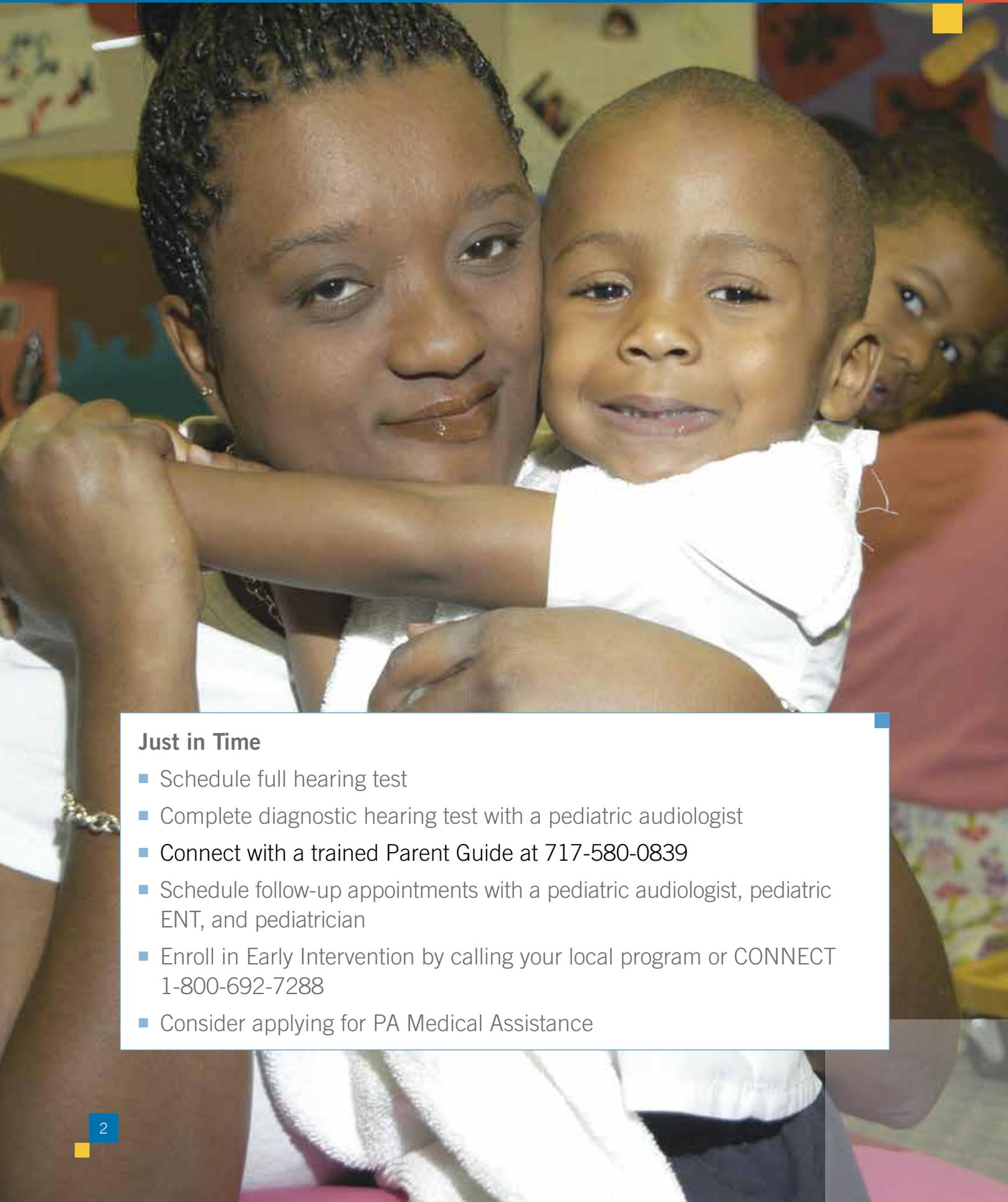


# Getting Started

Resources for Parents and Families  
of Infants and Young Children  
with Hearing Loss



### **Just in Time**

- Schedule full hearing test
- Complete diagnostic hearing test with a pediatric audiologist
- Connect with a trained Parent Guide at 717-580-0839
- Schedule follow-up appointments with a pediatric audiologist, pediatric ENT, and pediatrician
- Enroll in Early Intervention by calling your local program or CONNECT 1-800-692-7288
- Consider applying for PA Medical Assistance

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## Introduction

*Getting Started* is intended to provide support and resources to families who have a baby or young child with hearing loss. Pennsylvania parents contributed to this publication. These parents represent different communication methods as well as different regions of the state. Some are hearing and some are parents who are Deaf. Their children may wear one or more hearing aids or have cochlear implants. Their messages are contained in this publication.

*Getting Started* will introduce you to some of the important concepts and options that are available to you and your baby.

When your baby has hearing loss, there are things you can do right now to support your baby's well-being. A first step is to call CONNECT services. The CONNECT Helpline staff will refer a family to the appropriate local Early Intervention agency. The toll free number is 1-800-692-7288. Early Intervention is provided at no cost to families in Pennsylvania.

Remember, you are a team member with the specialists who are involved in your baby's development. Share your questions, concerns and priorities with them. You can also connect with other families and learn from their experiences through Hands & Voices Guide By Your Side of PA, our statewide family support program. Parent Guides are trained to provide unbiased information on all communication opportunities, support, mentorship and guidance.

*I felt so lost and overwhelmed in the beginning, but Early Intervention has provided so much support and direction for my daughter and for our family. Our daughter has come such a long way in just the first year of her life.*



Your baby with hearing differences will grow, change and surprise you! When we learned about our son's hearing situation we never expected him to be our most musical child, but he is. He enjoys cello, piano, orchestra and chorus. He is athletic and does not let his hearing hold him back from exploring his interests and talents. He is an amazing young boy and has opened a wonderful world to all of us.

## Bonding Through Early Communication

For many family members without hearing loss, the early decision about how to communicate with a baby with a hearing loss takes a long time and sometimes involves in-depth discussion and research. Yet, during the time this decision is being made, you still need to communicate with your baby. You may ask, “How can I bond with my baby if he or she can’t hear my voice?” It is not only possible, it is essential. Your baby may need additional help to communicate, but starting now gives your child the best opportunity to learn to communicate.

