# EARLY HEARING DETECTION DARRENDING DARRENDING





# PARENTING A CHILD WITH HEARING LOSS

By: Laura Sarsfield

Your child has recently been diagnosed with hearing loss. As a parent, you may be unsure of what you should do now and how this diagnosis will affect your role as a mother or father. The direction in which you were expecting your lives to go has changed dramatically, and you are not sure what to expect from the future. Parenting a child with hearing loss does bring its own set of challenges, but you will also find that it brings even sweeter and greater rewards as you watch your child learn, grow, and develop.

Once you receive the diagnosis, you will experience many different emotions along the way: denial, sadness, anger, grief, guilt, uncertainty, and feeling overwhelmed, just to name a few. They will soon be mixed with accomplishment, joy, pride, relief, and awe as your child grows and develops. It is important that you allow yourself to feel each emotion as it comes because each is a step in accepting the hearing loss, your child, and your "new normal" as you work to provide your child with the care he/ she needs,

The emotions may feel very strong early on. Just as you are trying to come to terms with the fact that your child has a permanent hearing loss, you are being called on to make many important decisions with the limited amount of knowledge that you have about hearing loss so far. To help with these decisions, educate yourself so that you can make informed decisions for your child. Learn all you can about the hearing loss itself, the options for treatment and amplification, and the communication modes available, as well as the long-term expected outcomes for each. To help with this, surround yourself with a trusted and respected team of experts in the field of pediatric hearing loss: ENT doctors, audiologists, therapists, early interventionists and educators, and other parents of children with hearing loss, and become an active member of your child's team.

While the professionals are the experts in their respective fields, you are the expert regarding your child. You know him/her better than anyone else, and as his/her advocate, it is now up to you to ensure that he/she receive the top quality care that he/she deserves--so don't be afraid to ask questions, and listen to your instincts as a parent. Based on the goals you have for your child, decide which choices you feel will work best for him/her and your family, and then communicate, communicate, communicate. Have high expectations for your child's abilities; set high, yet reasonable, short-term and long-term goals for progress, then work hard as a team to help your child and family reach these goals. You will be amazed at what you can accomplish together.

The State of Georgia recommends that all babies receive a hearing screening by 1 month, receive an audiologic evaluation and diagnosis of hearing loss by 3 months, and be enrolled in an Early Intervention program by 6 months of age when a hearing loss is diagnosed.

Research shows that children born with hearing loss who receive appropriate intervention by 6 months of age have a good chance of learning to talk and communicate as well as children who hear normally. For this reason, it is very important that you seek out the recommended care as soon as possible and meet these 1 month/3 months/6 months goals to maximize your child's potential.

In many ways, parenting a child with hearing loss is the same as parenting any other child. Although the hearing loss is a part of who your child is, it will not define WHO he/she is, and many of the universal parenting guidelines still apply to your child. Show your unconditional love, establish routines, and set realistic boundaries to provide the feelings of safety, stability, and security that all children need. Act as a role model by setting positive examples for your child to follow, giving positive reinforcements and providing consistent messages, actions, and reactions. When parenting frustrations arise, just remember that both you are your child are learning together. Learn to anticipate the circumstances that bring on the frustration and misbehavior and try to diffuse or redirect them. Being patient, flexible, and creative is very important as you raise your child and take on situations related to hearing loss.

As a parent, help promote your child's positive self-image by accepting him/her for who he/she is, help him/her develop an understanding of right and wrong, and help teach him/her different problem-solving techniques to deal with life's difficulties. A positive, proactive attitude is key and will help your child both in accepting his/her hearing loss and in learning how to cope with and handle many different types of situations. Be straightforward and honest with your child about his/her hearing loss; educate him/her about it at an age-appropriate level to provide him/her with the tools he needs to speak to others about it. For your child, knowledge about what to say or do will encourage feelings of power and confidence. Communicate with your child constantly, no matter the mode of communication you are using. Constantly provide stimulation using your preferred mode of communication to promote language development. Seize every situation and use them as opportunities to help your child learn new language skills and new vocabulary. Offer encouragement whenever needed, and always be there to listen to your child, in good times and in tough times—and be an active listener. Encourage your child to join in conversations.

Parenting a child with hearing loss is a challenging task, just as parenting any child can be. At times it may seem overwhelming, so don't be afraid to ask others for help when you need it. Take breaks occasionally, making time for yourself so that you will be better prepared to care for others, and remember to nurture the other important relationships in your life, such as with your spouse/partner, other children/family members, and friends. The ultimate goal is to raise a happy, healthy child while equipping him/ her with the tools he needs to maximize his/her potential, so that he can one day become an independent, self-confident adult who will be able to make his/her own unique contributions to society. This cannot be done by one person alone. Surround yourself and your child with a strong support system of family, friends, and professionals. Above all, remember that you are not parenting a "hearing loss," you are parenting a child who has a hearing loss—and every child is a gift to be treasured.





# TALK WITH ME BABY

Babies grow really fast. We see it. In no time, you will be buying bigger diapers and clothes. What you don't see is how fast their brains develop. Just as your baby's body depends on the right nutrition, your baby's brain depends on language and experiences to grow too. In the first three years of life, brain cells form trillions of connections and for most children, the greatest growth in language takes place during the first 18 months. An environment rich in sights, sounds, language, and a variety of experiences provides the "nourishment" needed for the brain cells to form important connections.

The number of words your child hears in the first three years of life determines how quickly your child will be able to learn new words. The more words your child learns and knows, the more words he or she will be able to read. The better your child reads the more he or she learns. Yes! It is true. Even though your baby cannot say words yet, when you communicate and read to your baby, you are helping that little brain to develop the language skills to one day become an excellent reader!

If your baby has difficulty hearing, the growing brain misses out on hearing all those words and making those important brain connections. Children with hearing loss who cannot hear words and speech in their environment will have an extremely hard time learning spoken language and are at risk for not being able to read well.\* Exposing babies and young children to visual communication like American Sign Language can provide full access to language in the early years and help to support language development."

