communication and learning. Potential candidate for the cochlear implant. With consistent use of cochlear implant or amplification, committed parent, auditory-oral or auditory verbal communication techniques or a communication system like cued speech, language development and speech may develop to be normal or near normal.

Refer to [http://www.cms-kids.com/SHINE/documents/Relationship\\_of\\_Hearing\\_Loss\\_Listening\\_Learning\\_Need\\_2perPg.pdf](http://www.cms-kids.com/SHINE/documents/Relationship_of_Hearing_Loss_Listening_Learning_Need_2perPg.pdf) for a handout on the RELATIONSHIP OF HEARING LOSS TO LISTENING AND LEARNING NEEDS

# COMMUNICATION



There are several choices (also called methods or options) for how you can communicate with your child with hearing loss. The choices range from using all spoken language to using all signed language with various combinations in between. There are people who feel very strongly about each option. As a parent, you need to choose the option that is best for your child and family. Although you are not an expert on hearing loss, you can trust your instinct about what feels right for you and your child.

- *Communication Building Blocks*
- *Communication Features*
- *Communication Options*
- *How Does Language Develop?*
- *What are Some Communication Tips?*

## **Communication Building Blocks**

### **A review of choices in communication**

A smile, a cry, a gesture, a look – all communicate thoughts or ideas. It can take many repetitions of a gesture, look, word, phrase, or sound before your child begins to understand. Communication surrounding your child is the basis for language development. Two-way communication, responding to your child and encouraging your child to respond to you, is the key to your child’s language development.

Even with a 25 – 40 dB hearing loss or hearing loss in just one ear, your child will not hear as well when a person is speaking from another room or in a noisy car. Conversations and pieces of language will not be overheard. Although your child appears to “hear”, the fullness of language and social skills may not be fully understood. Hearing aids can help, but will not solve all of your child’s difficulties hearing and understanding soft or distant speech. No matter what the degree of your child’s hearing loss, you need to learn how to adapt your communication style to meet the needs of your child.

There are different ways to communicate and different ideas about communication. Technology has expanded communication choices for young children with hearing loss. Choosing one manner of communication over another is a personal decision made by the family and does not need to be totally dependent upon a child’s amount of hearing loss.

### **IT’S NOT ABOUT HEARING LOSS, IT’S ABOUT COMMUNICATION**

As you think about how your family communicates now and how you would like to communicate with your child in the future, you are thinking about choosing building blocks of communication. The best way to decide which communication features to use for your family is to use them consistently throughout each day and to be open to the choices available. Ask questions, talk to adults who are deaf and hard of hearing and other families with children who have hearing loss. Discuss, read, and obtain as much information as you can about the different ways to communicate with a child who has a hearing loss. You may want to contact hearing-related organizations or read books describing choices in communication options. Organizations and books are listed in the Resource Section. Choosing one communication method over another is a personal decision.

Consider the following factors when choosing a communication method:

1. Does the communication method chosen enable all of your family members and regular caregivers to communicate with your child?
2. Is using this particular communication method in the best interest of your child? Does this allow your child to express his/her feelings and concerns and participate in the world of imagination and abstract thought?
3. The communication method chosen should promote enjoyable, meaningful communication among all family members and caregivers and enable your child to feel a part of your family and know what is going on.

## Choosing Communication Building Blocks: Taking the first steps to foster communication development

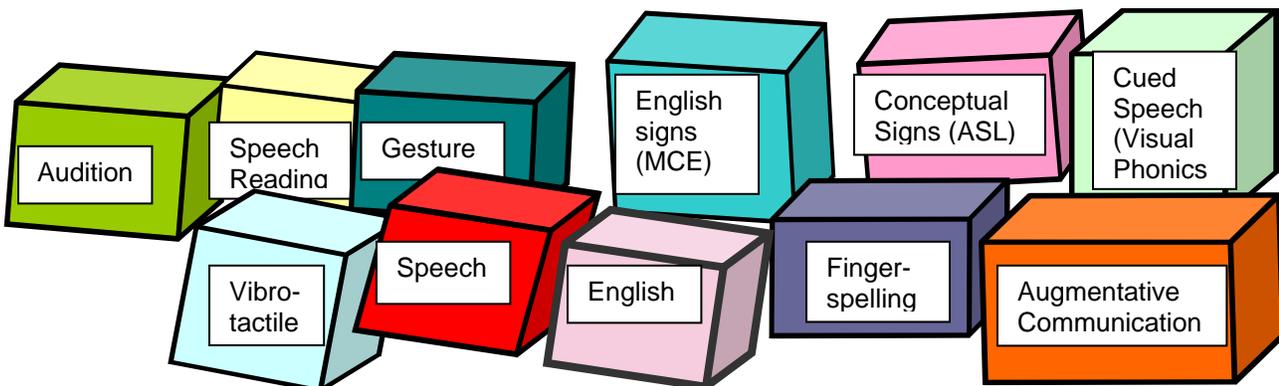
All children develop language skills over time. It is through the daily practice of language in all activities that children become effective communicators. Success for young children with hearing loss is measured by the child gaining at least one month in language skills for every month of early intervention. Parents are often asked to complete a check-off language ability list every 6 months that allows communication growth to be monitored. Think about communication building blocks, or features, as doors that lead you together with your child on different paths. Communication features are the specific components of language that can be combined in different ways to produce different communication methods. If there is a bump in the road and your family or child is not moving forward in using language at the expected rate, you can consider another path or a combination. Consultation with your child's team of professionals and other parents of children with hearing loss will help you better understand what some of these paths may be like for your child.

**One month of language development growth for every month of early intervention!**

Each child's hearing loss is unique. When making decisions for interventions for your child, you must understand the nature of his or her hearing loss. Your child's audiologist and early intervention service provider can help you understand your child's hearing ability. Intervention options for children can be divided into four categories – educational, audiological, medical, and fostering communication development.

### Communication Features

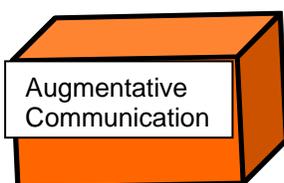
Communication features are the specific components of language, the building blocks of communication that can be combined in different ways to produce different communication options or methods.



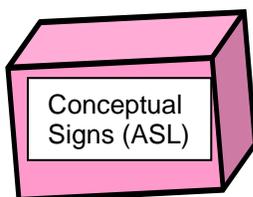
The five communication options that will be described include American Sign Language (Bilingual), Auditory-Oral, Auditory-Verbal, Cued Speech, and Total (Simultaneous) Communication. Think of each of these options as stacks of blocks made up of combinations of different communication features.



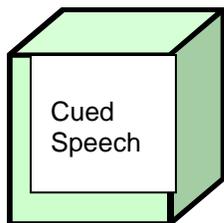
People with hearing loss have different degrees of residual, or useable, hearing. Some people labeled as “deaf” have limited hearing ability that may or may not respond to amplification and may not result in meaningful perception of sound. With full use of residual hearing via hearing aid use, spoken English may be learned through constant use of spoken language in the home accompanied by special attention to providing language and listening experiences. The maximum possible use of audition through optimal amplification is a key to success of the Auditory-Oral and Auditory-Verbal methods. A strong working relationship with an audiologist is vital. Individuals who are most successful with the Auditory-Oral and Auditory-Verbal based approaches have residual hearing, through the use of hearing aids or a cochlear implant. Auditory training instructs the family in how to help the child learn to listen and to understand what is heard.



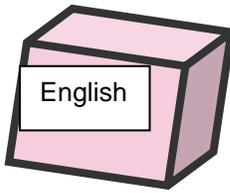
Augmentative communication refers to the use of communication techniques or devices that enhance expression of ideas or understanding. Augmentative communication can refer to how an individual looks at a certain symbol to communicate through the use of eye gaze, use of simple switches to turn on lighted toys, or the use of communication boards or electronic voice responders. Individuals with multiple disability conditions may use augmentative communication techniques or devices to enhance two-way communication with others.



American Sign Language, or ASL, is often thought of as the language of Deaf people. This complete visual language does not require the use of spoken words or sounds. ASL is not a way of using gestures to represent English. ASL has its own vocabulary and all of the language components of a true language, including grammar and sentence structure. It is a completely distinct language from any spoken language, including English. Humor, emotions, philosophical ideas and other abstract concepts can be fully conveyed in American Sign Language.



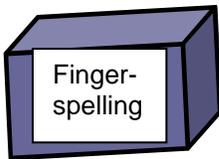
Cued speech is a visual code based on the sounds used within words. A system of hand-shapes visually represent speech sounds. Cued speech is used as a tool for speech reading spoken languages. This system is believed to encourage the development of reading through encouraging a child to learn the spoken language as his first language. Cued Speech consists of four main components: Cued Speech, speech reading, speech, and use of residual hearing. Cued Speech is not a language and must accompany speech. Cued Speech consists of eight hand-shapes representing consonant and vowel sounds. The parent, teacher, or other person talking with the child uses these codes to represent exact pronunciation of the words they are speaking. Cued Speech allows the child to learn to visually recognize pronunciation.



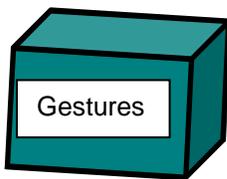
Receptive language refers to the words or language a person understands. Expressive language refers to how a person is able to share ideas or feelings in any method or mode of communication. Factors that may impact expressive language development include pragmatics, content and form. Pragmatics refers to the social use of language. The content of a language refers to meaning. One of the forms of language is how the words are put together to make sentences. English and American Sign Language differ in the order in which words or concepts are placed in a single sentence. Spoken English is somewhat different from written English in the way in which ideas and feelings are presented. Persons who are fluent in English will have a higher probability of becoming fluent readers of the English language.



There are a number of communication techniques that code the English language visually. Manually Coded English (MCE) is a system of signs (many of which are borrowed from ASL) presented in English word order. MCE is a visible representation of spoken English and is not a language. There are several manually coded English systems including Seeing Essential English (SEE 1), Signing Exact English (SEE 2), and Signed English. Signs that are used without full coding of the English language or the use of full conceptual ASL signs are considered to be Pigeon Signed English (PSE).



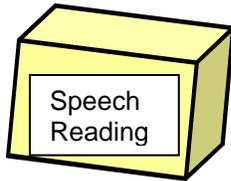
Fingerspelling is also known as a visual alphabet. Each of the letters of the alphabet has a distinct hand-shape. Many of these hand-shapes were formed to look similar to the written form of the alphabet letters. Most persons fingerspell much slower than they can talk, thus slowing down speech and communication in an unnatural manner. Fingerspelling is used mostly as a means to introduce new or unknown vocabulary words to people that sign, as not all words have defined signs. This is especially true of proper names or specialized vocabulary, such as in the sciences.



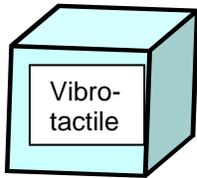
Natural gestures and body language consist of things that you would normally do for a child to help him or her understand your message. For instance, if you wanted to ask a toddler if he wanted to be picked up, you might stretch your arms toward him and ask “Up?”. For an older child you might gesture to him as you are calling him to come inside. Likewise, if you are expressing unhappiness about a teenager’s messy room, you might place your hands on your hips and show a concerned facial expression as you are delivering your message. These are examples of natural gestures and body language.



Emotion is expressed in the patterns of speech. Changing pitch at the end of a spoken statement typically means that a question has just been asked. Pitch, rate, and loudness all vary as we speak and can change depending upon the words preceding and following. These variations may be difficult or not possible to perceive for the person with impaired loss. It can take intensive work and time for a child with hearing loss to be able to discriminate these tiny speech differences through hearing alone or in combination with speech reading. Technological advances in hearing aids and cochlear implants may allow many people who are profoundly hearing impaired to access speech through hearing or audition.



Speech reading, or lip-reading, is a technique by which a person attempts to understand speech by watching the speaker's mouth and facial expressions. Some of the sounds in the English language can be understood by watching the mouth, but many cannot. Only 30 - 40% of the English sounds are visible. Much of the meaning of conversation is figured out through context and educated guessing. Not all listening environments are ideal to speech reading. Men with facial hair, people who chew gum, cover their mouth, or turn away when they talk and people who barely move their mouth when speaking are very difficult to speech read.



Vibro-tactile uses one of the natural senses – touch – to convey meaning. A child without hearing or who has very little residual hearing will turn to the source of vibration or even air movements in his or her environment. Some children who have little or no hearing can appear to inconsistently be turning to sound, when in fact, they feel vibrations through the floor, furniture, or air movements. Vibro-tactile senses can be increased through the use of Vibro-tactile aids that convert sound into vibration patterns. Vibro-tactile devices are sometimes used to train children to attend to the presence of sound in their environment. Our sense of touch and sensitivity to vibration is not an efficient replacement for the high discrimination ability of human hearing or sight. Vibro-tactile is a technique used with other communication features, and not as a stand-alone communication method.

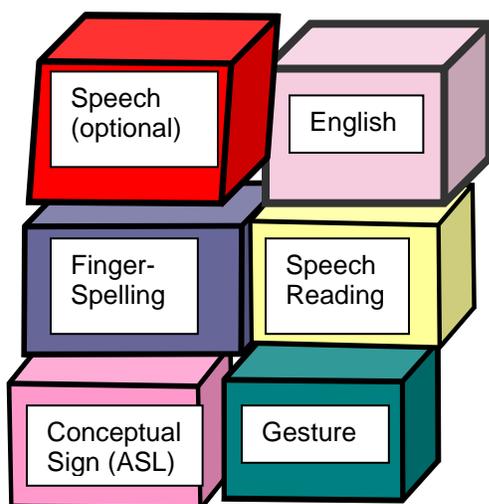
Normally hearing children absorb the language experiences that surround them and develop communication skills, with little apparent “teaching” needed from adults. Extra effort is needed by family members and caregivers to help a child with hearing loss learn language. It is through the daily exposure and practice of language in all activities that children become effective communicators.

Every child has areas of strength and non-strength, just as every family has different communication dynamics. Only you will know what feels right as you select communication features to match your child and family's needs. The child's personality, learning style, persistence, and motivation all will play an important part in communication growth. These are also qualities that we discover about our children as

we interact with them in many situations. Hearing evaluations need to be ongoing, as your child gets older in order to monitor his or her hearing and related listening devices. The communication features you select when your child is very young may or may not fit well with these personality qualities and the hearing loss information that becomes apparent when your child is older. If hearing loss changes, the amount and type of amplification may need to change as well. The need to adjust the choice of communication features or options is not unusual as parents learn more about their child.

## Communication Options

Communication features can be combined into different communication options, or methods. The best communication option for your child is the one that caregivers are willing and able to use comfortably and consistently and that meets the communication development needs of your child. No specific method will result in successful learning if caregivers and family members do not surround the child in the features of the communication option. Not every communication option will produce a successful outcome, even if all caregivers are highly committed to its consistent use. Your initial selection of communication features builds a foundation that supports your child's development of communication, cognitive, and social skills. Other blocks, or features, can be added to this foundation, or blocks can be substituted as needed.



### American Sign Language (Bilingual/Biculturalism)

The Bilingual/Biculturalism (Bi/Bi) communication option is designed to give children with hearing loss fluency in two languages – American Sign Language (ASL) and English or the family's native language. It also seeks to provide children with knowledge about and acceptance into two cultures – Deaf and hearing. American Sign Language, or ASL, is the language of the American Deaf Community. This language does not require the use of spoken words or sounds. It manipulates space, movement and signs to present information. Humor, emotion, philosophical ideas and concepts can be fully expressed in American Sign Language. ASL is usually taught as the child's primary or first language. English or the family's native language is taught as the child's second language focusing on the written form of the language. This option consists of two main communication features: ASL and the written form (sometimes the spoken form) of a language such as English.

### Family Responsibility

The child must have access to deaf and/or hearing adults who are fluent in ASL in order to develop this as a primary language. If the parents choose this option they will need to become fluent to communicate with their child fully.

### Parent /Caregiver Training

Intensive ASL training and education about Deaf culture is desired in order for the family and caregivers to become fluent in the language.

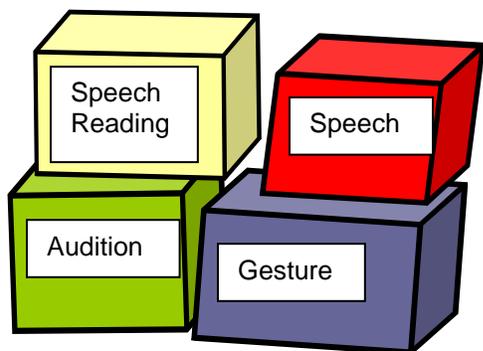
### Why choose this option?

This is a visual language that does not rely on speech or sound. As a visual language, very young infants develop the basics of ASL, just as a hearing child picks up the basics of a spoken language.

ASL is associated with the Deaf culture including the history, language and a society of people that sees themselves as distinct in their uniqueness. Within the Deaf culture exists Deaf humor, Deaf theater and associations for Deaf athletes. Some families find it immensely helpful to join together with one or more Deaf adults to introduce ASL and Deaf culture to their child and family.

### Why not to choose this option?

In order for a deaf child to be accepted in the Deaf community, he or she must be able to communicate in ASL. More than ninety percent of children with a hearing loss are born into families with hearing parents. The native language in the home of these children is English or another spoken language. To become fluent in ASL, the child must be surrounded with ASL and the families must find a way to bring it into the home. The acquisition of fluency in the language can take several years of intense training for adults. It can be difficult to communicate with non-signing relatives, neighbors and coworkers.



### Auditory-Oral

The Auditory-Oral option emphasizes maximum use of residual hearing through hearing aids, FM systems, cochlear implants and auditory training to develop speech and communication skills for full involvement in the hearing society. This option is based on the belief that most children with hearing loss can be taught to listen and speak with early

intervention and consistent training to develop their hearing potential. Unlike the Auditory-Verbal option, the Auditory-Oral option includes the use of speech reading and natural gestures. Manual forms of communication, such as Manually Coded English and American Sign Language, are not encouraged. Natural gestures and body language are accepted. The Auditory-Oral option consists of four main communication features: speech, audition, speech reading, and gestures or body language.

The Auditory-Oral option relies on enough residual amplified hearing to allow the child to understand his or her voice for monitoring of speech production (auditory feedback loop). The greater the amount of residual hearing an individual has, the better the chance for success with the Auditory-Oral option. A key to the success of Auditory-Oral option is optimal amplification of residual hearing or use of a cochlear implant. A strong working relationship with an audiologist is vital.

### **Family Responsibility**

Since the family is primarily responsible for the child's language development, parents are expected to incorporate learning techniques, learned from therapists, into the child's daily routine and play activities. The primary caregiver will have the responsibility of incorporating these techniques into the child's daily routine. The family is responsible for having the child consistently use the hearing aid, FM system and/or cochlear implant. Consistent meaningful listening and language (auditory input), is required for a child to develop speech and language skills in the Auditory-Oral option.

### **Parent/Caregiver Training**

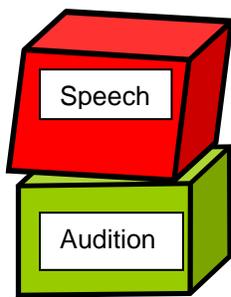
Parents need to be highly involved with their child's early interventionist, audiologist, therapists, or teachers, to carry over learning techniques to the home and create an "oral" learning environment. Every effort must be made to incorporate these activities and environmental requirements into the child care situation if there is no at-home parent. The learning techniques emphasize development of listening and language skills.

### **Why choose this option?**

The Auditory-Oral option teaches the child to rely on spoken language (such as English or the family's native language) and speech reading. The child will be able to communicate with the public and to blend into the family using the family's native spoken language. With the Auditory-Oral option, the family can continue to use the language that is spoken in the home and is not required to learn a new language, visual system, or code.

### **Why not choose this option?**

Some children may not be successful at using their residual hearing to learn speech. The child and family can become frustrated if the child's language does not develop with this approach. Children may undergo hours of speech and language therapy and make slow progress. Careful monitoring of language and speech development is necessary.