Bonding means to form a connection with another. This is especially important early in your baby’s life. Research has shown that babies who bond early in life will later trust other people and feel good about themselves. You, as the parent of a baby with a hearing loss, can bond in many different ways – by touch, smell, sight, and sound, when that applies. Here are some suggestions:

### **Gain and keep your baby’s attention.**

- Face your baby and maintain eye contact
- Get on the same eye level as your baby. If your baby is lying on the bed or floor, get down there with him or her.
- Tap your baby gently on the arm. Call or sign your baby’s name.
- Create visual gestures and facial expressions (to convey happiness, sleepiness, etc.) and body movements to explain the world to your baby.
- Point out things of interest to your baby. Offer books and read to your baby frequently.
- Encourage lots of sound for your baby, even if he/she has a hearing loss. Make noises to encourage him/her to look when his/her name is called.

- Consider reducing background sounds (such as dishwasher, TV, washers, or dryers) when communicating with your baby.
- Exaggerate facial expressions and words.
- Make lots of sounds for your baby!
- Sing to your baby. This provides abundant input to the natural rhythm and rise and fall of voices. Listen to music and sway or dance with your baby.
- Play games to engage your baby! Move his/her legs and engage in touching behaviors such as tapping, stroking, and tickling.

Although your baby may or may not be able to hear your voice, he or she will learn to read facial expressions. It may seem odd to talk to a baby with a profound hearing loss, but it gets easier as parents realize the benefits the baby receives. The most important thing to remember is to keep interacting with your baby, even though he or she may not hear you very well.

### **Keep the communication path clear and build “conversations.”**

- Clear the visual path between yourself or other speakers and your baby. Make it easy for your baby to see the person communicating.
- Conversation is a lot like a game of volleyball – one passes the ball back and forth, taking turns. When a baby cries or points, she is serving the ball to the adult. The adult responds as if to say, “What do you want?” The baby then communicates again.
- When your baby gestures, you should respond. By being a responder, you shape your baby’s gestures into true language.

*We fretted over how he would feel about himself and his hearing loss and then we calmed down, realizing he is just perfect exactly the way he is.*

## Develop turn-taking and conversation.

- Be a good observer. Watch, listen, and respond to your baby and become aware of the way he/she is trying to communicate.
- Your baby may communicate by:
  - Smiling
  - Fussing/crying
  - Looking around
  - Babbling
- When your baby tries to communicate, communicate back to them. If your baby is pointing to a ball, ask him/her, “Do you want the ball?” This helps your baby learn turn-taking in language.
- Follow your baby’s lead. As your baby explores and plays, comment on what is taking place and name the objects that are being played with.
- Be patient. The bond between you and your baby will continue to strengthen as you learn to communicate together.

Our children are amazing and wonderful...never forget that!

## Keep the conversation going.

- Smile, clap, and nod your head up and down
- Use encouraging words, signs and/or gestures: yes, right, good, thank you.
- Rephrase and expand on what your baby is communicating; for instance, if he or she points at the bear, you could say and sign or gesture, “The bear is big.”
- Act as if your baby’s signal has meaning and talk and/or sign back.
- Imitation is a good way to respond. If you can’t understand your baby’s babble, sign, or gesture, you should imitate it and say “yes.”
- Keep interactions fun and simple
- Be consistent between your use of voice, facial expression, body language and meaning. For example, when saying “No,” don’t smile. This might confuse your baby.
- After responding to your baby, be sure to pause and give your baby an opportunity to respond again.

Communication is an important way to bond with your baby. It reduces frustration and allows your baby to express feelings, ideas, wants and needs. It allows you to teach your baby about the environment and the world around us. Communication attaches meaning to things. By communicating with your baby, you are helping him/her build a foundation for language.

[Adapted from Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESP-DHH)-Outreach, Dept. of Public Instruction and Wisconsin Sound Beginnings, Dept. of Health Services, (2008). *Babies and Hearing Loss: An Interactive Notebook for Families with a Young Child who is Deaf or Hard of Hearing*. Wisconsin Department of Public Instruction, pages 25-28.]



## Background Information About Hearing Loss

### The Ear and How It Works

The ear is the organ responsible for hearing and balance. It is made up of three parts known as the outer ear, the middle ear, and the inner ear.

The **outer ear** is responsible for collecting and channeling sound waves. It consists of the pinna which is the visible portion, the ear canal, and the eardrum. The ear canal is a tunnel with tiny hairs and glands that produce a special kind of wax called cerumen. The hair and cerumen keep foreign particles from collecting on the eardrum. Some cerumen is normal; it usually migrates to the outside of the canal where it flakes off or can be wiped away. The eardrum is a thin membrane that stretches across the inner end of the ear canal. When incoming sound waves set the eardrum in motion, it serves as a bridge to stimulate the middle ear.

The **middle ear** is an air-filled cavity with three small bones called the malleus, incus, and stapes (also known as the hammer, anvil, and stirrup).

These are the smallest bones in the human body! The bones of the middle ear move sound from the outer ear to the inner ear. Inside the middle ear, there is a small tube that connects to the throat. This tube, called the Eustachian tube, makes sure that the pressure in the middle ear is the same as the pressure outside the middle ear. When this tube opens, we sometimes feel a “pop”. That means it’s working.

The **inner ear** lies just beyond the middle ear and includes two main structures: the cochlea and the semi-circular canals. The cochlea is a snail-shaped organ that is the control center for hearing. In the cochlea, there are small cells that tell our auditory nerve the different pitches of sound. The nerve then takes this information and moves it up to the brain. The semi-circular canals give us a sense of balance.

Sound travels to our **brain** from both ears on the auditory nerve. When this nerve meets from both sides, it is responsible for telling us what direction sound is coming from. Once it gets to the brain, the brain then uses the information to tell us if the sound is speech or noise. This processor starts before we are even born. When a hearing loss is present, the sound cannot get all the way up to the brain, which can make it hard for the brain to figure out what the sound is. That is why it is important that hearing losses are identified early.

Learn more about how your child’s ears work and the new terms people are using about hearing. Ask questions so you can become the expert on your child’s hearing.