Early intervention services are provided by skilled professionals (some of which are deaf and hard of hearing adult role models) that aim to support babies and young children with developmental delays and/or disabilities. These services are based on the needs of your family and are provided from birth to 3 years of age; and may include speech/language therapy, physical therapy, and other types of services. Research shows that early intervention makes a BIG difference; therefore, it is important to act quickly! Babies diagnosed as deaf or hard-of-hearing who receive early intervention later. In fact, many children with hearing loss who receive intervention early develop language equal to children with normal hearing. Don't wait! By acting quickly, you will place your child on the pathway to greater language, literacy, and learning. For more information on Talk with Me Baby, please visit https://dph.georgia.gov/talkwithmebaby.

\*Deaf children who are born to Deaf parents fluent in American Sign Language develop language at the same rate as typically hearing children.



## WHO ARE THE PROFESSIONALS?

Helping your child will take a team of people, which can be referred to as a medical home. Always remember that you, the parents, are the most important members of that team. In a family-centered medical home the pediatric care team works with a child and a child's family to make sure that all of the medical and non-medical needs are met. Here is a brief description of some of the people you may meet. When meeting new professionals, it is okay to ask about their experience level working with infants and children with hearing loss. It's important that the professionals helping your child are knowledgeable about working with children with hearing loss and have the tools and skills to best meet the needs of your child and family.

#### Audiologist

- A professional trained to test hearing and who will have the skills and equipment for pediatric hearing testing
- Works with other professionals, such as the pediatrician, ENT, and early intervention providers who work with your child, regarding the hearing loss.
- Will discuss your child's hearing loss and how it affects their ability to hear and understand speech.
- Will be able to make recommendations about amplification choices (hearing aid, cochlear implant, etc) and provide follow-up and monitoring.
- Will provide audiologic follow-up care, including testing your child's hearing with and without amplification.
- Will assist in providing information on early intervention options.

#### Ear, Nose and Throat (ENT) Physician

- A doctor who specializes in ear problems and may request for additional testing to determine causes of hearing loss.
- Provides possible medical or surgical treatment, including cochlear implants, for different types of hearing loss
- Provides medical clearance for hearing aids, if appropriate and recommended

#### Early Intervention (EI) Specialist or Educator

- Assesses the needs of your family and child, including strengths and weaknesses
- Affiliated with Georgia's Part C Program, Babies Can't Wait (BCW), Georgia Parent Infant Network Education System (PINES), or private therapy provider
- Describes resources and connects your child and family with services to fit needs
- Discusses educational and communication options for you and your child
- Assists in linking family to financial support resources, if needed

#### Pediatrician/Family Practitioner

- A doctor who provides continual care for check-ups and routine medical care
- Makes referrals to the audiologist, early intervention, genetics, and ophthalmologist
- Monitors the progress of your child's communication and development

#### Service Coordinator

- Works with early intervention programs to assist families in identifying needs
- Ensures providers work together in the best interest of the child and family

#### Speech Language Pathologist

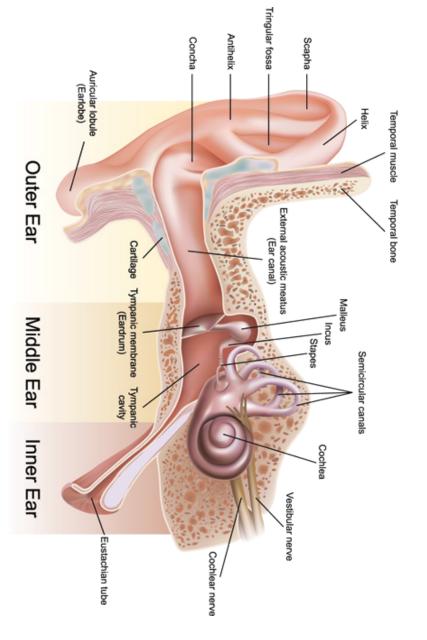
- A professional trained to know about how children learn language
- Teaches children how to use speech and language

#### Other Parents of Children Identified with Hearing Loss

- Provide emotional support and guidance
- Provide family support
- Provide information on parent/family support organizations
- Listen to you talk about your experience
- Share experiences
- Connect through the Guide by Your Side Program through Hands and Voices or through Parent to Parent of Georgia.







## UNDERSTANDING HEARING LOSS

#### Causes of Hearing Loss

Hearing loss in childhood may be caused by one or more reasons. Your child's ENT doctor may request additional testing such as MRI, CT scan, genetic testing, and vision testing be done to find out the cause of the hearing loss. Hearing loss most often has a genetic cause, and approximately 15% of genetic hearing loss is part of a syndrome such as Pendred, Wardenburg, CHARGE, and Down Syndromes. Non-genetic causes of hearing loss include malformations of inner and/or outer ear, trauma, and infections. Talk with the doctors working with your child to better understand possible causes of your child's hearing loss.

#### The Basics-The Ear

The ear can be divided into three parts:

#### **Outer Ear**

- Made up of three parts: The pinna (the part we see), the ear canal, and the eardrum
- Sound travels in waves through the ear canal to the eardrum setting the eardrum in motion

#### Middle Ear

 When the eardrum is set in motion, it causes the three middle ear bones or ossicles (malleus, incus, and stapes) to vibrate

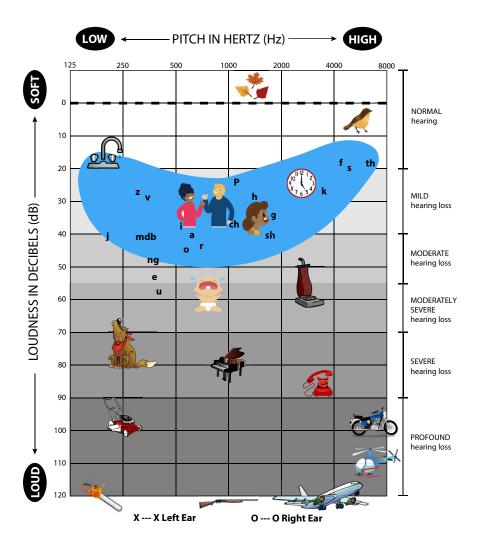
#### Inner Ear

 Sound vibrations cause movement of the fluid in the inner ear or cochlea which sends nerve impulses or signals through the auditory nerve to the brain. When the brain receives the signal it identifies it as sound

We hear with our ears and our brain. Both have to be working adequately for us to hear and interpret sound and understand speech.