### **Auditory-Verbal**

This communication option uses the child's residual hearing, hearing aids or cochlear implants, and teaching strategies to encourage children to develop listening skills so they can understand spoken language and communicate through speech. The focus is on development of speech and language through hearing. Speech reading, signing, and natural gestures and body language are discouraged. The Auditory-Verbal

option consists mainly of two communication features: audition and speech.

In the Auditory-Verbal option, the child is expected to rely on hearing (audition) alone during specific teaching times. One to one teaching with a therapist trained in the Auditory-Verbal option with parents present, and then daily one to one instruction time with the parents, is necessary. Use of the hand cue during formal teaching times is used in the Auditory-Verbal option. These hand cues are: the therapist, parent, or caregiver covering his/her mouth when the child is looking directly at the adult's face; the adult moving his or her hand toward the child's mouth as a prompt for vocal imitation or as a

signal for turn taking; and the adult “talking through” a screen placed in front of the speaker’s mouth. More subtle signals such as encouraging the child to look at something other than the speaker’s mouth when speaking and naturally covering the mouth when speaking are also used. It is not expected that the parents or caregivers would cover their mouths during all daily living activities outside of the direct instruction time.

### **Family Responsibility**

Since the family is primarily responsible for the child’s language development, parents are expected to incorporate on-going training into the child’s daily routine and play activities. They must provide a language-rich environment, make hearing a meaningful part of all of the child’s experiences, and ensure full-time use of hearing aids or a cochlear implant.

### **Parent/Caregiver Training**

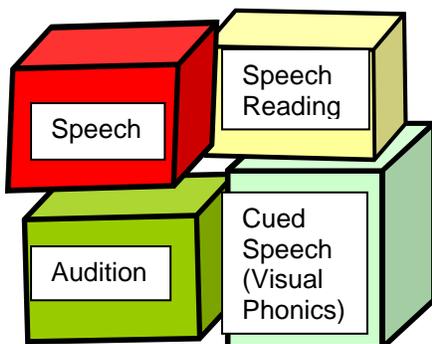
Parents need to be highly involved with the child’s teacher and/or therapists in order to learn training methods and carry them over to the home environment.

### **Why choose this option?**

The Auditory-Verbal option teaches the child to rely on listening carefully to spoken language (such as English or the family’s native language). The use of hearing aids or cochlear implants is necessary for a child to learn to listen and develop speech and language through Auditory-Verbal techniques. The child will be able to communicate with the public and to blend into the family using the family’s native language. The family can continue to use the language that is spoken in the home and not learn a new language, visual system, or code.

### **Why not choose this option?**

Some children with hearing loss will not be able to process all language through hearing alone. The child is expected to learn to fill in missing language information from experience and familiarity with the language. The child and family can become frustrated if the child’s language does not develop with this approach. Children may undergo hours of speech and language therapy and make slow progress. Careful monitoring of language and speech development is necessary.



### **Cued Speech**

Cued Speech is a system of eight hand shapes that represent groups of consonant sounds, and four hand placements that represent groups of vowel sounds, used with the natural lip movements of the speaker. The hand shapes and placements are grouped in sets that do not look alike on the lips, to make speech visible and clear to the cue-reader. Cued Speech is not a language and must accompany speech. Cued speech is used as a tool for speech reading spoken languages. This system is believed to encourage the development of reading through encouraging a

child to learn the spoken language as his first language. Parents of young deaf children are encouraged to use voice when they cue, in order to take advantage of any residual hearing their children have. The system has been used successfully with children who have no residual hearing. Cued speech consists of four main communication features: Cued speech hand shapes, speech reading, speech, and the use of residual hearing. Use of personal amplification such as hearing aids, FM systems, or cochlear implants is also important with this approach.

### **Family Responsibility**

Parents are the primary teachers of cued speech to their child. They are expected to cue at all times while they speak. Consequently, at least one parent (and the primary caregiver if there is not an at-home parent), and preferably all caregivers must learn to cue fluently for the child to develop age-appropriate speech and language.

### **Parent/Caregiver Training**

Cued speech can be learned through classes taught by trained teachers or therapists. Although the hand shapes can be learned during a long weekend training session, a significant amount of time must be spent using and practicing cues to become proficient.

### **Why choose this option?**

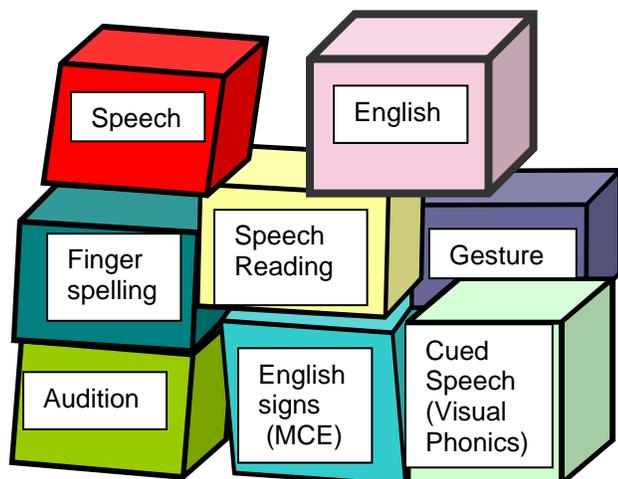
Many parents find it fairly easy to learn cued speech in a short time as they are not required to learn a completely new language. Intensive 3 to 7 day workshops equip a person with enough knowledge to begin to use cued speech. Continued use and practice over several months to a year will often be enough to become proficient with cued speech. In learning to read and write, children are able to phonetically sound out words. The rhyme and rhythm of English, idiomatic expressions and tongue twisters can all be appreciated by individuals who use this technique. Cued speech seems to help individuals become better speech readers even when cueing is not being used.

### **Why not to choose this option?**

This technique is relatively new and has been slow to capture interest. In many regions around the country, cued speech services are very difficult to access. Classroom programs are concentrated in select areas of the country and are not widespread. Often, trained Cued speech transliterators (since it is not a language they are not called interpreters) are not available. Some people have great difficulty thinking phonetically and do not become proficient in using this option. Cued speech has no similarities to American Sign Language and does not prepare children and their families to interact with members of the Deaf community. Since this technique looks very different from sign language, some users (particularly teens and pre-teens) are concerned about using Cued speech in public.

### **Total Communication**

Total Communication (TC) is an approach of communication and education for children with hearing loss that uses a combination of communication options, including oral and manual techniques. In this option, children and families are encouraged to both speak and sign. The communication features used are: Manually Coded English (MCE), speech



reading, speech, cued speech, natural gestures and body language. Hearing aids, FM systems, or cochlear implants are considered important in most total communication programs as children are encouraged to make maximum use of their residual hearing. Sometimes ASL is being introduced into total communication programs as a second language. Speech reading is encouraged in most Total Communication programs. Cued speech can be used in TC programs to enhance speech reading or literacy development.

### **Family Responsibility**

Preferably all family members and caregivers should learn the chosen sign language system in order for the child to develop age-appropriate language and the ability to communicate fully with his/her family (and within the child care setting if there is no at-home parent). It should be noted that a parent's acquisition of sign vocabulary and language is a long term, ongoing process. As the child's expressive sign language broadens and becomes more complex, so too should the parents in order to provide the child with an appropriate language learning environment. The family is also responsible for encouraging consistent use of amplification.

### **Parent/Caregiver Training**

Parents must consistently sign while they speak to their child (simultaneous communication). Sign language courses are routinely offered through many community colleges and other adult education providers. Many books and videos are widely available. To become fully fluent, signing must be used consistently and become a routine part of daily family communication.

### **Why choose this option?**

Children with some residual hearing may benefit from the combination of the visual code that closely matches what is being said. Also, MCE systems are generally easier for adults to learn than ASL. This is because the sign systems are not languages, and use the same grammatical structure and rules of spoken English. This option sometimes takes advantage of all communication techniques.

### **Why not choose this option?**

As children become proficient in the use of this communication method, they begin to cut corners in an attempt to increase the speed of signing. Many times the result is something that resembles Pidgin English or a combination of ASL and MCE. As each suffix, prefix, etc. is added, signing can become monotonous and tiresome. MCE systems emphasize grammar above communication – an emphasis that is not natural for young children. Most adults with hearing loss who grew up with MCE do not continue to

use these systems on a daily basis. If they continue to sign, they often switch to ASL. Availability of interpreters and interpreter certification programs for MCE systems can be a problem.

For families that speak a language other than English in their home, (i.e., Spanish, Creole), the use of MCE systems requires the parents to become fluent in a second language (English) at the same time that they are trying to teach their child a visual sign system. Since Total Communication is not a standardized approach, early intervention and school programs using this approach may differ widely in communication features emphasized, goals and objectives of the program, and support services and resources offered.

**No matter which communication features you select, remember it's not about hearing loss – it's all about COMMUNICATION!**

### **How Does Language Develop?**

It is helpful for families to understand the various aspects of language development in order to help their child. Babies develop at different speeds and these suggestions may be helpful regardless of the age of your child.

*Engage in frequent, positive communication with your baby to help language develop faster. Take time to respond to your baby's needs, to let your baby know by your smiles and your touch that he or she is loved.*

All babies need to develop positive bonds with parents or caregivers. These bonds develop, regardless of the hearing status of your baby, by responding to your baby's needs. Since babies cannot tell us what they need, we must observe them carefully, sometimes guess, and then try different things to satisfy them. Even though we sometimes have trouble figuring out exactly what a baby wants, the fact that we keep trying teaches babies how important they are to us. Playing with your baby by exchanging smiles, by gentle touches, and with little games like "peek-a-boo" constitute more than "play." It is the natural way to strengthen the bond between parent and baby. It is also a natural way to communicate with your baby and build your baby's understanding of communication. Babies who feel loved and secure have extra energy available for learning language and other skills.

*Use as many senses as you can to send messages to your baby with a hearing loss. Emphasize touching games. Move your body and face and hands around in front of your baby. Emphasize your facial expressions even more than usual. Talk to your baby.*

Without having to think about it, parents use special ways to communicate with young babies. Parents tend to raise the pitch of their voice when they talk to babies. They talk in a "sing-song" manner with a lot of rhythm. They often repeat phrases or sentences several

times, giving the baby a chance to anticipate and know what will be said next. Parents also gesture a lot to their babies, often making hand movements in rhythm with their words. They use facial expressions that are usually positive or happy and they exaggerate those facial expressions compared with those they use when talking to others. Parents also touch and stroke their babies frequently. Even if a baby cannot hear the parents' speech, the baby can receive the messages sent through the other senses.

***Be Responsive. Follow your Baby's Lead. Notice where your baby is looking or what your baby seems to be interested in. Talk about that object or activity.***

Babies will be more interested in communicating when they can set the "topic" of conversation. Even as adults, we don't like to communicate with people who seem to ignore our own ideas and interests. Babies and young children can get the same feeling if their conversation partners keep "changing the subject" instead of following up on their interest. This is the case even when the child's interest is shown through actions instead of any kind of real language.

Language learning occurs more quickly when parents talk about an object or activity that the baby exhibits an interest in. Here are examples of responding and of topic changing:

- Mother **responds** or follows child's topic: Child looks at toys spread around on the floor, and then picks up a baby doll. Mother says, "Oh, a baby. You want to play with the baby?"
- Mother **changes** topic: Child looks at toys spread around on the floor, and then picks up a truck. Mother, also looks around at toys, picks up a cup and saucer. "Here, Honey," mother says, "Let's have a tea party. Do you want a drink?"

Learning a new word is a cognitive or thinking task that requires mental energy. When a child is already thinking about an object or activity, she has only to connect a new word with that object or activity. It is a one-step task.

In the second situation, when the mother redirects the child's attention, the word-learning task becomes more complex. It involves at least three steps: the baby must figure out that the adult wants her to notice something new, then figure out exactly what and where the new thing is, then finally make the connection between the new word and that object or activity.

***Pay attention to the baby's arm, leg and body movements. These movements can tell us when the baby is excited. They might also show us that the baby is trying to communicate.***

When playing with and responding to your baby, it is important to notice the movements of his or her body, especially the arms and legs. Babies often show feelings and readiness for play by these movements.

***Respect the baby's right to stop playing or communicating. Sometimes babies look away or even begin to fuss when they have had too much playing, too much stimulation.***

It is important to keep in mind that babies, like adults, need "down time." When young babies play or communicate for a long time, they can become tired or even too excited. When this happens, babies often look away from the communication and lose their happy facial expressions. The best way to respond to this behavior is to wait quietly for a short time to see if the baby looks back to re-start the communication. Some babies are more sensitive than others and will need to rest more often.

***Especially with a young baby, often move your hand or body so your baby can see your communication while still looking at a toy or activity.***

During the early months of life, babies spend a lot of their time watching the person communicating or playing with them. However, by five or six months of age, most babies begin to display a great interest in objects. They want to explore objects and toys by looks and manipulation. They spend more time looking at objects and less time looking directly at parents and other people who want to communicate with them. This presents special challenges for persons communicating with babies who have hearing loss. A child with hearing loss will hear spoken language only partially, in a distorted way, or perhaps not at all. The child needs to see the message in order to understand it. It is helpful for the child to be able to see the face and body of the person who is sending the message. The child can get information from mouth movements, facial expression, and body language in addition to information from sound.

***Move an object (such as a toy) in front of your baby and then move it up toward your own face. When your baby can see your face and the object, communicate about it.***

Another way to help a baby see communication while looking at an object is for you to move an object in front of your baby. This almost always gets their attention. Then you can continue to move the object, bringing it up near your face. When your baby can see you and the object at the same time, you can communicate about the object. This is most effective when you move an object that you and your baby have been playing with, or move an object related to one your baby is playing with. That way, you can use language that is responsive to your baby's interest instead of changing the topic.

***When your baby is amplified, use an auditory signal (such as calling his or her name) first to get your baby's attention. Wait a few seconds. If he or she does not respond, call your baby's name again. Wait a few seconds. Gesture to him or her, or tap him or her lightly on the shoulder to get his or her attention. When your baby looks at you, talk with him or her.***

A good way to teach your baby his or her name is to say his or her name and wait for a response. Say the name again and wait for a response. If your baby does not look at you, then gesture or get in his or her line of vision to get his or her attention. When your baby is looking at you, repeat his or her name again and say something like "Julia, that's you". The more often your baby hears his or her name, the faster it will be learned.

***Tap on an object, perhaps several times, before and after you communicate something about it. This helps your baby know what your communication is about.***

Pointing to or tapping directly on an object before saying something about it shows your baby exactly what your language means.

***Relax, wait for your baby to look up on his or her own. You do not have to fill every moment with communication and language. It is more important to follow up on your baby's interests and make sure he or she can see your communication.***

One of the best ways to ensure that a baby takes note of communication is to wait for your baby to look up, then quickly say something to your baby. This may require a lot of patience, because some babies will not look up. But, when you communicate in an interesting and responsive way during the times that your baby does decide to look up, it is like giving your baby a reward. It encourages looking up in the future.

***Use very short sentences- one, two, or three words at a time, plus pointing or tapping on objects. Remember to allow your baby time to process and understand your words.***

Use short and simple sentences with your babies. Between about 9 and 15 months of age babies start to show that they understand language, and most babies themselves begin to produce language. Without really thinking about it, their parents give them a "model" of language that is easy to understand and easy to learn. Then, when the babies begin to talk more, parents gradually move onto more complicated language.

***Repeat words or short sentences several times. Always give your baby time to process the sentences. Also tap on objects or point to activities to show your child what you are communicating about.***

This gives your baby several chances to notice and recognize the language patterns. Babies seem to find repeated language interesting. Tap on objects, point, use interesting facial expressions, and bring the object near your mouth to help your baby see and pay attention to language.

*Excerpted and adapted from "A Good Start: Suggestions for Visual Conversations with Deaf and Hard of Hearing Babies and Toddlers", Dr. Patricia Spencer, cc 2001 Laurent Clerc National Deaf Education Center, Gallaudet University*

### **What are Some Communication Tips?**

Communication with your child is very important! Two-way communication, responding to your child and encouraging your child to respond to you, is the key to your child's language development. Here are some tips that may help.

- Name **objects** in the environment as you see or use them.
- Talk about the **actions** you or your child are doing or seeing.
- Talk about **how** things look, feel and sound.
- Talk about **where** objects are located. You will use many prepositions such as in, on, under, behind, beside, next to, and between.
- Compare how objects or actions are **similar** and **different** in size, shape, smell, color, and texture.
- Talk about the **steps** involved in activities as you are doing them.

Tell familiar **stories** or stories about events from your day or your past. Keep the stories simple for younger children and increase the complexity as the child grows.

### A BRIEF LIST OF INTERNET RESOURCES ON COMMUNICATION

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

Alexander Graham Bell Association

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

Unbiased communication support for families

[www.sign2me.net](http://www.sign2me.net)

Benefits of teaching sign language to babies

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

Documents to download

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

John Tracy Clinic

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

National communication network for parents of deaf

And hard of hearing children

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

American Society for Deaf Children

Resources for parents English, French

Chinese, Spanish

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

National Cued Speech Association

[www.listen-up.org/](http://www.listen-up.org/)

Specializing in information for the deaf and

hard of hearing

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

Oral Deaf Education/Oberkotter Foundation

Communication Building Block information adapted by Karen L. Anderson, Audiology Consultant, Florida EHDI Project (January, 2002) from K. Biernath, MD., (1999), Center for Disease Control (2002)

# INTERVENTION TEAM



Children with hearing loss are likely to develop social, emotional, or developmental delays when no intervention is received. When your child has a hearing loss, necessary audiological management and care to communicate with the child effectively should be provided early in life if delays related to hearing loss are to be prevented. Florida's Early Steps Program provides family-centered early intervention services. Your family is the most important part of your child's life. Services are designed to help you meet the needs of your child at no or minimal cost.

- *Early Steps - Florida's Early Intervention Program*
- *Individualized Family Support Plan*

*Quality intervention has a team approach with the family as the most important member.*

### **EARLY STEPS - Florida's Early Intervention Program**

Early Steps provides early intervention services in Florida and assures that services and supports are available for young children with special needs from birth to age three. A child with a diagnosed hearing loss has an established condition and is eligible for early intervention services in Florida. Any child may be referred to Early Steps upon the identification of a hearing loss. Referrals to Early Steps can come through the toll-free Central Directory number at 1-800-654-4440 or directly to one of the 16 local Early Steps offices across the state. Physicians, audiologists, parents, caregivers, teachers, childcare providers, or anyone else who may have a concern about a child can make referrals.

Funding for Early Steps is made possible through the State of Florida and Part C of the Individuals with Disabilities Education Act (IDEA). IDEA is a federal program that helps Florida provide family-centered early intervention services provided in the natural environment. Federal funds enhance state and local resources.

### **Hearing Loss Criteria for Early Intervention Program Eligibility**

The degrees of hearing loss specified below place an infant or toddler at risk for developmental delays. Infants and toddlers with hearing loss of this degree or greater are eligible for audiological management (including provision of hearing instruments when appropriate) and family-centered early intervention services.

#### **Criteria**

1. Evidence of a documented permanent hearing loss level of:
  - a. 25 dB or greater based on pure tone average of 500, 1000, or 2000 Hz unaided in the better ear. Air-bone gap not to exceed 10 dB HL.
  - b. Air conduction thresholds, unaided in the better ear, greater than 25 dB HL at two or more frequencies in the high frequency range (2000, 3000, 4000, 6000 HZ) in both ears with air-bone gaps no greater than 10 dB HL.
  - c. Evidence of an anatomical malformation of the outer and/or middle ear in conjunction with a hearing loss  $\geq$  30 dB HL pure tone average of 500, 1000, and 2000 Hz in the better ear.
  - d. Sensorineural hearing loss in excess of 25 dB HL in the worse ear based on pure tone average of 500, 1000, 2000 Hz. Air-bone gap not to exceed 10 dB HL (except in cases of anatomical malformation).
2. Evidence of a documented unresolved or chronically recurrent conductive hearing loss in combination with at least 4 of the following:
  - a. 4 or more episodes of otitis media in 12 months; primarily occurring in both ears
  - b. Single episode of otitis media lasting longer than 3 months; primarily occurring in both ears
  - c. Indication of fluctuating hearing loss (audiological hearing evaluation(s) revealing pure tone average of 20 dB or worse in the better-hearing ear; OR caregiver or physician report)

- d. Caregiver or physician concern over speech and/or language development (i.e., as compared to “Sequence of Development for Infants and Toddlers: Auditory, Language, and Speech”)
  - e. Caregiver concern over behavioral response when child is given a direction or placed in new situations
  - f. Chronological age of 18 months or greater
3. Evidence of auditory dys-synchrony (auditory neuropathy) in both ears characterized by a unique constellation of behavioral and physiologic auditory test results.