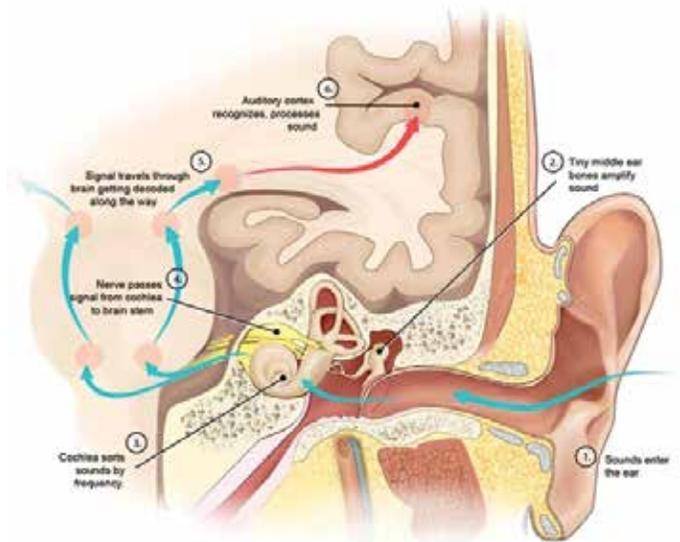
## How We Hear

In order to hear well, all parts of the ear must be working correctly. Sound enters the outer ear and passes through the ear canal to the eardrum, causing it to vibrate. The vibration of the eardrum moves the middle ear bones. Through these bones, sound is changed from sound waves moving in air, to mechanical waves vibrating in bone. These waves are transmitted to the cochlea of the inner ear. The cochlea changes the mechanical sound impulses into electrical impulses for transmission along the auditory nerve to the brain. Finally, the sound is perceived and interpreted by the brain as speech, music, noise, etc. If any part of this pathway does not function properly, the result may be a hearing loss.

The **loudness** (intensity) of a sound is measured in units called **decibels** (dB). Decibels are used to express the level at which sound can be heard—the **hearing level** (HL). On this scale a whisper is about 20 dB HL, conversational speech about 60 dB HL, and a shout is around 80 dB HL. at most. 90 dB HL is quite loud and generally requires noise protection.

“**Hertz**” (Hz) is the technical term used to measure pitch in vibrations or cycles per second. Pitch refers to how high or low a tone sounds. Speech generally falls in the 200 - 6000 Hz range.

Figure 1: Anatomy of the Hearing System



Source: By Zina Deretsky, National Science Foundation – [http://www.nsf.gov/news/special\\_reports/linguistics/speech.jsp](http://www.nsf.gov/news/special_reports/linguistics/speech.jsp), Public Domain, <https://commons.wikimedia.org/w/index.php?curid=9853164>.

The **degree of hearing loss** is measured in terms of decibels of hearing loss (dB HL). Hearing losses range from slight or minimal to profound in degree. Even a slight hearing loss can affect a baby's ability to hear language and make sense of it. Remember that a baby is learning a new language and has no background on which to rely for filling in missed parts that he or she cannot hear. When a baby's hearing loss in both ears is greater than 20-25 dB HL on an audiogram, he or she is likely to need help hearing and learning language. If the hearing loss cannot be medically corrected, then amplification becomes an option.

**Table 1: Degree of Hearing Loss Table**

<b>Degree of hearing loss</b>	<b>Hearing loss in decibels</b>	<b>Challenges</b>
Mild Hearing Loss	20 – 40 dB HL	Difficulty in noise, finding sounds, and paying attention
Moderate Hearing Loss	41- 55 dB HL	Speech delay, missed consonant sounds
Moderately Severe Hearing Loss	56 – 70 dB HL	Missed vowel sounds
Severe Hearing Loss	71 – 90 dB HL	Little to no speech perception
Profound Hearing Loss	91 dB HL or more	Little to no speech perception

Your child’s care depends on a whole team of medical professionals. This team includes, yourself, your child’s pediatrician, audiologist, teachers, speech-language pathologists, and any early interventionists. It’s important to keep communication open between your entire team!

## The Audiogram

An **audiogram** is a graph showing a person’s response to sounds ranging from low to high-pitched sounds and presented at various levels of loudness. (See Figure 2). Across the top of the audiogram, the **frequencies** of sounds (different pitches) are listed. The lower the number, the lower the pitch, from the sound of a bass drum (250 Hz) up to birds chirping (8000 Hz) looking from left to right. Looking up and down the side of the audiogram, the **intensities** (loudness) of sounds needed to hear are listed. The lower the number (0 dB HL), the quieter are the sounds that the person can hear. The higher the number, the greater the hearing loss.

Many people are confused when they first look at an audiogram. You should review your child’s audiogram with a professional, such as an audiologist or teacher of the deaf.

### *Nicole’s Message*

*Mark was the “first born” of a set of quadruplets (Mark, Andrew, Tristan, and Lorelei), coming into this world long before they were ready. The children all miraculously survived their rough beginnings. Unlike his other three siblings, Mark did not pass his newborn hearing screening. Our family did not know what to do or where to turn after receiving the news of Mark’s potential hearing loss. We found an audiologist who specialized in treating children with hearing loss. She was able to direct us to the appropriate services and to guide us through the decisions that needed to be made for our son, Mark. A diagnosis of hearing loss requires the services of so many different providers – it is truly a team effort.*



## Types of Hearing Losses

A problem in any of the three parts of the ear reduces the amount and may change the quality of sound getting through to the brain, causing a hearing loss. Hearing losses can be **permanent** or **temporary**. There are three types of hearing loss: conductive, sensorineural and mixed, depending on where the problem occurs along the outer, middle or inner ear.

**Conductive** hearing losses can reach up to 60dB HL, which is considered a moderately-severe hearing loss.

A **sensorineural** hearing loss is a problem in the inner ear or cochlea, or the auditory nerve. The sensory nerves may be damaged or missing. This type of hearing loss can range from slight to profound.

A **mixed** hearing loss may result if there is a problem in the outer or middle and inner ear. The conductive problem in the middle ear may be medically treatable. A mixed hearing loss can range from slight to profound in degree.

As a result of an ear infection which comes and goes, or other causes, the child may experience a **fluctuating** hearing loss; that is, the baby may appear to have better hearing one day and a greater hearing loss the next. A hearing loss that gets worse over time is said to be **progressive**. In some cases, medical treatment may halt or slow progressive hearing loss.

A **congenital** hearing loss can either be present at birth or progressive and present later in childhood.