#### **Describing Hearing Loss**

Hearing is graphed on an audiogram. An audiogram is a graphic record of hearing ability across the tested pitches. Hearing loss is described by the shape of the hearing loss, type of hearing loss, severity/degree of hearing loss, and whether one ear or both ears (laterality) have hearing loss. Characteristics of your child's hearing loss may change at any time. If you notice your child not responding to sounds that he/she once heard, it is important to have your child's hearing re-tested. Your child's audiologist can help you understand how and what your child hears. Examples of what hearing loss sounds like can be found at <u>https://www.hearinglikeme.com/hearing-loss-simulator/</u>, which may help you better understand your child's hearing loss.



## AUDIOGRAM OF FAMILIAR SOUNDS

#### Shape of Hearing Loss

Hearing loss can be described in terms of the shape it makes on the audiogram or the frequency/pitch that is affected by the hearing loss. The hearing loss can be flat, meaning the person has the same amount of hearing loss at every frequency. The hearing loss can also have a rising or falling pattern. A falling pattern, where the hearing loss is better in the low pitches and becomes worse in the higher pitches is called a high frequency hearing loss or sloping hearing loss. A child with this type of hearing loss misses such speech sounds as s, sh, th, f, and p. A low frequency hearing loss means their hearing is poorer for lower pitches than it is for higher pitches. All hearing losses can cause difficulty in understanding spoken language.

#### **Types of Hearing Loss**

#### **Conductive Hearing Loss**

- Hearing loss caused by something that stops sounds from getting through the outer or middle ear
- Often medically correctable, but sometimes a hearing aid is used to help the person hear

#### **Sensory Hearing Loss**

- Hearing loss that occurs when there is a problem in the inner ear (cochlea)
- This type of hearing loss is generally not medically correctable

#### **Neural Hearing Loss**

- Sound enters the inner ear normally but the transmission of signals from the inner ear to the brain is disrupted
- Permanent type of hearing loss and cannot be treated with medications or surgery
- Example of neural hearing loss is Auditory Neuropathy Spectrum Disorder (ANSD)
- People with ANSD may have normal hearing, or hearing loss ranging from mild to severe; they always have trouble understanding speech clearly. Often, speech perception is worse than would be predicted by the degree of hearing loss.

#### Mixed Hearing Loss

 Combination of the types of hearing loss and occurs when more than one hearing loss contributes to the hearing loss

#### Degree of Hearing Loss

Hearing loss and the degree of hearing loss are measured in decibels (dB). The softest sounds are made at zero dB (HL), and the loudest are 120 dB (HL). Conversational speech is roughly 50 dB (HL).

The table shows the various degrees of hearing loss. Hearing loss (HL) is never given in percentages, only in decibels. Talk with your child's audiologist about how your child's degree of hearing loss impacts what can be heard.

Degree of hearing loss	Hearing loss range (db HL)
Normal	-10 to 15
Slight	16 to 25
Mild	26 to 40
Moderate	41 to 55
Moderately severe	56 to 70
Severe	71 to 90
Profound	91+

The table below shows a common way to classify hearing loss.

Source: Clark, J.G. (1981). Uses and abuses of hearing loss classification. Asha, 23, 493-500.

#### Hearing Loss Laterality

- Bilateral hearing loss means hearing loss in both ears
- Unilateral hearing loss means that hearing is normal in one ear but there is hearing loss in the other ear, which can be of any severity and type. Individuals with unilateral hearing loss have increased difficulties hearing in background noise and determining where the sound is coming from

Each child is an individual and so the success of each child with language and communication varies. Success may not necessarily be dependent on the type, degree, shape, or laterality of the hearing loss. Age of onset (when hearing occurs), timeliness in diagnosing the hearing loss, and enrollment in early intervention are key factors in a child's success. Some children with mild hearing losses are not as successful at communicating as children with profound hearing losses. A child's educational achievement is influenced by a variety of factors in addition to the hearing loss, such as learning challenges, family support, communication choices, other medical concerns, educational program availability, and the child's own motivation.





## TYPES OF HEARING TESTS

Multiple tests can be used with children to determine the type and amount of hearing loss. The type of hearing test will depend on the child's age and development. There are tests that require the child to respond and other tests that do not require the child to participate. Here are a few audiometric tests that your child may have throughout childhood.

**Tympanometry:** Used for children of all ages to detect problems in the middle ear. This test does not require the child to respond. A probe is placed in the ear which measures the function of the middle ear.

**Acoustic Reflex Testing:** Used for children of all ages. This test uses a probe in the ear canal to record the movement of the eardrum when a muscle in the middle ear contracts to a loud noise.

**Otoacoustic Emissions (OAE):** Provides information about the outer hair cell function in the inner ear or cochlea. A small probe with an ear tip is placed in the child's ear canal that emits soft sounds. The inner ear responds to the sounds by producing another sound or echo that can be measured by the probe in the child's ear canal. This test can be used on children of all ages.

Auditory Brainstem Response (ABR): This test is used for children of all ages. Electrodes are placed on the scalp to record the brainstem activity of the auditory pathway when sounds are presented by earphones. An audiologist interprets the waveforms recorded to determine hearing levels.