### **Individualized Family Support Plan (IFSP)**

Once a child is determined to be eligible for Early Steps, an IFSP is developed. The IFSP is based on family concerns. It documents specific supports and services that are necessary to help meet the unique needs of the child and family in their daily life. A periodic review of the IFSP is conducted at least every six months and evaluated annually or more often at the family or team members request. The IFSP will typically include family training to assist families to learn more about:

- parent-child interaction strategies that maximize language development opportunities
- ideas to help your child maximize the use of his or her hearing
- how to use your child’s hearing technology
- how to effectively communicate
- general development of infants and toddlers including social and emotional development
- opportunities to meet with other families who have children with a hearing loss
- opportunities for sibling support
- counseling support for families to discuss family issues related to your child’s hearing loss
- communication development monitoring at least every 6 months
- hearing aid follow up checks with your child’s audiologist
- hearing aids, earmolds and, when warranty runs out, hearing aid insurance
- how to prepare for a transition to new services once your child turns three years old

# HEARING TECHNOLOGY



No child is too young to have their hearing tested or to begin wearing hearing aids. Major advances in technology are continually being made so that children with a severe to profound hearing loss can have access to a surprisingly large amount of sound that can be used to develop language primarily through hearing. If you get hearing aids as soon as your child's hearing loss is diagnosed it will give your child the earliest opportunity to begin to learn about sound.

- ***Hearing Aids and Cochlear Implants***
  - *What is a Hearing Aid?*
  - *Why is it so Important for My Child to Wear Hearing Aids?*
  - *What is Available When a Hearing Aid Isn't Powerful Enough?*
  - *Who Decides Which--Hearing Aid or Cochlear Implant?*
  - *How Often do We Need to Adjust Hearing Aids?*
  - *How do I Troubleshoot Hearing Aids?*
  - *How does a Hearing Aid Work?*
  - *How does a Cochlear Implant Work?*
  - *What are the Different Types of Hearing Aids?*
- *How do I Keep Hearing Aids in Place?*
- *How Often do Ear Molds Need to be Remade?*
- *What Other Devices Might be an Option for my Child?*
- *What is the Relay Service?*

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## Hearing Aids

***Parents need to understand and manage the hearing aids and/or auditory equipment for their child.***

### **What is a Hearing Aid?**

We actually hear with our brains. Hearing aids are a way of delivering sound to a child's brain to allow him or her to grow the brain connections needed to learn to process and understand sound. A hearing aid is a device for the ear, which amplifies or makes sounds louder for a particular hearing loss. The goal is to provide enough amplification for a child to hear speech and environmental sounds at a comfortable level. When hearing loss is severe or profound (70 – 110 dB) it is very difficult for hearing aids to provide enough amplification for a person to be able to hear all of the speech sounds.

### **Why is it so Important for My Child to Wear Hearing Aids?**

Babies begin hearing in the womb before birth and within the first three months of life can tell the difference between voices and some speech sounds. A child born with a hearing loss is already behind in developing the skills needed to understand what sounds mean, including speech. The sooner amplification is worn by the baby throughout all waking hours, the better opportunity he or she will have to learn to understand sounds and to develop language and speech.

Even children with very mild (25 – 40 dB) hearing loss require consistent amplified sound to develop to their potential without social, behavioral or learning consequences. With every passing month without optimal amplified hearing, the child is at an increased risk for communication delays. With appropriate amplification in use and active family involvement in early intervention, a child can be expected to develop about one month of language for every month of early intervention. Without amplification, a child with hearing loss cannot be expected to develop verbal speech and language skills at the same rate or complexity.

Even if your child is deaf (hearing loss 90 – 100 dB or greater) the first step is hearing aids. Why? Because when babies are very young their brains are developing neural connections, pathways that allow different stimuli to be processed. If the hearing nerve and brain are not stimulated then the auditory portion of the brain will not develop. Similar to keeping the water dripping to prevent a pipe from freezing in cold weather, hearing aids worn by deaf children continue to stimulate the brain, even if the child is still not able to hear enough to perceive speech. A healthy, growing hearing nerve and brain provide your baby with more options in the future (see cochlear implants) if you become interested in exploring these possibilities.

Parents who do not have their child consistently wear amplification should consider visual communication options as the primary means of communication to develop language. Recent research has shown that babies with hearing loss, and no other disabilities, who receive appropriate intervention services prior to six months of age, have a high likelihood of having normal language ability upon school entry, regardless of the communication option used by the family.

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### **What is Available When a Hearing Aid Isn't Powerful Enough?**

Cochlear implants are designed to help children and adults with sensorineural hearing loss or “nerve deafness” become aware of sounds again or even for the very first time. Cochlear implants are an option for children as young as 12 months who are profoundly deaf in both ears; lack progress in the development of auditory skills; and have high motivation and appropriate expectations from their family. Children older than 2 years are potential candidates for cochlear implantation if they have severe-to-profound sensorineural hearing loss in both ears (nerve deafness); receive little or no benefit from hearing aids; and lack progress in the development of auditory skills.

A cochlear implant changes sound into electrical impulses, which stimulate the hearing nerve and can then be interpreted by the brain as sound. There is an adjustment period for the child while their brain begins to interpret and understand the sounds from the cochlear implant. The length of the adjustment period and how well a child will learn to use the sounds for communication and learning varies from individual to individual.

### **Who Decides Which--Hearing Aid or Cochlear Implant?**

Children identified with hearing loss who are less than a year old will typically be fit with hearing aids. As the child reaches 6 months or so and if there is little or no response to sound or auditory development then the parents and the child's audiologist should come to a careful decision regarding amplification or cochlear implants. Hearing aids are required to be worn consistently a minimum of 3-6 months before cochlear implantation will be considered. Hearing loss in both ears almost always requires fitting of hearing aids in each ear. As more specific information about the hearing loss is obtained, the hearing aids will be adjusted. Cochlear implantation can occur in one or both ears. A member of a cochlear implant team adjusts the cochlear implant. The audiologist will perform tests with the hearing aids or cochlear implant on your child to further confirm the benefit of these adjustments.

### **How Often do We Need to Adjust Hearing Aids?**

Up to age three, hearing and amplification equipment should be monitored at least **every three months**. Children under the age of 6 months will require more frequent monitoring to replace earmolds as the child grows. During the preschool years (ages 3-5) audiological evaluations should occur **every six months** unless changes in responses indicate a need for an earlier check-up.

### **How do I Troubleshoot Hearing Aids?**

Not surprisingly, hearing aids on children require daily maintenance by the adults in the child's life. The most common problems are the battery dies, moisture gets into the hearing aid, earmolds get clogged with wax, earmolds are outgrown, or the case of the hearing aid cracks. When any of these problems occur, the child is not hearing as well as he or she should. Parents should be sure to check with the audiologist for information and a demonstration of how to troubleshoot their child's equipment. A free hearing aid listening kit is available through the audiologist for children receiving Early Steps services.

## How does a Hearing Aid Work?

Sounds are picked up by a microphone and carried to a signal processor (amplifier) where they are made louder and shaped to match the hearing loss. The sound is then sent through the receiver and delivered by the earmold into the ear.

**Earmold:** a soft plastic custom-made piece that seals the ear to prevent sound leakage that causes feedback (whistling).

**Tubing:** connects the earmold to the hearing aid. It is securely attached to the earmold and is detachable from the ear hook. It can be replaced if torn, cracked, or too small.

**Earhook:** hard plastic hook that supports the hearing aid on top of the ear; protects the receiver, and channels sound to the earmold. May have a filter to further shape the sound for the hearing loss. It can be replaced if cracked or chewed.

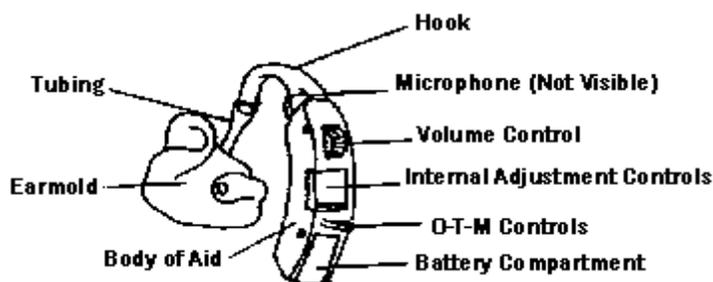
**Receiver:** sound speaker inside the hearing aid that opens into the earhook.

**Microphone:** collects sound for amplification through a small opening in the hearing aid case.

**Switch:** used to turn hearing aid on and off. Usually O = off; T = telephone or FM system, MT = hearing aid microphone and FM system; M = microphone picking up sound around the hearing aid.

**Volume control:** usually a numbered wheel that changes the loudness of the sound. Typically the smaller the number the lower the volume. Some hearing aids have automatic volume adjustments instead and no volume wheel.

**Battery Door:** holds the battery, which is changed every 1-2 weeks, depending on power needed and number of hours the child wears the hearing aid. Opening the door will turn off the hearing aid. Batteries are TOXIC if swallowed and tamper resistant doors are required for young children.



Hearing aid batteries are poisonous and should not be placed in areas where young children can reach them. If they are swallowed, call either the **National Poison Hotline (800) 222-1222**.

## How Does a Cochlear Implant Work?

A cochlear implant is a device that has two sets of components, external (those worn on the outside) and internal (those that are surgically implanted in the skull). The external components include a behind the ear microphone, a body-worn speech processor, and a transmitter worn on the scalp behind the ear. The internal components consist of a receiver, a magnet anchored under the skin behind the ear, and wire electrodes set in the cochlea of the ear. In some newer models, the speech processor and transmitter have been combined into one unit and can be worn at ear-level (looks like a BTE hearing aid).

The cochlear implant receives sound waves through the external microphone and changes them into specially coded electrical energy in the speech processor. That signal is transmitted to the internal electrodes that stimulate the auditory nerve and sends a signal to the brain. A specially trained otolaryngologist conducts cochlear implant surgery at a specially designated hospital. After the surgery and short recovery period (one month), the implant is set (mapped) for the specific child. The mapping must be repeated on a regular basis to ensure that the child is hearing properly. Children with cochlear implants are evaluated and managed by pediatric audiologists trained in cochlear implant mapping and management.

1. The microphone of the speech processor receives sound.
2. The sound is analyzed, digitized and coded into a signal.
3. Coded signals are sent to the transmitter.
4. The transmitter sends the code across the skin to the internal implant where it is converted to electronic signals.
5. Signals are sent to the electrode array to stimulate the nerve fibers in the cochlea.
6. Signals travel to the brain where they are recognized as sounds that produce a hearing sensation.



## What are the Different Types of Hearing Aids?

**Behind the Ear Hearing Aids (BTE):** This unit has all the components of the hearing aid encased in a device that fits behind the ear. The signal is delivered to the ear by an earmold. The BTE hearing aid is the most common hearing aid recommended for young children.

**In The Ear (ITE):** These hearing aids are hard shelled and custom molded to fit in the bowl of the ear. Young children have ears that are too small for these hearing aids and their rate of growth would require frequent hearing aid recasing, leaving them without hearing aids for frequent intervals.

**In The Canal (ITC):** These hearing aids are hard shelled and custom molded to fit in the canal portion of the ear. They extend slightly out of the opening of the ear canal and are smaller than ITE aids. Again, young children have ears that are too small for these hearing aids and their rate of growth would require frequent hearing aid recasing, leaving them without hearing aids for frequent intervals.

**Bone Conduction Hearing Aids:** A specially adapted version of a behind-the-ear style of hearing aid. Children with a conductive hearing loss and/or malformed or missing outer ears that cannot be medically or surgically corrected use bone conduction hearing aids that typically consist of a small vibrator attached to a headband worn by the child.

**Transposition Hearing Aids:** This is a specialized hearing aid that takes high frequency (pitch) sounds and shifts them into the low frequency range of hearing so that they are audible to the person with residual hearing in only the low and mid frequency range. In this manner all of the speech sounds are represented audibly, although they would not sound normal to a person with hearing in the normal range.

**Vibro-Tactile Hearing Aids:** Frequently used as a way for children with little or no residual hearing to become aware that sound/speech is occurring around them. Some vibro-tactile aids have various sensors that relay high versus low pitch information.

### **How do I Keep Hearing Aids in Place?**

If you are having a problem with this, be sure to mention this to your audiologist right away. There are simple adjustments that can be made in the placement or length of tubing or in parts of the earpiece that may help. In addition, there are several devices that may help keep the hearing aids securely on your child's ear. One of these is a product called "Huggies." Another solution is to use double-sided cloth tape or toupee tape (check to be sure the tape does not irritate your child's skin). Some parents have found it useful to tie a small piece of dental floss from the child's hearing aid to a safety pin which is attached to the back of the child's shirt. This way, if the aid comes out of the child's ear, it will still be attached and the expensive hearing aid will not be lost. A website that has useful information is <http://www.listen-up.org/aids-out.htm>.

### **How Often do Ear Molds Need to be Remade?**

Young children's bodies, including their ears, grow at an incredibly fast rate and earmolds will need to be replaced quite often. There may be a need to remake the earmolds as often as every 3-6 weeks when a child is very young. As the child matures, his or her growth rate slows and the earmolds need to be remade less often. Earmolds must fit tightly in the ear or feedback (high pitch squealing) will occur. Although turning down the volume of the hearing aids reduces the feedback for a few days, it also reduces the strength of the speech signal the child hears. At the first notice of squealing, the parent needs to call the audiologist to schedule a time to make new earmold impressions. Once the impressions are made, it takes approximately 1-2 weeks for the earmold lab to make the actual earmolds. Waiting to have the earmolds remade can result in weeks of squealing hearing aids, or hearing aids with the volume turned down low. Early Steps can authorize monthly hearing aid follow up checks with the audiologist when a child is under a year old and every other month when he or she is 1-3 years old. The best way to deal with squealing hearing aids is to prevent the squealing from happening!

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## **What Other Devices Might be an Option for my Child?**

### **FM System Hearing Technology**

Children who use hearing aids will have much greater difficulty hearing speech in the presence of background noise or when the speaker is at a distance greater than one - three feet away. For these situations, a wireless FM system may be recommended. An FM system has two primary components, the amplifier/receiver worn by the child and the microphone/transmitter worn by the speaker. The FM system is designed to amplify the signal from the microphone/transmitter so that it is louder than the signal received by the receiver/ microphone. In this way, speech from the speaker is always louder than any background noise that the child is hearing. Some children may use the FM system as the primary form of amplification while others may use it only in settings that are particularly noisy.

Even if an FM is used as the primary amplification, children should have time during the day when they listen through the environmental microphones rather than the FM microphone so they can develop sound localization skills. Early Steps can authorize an FM receiver for one ear and a microphone/transmitter. It is typical to do a trial period using the FM system for a few weeks to determine its benefit to the child and frequency of use by the family or other caregivers.

### **Telephone Amplifier**

This type of assistive listening device makes the telephone signal louder and may be used with or without a hearing aid.

### **Closed Captioning**

This assistive device is either attached to a television or built into a television to provide written text of the spoken words.

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## WHAT SHOULD I EXPECT?

### Setting Reasonable Expectations about Hearing Aid Wear

#### How much should my child wear his hearing aids at first?

- During the first few days of use, put the hearing aids on your child 3-4 times a day for 15 - 30 minutes each time.
  - If meals are one of your child's favorite times, put the hearing aids on as you feed him.
  - During other periods of hearing aid use, play with favorite toys, look at books, or sing nursery rhymes.
  - Your child will be distracted by these activities from the feeling of something new in his ears. He will be hearing your voice at the same time.
- Each day, increase the length of each period of use until the periods blend together and the child is wearing the aids full time during his waking hours. Your child should not wear his aids while he is sleeping.
- Talk with your audiologist and early intervention specialist to **set a date** by which your child will be using hearing aids full time.
  - One rule of thumb is: Full-time use during the child's waking hours **within three weeks of the initial fitting.**
  - *The sooner you establish full-time use of hearing aids, the sooner the child will be able to rely on hearing as a way of getting information.*
  - You can establish a schedule: First thing in the morning (or after a nap) we get you dressed, put your hearing aids on and have some breakfast (snack).

**"If your baby wears hearing aids only four hours each day, it will take six years to give him as much listening experience as a normally hearing infant accumulates in one year."**

(Stovall, D. [1982]. *Teaching Speech to Hearing Impaired Infants and Children*. Springfield, IL: Charles C. Thomas.)

#### What should I expect to see in the way of his response to sounds?

Your child's age at the time hearing aids are first placed, the degree of his/her hearing loss, and the amount of amplification provided are all factors which will affect how your child responds to sounds when he first begins wearing hearing aids. Ask your specialist and audiologist how they think your child might respond to sounds.

#### Here are some descriptions of behaviors you may see.

When you first put hearing aids on, some young children become very still as they hear voices for the first time. They do not know what voice is or what it means, but if they see their parents smiling at them and moving their mouths as this sound is occurring, they may be reassured that they are safe! Some children begin crying as the hearing aids are placed, so the first sound they hear is their own cry (though they don't know that's what it is). Some children are startled by this noise and stop crying to listen!

**As you put the hearing aids on your child at home, you may see one or more of the following responses.**

- A baby up to the age of 5 - 6 months may startle to sounds or show surprise when a sound occurs by widening his eyes, starting to cry, stilling, ceasing crying or movement.
- A child older than six months may look up when a sound occurs then may look around. He has no idea what made the sound or what it means, but it is an unusual event for him if he is hearing for the first time. Be sure you show the child what is making the sound and repeat the sound. It is very important that the child start learning that sounds mean something or he may stop responding to them.
- A child with a profound hearing loss may receive sound at very soft levels. He may not give much indication that he is hearing, since he has not yet learned to listen for these
- soft sounds. Talk in normal tones within 6-12 inches of this child's hearing aids about things he is doing or seeing. Use lots of intonation in your voice; play with animals and vocalize the sounds they make. Use the gesture of pointing to your ear and then to his ear to indicate that, yes, he *is* hearing something, however faint.

**What if he cries or pulls the hearing aids out?**

- Working through the child's resistance to having the hearing aids put on takes courage! *You must be convinced that the benefits the child will get from wearing hearing aids will outweigh the child's discomfort in adjusting to something new.* Your child does not yet know that the hearing aids will bring him sound. Talk and laugh with your child as you put the aids on - surely this can't be all bad if Mom is smiling and joking!
- The caregiver must be the one who makes the decisions about when the child's hearing aids are removed. When the child takes an aid off, calmly replace it and distract him with a toy or game. If it is close to the time when you would be removing his aids, play with him for at least five minutes before doing so, then tell him, "Time to take your hearing aids off."
- Remove the hearing aids without a lot of fanfare. Do not associate removal of the aids with expressions of relief or happiness.
- A normally hearing baby listens for about 10 hours a day, 365 days a year. That adds up to 3,650 listening hours per year!
- A normally hearing toddler or preschooler listens about 12 hours per day 365 days per year. That adds up to 4,380 listening hours per year.
- If a toddler or preschooler only wears amplification only at preschool (about 2.75 hours a day) it would take 9 years for the child to have as much listening experience as a hearing preschooler or a preschooler with hearing loss that wears amplification all waking hours (12 hours).

**The day your child begins wearing hearing aids  
is the day you start helping him overcome  
some of the challenges created by hearing impairment.**

Excerpts of What Should I Expect have been reprinted with permission from *For Families Guidebook* (1997), Hearing & Speech Institute, Portland Or, and Talk Around the Clock, AG Bell Association for Deaf and Hard of Hearing (2003) (Reproducible materials for families.)