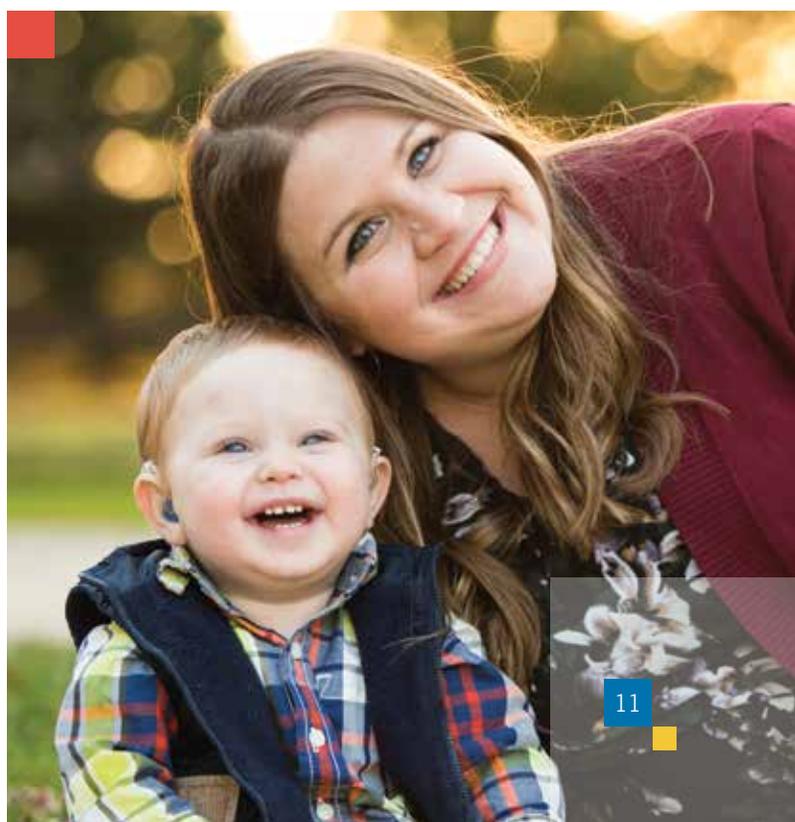
A **bilateral** hearing impairment is a hearing loss in both ears; a **unilateral** hearing loss occurs in only one side.

Many people underestimate the impact of a unilateral hearing loss; it can be conductive, sensorineural or mixed. Although a child with this loss has good hearing in one ear, he/she will have difficulty knowing where sound is coming from, hearing in noisy environments, and hearing on the affected side.

Table 2: Degree of Hearing Loss Table

Type	Description	Range
Conductive Hearing Loss	A problem in the outer/middle ear stops sound from reaching inner ear	Mild to moderately-severe
Sensorineural Hearing Loss	A problem in the cochlea/auditory nerve stops sound from reaching the brain	Mild to profound
Mixed Hearing Loss	There are problems in the multiple parts of the hearing system including both the outer/middle and inner ears	Mild to profound

*Our family is very thankful for the early hearing screening done at the hospital. We feel very blessed that our son's hearing loss was found early.*



## Identifying Hearing Losses

In accordance with Pennsylvania state law (Pennsylvania's Infant Hearing Education, Assessment, Reporting, and Referral (IHEARR), Act 89, 2001) all babies born in the state must have their hearing screened before you leave the hospital. For babies born outside the hospital, many regions also have community-based facilities that will screen hearing. The newborn hearing screening is a quick and painless assessment that is completed while your baby is sleeping. If your baby does not pass the screening in the hospital, it does not immediately mean that your child has a hearing loss. There are many factors that can influence the screening. Instead, it means that more information is needed about your child's hearing. If this is the case, it is important to schedule a repeat hearing screening with an audiologist as soon as possible. Your audiologist will be able to do a complete diagnostic test to determine your baby's hearing level.

When looking for an audiologist, it is important to find a facility experienced with infants and young children. The national Early Hearing Detection and Intervention (EHDI) program provides an excellent digital resource for families looking for these facilities. Simply visit the EHDI Pediatric Audiology Link to Services (PALS) website at [www.ehdipals.org](http://www.ehdipals.org) to find a facility near your home.

Hearing testing is done to find out how well your baby can hear. If your baby is found to have a hearing loss, the audiologist may do different tests to find out more specific information about it, for example, the type and degree of the hearing loss.



Your audiologist is an important player on that team, so try to find an audiologist who is a good fit for you and your child. You will most likely be working with them for years so try to create a positive working relationship.

Following the testing, the audiologist will discuss different ways to help your baby and family. When a child is very young, it may take a series of evaluations to complete a hearing profile.

If a hearing aid is suggested, be sure to ask if the audiologist provides loaner hearing aids and if he is a Pennsylvania Medical Assistance service and durable goods provider (see Financial Information section). Parents should request a trial period with any new hearing aid.

In addition to your medical team, a trained Pennsylvania parent of a child with hearing concerns is available to reach out to you during this process. The Parent Guide, from Hands & Voices Guide By Your Side of PA, will provide unbiased information on communication, support to your family and ongoing contact through mailings, phone, or technology. The Guide By Your Side program is available at no cost to your family.

New families should find the support of a peer, another parent of a deaf or hard of hearing child, who has “been there and done that.” He/she can provide you with the hope you will need to get your family through your journey.

### ***Nikki’s Message***

*As a Deaf person and a mother to a child who is deaf, I have what you might call a “360 degree perspective” on hearing loss and what it is like to live with a hearing loss. Firstly, I encourage you to look at your child’s hearing loss with an open mind and a positive outlook. When I say to have an open mind, I mean this: Navigating through life with so many decisions and choices of how to raise your child can be hard at times, and yes, even harder when your child has a hearing loss. But the beautiful thing about it is this: You are not limited in your choices. You can try a variety of things, like communication modes, assistive technology, and different programs/schools. Consider them many opportunities to figure out what works best for your child and family. Also, keep in mind that every child is **different**. This means that the method that works with one child and family may not work for another. I cannot repeat this enough. It is so important to surround yourself and your child with a support system that not only includes family and friends, but also parents who understand your situation, early intervention teachers/therapists, and caring medical professionals who listen to you. Be well informed about different options, ask lots of questions, and network with a variety of people, including Deaf adults. Raise your child the SAME way you would with your hearing child- read books, sing to them, talk to them about anything and everything, and just LOVE them!*

## Communication Opportunities: Options and Outcomes

As a parent of a baby with a hearing loss, you will hear many opinions from professionals and other parents about how you can or should be communicating with your child. It may be confusing at first because you will hear so many terms, teaching methods and philosophies! You need to know that there is not one “right way” for your family to communicate with your baby. You will need to pick the way that fits best for your child and family. You also need to know that even after you make this decision, if it doesn’t seem to be working for your child, you can always change. Investigate all the options in order to make your choice and remember that choices can be changed. Talking to other parents and deaf or hard of hearing adults may also assist you in making communication decisions for your child.