Automated Auditory Brainstem Response (aABR): Performed only on newborns to screen hearing at the birthing facility or as an outpatient. For this test, sounds are played to the baby's ears. Band-aid like electrodes are placed on the baby's head to detect responses. This test measures how the hearing nerve responds to sounds and can identify babies who have a hearing loss. Results are fully automated and result in a pass or refer.

**Behavioral Observation Audiometry (BOA):** Used with babies who are 0 to 5 months old and too young for visual reinforcement audiometry (VRA). The infant sits with a parent or other adult. Sounds are presented through earphones or speakers and the audiologist watches for any reaction to those sounds from the infant.



**Visual Reinforcement Audiometry (VRA):** Hearing test used for children 6 months to 2.5 years of age. Testing is done in the test booth where the child sits on the parent's lap. Sounds are presented from speakers or earphones, and the child is conditioned to turn their head when the sound is presented by being visually rewarded with a light up toy or another object.

**Conditioned Play Audiometry (CPA):** Hearing test used for children 2.5 to 5 years old. The child is trained to perform an easy task (e.g. dropping block in bucket) in a response to a sound in order to determine hearing ability.

# COMMUNICATION OPTIONS

In order to learn sign or spoken language, constant, frequent, and consistent communication is very important. Children will learn to enjoy communicating if the family and those around them are committed to a two-way communication (i.e., responding to the child and encouraging the child to respond back) approach (This approach is called "serve and return"). Choosing a communication approach or method for a child with a hearing loss may take time and may change if your child is not making progress as expected. Information on all communication options should be discussed with professionals who can help you make informed decisions about what is best for your child and family. It is recommended to be open to all approaches, ask questions, and talk to families with children who use a variety of communication modes so you can make an educated decision for your child and family.

#### Factors to consider when looking at communication options:

- Your communication goals for your child
- Communication method should promote meaningful, enjoyable communication among the family members
- Ability to consistently use communication style
- Communication method should enable everyone in the family to communicate with the child
- Communication method should be in the best interest of the child. The child should be able to use language to express feelings, ask questions, obtain information, and participate in the world of imagination and abstract thought
- Degree of hearing loss and other disabilities the child may have
- Age of onset hearing loss and when diagnosed

#### **Communication Methods and Approaches**

- Visual Language: American Sign Language (ASL) is a visual language. It is a complete language. It is much more than making gestures or "pictures in the air." ASL has its own vocabulary and grammar that is different from English. Signs and sentences in ASL are made using handshapes (for example, a pointing handshape, or the fingers spread out to show the number 5), moving the hands and arms (for example, in a straight line, or bouncing), and different facial expressions (for example, frowning or raising your eyebrows). You can share feelings, abstract ideas, and make jokes using ASL. You can take ASL classes and start teaching your baby even while you are still learning it yourself.
- Listening and Spoken Language: Listening and spoken • language programs promote communication through spoken language without the use of sign language, for children with all degrees of hearing loss. Spoken language development is based on making the most of the child's remaining hearing through appropriately programmed amplification/hearing aid(s) or a cochlear implant(s). Parents and children learn ways for the child to use listening skills and spoken language through concentrated, systematic, language-based interactions throughout the child's day. Children also learn to make use of visual cues, such as speech reading or looking at the face or body to help with understanding when the auditory information is unclear. Language is encouraged by involvement as much as possible with other children who use listening and speaking, whether or not the children have hearing loss.
- Combination of Visual and Spoken Communication uses both visual and spoken language individually or together to communicate, depending on the needs of the child. Establishing clear communication becomes more important than sticking with one communication method. Simultaneous Communication (SimCom) is a type of combining visual and spoken language, where signs are used in English word order rather than ASL word order, which has a different grammatical structure. Cued Speech is another method that visual and spoken language is combined. Cued speech uses system of hand cues to allow a person who has a hearing loss to see every spoken syllable that a hearing person hears. Currently, Georgia does not have a program/ school that supports Cued Speech as a communication modality.



# AMPLIFICATION CHOICES

Depending on the degree of hearing loss and type of hearing loss, a hearing aid or other type(s) of assistive listening device might be recommended for your child. It is important for your child to have access to a full range of sounds and be fit with amplification as early as possible after diagnosis of hearing loss, if appropriate. Access to speech sounds and receptive language skills is the first step in developing spoken language. The next section explains types of devices that might be recommended for your child.

#### **Hearing Aid**

A hearing aid is a device for the ear that makes sounds louder for the range of a particular hearing loss. The goal is to provide the ability to hear speech and environmental sounds at a comfortable level. If learning speech or responding to sounds in the environment is a communication goal, either a hearing aid or a cochlear implant (surgically implanted device that stimulates the hearing organ) would be used to provide necessary amplification to access speech sounds. Hearing aids can be adjusted if the hearing loss changes or if child does not seem to respond to certain sounds in his/her environment.

Every hearing aid has a microphone (picks up sounds in environment), an amplifier (makes sounds louder), a receiver (where sounds exit the aid and are directed into a child's ear), and a battery (see picture below).

Hearing aids come in several sizes, colors, and styles. Some hearing aids may have a volume wheel where others might not. Your child's audiologist will discuss the options for your child. For infants and children, it is recommended that they are fit with a behind-the-ear (BTE) style hearing aid. A BTE hearing aid includes a hearing aid that fits behind the ear and an earmold made to fit the child's ear. The earmold is attached to the hearing aid by an ear hook and tubing. This style of hearing aid is most appropriate for infants and children.