**What is the Relay Service?****CALL 1-800-955-8771**

Telecommunications relay service provides full telephone accessibility to people who are deaf, hard of hearing or speech disabled. Specially trained Communication Assistants (CAs) complete all calls and stay on-line to relay messages either electronically over a Text Telephone (TT/TTY) or verbally to hearing parties. The toll free access number is 1-800-955-8771.

The service is available 24 hours a day, 365 days a year, with no restrictions on the length or number of calls placed. This valuable communications tool gives all individuals who are deaf, hard of hearing or speech disabled the opportunity to make personal and business calls just like any other telephone user. Both TT/TTY and voice users may initiate calls through the Relay Service. The person who cannot speak or listen on the phone needs to have a TTY.

Relay calls made in the Florida Relay System are strictly confidential. All calls will be kept private, and no records of any conversation will be maintained.

**Who is Florida Telecommunications Relay Inc.?**

Florida Telecommunications Relay Inc. (FTRI) is a not-for-profit organization that provides specialized telecommunications equipment for Florida residents who are Deaf, Hard of Hearing, Deaf/Blind and Speech-Impaired *at no charge*. Specialized telephones and ring signaling devices can help friends or family members who have difficulty communicating over the telephone.

1. Fill out an FTRI application.
2. Have the application certified by a licensed professional (physician, audiologist, hearing-aid specialist, speech pathologist, etc).
3. Return application to FTRI, or visit one of our 35 regional locations statewide.

**How do you qualify for the Program?**

1. Be a Florida resident.
2. Be 3 years of age or older to receive equipment.
3. Be certified as having a hearing or speech-impairment.

**How much will this cost?*****ABSOLUTLY NOTHING!!***

- **No cost** for any of FTRI's equipment.
- No charge to use Florida Relay 711.
- Keep the equipment for as long as the individual needs it.

**How can we take advantage of this statewide program?**

Call FTRI 1-888-292-1950 ext. 232, or visit us online at [www.ftri.org](http://www.ftri.org)

# PARENTING



All children need three types of inner resources if they are to become adults with self-discipline:

1. Good feelings about themselves and others;
2. An understanding of right and wrong; and
3. Alternatives for solving problems.

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## **Twelve Strategies for Raising Children Who will Be Self-Disciplined and Responsible Adults:**

### **1. Express Love**

Expressions of love can head off undesirable behavior. When a child feels loved, he or she wants to please his or her 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 game or special time with mom or dad.

### **2. Be Predictable**

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

### **3. Communicate Clearly**

Make sure your words and actions are sending the same message. 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 hearing loss, acknowledge the need to purposefully develop strategies to close the gap. With a child who has hearing loss, consider creating a routine way to make sure your message was understood as intended. Have him or her repeat back what was understood. Role-play to teach productive, appropriate questioning techniques that will be essential at home, at school, and throughout the child’s environment.

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

By being a good observer, you can gather information that will help you understand what your 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 and lashing out? Does he or she feel threatened, hurried or ignored? Is your child seeking attention in an unappealing way? Is he or she having trouble expressing himself or herself and projecting his or her 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 like. This makes it easy to neglect opportunities to praise good behavior and instead 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 that antique vase.”

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

Children love to explore and thrive in environments where things can be pulled on, climbed over, taken apart and put back together again (maybe). This isn't being naughty, this is their nature. Make their environment safe. The more appropriate things there are available to explore, the fewer problems with inappropriate behavior a child 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.

## **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. 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, he or she should be rewarded with certain privileges. If he or she demonstrates 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 children with hearing loss, not being understood because of a communication difference or understanding gap is a common occurrence, and one that lends itself to frustration and anger. Anticipate these kinds of circumstances. Parents can often 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 why. 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 children who can express themselves and think abstractly, ask them what they could do next time that would be better. Suggest additional alternatives. As children get older and mature, they will be able to employ these tactics more successfully if they have had practice since childhood.

If a problem stems from communication gaps, which is often true for children with hearing loss, use the same strategies and exploit every opportunity to expand the child's language base around conflict resolution. Knowing how to express thoughts and feeling and state his or her 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 another set of problems. Telling your child to go to a time out place or removing him or her from the play area where he or she misbehaved, delivers a consequence for bad behavior without drawing attention to the activity.

**11. Seek Professional Help When Needed**

Most children grow out of common behavioral problems with the patient guidance of parents and other caring adults. But for a small percentage, 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. And a key to the healthy psychological development lies in the child's ability to do just that. If you follow all 12 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 a mature adult.

*Excerpted and adapted by Leanne Seaver, Colorado Hands & Voices, from Thelma Harms Ph.D., University of North Carolina, Chapel Hill*

# ADVOCATE FOR YOUR CHILD



There is so much to do when you learn that your child has a hearing loss. Your child should be fit quickly with amplification. You need to work with your insurance company to cover the new medical expenses. Advocating for your child's needs takes energy and dedication. It can be discouraging when things don't seem to be going well and thrilling when you finally achieve what you set out to do.

- ***The Law***
  - ***IDEA***
  - ***Part C***
  - ***Part B***
  - ***Section 504***
  - ***ADA***

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## **The Law**

### ***Parents are advocates for their children who are hard of hearing or deaf.***

As a parent, you have the right to expect professionals to treat your concerns seriously and respectfully. It is your right to decide what is best for your child and to participate in decisions regarding him or her. You do not have to accept what a professional or school district offers if it is not what you want for your child. You may advocate for something else. This will involve writing letters, making phone calls, recruiting professional support and attending meetings. Advocacy is hard work. You are the best advocate for your child throughout his or her school years.

There have been many forms of legislation passed that specify services and rights for individuals who are hard of hearing or deaf. As a parent, you must know your rights.

### **Individuals with Disabilities Education Act (IDEA)**

This law requires that all children be given a free, appropriate public education with meaningful access to the general curriculum. This includes high expectations and standards.

### **Part C of the Individuals with Disabilities Education Act**

Part C regulates services for infants and toddlers from birth to three years of age. This section of the law refers to services occurring in natural environments. The natural environment is the community in which the child and family participate. For children with hearing loss, the natural environment can be defined as a language rich environment in which the child can effectively communicate.

There are occasions when children must receive services outside of the community or home setting. These clinical services should be one component of a comprehensive program that also includes opportunities for the child to participate in intervention in the natural environment (e.g. home, grandma's house, child care).

Another essential component of Part C of the IDEA is the focus on families and their right to make decisions regarding what is best for their child. Families are guided through this decision making process. Parents are encouraged to choose the program that they feel is the best match for their family.

### **Part B of the Individuals with Disabilities Education Act**

Part B regulates individualized special education services for children ages 3-21. At least six months prior to your child's third birthday, the Florida Early Steps program will make a formal referral to the local school district. This will initiate the process of determining if your child will be eligible to receive services as a special education student when he or she turns three years old.

Eligibility for special education services is based on two issues. First, if it is determined that your child's hearing loss significantly affects his or her ability to learn and second that he or she will require some specially designed instruction. Your child will be eligible for services from the local school district on his or her third birthday. The Florida Early

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Steps program will work with you and the school district to plan for the transition to school services. The transition plan identifies the activities needed to develop an appropriate program for your child. This program showing the services and supports for your child is described in a document called an Individualized Educational Plan or IEP. Some items that should be included in the IEP are:

- Need for equipment (e.g., FM system so child can access teacher instruction at a distance greater than 3 feet or in the presence of typical levels of classroom noise)
- The classroom acoustics (open plan schools, classrooms with noisy ventilation systems, or adjacent to noisy activities. These typically prevent access of the child who is hard of hearing to verbal instruction, even when using an FM system)
- The philosophy of the program (i.e., auditory-oral, total communication)
- Staffing
- Training needs for staff and therapists
- Levels of support needed
- Interaction with peers including children who have and do not have hearing loss

### **Section 504 of the Rehabilitation Act of 1973**

This ensures that all people with disabilities receive special accommodations or services in the classroom to provide equal access to classroom instruction. Even if you are not eligible under Part B, schools may still need to provide accommodations under Section 504 of the Rehabilitation Act of 1973.

### **Americans with Disabilities Act of 1990 (ADA)**

This ensures that all people with handicaps have access to public events, spaces and opportunities. Families often find the ADA law supportive in determining accommodations for involvement in community resources such as childcare or recreational activities.

<p>If you have private insurance, you should check about the coverage for your child's needs including audiology testing, hearing aids, follow-up services, and speech/language/auditory therapy. It may be necessary for you to educate insurance companies and/or your employer in order to obtain coverage for your child's needs.</p>
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# CONCLUSION



Families with young children, who have a hearing loss, will receive much information and be asked to make many decisions. You have many choices. Your team of professionals can help guide you through this decision-making period and provide support for your family. **Remember that you know what is best for your child and family.**

Early Steps – Florida’s Early Intervention Program works with families to develop services that meet the unique needs of each child and family. Working early with children helps them learn and develop. Early Steps provides families with ways to help their child so they are ready to learn when they enter school. Early Steps includes the family’s concerns and priorities, and assists families plan for the future.

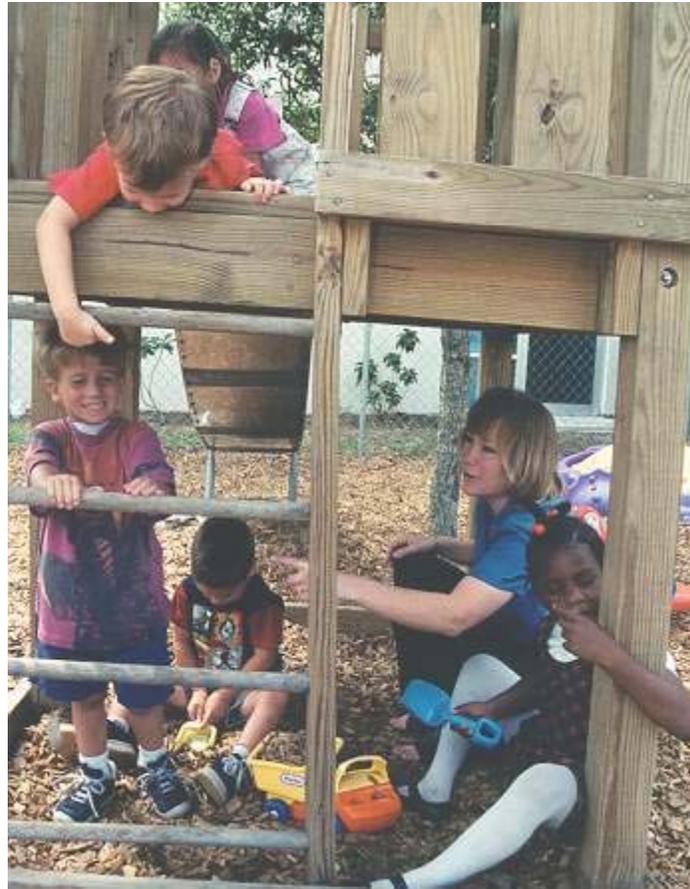
Families who find out their baby has hearing loss early and get help as soon as possible can help prevent language delays. You will discover that you and your family play the most important role in helping your child learn.

It is important to have your child’s vision screened. Children with hearing loss have a greater chance of having vision loss. It is recommended that your child have an ophthalmologic examination regularly. Vision is important for all children with hearing loss since many use their eyes to help understand their world.

The first months after the hearing loss is diagnosed is a time when much information is shared. There are many methods of communicating with a young child with hearing loss. People who believe one method is better than another may be passionate about this belief. It is important for families to talk with professionals and people in the hard of hearing or deaf community. This will help you with making decisions for your child.

Regular monitoring of your child’s communication you will show you how your child’s language is developing. This information helps you make communication method changes to further help your child.

# DEFINITIONS



There is a lot to learn about hearing loss. This section should help you learn the new words that you will see and hear. The world of hearing loss is filled with unfamiliar phrases and words.

**ABR / AUDITORY BRAINSTEM RESPONSE / ASSR / AUDITORY STEADY STATE RESPONSE** – *An objective, non-invasive test that measures responses to auditory stimuli by the synchronous discharge of neurons in the auditory nerve and brainstem. This test can indicate whether or not sound is being detected in the brain, even in an infant.*

**ACOUSTIC FEEDBACK** – *Whistle or squeal caused when amplified sound recycles through the microphone of an amplifying system, such as a public address system or a hearing aid.*

**ACOUSTICS** – *Pertaining to sound, the sense of hearing or the science of sound. Often used to refer to the quality of the listening environment.*

**ACQUIRED HEARING LOSS / LATE ONSET / PROGRESSIVE HEARING LOSS** – *Hearing loss, which is not present at birth.*

**ADVOCACY** – *Refers to the role parents or guardians play in developing and monitoring their child's educational program. Advocating for your child means knowing what rights are assured you by the law and actively participating in the decision-making process to ensure that the services are delivered according to your goals for your child's development and education.*

**AMBIENT NOISE** – *Background noise, which competes with the main speech signal.*

**AMERICAN SIGN LANGUAGE (ASL)** – *A language that is communicated by sign, expressions, and gestures, rather than by spoken speech. ASL is a language of its own, not related to written or spoken English. It has a unique grammar and syntax.*

**AMPLIFICATION** – *The use of hearing aids and other electronic devices to increase the loudness of sound so that it may be more easily perceived and understood.*

**ASSISTIVE LISTENING DEVICE (ALD)** – *Any type of electronic aid to hearing including personal hearing aids, FM systems, special inputs for telephones or televisions, and amplified alarms and signals that are available to help deaf and hard of hearing people improve communication, adapt to their environment, and function in society more effectively.*

**ATONAL** – *Voice quality that lacks inflection, modulation, musical tonality or harmonics.*

**AUDIOGRAM** – *A graph on which a person's ability to detect different pitches (frequencies) at different volumes (intensities) of sound is recorded.*

**AUDIOLOGICAL ASSESSMENT / AUDIOLOGIC EVALUATION** – *A hearing test conducted by an audiologist to discover how well your child hears at different frequencies (pitches), along with recommendations for whether or not additional actions are indicated.*

**AUDIOLOGIST** – *A professional who holds a graduate degree and professional certification in the assessment and management of hearing loss and balance disorders. Audiologists fit and dispense hearing aids and other listening devices.*

**AUDITORY-ORAL** – *Teaches children to listen and speak by maximizing residual hearing and using audition as the main channel of acquiring speech and language. These children go through intensive intervention, to develop natural language and age appropriate academic skills, and to grow up to become independent, contributing members of society.*

**AUDITORY TRAINING** – *Training a person’s residual hearing in the awareness, identification, and interpretation of sound. This usually involves both the help of technology (a hearing aid or cochlear implant) and training to recognize and interpret sound correctly.*

**AUDITORY-VERBAL** – *The auditory-verbal philosophy supports the right of children with all degrees of hearing loss to develop the ability to listen and communicate using spoken language. Individualized therapy uses parents as primary facilitators for language development. The goal is that children with a hearing loss grow up in regular learning and living environments and that they become independent, contributing citizens. The Auditory-Verbal Therapist is a qualified educator of children with hearing loss, an audiologist and/or a speech language pathologist who supports the principles of the Auditory-Verbal approach.*

**AURAL (RE) HABILITATION** – *Training designed to help persons who have lost their hearing or children who have a prelingual hearing loss to learn to use residual hearing. The training may include auditory skill development, speechreading, language development and counseling for psychosocial adjustment for individuals and families.*

**BEHAVIORAL OBSERVATION AUDIOMETRY** – *Assessment of a young child’s response to sound by observing specific behaviors when sounds are presented in a sound suite.*

**BILINGUAL / BICULTURAL** – *Being fluent in two languages and membership in two cultures such as hearing (spoken language) and the Deaf culture (American Sign Language).*

**BILATERAL HEARING LOSS** – *A mild to profound hearing loss in both ears.*

**BODY AID** – *An amplification unit that is worn on the body with cords leading to earmolds. It provides increased gain (power) and less feedback for people with a severe to profound hearing loss. Primarily used only in special situations where ear-level hearing aids cannot be used.*

**BONE CONDUCTION** – *Sound received through the bones of the skull. Bone conduction hearing testing bypasses the outer and middle ear and directly stimulates the cochlea by passing sound vibrations through the skull bone.*

**CHRONOLOGICAL AGE / ADJUSTED AGE** – *Chronological age is the age of the child based on his/her date of birth. It is referred to when comparing him or her to other children born at that same time. If a baby is born prematurely his/her development may be measured at his/her adjusted age. Adjusted age takes into account the time between premature birth and the actual due date of a full term pregnancy. Doing this gives a truer reflection of what the baby’s developmental progress should be. Adjusted hearing age refers to how long a child has been amplified and relates to expectations on auditory and speech skill development.*

**COCHLEAR IMPLANT** - *An electronic device surgically implanted to stimulate nerve endings in the inner ear (cochlea) in order to receive and process sound and speech for persons with severe to profound hearing loss. Children can be implanted as young as one year of age.*

**COGNITIVE** – *Refers to the ability to think, learn and remember.*

**CONDITIONED PLAY AUDIOMETRY** – (CPA) – *The audiologist helps the child understand the rules for playing a game based on a conditioned response to sound. For example, when the child is presented with a sound he or she is to drop a block into a container, indicating that the sound was heard. Generally used when the child is at least 18 months old.*

**CONDUCTIVE HEARING LOSS** – *Failure of sound waves to reach the inner ear through the normal air conduction channels of the outer and middle ear. In children, conductive loss is typically medically correctable, and is most often associated with otitis media.*

**CONGENITAL HEARING LOSS** – *Hearing loss present at birth or associated with the birth process, or which develops in the first few days of life.*

**CONTENT** – *Refers to vocabulary. Children may understand everyday words such as cup and shoe, but not understand a larger, more sophisticated number of words such as glass, tumbler, sippy cup, boot, slipper or cleats.*

**CUED SPEECH** – *An oral system that uses hand shapes to clarify lipreading in spoken language. Cued speech gives the person with hearing loss additional clues about the sound the speaker is making, but is not a language in itself (such as ASL).*

**DEAF** – *A hearing loss, which is so severe that a child is unable to process information through hearing alone.*

**DEAF COMMUNITY** – *A group of people who share common interests and a common heritage. Their mode of communication is American Sign Language (ASL). The Deaf community is comprised of people who are both deaf and hearing.*

**DEAF CULTURE** - *A view of life manifested by the mores, beliefs, artistic expression, understandings and language (ASL) particular to Deaf people. A capital “D” is often used in the word Deaf when it refers to community or cultural aspects of deafness.*

**DECIBEL: (dB)** – *A measure of sound intensity. The higher the decibel level, the louder a sound will be perceived. The normal range of hearing is from 0 dB (the faintest sounds) to 120 dB (the threshold of discomfort). Hearing loss is present when detection of sound does not occur until sounds are louder than 16 dB*

**DECODER** – *An electronic device or computer chip that can display closed captions encoded in television programs or videocassettes. Also called a telecaption adapter.*

**DETECTION** – *Ability to sense the presence or absence of sound. It is the most basic hearing skill.*

**EARMOLD** – *A custom made plastic or vinyl ear insert that channels sound reproduced by the hearing aid or FM system through the ear canal.*

**EDUCATIONAL INTERPRETER** – *A person who is able to perform conventional interpreting, together with special skills for working in the educational environment.*

**ELIGIBILITY** – *A child must be determined eligible for special education services, based on specific hearing loss criteria and an exhibited delay in one or more of the following areas: cognitive ability, motor skills, social/adaptive behavior, perceptual skills, and communication skills.*

**ENT** – *A medical doctor, who specializes in the ears, nose and throat. Sometimes referred to as an Otolaryngologist or an Otologist.*

**EXPRESSIVE LANGUAGE** – *How a person is able to share ideas or feelings.*

**INDIVIDUALIZED FAMILY SUPPORT PLAN (IFSP)** – *Addresses: 1) the family’s strengths, needs, concerns and priorities and 2) identifies support services available to meet need. It is a written plan developed by parents or guardians with input from a multi-disciplinary team. Refer to Part C.*