There are two languages that the majority of children who are deaf or hard of hearing use in the United States. They are American Sign Language (ASL) and English or other spoken language. These can be categorized as visual, auditory or a combination of visual and auditory approaches along a continuum. This is the overarching difference between approaches.

### **Hadley’s Message:**

*My husband and I have two sons. Both boys are deaf as the result of Connexin 26, a recessive, genetic trait and the most common genetic cause of hearing loss. Neither my husband, nor I, had any personal experience with hearing loss when our older son was finally diagnosed at two years old. My message for parents is to be optimistic, to act quickly and to set expectations high. It is critical to make sure to share your expectations with everyone on your child’s support team (speech therapists, hearing support teachers, regular education teachers, etc.) and make sure they are “on-board” with them. In addition, I’ve learned that what may appear to be challenges can become great blessings. When our younger son was diagnosed with hearing loss, people felt sorry for us, told us it wasn’t “fair.” I believe that having a brother as a built-in peer supporter has become, and will continue to be, a great advantage for both our sons.*

My sons are both now mainstreamed into our local school. The boys play musical instruments in the band and participate in sports including baseball, soccer, basketball and swimming. They are honor roll students and are fully participate in our community.

When considering communication for your child with hearing loss, it is important to consider all possible options and approaches. Some options for your child are outlined below ranging from most visual approaches to most auditory-centered approaches.

## **American Sign Language**

American Sign Language (ASL) is a complete, complex language that employs signs made by moving the hands combined with facial expressions and postures of the body. It is the primary language of many North Americans who are deaf and is one of several communication options used by people who are deaf or hard-of-hearing.

ASL is a language completely separate and distinct from English. It contains all the fundamental features of language—it has its own rules for pronunciation, word order, and complex grammar. While every language has ways of signaling different functions, such as asking a question rather than making a statement, languages differ in how this is done. For example, English speakers ask a question by raising the pitch of their voice; ASL users ask a question by raising their eyebrows, widening their eyes, and tilting their bodies forward.

[www.nidcd.nih.gov/health/american-sign-language](http://www.nidcd.nih.gov/health/american-sign-language)

## **Total Communication**

Total Communication (TC) is philosophy of educating children with hearing loss that incorporates all means of communication; formal signs, natural gestures, fingerspelling, body language, listening, lipreading and speech...The goal is to optimize language development in whatever way is most effective for the individual child. Total Communication is truly a philosophy rather than a methodology. As a result, the implementation of the TC philosophy with one child may look entirely different than its implementation with another child.

[www.handsandvoices.org/comcon/articles/totalcom.htm](http://www.handsandvoices.org/comcon/articles/totalcom.htm)

## **Cued Speech**

Cued Speech is a visual mode of communication in which mouth movements of speech combine with “cues” to make the sounds (phonemes) of traditional spoken languages look different. Cueing allows users who are deaf, hard of hearing or who have language / communication disorders to access the basic, fundamental properties of spoken languages through the use of vision.

<http://www.cuedspeech.org/>

## **Listening and Spoken Language**

The Listening and Spoken Language approach teaches a child spoken language through listening. You may be thinking: How is this possible for a child who is deaf? First, think about how a baby with normal hearing learns to talk. They learn by listening to the speech and spoken language of their parents, caregivers, and family members. Little brains are built to learn spoken language in this way – it’s developmental.

Children with hearing loss can learn spoken language the same way when they are identified early, have appropriate hearing devices, and are taught to listen through special LSL techniques. LSL is a developmental approach which follows typical child milestones by introducing skills at the ages and stages when little brains are primed to learn.

<https://hearingfirst.org/lsl/what-is-lsl>

**Table 3: Communication Opportunities**

Language	American Sign Language	English or other Spoken Language		
Approach	Visual Approach	More Visual < -----	Combined Visual & Auditory Approaches -----	> More Auditory
Options	American Sign Language (ASL)	Total Communication /Simultaneous Communication (SimCom)	Cued Speech (CS)	Listening and Spoken Language (LSL)
<b>Definitions</b>	<p>ASL is a visual language which is totally accessible to children who are deaf.</p> <p>It is a unique, signed language that is different from English with its own grammar and syntax.</p> <p>Children who learn ASL as their first language are also taught English as a second language. This is called a Bilingual approach.</p>	<p>Total Communication combines a sign language system with spoken language.</p> <p>Children are encouraged to use their eyes (speech reading), ears (use of residual hearing), voices (speech) and hands (natural gestures, sign language, fingerspelling).</p>	<p>Cued Speech helps children hear and “see” speech.</p> <p>Teachers and parents use a combination of hand cues with the natural mouth movements of speech, specifying each sound (phoneme) of spoken language clearly.</p> <p>This helps children tell the difference between words that can sound or look alike as parents coo, babble and talk.</p>	<p>Listening and Spoken Language approaches teach children to rely on residual hearing as they learn to speak. Methods may be called “auditory oral” or “auditory verbal”.</p> <p>Today, as a result of advances in newborn hearing screening, hearing technologies, early intervention programs and the specialty skills of professionals, these two approaches have more similarities than differences and they lead to similar outcomes.</p> <p>The use of any sign language communication is not encouraged.</p>
<b>Goals</b>	<p>To acquire an age-appropriate internal language as a basis for learning a second language (written and, when possible, spoken English); and to provide access to opportunities for academic achievement.</p> <p>To develop a positive self-image and cultural identity providing access to the Deaf community.</p>	<p>To provide a bridge to the development of spoken language in the very young child.</p> <p>To provide communication between the child and his/her family, teachers and peers using sign language.</p> <p>To support integration into both the hearing and the Deaf communities.</p>	<p>To provide clear communication in the spoken language of the home.</p> <p>To develop the phonemic language base to achieve full literacy in conversation, reading and writing.</p> <p>To support speech reading, speech and auditory skill development.</p>	<p>To teach the child to use his/her listening and spoken language to interact with the community and the hearing world.</p> <p>To guide parents and caretakers to provide children with optimal hearing, speech and language stimulation.</p> <p>To provide children with hearing loss with an inclusive education in the regular classroom environment when appropriate.</p>

Table 3 was prepared in order to assist parents to discern the differences and similarities among communication opportunities.