# HEARING AID CARE AND MAINTENANCE

Cleaning and caring for your child's hearing will improve the lifespan of the hearing aid. Your child's audiologist should provide you with tools for cleaning the hearing aid and check to ensure the hearing aid is working. Tools may include: a listening tube to perform listening checks to ensure hearing aid is working and the sound from the hearing aid is not distorted, a battery tester to show how much battery power is remaining, an air blower to push out moisture or earwax found in the earmold and/or tubing, and picks and brushes to clean off the microphone and to remove ear wax from the earmold. To assist in daily care of your child's hearing aid, here is a recommended checklist of items that should be completed daily:

- □ Check the case of the hearing aid for cracks and dents
- □ Check the tubing for slits, which are often found at the entry of the earmold
- □ Check the tubing for moisture; if found blow out moisture with air blower
- □ Check the earmold for wax; if found, remove wax with tools
- □ Check battery power; use battery tester and replace as needed
- □ Listen to the hearing aid by using the listening tube or stethoscope; a listening check should be done with and without the earmold on. When listening to the hearing aid, or when speaking into the hearing aid, listen and check for distortion, check to see if volume control works, if applicable, and listen to the hearing aid in all programs.

#### **Troubleshooting a Hearing Aid**

Occasionally you might have to troubleshoot your child's hearing aid. Here are some common problems and things to try before contacting your child's audiologist. When there is no sound or the sound is unclear during a listening check:

- □ Put in a new battery and perform listening check again
- Check for corrosion on the battery contacts (metal pieces inside the battery compartment); if you find corrosion, contact your child's Audiologist
- Double check that hearing aid is on
- □ Clean any wax from the earmold
- □ Check the tubing for moisture; if you find moisture or debris, blow it out with the air blower

If the hearing aid is whistling (feedback) when in your child's ear:

Check earmold placement in ear and make sure the earmold fits tightly inside the ear

- □ Remove any wax from the earmold
- Check for moisture in the earmold tubing, blow it out as needed
- □ Check for cracks in earmold and tubing. If cracked or signs of damage, contact your child's audiologist
- □ Wax may be blocking the ear canal. Contact your child's audiologist or primary care physician

#### Hearing aid Frequently Asked Questions

#### Do all children with hearing loss need a hearing aid?

No. Some hearing losses can be corrected by medical or surgical treatment. Once treatment has been provided, hearing should be retested to see if it has returned to normal. With hearing losses that are permanent and not medically correctable, amplification is an option that should be considered.

For children with unilateral hearing loss (hearing loss in only one ear), some may or may not get a hearing aid for the ear with the hearing loss, depending on the degree of hearing loss and the child's listening environment. Some children with profound hearing loss in both ears get little benefit from the strongest hearing aids. After a trial period with hearing aids, families of these children may decide to get a cochlear implant for their child.

#### When can my child get a hearing aid?

A newborn may be fit with a hearing aid shortly after hearing loss is diagnosed and medically cleared by an ENT doctor. A baby as young as 7 days old can be fit with a hearing aid. Research tells us that fitting a hearing aid as soon as the hearing loss is diagnosed helps to maximize speech and language development.

#### Who decides which hearing aid is best?

Parents and the child's audiologist should carefully decide on hearing aid(s), based on the child's needs, degree and type of hearing loss, available technology and financial resources. Hearing aid(s) should have a fitting range that provides adequate amplification for the child's hearing loss; however, the aid(s) should be adjustable to accommodate any changes in hearing sensitivity. The audiologist will conduct tests while the child is wearing amplification to determine the benefit of the hearing aid(s) on a regular basis. Some other factors to consider when selecting amplification are the durability of different hearing aid(s) and compatibility with assistive technologies the child may need now or in the future. Hearing aids must also adjust with children as they grow. Because of this, behind-the-ear (BTE) hearing aid(s) are more practical. Ear molds, which sit in the ear and attach to the BTE hearing aid(s) preferable to smaller custom hearing aids that fit in the ear.

#### Bone Conduction Hearing Aid

Some children may not be able to wear a conventional BTE hearing aid(s) due to a malformed outer ear or because of continuous drainage from the ear canal. Children who cannot wear a BTE style hearing aid may be fitted with a bone conduction hearing aid. A bone conduction hearing aid can be worn with a headband (elastic or metal) and it sits snuggly behind the ear. This hearing aid style picks up the sounds with a microphone and converts the sounds into vibrations, which directly stimulate the hearing organ.

#### Assistive Listening Technology

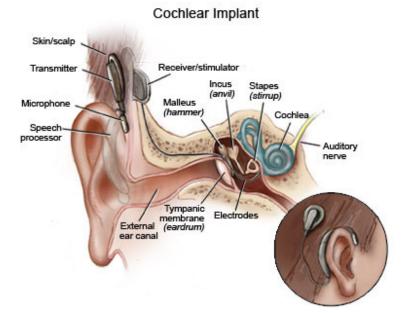
FM (frequency modulation) Systems help improve speech understanding in situations that are more challenging for listening, like in a classroom. FM Systems can be used with hearing aids because even hearing aids that are properly adjusted to a child's needs can't always provide adequate amplification with competing background noise. FM systems pick up speech at the source, from a microphone, and transmit the speech directly to the ear which is helpful in difficult listening environments.



#### **Cochlear Implant**

A cochlear implant is an electronic device that is surgically placed to replace a damaged cochlea. The cochlear implant has an internal piece that is implanted in the cochlea and an external component that picks up the sound and changes the sound into an electrical signal. The signal is sent to the internal component within the cochlea, which stimulates the auditory nerve. The external piece is worn at ear level like a behind the ear hearing aid. A speech processor is typically located inside the earpiece. The cochlear implant does not provide normal hearing, but it does allow the person implanted to detect a wide range of sounds. Cochlear implants can be paired with assistive listening technologies to improve speech detection and understanding.

A cochlear implant may be an option when hearing aids do not provide enough benefit to individuals with severe to profound sensorineural hearing loss. A team of professionals including an audiologist, otolaryngologist, speech pathologist, and others determine if a cochlear implant is an option for your child.