**FAMILY RESOURCE SPECIALIST (FRS)** – *Individuals employed by the local Early Intervention (EI) program who assist families of children in the early intervention system with information and support, as well as serving as a community link to support family centered efforts and activities within local EI programs.*

**FINGERSPELLING** – *A standardized series of handshapes to spell out words. Each letter has its own particular shape. Usually it is used when there is no sign for a particular word.*

**FM SYSTEM** – *Assistive listening device where a microphone transmitter is worn by the speaker to transmit his voice directly to the listener’s ears. The device reduces background noise interference and the problem of distance between the speaker and the listener with hearing loss.*

**FORM** – *How words are put together to make sentences.*

**FREQUENCY** – *The number of vibrations per second of a sound. Frequency, expressed in Hertz (Hz), determines the pitch of the sound.*

**GAIN** – *The range that describes how well the amplification is performing. For example, a child with unaided hearing at 70 dB hearing loss who, when amplified, hears at 30 dB hearing loss, is experiencing a gain of 40 dB.*

**GENETIC COUNSELING** – *Counseling for individuals with birth defect/genetic disorders. Approximately 50% of congenital hearing loss is due to genetic factors.*

**HARD OF HEARING / HEARING IMPAIRED** - *Hearing loss severe enough to interfere with school or work. Hard of hearing people can typically process speech and language quite well with the help of an auditory device, such as a hearing aid.*

**HEARING AID** – *An electronic device that conducts sound to provide amplification of a person’s residual hearing.*

**HEARING AID SPECIALISTS** – *A person who sells and services hearing aids. While licensed to provide these services, only Clinical Audiologists are specially trained to evaluate and fit hearing aids on infants and toddlers.*

**HEARING LOSS** – *The following hearing levels for children are typically characterized as follows:*

<i>Normal Hearing</i>	<i>0 dB to 15 dB</i>
<i>Minimal loss</i>	<i>16 dB to 25 dB</i>
<i>Mild loss</i>	<i>26 dB to 40 dB</i>
<i>Moderate loss</i>	<i>41 dB to 55 dB</i>
<i>Moderate/Severe loss</i>	<i>56 dB to 70 dB</i>
<i>Severe loss</i>	<i>71 dB to 90 dB</i>
<i>Profound loss</i>	<i>91 dB or more</i>

**HEARING SCREENING** – *Screening provides a yes/no answer to the question, “Does this individual have detectable hearing loss of at least a certain degree at selected pitches (frequencies)?” Persons who fail a screening require further hearing testing to determine if a hearing problem exists.*

**HEARING SPECIALIST** – *A professional who works for Early Steps with special training in providing early intervention services to families of infants and toddlers with hearing loss.*

**HERTZ (Hz)** – *The measurement of frequency, or cycles per second (CPS), of sound waves.*

**HUGGIES** – *A plastic-ringed device designed to “hug” the hearing aid to the ear. Popular for infants and toddlers whose ears may be too small to hold the hearing aid snugly in place.*

**I.D.E.A.** – *The Individuals with Disabilities Education Act, Public Law PL 105-17, formerly known as 101-476, PL 94-142 and PL 99-457, provides for specialized instruction for individuals with disabilities that meet eligibility requirements, typically evidence that the disability is causing adverse educational effects. Part C (See “Part C”) provides services to children birth to three years of age with disabilities.*

**INCLUSION** – *Refers to the concept that students with disabilities should be integrated and included to the maximum extent possible with their (typically developing) peers in the educational setting. Often used synonymously with the term “mainstreaming”.*

**INDIVIDUALIZED EDUCATION PLAN (IEP)** – *A team-developed, written plan, which identifies goals and objectives that address the educational needs of a student aged 3-21 with a disability. An IEP for a child with hearing loss should take into account such factors as 1) communication needs and the child’s and family’s preferred mode of communication 2) linguistic needs; 3) academic progress, 4) social, emotional needs; and 5) appropriate accommodations required to provide full access in the learning environment.*

**INTENSITY** – *The loudness of a sound, measured in decibels (dB).*

**INTERPRETER** – *A person who facilitates communication between hearing people and people with a hearing loss through interpretation into an American sign language, Manually coded English or transliteration into a visual and/or phonemic code by an oral interpreter, a signed language interpreter or cued speech transliterator.*

**INTONATION** – *The aspect of speech made up of changes in stress and pitch in the voice.*

**LEAST RESTRICTIVE ENVIRONMENT** – *A basic principle of Public Law 101-476 (IDEA) which requires public agencies to establish procedures to ensure children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. For children with hearing loss, least restrictive environment should reflect a language rich environment in which a child can have the greatest access to instruction and peer communication.*

**MAINSTREAMING** – *Integrating students with hearing loss in classrooms with normally hearing students as much as possible. The term is used synonymously with “inclusion”.*

**MONAURAL AMPLIFICATION** – *The use of one hearing aid instead of two.*

**MORPHEME** – *A linguistic unit of relatively stable meaning that cannot be divided into smaller meaningful parts.*

**MULTI-DISCIPLINARY ASSESSMENT AND EVALUATION** – *Qualified persons representing two or more disciplines or professions, i.e. a speech therapist and an audiologist make the assessment and evaluation of the child. The child's development is evaluated to determine if there are any delays or conditions that would indicate the need for special services.*

**NATIVE LANGUAGE** – *The language used in the home environment.*

**ORAL** – *A non-specific term that can be used when referring to individuals with hearing loss and deafness who have speech skills (may or may not use a sign system). Emphasis is placed on use of residual hearing, lip reading and contextual cues to communicate using spoken language.*

**ORAL DEAF EDUCATION** – *Based on the principle that most children who are deaf and hard-of-hearing can be taught to listen and speak with maximizing residual hearing and using audition as the main channel of acquiring speech and language. The goal is for these children to become independent, participating citizens in mainstream society.*

**OTITIS MEDIA** – *Fluid or infection developing behind the eardrum in the middle ear cavity. Children with recurring episodes may experience fluctuating hearing loss and may be at risk for speech and language delays. Fluid can be present with or without infection, and may cause temporary hearing loss, which can evolve into permanent loss.*

**OTOACOUSTIC EMISSIONS (OAE) TEST**– *An objective audiological test that verifies outer hair cell cochlear activity. Often is used in testing infants suspected of hearing loss. A probe is placed in the ear canal for this measurement. Middle ear effusion or children's movements can affect the accuracy of OAE tests.*

**OTOLARYNGOLOGIST** – *A physician who has advanced training in disorders of the ear, nose, throat, head, and neck.*

**OUTPUT** – *Refers to how much amplification is being put out by a hearing aid.*

**PARENT-INFANT PROGRAM** – *A program of family-centered education and infant intervention that stresses early exposure to language and attention to developmental processes which enhance learning language.*

**PART B** – *Part B is the section of Public Law PL 105-17 (I.D.E.A) that refers to early intervention services available to eligible children aged three to twenty-one in the public schools. These services are administered by the Florida Department of Education.*

**PART C** – *Part C is the section of Public Law PL 105-17 (I.D.E.A) that refers to early intervention services available to eligible children from birth through three years of age and their families. In Florida, the Department of Health, Children's Medical Services, Early Steps program administers Part C Services.*

**PITCH** – *The brain's interpretation of the physical frequency of sound waves.*

**POST-LINGUAL DEAFNESS** – *Hearing loss acquired after learning a first language.*

**PRAGMATICS** – *Refers to how we use the rules of speech in social situations. For example, children may not know how to start a conversation or may misunderstand that when someone asks a question, they expect an answer.*

**PRE-LINGUAL DEAFNESS** – *Refers to hearing loss, which is congenital or acquired before acquisition of language.*

**PURE-TONE** – *A tone or note that has only one frequency, with no harmonics or overtones. Pure tone detection thresholds are obtained during a hearing evaluation.*

**PURE-TONE AVERAGE** – *Average detection levels measured at 500, 1000, and 2000 Hz.*

**REAL-EAR MEASUREMENT** – *An audiological test that measures the actual output of the hearing aid in the ear canal. This test uses a “probe-microphone” that is placed into the ear canal along with the hearing aid and ear mold fitted in place. Real-ear measurements should be performed every time earmolds are replaced on a growing child.*

**RECEPTIVE LANGUAGE** – *Words or signs that a person understands.*

**RELAY TELEPHONE SERVICES** – *Relay Telephone Service/Relay Network is a service which involves an operator “relaying” conversation between a TDD/TTY user (generally a person with a hearing loss and/or speech impairment) and a hearing /speaking individual using an ordinary, non-adapted phone.*

**RESIDUAL HEARING** – *The amount of usable hearing that a person with hearing loss has.*

**SEMANTICS** – *The meaning-related aspects of language.*

**SENSORINEURAL** – *A type of hearing impairment caused by deformity or damage that occurs to the hair cells or other structures of the inner ear (cochlea) and/or nerve of hearing. Currently sensorineural damage to the hair cells of the cochlea is usually irreversible.*

**S.H.I.N.E.** – *The component of the Early Steps program that presents families with initial information about hearing loss, different methods of communication, and a choice of Hearing Specialist service providers.*

**SOUND FIELD** – *Hearing test term for an area or room in which sound waves are transmitted through a loudspeaker, in contrast to sounds that are delivered directly to the ear through earphones.*

**SPEECH AWARENESS THRESHOLD (SAT)** – *This is the faintest level at which an individual detects speech 50% of the time. This is indicated in an audiological test, with or without hearing aids.*

**SPEECH INTELLIGIBILITY** – *The ability to be understood when speaking.*

**SPEECH / LANGUAGE PATHOLOGIST (SLP)** – *A professional who works with individuals who have specific needs in the areas of speech and language.*

**SPEECHREADING** – *The interpretation of lip and mouth movements, facial expressions, gestures, prosodic and melodic aspects of speech, structural characteristics of language, and topical and contextual clues. Only 30-40% of speech sounds are visible on the lips and highly skilled speechreaders rely heavily on context and knowledge of language.*

**SPEECH RECEPTION THRESHOLDS (SRT)** – *This is the faintest level at which an individual identifies and repeats 50% of the simple spoken words presented by the audiologist (baseball, hot dog, high chair, airplane).*

**SPEECH SPECTRUM** – *The range of frequencies in which speech sounds are carried.*

**SPEECH ZONE (SPEECH BANANA)** – *On an audiological graph measured in decibels and frequencies, the area where most conversational sounds of spoken language can be detected in quiet at a distance of 2 meters. Sometimes called the “speech banana” because of the shape this area depicts on the graph. It is important that hearing aids amplify sound into this zone.*

**SYNTAX** – *Defines the word classes of language, i.e. noun, verbs, etc, and the rules for their combination, i.e. which words can combine and in what order to form sentences.*

**TACTILE AIDS** – *Assistive communication device that emits a vibration or “tactile” signal to indicate the presence of sound(s). It is worn on the body and triggers the sense of touch or feeling to draw attention to information that cannot be heard by the individual with hearing loss. The sense of touch cannot discriminate fine differences as effectively as hearing or vision senses.*

**TELECOMMUNICATIONS DEVICES FOR THE DEAF (TDD’S)** – *Originally and often still called TTY’s, these electronic devices allow the deaf and hard of hearing to communicate via a text telephone system.*

**THRESHOLD INFORMATION** – *This is the smallest intensity or loudness of sound the child can detect.*

**TOTAL COMMUNICATION** – *An educational philosophy that uses manual supports for spoken English. Sign, gestures, fingerspelling, facial expressions, and body language are used as needed for full and expressive communication.*

**TRANSLITERATOR** – *A person who facilitates communication between hearing people and people with a hearing loss through transliteration into a visual and/or phonemic code by a cued speech transliterator.*

**TYMPANOGRAM** – *It can show how the ear canal, eardrum, Eustachian tube, and middle ear bones are working together. It is not a hearing test. Tympanometry is useful in detecting the pressure of fluid or infection behind the eardrum.*

**UNILATERAL HEARING LOSS** – *A mild to profound hearing loss in one ear.*

**VISUAL REINFORCEMENT AUDIOMETRY (VRA)** – *Audiological assessment in which the child is conditioned to look at a toy that lights each time he or she hears a sound. Used with children at least 5-6 months developmental age and any child not able to be conditioned for play audiometry.*

# RESOURCES



- *Local Resources*
- *State Resources*
- *National Resources*
- *Websites*
- *Catalogs*
- *Books*
- *Videos*
- *Funding Sources*
- *Questionnaires*

## Local Resources

### Early Steps Program Coordinators

Each Early Steps program Coordinator serves in one of the sixteen regions throughout the state and assists families with receiving services specified in the Individualized Family Support Plan. The Early Steps Program Coordinator can also connect families with others who have children with hearing loss. For the most up to date listing of contact information refer to <http://www.cms-kids.com/ContactUs/EIPdir.pdf>.

#### **Western Panhandle**

##### **Joy McAfee – Director**

SACRED HEART HOSPITAL/Early Steps  
5150 BAYOU BLVD., SUITE 1-N  
PENSACOLA, FLORIDA 32503  
(850) 416-7656  
Fax: (850) 416-7348  
Email: [jmcafee@shhpens.org](mailto:jmcafee@shhpens.org)  
(Counties served: Escambia, Okaloosa, Santa Rosa, & Walton)

#### **Big Bend**

##### **Dynitia Brimm- Program Director for Tall.**

CHS/EARLY STEPS  
1801 MICCOSUKEE COMMONS DRIVE  
TALLAHASSEE, FL 32308  
(850) 921-0330  
Fax: (850) 921-0283  
Email: [dynitia.brimm@chsfl.org](mailto:dynitia.brimm@chsfl.org)

##### **Shelly Bear – Program Director for PC**

CHILDREN'S HOME SOCIETY  
914 HARRISON AVE  
PANAMA CITY, FLORIDA 32401  
(850) 747-5411  
Fax: (850) 747-5583  
Email: [shelly.bear@chsfl.org](mailto:shelly.bear@chsfl.org)  
(Counties served: Bay, Calhoun, Gulf, Holmes, Jackson, Washington, Franklin, Gadsden, Jefferson, Leon, Liberty, Madison, Taylor, & Wakulla)

#### **North Central**

##### **Dominique Fethiere-Coordinator**

##### **Fonda Davis-Eyler – Director**

##### **MaryLou Benhke – EIP Medical Director**

DEPARTMENT OF PEDIATRICS  
1600 S.W. ARCHER ROAD, RM. HD 119  
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Fax: (352) 392-7829, SC 625-1359  
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(Counties served: Alachua, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Marion, Suwannee, Union)

#### **Northeastern**

##### **Daniel Kurmaskie – Early Steps Director**

##### **Ann Milton – ES Program Coordinator**

910 NORTH JEFFERSON STREET  
JACKSONVILLE, FLORIDA 32209  
(904) 360-7022 ext. 272 Suncom: 826-7022  
**Fax: (904) 798-4545 or 4544**  
Email: [Daniel\\_Kurmaskie@doh.state.fl.us](mailto:Daniel_Kurmaskie@doh.state.fl.us)  
Email: [Ann\\_Milton@doh.state.fl.us](mailto:Ann_Milton@doh.state.fl.us)  
Counties served: Baker, Bradford, Clay, Duval, Nassau, & St. Johns)

#### **West Central**

##### **Louise Boothby-Llorente Ph. D.- Director**

**Mary Pavan, M.D. – Medical Director**  
ALL CHILDREN'S HOSPITAL  
CENTER FOR CHILD DEVELOPMENT  
801 Sixth Street South  
ST. PETERSBURG, FLORIDA 33701  
(727) 767-4403, 1-800-374-4334  
Fax: (727) 767-6727 or 4715  
Email: [LLorenteL@allkids.org](mailto:LLorenteL@allkids.org)  
(Counties served Citrus, Hernando, Pasco, Pinellas & Sumter)

#### **Bay Area**

##### **Carol Lilly, M.D. – Early Steps Medical Director**

##### **Annalise Campisi – Early Steps Core Coordinator**

##### **John Landi- Hillsborough ES Coordinator**

##### **Louise Solomon, RN – Polk Early Steps Coord.**

##### **Brenda Ham – Bay Area Data Custodian**

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**Louise Solomon, R.N., Program Coordinator**

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**Pat Grosz Ph D – Executive Director**

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**Central Florida****Lourdes Quintana – Early Steps Director**

CENTRAL FLORIDA EARLY STEPS  
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ORLANDO, FLORIDA 32805  
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Email: Lourdes.Quintana@orhs.org  
(Counties served: Orange, Osceola, & Seminole)

**North Beaches****Gayla Clark – Early Steps Coordinator**

CHILDREN'S ADVOCACY CENTER OF VOLUSIA  
AND FLAGLER COUNTIES, INC.  
421 SOUTH KEECH STREET  
DAYTONA BEACH, FLORIDA 32114-4623  
(386) 258-7434  
Fax: (386) 258-2283  
Email: gayla\_clark@doh.state.fl.us  
(Counties served: Flagler, Lake, Putnam, & Volusia)

**Space Coast****Althea Puzio – Early Steps Program Manager**

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1024 SOUTH FLORIDA AVENUE, SUITE A  
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(321) 634-3688 Suncom: 362-3688  
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**Southwest Florida****Joan Foss, Early Steps Program Director**

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(Counties served: Collier, Lee, Hendry, & Glades)

**Gulf Central****Eileen Welch, Early Steps Director**

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SYSTEM  
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(866) 510-5594  
Fax: 941-487-5430  
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Highlands, Manatee, & Sarasota)

**Treasure Coast****Wanda Baldwin, MSW – ES Coordinator**

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(County served: Palm Beach)

**Lori Shamroth-Carver, MS – Coordinator**

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**North Dade****Charles R. Bauer - Director**

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MIAMI, FLORIDA 33136  
(305) 243-6660  
Fax: (305) 243-3501  
Email: ematthews@med.miami.edu  
(County served: North Dade County)

**Gold Coast**

**Ellie Schrot – Early Steps Coordinator**  
 CHILDREN'S DIAGNOSTIC & TREATMENT  
 CENTER  
 1401 SOUTH FEDERAL HIGHWAY  
 FT. LAUDERDALE, FLORIDA 33316  
 (954) 728-1083  
 Fax: (954)779-2316  
 Email: eschrot@nbhd.org  
 (County served: Broward)

**Southernmost Coast**

**Ginger Henry - Director**  
 MIAMI CHILDREN'S HOSPITAL – South  
 Dade Center  
 17615 S.W. 97th AVENUE  
 PALMETTO BAY, FLORIDA 33157  
 (786) 268-2611  
 Fax: (786) 268-1748  
 Email: Ginger.Henry@mch.com

**Marie Severe – Operations Manager**  
 MIAMI CHILDREN'S HOSPITAL – S. Dade  
 Center  
 17615 S.W. 97<sup>TH</sup> AVENUE  
 PALMETTO BAY, FLORIDA 33157  
 (786) 268-2611  
 Email: Marie.Severe@mch.com  
 (County served: South Dade County)

**Southernmost Coast**

**Rob Porcaro – Monroe County Program  
 Director**  
 EASTER SEALS FLORIDA KEYS REGION  
 5220 COLLEGE ROAD  
 KEY WEST, FLORIDA 33040  
 (305) 294-1089 ext. 14  
 Fax: (305) 296-1530  
 E-mail: rporcaro@fl.easterseals.com  
 (County served: Monroe County)

**State Resources****AG Bell Florida**

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

*Florida chapter of the Alexander Graham Bell Association for the Deaf and Hard of Hearing, which advocates independence through listening and talking. Information and resources for parents and professionals.*

**CARD – Center for Autism and Related Disabilities-Tallahassee**

Florida State University  
 625-B North Adams St.  
 Tallahassee, FL 32301  
 850-644-4367 or 800-769-7926  
<http://autism.fsu.edu>

*Provides support and assistance to people with autism and additional disabilities like hearing loss.*

**CARD – Center for Autism and Related Disabilities-Tampa**

University of South Florida  
 CARD-USF MHC2113A  
 13301 Bruce B. Downs Blvd.  
 Tampa, FL 33612-3899  
 813-974-2532 or 800-333-4530  
<http://card-usf.fmhi.usf.edu>

**CARD – Center for Autism and Related Disabilities-Gainesville**

University of Florida at Gainesville  
 Department of Psychiatry  
 PO Box 100234  
 Gainesville, FL 32610-0234  
 352-846-2761 or 800-754-5891  
<http://www.card.ufl.edu>

**CARD – Center for Autism and Related Disabilities-Jacksonville**

University of Florida at Jacksonville  
 6026 San Jose Blvd.  
 Jacksonville, FL 32217  
 904-737-5239

**CARD – Center for Autism and Related Disabilities-Orlando**

University of Central Florida  
 12001 Science Drive, Suite 145  
 Orlando, FL 32826  
 407-737-2566 or 888-558-1908  
<http://www.ucf-card.org>

**CARD – Center for Autism and Related Disabilities-Miami**

University of Miami, Dept. of Psychology  
 5665 Ponce de Leon Blvd.  
 Coral Gables, FL 33124-0725  
 305-284-6563 or 800-9-AUTISM  
<http://www.psy.miami.edu/card>

Clearinghouse Information Center

Florida Department of Education  
Room 628 Turlington Building  
Tallahassee, FL 32399-0400  
850-488-1879

*Materials about children ages birth through 4 focusing on child development, early intervention, education, disabilities, developmental delays, health and related topic.*

Florida Outreach Project

University of Florida  
PO Box 100234  
Gainesville, FL 32610  
(352) 846-2757 V (352)846-2759 TTY  
Web: [www.deafblind.ufl.edu](http://www.deafblind.ufl.edu)

*Assists families aged birth through 21 who have both hearing loss and vision disabilities.*

Florida Speech-Language-Hearing Association

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

*Serves the needs of Florida Professionals by providing support, opportunities and professional growth..*

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**National Resources**Advanced Bionics Corporation

25129 Rye Canyon Loop  
Valencia, CA 91355  
1-877-829-0026 1-800-678-3575 TDD  
[www.cochlearimplant.com](http://www.cochlearimplant.com)

*Information on cochlear implants*

Alexander Graham Bell Association for the Deaf and Hard of Hearing

3417 Volta Place, NW  
Washington, DC 20007-2778  
(202) 337-5220 (202) 337-5221 TTY  
[www.agbell.org](http://www.agbell.org)

*An international organization of parents, professionals, and oral hard of hearing children and adults that provide newsletters, journals, and information..*

American Academy of Audiology

11730 Plaza America Dr., Suite 300  
Reston, VA 20190  
1-800-222-2336 V/TTY  
[www.audiology.org](http://www.audiology.org)

*Professional organization for audiologists that provides information on audiology issues.*

American Speech-Language-Hearing Assoc.