*All families should be as fortunate as I was to have a meeting about all the options before being asked to make a decision as to our preferred methodology.*

Table 3: Communication Opportunities – *continued*

Language	American Sign Language	English or other Spoken Language		
Approach	Visual Approach	More Visual < -----	Combined Visual & Auditory Approaches -----	> More Auditory
Options	American Sign Language (ASL)	Total Communication /Simultaneous Communication (SimCom)	Cued Speech (CS)	Listening and Spoken Language (LSL)
<b>Language Development/ Methods</b>	<p>The child develops early language as well as concepts and higher order thinking skills through the use of ASL and fingerspelling. Written English is added in the early years. ASL users can also develop spoken English.</p> <p>They develop the ability to code switch from ASL to English (signed, spoken or written) as needed.</p> <p>Individual decisions about hearing aids and cochlear implants are encouraged.</p>	<p>The child develops language through speech reading, listening and exposure to a combination of spoken English and signing in English word order.</p> <p>Written English is added in the early years.</p> <p>Hearing technology (hearing aids, cochlear implants, FM systems) is strongly encouraged.</p>	<p>The child develops language through the use of Cued Speech, speech reading and hearing.</p> <p>Cueing has been adapted to 60+ cued languages.</p> <p>Cueing boosts auditory awareness, discrimination and understanding.</p> <p>Hearing technology (hearing aids, cochlear implants, FM systems) is strongly encouraged.</p>	<p>The child develops language through listening and talking with the support of hearing technology, such as hearing aids and/or cochlear implants.</p> <p>Children learn to listen and to talk with a therapist guiding their parents through individual 1-1 sessions (Auditory Verbal).</p> <p>Hearing technology (hearing aids, cochlear implants, FM systems) is strongly encouraged.</p>
<b>Family Responsibilities</b>	<p>Parents are committed to learning and using ASL consistently. ASL is learned through classes, media, websites, and interaction with members of the Deaf community.</p>	<p>Families are expected to learn and consistently use the chosen English-based sign language system.</p> <p>Parents need to work with the child's teacher(s) and/or therapist(s) to learn strategies that promote language expansion.</p>	<p>Parents are expected to learn to speak-and-cue at all times in order for children to absorb the phonemes critical to language and reading readiness.</p> <p>The system is taught through multi-media, classes, and Family Cue Camps.</p> <p>Consistent daily use and practice lead to conversational ease within a year.</p>	<p>Use of amplification 100% of the child's waking hours should occur within two to three weeks of the initial fitting. Hearing is considered something we do all the time and it is critical for a baby's learning brain to have constant, meaningful access to sound.</p> <p>Families and professionals observe the child's response to sound and determine how well he or she is learning through hearing. These observations will help determine whether the hearing aids need adjustments, or if a cochlear implant may be pursued.</p> <p>Families are expected to carry over established goals in the child's daily routines and play activities.</p> <p>Therapist and parent help the child develop skills comparable to their hearing peers.</p> <p>As a child learns to listen he/she will benefit from listening to typical hearing peers.</p>

(Adapted from Beginnings for Parents of Children Who Are Deaf or Hard of Hearing, Inc. "Communication Approaches: What Parents Should Know About Communication Approaches". BEGINNINGS, P.O. Box 17646, Raleigh, North Carolina, 27619. Retrieved from [www.ncbegin.org](http://www.ncbegin.org))

When family members need instruction in communication methods, there are a number of resources. Classes are offered by school districts, intermediate units, schools for the deaf, colleges, community groups, and agencies. Parents can also learn through tutoring by a Deaf person who uses sign language. Your Early Intervention program can help you find resources.

No one communication option or education method is appropriate for all children. What is most important is that you keep communicating with your baby!

### ***Mary Ann's Message***

*My husband's family and my own include a number of deaf people, including us. We knew beforehand that our children might be deaf, and we now have three beautiful boys. My husband and I use American Sign Language and this is the language that our boys learned first as well. Our children have full access to the language in their environment at home. At school and in the community, that is not always the case. Our biggest concern has been providing our boys with an ideal educational environment. Our hopes and dreams for their future are to continue to have teachers who communicate proficiently in sign language and who have high expectations of deaf children.*



## Technology

Whether your baby learns from visual input, auditory input, or both, sophisticated technological devices exist to facilitate the communication process. Because technology is constantly changing, you will need to learn about the most advanced levels of equipment available. If your child uses any type of device, you should be prepared to share information with others who see your child regularly, such as extended family members, early care and education staff, church and library personnel, teachers and others. This information may include basic instruction on the use and care of the device.

### Hearing Aids

A hearing aid is an electronic device that is worn in or behind the ear. Hearing aids are appropriate for mild to profound hearing losses. They work by amplifying sounds in the frequencies where a hearing loss is identified to provide your child with the most access to sound possible. Hearing aids vary in size and power.

When young children are fitted with hearing aids, they are usually behind the ear (BTE) hearing aids for audiological and practical reasons. The hearing aids are acoustically flexible and can be adjusted to best meet your baby's amplification needs. When children have hearing loss in both ears, they are typically fitted with a hearing aid for each ear. This is especially true for babies, since the goal is to provide them with the best access to auditory stimuli in all listening situations. Hearing aids that are fit properly will never amplify a sound that could harm your child or your child's hearing.