## UNDERSTANDING YOUR CHILD'S RIGHTS UNDER THE AMERICANS WITH DISABILITIES ACT

Whether your child is deaf or hard of hearing, whether your child signs or is oral, your child may experience discrimination at some time in life because of his or her hearing loss. It is your job as a parent to learn about your child's rights and advocate for those rights during your child's youth and teach your child about those rights to foster self-advocacy in adulthood.

There are state and federal laws, rules, and regulations that protect the rights of people with disabilities. One federal law is the Americans with Disabilities Act (ADA) which was signed into law in 1990 and has four main sections called "Titles." In order to be protected by the provisions of the ADA, you must be a person with a disability, which has several definitions. The main definition of experiencing a disability is being limited in one or more major life activities, such as hearing, walking, or seeing. Another federal law is the Rehabilitation Act of 1973, which mirrors the ADA but applies to the federal government and any place that receives federal funding.

#### Americans with Disabilities Act (ADA) and Its Four Titles

Title I of the ADA prohibits employers, employment agencies, labor unions and joint labor-management committees in the private sector from discriminating against persons with disabilities. The law applies to private employers who have 15 or more employees, although some states have additional laws that apply to employers who have less than 15 employees. The law also applies to state governments and agencies in their employment practices. However, federal employees, such as postal workers, are protected by Section 501 of the Rehabilitation Act of 1973, rather than by the ADA. The ADA requires employers to not consider a job applicant's disability when hiring. The ADA also requires employers to provide employees with disabilities a "reasonable accommodation" when necessary to aid such employees in performing essential functions of the job. Reasonable accommodation is defined as a modification or adjustment to a job, the work environment, or the way things are usually done to enable a qualified individual with a disability to have an equal employment opportunity (29 C.F.R. \$1630.9(a). Accommodations may include TTYs, interpreters, real-time captioning, amplified phones, visual alarms, assistive listening devices, note takers, etc.

**Title II** of the ADA prohibits state and local government from discriminating against persons with disabilities. Examples of state and local government are schools, social service agencies, libraries, state and local courts (civil, criminal, traffic, small claims, etc. whether you are a defendant, plaintiff, juror, witness, or member of the public), prisons, jails, etc. State or local agencies that receive federal financial assistance are also covered under Section 504 of the Rehabilitation Act of 1973.

**Title III** of the ADA prohibits places of public accommodation, regardless of size or non-profit status, from discriminating against persons with disabilities. Places of public accommodation include: doctors' and lawyers' offices, trade shows and conferences, hotels and motels, theatres, banks, museums, parks, restaurants, private schools, etc. These places must provide auxiliary aids and services to ensure effective communication so that the person with a hearing loss is able to benefit from the offered services and facilities.

**Title IV** of the ADA requires telephone companies to establish interstate and intrastate Telecommunications Relay Services (TRS) 24 hours a day, 7days a week. TRS allows persons who have a hearing loss who use a TTY (teletypewriters), a pager, or a computer to communicate through an operator or interpreter, directly with a hearing/voice telephone user. Title IV has expanded to include video relay services (VRS) for people who are deaf to use as an alternative to TRS.

#### What Does the ADA Say About Communication Access for the Deaf/ Hard of Hearing?

Effective communication can look different for each person who is deaf or hard of hearing, so the law does not dictate which form it could take. The ADA does not specify that only a sign language interpreter be provided for a person with a hearing loss, but it does require that "effective communication" be provided. This could be accomplished using a sign language interpreter, writing back and forth, lip-reading, etc., depending on the communication mode and needs of the person with a hearing loss. While an interpreter might be the only means to effective communication for one, various different means of communication might be used for another individual.

#### Who Requests Communication Access or Interpreting Services?

The ADA was written so that the person with the disability is supposed to ask for an accommodation. The provider is not always required to ask the person who is deaf, "Do you need an interpreter?" You, as a parent, need to teach your child how to ask for the help s/he needs to access communication, whether it's signed or spoken. If your child can only "effectively communicate" via sign language, then you/he should state "in order to effectively communicate with you, I require a sign language interpreter." If your child can effectively communicate via sign language and written communication, then it is the provider who gets to choose which method to use. There are many technologies in place to support non-signed communication, (including telephone relay services, voice relay, pager and even chat features online) so be sure to specify which your child prefers and provide easy instructions on use so the provider will find it easy to accommodate this request.

It is also the provider who chooses which interpreter/interpreter agency to use, not the person who has a hearing loss. As long as a qualified interpreter is used, then the provider is fulfilling his/her obligations under the ADA. A "qualified interpreter" is defined as ". . . an interpreter who is able to interpret effectively, accurately and impartially both receptively and expressively, using any necessary specialized vocabulary." 28 C.F.R. 36.303(b)(1) Many states have additional requirements for interpreters, some in educational settings, some in legal/court settings, and some require licensure.

Taken from: <u>http://www.handsandvoices.org/articles/education/law/V12-</u> 4\_childrights.htm

#### Knowledge is Power:

Your child is afforded safeguards under the Individuals with Disabilities Education Act, 34 C.F.R.§ 300 et seq. (IDEA). For more information on dispute resolution options, please visit <u>www.cadreworks.org</u>

# GEORGIA DEPARTMENT OF **PUBLIC HEALTH**

Georgia's public health programs for children birth to five are located within the Department of Public Health. The single point of entry for all of Georgia's birth to five programs is Children 1st. Therefore:

**Children 1st** processes the referral and forwards to any program that may be of benefit for the child, such as Babies Can't Wait (BCW) Early Intervention Program, Children's Medical Services (CMS), and Georgia Parent Infant Network for Educational Services (PINES). Children 1st can link you to these programs as well as other public and private services providers in your community and throughout the state. A statewide contact list for the Children 1st District Coordinator can be found on the Children 1st webpage: <u>http://dph.georgia.gov/children-first</u>.