2200 Research Blvd.  
Rockville, MD 20850-3289  
(301) 897-5700 1-800-638-8255  
[www.asha.org](http://www.asha.org)

*Professional organization for speech language pathologists & audiologists.*

American Society for Deaf Children

3820 Hartzdale Drive  
Camp Hill, PA 17011  
Parent hotline 1-(800) 942-2732 V/TTY  
[www.deafchildren.org](http://www.deafchildren.org)

*Provides parent support, especially for information regarding the use of American Sign Language.*

Central Institute for the Deaf

825 S Taylor Ave.  
St. Louis, MO 63110  
(314) 977-0132  
[www.cid.edu](http://www.cid.edu)

*Research, information, and resources about deafness.*

Cochlear Corporation

400 Inverness Pkwy., Suite 400  
Englewood, CO 80112  
1-800-523-5798 V/TDD  
[www.cochlear.com](http://www.cochlear.com)  
*Information on cochlear implants.*

Gallaudet University

800 Florida Avenue NE  
Washington, DC 20002  
(202) 651-5051  
<http://clerccenter.Gallaudet.edu>  
*Information on deafness and hearing loss*

Hearing Loss Association of America

7910 Woodmont Ave., Suite 1200  
Bethesda, MD 20814  
(301) 657-2248  
[www.shhh.org](http://www.shhh.org)

*Information on hearing loss and supports..*

Hear Now

6700 Washington Avenue South  
Eden Prairie, MN 55344  
1-800-648-HEAR V/TDD  
[www.sotheworldmayhear.org/hearnow](http://www.sotheworldmayhear.org/hearnow)

*Donates hearing instruments to individuals who cannot otherwise afford them.*

House Ear Institute

2100 West Third Street  
Los Angeles, CA 90057  
(213) 483-4431 (213) 484-2642 TTY  
[www.hei.org](http://www.hei.org)

*A non-profit organization that provides information on hearing loss.*

International Hearing Dog, Inc.

5901 East 89<sup>th</sup> Ave.  
Henderson, CO 80640  
(303) 287-3277 V/TDD  
[www.ihdi.org](http://www.ihdi.org)

*Hearing dog training and placement*

John Tracy Clinic

806 W. Adams Blvd.  
Los Angeles, CA 90007  
1-800-522-4582 (213) 748-5481  
[www.jtc.org](http://www.jtc.org)

*Provides free home study program on teaching spoken language to infants & young children.*

League for the Hard of Hearing

2800 W. Oakland Park Blvd., Suite 306  
Oakland Park, FL 33311  
(954) 731-7200 (954) 731-7208 TTY  
[www.lhh.org](http://www.lhh.org)

*Non-profit organization striving to improve the quality of life of people with hearing loss*

Marion Downs National Center for Infant Hearing

University of Colorado at Boulder  
Campus Box 409  
Boulder, CO 80309-0409  
[www.colorado.edu/slhs/mdnc](http://www.colorado.edu/slhs/mdnc)

*Information on newborn hearing screening assessment, diagnosis, and early intervention.*

MED-EL Corporation

2511 Old Cornwallis Rd., Suite 100  
Durham, North Carolina 27713  
(919) 572-2222

[www.medel.com](http://www.medel.com)

*Information on cochlear implants.*

National Association of the Deaf

8630 Fenton Street, Suite 820  
Silver Springs, MD 20910  
(301) 587-1788 TTY

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

National Cued Speech Association

23970 Hermitage Rd.  
Cleveland, OH 44122  
(216) 292-6213 V/TTY  
[www.cuedspeech.com](http://www.cuedspeech.com)

*For general information and local contacts on cued speech..*

National Institute on Deafness and Other Communication Disorders (NIDCD)

31 Center Dr. , MSC 2320  
Bethesda, MD 20892-2320  
(800) 241-1044 (800) 241-1055 TTY  
[www.nidcd.nih.gov](http://www.nidcd.nih.gov)

*Researches the processes of hearing*

National Technical Institute for the Deaf at Rochester Institute of Technology

52 Lomb Memorial Drive  
Rochester, NY 14623-5604  
(585) 475-6400  
[www.ntid.rit.edu](http://www.ntid.rit.edu)

SKI\*HI Institute

Utah State University  
6500 Old Main Hill  
Logan, UT 84322-6500  
(435) 797-5600

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

*Early intervention curriculum for children with hearing loss.*

## Websites

### Center for Disease Control

[www.cdc.gov/ncbddd/ehdi](http://www.cdc.gov/ncbddd/ehdi)

*Early Hearing Detection and Intervention*

### Children's Medical Services

[www.cms-kids.org](http://www.cms-kids.org)

*Provides children with special health care needs a family centered, managed system of care*

### Families for Hands & Voices, Intl

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

*Communication support for families*

### Listen Foundation

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

*Information on teaching children with hearing loss to listen and speak.*

### My Baby's Hearing

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

*Information about babies and children with hearing loss.*

### National Center for Hearing Assessment and Management NCHAM

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

*Assists families to manage hearing loss*

### Oral Deaf Education/Oberkotter Foundation

877-ORALDEAF

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

*Information for parents of children with hearing loss about oral education.*

### Raising Deaf Kids

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

*Information about children with hearing loss*

### Sign with Your Baby

[www.sign2me.net](http://www.sign2me.net)

*Sign language information for babies*

### Specializing in Information for the Deaf and Hard of Hearing

[www.listen-up.org](http://www.listen-up.org)

*Advocates for the rights of children with hearing loss.*

### WrightsLaw

<http://www.wrightslaw.com>

*Special education law and advocacy for parents, advocates and educators of children with disabilities*

## Additional Websites

- ASL Browser - <http://commtechlab.msu.edu/sites/aslweb/browser.htm>
- ASL Info - <http://www.aslinfo.com/links.cfm>
- Fingerspelling Fonts - <http://babel.uoregon.edu/yamada/fonts/asl.html>
- Handspeak- <http://www.handspeak.com>
- Deaf and Hearing Impaired Links - <http://www.irsc.org/deaf.htm>
- Deaf Linx - <http://www.deaflinx.com>
- Deafness/Hard of Hearing - Guide - <http://deafness.about.com/health/deafness/>
- Deaf Notes - <http://www.deafnotes.com>
- Deaf Resource Library - <http://www.deaflibrary.org/>
- DeafSoup - <http://www.deafsoup.com>
- DeafWeb Washington: - <http://www.deafweb.org/>
- S.E.E. Center – <http://www.seecenter.org/>
- Sign Language - <http://www.surfnetkids.com/signlanguage.htm>
- Sign Writing - <http://www.SignWriting.org/>
- Sign the Alphabet - <http://www.funbrain.com/signs/index.html>

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**CATALOGS****A.G. Bell**

3417 Volta Place NW  
Washington, DC 20007-2778  
(202) 337-5220  
[www.agbell.org](http://www.agbell.org)

**HITEC Assistive Communication Center**

8160 S. Madison Street  
Burr Ridge, IL 60527  
(800) 288-8303  
[www.hitec.com](http://www.hitec.com)

**Boys Town Press**

(800) 282-6657  
[www.boystownpress.org](http://www.boystownpress.org)

**Butte Publications**

PO Box 1328  
Hillsboro, OR 97123-1328  
(866) 312-8883  
[www.buttepublications.com](http://www.buttepublications.com)

**Dawn Sign Press**

6130 Nancy Ridge Drive  
San Diego, CA 92121-3223  
(858) 625-0600  
[www.dawnsign.com](http://www.dawnsign.com)

**Discovery Toys**

(800) 341-8697  
[www.discoverytoysinc.com](http://www.discoverytoysinc.com)

**HARC Mercantile, LTD.**

1111 W. Centre Ave  
Portage, MI 49024  
(800) 445-9968  
[www.harcmercantile.com](http://www.harcmercantile.com)

**Harris Communications**

15155 Technology Dr.  
Eden Prairie, MN 55344  
(800) 825-6758  
[www.harriscomm.com](http://www.harriscomm.com)

**Hear-More Products for the Deaf**

(800) 881-4327  
[www.hearmore.com](http://www.hearmore.com)

**Lakeshore**

(800)421-5354  
[www.grades123.com](http://www.grades123.com)

**LinguiSystems**

(800) 776-4332  
[www.linguisystems.com](http://www.linguisystems.com)

**Modern Signs Press, Inc.**

PO Box 1181  
Los Alamitos, CA 90720  
(562) 596-8548  
[www.modernsignspress.com](http://www.modernsignspress.com)

**Oberkotter Foundation**

(877) 672-5332  
[www.oraldeafed.org](http://www.oraldeafed.org)

**Super Duper**

(800) 277-8737  
[www.superduperinc.com](http://www.superduperinc.com)

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**BOOKS**

ABCs of AVT: Analyzing Auditory-Verbal Therapy, by Warren Estabrooks, [www.agbell.org](http://www.agbell.org), (202) 337-5220

A Child Sacrificed to the Deaf Culture, by Tom Bertling. Wilsonville, OR: Kodiak Media Group

Acoustics, Audition and Speech Reception, by Daniel Ling, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Auditory Verbal Therapy for Parents and Practice, Warren Estabrooks, [www.agbell.org](http://www.agbell.org)

Balancing Act, by Virginia M. Scott. Butte Publications, Inc., (1997)

Choices in Deafness: A Parent's Guide a collection of family stories about their deaf child and the communication method they use. Edited by Sue Schwartz, Ph.D. Woodbine House

Classroom G.O.A.L.S.: guide for Optimizing Auditory Learning Skills, by Jill B. Firszt, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Cochlear Implantation for Infants and Children: advances/senior editor, Graeme M. Clark: editors, Robert S.C. Cowan, Richard C. Dowell. Published by San Diego: Singular Pub. Group

Cochlear Implants: A handbook, by Bonnie Poitras Tucker. Published by Jefferson, N.C. McFarland, (1998)

Cochlear Implants and Children, Spencer, Patricia Gallaudet University Press (2002)

Cochlear Implants: Audiological Foundations, (1993) Singular Publishing Group

Cochlear Implant Compass Cards Program 2, by David Sindrey, WordPlay, , [www.agbell.org](http://www.agbell.org), (202) 337-5220

Cochlear Implants for Kids, by Warren Estabrooks, , [www.agbell.org](http://www.agbell.org), (202) 337-5220

Cochlear Implants in Young Deaf Children, (1989) Boston: College Hill Press

Come Sign with Us: Sign Language Activities for Children, by Jan C. Hafer and Robert M. Wilson. Illustrated by Paul Setzer

Cued Speech Resource Book for Parents of Deaf Children, Second Edition, Orin R. Cornett, Mary Elsie Daisey, (2001), Cued Speech Discovery

Cumulative Record of Speech Skill Acquisition, by Daniel Ling, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Dancing without Music: Deafness in America, Beryl Leiff Benderly (1980), Anchor/Doubleday

Deaf History Unveiled: Sixteen Essays Offer the Current Results of Harlan Lane, Renate Fischer, Margaret Winzer, William McCagg, and 12 Other Noted Historians in this Field, John Vickrey Van Cleve, Editor

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Deafness in Perspective, (1986), College-Hill Press

Deaf President Now: The 1988 Revolution at Gallaudet University, John B. Christiansen and Sharon N. Barnartt

Early Childhood Deafness, Ellen Kurtzer-White and David Luterman (2001), York Press

Facilitating Hearing and Listening in Young Children, Carol Flexer, Singular Publishing Group, 1994

50 FAQs About AVT, Warren Estabrooks, editor, (2001) Learning to Listen Foundation, [www.agbell.org](http://www.agbell.org)

Foundations of Bilingual Education and Bilingualism, Baker, C. (1996) Clevedon: Multilingual Matters

Handtalk School, by Mary Beth, New York: Toronto: New York: Four Winds Press, Collier Macmillan Canada, Maxwell Macmillan International, (1991)

Hear and Listen! Talk and Sing!, Warren Estabrooks, Lois Birkenshaw-Fleming, (1994), [www.agbell.org](http://www.agbell.org), (202) 337-5220

Hearing Impaired Infants: Support in the First Eighteen Months, Edited by Jacqueline Stokes (1999)

Hearing Loss in Children, Pediatric Clinics of North America. Vol 46, 1999

IDEA Advocacy for Children who are Deaf or Hard of Hearing: A Guide for Parents of Children who are Deaf or Hard of Hearing and the Professional Involved in their Education, by Bonnie Poitras Tucker, J.D. Singular Publishing Group, (1997)

Infants and Toddlers with Hearing Loss: Family-Centered Assessment and Intervention, edited by Jackson Roush and Noel D. Matkin (1994)

It Takes Two to Talk: A Parent's Guide to Helping Children Communicate, by Ayala Manolson, English and Spanish

Kid-Friendly Parenting with Deaf and Hard of Hearing Children, by Daria J. Medwid, Denise Chapman Weston. Washington, D.C. Clerc Books, (1995)

Learn to Talk Around the Clock a Professional's Early Intervention Toolkit, by Karen Rossi, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Listen to This, Volume One, by Warren Estabrooks, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Listen to This, Volume Two, by Warren Estabrooks, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Listening and Talking: A Guide to Promoting Spoken Language in Young Hearing-Impaired Children, by Elizabeth B. Cole, Ed.D. (1992)

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Listening to Learn: A Handbook for Parents with Hearing-Impaired Children, by Arlie Adam, Pam Fortier, Gail Schiel, Margaret Smith and Christine Soland (1990)

Listen Little Star, by Dimitry Dornan, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Literacy Learning for Children Who are Deaf or Hard of Hearing, by Lyn Robertson, Ph.D. (2000)

Literacy, Classroom Amplification and the Brain, by Carol Flexer, [www.agbell.org](http://www.agbell.org)

My Sense of Silence: Memoirs of a Childhood with Deafness, by Lennard J. Davis. Urbana: University of Illinois Press, (2000)

Negotiating the Special Education Maze: A Guide for Parents and Teachers, Winifred Anderson, (1990) Woodbine House

Never the Twain Shall Meet: Bell, Gallaudet, & the Communications Debate, Richard Winefield

Not Deaf Enough: Raising a Child Who is Hard of Hearing with Hugs, Humor, and Imagination, by Patricia Ann Morgan Candish (1996)

Our Forgotten Children: Hard of Hearing Pupils in the Schools, edited by Julia Davis, Ph.D., SHHH Publications, (1990), [www.shhh.org](http://www.shhh.org)

Parenting with Love and Logic: Teaching Children Responsibility, Foster Cline, Jim Fay (1990) Love & Logic Press

Parents & Teachers: Partners in Language Development, by Audrey Simmons-Martin, Ph.D. and Karen Glover Rossi, M.A. (1990)

Pediatric Cochlear Implants: An Overview of Options and Alternatives in Education and Rehabilitation, Judith Barnes, (1994)

Phonetic-Phonologic Speech Evaluation Pads, by Daniel Ling, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Raising and Educating a Deaf Child, by Marc Marschart. New York: Oxford University Press

Reading Between the Lips: A Totally Deaf Man Makes It in the Mainstream, by Lew Golan

Schedules of Development in Audition Speech Language Communication of Hearing-Impaired Infants and their Parents, by Agnes Ling Phillips, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Songs for Listening! Songs for Life!, by Warren Estabrooks, [www.agbell.org](http://www.agbell.org), (202) 337-5220

Sounds Like Home: Growing Up Black and Deaf in the South, by Mary Hering Wright

Special Children, Challenged Parents: the Struggles and Rewards of Raising a Child with a Disability, by Robert A. Naseef. Secucus, N.J.: Carol Pub. Group, (1997)

Speech and the Hearing –Impaired Child, by Daniel Ling, [www.agbell.org](http://www.agbell.org), (202) 337-5220

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The Baby is Listening, by Warren Estabrooks, [www.agbell.org](http://www.agbell.org), (202) 337-5220

The Classroom Notetaker: How to Organize a Program Servicing Students with Hearing Impairments, by Jimmie Joan Wilson, [www.agbell.org](http://www.agbell.org), (202) 337-5220

The Deaf Child in the Family and at School, Spencer, Erting and Marschark, (2000) Lawrence Erlbaum Associates

The Feel of Silence: A Compelling Memoir about a Lawyer and Professor with a Profound Hearing Loss Surviving the Trials of Accommodating the Hearing World, by Bonnie Poitras Tucker, J.D. Temple University Press, (1996)

The New Language of Toys, Sue Schwartz, Joan E. Heller Miller (1996), Woodbine House

The Politics of American Sign Language in Deaf Education, Nover, S. & Ruiz, R. (1994) Brenda Schick and Mary P. Moeller (Eds.), Boys Town National Research Hospital: Omaha, Neb.