*The audiologists we have met are truly advocates for our children and want to help all of us get the technology that our children need. They will support you in many ways. Take advantage of every appointment and go prepared with a list of questions.*

Despite the many variations in hearing aids, all hearing aids have the following basic parts:

- a microphone to pick up sound waves
- an amplifier to change the sound into an electrical signal and amplify it (make it louder)
- a receiver to change the amplified sound back into sound waves
- an earmold to deliver them to the ear

Earmolds are custom-made. They must fit comfortably and well into the ear canal. If an earmold does not fit well, the amplified sound leaks out around the earmold, goes back into the hearing aid, and is amplified again. This produces a loud squealing or whistling sound, called feedback, which can be annoying. Earmolds should be checked every few months. As your baby grows, new earmolds will be needed in order to accommodate growing ears and maintain an appropriate fit.

Taking care of the hearing aid requires daily checking and care. It must be kept dry, safe, and away from pets or toddlers who can quickly chew or play with a hearing aid and break it. Hearing aid batteries are small and batteries can be harmful if swallowed. Keep all loose batteries out of the reach of small babies, children, and pets. Hearing aids must NOT get wet. Several drying agents are available for nighttime use to absorb moisture that may collect in the hearing aid. For questions about hearing aids, earmolds, batteries, and the use of hearing aids in different settings (home, school, child care), you should talk to your audiologist.

Your audiologist is your primary resource for information about hearing aids. He/she will work with you to select specific hearing aids, adjust them internally to meet your baby's unique needs, teach you how to take care of them, and help you to monitor your baby's use of amplification to ensure success.

Additional information about hearing aids can be accessed at [www.cdc.gov/ncbddd/hearingloss/treatment.html](http://www.cdc.gov/ncbddd/hearingloss/treatment.html)

### ***Betsy's Message***

*Emily is the youngest of our three kids. When she wasn't walking or talking at 15 months, she was evaluated and found to have a severe-profound hearing loss. Emily had hearing aids which helped, but not enough to get her hearing into the speech range. Later, she was found to have a profound loss bilaterally. We had sort of known, but my heart was broken anyway. That diagnosis led us to decide to have her receive a cochlear implant. She entered kindergarten with a mix of inclusion and special education class time. We will probably never figure out why Emily is deaf. But when we hear ourselves tell her "Will you please be quiet?" we always say it with a **big grin!!***

## **Cochlear Implants**

A cochlear implant is a consideration for children with profound hearing loss who do not receive enough benefit from hearing aids alone. Unlike hearing aids, a cochlear implant is a device that is implanted through surgery and directly stimulates the auditory nerve. There are two main parts of a cochlear implant: the internal component, which is surgically implanted into the cochlea, and an external component, which is worn on the ear and on the head and includes a microphone, speech processor, and transmitter. These two components communicate between each other, giving your child access to sound. If your child is a cochlear implant candidate, it is important that they are implanted early. Current research suggests that children implanted by 18 months can achieve language milestones similar to children with normal hearing sensitivity.

As with hearing aids, a variety of factors contribute to the level of success that a young child experiences with a cochlear implant. Family involvement, intensive aural habilitation, and language-rich environments all increase the probability of success. For these reasons your baby or young child must be evaluated for candidacy at a medical center that serves children with cochlear implants. A medical evaluation must also be done and certain criteria met.

## **Amplification through Bone Conduction**

For some children, traditional hearing aids may not be beneficial due to physical limitations. These include children with closed or absent ear canals (known as atresia), chronic ear infections with drainage, and some genetic syndromes. For these

children, amplification can be achieved through bone conduction, where sound travels through bone instead of directly through the ear. These sorts of amplification can either be worn on a head band or surgically implanted. If you think your child may benefit from amplification through bone conduction, speak with your audiologist or pediatric Otolaryngologist to learn more.

## **Other Assistive Technology**

A personal FM system is a listening device that can be used when there is significant distance between the child and the person speaking. It sends sound from a microphone used by the person speaking to a baby wearing the receiver. The system can be used with or without hearing aids or cochlear implants in order to help the listener separate language from background noise.

In addition to the devices described above, many other "assistive devices" are available to help your child access information. Alerting devices that use blinking lights to let you know that the doorbell is ringing, phones that use text messages to relay information, and closed captioning on your television are just a few examples. Your audiologist will work with you and your family to determine which devices are appropriate for your child. Several national resources and websites in the Appendix can provide the reader with access to websites or catalogs of these devices.

(Adapted from Virginia Department of Health, (n.d.). *Information for Parents of Babies with Hearing Loss: Virginia's Resource Guide for Parents*. Virginia Departments of Health, Department of Education, Department for the Deaf and Hard of Hearing, Virginia's Early Intervention System, Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, pages 20-21.)

## Early Intervention

### What is Early Intervention in Pennsylvania?

Early Intervention in Pennsylvania consists of services and supports designed to help families with children who have developmental delays or disabilities. Early Intervention builds upon the natural learning occurring in those first few years. It is a process that promotes collaboration among parents, service providers, and others significantly involved with your child.

#### Early Intervention:

- Helps children with disabilities develop and learn to their fullest potential
- Enhances each family's capacity to meet the developmental needs of their child in the settings where children would be if they did not have a disability
- Respects the family's strengths, values, diversity and competencies and answers families' questions about their child's development
- Supports communities to become more aware of the gifts and abilities of all its children
- Helps prevent the need for more and costly intervention in the future

### What are Early Intervention supports and services?

Early Intervention supports and services are provided at no cost to families. Early Intervention services can include: information about how children develop, parent or caregiver education, family supports, and developmental and instructional therapies that assist in child development. Early Intervention is individualized and provides supports to the child and family at home and in the community and is individualized to enhance the child's growing and learning. When a child attends an early care education setting, Early Intervention can assist the early childhood staff with strategies to promote the child's development. Early Intervention can also assist families to link to a variety of community services and supports.

You are the expert about your child. The recommendations or suggestions that you have for your child and family are uniquely yours. Sharing them with other members on your Early Intervention team allows others to know what is important to your family. This information will help your Early Intervention team to create meaningful individualized services and supports.

*My youngest child is hard of hearing. He was not my first child who did not pass the newborn hearing screening, so I was not too concerned when the nurse talked about it to me. I listened to the comment I had heard a few years before when my other child was born, something like, "Oh, it's probably just fluid." This time it wasn't just fluid; it really was a hearing loss. Early intervention was available to us when our baby was only a few weeks old. They provided us with a teacher of the deaf and hard of hearing. She was able to explain things to us in terms that we understood. She gave us information about how people hear, what our baby could hear, and explained all of the terminology the professionals in our new baby's life were using. She let us know that our little one really was an adorable baby and we did not need to define him by the audiogram we were given. Early intervention gave our son the right start. He gained all of the language that he needed to enter school on target with age-level peers through the things that our whole family learned through Early Intervention.*

## Financial Information

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Many commercial health insurance companies do not cover hearing aids or other assistive listening devices in their policies. However, any child who lives in Pennsylvania and is identified with a permanent hearing loss may apply for Medical Assistance (MA, the state's Medicaid program). The Department of Health and Human Services has expanded eligibility for MA benefits to include children with a qualifying disability such as a hearing loss.