**Babies Can't Wait (BCW)** is an intervention program for infants and toddlers, birth to three years old, who are Georgia residents, and are at risk for developmental delay, or are experiencing developmental challenges. All children with hearing loss, regardless of degree, are automatically eligible for BCW. There is no income eligibility for this program, but services are provided on a sliding fee scale. BCW can offer a variety of resources for families of infants and children with hearing loss, including assistance with hearing aids, other assistive technology devices and services, service coordination, speech and language therapy, and family support and training. For more information or to view a program contact list, visit the BCW webpage: <a href="http://dph.georgia.gov/Babies-Cant-Wait">http://dph.georgia.gov/Babies-Cant-Wait</a>.

**Parent to Parent of Georgia** is a central resource and parent directory linked with BCW. Other parents can be a great resource of information based on their own experiences. They can discuss their feelings related to parenting a child with hearing loss and listen to you and your challenges. They can share achievements and setbacks of your child and relate to the feelings you are having. In the state of Georgia, you can talk with other parents who have experienced the same things you are going through right now so that you can begin sharing information. For more information, please visit <u>https://www.p2pga.org/</u>.

**Children's Medical Services (CMS)** is a medical program for children and young adults, birth to age 21, with chronic medical conditions. Eligibility is based on income and diagnosis. Services available through this program include programs for children with hearing loss. For more information or to view a program contact list, visit the CMS webpage: <u>https://dph.georgia.gov/CMS</u>.



The **Early Hearing Detection and Intervention (EHDI)** Program is a statewide initiative to develop and sustain a comprehensive coordinated system for Universal Newborn Hearing Screening in Georgia to assure that all newborns receive a hearing screen prior to hospital discharge, infants with hearing loss are diagnosed by 3 months of age, and are referred for appropriate intervention by 6 months of age. For more information, please visit the EHDI webpage: <u>https://dph.georgia.gov/</u><u>EHDI</u>.

# GEORGIA DEPARTMENT OF EDUCATION

Within the Department of Education is the Georgia Parent Infant Network for Educational Services (PINES) and Georgia Hands & Voices<sup>™</sup> Guide By Your Side<sup>™</sup> (GBYS) program. Georgia PINES is a free, statewide, home intervention program available to families of children birth to five years who have hearing loss or vision loss.

Georgia PINES mission is to support, educate, and empower families of young children with sensory loss to positively impact their quality of life through collaborative efforts in natural environments. Georgia PINES provides weekly home visits to train the family using the SKI-HI, INSITE, VIISA, or Deaf Mentor Model depending on the child and family. Georgia PINES offers services to all families of children with permanent hearing loss. For more information on Georgia Pines, please visit their webpage: <a href="http://gapines.us/">http://gapines.us/</a>.

GBYS is a family support program that provides support and resources in an unbiased manner to families with children who are deaf or hard of hearing (DHH). GBYS has specially trained parents of children with deafness or hearing loss who work as "guides" directly with families who have just learned their child cannot hear, or who have older children and are in need of the unique support that comes from someone else who has walked this path him/herself and can share from direct experience and wisdom. This is a free program for all families in Georgia with a DHH child and is supported by the Georgia Department of Education. Requests for a Parent Guide may be obtained through an electronic form on the Georgia Hands & Voices website (gahandsandvoices. org) by parent self referral, or a service provider, with parent consent. GBYS services are offered to all families with a child who has received a diagnosis of hearing loss.



# GLOSSARY

**Aided response threshold(s)**: reflect responses to the softest sounds at different pitches that a person wearing amplification can detect during a hearing test.

Acquired hearing loss: hearing loss that occurs after birth.

Americans with Disabilities Act (ADA): signed into law in 1990, this is a "civil rights" act for persons with disabilities, which requires public services and buildings to make reasonable accommodations to allow access by persons with disabilities.

**Amplification:** Amplification can refer to many types of technologies that provide access to sound, including hearing aids, cochlear implants, assisted listening devices, and so forth.

Assistive listening device/system: any device used to help a person hear better. Usually used to describe a device or system that places a microphone near a sound source to provide a clearer or amplified signal to a listener in a situation where there is or may be a lot of background noise.

**Audiogram:** a graphic record of hearing ability across the tested frequencies which is used to describe hearing loss.

Audiologist: a licensed professional specializing in hearing.

Auditory Brainstem Response (ABR): a test that uses electrodes to record the response of the brainstem and auditory pathway from sounds presented by earphones.

Auditory Neuropathy: a condition with normal cochlear function (OAEs are present) but have abnormal auditory nerve function (ABR is absent).

Auditory nerve: the cranial nerve (CN VIII) that carries nerve impulses from the inner ear to the brain.

Auditory training: exercises in listening to environmental sounds, music, and speech to practice recognizing what has been heard without facial cues.

**Aural habilitation/rehabilitation:** a training program for people who are deaf and hard of hearing. Program focuses on learning to use residual hearing, speech-reading, and other techniques to communicate.

Bilateral hearing loss: hearing loss in both ears.

Binaural: involving both ears; refers to hearing aids worn in both ears.

**Bone Conduction:** sound that is sent from the surface of the skull to the inner ear; can refer to a type of hearing aid or direct way to test the function of the inner ear.

**Cochlea:** the organ of hearing located within the inner ear. In the cochlea, sound vibrations are converted to nerve impulses, which travel up the auditory nerve to the brain.

**Cochlear implant:** a surgically implanted device to transmit sounds in the environment to electro-acoustical impulses to stimulate the hearing nerve.

**Conditioned Play Audiometry:** a type of hearing test used with children from 2.5 to 5 years of age where the child is trained to perform an easy task (e.g. dropping block in bucket) in response to a sound

**Conductive hearing loss:** a hearing loss occurring in the outer and/or middle ear.

Congenital: present at or before birth.

**Deaf:** a term sometimes used to refer to persons who have a severe to profound hearing loss (greater than 70 dB HL) in both ears. The term also sometimes used to refer to those who consider themselves to be a part of the Deaf culture or community and use American Sign Language (ASL).