The Signed English School Book, Harry Bornstein (1987) Kendall Green Publications

The Signing Family: What Every Parent Should Know about Sign Communication, by David A. Stewart, Washington, DC: Gallaudet University Press, (1998)

The Silent Garden: Raising Your Deaf Child, Ogden, P.W. & Lipsett, (1982), New York: St. Martin Press

The Six-Sound Song, by Warren Estabrooks, [www.agbell.org](http://www.agbell.org), (202) 337-5220

The Young Deaf Child, by David M. Luterman, (1999), York Press

Train Go Sorry: Inside a Deaf World, Leah Hager Cohen (1994), Houghton Mifflin

25 Ways to Promote Spoken Language in Your Child with a Hearing Loss, by Amanda Mangiardi (1995)

We Can Hear and Speak, Parents and Families of National Communication, Inc., [www.agbell.org](http://www.agbell.org), (202) 337-5220

What's That Pig Outdoors?, an inspiring autobiography of Henry Kisor, oral deaf book editor and columnist for the Chicago Sun Times, Henry Kisor, (1990)

When Bad Things Happen to Good People, Kushner, H. (1981) New York: Avon Books

When the Mind Hears, by Harlan Lane

When the Phone Rings, My Bed Shakes: Memoirs of a Deaf Doctor, by Philip Zazove, M.D. (1994)

Why We Can Hear and Speak, by Parents and Families of Natural Communication, [www.agbell.org](http://www.agbell.org), (202) 337-5220

## Florida Funding Sources

Local Service Clubs such as Lion's, Rotary, Kiwanis, and Sertoma frequently are open to considering providing funds or matching funds to support hearing aids and services for children residing in their communities. Contact people for these clubs can often be found in your local telephone book.

### Sertoma Speech & Hearing Foundation of FL, Inc.

4443 Rowan Road  
New Port Richey, FL 34653  
Contact: Craig McCart  
Phone: 866-999-2443  
Website: [www.childrenshearinghelpfund.org](http://www.childrenshearinghelpfund.org)

## National Funding Sources

### A G Bell

[www.agbell.org](http://www.agbell.org)  
*Resources for financial assistance include habilitation, rehabilitation services, hearing aids and other assistive devices*

### CNI Center for Hearing

Cochlear Implant Assistance Program  
701 East Hampden Ave., Suite 330  
Englewood, CO 80113  
<http://www.thecni.org/hearing/assistance.htm>  
*Financial assistance for cochlear implants for children*

### Children's Hearing Aid Bank Hearing Aid Foundation, Inc.

20361 Middlebelt  
Livonia, MI 48152  
(800) 521-5247 VERIFY by phone

### Children of the Silent World

P.O. Box 2425  
Cridersville, OH 45806  
[www.metroevents.com/silent](http://www.metroevents.com/silent)  
*Assists low-income children with purchasing hearing aids*

### Disabled Children's Relief Fund (DCRF)

PO Box 89  
Freeport, NY 11520  
(202) 331-9694  
[www.dcrf.com](http://www.dcrf.com)  
*Provides assistance to obtain hearing aids*

### Hear Now

6700 Washington Avenue South  
Eden Prairie, MN 55344  
1-800-648-HEAR V/TDD  
[www.sotheworldmayhear.org/hearnow](http://www.sotheworldmayhear.org/hearnow)  
*Donates hearing instruments to individuals who cannot otherwise afford them.*

### Hike Fund, Inc.

The Hike Fund Inc.  
c/o Hike Board Secretary  
10115 Cherryhill Pl.  
Spring Hill, FL 34608-7116  
Phone and Fax:  
[www.thehikefund.org](http://www.thehikefund.org)  
*Provides low-income children between 0-20 years with hearing aids and assistive devices*

### International Association of Lion Clubs

300 West 22<sup>nd</sup> Street  
Oak Brook, IL 60523  
[www.lionsclubs.org](http://www.lionsclubs.org)  
*Assists low income individuals with purchasing hearing aids.*

### Kiwanis International Inc.

3636 Woodview Place  
Indianapolis, IN 46268-3196  
(800) 549-2647  
[www.kiwanis.org](http://www.kiwanis.org)

Miracle Ear Children's Foundation

P.O. Box 59261

(800) 234-5422

<http://www.mnplan.state.mn.us/star/program.html?Id=18>*Assists low-income children and families with purchases of hearing aids from this manufacturer.*Optimists Club

Optimist International Youth Program

Help Them Hear Program

Contact your local Optimists Club

*Provides aids and services to hearing impaired youth*Quota International Inc.

We Share Foundation

1420 21<sup>st</sup> Street NW

Washington, DC 20036

(202) 331-9694

[www.quota.org](http://www.quota.org)*Known for service to deaf and hard of hearing people. Assists low income individuals with purchasing hearing aids*Sertoma International

1912 East Meyer Boulevard

Kansas City, MO 64132-9990

816-333-8300

<http://www.sertoma.org/>*Assists low-income persons with purchasing hearing aids*Supplemental Security Income (SSI)

(800) 772-1213

[www.ssa.gov/ssi/](http://www.ssa.gov/ssi/)Travelers Protective Association Scholarship Trust for the Hearing Impaired

3755 Lindell Boulevard

St. Louis, MO 63108

314/371-0533 (voice)

[http://www.travelersprotectiveasn.com/deaf\\_scholarships.htm](http://www.travelersprotectiveasn.com/deaf_scholarships.htm)*Provides assistance for mechanical devices, medical care, and/or specialized education or treatment, to those who demonstrate financial need. U.S. citizens only. Grants may be used to purchase hearing aids, assistive listening equipment, or may help with the cost of a cochlear implant.*

If you have private insurance, you will want to check about the coverage for your child's needs including audiology testing, hearing aids, follow-up services, and speech/ language/auditory therapy. It may be necessary to advocate and educate insurance companies and/or your employer in order to obtain any coverage for your child's needs.

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## VIDEOS

### **Captioned Media Program**

The Captioned Media Program loans media without rental fees. The films are open-captioned and there is no need for a decoder. Funded by the US Department of Education. Includes prepaid return labels. Deaf and hard of hearing persons, teachers, parents, and others may borrow materials. Other services include provision of free captioning information.

Over 4,000 educational and general-interest open-captioned titles are available. Educational titles include topics in school subject areas, preschool through college. Lesson guides accompany educational videos. General-interest titles include classic movies and special-interest topics such as travel, hobbies, recreation, and others. Approximately 300 new titles are added each year based on users' recommendations.

### **Described Captioned Media Program**

#### **National Association of the Deaf**

<http://deafness.about.com/od/captioning/a/captionedmedia.htm>

**American Culture: The Deaf Perspective** (4 tapes) Available from the San Francisco Public Library, TDD (415) 557-4433 or V (415) 557-4434

**Auditory-Verbal Therapy for Parents and Professionals:** Introduces AV therapy, speech language development, etc. Via parent stories and taped therapy sessions, AG Bell (202) 337-5220

**Beginnings: A program that examines all communication choices without bias;** from Beginnings, V/TTD (919) 850-2746

**Building Conversations: A Family Sign Language Curriculum,** produced by Boys Town National Research Hospital (2 tapes)

**Come Sign with Us:** Children can learn sign language from popular activities featured in the best-selling book: "Come Sign With Us" on videotape. Gallaudet University Press

**Computer-Assisted Notetaking (CAN):** You can see it-visual technologies for Deaf and Hard of Hearing People, Gallaudet University

**Do You Hear That?** Shows auditory-verbal therapy session with children with hearing aids or cochlear implants; for parents, educators and professionals, AG Bell (202) 337-5220

**Dreams Spoken Here:** A film exploring oral deaf education from infancy through adulthood available in 20 and 60-minute formats [www.oraldeafed.org](http://www.oraldeafed.org) or (877) 672-5332

**I Can Hear!** Describes the auditory-verbal approach for developing speech and Language; families and professionals profiles, available from AG Bell (202) 337-5220

**I See What You Say:** A 12-minute introduction to Cued Speech from the Cued Speech Center, (216) 292-6213

**Language Says It All:** Los Angeles, CA TRIPOD Productions, (1987)

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**Mother's Look at Total Communication:** A VHS tape available by Modern Signs Press

**Parents' Guide to Deafness and Hearing Loss:** Covers such topics, as how to communicate, where to go for help and what the child's educational experience will be. Madison, WI: University of Wisconsin Hospital and Clinics, Dept. of Outreach Education.

**Positive Parenting: A Family Sign Language Curriculum.** Produced by the Center for Hearing Loss in Children (2 tapes)

**Show and Tell:** Explains the challenges hearing impairments impose on mainstream teachers, from the Clarke School, available from AG Bell (202) 337-5220

**Speaking for Myself:** A film about auditory/oral communication and education available in a 10-minute format, [www.oraldeafed.org](http://www.oraldeafed.org) or (877) 672-5332

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### INTRODUCTION TO "QUESTIONS PARENTS COULD ASK"

Learning your child has hearing loss can be overwhelming with all the information and decisions parents face. Parents of children who have hearing loss and professionals in the field of hearing loss developed the following sets of questionnaires. These questions are not meant to be comprehensive, but rather they are intended to open a dialogue between professionals and parents. The order of the questions is not significant, as you will have a better idea of how to approach each topic. Just remember this: you are your child's best advocate. The more information you have, the more assistance you can offer your child.

**QUESTIONS TO ASK EAR, NOSE AND THROAT DOCTOR (ENT)**

Name of ENT: \_\_\_\_\_

Phone: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

Test Name: \_\_\_\_\_

Name/Location of Test: \_\_\_\_\_

**A pediatric ear, nose and throat (ENT) doctor is a specialist trained to diagnose and treat children with disorders of the ear or nose or throat.**

An ear, nose, and throat (ENT) doctor, also called an otolaryngologist, can tell you if there is a medical condition in your child's outer, middle, or inner ear that is causing the hearing loss. They can answer your questions about medical or surgical treatments. This will ensure intervention occurs within the "1-3-6" timeline (hearing screening before 1 month of age, hearing diagnostic audiological evaluation before 3 months of age, and early intervention before 6 months of age.)

An ENT who has training and experience to evaluate and treat infants and young children will offer the best care for your baby.

**Questions about my/our child's hearing loss:**

1. Do you have experience in evaluating and treating babies and children with hearing loss?  
 \_\_\_\_\_  
 \_\_\_\_\_
  
2. Do you have the most recent report from my child's audiologist (hearing specialist)?  
 \_\_\_\_\_
  
3. What type of hearing loss does my child have (sensorineural, conductive or mixed)? Please explain these terms.  
 \_\_\_\_\_  
 \_\_\_\_\_
  
4. Should I make appointments with other health professionals? For example, an eye doctor or a geneticist?  
 \_\_\_\_\_  
 \_\_\_\_\_

5. Would you suggest genetic counseling for our family?  
\_\_\_\_\_  
\_\_\_\_\_
  
6. Are there other tests that my child needs? For example, brain scans (CT scan, MRI); heart tests (EKG); and blood or urine tests, or both. What will these tests tell you about my child's hearing loss?  
\_\_\_\_\_  
\_\_\_\_\_
  
7. Can you tell if my child's hearing loss will get worse or change?  
\_\_\_\_\_  
\_\_\_\_\_
  
8. Is there some cause for my child's hearing loss?  
\_\_\_\_\_  
\_\_\_\_\_
  
9. How do I describe these results to family members?  
\_\_\_\_\_  
\_\_\_\_\_
  
10. What treatments are available? For example, ear tubes, other surgery, or cochlear implants)?  
\_\_\_\_\_  
\_\_\_\_\_
  
11. Would my child benefit from a hearing aid? If so, how?  
\_\_\_\_\_  
\_\_\_\_\_
  
12. Do I need a form signed by a health care professional to allow my child to be fitted with hearing aids?  
\_\_\_\_\_  
\_\_\_\_\_
  
13. Is my child a candidate for a cochlear implant? Where can I go for more information?  
\_\_\_\_\_  
\_\_\_\_\_
  
14. How often will we meet with you, onetime or ongoing?  
\_\_\_\_\_  
\_\_\_\_\_

## QUESTIONS TO ASK THE SPEECH-LANGUAGE PATHOLOGIST

A speech-language pathologist (SLP) is trained to assess speech and language skills of children and adults. They may work in schools, hospitals, universities or in private practice. If a child or an adult has a communication problem, the speech-language pathologist, with the family, will help determine the best approach for therapy.

Many speech-language pathologists have limited training or experience with deaf or hard of hearing children. A different approach is required when a child has never heard sounds correctly. There may be different things to be aware of when developing speech and language with a child who had a hearing loss. For example children with a hearing loss often leave off final sounds or sounds that they do not hear.

Name of SLP: \_\_\_\_\_

Phone: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

### **You might ask the speech-language pathologist the following questions:**

1. What kind of specific training have you had for working with deaf or hard of hearing children?

\_\_\_\_\_  
\_\_\_\_\_

2. What experience have you had with deaf or hard of hearing children? Could you describe their hearing losses?

\_\_\_\_\_  
\_\_\_\_\_

3. How many of your current clients have hearing losses? What are their ages?

\_\_\_\_\_  
\_\_\_\_\_

4. What communication methods do you have experience with? (Cued Speech, Total Communication, Oral, Auditory Verbal, , etc.) How do you decide which method to use? What do you use in your practice?

\_\_\_\_\_  
\_\_\_\_\_

5. If you sign, which sign language system do you prefer? (Signing Exact English, American Sign Language, Signed English)

\_\_\_\_\_  
\_\_\_\_\_

- 6. What kinds of things do you do to evaluate communication skills?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 7. How do you monitor the speech and language progress of a child and what tools do you use?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 8. What kind of parent involvement do you encourage?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 9. How do you coordinate your efforts with other professionals such as the audiologist, teacher of the deaf and other school personnel?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 10. Do you have experience with children with cochlear implants?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 11. Would it be possible to observe a session with a deaf or hard of hearing child? To talk with their parents?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 12. How do you determine an amount of time to work on speech, language and/or auditory training?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 13. Do you follow a specific instructional method or curriculum, such as Ling?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 14. Do you have an auditory curriculum which you prefer such as; Beckman tests, SPICE Auditory curriculum or the DASL Auditory Curriculum?  
\_\_\_\_\_  
\_\_\_\_\_
  
- 15. How can I get financial assistance to help cover costs?  
\_\_\_\_\_  
\_\_\_\_\_

## QUESTIONS TO ASK AUDIOLOGISTS

Name of Audiologist: \_\_\_\_\_

Phone: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

Hearing Test Name: \_\_\_\_\_

Name/Location of Hearing Test: \_\_\_\_\_

**An audiologist is a person who is trained to evaluate hearing.**

An audiologist can find a hearing loss, describe hearing test results, and test to see if amplification devices will help your child. An amplification device helps someone hear sounds better. For example, a hearing aid is an amplification device. An audiologist may also give suggestions about hearing aids and some audiologists may sell and fit hearing aids on children. Most audiologist can provide you with information about therapies or services such as auditory “hearing” training and different ways to communicate with children with hearing loss. An audiologist who has experience and training to test and give services to infants and young children will offer the best care for your baby.

The following list of questions may be helpful when working with your child’s audiologist. Use only the questions that apply to your child’s hearing loss.

**Details about my/our child’s hearing loss:**

1. How much hearing loss does my child have? Please explain the terms: severe, mild, moderate, profound, sensorineural, conductive, mixed, auditory neuropathy?

\_\_\_\_\_  
 \_\_\_\_\_

2. Do both ears have the same hearing loss?

\_\_\_\_\_  
 \_\_\_\_\_

3. Is the loss permanent? Does my child need more testing? How often should my child’s hearing be tested?

\_\_\_\_\_  
 \_\_\_\_\_

4. Can you tell if my child’s hearing loss will get worse or change?

\_\_\_\_\_  
 \_\_\_\_\_

5. How will the hearing loss affect my child's speech and language development?

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6. What could have caused my child's hearing loss?

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7. Would you suggest genetic counseling for our family?

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8. May I have a copy of the hearing test results? (Attach and explain the audiogram or other information to this form)

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**Questions about hearing aids and cochlear implants (an electronic device placed under the skin behind the ear):**

9. Does my child need a hearing aid? What are my choices? Should he or she have a hearing aid in both ears?

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10. How much do hearing aids cost? Can I get help to pay for the hearing aids?

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11. Can you help me contact a program that can lend me hearing aids?

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12. What will my child hear with the hearing aids?

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13. How often will my child need new hearing aids or parts?

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14. What are the parts of a hearing aid that may need to be replaced?

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15. What should I do if my child does not want to wear the hearing aid?

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16. With my child's hearing loss, should I consider a cochlear implant (an electronic device placed under the skin behind the ear)? Where can I go for more information?

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**Questions about communication options, education and support:**

17. Can you help me learn about the different types of communication options (for example: total communication, oral, sign language)?

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18. When should I begin early intervention, school, speech and other therapy, or classes for my child? What is available in this area?

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19. Is there a parent group in my area? Where? Who should I contact?

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20. Can you help me meet another parent of a child with hearing loss that is similar to my child's?

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21. Can you tell me about other ways I can learn about hearing loss – books, videotapes, films, websites, and courses?

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22. How do I describe the results of the hearing tests to family members?

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23. What are some tips for working with my child at home?

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## QUESTIONS TO ASK YOUR CHILD’S EARLY INTERVENTIONIST

Name of Early Interventionist: \_\_\_\_\_

Phone: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

**Early intervention is a program for children from birth to 3 years of age who have a developmental delay. Children with hearing loss usually need early intervention services. An early interventionist, a specialist who works with infants and toddlers, will help identify your child’s needs and create an Individualized Family Service Plan (IFSP). This plan will be used to provide your child with the services he or she needs.**

Early intervention services support families to help their children reach their full potential. It is important that children with hearing loss begin early intervention services as soon as possible. The goal for every child with hearing loss identified at birth is to start early intervention no later than 6 months of age or within 3 month of diagnosis. This will help your child develop communication and language skills that will last a lifetime.

1. What is early intervention? What can you do for my child? What services do you provides?

\_\_\_\_\_

\_\_\_\_\_

2. Why is it so important for my child to start intervention this early?

\_\_\_\_\_

\_\_\_\_\_

3. Does my child need a hearing aid? What are my options? Should she/he have an aid in both ears?

\_\_\_\_\_

\_\_\_\_\_

4. How can my child learn to communicate? Can you tell me about sign language? Can you tell me about the different ways my child can learn to talk?

\_\_\_\_\_

\_\_\_\_\_

5. How are hearing aids and cochlear implants different?

\_\_\_\_\_

\_\_\_\_\_

6. Does your program have staff trained to work with very young infants and toddlers with hearing loss for all communication methods?

\_\_\_\_\_

\_\_\_\_\_

7. Will you send progress reports for our child to his or her doctor and the state EHDI program?

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8. How much time will we spend in early intervention activities?

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9. Where can I learn more about children with hearing loss? How can I meet other families who have young children with hearing loss?

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10. What will happen when my child is too old for your program?

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## QUESTIONS TO ASK YOUR CHILD’S MEDICAL PROFESSIONAL

Name of Medical Professional: \_\_\_\_\_

Phone: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

**Medical professionals are trained to diagnose and treat medical conditions in people. Examples include pediatricians, family physicians, primary care doctors, and nurse practitioners.**

Your child’s medical professional oversees your child’s overall growth, health and development. You might see your child’s medical professional in an office, clinic or hospital.

This person will coordinate all areas of your child’s medical care. In addition to receiving routine care, a child with hearing loss may need to see specialists who will look at the child’s specific health needs. These specialists may look at eyes, language or speech needs, genetics, or other areas. Your child’s medical professional will help decide which specialist your child should see and when to see them. In this way, your child will receive coordinated care by all of his or her medical professionals.

Your medical professional may send your child to some or all of the following specialists:

- **Ophthalmologist:** A doctor who specializes in eyes.
- **Otolaryngologist:** A doctor who specializes in the ear, nose, and throat. Often called an ENT.
- **Geneticist:** A professional who is trained to know about genes and the medical conditions (including hearing loss) that might be related to genetics.
- **Audiologist:** A professional trained to test hearing.
- **Speech-language pathologist:** A professional trained to know how children learn language and to teach children how to use speech and language.
- **Early intervention provider:** A person who is trained to provide services that support families and children, ages birth to 3 years, who have or are at risk for developmental delays.

1. Do you know why my child has hearing loss? Could my child’s hearing loss be related to any other medical conditions? Could it be genetic?

\_\_\_\_\_

\_\_\_\_\_

2. Are there specialists who are knowledgeable about childhood hearing loss that my child should see?

\_\_\_\_\_

\_\_\_\_\_

3. How do I get the referrals for the specialist my child might need to see (e.g., speech, audiology, ENT, genetic, ophthalmology)? To get the referrals, do I need an appointment with you first or can I request them by calling your office?