Once you have obtained your child's MA card, contact your managing audiologist with the following information:

- Name of the insurance you have chosen or were assigned
- Identification number

### Referrals for Audiological Services

If your primary health insurance and/or MA insurance requires you to obtain a referral, you should make certain it contains the following information:

1. Appropriate place of service/provider
2. Appropriate service type – check with your audiologist to determine which services will be provided:
  - Audiogram
  - Tympanogram
  - Hearing aid evaluation
  - Hearing aid check

### Referrals for Durable Goods

Not all audiologists participating as “service providers” for MA are “durable goods providers”.

If you will be obtaining your child's hearing aids or related equipment through MA insurance, you will need to have the equipment (durable goods) dispensed by an MA durable goods provider.

Obtaining the appropriate referrals and medical clearance ensures timely processing of your child's order. Hearing aids, under all plans, require preapproval.

If you participate in an MA-HMO, please make sure the referral contains the following information:

1. Provider: This varies depending upon your insurance and which durable goods providers participate in your insurance. Please be sure your referral is made out to one provider. Your audiologist can help you determine the most convenient location.
2. Type of durable good:
  - Hearing Aids
  - Earmolds
  - FM System
3. In addition to the referral, to apply for hearing aids through MA, you will need to provide the following documentation to your durable goods provider:
  - Hearing test results
  - Hearing Aid Evaluation Report which includes hearing aid (or other technology) recommendations
  - Medical Clearance form signed by an ENT physician

[Adapted and updated from material provided by the Center for Childhood Communication at the Children's Hospital of Philadelphia, *Parent Information Packet*.]

## Appendix

### Selected Parent Resources

#### **Hands & Voices Guide By Your Side (GBYS) of PA**

800-360-7282 (PA Only) / 717-580-0839  
Email: [agaspich@pattan.net](mailto:agaspich@pattan.net)  
<http://www.paearlyhearing.org/families/diagnosed/item/70>

**H&V GBYS of PA** is a specialized parent support program that links trained and experienced Parent Guides and Deaf/Hard of Hearing Guides with families of infants and toddlers identified with deafness, hearing loss or deafblindness. Geographically dispersed throughout PA, Parent Guides are other parents of children with deafness and hearing loss who provide unbiased information and emotional support. They offer the opportunity to talk to or meet face-to-face and bring their direct experience, specialized knowledge and personal compassion to their role while making the family's needs their primary focus. DHH Guides are Deaf/Deaf or Hard of Hearing adults who support families as mentors. Services are free and confidential.

#### **Early Hearing Detection and Intervention (EHDI) of PA**

PA Dept. of Health, Bureau of Family Health Division of Newborn Screening & Genetics  
7th Floor East Wing, 625 Forster Street  
Harrisburg, PA 17020-0701  
717-783-8143 (Voice)  
717-705-9386 (Fax)  
[www.paearlyhearing.org](http://www.paearlyhearing.org)

The PA Early Hearing Detection and Intervention program's website offers information and resources for families, physicians, audiologists and birth facilities regarding newborn hearing screening and caring for babies and young children who are deaf or hard of hearing.

#### **A.G. Bell Association for the Deaf and Hard of Hearing**

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

#### **American Society for Deaf Children (ASDC)**

800 Florida Ave NE #2047  
Washington DC 20002  
800-942-ASDC (2732)  
[www.deafchildren.org](http://www.deafchildren.org)

#### **Sign IT! American Sign Language Made Easy**

The free resource is an online curriculum for learning American Sign Language (ASL). It's called SignIt ASL. NCHAM has partnered with the Signing Time Foundation to make this resource available for free to families of 0-3 year-old children who are DHH who want to learn ASL.  
[www.mydeafchild.org](http://www.mydeafchild.org)

#### **Boys Town National Research Hospital**

555 N. 30th Street  
Omaha, NE 68131  
402-498-6511  
[www.babyhearing.org](http://www.babyhearing.org) (English)  
[www.audiciondelbebe.org/portada.asp](http://www.audiciondelbebe.org/portada.asp) (Español)

#### **Laurent Clerc National Deaf Education Center**

Gallaudet University  
800 Florida Avenue NE  
Washington, DC 20002-3695  
202-651-5000  
<http://clerccenter.gallaudet.edu/>

#### **National Association of the Deaf (NAD)**

8630 Fenton Street  
Silver Spring, MD 20910  
301-587-1788 (Voice)  
301-587-1789 (TTY)  
[www.nad.org](http://www.nad.org)

#### **National Center for Hearing Assessment and Management (NCHAM)**

Utah State University  
[www.infanthearing.org](http://www.infanthearing.org)

#### **National Cued Speech Association (NCSA)**

1300 Pennsylvania Ave, NW, Suite 190-713  
Washington DC 20004  
800-459-3529 (Voice/TTY)  
[www.cuedspeech.org](http://www.cuedspeech.org)

#### **Parent to Parent of Pennsylvania (P2P)**

888-727-2706 (toll-free)  
Email: [Info@parenttoparent.org](mailto:Info@parenttoparent.org)  
[www.parenttoparent.org](http://www.parenttoparent.org)

#### **The SEE\* Center for the Advancement of Deaf Children**

P.O. Box 1181  
Los Alamitos, CA 90720  
562-430-1467  
[www.seecenter.org](http://www.seecenter.org)  
\* Signing Exact English (SEE2)

#### **The Described and Captioned Media Program**

A free loan library of accessible materials for use by teachers and families. Cued speech and ASL instructional videos are available  
[www.dcmp.org](http://www.dcmp.org)

#### **John Tracy Clinic** offers world wide parent education to

develop speech, language and listening skills  
[www.jtc.org](http://www.jtc.org)

#### **CDC Centers for Disease Control and Prevention**

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