**Deaf Culture:** the set of shared attitudes, values, goals, and practices of the Deaf, based on a common heritage and use of ASL for communication.

**Decibel (dB):** the units used to measure the loudness of a sound. The higher the dB level, the louder the sound.

**Earmold:** a custom-molded piece of material that fits snugly into the outer portion of the ear. The earmold is attached to the behind-the-ear (BTE) hearing aid by tubing.

**Expressive language:** words, signs, gestures, and language concepts used to communicate a person's thoughts and meaning.

**Feedback:** the high pitch, whistling noise caused by a hearing aid that is not fit properly.

**Frequency:** a term used to describe the pitch of a sound, which ismeasured in cycles per second. Frequency is measured in hertz (Hz). The more cycles per second the sound is, the higher the pitch of the sound.

**Hard of hearing:** a term sometimes used to describe a person with hearing loss in one or both ears, usually those with hearing loss in the mild to severe range.

**Hearing aid:** a device worn, used to make environmental sounds audible to the person. The device is programmed specifically for the person's hearing loss to make sounds audible at the pitches with hearing loss.

**Hearing loss:** the partial or total inability to hear sounds within a given frequency (pitch) range due to a problem with the outer, middle, inner, and/or hearing nerve. Hearing loss may be permanent, transient, progressive, stable, and occur in one or both ears.

Hertz (Hz): a unit of measure for frequency (pitch).

**Immittance testing:** testing that measures and records middle ear function.

**Individual Education Plan (IEP):** a child-focused plan for schooling the pre-school and school aged child.

**Individual Family Service Plan (IFSP):** a family-focused plan for follow up care that covers the child until 3 years old.

**Individuals with Disabilities Education Act (IDEA):** a law that governs early intervention programs for children with disabilities.

**Intensity:** a term used to describe the loudness of a sound, which is measured in decibels (dB). The larger the number of decibels, the louder the sound is in the environment.

Localization: ability to determine where a sound comes from.

**Mixed hearing loss:** hearing loss that is a combination of any two types of hearing loss.

Monaural: affecting one ear; refers to hearing aid worn in only one ear.

**Ossicles:** the chain of three tiny bones in the middle ear space (malleus, incus, and stapes).

**Otoacoustic Emissions (OAE):** a test that uses a probe in the ear to measure the response of the cochlea to sounds that are presented to the ear.

**Otolaryngologist:** a medical doctor specializing in problems of the ear, nose, and throat.

Otologist: a medical doctor specializing in problems of the ear.

**Post-lingual hearing loss:** hearing loss that is acquired or begins after a person has learned language.

**Pre-lingual hearing loss:** hearing loss that is present or begins before a person has learned language (usually before two years of age).

**Pure tone average (PTA):** an average of the hearing thresholds at the frequencies of 500 Hz, 1000 Hz, 2000 Hz, and 4000 Hz. PTA is used to determine overall degree/severity of hearing loss.

**Real ear measurement:** a measurement of the hearing aid function, while it's being worn in the ear.

**Receptive language:** words and language concepts that one understands.

**Residual hearing:** any measurable hearing that a person with hearing loss still has and can use for communication, with or without amplification.

**Sensory hearing loss:** hearing loss caused by a problem in the cochlea (hearing organ). This type of hearing loss is generally permanent.

**"Speech banana":** an area often marked on an audiogram to show the range of frequencies (pitch) and intensity (loudness) that are necessary for hearing all parts that make up the sounds of speech.

**Speech-Language Pathologist:** a licensed and certified professional with special training to evaluate and work with individuals who have speech and language needs.

**Speech-reading:** observing lip and mouth movements and facial expressions to understand spoken words; also referred to as lip-reading.

**Telecommunication Device for the Deaf (TDD):** an electronic device that allows persons with hearing loss to communicate by a telephone, which uses text to relay the message.

**Threshold:** the softest, faintest level at which a sound (or speech) is heard 50% of the time by the person whose hearing is being tested.

**Tympanic membrane:** the eardrum; separates the outer and middle parts of the ear and moves to transmit sound.

**Unaided responses:** responses to sounds during a hearing test, when the person being tested is not wearing any amplification or assistive listening device.

Unilateral hearing loss: hearing loss occurring in only one ear.

**Visual Reinforcement Audiometry (VRA):** a type of hearing testing used with children from 6 months to 2.5 years where a sound is presented, and the child turns his/her head to the sound. After the child turns his/her head to the sound, a visual reinforcement is presented to the child as a visual reward.

# **MY CONTACTS**

EHDI Coordinator:

Pediatrician/ Family Doctor:

ENT Physician:

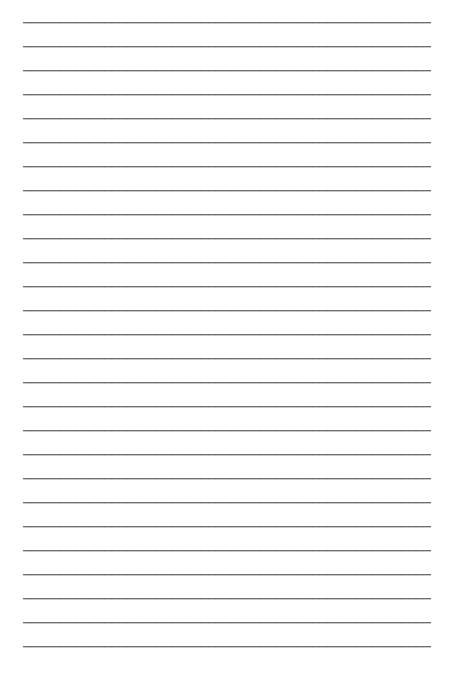
Audiologist:

Children 1st Coordinator:

Early Intervention Specialist:

Speech/ Language Pathologist:

#### Notes





### dph.georgia.gov/EHDI

February 2020