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4. How will the specialists we see share their finding with you? How long does that process usually take? How am I (as parent/guardian) involved in the communication between the specialists, and will I get copies of the reports?

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5. Have you already received any reports about my child’s hearing loss (e.g., from audiology, ENT)?

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6. Will my child need more tests because of the hearing loss? For example, brain scans (CT, MRI) or blood or urine tests? What will these tests tell you about my child’s hearing loss?

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7. If I have problems with the referrals, or if my insurance company has questions, what should I do? Can your office help me?

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8. Are there any medications that may have harmful effects on my child’s hearing?

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9. Will ear infections or fluid in the ears affect my child’s hearing loss? Should infection or fluid in the ears be treated differently because of my child’s hearing loss?

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10. Will you need to see my child more often because of the hearing loss? How often?

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11. Other than my child’s hearing loss, do you have other concerns about my child’s development? Is he or she meeting the developmental milestones as he or she should?

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12. Can you tell me about early intervention services that are available in the area?

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13. Do you know of any community resources or support groups for my family?

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14. Is there anything more I should know or consider about my child's hearing loss or general health?

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## QUESTIONS TO ASK YOUR CHILD’S GENETICS TEAM

Name of Geneticist and Genetic Counselor: \_\_\_\_\_

Phone: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Next Appointment Date: \_\_\_\_\_

**A genetics team is made up of a clinical geneticist, a genetic counselor, and other health care professionals. A clinical geneticist is a doctor who specializes in diagnosing and caring for people with genetic conditions. A genetic counselor is a health care professional who talks with people about the risk for genetic conditions and provides counseling and support. Members of the genetics team work together during a genetics exam. .**

The purpose of a genetics exam or genetic testing is to find out if the cause of your child’s hearing loss is genetic. About half of all hearing loss in babies is genetic. This means that the hearing loss is caused by changes in genes. Genes contain the instructions that tell a person’s cells how to grow and work. Sometimes a change in a gene can cause hearing loss. Hearing loss can also be caused by infections, premature birth, and other factors in the environment. For many children, the cause of hearing loss is not known.

Members of the genetics team will ask you questions and give your child a thorough physical exam to try to find the cause of your child’s hearing loss. They may recommend that your child have a blood test. They may also ask that you have a blood test. They may suggest that your child see another doctor or specialist to help them better understand the cause of your child’s hearing loss. Knowing the cause might help you and your child’s doctors better understand your child’s health care needs. It might also give you and your family information about the chance of having other children with hearing loss. Sometimes the cause of a child’s hearing loss cannot be found, even if the child has a genetic evaluation.

**Questions you may want to ask your child’s genetics team:**

1. Will a genetic exam and genetic testing tell me the cause of my child’s hearing loss? What are some common genetic causes of hearing loss?

\_\_\_\_\_

\_\_\_\_\_

2. Why should I try to find out the cause of my child’s hearing loss? How can this information help my child?

\_\_\_\_\_

\_\_\_\_\_

3. What will the results of genetic testing tell me? Does a negative test result mean that my child’s hearing loss is not genetic?

\_\_\_\_\_

\_\_\_\_\_

4. Can the results of genetic testing tell me if my child's hearing loss will get better or worse?

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5. How will genetic tests be done? What other kinds of tests might be done to find out the cause of my child's hearing loss?

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6. Will my child need to come back to your office after testing? If so, why?

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7. Why is it important to know if members of my family have had hearing loss and what type they had? How can hearing loss be inherited?

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8. If no one in my family has hearing loss, how can my child's hearing loss be genetic?

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9. Should my other children have genetic testing, too? Why?

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10. If I have another child, what is the chance that he or she will also have hearing loss?

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11. Should I share test results with other members of my family? Could other people in my family also have children with hearing loss?

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12. Where can I learn more about genetic testing for hearing loss? How can I meet other families who have children with hearing loss?

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# APPENDICES



- *Audiogram*
- *Suggestions for Beginning Vocabulary*
- *Mainstream Kindergarten Readiness Skills*
- *Questions and Answers*

## Description of an Audiogram

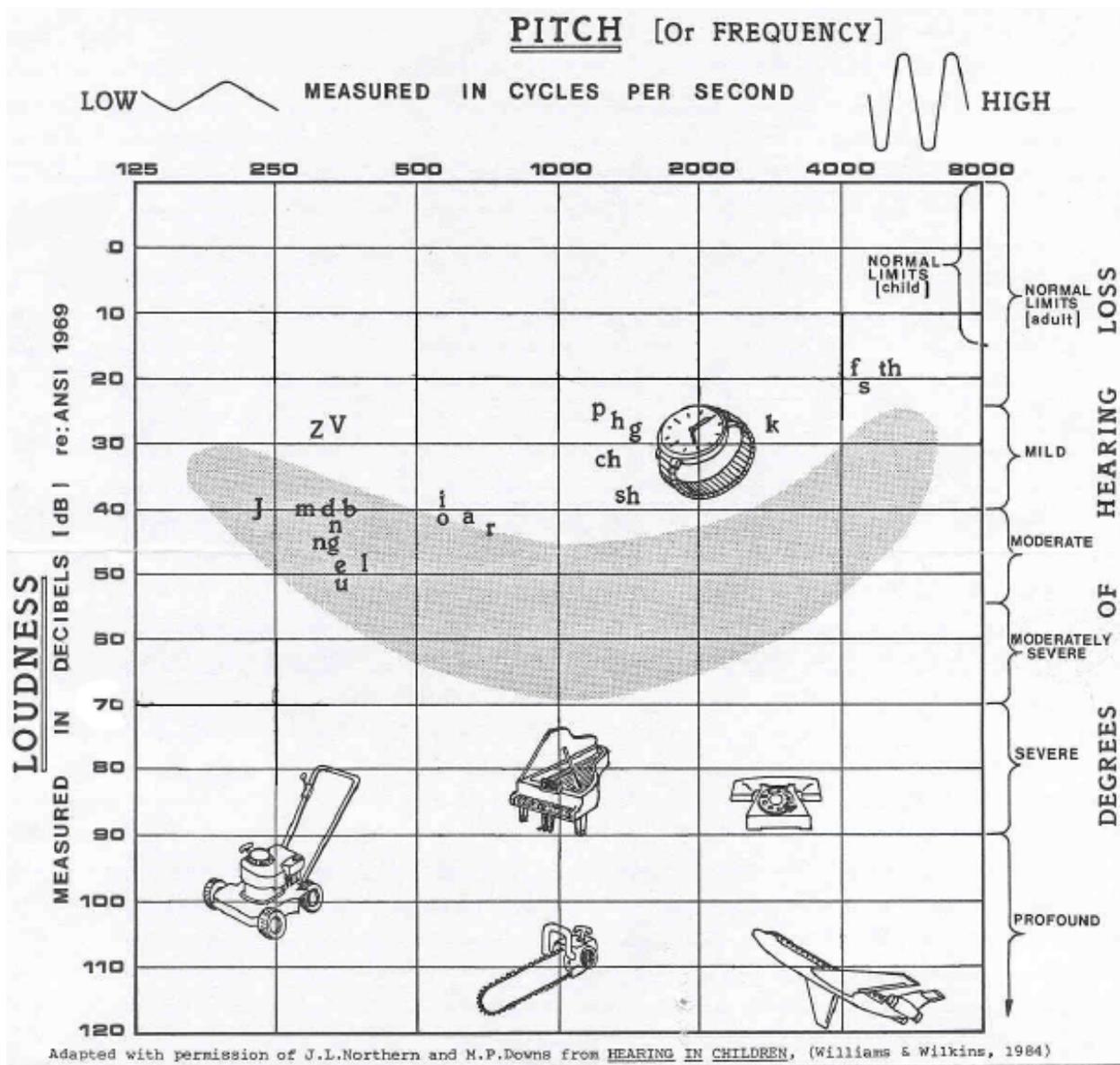
An audiogram is a picture of ability to hear sounds at different pitches. Your hearing test results are recorded on an audiogram. The audiogram below graphs where different sounds are located on the audiogram. The banana shaped area represents all the sounds that make up the human voice when speaking at normal conversational levels.

**Frequency:** The vertical lines on an audiogram represent pitch or frequency. The sounds on the left side of the audiogram represent a very low pitch and each vertical line to the right represents a higher pitch sound. The most important pitches for speech are between 500 -4000 Hertz (Hz).

**Intensity:** The horizontal lines represent loudness or intensity. The unit for intensity measurement is decibel (dB). The 0 dB line near the top of the audiogram represents the average loudness a young adult can barely detect or hear sounds of different pitches. Each horizontal line below represents louder sounds.

**Hearing Level:** The audiologist determines the quietest level (threshold) a person can hear a particular frequency and marks that on the audiogram. Since the quieter intensity is at the top of the audiogram, hearing levels marked on the upper part of the audiogram are closest to normal hearing. Hearing levels marked at the very lowest part are closest to no hearing, or complete deafness. The greater the degree of hearing loss, the further down on the audiogram it appears.

- **Air Conduction:** Hearing level is determined using headphones and is marked as a circle for the right ear (red is the designated color) and an X for the left ear (blue is the designated color).
- **Bone conduction:** Hearing level is determined using a vibrator placed on the mastoid bone behind the ear. A bracket is the symbol that designates the bone conduction response.
- **Sound field:** Hearing level is determined using a loudspeaker. An S is used to indicate the sound field response. A indicates ability to hear in soundfield while wearing hearing aid(s).
- **Normal Hearing:** Normal hearing in young children is defined as 0-15 dB.



**LOUDNESS LEVELS OF COMMON SOUNDS [IN DECIBELS]**

10 dB    Breathing	80 dB    Rush Hour Traffic	120 dB    Jet Airport
30 dB    Whisper	90 dB    Food Blender	140 dB    Shotgun Blast
40-60 dB    Conversation	100 dB    Train	
70 dB    Typewriter	110 dB    Chain Saw	

SHADED AREA REPRESENTS RANGE OF CONVERSATIONAL SPEECH

The shaded area, called the speech banana, represents conversational speech.

## Suggestions for Beginning Vocabulary

### Common Phrases

Bye-bye  
 Look at that  
 It's too heavy  
 Ow, it's sore  
 I want a \_\_\_\_\_  
 No-no-no, don't touch

Uh-oh it fell down  
 That's pretty  
 m-m-m that's good  
 what a mess  
 that's funny  
 stop it

brr that's cold  
 help me  
 I want more  
 Pick it up  
 Wait a minute

### Action Words

Push push it down  
 Mmm smell the flower  
 Wake up  
 Pop-pop the bubbles  
 Shh go to sleep  
 Sit down  
 Wash wash your hands  
 Have a drink  
 Blow blow the feather  
 Walk walk walk  
 Bounce bounce the ball

Go up up up the stairs/lift  
 me up  
 It goes round and round  
 Cut cut the banana  
 Brush your hair/teeth  
 Jump jump jump  
 That's hot  
 It's all gone  
 It's dirty  
 It's soft  
 It's broken  
 It's wet

It's sticky  
 The watch goes tic tock  
 Hi baby  
 I'm Mommy/Daddy  
 That's my shoe  
 Slide up, up up weee  
 That's my eye/nose  
 /mouth  
 Look at the fish  
 The clown says ha ha ha  
 Santa says ho ho ho

### Pronouns

That's mine  
 Give it to me

### Animal Sounds

Cow—moo  
 Cat—meow  
 Pig—oink oink  
 Bird—chirp chirp  
 Owl—hoo

Dog—bow-wow  
 Lamb—baa  
 Frog—hop hop hop  
 Duck—quack quack  
 Lion—roar roar

Horse—neigh  
 Fish—swish  
 Chicken—cluck  
 Monkey—ee ee ee  
 Bear—grr grr

### Vehicles

Boat – p-p-p  
 Airplane—aahh

Car—beep beep  
 Train—choo choo choo

Bus—bu bu bu

*Excerpted and adapted from Judith I. Simser, O.Ont,B.Ed.,Cert.AVT, Aural Habilitation Program  
 Children's Hospital of Eastern Ontario*

## Mainstream Kindergarten Readiness Skills

### Understand and use the following words:

Yesterday	Nighttime	Rectangle
Today	Square	Major colors
Tomorrow	Triangle	
Morning	Circle	

### Understand Boehm Concepts:

Top	Corner	Match
Through	Several	Always
Away	Behind	Medium-sized
Next to	Row	Right
Inside	Different	Forward
Some but not many	After	Zero
Middle	Almost full	Above
Few	Half	Every
Farthest	Center	Separated
Around	As many as	Left
Over	Side	Pair
Widest	Beginning	Skip
Most	Other	Equal
Between	Alike	In order
Whole	Not first or last	Third
Nearest	Never	Least
Second	Below	

### Demonstrate the following Cognitive/language skills:

- Sing the ABC song
- Count to ten
- Identify written numbers 1-5
- Categorize items (things that go in water, something you wear, fruits, vegetables, which doesn't belong)
- Retell stories of common knowledge (Three Little Pigs)
- Sing variety of children's songs (Happy Birthday, Itsy Bitsy Spider, etc.)
- Recite variety of Nursery Rhymes
- Describe objects
- Demonstrate understanding of If-Then
- Exposure to sorting/matching of picture/objects that have common initial consonant
- Exposure to letter-sound relationships
- Name
- Address
- How old are you now? How old will you be on your next birthday?
- Multi-step directions "on paper" (i.e.: draw a line under the yellow cat and put a circle around the green man)
- Exposure to colloquial saying, similes

*Excerpted and adapted from Beth Walker, M.Ed., C.E.D., Cert.AVT, East Alabama Ear, Nose, Throat*

# QUESTIONS & ANSWERS



**Q: *My child's audiologist has not completed an audiogram on my child, yet they want him to wear hearing aids. Is this OK?***

**A:** Yes, the identification of a child with a hearing loss is the first step in a process of audiological services and usually provides the audiologist with an idea of the general degree and configuration of the hearing loss. When a child is very young, it may take a series of evaluations to complete a detailed hearing profile. At the same time, the audiologist will put hearing aids on as soon as possible and refine and adjust the hearing aids over time. A pediatric audiologist will use the information acquired in testing as well as trial periods with hearing aids to complete the audiological recommendations for your child. Your input as a parent who has observed your child with hearing aids in the home environment can be very valuable in this amplification refinement process.

**Q: *We would like our son to learn to use his unaided hearing more. We feel if he wears his hearing aids all the time he'll never learn to hear without them. Should we leave his hearing aids off for a part of the day?***

**A:** No, only through consistent use of hearing aids will your child learn to identify sounds in his environment and learn to attach meaning to these sounds. For children with normal hearing, this is a skill that requires exposure to speech and environmental sounds in context over a period of time. You can help your son learn to use his hearing more by supporting listening skill development such as providing exposure to different sounds in his environment and calling attention to the sounds. Periodic non-use of a hearing aid does not improve the function of residual hearing.

**Q: *My pediatrician told me that my daughter was too young to have her hearing accurately tested. She is 7 months old. Is this true?***

**A:** No, although it is not possible for a pediatrician to test the hearing of a young infant or toddler, a pediatric audiologist who has specific training and equipment to test young children can test hearing reliability with the first few weeks of life.

**Q: *Does insurance cover the cost of hearing aids?***

**A:** Medical insurance policies do not usually cover the cost of hearing aids. This is determined on a case-by-case basis depending on the benefits of your particular policy. There are some programs such as Medicaid and Children with Special Health Care Needs that do cover the purchase of hearing aids. Your hearing specialist will assist you with pursuing financial assistance to purchase your child's hearing aids. As the payer of last resort, Florida's Services Early Steps Program will cover the cost of hearing aids as assistive technology listed on an Individualized Family Support Plan, only if there is no other method of payment.

**Q: *What happens to equipment purchased by Florida's Early Steps program when my child turns 3 years old?***

**A:** Children may keep the assistive technology devices purchased by the Program as long as it is needed. The equipment should be listed on the transition plan developed with the family and the local school district. If the children outgrow equipment and it can be used by other children, the early intervention program may want to put it in their equipment "library".

**Q: *Can hearing aids damage my child's hearing?***

**A:** There are procedural safeguards and test techniques performed by pediatric audiologists to prevent any damage to your child's ears and hearing. The audiologist will adjust the settings of the hearing aids so that they will not damage your child's hearing.

**Q: *How do I know if my son is a candidate for a cochlear implant?***

**A:** This is a discussion you will need to have with a variety of people, including your son's primary health care provider, audiologist, and intervention team. This decision will be made based on the extent of your son's hearing loss, the benefit he gets from wearing hearing aids, and an evaluation performed at a cochlear implant center. Your son's service coordinator can provide you with information and resources about this process. Also, internet sites for cochlear implants usually describe candidate qualifications.

**Q: *Who pays for cochlear implants?***

**A:** Typically, your health insurance will cover the cost of a cochlear implant. This should be discussed with your insurance company. Florida's Services Early Steps Program does not pay for any medical or surgical procedures but will support the intervention required prior to and after cochlear implant surgery.

**Q: *Someone told me that if my child uses sign language she would never learn to speak. Is this true?***

**A:** It has been shown that normal hearing babies that begin to learn signs early in life will use sign until they develop the ability to express their wants and needs using speech. Learning signs may not be the factor that interferes with a child's ability to learn to speak. That may be more related to their amount of hearing ability, consistency of language stimulation, motivation, cognitive ability, and learning style. There are many different philosophies about the use of sign language and the development of spoken language, but research is not yet available to substantiate these many different philosophies. Your intervention team should discuss your child's use of communication features and the intervention services available to your family to address any concerns you may have regarding the development of spoken language.

**Q: *If we choose sign language, can my child attend my neighborhood school?***

**A:** A school district is required to provide a free appropriate public education to your child. The school district is required to provide the services and supports your child will need to succeed in school. The school district is not required to provide all of these specialized services in every school. Therefore, your child may need to attend a school other than your local school to receive the support he or she needs. Attending a school with multiple children with hearing aids, cochlear implants and/or visual modes of communication can enhance the self esteem and sense of belonging of the child with hearing loss in addition to clustering the knowledgeable professionals that can respond to your child's immediate needs without having to travel between schools. There are also advantages to having regular education teachers and students who are accustomed to having children with hearing loss as a typical and well-accepted part of the student body. The fewer supports and specialized services your child requires to succeed in school, the greater the likelihood that his or her specialized needs will be able to be provided in the local school.

**Q: *My 9-month-old daughter is constantly throwing her hearing aids off. What can I do to keep them on?***

**A:** You should work with the members of your intervention team to develop a plan to address this problem. This may include some specific activities designed to get her adjusted to wearing the aids, some additional devices that will keep the aids in place, or some further audiological assessment to determine if the aids are working well for her type of hearing loss.

**Q: *How can I learn more about “Deaf Culture?”***

**A:** The best way to become exposed to the Deaf culture is to meet families and adults who are part of the Deaf culture. There are Deaf Service Centers throughout the state that assist Deaf individuals who may be helpful linking people together to learn more about one another. Your hearing specialist at the early intervention program can assist you in making the necessary contacts. Another way to learn more about the Deaf culture is to read books and view videos. Some books and videos are listed in the resource section of this guide.

**Q: *If my child uses sign language, how can I communicate with him?”***

**A:** Sign language, like any language, is learned by doing and using the language throughout the day. Parents often start by finding sign language books and watching sign language videos. Soon, the baby’s need for new signs to explain and comment on the world around them requires more than books or videos. You can enroll in sign language classes offered in your community. These classes offer either American Sign Language, the language of the Deaf culture, or instruction in a manual communication system (signs in English word order). You can connect with other families who use sign with their children, and your child and you can learn through fun, interactive communication. A Deaf mentor may be available in your community. There are Deaf individuals who have a desire to assist the family and child who is deaf with learning American Sign Language and developing a better understanding of the Deaf culture. As your child is better able to communicate through sign language, your skills will need to continue to grow and develop in order to communicate at or above your child’s level. Time and commitment with your child and other persons who sign will result in your becoming proficient in the use of sign language or manual communication systems.

**Copies of this guide are available by contacting:**

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